THE HEALTH OF CHILDREN AND YOUNG PEOPLE

WITH CHRONIC CONDITIONS AND DISABILITIES

IN TARANAKI

The Health of Children and Young People with Chronic Conditions and Disabilities in Taranaki

This Report was prepared for Taranaki DHB by Elizabeth Craig, Gabrielle McDonald, Judith Adams, Anne Reddington and Andrew Wicken on behalf of the New Zealand Child and Youth Epidemiology Service,

November 2010

This report was produced as a result of a contract between the DHB and the Paediatric Society of New Zealand, on behalf of the New Zealand Child and Youth Epidemiology Service (NZCYES). The NZCYES is located in the Department of Women's and Children's Health at the University of Otago's Dunedin School of Medicine. While every endeavour has been made to use accurate data in this report, there are currently variations in the way data is collected from District Health Boards and other agencies that may result in errors, omissions or inaccuracies in the information in this report. The NZCYES does not accept liability for any inaccuracies arising from the use of this data in the production of these reports, or for any losses arising as a consequence thereof.

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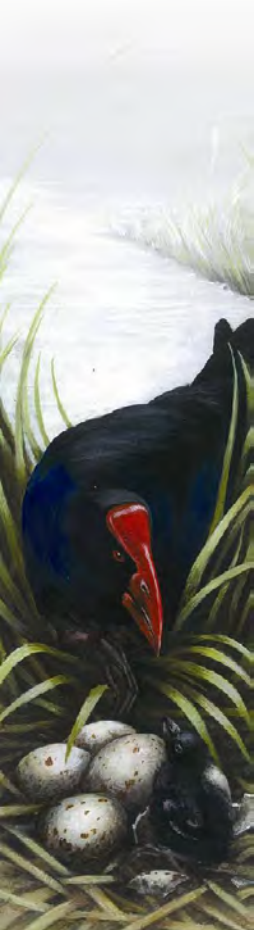

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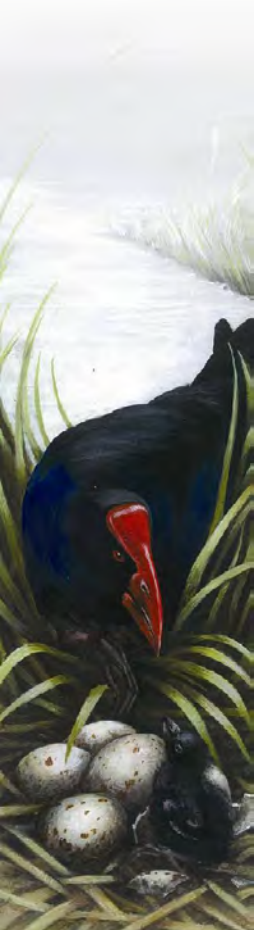

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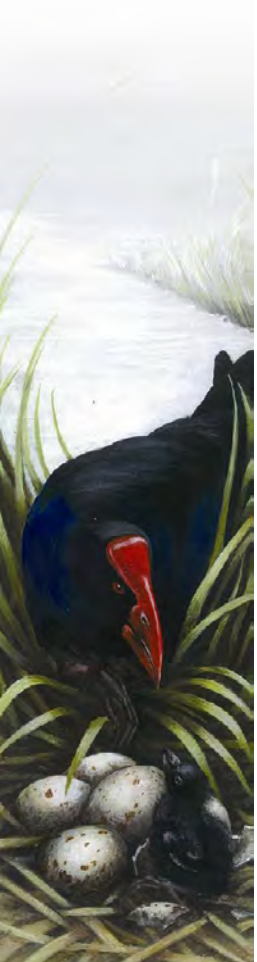

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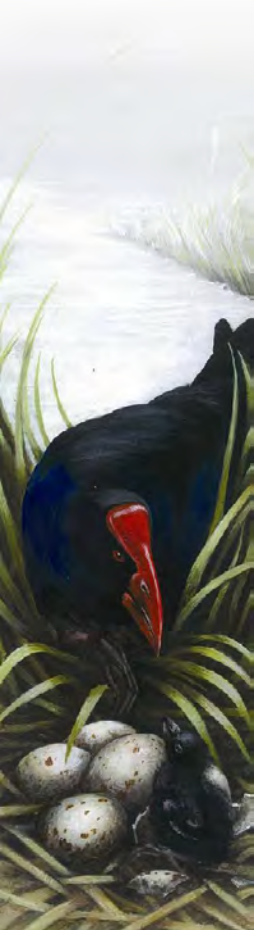

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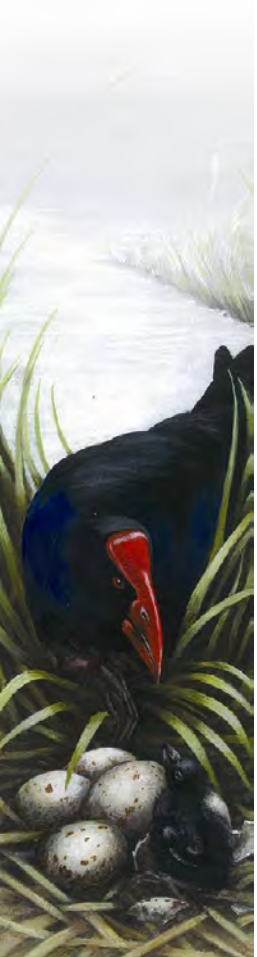

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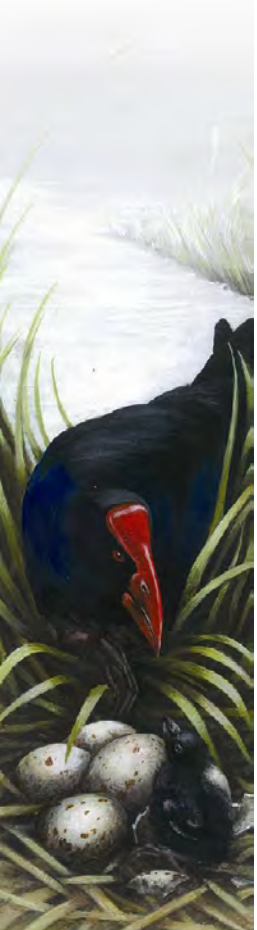

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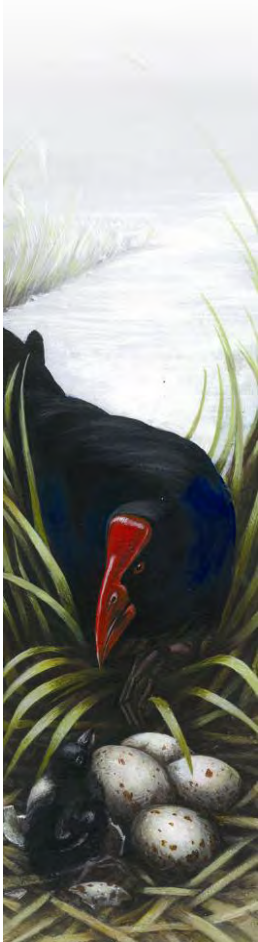

INTRODUCTION AND OVERVIEW

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Introduction

In 1995, a report on the Health of Infants and Children in the Midland Region noted:

> "*There is a dearth of information on people who have disabilities living in Midland, as well as New Zealand"* and that "*the dearth of useful information on disabilities and people with disabilities, is a serious impediment to rational and effective service planning and delivery" [1].*

Since the time of this report, little has changed and it remains very difficult to access useful information on the nature and prevalence of disabilities amongst New Zealand children and young people. Nevertheless, children and young people with disabilities and chronic conditions require a range of health and disability support services in order to reach their full potential, and it is undesirable that a paucity of data should preclude them featuring prominently in prioritisation, planning and resource allocation decisions.

Report Aims and In-Depth Topics

This report reviews a range of routinely collected data on children and young people in Taranaki, with a view to identifying the numbers of children and young people with chronic conditions and disabilities accessing health services within the region. In addition, given a trend towards deinstitutionalisation and a greater emphasis on community care, this year's in-depth topics consider common areas of unmet need for families caring for children and young people with chronic conditions and disabilities, as well as the impact health and disability support services may have on their wellbeing. Specifically, the issues considered in this year's in-depth topics include:

1. **Disability, Disability Support Services and Transitions to Adult Care**: This review provides a brief overview of disability, disability support services and issues with transition to adult care. It begins by briefly defining disability, before reviewing the most common conditions leading to disabilities in New Zealand children and young people. New Zealand's historical approaches to service delivery for those with disabilities are then reviewed, before an overview is provided of New Zealand's current disability support services, and the areas of unmet need most commonly identified by families caring for children and young people with disabilities, both in New Zealand and overseas. A final section considers the transition of young people with disabilities from paediatric to adult care, some of the difficulties inherent with this transition, and a range of overseas models which consider how such transitions might be improved.
2. **Models of Care for Medically Fragile Children**: Medical advances over recent decades have resulted in an increase in the number of medically fragile or technology-dependent children. This, in combination with advances in portable technology and a trend for shorter hospital stays and less institutional care, has meant that there are increasing numbers of children with complex health care needs living at home. This review examines the funding supports available, some of the inherent problems that arise from caring for medically fragile children at home, and some models of care. The section concludes with a review of transitions from paediatric to adult services for adolescents with chronic medical conditions.

Report Sections and Indicators

As previously, this report is based on the *Indicator Framework* developed during the first three year reporting cycle, with the majority of indicators in the *Chronic Conditions and Disabilities* streams being updated in this year's edition. A number of new indicators have also been added / sections have been expanded, as new data has become available, or as more experience has been gained in working with New Zealand's national data collections.

Again, as previously, where high quality data was not available, yet an issue was deemed to be of public health importance, "bookmark" indicators were created (e.g. hospital

admissions for children and young people with iron deficiency anaemia) so that the issue did not fall below the public health radar. In such cases however, the reader is strongly urged to read the cautions on interpretation which accompany each indicator, in order to gain a better understanding of the strengths and weaknesses of the data used.

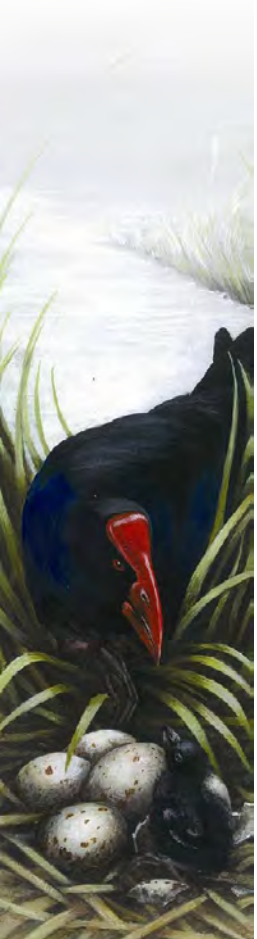
In addition, each of the indicators in this year's report has been assigned to one of the four sections outlined below:

Antenatal and Neonatal Screening: This section considers five conditions which may lead to significant long term disability, and which may be detected by routine screening in the antenatal or neonatal periods. The first four: *Congenital Anomalies Evident at Birth*, *Cardiovascular Anomalies*, *Down Syndrome*, and *Neural Tube Defects*, describe the prevalence and distribution of selected congenital and chromosomal anomalies in hospital born babies, while the fifth, *Cystic Fibrosis*, reviews hospital admissions for children and young people aged 0-24 years who had any mention of cystic fibrosis in any of the first 15 diagnoses.

Other Disabilities: As a result of the paucity of other routine data sources, the indicators in this section review hospital admissions for children and young people aged 0-24 years with any mention of *Developmental Delays and Intellectual Disabilities*, *Cerebral Palsy*, and *Autism and Other Pervasive Disorders* in any of the first 15 diagnoses. For each condition, the main reasons for hospital admission are explored, along with their distribution by age, ethnicity, gender and NZ Deprivation index decile.

Other Chronic Medical Conditions: This section reviews hospital admissions and mortality for children and young people aged 0-24 years with any mention of *Insulin Dependent or Non-Insulin Dependent Diabetes* and *Epilepsy or Status Epilepticus* in any of the first 15 diagnoses. Again the main reasons for hospital admission are described, along with their distribution by age, ethnicity, gender and NZ Deprivation index decile. An additional section reviews *Cancer* incidence and mortality in the same age group, using NZ Cancer Registry and National Mortality Collection data.

Obesity, Nutrition and Physical Activity: This section is divided into two main parts, with the first using 2006/07 New Zealand Health Survey data to review the prevalence of *Overweight and Obesity* and some of its risk factors (e.g. soft drink and takeaway consumption, television watching and modes of travel to school) in New Zealand children. A second indicator explores hospital admissions for children and young people with any mention of *Iron Deficiency Anaemia* in any of the first 15 diagnoses. While the methodology used significantly underestimates the prevalence of iron deficiency anaemia in this population, the information presented does provide some insights as to the groups most likely to warrant further attention in terms of their iron status and nutritional intake.



The New Zealand Children's Social Health Monitor

The *NZ Children's Social Health Monitor*, an indicator set developed to monitor the impact of the economic downturn on child wellbeing, was presented for the first time in last year's report. Data on each of the indicators in the Monitor (Economic Indicators: *GDP*, *Income Inequality*, *Child Poverty*, *Unemployment Rates* and *Number of Children Reliant on Benefit Recipients*; Child Wellbeing Indicators: *Hospital Admissions and Mortality with a Social Gradient*, *Infant Mortality*, *Hospital Admissions for Injuries Arising from Assault in Children*) is updated in this year's report, with a view to reviewing how children, both nationally and locally, are faring in the current economic climate.

Evidence Based Approaches to Intervention

As previously, each of the sections in this year's report concludes with a brief overview of local policy documents and evidence based reviews which consider population level approaches to prevention / management. **Appendix 2** provides an overview of the methodology used to develop these reviews. As previously, the quality and depth of evidence available varied from indicator to indicator (e.g. a large number of reviews were available on the medical management of children and young people with cystic fibrosis, but

few (with the exception of folate for neural tube defects) were available on the primary prevention of congenital anomalies).

Data Quality Issues and the Signalling of Statistical Significance

As previously **Appendix 1** outlines the rationale for the use of statistical significance testing in this report and **Appendices 4-9** contain information on the data sources used to develop each indicator. Readers are urged to be aware of the contents of these Appendices when interpreting the information contained in this report. (Note: As outlined in **Appendix 1**, in order to assist the reader to determine whether tests of statistical significance have been used in a particular section, the significance of the associations presented has been signalled in the text with the words *significant*, or *not significant* in italics. Where the words *significant* or *non-significant* do not appear in the text, then the associations described do not imply statistical significance or non-significance).

Overview of Findings for Taranaki

Table 1 provides a brief overview of the indicators in this year's report, and the main findings as they relate to children and young people in Taranaki, as well as for New Zealand as a whole.

Children and Young People with Chronic Conditions and Disabilities: In Taranaki, the review of admissions for children and young people with chronic conditions and disabilities presented a mixed picture, with admissions for those with some conditions (e.g. autism, insulin dependent diabetes, and epilepsy) being similar to the New Zealand average. In contrast, admissions for those with other conditions (e.g. cystic fibrosis, cerebral palsy, non-insulin dependent diabetes) were *significantly* lower.

Children's Social Health Monitor: As in last year's report, the deteriorating economic conditions seen nationally were reflected in Taranaki's data, with ongoing increases in the number of children reliant on DPB and unemployment benefit recipients between April 2008 and 2010. When hospital admissions with a social gradient were considered, hospitalisations for medical conditions declined during the mid-2000s, reached their lowest point in 2007, and then rose rapidly during 2008-2009. When broken down by ethnicity, rates were higher for Māori than for European children, with rates for both ethnic groups declining during the mid 2000s, and then increasing again during 2008-2009 (with the largest increases being seen for Māori children). In contrast, injury admissions declined gradually, both for the DHB as a whole and for its two largest ethnic groups.

Concluding Comments

This report provides an overview of secondary health service utilisation for children and young people with chronic conditions and disabilities in Taranaki. While the data presented is at times imperfect, and at best only provides a glimpse of the health needs of these children and young people, the current paucity of data should not preclude the DHB reviewing the disability support services available locally, with a view to considering whether any of the issues identified nationally are an issue within the region. Further, while high quality evidence (e.g. from randomised control trials) is lacking, there is nevertheless sufficient information to direct future initiatives towards the areas of greatest need, which potentially may include access to respite care, continuity and coordination between services, and the adequate resourcing of caregivers (both paid and informal) looking after children and young people with disabilities. Attention to ongoing quality improvement in these areas will ensure that over time, the health sector is better able to respond to the needs of these children and young people, who are amongst some of the most vulnerable in New Zealand.

Table 1. Overview of the Health of Children and Young People with Chronic Conditions and Disabilities in Taranaki

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Conditions Detectable by Antenatal and Neonatal Screening			
Antenatal and Neonatal Screening	Congenital Anomalies Evident at Birth	In New Zealand during 2005-2009, a large number of congenital anomalies were evident at birth, with these ranging in severity from minor skin conditions through to anomalies which were incompatible with life. While in numerical terms the largest number of babies born with congenital anomalies had mothers aged 30-34 years, the risk of congenital anomalies rose with increasing maternal age, with babies whose mothers were 40+ years having rates 1.35 (95% CI 1.24-1.48) times higher than those whose mothers were in their teens. While no socioeconomic differences were evident, the proportion of babies with one or more congenital anomalies was significantly higher for males, and for Pacific and Asian > European and Māori babies. On average during 2000-2009, 3,159 babies per year had one or more congenital anomalies evident at birth, although the severity of these anomalies varied considerably. During 2009, this equated to 4.1% of all births.	In Taranaki during 2005-2009, a large number of congenital anomalies were evident at the time of birth, with these ranging in severity from minor (e.g. tongue tie) through to more serious anomalies (e.g. malformations of the great arteries). When the number of babies with one or more congenital anomalies, rather than the number of congenital anomalies was considered, on average during 2005-2009, 71.0 Taranaki babies per year (4.8 % of all births), had one or more congenital anomalies identified at the time of birth, with rates in Taranaki being significantly (albeit only slightly) lower than the New Zealand average (RR 0.90, 95% CI 0.81 – 0.99).
	Cardiovascular Anomalies	In New Zealand during 2005-2009, patent ductus arteriosus (PDA) was the most frequent cardiovascular anomaly identified at birth, with 57.8% of PDAs being in preterm babies (<37 weeks gestation) who had no other cardiovascular anomalies. Atrial septal and ventricular septal defects were the next most frequent anomalies. During this period, no significant ethnic, gender or socioeconomic differences were seen in the proportion of babies being born with cardiovascular anomalies. Rates rose progressively with increasing maternal age however, with rates for babies whose mothers were 30+ years being *significantly* higher than for those whose mothers gave birth in their teens. During 2000-2009, the number of babies born with one or more cardiovascular anomalies (excluding isolated preterm PDAs) remained relatively constant, averaging around 393 cases per year.	In Taranaki during 2005-2009, patent ductus arteriosus was the most frequent type of cardiovascular anomaly evident at the time of birth, although 38.2% were in preterm babies with no other cardiovascular anomalies. Atrial septal and ventricular septal defects were the second and third leading types of anomalies respectively. When the number of babies with one or more CVS anomalies (rather than the number of CVS anomalies) was considered, on average 12 babies each year (excluding isolated preterm PDAs) were born with one or more CVS anomalies, with rates in Taranaki being similar to than the New Zealand average (RR 1.18 95% CI 0.91 – 1.52). During 2000-2009, the proportion of babies with one or more cardiovascular anomalies increased during the early 2000s, reached a peak in 2004-05 and then declined, with rates being higher than the New Zealand average during the early-mid 2000s, and more similar thereafter, It is unclear however whether these trends reflected real changes in the underlying prevalence of cardiovascular anomalies, random year to year variations, or differences in the way in which more minor anomalies were recorded in the hospital admission dataset.

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Antenatal and Neonatal Screening	Down Syndrome	In New Zealand during 2005-2009, Down Syndrome was the most frequent chromosomal anomaly identified at the time of birth, accounting for 88.3% of chromosomal anomalies during this period. Overall, 51.9% of babies with Down Syndrome had one or more co-existing cardiovascular anomalies, with the most frequent being atrial septal defects and patent ductus arteriosus. While the highest absolute numbers of babies with Down Syndrome were born to women aged 35-39 years, Down Syndrome rates rose exponentially with maternal age, with the highest rates being seen in babies whose mothers were 40+ years. There were no statistically significant socioeconomic, ethnic or gender differences in the proportion of babies with Down syndrome during this period although during 2000-2009, rates were generally lower for Māori than for European babies.	In Taranaki during 2005-2009, 12 babies were identified with Down Syndrome at the time of birth, with this equating to 2.4 births per year. A smaller number were identified as having Edwards or Patau Syndromes, or other chromosomal anomalies. During this period, the proportion of babies with Down Syndrome identified at birth was significantly higher than the New Zealand average (RR 1.85 95% CI 1.04 – 3.30), although there was considerable year to year variability during 2000-2009.
	Neural Tube Defects	In New Zealand during 2000-2009, on average, 13.3 babies per year had one or more neural tube defects (NTDs) evident at the time of birth, with large year to year fluctuations being evident during this period. During 2005-2009, NTDs identified at birth were significantly higher for babies born to teenage mothers (vs. mothers aged 20-39 years). Rates were also significantly higher for Māori babies than for European babies, and for those in the most deprived (NZDep Decile 9-10) areas.	In Taranaki during 2005-2009, a total of 3 neural tube defects were evident at the time of birth, with these accounting for 21.4% of all nervous system malformations during this period. When the number of babies with one or more NTDs, rather than the total number of NTDs was taken into account, the numbers were the same, with 3 Taranaki babies having a neural tube defect evident at birth, equating to 0.6 babies per year, and a rate that was not significantly different from the New Zealand average (RR 1.67 95% CI 0.53 – 5.31).
	Cystic Fibrosis	In New Zealand during 2005-2009, 84.6% of hospital admissions for children and young people with cystic fibrosis had cystic fibrosis listed as the primary diagnosis. Of those with cystic fibrosis as the primary diagnosis, the vast majority also had a secondary diagnosis, with these including a range of infectious (e.g. pseudomonas, staphylococcus aureus, aspergillosis), respiratory (e.g. bronchiectasis, pneumonia) and other (e.g. diabetes) complications. During this period, hospital admissions were similar for males and females, and no marked social gradients were evident (with rates being highest for those living in average NZDep decile areas, and *significantly* lower for those in the most deprived (decile 10) areas). Admissions however, were *significantly* higher for European > Māori > Pacific and Asian children and young people.	In Taranaki during 2005-2009, a total of 10 individual children and young people were admitted to hospital with cystic fibrosis listed in any of the first 15 diagnoses. Admission rates per 100,000 population were significantly lower than the New Zealand average (RR 0.75 95% CI 0.58-0.98). Admission rates increased during the early 2000s, reached a peak in 2002-03 and then declined, with rates during the early 2000s being similar to the New Zealand average, while rates during the mid-late 2000s were lower.

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Other Disabilities			
Other Disabilities	Developmental Delays and Intellectual Disabilities	In New Zealand during 2005-2009, 23.6% of hospitalisations for children and young people with developmental delays had the developmental delay listed as the primary diagnosis. A further 15.5% had respiratory infections and diseases listed as the primary diagnosis, while 8.9% were admitted primarily for epilepsy or convulsions. Similarly, only 7.2% of hospitalisations for children and young people with intellectual disabilities had their intellectual disability listed as the primary diagnosis, with 14.7% being admitted for dental caries or other oral health issues, and 13.1% for epilepsy or convulsions. Hospitalisations for those with developmental delays were highest during the first year of life, with rates dropping away rapidly thereafter. In contrast, hospitalisations for those with intellectual disabilities were relatively infrequent in the first two years of life, but increased during childhood and the early teens. Hospitalisations for those with developmental delays were significantly higher for males, Pacific > Māori and European > Asian children and young people and those living in average-more deprived (NZDep deciles 5-10) areas, while hospitalisations for those with intellectual disabilities were significantly higher for males, Pacific and Māori > European > Asian children and young people and those living in average-more deprived (NZDep deciles 5-10) areas.	In Taranaki during 2005-2009, a total of 76 individual children and young people were admitted to hospital with a developmental delay listed in any of the first 15 diagnoses. Admission rates per 100,000 population were significantly lower than the New Zealand average (RR 0.71 95% CI 0.59 – 0.87). In addition, 32 individual children and young people were admitted to hospital with an intellectual disability listed in any of the first 15 diagnoses, although admission rates per 100,000 population were not significantly different from the New Zealand average (RR 0.87 95% CI 0.65 – 1.16).
	Cerebral Palsy	In New Zealand during 2005-2009, only 4.98% of acute and arranged hospital admissions for children and young people with cerebral palsy had cerebral palsy listed as their primary diagnosis, with 10.8% of admissions being for epilepsy or convulsions and 14.5% being for respiratory infections / diseases. Overall, acute and arranged admissions accounted for 57.6% of admissions, while 42.4% were from the waiting list. Orthopaedic procedures accounted for 46.8% of waiting list admissions, and for 19.8% of all admissions in children and young people with cerebral palsy. During this period, hospital admissions were significantly higher for males and those living in average-more deprived (NZDep deciles 4-10) areas. Admission rates were similar for Māori, Pacific and European children and young people, but significantly lower for Asian children and young people.	In Taranaki during 2005-2009, a total of 36 individual children and young people were admitted to hospital with cerebral palsy listed in any of the first 15 diagnoses. Admission rates per 100,000 population were significantly lower than the New Zealand average (RR 0.62 95% CI 0.50 – 0.77) (Table 38). Similar differences were seen during 2000-2009.

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Other Disabilities	Autism and Other Pervasive Developmental Disorders	In New Zealand during 2005-2009, autism or other pervasive developmental disorders were listed as the primary diagnosis in only 12.1% of hospitalisations for children and young people with pervasive developmental disorders. Of this 12.1%, 61.9% had childhood autism listed as the primary diagnosis, while 34.0% had pervasive developmental disorder NOS and 4.2% had other pervasive developmental disorders listed. Overall, 20.2% of admissions in those with pervasive developmental disorders were for dental caries or other oral health problems, while a further 9.9% were for epilepsy or convulsions. Hospital admissions were significantly higher for males and for European than for Māori, Pacific and Asian children and young people. No consistent socioeconomic gradients were evident, with admission rates being similar for those living in the most and least deprived NZDep areas.	In Taranaki during 2005-2009, a total of 34 individual children and young people were admitted to hospital with autism or other pervasive developmental disorders listed in any of the first 15 diagnoses. Admission rates per 100,000 population were not significantly different from the New Zealand average (RR 0.87 95% CI 0.65 – 1.16). During 2000-2009, while there were some year to year variations, overall admission rates for those with autism in Taranaki remained relatively static, while rates nationally increased. Thus while rates were initially higher than the New Zealand average during the early 2000s, by 2004-2009, rates were similar to the national average.
Other Chronic Medical Conditions			
Other Chronic Medical Conditions	Diabetes	**Insulin Dependent Diabetes**: In New Zealand during 2005-2009, 67.5% of hospitalisations for children and young people with IDDM were for diabetes related diagnoses, with ketoacidosis accounting for 30.2%, and IDDM without complications for 27.9% of admissions. A further 32.5% were for non-diabetes diagnoses, with gastroenteritis, injuries, and respiratory diseases being the leading causes. Admissions increased during childhood, reached a peak in those in their late teens and then declined during the early 20s. Admissions were significantly higher for females, European > Māori and Pacific > Asian children and young people, and those in average-more deprived (NZDep Decile 3-10) areas. **Non-Insulin Dependent Diabetes**: In New Zealand during 2005-2009, 17.8% of hospitalisations for children and young people with NIDDM were for diabetes related diagnoses, with NIDDM without complications accounting for 5.6% of admissions. The remaining 82.2% were for other diagnoses, with cystic fibrosis (17.98%) and pregnancy and childbirth (10.2%) being the leading causes. Hospitalisations were infrequent during childhood but increased gradually thereafter. Admissions were significantly higher for females, Pacific > Māori > European > Asian children and young people, and those in average-more deprived areas.	**Insulin Dependent Diabetes**: In Taranaki during 2005-2009, a total of 76 individual patients were admitted to hospital with Insulin Dependent Diabetes listed in any of the first 15 diagnoses. When hospitalisations per 100,000 population were considered, rates for IDDM in Taranaki were similar to the New Zealand average (RR 0.98 95% CI 0.85 – 1.13). **Non-Insulin Dependent Diabetes**: In Taranaki during 2005-2009, a total of 12 individual patients were admitted with Non-Insulin Dependent Diabetes listed in any of the first 15 diagnoses. When hospitalisations per 100,000 population were considered, rates for NIDDM in Taranaki were significantly lower than the New Zealand average (RR 0.55 95% CI 0.34 – 0.89).

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Other Chronic Medical Conditions	Epilepsy and Status Epilepticus	In New Zealand during 2005-2009, 70.5% of hospital admissions in children and young people with epilepsy or status epilepticus were for epilepsy related diagnoses, with generalised idiopathic epilepsy (27.3%) and unspecified epilepsy (21.1%) making the greatest contribution. A further 29.5% of admissions were for conditions unrelated to epilepsy, with respiratory infections and diseases, pregnancy and childbirth, and injuries making the largest contributions. Secondary diagnoses for those admitted with epilepsy or status epilepticus as a primary diagnosis, fell into two main categories: conditions which may have increased the risk of developing epilepsy (e.g. cerebral palsy, congenital anomalies of the nervous system); and acute concurrent illnesses such as respiratory infections and otitis media. During 2005-2009, admissions were highest during the first five years of life, with rates declining during mid-late childhood, but increasing again during the mid-late teens. Mortality was more frequent for those in their teens and early 20s, with a total of 57 children and young people dying from epilepsy or status epilepticus during 2003-2007. Hospital admissions were significantly higher for males, Māori and Pacific > European > Asian children and young people and those in average-more deprived (NZDep deciles 3-10) areas.	In Taranaki during 2005-2009, a total of 99 individual children and young people were admitted with a diagnosis of epilepsy or status epilepticus, with hospital admission rates per 100,000 population being similar to the New Zealand average (RR 1.07 95% CI 0.94 – 1.21). Similar patterns were seen during 2000-2009.
	Cancer	In New Zealand during 2003-2007, carcinoma in situ of the cervix was the most frequent reason for a notification to the NZ Cancer Registry in children and young people aged 0-24 years, and accounted for 60.4% of notifications in this age group. Acute lymphoblastic leukaemia was the second leading reason for notification, followed by malignant melanomas of the skin. During the same period, cancers of the brain were the leading cause of cancer mortality in New Zealand children and young people, followed by acute lymphoblastic leukaemia.	In Taranaki during 2003-2007, carcinoma in situ of the cervix was the most frequent reason for a notification to the NZ Cancer Registry in children and young people aged 0-24 years, and accounted for 50.5 % of notifications in this age group. Acute lymphoblastic leukaemia was the second leading reason for notification, followed by malignant melanomas and cancers of the brain. Cancers of the brain were also the leading cause of cancer mortality in Taranaki children and young people.

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Obesity, Nutrition And Physical Activity			
Obesity, Nutrition And Physical Activity	Overweight and Obesity	In the 2006/07 NZ Health Survey, there were no significant gender differences in overweight or obesity in those aged 2-14 years. Adjusted for age, Māori and Pacific children however were *significantly* more likely to be overweight or obese than those in the total population, while Asian and European / Other children were *significantly* less likely to be overweight, and European / Other children were also *significantly* less likely to be obese. Children in the most deprived (NZDep deciles 9-10) areas were *significantly* more likely to be obese than those in the least deprived-average ((NZDep decile 1-8) areas. Children in the most deprived (NZDep deciles 9-10) areas were also *significantly* more likely to be overweight than those living in more affluent (NZDep deciles 1-4) areas. Similar patterns were identified in the 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours, for those aged 5-24 years.	
	Nutrition	**Fruit and Vegetable Intake**: In the 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours, there were no significant gender, ethnic or socioeconomic differences in the proportion of those aged 5-24 years achieving fruit intake guidelines. The proportion of Pacific and Asian children and young people achieving vegetable intake guidelines however was *significantly* lower than for European / Other children and young people. **Breakfast at Home**: In the 2006/07 NZ Health Survey (06/07 NZHS), boys were *significantly* more likely to have eaten breakfast at home every day in the previous week than girls. This proportion decreased with increasing age, with those aged 10-14 years being *significantly* less likely to eat breakfast at home every day than those aged 2-4 years. Rates for Māori and Pacific children were *significantly* lower than for the total population. Rates for boys in the most deprived (NZDep decile 9-10) areas were also *significantly* lower than for boys from the least deprived (NZDep Decile 1-2) areas, although no significant differences were seen for girls.	

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Obesity, Nutrition And Physical Activity	Nutrition	**Fizzy Drinks**: In the 06/07 NZHS, boys aged 10-14 years were *significantly* more likely to have consumed 3+ fizzy drinks in the previous week than girls aged 10-14 years. In addition, rates for children aged 10-14 years were *significantly* higher than for children aged 2-4 years. Rates for Māori and Pacific children were *significantly* higher than for the total population, while rates for European / Other children were *significantly* lower. Rates were also *significantly* higher for those in the most deprived (NZDep decile 9-10) areas. **Takeaways / Fast Food**: In the 06/07 NZHS, there were no significant gender or age differences in the proportion of children aged 2-14 years who had consumed takeaways / fast food 3+ times in the past week. Rates for Māori and Pacific children were *significantly* higher than for children in the total population. Rates for children living in the most deprived (NZDep decile 9-10) areas were also *significantly* higher than for children in the least deprived (NZDep deciles 1-2) areas.	
	Physical Activity	**Physical Activity Guidelines**: In the 2008/09 Survey of Children and Young People's Physical Activity and Dietary Behaviours, the proportion of children and young people meeting the NZ Physical Activity Guidelines (as measured by an accelerometer) declined *significantly* with increasing age. Differences by ethnicity and NZ Deprivation index decile however, did not reach statistical significance. **Screen Time Guidelines**: In the NZS-CY-PA-DB-2008/09 children and young people aged 5-24 years were considered to have met the screen time guidelines if they had <2 hours per day of screen time. Females were *significantly* more likely to achieve screen time guidelines than males, with those aged 5-9 years also being *significantly* more likely to achieve the guideline than older age groups. There were no significant differences by ethnicity or NZDep deprivation. **Television Viewing**: In the 2006/07 NZHS, 64.1% of children aged 5-14 years usually watched 2+ hours of television per day. Children aged 10-14 years were *significantly* more likely to watch television 2+ hours per day than those 5-9 years. Rates were *significantly* higher in Māori children and for those in the most deprived (NZDep deciles 9-10) areas.	

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Obesity, Nutrition And Physical Activity	Physical Activity	**Travel to School by Active Means**: In the 2006/07 NZHS, private cars, followed by walking, were the most common ways for children to get to school. Use of active transport for Māori and Pacific boys was *significantly* higher than for the total population, while European / Other boys were *significantly* less likely to travel to school by active means. For girls ethnic differences did not reach statistical significance. There were no significant differences by NZDep deprivation. Barriers which prevented children using active transport to travel to school included the distances being too far, the traffic being too busy, it being too dangerous and the time it would take.	
	Iron Deficiency Anaemia	In New Zealand during 2005-2009, 7.1% of hospitalisations in children 0-4 years with iron deficiency anaemia had their anaemia listed as the primary diagnosis, with 41.1% of admissions being for respiratory infections / diseases. In contrast, 14.8% of admissions in women aged 15-24 years with iron deficiency anaemia had their anaemia listed as the primary diagnosis, with 36.1% of admissions being related to pregnancy or childbirth, and 7.7% being for irregular or excessive uterine bleeding. During this period, admissions were highest in infants during the first two years of life, with a male predominance evident in this age group. Rates were also higher amongst young women in their teens and early twenties. Rates for children aged 0-4 years were *significantly* higher for males, Pacific > Māori and Asian > European children and those living in average-more deprived areas. Similarly for women aged 15-24 years, rates were *significantly* higher for Pacific > Māori > European and Asian women and those living in average–more deprived areas. When the proportion of hospital admissions rather than rates per 100,000 population were considered, socioeconomic gradients, while still present, were less marked. In addition, rate ratios for Asian women aged 15-24 years became more prominent.	In Taranaki during 2005-2009, hospital admissions for children aged 0-4 years with iron deficiency anaemia were significantly lower than the New Zealand average, while admissions for women aged 15-24 years and children and young people aged 0-24 years were not significantly different from the New Zealand average. These differences persisted, even when the unit of analysis was the proportion of hospital admissions, rather than rates per 100,000 population. It remains unclear however, whether these differences reflect real differences in the prevalence of iron deficiency anaemia, or differences in the way secondary diagnoses (e.g. iron deficiency anaemia) were recorded in the hospital admission dataset.

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Children's Social Health Monitor			
Children's Social Health Monitor: Economic Indicators	Gross Domestic Product (GDP)	In New Zealand, GDP decreased for 5 consecutive quarters from March 2008-March 2009. GDP has since increased for five consecutive quarters, with economic activity being up 0.2% in the June 2010 quarter, following a 0.5% increase in the March 2010 quarter. Economic activity for the year ending June 2010 was up 0.7% when compared to the year ending June 2009, with this being the first annual increase in economic activity since a 1.5% rise in the year ended September 2008.	
	Income Inequality	In New Zealand during 1984-2009 income inequality, as measured by the P80/P20 ratio and Gini coefficient, was higher after adjusting for housing costs than prior to this adjustment. The most rapid rises in income inequality occurred between the late 1980s and early 1990s. During the early-mid 2000s however, income inequality declined, a change Perry attributes largely to the Working for Families package. Rises in income inequality were again evident between 2007 and 2009, although another year's data may be required, before it is possible to determine whether this is the beginning of an upward trend, or just a statistical fluctuation.	
	Child Poverty	In New Zealand during 1988-1992, child poverty rates increased markedly, as a result of rising unemployment and the 1991 Benefit cuts. During 1994-1998 however, rates declined, as economic conditions improved and unemployment fell. During 1998-2004, child poverty trends varied, depending on the measure used, but between 2004 and 2007 they again declined, following the roll out of the Working for Families package. For the majority of this period, child poverty rates were higher for younger children (0-11 vs. 12-17 years), larger households (3+ children vs. 1-2 children), sole parent households and households where the adults were either workless, or where none worked full time.	

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Children's Social Health Monitor: Economic Indicators	Living Standards	The Ministry of Social Development has undertaken 3 Living Standards Surveys, in 2000, 2004 and 2008. At the time of writing, some preliminary findings from the 2008 Living Standards Survey suggest that: *The % of children living in hardship (ELSI Levels 1-2) fell from 26% to 19% between 2004 and 2008 *Most of these gains were for low to middle income working families, with hardship rates for sole parent beneficiary families remaining at around 55% *Hardship rates for sole parent families were around 4 times those for two parent families (39% vs. 11%) *Beneficiary families with dependent children had hardship rates around 5 times those of working families with children (50% vs. 11%), with half of children in hardship being from working families and half from beneficiary families *Sole parent families in work (20%) had hardship rates well below sole parent beneficiary families (54%) *Although hardship rates for children had fallen, children remained significantly over represented in the hardship group	
	Unemployment Rates	In the quarter ending September 2010, seasonally adjusted unemployment fell to 6.4%, with seasonally adjusted unemployment numbers decreasing by 10,000 to 150,000. During September 1987-2010, unemployment rates were higher for younger people (15-19 years > 20-24 years > 25-29 years > 35-39 years and 45-49 years) and those with no qualifications > school qualifications, or post school but no school qualifications > both post school and school qualifications, although there were no consistent gender differences for young people 15-24 years. During 2007(Q4)-2010(Q3) unemployment rates were higher for Māori and Pacific > Asian > European people. While unemployment rates increased for all ethnic groups, in absolute terms, increases were greatest for Māori and Pacific people.	In Taranaki during the years ending September 1987-2010, unemployment trends were similar to those occurring nationally, with the highest rates being seen in the year ending September 1992, when they peaked at 12.2%. During the 2000s, rates reached their lowest point, at 3.2% in the year ending September 2008, before climbing again to 5.3% in the year ending September 2010. On a quarterly basis, during 2004(Q1)-2009(Q1) unemployment rates fluctuated, but began to rise thereafter, reaching 6.0% by 2009(Q4) before declining again to 5.0% in 2010(Q3). During 2008-2010(Q3), unemployment rates in Taranaki were lower than the New Zealand average.

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Children's Social Health Monitor: Economic Indicators	Children Reliant on Benefit Recipients	In New Zealand the proportion of children aged 0-18 years who were reliant on a benefit, or benefit recipient, fell from 25.6% in April 2000 to 18.3% in April 2008, before increasing again to 20.7% in April 2010. A large proportion of the initial decline was due to a fall in the number of children reliant on unemployment benefit recipients (from 4.5% of children in 2000 to 0.5% in April 2008 → to 1.4% in April 2010). While the proportion of children reliant on DPB recipients also fell (17.2% of children in April 2000, to 13.6% in April 2008, to 15.1% in April 2010), the rate of decline was much slower than for unemployment benefits, meaning that in relative terms, the proportion of benefit dependent children reliant on DPB recipients actually increased, from 67.2% of all benefit dependent children in April 2000, to 72.7% in April 2010.	At the end of April 2010, there were 5,586 children aged 0-18 years who were reliant on a benefit or benefit recipient and who received their benefits from Service Centres in the Taranaki catchment. While the majority of these children were reliant on DPB recipients, increases in the number reliant on DPB and unemployment benefit recipients were evident between April 2008 and April 2010.
Children's Social Health Monitor: Child Health and Wellbeing	Hospital Admissions and Mortality with a Social Gradient	Medical admissions with a social gradient in children increased during the early 2000s, reached peak in 2002 and then declined, with an upswing in rates again being evident during 2007-2009. In contrast, injury admissions with a social gradient declined throughout 2000-2009. Medical admissions for Pacific children increased during the early 2000s, reached a peak in 2003 and then declined, with an upswing in rates again being evident during 2007-2009. For Māori children, rates were static during the early-mid 2000s, but increased after 2007, while for Asian children rates during 2002-2009 were static. Rates for European children declined gradually during 2002-2009. During 2005-2009, infectious and respiratory diseases were responsible for the majority of hospitalisations for medical conditions with a social gradient, while falls, followed by inanimate mechanical forces were the leading causes of injury admissions. In contrast, during 2003-2007 SUDI made the single largest contribution to mortality with a social gradient. Vehicle occupant deaths were the second leading cause, followed by pedestrian injuries and drowning, while bacterial / non viral pneumonia was the leading cause of death from medical conditions.	In Taranaki, hospitalisations for medical conditions with a social gradient increased during the early 2000s, reached a peak in 2002 and then declined. Rates reached their lowest point in 2007, before rising again rapidly during 2008-2009. In contrast, injury admissions with a social gradient decreased gradually during 2000-2009. When broken down by ethnicity, hospital admissions for medical conditions with a social gradient were higher for Māori than for European children. Rates for both ethnic groups declined during the mid 2000s, reached their lowest point in 2007 and then increased again, with the largest absolute increases being for Māori children. In contrast, injury admissions declined gradually for both ethnic groups. In addition, during 2000-2007, 13 Taranaki children died from injuries and 10 from medical conditions with a social gradient, while 15 (post neonatal) infants died as a result of SUDI.

Stream	Indicator	New Zealand Distribution and Trends	Taranaki Distribution and Trends
Children's Social Health Monitor: Child Health and Wellbeing	Infant Mortality	In New Zealand during 1990-2007, neonatal and post neonatal mortality both declined, with neonatal mortality exceeding post neonatal mortality during the 2000s. When broken down by ethnicity, neonatal mortality was higher for Pacific and Māori > European > Asian infants during the late 1990s, although ethnic differences were less consistent during the 2000s. In contrast, post neonatal mortality was higher for Māori > Pacific > European and Asian infants throughout 1996-2007. When broken down by cause, extreme prematurity and congenital anomalies were the leading causes of neonatal mortality in New Zealand during 2003-2007. In contrast, SUDI was the leading cause of post-neonatal mortality, followed by congenital anomalies. During this period, neonatal mortality was *significantly* higher for Pacific > Māori, European and Asian infants, males and those in more deprived areas, while post neonatal mortality was *significantly* higher for Māori and Pacific > European and Asian infants, males and those in more deprived areas. SUDI was *significantly* higher for Māori > Pacific > European > Asian infants, and those in average to more deprived areas.	In Taranaki during 2003-2007, both neonatal mortality (RR 0.96 95% CI 0.62-1.47) and post neonatal mortality (RR 1.30 95% CI 0.84 - 2.01) were not significantly different from the New Zealand average. During this period, congenital anomalies were the most frequent causes of neonatal mortality, while SUDI was the most frequent cause of post neonatal mortality.
	Injuries Arising from the Assault, Neglect or Maltreatment of Children	In New Zealand during 2005-2009, hospital admissions for injuries sustained as the result of the assault, neglect or maltreatment of children exhibited a J-shaped distribution with age, with rates being highest for infants < 1 year, and those > 11 years of age. In contrast, mortality was highest for infants < 1 year. While the gender balance for admissions was relatively even during infancy and early childhood, hospital admissions for males became more predominant as adolescence approached. In addition, admissions were also significantly higher for males, Māori > Pacific > European and Asian children, and those in the most deprived areas.	In Taranaki during 2005-2009, hospital admissions for injuries arising from the assault, neglect or maltreatment of children were similar to the New Zealand average (RR 1.02 95% CI 0.67-1.55), with large year to year variations being evident during 2000-2009. During 2000-2007, 3 Taranaki children died as the result of assault, neglect or maltreatment.

CHILDREN AND YOUNG PEOPLE WITH CHRONIC CONDITIONS AND DISABILITES

INTRODUCTION TO ANTENATAL AND NEONATAL SCREENING

ANTENATAL AND NEONATAL SCREENING

Introduction

Overseas research suggests that up to 25% of babies with severe forms of congenital heart disease are discharged from hospital undiagnosed [2]. Similarly, in the New Zealand context, a small number of babies each year are born with inborn errors of metabolism (e.g. galactosaemia), which if left untreated, may lead to permanent end organ damage within a relatively short period of time [3]. Even for non-life threatening conditions, delayed diagnosis may lead to the loss of opportunities for early intervention (e.g. congenital hearing loss: identified with newborn screening vs. at an average age of 35.1 months if screening is based on the presence of risk factors [4]).

The early detection of such conditions thus confers significant advantage, with antenatal diagnosis also providing the opportunity to exclude additional congenital or chromosomal abnormalities, to discuss pregnancy options with parents, and to plan for delivery in a tertiary centre, if additional services are to be required [5]. For a number of conditions however (e.g. congenital deafness, inborn errors of metabolism where the placenta clears metabolites in-utero) antenatal diagnosis is not possible, and in such cases early detection in the neonatal period becomes of critical importance.

In New Zealand, a number of screening programmes have been established to detect congenital anomalies and inborn errors of metabolism in the antenatal period, or as soon as possible after birth. The following sections briefly review each of these in turn.

Screening During the Antenatal Period

Antenatal Screening for Down Syndrome and Other Conditions

Antenatal screening for Down Syndrome and other conditions has been available to pregnant women since 1968 [6], although concerns during the mid-2000s that the current screening processes were ad-hoc [7], led to the National Screening Unit releasing a set of guidelines for maternity providers in 2009 [6]. These guidelines suggest that all pregnant women be offered antenatal screening for Down syndrome and other conditions in either the first or second trimester of pregnancy as follows:

1. **For Women Presenting in their First Trimester**: A blood test that measures two maternal serum markers (pregnancy-associated plasma protein A (PAPP-A) and Beta-human chorionic gonadotrophin (βhCG)) should be combined with the results of an ultrasound which assesses nuchal translucency (a marker which measures the fluid filled space in the tissue at the back of a fetus' neck and is a marker for chromosomal and other anomalies) and other parameters (e.g. crown-rump length). The optimal time for screening using maternal serum markers is 10-12 weeks, while the optimal time for an ultrasound to assess nuchal translucency is 11.5-13.5 weeks [6].
2. **For Women Presenting in their Second Trimester**: A blood test that measures four maternal serum markers (βhCG, alpha-fetoprotein, unconjugated oestriol and inhibin A), with the optimal time for serum screening being 14-18 weeks [6].

The Screening Unit also recommends that the provision of accurate and non-directive information (both medical and non-medical) be combined with unconditional support for the decisions made by women, including the decision as to whether or not to participate in screening. After undergoing screening, all women who are deemed to be at a high risk of Down Syndrome or other conditions should then be offered an obstetric referral to discuss diagnostic testing options including: chorionic villus sampling (usually performed at 10-13 weeks); and amniocentesis (usually performed at 15-20 weeks). Maternity providers should also advise women with an increased risk of the availability of genetic counselling services [6].

In addition, while not being part of a formal screening programme, ultrasounds are frequently undertaken between 18-20 weeks of gestation to screen for obvious structural

anomalies, although such scans are thought not to be as effective for Down Syndrome screening as the screening modalities listed above [6].

Screening During the Neonatal Period

Newborn Examination

The Well Child / Tamariki Ora Schedule recommends that a detailed clinical examination be undertaken within 48 hours of birth (initial examination usually undertaken at birth), with a further clinical examination being undertaken within 7 days, and another at 4-6 weeks (at the time of discharge from maternity services) [8]. At the initial (newborn) examination the Schedule recommends that clinicians undertake a thorough assessment which includes: the child's overall health and wellbeing, weight, length and head circumference, and a more detailed examination of their hips, cardiovascular system (heart, umbilicus, and femoral pulses), eyes (red reflex), colour, respiration, tone, Moro reflex, grasp reflex, movements, skin, head, fontanelles, ears, mouth, lungs, abdomen, umbilicus, genitalia, anus, spine, and limbs [9].

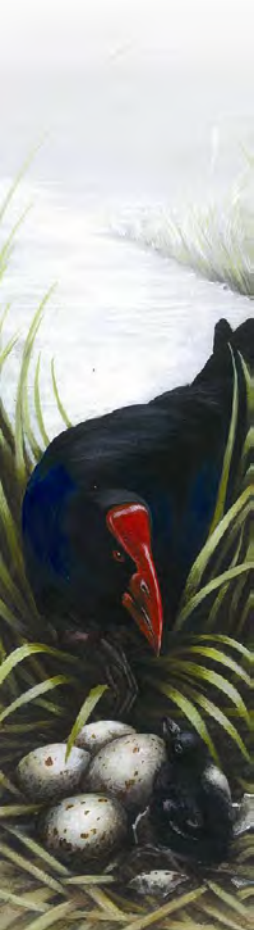
Newborn Metabolic Screening Programme

When New Zealand first commenced newborn metabolic screening in 1969, screening was initially only undertaken for phenylketonuria (PKU) [3]. The current Newborn Metabolic Screening Programme (NMSP) however, screens for 28 metabolic disorders [3], with these conditions being outlined in **Table 2**.

Table 2. Conditions Included in New Zealand's Newborn Metabolic Screening Programme

Disorder	Incidence
Congenital Hypothyroidism	1 in 4,000 babies (≈15 babies a year)
Cystic Fibrosis	1 in 7,000 babies (≈ 8 babies a year)
Amino Acid Disorders (14 disorders including e.g. Phenylketonuria (PKU))	1 in 12,000 babies (≈ 5 babies a year)
Fatty Acid Oxidation Disorders (9 disorders including e.g. Medium Chain acyl-CoA Dehydrogenase Deficiency)	1 in 12,000 babies (≈ 5 babies a year)
Congenital Adrenal Hyperplasia	1 in 20,000 babies (≈ 3 babies a year)
Galactosemia	1 in 100,000 (≈ 1 baby every 2 years)
Biotinidase Deficiency	1 in 150,000 (≈ 1 baby every 3 years)

Source: National Screening Unit http://www.nsu.govt.nz/current-nsu-programmes/2097.asp



Lead Maternity Carers (LMCs) are responsible for undertaking newborn metabolic screening, with their tasks including giving information and advice, offering screening, ensuring informed consent, taking the sample and following up on the results. The National Screening Unit recommends that LMCs take samples when the baby is 48 hours old, or as soon as possible thereafter. Timing is important as samples taken earlier (e.g. at the time of birth) may be negative due to the placenta eliminating abnormal markers, while samples taken later may result in a lost window for early intervention, as severe forms of some metabolic disorders may be fatal within 7-10 days, but may not show any signs or symptoms until irreversible damage has occurred [3]. Blood samples are usually taken by heel prick, with blood being collected onto a blood spot card, which has two main parts: a smaller portion with specimen collection paper for the sample itself, and a larger portion for demographic and other information [3]. At the time the sample is taken, parents are asked whether they wish the card to be stored for possible future use, or returned to them.

National Newborn Hearing Screening Programme

In New Zealand each year, it is estimated that 135-170 babies are born with mild to profound permanent congenital hearing loss, representing an incidence of 3 per 1,000 births [10]. In response to concerns regarding the late age of diagnosis of congenital hearing losses (average age 35.1 months when screening was based on the presence of risk factors [4]), the Government in its 2006 Budget, announced a funding package ($16 million over four years) to establish a National Newborn Hearing Screening Programme. The Programme has been rolled out progressively across the country, with screening now

underway in all 20 DHBs, with 11 DHBs having been screening for a full year, and with at least 32 babies with hearing losses being identified by the Programme during this period [11].

For babies born in hospital, screening is offered in most cases before the baby goes home, with those born elsewhere, or not managing to be screened prior to discharge being able to access screening on an outpatient basis. Screening is usually undertaken while the baby is asleep or quietly resting, with two type of screening being available:

1. **Automated Otoacoustic Emissions (AOAE)**: Sensory cells in the cochlea of the inner ear oscillate in response to an external sound, with these oscillations generating an „echo', which passes from the inner ear to the ear canal, and which can be detected as sound. These sounds, known as otoacoustic emissions (OAEs) are a sign that the ear is functioning normally and the measurement of OAEs can be used to test normal cochlear function in the newborn. Testing involves placing a small earphone and microphone in the ear, playing a sound and recording the response from the ear. If a baby has a normally functioning inner ear, an OAE is produced and this can be picked up by the microphone in the ear-canal [12].
2. **Auditory Brainstem Response (ABR)**: The ABR is a series of electrical waves that can be recorded from electrodes on the scalp, in response to brief sounds being played into the ear. The presence of these waves with changing sound intensity is highly correlated with different hearing thresholds, with the ABR being used to assess the integrity of the ear and auditory nerve pathways to the brainstem in newborn babies [12].

Conditions Detectable by Antenatal and Newborn Screening

The sections which follow briefly review a number of conditions which are potentially detectable by antenatal or neonatal screening, with a view to determining the relative contribution each might make to future health service demand.

The conditions reviewed are:

- Congenital Anomalies Evident at Birth (**Page 28**)
- Cardiovascular Anomalies Evident at Birth (**Page 40**)
- Down Syndrome (**Page 49**)
- Neural Tube Defects (**Page 58**)
- Cystic Fibrosis (**Page 64**)

While local policy documents and evidence based reviews relevant to these conditions are reviewed at the end of each section, **Table 3** provides an overview of publications which consider antenatal and neonatal screening in more general terms.

Finally, while the National Newborn Hearing Screening Programme means that congenital hearing losses are now detectable in the neonatal period, the first screening data from the Programme will not be released until mid-next year, and thus congenital hearing loss will be reviewed in next year's report.

Local Policy Documents and Evidence Based Reviews Relevant to Antenatal and Neonatal Screening

In New Zealand there is a paucity of policy documents and evidence based reviews which consider antenatal and neonatal screening collectively, with the available local publications being summarised in **Table 3,** alongside a number of reviews which consider these issues in the overseas context. In addition, **Table 10** on **Page 38** considers the early detection and management of congenital anomalies collectively, while **Table 15** on **Page 47** considers the early detection and management of cardiovascular anomalies, **Table 20** on **Page 56** considers the antenatal diagnosis and management of children with Down Syndrome, and **Table 24** on **Page 63** considers folic acid supplementation and the diagnosis and management of children with neural tube defects.

Table 3. Local Policy Documents and Evidence Based Reviews Relevant to Antenatal and Neonatal Screening

New Zealand Policy Documents
National Screening Unit. **Guidelines For Practitioners Providing Services Within the Newborn Metabolic Screening Programme in New Zealand February 2010**. Wellington: National Screening Unit, 2010. Lead Maternity Carers are contractually obliged to provide services within screening programmes endorsed by the Ministry of Health, including the Newborn Metabolic Screening Programme, under the Primary Maternity Services Notice 2007. These best practice guidelines are for all practitioners involved in the Newborn Metabolic Screening Programme including Lead Maternity Carers, hospital midwives, nurses and phlebotomists.
Ministry of Health. **Memorandum of Understanding Relating to the Disclosure of Newborn Blood Spot Samples and Related Information**. Wellington: Ministry of Health, New Zealand Police, 2009**.** URL: http://www.nsu.govt.nz/current-nsu-programmes/1316.asp This memorandum, which came into effect on 28th February 2006, regulates requests from the police to the Ministry of Health for access to blood spot samples. It sets out the circumstances in which such requests may be granted for example to identify dead or missing persons on parental request.
International Guidelines and Systematic and Other Reviews
Green K, Oddie S. **The value of the postnatal examination in improving child health.** Archives of Disease in Childhood Fetal & Neonatal Edition 2008; 93(5):F389-93. This paper reviews the evidence regarding the effectiveness of a standard newborn examination in improving infant health. It considers number of examinations (repeated examinations are of benefit for pre term or unwell babies), timing of examinations (which need to be done after 24 hours to improve the chances of detecting congenital heart disease), who performs the examination, detecting congenital heart disease, hip dysplasia, congenital cataracts and cleft lip and palate. The authors concluded that the neonatal examination is highly valued by parents and professionals and probably improves the health of some infants significantly. They also considered that additional screening e.g. by pulse oximetry may be justified.
National Collaborating Centre for Women's and Children's Health. **Antenatal care: Routine care for the healthy pregnant woman**. London: RCOG Press, 2008. URL: http://www.nice.org.uk/nicemedia/live/11947/40145/40145.pdf Section 9.1 of this publication covers screening for structural anomalies and reviews studies relating to the use of ultrasound and serum screening (alpha-fetoprotein, AFP) for this purpose. Second trimester ultrasound seemed in general to show high specificity but poor sensitivity for identifying foetal structural anomalies but the actual values varied considerably depending on the centre and the particular anomaly. There were only a few high quality studies looking at first trimester ultrasound. It was reported to have high specificity and positive likelihood ratio but (as reported by a single centre in the U.K.) moderate sensitivity and negative likelihood ratio. There was good evidence that routine, rather than selective, ultrasound before 24 weeks resulted in better assessment of gestational age, earlier detection of multiple pregnancies and improved detection of foetal anomalies which led to higher termination rates of affected pregnancies. One systematic review (of 5 studies) and two other studies looked at foetal echocardiography. There was a wide range of reported values for sensitivity by centre and condition but the reported specificity was generally high. There was some evidence from 2 uncontrolled observational studies that babies with transposition of the great arteries (and possibly hypoplastic left heart syndrome) diagnosed prenatally had reduced mortality compared with those diagnosed postnatally. Nuchal translucency measurement seemed to have poor diagnostic value for detecting cardiac anomalies. There were two studies identified that investigated maternal serum alpha-fetoprotein (AFP) as a screening test for neural tube defects. One found that maternal AFP had good diagnostic value in both predicting and ruling out anomalies while the other found it to have less diagnostic value than a routine ultrasound. There was no evidence on the value and effectiveness of a combination of routine ultrasound and maternal AFP screening. Section 9.2 of this publication covers screening for Down syndrome and reviews published studies relevant to the diagnostic value and effectiveness screening methods, women's views and psychosocial aspects, and health economics. The recommendations for Down syndrome screening are essentially the same as those in New Zealand.
Bryant L, Fisher A, et al. **Fetal anomaly ultrasound screening programme study: Literature survey**. Plymouth: Social Research and Regeneration Unit, University of Plymouth, 2007. This literature survey was commissioned by the Fetal Anomalies steering group. It relates to routine mid-trimester ultrasound screening and its main purpose was to populate tables relating to the detection rates, false positives and frequencies of a specified list of anomalies, organised under the following headings: Central Nervous System (CNS), Cardio Vascular System (CVS), Chest, Abdomen, Renal, Limbs and Face. A summary of information from this report can be found at: http://www.library.nhs.uk//screening/ViewResource.aspx?resID=269076

Tarini BA. **The current revolution in newborn screening: New technology, old controversies.** Archives of Pediatrics & Adolescent Medicine 2007;161(8):767-72.

This review covers the history of newborn metabolic screening particularly in the U.S. and discusses the implications of the development of tandem mass spectrometry which has made it possibly to test for multiple conditions without needing to collect more blood. Further technological advances are on the way including DNA microarrays which will permit screening for hundreds of potentially disease causing genetic mutations. Parents will be able to pay for testing of their child's blood by private laboratories which need not provide any counselling or follow up care and there is currently little evidence on the consequences of this.

Pandor A, Eastham J, et al. **Clinical effectiveness and cost-effectiveness of neonatal screening for inborn errors of metabolism using tandem mass spectrometry: A systematic review**. Health Technology Assessment 2004; 8(12:iii):1-121.

This review found that there was good evidence to justify the current UK screening programme for phenylketonuria (PKU). It stated that the available evidence appeared to support the introduction of screening using tandem mass spectrometry for PKU and medium-chain acyl-coenzyme A dehydrogenase deficiency combined. It noted that tandem mass spectrometry has the potential to simultaneously screen for multiple diseases using a single analytical technique and that the marginal cost of extending screening to include additional disorders may not be great. This does not necessarily imply that all disorders that can be detected by tandem mass spectrometry should be included in screening.

Other Relevant Publications and Websites

Centers for Disease Control and Prevention. URL: http://www.cdc.gov/index.htm accessed 4/10/2010

The U.S. Centers for Disease Control and Prevention fund The Centers for Birth Defects Research and Prevention (CBDRP) which take part in the National Birth Defects Prevention Study. This is the largest on-going population-based study of its kind. Information about this study can be found at: http://www.cdc.gov/ncbddd/bd/research.htm and a list of the scientific publications at: http://www.cdc.gov/ncbddd/bd/key_pubs.htm.

Wilson C, Webster D. **Position Statement Expanded Newborn Metabolic Screening**. The Paediatric Society of New Zealand, 2006.

Wilson C, Webster D. Position Statement: Expanded Newborn Metabolic Screening. The Paediatric Society of New Zealand, 2006. URL: http://www.paediatrics.org.nz/files/positionstatements/Newborn%20screening%20final.doc

The Paediatric Society of New Zealand supports the introduction of tandem mass spectrometry in order to screen for a greater number of disorders. This position statement sets out their reasons for this and recommends that the Ministry of Health asks the committee for Newborn Screening consider the evidence concerning the benefits of expanded newborn screening with a view to the purchase of a tandem mass spectrometer.

CONGENITAL ANOMALIES EVIDENT AT BIRTH

Introduction

In New Zealand there is little recent data on the prevalence of congenital anomalies at the time of birth, although the Plunket National Child Health Study estimated an overall prevalence of 4.3% in 1990-1991 [13]. Similarly, the 2001 Household Disability Survey estimated that of the 11% of children (0-14 yrs) with a disability, 41% had a disability which had existed from the time of birth [14].

These estimates are similar to those of other developed countries, with a review of congenital anomalies in Glasgow during 1980-1997 finding an overall rate of 324 per 10,000 births [15]. In this study, the overall prevalence fell during the study period, from 382 per 10,000 in 1980, to 238 per 10,000 in 1997, with the authors citing changes in case ascertainment, antenatal screening and diagnostic methods as possible reasons for these trends [15]. Similarly in New Zealand during 1980-1999, late fetal deaths from congenital anomalies declined by 70%, with the authors questioning whether increasing uptake of prenatal diagnosis and the selective termination of pregnancy may have played a role [16]. Such conclusions are supported by a review of fetal and infant deaths from congenital anomalies in Canada, the USA and the UK, which found that while fetal deaths from congenital anomalies at very early gestations (20-25 weeks) had increased markedly, fetal and infant deaths at later gestations had declined, with prenatal diagnosis and the selective termination of pregnancies appearing to be the major factor responsible for the accelerated decline in infant deaths from congenital anomalies during this period [17].

The following section uses the National Minimum Dataset to review the number of congenital anomalies evident at the time of birth, as well as the number of babies born with one or more congenital anomalies. In reviewing this data, the reader is urged to bear in mind that the analysis includes all congenital anomalies in the ICD-10-AM Q00-Q99 range, irrespective of whether they were minor (e.g. skin tags) or major (e.g. spina bifida), and thus the overall prevalence estimates given for some categories may be higher than for comparable overseas estimates which consider only major anomalies. In addition, while this section aims to provide a cross-sectional overview of the types of congenital anomalies seen in the current New Zealand birth cohort, later sections consider cardiovascular anomalies, Down Syndrome and Neural Tube Defects in more detail.

Data Source and Methods

Definition

1. Number of Congenital Anomalies Evident at the Time of Birth (by Anomaly Type)
2. Number of Babies with One or More Congenital Anomalies Evident at the Time of Birth (by Anomaly Type)

Data Source

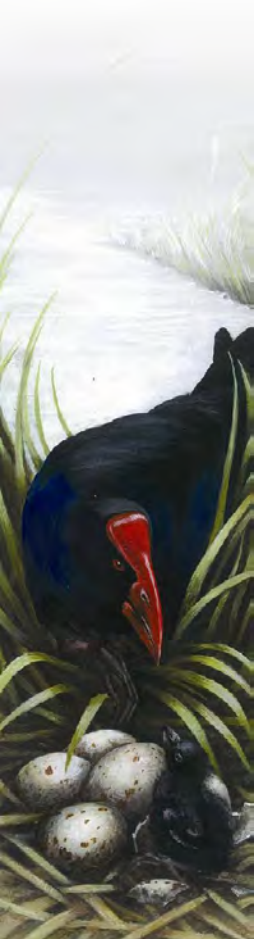
1. National Minimum Dataset

Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly (Q00-Q99) listed in any of the first 15 diagnoses.

Denominator: All Hospital Admissions with Event Type = Birth

Notes on Interpretation

The analysis includes all admissions recorded in the National Minimum Dataset where the Event Type was listed as a Birth (Note: Only one birth event is allowed per NHI number, with babies being born prior to hospital admission, or being readmitted shortly after discharge being listed as a routine inpatient event). Thus the analysis does not include babies born prior to hospital admission, babies born at home, or babies whose congenital anomaly was overlooked at the time of initial hospital discharge, but who re-presented shortly thereafter. Further, the methodology used may significantly undercount those conditions where the congenital or chromosomal anomaly usually only becomes evident at a later age, when the child fails to achieve their normal developmental milestones (e.g. many chromosomal or CNS anomalies), or where the condition may be difficult to detect on routine newborn examination.



Further, because of the large number of ICD-10 diagnoses within the Q00-Q99 range, and the lack of additional supporting information, no attempt has been made to grade the severity of the congenital anomalies identified. The reader must thus bear in mind that in the analyses which follow, minor anomalies such as skin tags and undescended testes (many of which subsequently spontaneously descend), or anomalies which may in some cases be considered a part of normal physiological development (e.g. isolated patent ductus arteriosus in preterm babies), have been counted equally alongside more serious anomalies such as spina bifida, Down Syndrome and Tetralogy of Fallot in the rate calculations. Thus when considering the impact congenital anomalies might have on children's subsequent developmental trajectories, or on future health service demand, the reader is urged to consider the information presented on an anomaly by anomaly basis.

For a list of the ICD-10 codes used to assign anomaly type see **Table 94** and **Table 95** in **Appendix 8.**

Indicator Category Ideal B

New Zealand Distribution and Trends

New Zealand Distribution

In New Zealand during 2005-2009, a large number of congenital anomalies were evident at the time of birth, with these ranging in severity from minor skin conditions (e.g. non-neoplastic nevus), through to anomalies which were incompatible with life (e.g. anencephaly). When interpreting the information in **Table 4** and **Table 5** however, it must be remembered that the figures presented relate to the number of anomalies detected, rather than the number of babies, with many babies having more than one anomaly.

New Zealand Trends

In New Zealand, the number of babies with one or more congenital anomalies identified at birth increased gradually during the early 2000s, reached a peak in 2005 and then declined, with this decline being more rapid after 2007. On average during 2000-2009, 3,159 babies per year had one or more congenital anomalies evident at birth, although the severity of these anomalies varied considerably. During 2009, this equated to 4.1% of all births (**Figure 1**).

Distribution by Maternal Age

In New Zealand during 2005-2009, while in numerical terms the largest number of babies born with congenital anomalies had mothers who were aged 30-34 years, the risk of congenital anomalies rose with increasing maternal age, with babies whose mothers were aged 40+ years having rates 1.35 (95% CI 1.24-1.48) times higher than those whose mothers gave birth in their teens (**Figure 2**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2005-2009, while no socioeconomic differences (as measured by NZ Deprivation Index quintile) were evident, the proportion of babies with one or more congenital anomalies evident at birth was *significantly* higher for males, Pacific and Asian > European and Māori babies, and those whose mothers were aged 35+ years (vs. teenage mothers (**Table 6**)). Similar ethnic differences were seen during 2000-2009 (**Figure 3**).

Table 4. Congenital Anomalies Evident at Birth, New Zealand 2005-2009 (Table 1 of 2)

Congenital Anomaly	Number: Total 2005-2009	Number: Annual Average	Anomalies per 100,000 Births*
Anencephaly	10	2.0	3.3
Encephalocele	10	2.0	3.3
Microcephaly	61	12.2	20.4
Congenital Hydrocephalus	71	14.2	23.8
Other Brain Malformations	150	30.0	50.2
Spina Bifida	60	12.0	20.1
Other Spinal Cord Malformations	10	2.0	3.3
Other CNS Malformations	21	4.2	7.0
Total Malformations of Nervous System	393	78.6	131.5
Eyelid / Lacrimal / Eye / Orbit Malformations	120	24.0	40.1
Ear Malformations Impairing Hearing	22	4.4	7.4
Accessory Auricle	462	92.4	154.6
Other Ear Malformations	271	54.2	90.7
Other Face / Neck Malformations	130	26.0	43.5
Total Malformations of Eye, Ear, Face and Neck	1,005	201.0	336.2
Malformations Cardiac Chambers / Connections	159	31.8	53.2
Ventricular Septal Defect	546	109.2	182.7
Atrial Septal Defect	679	135.8	227.2
Atrioventricular Septal Defect	48	9.6	16.1
Tetralogy of Fallot	82	16.4	27.4
Pulmonary / Tricuspid Valve Malformations	117	23.4	39.1
Aortic / Mitral Valve Malformations	92	18.4	30.8
Other Heart Malformations	351	70.2	117.4
Patent Ductus Arteriosus	1,462	292.4	489.1
Malformations Great Arteries (Excluding PDA)	268	53.6	89.7
Malformations Great Veins	50	10.0	16.7
Other Peripheral Vascular Malformations	253	50.6	84.6
Other Circulatory Malformations	378	75.6	126.5
Total Malformations of Circulatory System	4,485	897.0	1,500.5
Nose Malformations	55	11.0	18.4
Trachea / Bronchus Malformations	114	22.8	38.1
Lung Malformations	117	23.4	39.1
Other Respiratory Malformations	5	1.0	1.7
Total Malformations of Respiratory System	291	58.2	97.4
Ankyloglossia (Tongue Tie)	1,765	353.0	590.5
Tongue / Mouth / Pharynx Malformations	87	17.4	29.1
Oesophagus / Upper Alimentary Malformations	75	15.0	25.1
Intestinal Malformations	256	51.2	85.7
Other Digestive Malformations	42	8.4	14.1
Total Malformations of Digestive System	2,225	445.0	744.4

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth.
*Anomalies per 100,000 Births refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly.

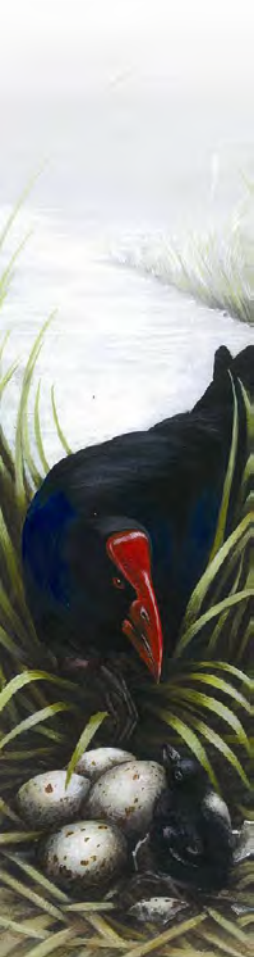


Table 5. Congenital Anomalies Evident at Birth, New Zealand 2005-2009 (Table 2 of 2)

Congenital Anomaly	Number: Total 2005-2009	Number: Annual Average	Anomalies per 100,000 Births*
Cleft Palate	190	38.0	63.6
Cleft Lip	78	15.6	26.1
Cleft Palate and Lip	134	26.8	44.8
Total Cleft Lip and Palate	402	80.4	134.5
Female Genital Malformations	81	16.2	27.1
Undescended Testicle	1,192	238.4	398.8
Hypospadias	745	149.0	249.3
Other Male Genital Malformations	224	44.8	74.9
Indeterminate Sex / Pseudohermaphrodism	30	6.0	10.0
Total Malformations of the Genital Organs	2,272	454.4	760.1
Renal Agenesis / Reduction Defects	83	16.6	27.8
Cystic Kidney Disease	148	29.6	49.5
Renal Pelvis Obstruction / Ureter Malformations	467	93.4	156.2
Other Kidney / Urinary Malformations	365	73.0	122.1
Total Malformations of the Urinary System	1,063	212.6	355.6
Congenital Dislocation Hip	111	22.2	37.1
Congenital Subluxation Hip	32	6.4	10.7
Other Deformities Hip	570	114.0	190.7
Foot Deformities	2,080	416.0	695.9
Other Musculoskeletal Malformations	620	124.0	207.4
Polydactyly	311	62.2	104.1
Syndactyly	155	31.0	51.9
Reduction Defects / Other Limb Malformations	275	55.0	92.0
Skull / Facial Bones / Spine / Thorax Malformation	290	58.0	97.0
Osteochondrodysplasia	29	5.8	9.7
Total Malformations of the Musculoskeletal System	4,473	894.6	1,496.5
Ichthyosis	7	1.4	2.3
Non-Neoplastic Naevus	1,161	232.2	388.4
Other Skin Malformations	1,368	273.6	457.7
Breast Malformations	28	5.6	9.4
Other Integument Malformations	745	149.0	249.3
Other Malformations	389	77.8	130.1
Total Other Congenital Malformations	3,698	739.6	1,237.2
Down Syndrome	264	52.8	88.3
Edwards and Patau Syndromes	43	8.6	14.4
Monosomies / Autosomal Deletions / Rearrangements	28	5.6	9.4
Turners Syndrome	12	2.4	4.0
Sex Chromosome Anomalies Male Phenotype	32	6.4	10.7
Other Chromosome Anomalies	10	2.0	3.3
Total Chromosomal Anomalies	389	77.8	130.1

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type= Birth.
* Anomalies per 100,000 Births refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly.

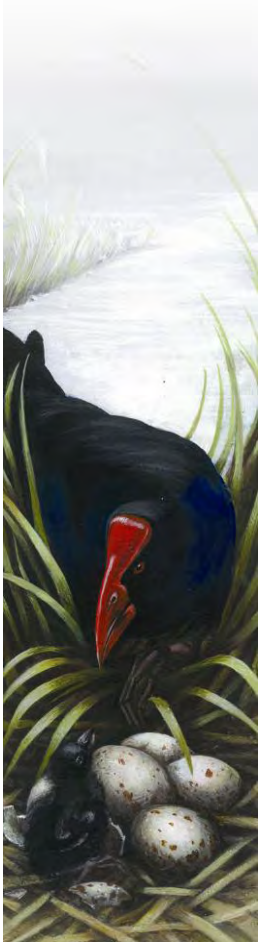
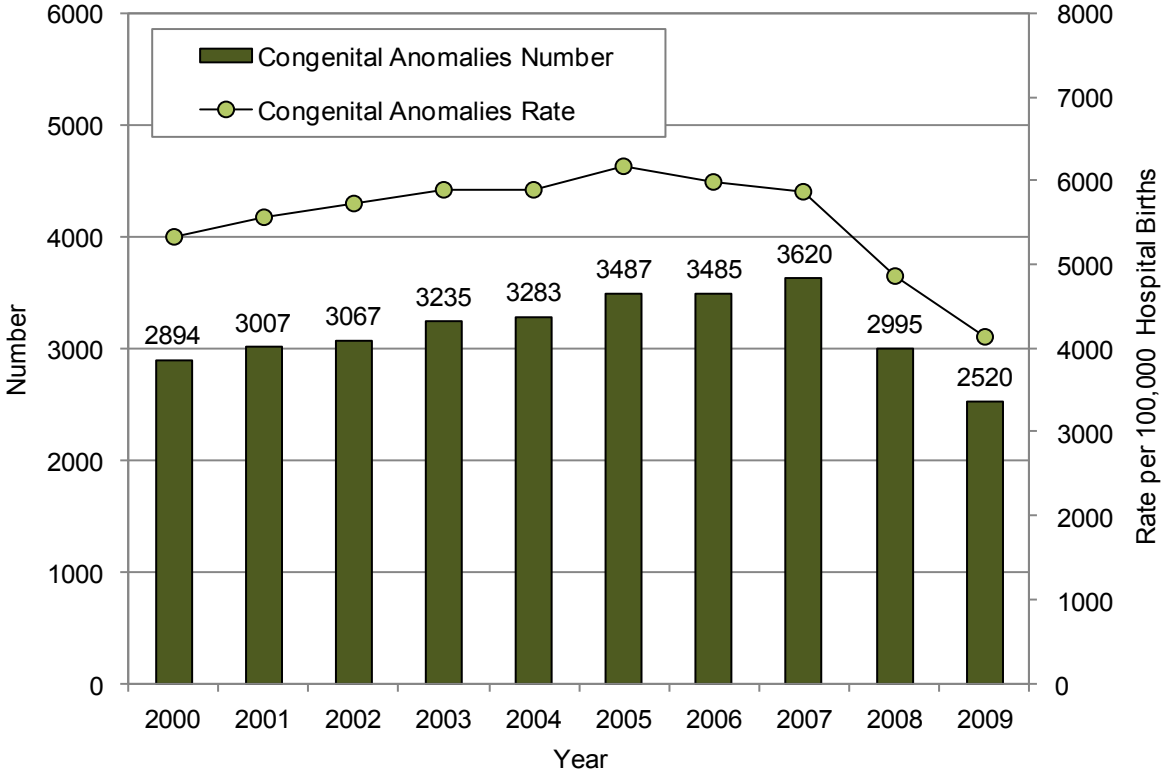
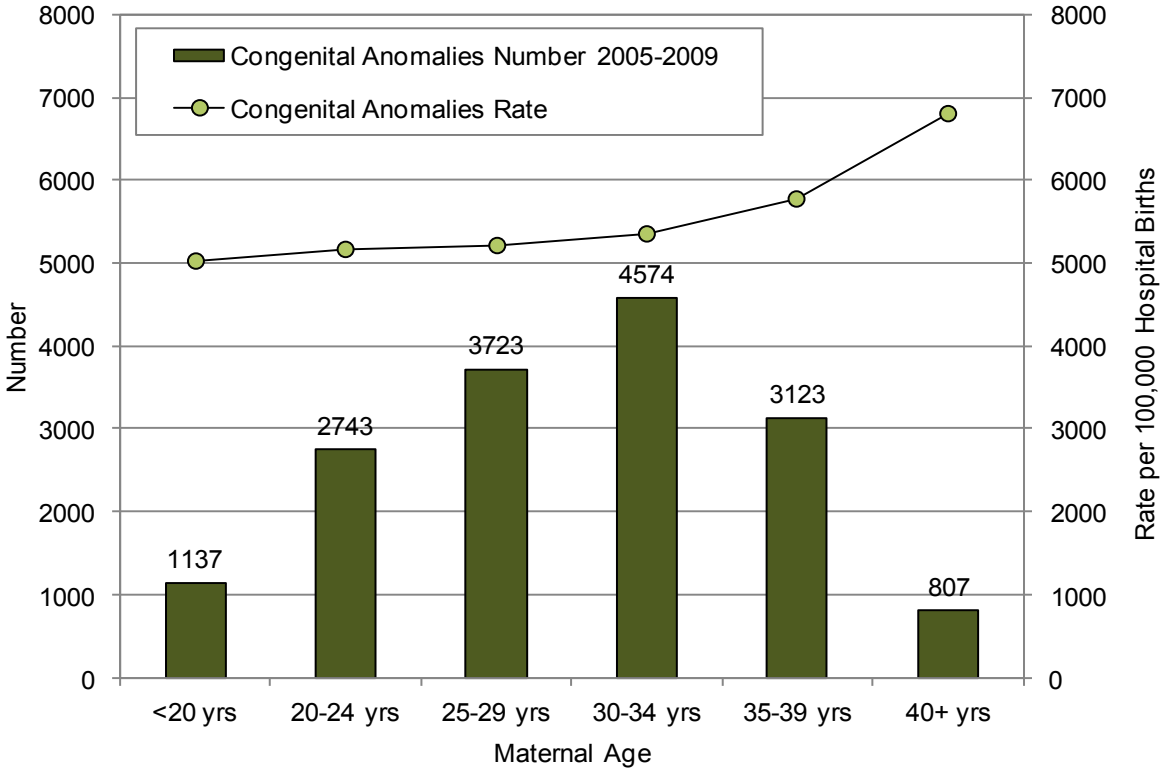


Figure 1. Babies with Congenital Anomalies Evident at Birth, New Zealand Hospital Births 2000-2009



Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with one or more anomalies, rather than number of anomalies.

Figure 2. Babies with Congenital Anomalies Evident at Birth by Maternal Age, New Zealand Hospital Births 2005-2009



Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type=Birth. Note: Rate per 100,000 refers to number of babies with one or more anomalies, rather than number of anomalies.

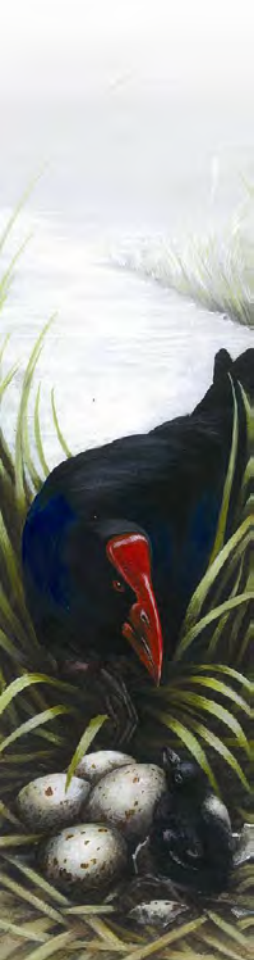
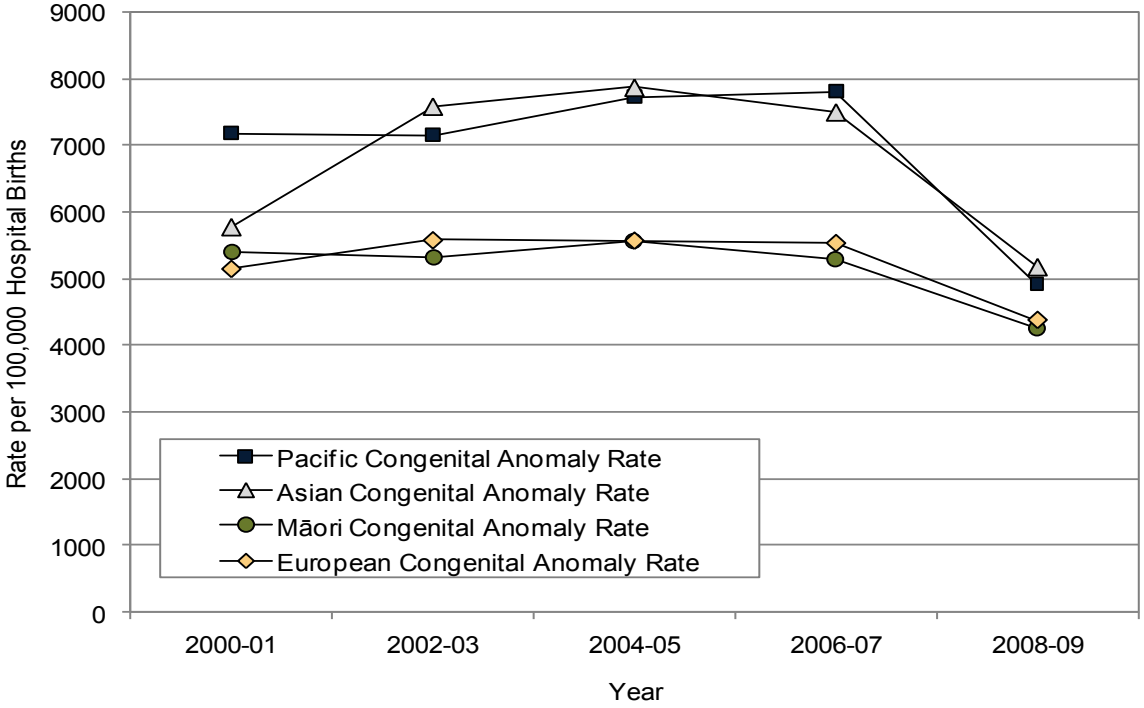


Table 6. Distribution of Babies with Congenital Anomalies Evident at Birth by Prioritised Ethnicity, NZ Deprivation Index Decile, Gender and Maternal Age, New Zealand Hospital Births 2005-2009

Variable	Number of Babies: Total 2005-2009	Rate per 100,000 Births	Rate Ratio	95% CI
Any Congenital Anomaly				
Prioritised Ethnicity				
Māori	3,231	4,939.4	0.97	0.93 - 1.01
Pacific	2,131	6,662.5	1.31	1.25 - 1.37
European	8,355	5,085.2	1.00	
Asian	1,809	6,548.7	1.29	1.23 - 1.35
NZ Deprivation Index				
Decile 1-2	2,274	5,457.7	1.00	
Decile 3-4	2,439	5,334.7	0.98	0.92 - 1.03
Decile 5-6	2,813	5,219.6	0.96	0.91 - 1.01
Decile 7-8	3,583	5,470.4	1.00	0.95 - 1.05
Decile 9-10	4,725	5,476.8	1.00	0.96 - 1.05
Gender				
Female	6,742	4,635.7	1.00	
Male	9,365	6,102.8	1.32	1.28 - 1.36
Maternal Age				
<20 Years	1,137	5,022.3	1.00	
20-24 Years	2,743	5,152.3	1.03	0.96 - 1.10
25-29 Years	3,723	5,200.0	1.04	0.97 - 1.10
30-34 Years	4,574	5,352.1	1.07	1.00 - 1.14
35-39 Years	3,123	5,775.5	1.15	1.08 - 1.23
40+ Years	807	6,791.8	1.35	1.24 - 1.48

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with one or more anomalies, rather than number of anomalies. Rate Ratios are Unadjusted.

Figure 3. Babies with Congenital Anomalies Evident at Birth by Prioritised Ethnicity, New Zealand Hospital Births 2000-2009



Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with one or more anomalies, rather than number of anomalies.

Taranaki Distribution and Trends

Taranaki Distribution

In Taranaki during 2005-2009, a large number of congenital anomalies were evident at the time of birth, with these ranging in severity from minor (e.g. tongue tie) through to more serious anomalies (e.g. malformations of the great arteries) (**Table 8** and **Table 9**). When the number of babies with one or more congenital anomalies, rather than the number of congenital anomalies was considered, on average during 2005-2009, 71.0 Taranaki babies per year (4.8 % of all births), had one or more congenital anomalies identified at the time of birth, with rates in Taranaki being *significantly* (albeit only slightly) lower than the New Zealand average (RR 0.90 95% CI 0.81 – 0.99 (**Table 7**)).

Taranaki Trends

In Taranaki, the number of babies with one or more congenital anomalies identified at birth increased during the early 2000s, reached a peak in 2002-03 and then declined, with rates when considered across the entire 10 year period, being generally similar to the New Zealand average (**Figure 4**).

Table 7. Babies with Congenital Anomalies Evident at Birth, Taranaki vs. New Zealand Hospital Births 2005-2009

DHB	Number: Total 2005-2009	Number: Annual Average	Rate per 100,000	Rate Ratio	95% CI
Congenital Anomalies					
Taranaki	355	71.0	4,833.9	0.90	0.81 - 0.99
New Zealand	16,107	3,221.4	5,388.9	1.00	

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with one or more anomalies, rather than number of anomalies. Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

Table 8. Congenital Anomalies Evident at Birth, Taranaki 2005-09 (Table 1 of 2)

Congenital Anomaly	Number: Total 2005-2009	Number: Annual Average	Number of Anomalies per 100,000 Births*
Taranaki			
Anencephaly	<5	s	s
Congenital Hydrocephalus	<5	s	s
Other Brain Malformations	5	1.0	68.1
Spina Bifida	<5	s	s
Other Spinal Cord Malformations	<5	s	s
Other CNS Malformations	<5	s	s
Total Malformations of Nervous System	14	2.8	190.6
Eyelid / Lacrimal / Eye / Orbit Malformations	5	1.0	68.1
Ear Malformations Impairing Hearing	<5	s	s
Accessory Auricle	12	2.4	163.4
Other Ear Malformations	6	1.2	81.7
Other Face / Neck Malformations	10	2.0	136.2
Total Malformations of Eye, Ear, Face and Neck	34	6.8	463.0
Malformations Cardiac Chambers / Connections	10	2.0	136.2
Ventricular Septal Defect	14	2.8	190.6
Atrial Septal Defect	30	6.0	408.5
Atrioventricular Septal Defect	<5	s	s
Tetralogy of Fallot	<5	s	s
Pulmonary / Tricuspid Valve Malformations	<5	s	s
Aortic / Mitral Valve Malformations	<5	s	s
Other Heart Malformations	11	2.2	149.8
Patent Ductus Arteriosus	34	6.8	463.0
Malformations Great Arteries (Excluding PDA)	12	2.4	163.4
Malformations Great Veins	6	1.2	81.7
Other Peripheral Vascular Malformations	12	2.4	163.4
Other Circulatory Malformations	6	1.2	81.7
Total Malformations of Circulatory System	147	29.4	2,001.6
Nose Malformations	<5	s	s
Trachea / Bronchus Malformations	5	1.0	68.1
Lung Malformations	<5	s	s
Total Malformations of Respiratory System	11	2.2	149.8
Cleft Palate	<5	s	s
Cleft Lip	<5	s	s
Cleft Palate and Lip	<5	s	s
Total Cleft Lip and Palate	8	1.6	108.9

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth.
*Note: Anomalies per 100,000 refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly.

Table 9. Congenital Anomalies Evident at Birth, Taranaki 2005-09 (Table 2 of 2)

Congenital Anomaly	Number: Total 2005-2009	Number: Annual Average	Number of Anomalies per 100,000 Births*
Taranaki			
Ankyloglossia (Tongue Tie)	32	6.4	435.7
Tongue / Mouth / Pharynx Malformations	<5	s	s
Oesophagus / Upper Alimentary Malformations	<5	s	s
Intestinal Malformations	<5	s	s
Total Other Malformations of Digestive System	40	8.0	544.7
Female Genital Malformations	<5	s	s
Undescended Testicle	45	9.0	612.8
Hypospadias	28	5.6	381.3
Other Male Genital Malformations	<5	s	s
Indeterminate Sex / Pseudohermaphrodism	<5	s	s
Total Malformations of the Genital Organs	78	15.6	1,062.1
Renal Agenesis / Reduction Defects	<5	s	s
Cystic Kidney Disease	<5	s	s
Renal Pelvis Obstruction / Ureter Malformations	11	2.2	149.8
Other Kidney / Urinary Malformations	<5	s	s
Total Malformations of the Urinary System	21	4.2	286.0
Congenital Dislocation Hip	20	4.0	272.3
Other Deformities Hip	24	4.8	326.8
Foot Deformities	29	5.8	394.9
Other Musculoskeletal Malformations	8	1.6	108.9
Polydactyly	12	2.4	163.4
Syndactyly	<5	s	s
Reduction Defects / Other Limb Malformations	<5	s	s
Skull / Facial Bones / Spine / Thorax Malformation	<5	s	s
Total Malformations of the Musculoskeletal System	103	20.6	1,402.5
Non-Neoplastic Naevus	<5	s	s
Other Skin Malformations	9	1.8	122.6
Other Integument Malformations	9	1.8	122.6
Other Malformations	14	2.8	190.6
Total Other Congenital Malformations	35	7.0	476.6
Down Syndrome	12	2.4	163.4
Edwards and Patau Syndromes	<5	s	s
Sex Chromosome Anomalies Male Phenotype	<5	s	s
Total Chromosomal Anomalies	17	3.4	231.5

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth.
*Note: Anomalies per 100,000 refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly.

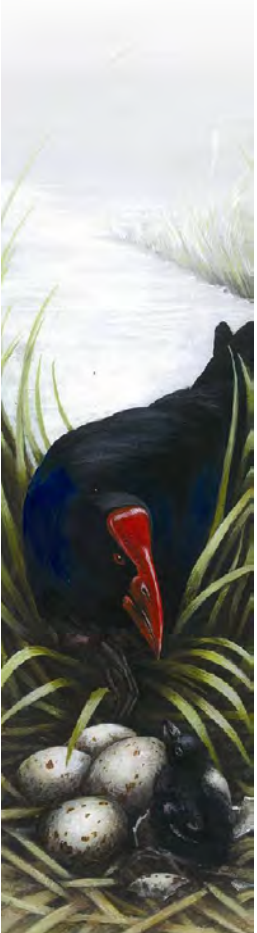
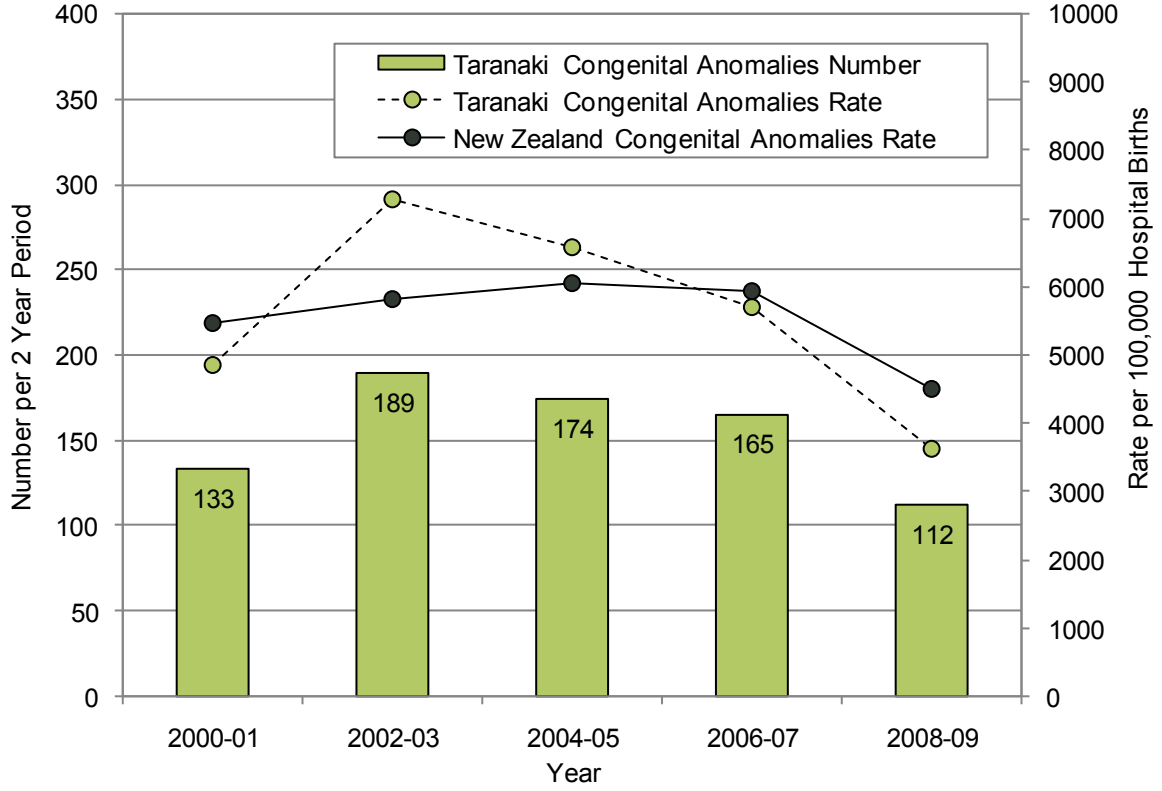


Figure 4. Babies with Congenital Anomalies Evident at Birth, Taranaki vs. New Zealand Hospital Births 2000-2009



Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Congenital Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with one or more anomalies, rather than number of anomalies.

Summary

In New Zealand during 2005-2009, a large number of congenital anomalies were evident at birth, with these ranging in severity from minor skin conditions through to anomalies which were incompatible with life. While in numerical terms the largest number of babies born with congenital anomalies had mothers aged 30-34 years, the risk of congenital anomalies rose with increasing maternal age, with babies whose mothers were 40+ years having rates 1.35 (95% CI 1.24-1.48) times higher than those whose mothers were in their teens. While no socioeconomic differences were evident, the proportion of babies with one or more congenital anomalies was significantly higher for males, and for Pacific and Asian > European and Māori babies. On average during 2000-2009, 3,159 babies per year had one or more congenital anomalies evident at birth, although the severity of these anomalies varied considerably. During 2009, this equated to 4.1% of all births.

In Taranaki during 2005-2009, a large number of congenital anomalies were evident at the time of birth, with these ranging in severity from minor (e.g. tongue tie) through to more serious anomalies (e.g. malformations of the great arteries). When the number of babies with one or more congenital anomalies, rather than the number of congenital anomalies was considered, on average during 2005-2009, 71.0 Taranaki babies per year (4.8 % of all births), had one or more congenital anomalies identified at the time of birth, with rates in Taranaki being *significantly* (albeit only slightly) lower than the New Zealand average (RR 0.90, 95% CI 0.81 – 0.99).

Evidence Based Reviews Relevant to the Identification and Management of Congenital Anomalies

In New Zealand, while there is a paucity of policy documents and evidence based reviews which consider the identification and management of congenital anomalies collectively, **Table 10** summarises a number of reviews which consider these issues in the overseas context. In addition, **Table 3** on **Page 26** considers antenatal and newborn screening in general, while **Table 15** on **Page 47** considers the early detection and management of cardiovascular anomalies, **Table 20** on **Page 56** considers the antenatal diagnosis and management of children with Down Syndrome and **Table 24** on **Page 63** considers folic acid supplementation and the diagnosis and management of children with neural tube defects.

Table 10. Evidence Based Reviews Relevant to the Identification and Management of Congenital Anomalies

International Guidelines and Systematic and Other Reviews
National Collaborating Centre for Women's and Children's Health. **Antenatal care: Routine care for the healthy pregnant woman**. London: RCOG Press, 2008. URL: http://www.nice.org.uk/nicemedia/live/11947/40145/40145.pdf Section 9.1 of this publication covers screening for structural anomalies and reviews studies relating to the use of ultrasound and serum screening (alpha-fetoprotein, AFP) for this purpose. Second trimester ultrasound seemed in general to show high specificity but poor sensitivity for identifying foetal structural anomalies but the actual values varied considerably depending on the centre and the particular anomaly. There were only a few high quality studies looking at first trimester ultrasound. It was reported to have high specificity and positive likelihood ratio but (as reported by a single centre in the U.K.) moderate sensitivity and negative likelihood ratio. There was good evidence that routine, rather than selective, ultrasound before 24 weeks resulted in better assessment of gestational age, earlier detection of multiple pregnancies and improved detection of foetal anomalies which led to higher termination rates of affected pregnancies. One systematic review (of 5 studies) and two other studies looked at foetal echocardiography. There was a wide range of reported values for sensitivity by centre and condition but the reported specificity was generally high. There was some evidence from 2 uncontrolled observational studies that babies with transposition of the great arteries (and possibly hypoplastic left heart syndrome) diagnosed prenatally had reduced mortality compared with those diagnosed postnatally. Nuchal translucency measurement seemed to have poor diagnostic value for detecting cardiac anomalies. There were two studies identified that investigated maternal serum alpha-fetoprotein (AFP) as a screening test for neural tube defects. One found that maternal AFP had good diagnostic value in both predicting and ruling out anomalies while the other found it to have less diagnostic value than a routine ultrasound. There was no evidence on the value and effectiveness of a combination of routine ultrasound and maternal AFP screening. Section 9.2 of this publication covers screening for Down syndrome and reviews published studies relevant to the diagnostic value and effectiveness screening methods, women's views and psychosocial aspects, and health economics. The recommendations for Down syndrome screening are essentially the same as those in New Zealand.
Bryant L, Fisher A, et al. **Fetal anomaly ultrasound screening programme study: Literature survey**. Plymouth: Social Research and Regeneration Unit, University of Plymouth, 2007. This literature survey was commissioned by the Fetal Anomalies steering group. It relates to routine mid-trimester ultrasound screening and its main purpose was to populate tables relating to the detection rates, false positives and frequencies of a specified list of anomalies, organised under the following headings: Central Nervous System (CNS), Cardio Vascular System (CVS), Chest, Abdomen, Renal, Limbs and Face. A summary of information from this report can be found at: http://www.library.nhs.uk//screening/ViewResource.aspx?resID=269076
Glenny A-M, Hooper L, et al. **Feeding interventions for growth and development in infants with cleft lip, cleft palate or cleft lip and palate**. Cochrane Database of Systematic Reviews 2009(1). Feeding difficulties are associated with cleft lip and palate leading to delayed growth. This review, based on four RCTs with a total of 232 babies, considered the benefits of a variety of advice and feeding devices on growth, development and parental satisfaction. It found that Squeezable bottles appeared to be easier to use than rigid feeding bottles for babies born with clefts of the lip and/or palate but that there was no evidence of a difference in growth outcomes between the bottle types. It found weak evidence that babies should be breastfed rather than spoon-fed following surgery for cleft lip. There were no studies found that assessed the use of any types of maternal advice and/or support for these babies.

Long V, Chen S, et al. **Surgical interventions for bilateral congenital cataract**. Cochrane Database of Systematic Reviews 2009(1).

It is generally accepted that the sooner surgery is carried out the greater the chance of a good visual result. This review aimed to determine which surgical approach produced the best visual improvement. It considered four RCTs (130 eyes of 65 children 3 months to 10 years in India, 50 eyes of 34 children aged 2 to 15.5 years, 34 eyes of 28 children 1.5 to 12 years, 41 eyes of 25 children 5 to 12 years) which examined different surgical techniques concerned with reducing the development of visual axis opacification (reclouding of the central visual area) post surgery. Techniques that included an anterior vitrectomy or optic capture achieved this except in older children. Posterior capsulotomy alone was inadequate. In the included studies, there were no differences between surgical techniques in the level of vision achieved. The authors felt that the limited amount of high quality evidence reported in this review did not provide clear guidance regarding the most suitable surgical technique and they highlighted areas in which further research is needed.

Green K, Oddie S. **The value of the postnatal examination in improving child health**. Archives of Disease in Childhood Fetal & Neonatal Edition 2008;93 (5): F389-93.

This paper reviews the evidence regarding the effectiveness of a standard newborn examination in improving infant health. It considers number of examinations (repeated examinations are of benefit for pre term or unwell babies), timing of examinations (which need to be done after 24 hours to improve the chances of detecting congenital heart disease), who performs the examination, detecting congenital heart disease, hip dysplasia, congenital cataracts and cleft lip and palate. The authors concluded that the neonatal examination is highly valued by parents and professionals and probably improves the health of some infants significantly. They also considered that additional screening e.g. by pulse oximetry may be justified.

Other Relevant Publications and Websites

Centers for Disease Control and Prevention. URL: http://www.cdc.gov/index.htm accessed 4/10/2010

The U.S. Centers for Disease Control and Prevention fund the Centers for Birth Defects Research and Prevention (CBDRP) which take part in the National Birth Defects Prevention Study. This is the largest on-going population-based study of its kind. Information about this study can be found at: http://www.cdc.gov/ncbddd/bd/research.htm and a list of the scientific publications at: http://www.cdc.gov/ncbddd/bd/key_pubs.htm. Relevant publications from this study include:

Waller DK, Shaw GM, et al. **Pre-Pregnancy obesity as a risk factor for structural birth defect**s. Archives of Pediatrics & Adolescent Medicine 2007; 161(8): 745–50.

This study found that maternal obesity was significantly linked with the following defects: spina bifida, heart defects, anorectal atresia, hypospadias, limb reductions, diaphragmatic hernias and omphalocoele. It also slightly increased the risk of cleft palate and significantly decreased the risk of gastroschisis. Maternal underweight was not linked to birth defects except for a modestly increased risk of orofacial clefts.

Honein MA, Rasmussen SA, et al. **Maternal smoking, environmental tobacco smoke, and the risk of oral clefts**. Epidemiology. 2007; 18(2): 226–33.

This study confirmed the results of other studies in finding that maternal smoking is a risk factor for orofacial clefts with mothers who smoked heavily in the peri-conceptual period having twice the risk of women who did not smoke.

Tilford JM, Robbins JM, et al. **Improving estimates of caregiver time cost and family impact associated with birth defects**. Teratology 2001;64 Suppl 1:S37-41.

This study reviewed the literature on measuring both caregiver time costs and family impact associated with caring for a child with a birth defect in an economic framework. The economic frame work is one which translates caregiver time or difficulties into units such as quality adjusted life years (QALYs) or cost. The authors found that there had been only two studies which provided cost estimates. They concluded that improved estimates of caregiver time costs and impact on the family are needed to assist policy makers in allocating resources for the prevention and treatment of birth defects and that there should be more research on this.

CARDIOVASCULAR ANOMALIES

Introduction

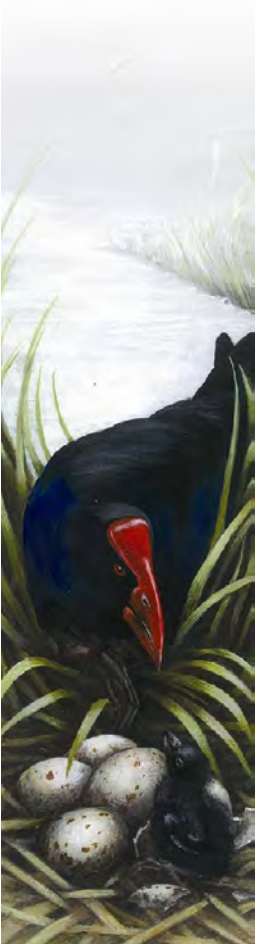
The incidence of severe congenital heart disease (CHD) (e.g. transposition of the great arteries, Tetralogy of Fallot) requiring expert cardiological care has been estimated at 2.5-3.0 per 1,000 live births, with moderately severe forms of CHD (e.g. large atrial septal defects, complex forms of ventricular septal defects) accounting for another 3 per 1,000 live births. The overall incidence increases to 75 per 1,000 however, if minor anomalies (e.g. small ventricular septal defects, atrial septal defects, or patent ductus arteriosus) are included, with international variations in rates largely being attributed to differences in the detection and reporting of these minor anomalies [18].

In terms of known risk factors, the epidemiology of cardiovascular anomalies is relatively poorly understood, with factors such as older maternal age not being consistently associated with an increased risk, once babies with underlying chromosomal anomalies have been excluded. The associations between maternal diabetes and an increased risk of CHD however, appear to be more consistent. Male gender has also been associated with an increased risk of transposition of the great arteries and hypoplastic left heart syndrome in some but not all studies [19].

While prevention may need to await a better understanding of causal pathways, early detection and timely management remain of prime importance, with research suggesting that up to 25% of babies with severe forms of congenital heart disease are discharged from hospital undiagnosed. While recent research suggests that pulse oximetry may be a useful adjunct to newborn clinical examination when screening for serious congenital heart disease [2], it is likely that a number of babies with serious cardiovascular anomalies will still be missed in the neonatal period and as a result, antenatal screening has become an established practice in many centres.

In tertiary centres dealing with the diagnosis and management of fetal cardiac anomalies, a high degree of diagnostic accuracy is possible, with most (but not all) major forms of CHD being possible to detect antenatally [2]. In the majority of cases however, congenital heart disease will occur in low risk groups and will only be detected antenatally if examination of the fetal heart is included as part of routine obstetric ultrasound screening (e.g. using a four chamber view of the fetal heart). In such cases, detection rates are likely to depend on the level of sonographer training and experience, the adequacy of the equipment available, and the time allowed for sonographers to undertake each routine examination [2]. Investing in such resources is important however, as early detection confers significant advantages, in that it provides an opportunity to exclude associated extra-cardiac and chromosomal abnormalities, discuss pregnancy options, prepare parents, and plan for delivery in a tertiary centre [5].

The following section uses data from the National Minimum Dataset to review the number of babies with cardiovascular anomalies evident at the time of birth.



Data Source and Methods

Definition

1. Number of Cardiovascular Anomalies Evident at Birth (by Anomaly Type)
2. Number of Babies with 1 or more Cardiovascular Anomaly Evident at Birth (by Anomaly Type)

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly (ICD-10 Q20-Q28) listed in any of the first 15 diagnoses.

Denominator: All Hospital Admissions with Event Type = Birth

Notes on Interpretation

The analysis includes all admissions recorded in the National Minimum Dataset where the Event Type was listed as a Birth (Note: Only one birth event is allowed per NHI number, with babies being born prior to hospital admission, or being readmitted shortly after discharge being listed as a routine inpatient event). Thus the analysis does not include babies born prior to hospital admission, babies born at home, or babies whose

cardiovascular anomaly was overlooked at the time of initial hospital discharge, but who re-presented shortly thereafter. Further, the methodology used may significantly undercount those cardiovascular anomalies which are difficult to detect on routine newborn examination.

Note: In the analysis which follows, 57.8% of patent ductus arteriosus (PDA) cases identified during 2005-2009 were in preterm babies (<37 weeks gestation) who had no other cardiovascular anomalies. Prematurity is known to increase the risk of PDA as a result of increased exposure to hypoxia and underdeveloped heart and lungs. Because 18.8% of all cardiovascular anomalies identified during 2005-2009 were isolated PDAs in preterm infants, because many of these babies would not have experienced a PDA had they been born at term, and because of the possibility that any analysis of risk factors for cardiovascular anomalies may have inadvertently been distorted by the risk factor profiles of those babies being born prematurely, after the first initial overview tables, preterm (<37 weeks) babies with isolated PDAs (i.e. a PDA with no other cardiovascular anomaly) have been excluded from rate calculations.

For a list of the ICD-10 codes used to assign cardiovascular anomaly types see **Table 94** and **Table 95** in **Appendix 8.**

Indicator Category Ideal B

New Zealand Distribution and Trends

Cardiovascular Anomalies Evident at Birth

In New Zealand during 2005-2009, patent ductus arteriosus (PDA) was the most frequent cardiovascular anomaly identified at the time of birth, with 57.8% of PDAs being in preterm babies (<37 weeks gestation) who had no other cardiovascular anomalies (see Methods section for rationale for exclusion of these cases from subsequent analyses). Atrial septal and ventricular septal defects were the next most frequent causes of cardiovascular anomalies, followed by other malformations of the great arteries (**Table 11**).

New Zealand Trends

In New Zealand during 2000-2009, the number of babies born with one or more cardiovascular anomalies remained relatively constant, averaging around 393 cases per year during this period (**Figure 5**).

Distribution by Maternal Age

In New Zealand during 2005-2009, while in numerical terms the largest number of babies born with cardiovascular anomalies had mothers who were aged 30-34 years, the risk of cardiovascular anomalies rose progressively with increasing maternal age, with babies whose mothers were aged 40+ years having rates which were 2.03 (95% CI 1.59-2.58) times higher than those whose mothers gave birth in their teens (**Figure 6**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

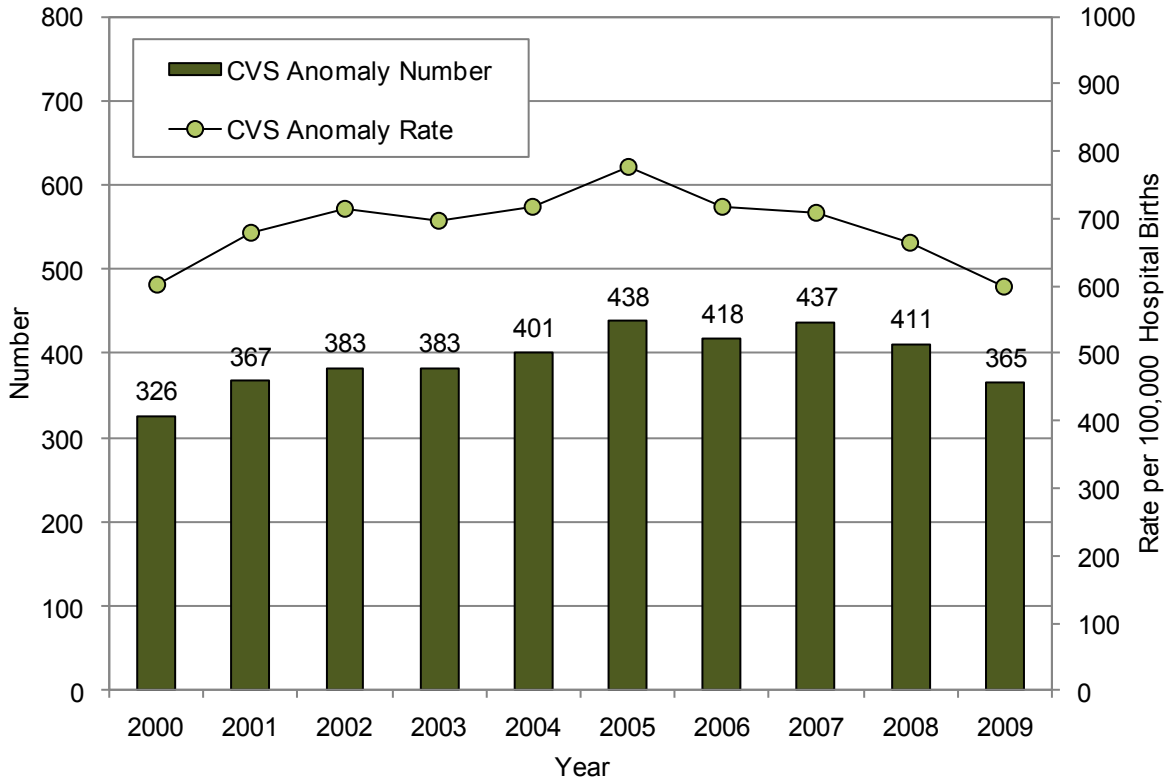
In New Zealand during 2005-2009, no significant ethnic, gender or socioeconomic (as measured by NZ Deprivation Index decile) differences were seen in the proportion of babies being born with cardiovascular anomalies. Rates rose progressively with increasing maternal age however, with rates for babies whose mothers were 30+ years being *significantly* higher than for those whose mothers gave birth in their teens (**Table 12**). During 2000-2009, the proportion of babies born with congenital anomalies was similar for European, Pacific and Asian babies, although rates for Māori babies were lower than for European babies during this period (**Figure 7**).

Table 11. Cardiovascular Anomalies Evident at Birth, New Zealand 2005-2009

Cardiovascular Anomaly	Number: Total 2005-2009	Number: Annual Average	Anomalies per 100,000 Births[1]
New Zealand			
Malformations Cardiac Chambers / Connections	159	31.8	53.2
Ventricular Septal Defect	546	109.2	182.7
Atrial Septal Defect	679	135.8	227.2
Atrioventricular Septal Defect	48	9.6	16.1
Tetralogy of Fallot	82	16.4	27.4
Pulmonary / Tricuspid Valve Malformations	117	23.4	39.1
Aortic / Mitral Valve Malformations	92	18.4	30.8
Other Heart Malformations	351	70.2	117.4
Patent Ductus Arteriosus[2]	1,462	292.4	489.1
Malformations Great Arteries (Excluding PDA)	268	53.6	89.7
Malformations Great Veins	50	10.0	16.7
Other Peripheral Vascular Malformations	253	50.6	84.6
Other Circulatory Malformations	378	75.6	126.5
Total Malformations of Circulatory System[2]	4,485	897.0	1,500.5

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Anomalies per 100,000 Births refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly; Note 2: Patent Ductus Arteriosus includes 845 cases of Isolated PDA in preterm infants (<37 weeks), which have been excluded in subsequent analyses.

Figure 5. Babies with Cardiovascular Anomalies Evident at Birth, New Zealand Hospital Births 2000-2009



Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Rate per 100,000 refers to number of babies with one or more CVS anomalies, rather than the number of anomalies; Note 2: Preterm (<37 weeks) babies with Isolated Patent Ductus Arteriosus have been excluded.

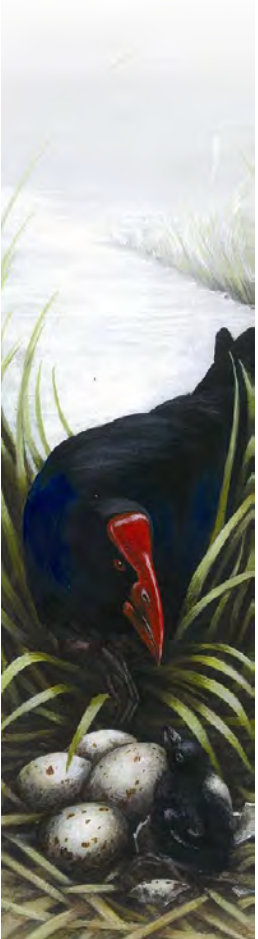
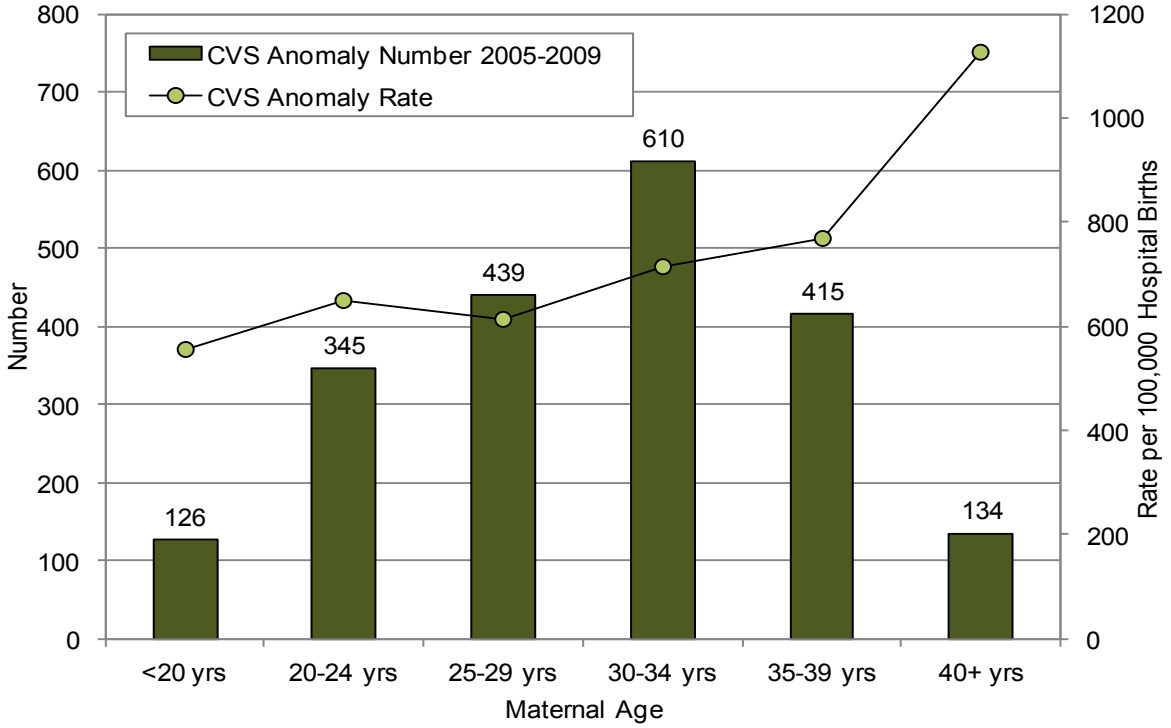
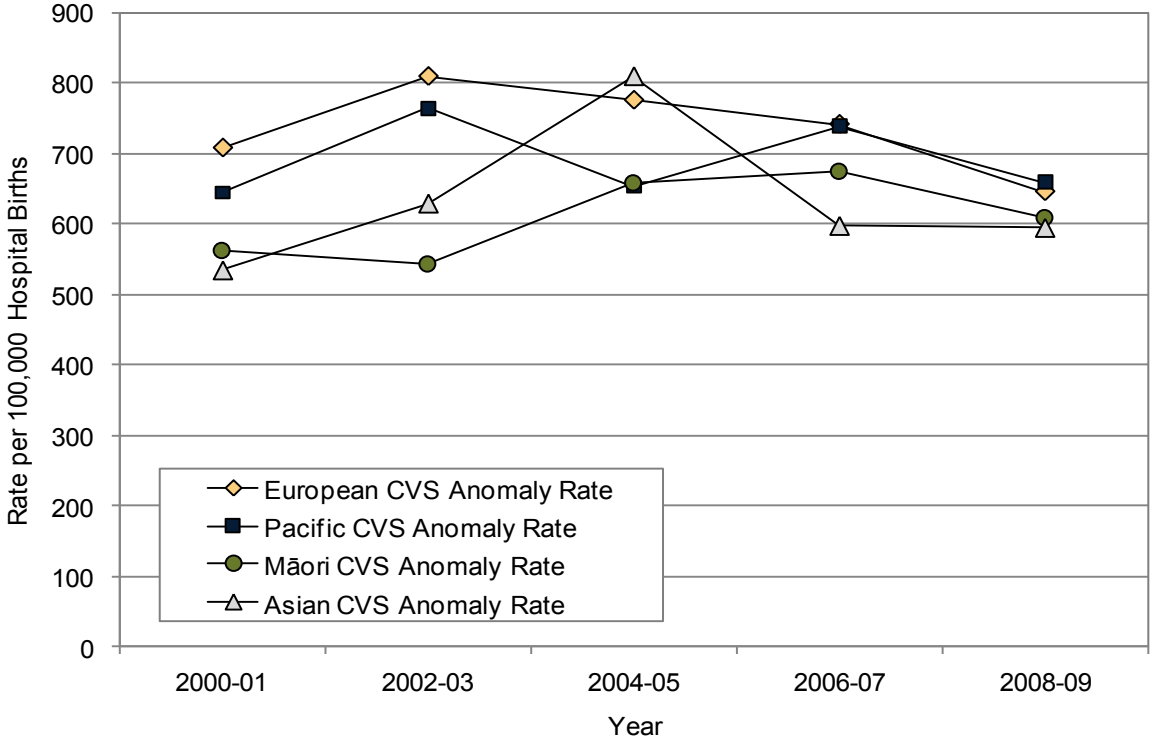


Figure 6. Babies with Cardiovascular Anomalies Evident at Birth by Maternal Age, New Zealand Hospital Births 2005-2009



Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Rate per 100,000 refers to number of babies with one or more CVS anomalies, rather than the number of anomalies; Note 2: Preterm (<37 wks) babies with Isolated Patent Ductus Arteriosus excluded.

Figure 7. Babies with Cardiovascular Anomalies Evident at Birth by Prioritised Ethnicity, New Zealand Hospital Births 2000-2009

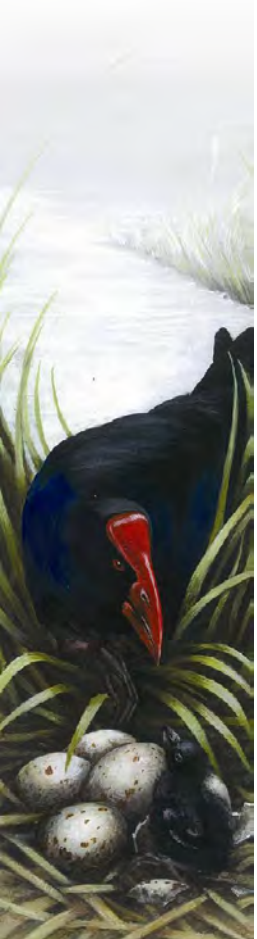


Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Rate per 100,000 refers to number of babies with one or more CVS anomalies, rather than the number of anomalies; Note 2: Preterm (<37 wks) babies with Isolated Patent Ductus Arteriosus excluded.

Table 12. Distribution of Babies with Cardiovascular Anomalies Evident at Birth by Prioritised Ethnicity, NZ Deprivation Index Decile, Gender and Maternal Age, New Zealand Births 2005-2009

Variable	Number of Babies: Total 2005-2009	Rate per 100,000 Births	Rate Ratio	95% CI
Cardiovascular Anomalies				
Prioritised Ethnicity				
Māori	421	643.6	0.90	0.81 - 1.01
Pacific	220	687.8	0.96	0.83 - 1.11
European	1,175	715.2	1.00	
Asian	177	640.8	0.90	0.77 - 1.05
NZ Deprivation Index				
Decile 1-2	297	712.8	1.00	
Decile 3-4	313	684.6	0.96	0.82 - 1.13
Decile 5-6	370	686.6	0.96	0.83 - 1.12
Decile 7-8	465	710.0	1.00	0.86 - 1.15
Decile 9-10	574	665.3	0.93	0.81 - 1.07
Gender				
Female	979	673.1	1.00	
Male	1,090	710.3	1.06	0.97 - 1.15
Maternal Age				
<20 Years	126	556.6	1.00	
20-24 Years	345	648.0	1.16	0.95 - 1.43
25-29 Years	439	613.2	1.10	0.90 - 1.34
30-34 Years	610	713.8	1.28	1.06 - 1.55
35-39 Years	415	767.5	1.38	1.13 - 1.68
40+ Years	134	1,127.8	2.03	1.59 - 2.58

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Rate per 100,000 refers to number of babies with one or more CVS anomalies, rather than the number of anomalies; Note 2: Preterm (<37 weeks) babies with Isolated Patent Ductus Arteriosus excluded.



Taranaki Distribution and Trends

Taranaki Distribution

In Taranaki during 2005-2009, patent ductus arteriosus was the most frequent type of cardiovascular anomaly evident at the time of birth, although 38.2% were in preterm babies with no other cardiovascular anomalies. Atrial septal and ventricular septal defects were the second and third leading types of anomalies respectively (**Table 13**). When the number of babies with one or more CVS anomalies (rather than the number of CVS anomalies) was considered, on average 12 babies each year (excluding isolated preterm PDAs) were born with one or more CVS anomalies, with rates in Taranaki being similar to than the New Zealand average (RR 1.18 95% CI 0.91 – 1.52 (**Table 14**)).

Taranaki Trends

In Taranaki during 2000-2009, the proportion of babies with one or more cardiovascular anomalies identified at birth increased during the early 2000s, reached a peak in 2004-05 and then declined, with rates being higher than the New Zealand average during the early-mid 2000s, and more similar thereafter, It is unclear however whether these trends

reflected real changes in the underlying prevalence of cardiovascular anomalies, random year to year variations, or differences in the way in which more minor anomalies were recorded in the hospital admission dataset (**Figure 8**).

Table 13. Cardiovascular Anomalies Evident at Birth Taranaki 2005-2009

Cardiovascular Anomaly	Number: Total 2005-2009	Number: Annual Average	Number of Anomalies per 100,000 Births[1]
Taranaki			
Malformations Cardiac Chambers / Connections	10	2.0	136.2
Ventricular Septal Defect	14	2.8	190.6
Atrial Septal Defect	30	6.0	408.5
Atrioventricular Septal Defect	<5	s	s
Tetralogy of Fallot	<5	s	s
Pulmonary / Tricuspid Valve Malformations	<5	s	s
Aortic / Mitral Valve Malformations	<5	s	s
Other Heart Malformations	11	2.2	149.8
Patent Ductus Arteriosus[2]	34	6.8	463.0
Malformations Great Arteries (Excluding PDA)	12	2.4	163.4
Malformations Great Veins	6	1.2	81.7
Other Peripheral Vascular Malformations	12	2.4	163.4
Other Circulatory Malformations	6	1.2	81.7
Total Malformations of Circulatory System[2]	147	29.4	2,001.6

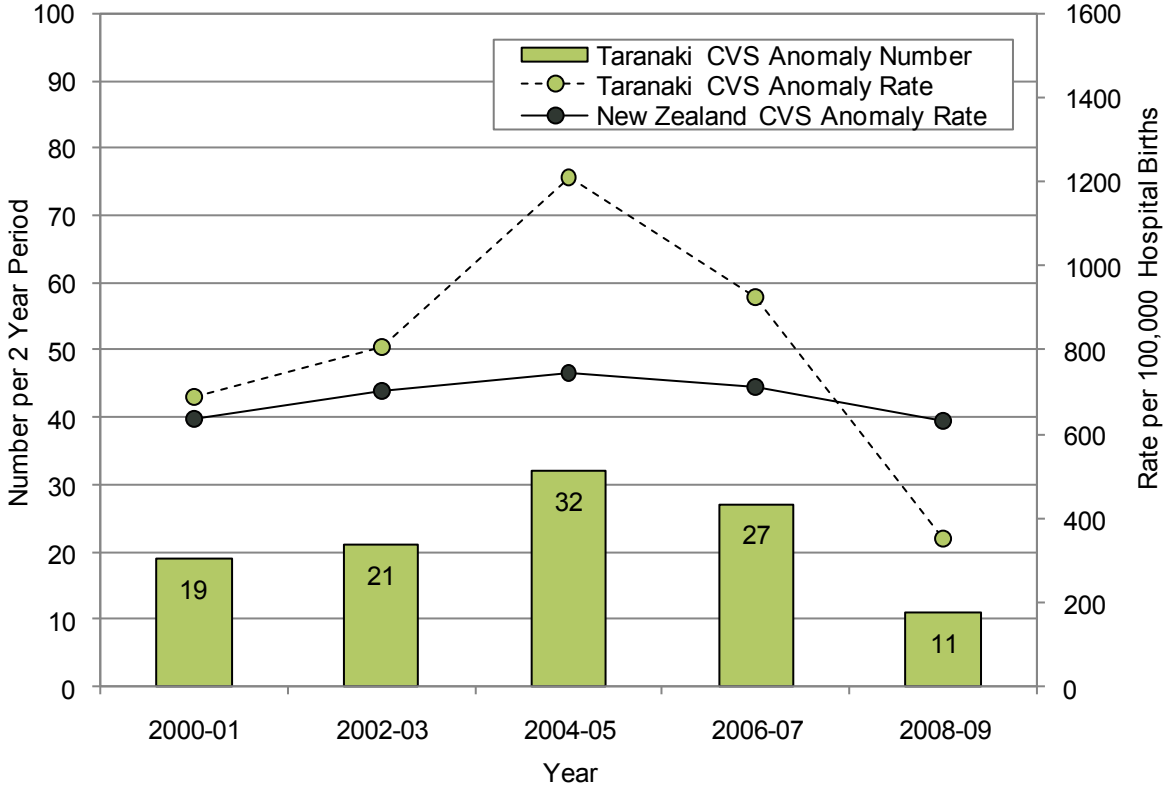
Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Anomalies per 100,000 refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly. Note 2: Patent Ductus Arteriosus includes 13 cases of isolated PDA in preterm infants (<37 weeks), which have been excluded from subsequent analyses.

Table 14. Number of Babies with One or More Cardiovascular Anomalies Evident at Birth, Taranaki vs. New Zealand Hospital Births 2005-2009

DHB	Number: Total 2005-2009	Number: Annual Average	Rate per 100,000	Rate Ratio	95% CI
Cardiovascular Anomalies					
Taranaki	60	12.0	817.0	1.18	0.91 - 1.52
New Zealand	2,069	413.8	692.2	1.00	

Source: National Minimum Dataset: Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with one or more CVS anomalies, rather than the number of anomalies; Preterm (<37 weeks) babies with Isolated Patent Ductus Arteriosus excluded. Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

Figure 8. Babies with Cardiovascular Anomalies Evident at Birth, Taranaki vs. New Zealand Hospital Births 2000-2009

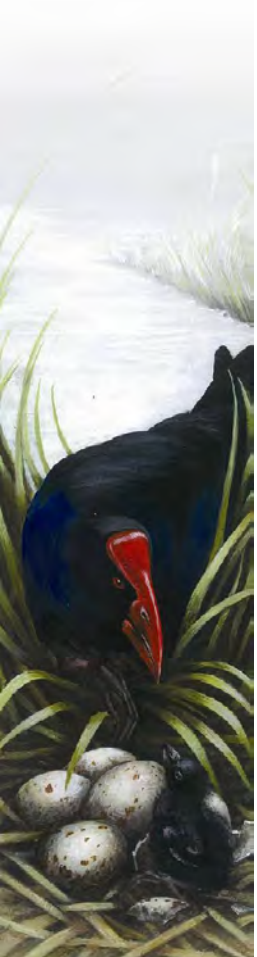


Source: National Minimum Dataset: Numerator: Hospital Admissions with Event Type = Birth and a Cardiovascular Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Rate per 100,000 refers to number of babies with one or more CVS anomalies, rather than the number of anomalies; Note 2: Preterm (<37 weeks) babies with Isolated Patent Ductus Arteriosus excluded.

Summary

In New Zealand during 2005-2009, patent ductus arteriosus (PDA) was the most frequent cardiovascular anomaly identified at the time of birth, with 57.8% of PDAs being in preterm babies (<37 weeks gestation) who had no other cardiovascular anomalies. Atrial septal and ventricular septal defects were the next most frequent causes of cardiovascular anomalies. During this period, no significant ethnic, gender or socioeconomic differences were seen in the proportion of babies being born with cardiovascular anomalies. Rates rose progressively with increasing maternal age however, with rates for babies whose mothers were 30+ years being *significantly* higher than for those whose mothers gave birth in their teens. During 2000-2009, the number of babies born with one or more cardiovascular anomalies (excluding isolated preterm PDAs) remained relatively constant, averaging around 393 cases per year during this period.

In Taranaki during 2005-2009, patent ductus arteriosus was the most frequent type of cardiovascular anomaly evident at the time of birth, although 38.2% were in preterm babies with no other cardiovascular anomalies. Atrial septal and ventricular septal defects were the second and third leading types of anomalies respectively. When the number of babies with one or more CVS anomalies (rather than the number of CVS anomalies) was considered, on average 12 babies each year (excluding isolated preterm PDAs) were born with one or more CVS anomalies, with rates in Taranaki being similar to than the New Zealand average (RR 1.18 95% CI 0.91 – 1.52). During 2000-2009, the proportion of babies with one or more cardiovascular anomalies increased during the early 2000s, reached a peak in 2004-05 and then declined, with rates being higher than the New Zealand average during the early-mid 2000s, and more similar thereafter, It is unclear however whether these trends reflected real changes in the underlying prevalence of cardiovascular anomalies, random year to year variations, or differences in the way in which more minor anomalies were recorded in the hospital admission dataset.



Evidence Based Reviews Relevant to the Early Detection and Management of Cardiovascular Anomalies

While in New Zealand there is a paucity of policy documents and evidence based reviews which consider the early detection and management of cardiovascular anomalies, **Table 15** summarises a number of international reviews which consider these issues in the overseas context. In addition, **Table 3** on **Page 26** considers antenatal and newborn screening in general.

Table 15. Evidence Based Reviews Relevant to the Early Diagnosis and Management of Cardiovascular Anomalies

International Guidelines and Systematic and Other Reviews
Bryant L, Fisher A, et al. **Fetal anomaly ultrasound screening programme study: Literature survey**. Plymouth: Social Research and Regeneration Unit, University of Plymouth, 2007. This literature survey was commissioned by the Fetal Anomalies steering group. It relates to routine mid-trimester ultrasound screening and its main purpose was to populate tables relating to the detection rates, false positives and frequencies of a specified list of anomalies, organised under the following headings: Central Nervous System (CNS), Cardio Vascular System (CVS), Chest, Abdomen, Renal, Limbs and Face. A summary of information from this report can be found at: http://www.library.nhs.uk//screening/ViewResource.aspx?resID=269076
National Collaborating Centre for Women's and Children's Health. **Antenatal care: Routine care for the healthy pregnant woman**. London: RCOG Press, 2008. URL: http://www.nice.org.uk/nicemedia/live/11947/40145/40145.pdf Section 9.1 of this publication covers screening for structural anomalies and reviews studies relating to the use of ultrasound and serum screening (alpha-fetoprotein, AFP) for this purpose. Second trimester ultrasound seemed in general to show high specificity but poor sensitivity for identifying foetal structural anomalies but the actual values varied considerably depending on the centre and the particular anomaly. There were only a few high quality studies looking at first trimester ultrasound. It was reported to have high specificity and positive likelihood ratio but (as reported by a single centre in the U.K.) moderate sensitivity and negative likelihood ratio. There was good evidence that routine, rather than selective, ultrasound before 24 weeks resulted in better assessment of gestational age, earlier detection of multiple pregnancies and improved detection of foetal anomalies which led to higher termination rates of affected pregnancies. One systematic review (of 5 studies) and two other studies looked at foetal echocardiography. There was a wide range of reported values for sensitivity by centre and condition but the reported specificity was generally high. There was some evidence from 2 uncontrolled observational studies that babies with transposition of the great arteries (and possibly hypoplastic left heart syndrome) diagnosed prenatally had reduced mortality compared with those diagnosed postnatally. Nuchal translucency measurement seemed to have poor diagnostic value for detecting cardiac anomalies.
LeRoy S, Elixson EM, et al. **Recommendations for preparing children and adolescents for invasive cardiac procedures: A statement from the American Heart Association Pediatric Nursing Subcommittee of the Council on Cardiovascular Nursing in collaboration with the Council on Cardiovascular Diseases of the Young**. Circulation 2003; 108(20): 2550-64. These guidelines are based on a review of the literature and expert consensus. Key factors affecting pre-procedure preparation are stage of cognitive development, previous hospital experiences, temperament, and parent stress and coping. Methods for procedure preparation include information giving, cognitive behavioural intervention, biofeedback, distraction, play therapy, peer modelling and counselling and pharmacological anti-anxiety agents. Also covered are recommendations for personnel training, roles and resources, and preparation for cardiac procedures.
Mahle WT, Newburger JW, et al. **Role of pulse oximetry in examining newborns for congenital heart disease: A scientific statement from the AHA and AAP**. Pediatrics 2009; 124(2): 823-36. This review aimed to assess the evidence on the routine use of pulse oximetry to detect congenital heart disease in newborns. Not all congenital heart disease is detected before hospital discharge, resulting in significant morbidity and occasional mortality. Routine pulse oximetry on newborns after the first 24 hours is low cost and low risk and may detect congenital heart disease. It was estimated to have a sensitivity of 69.6% (although there was a wide variation between studies), a positive predictive value of 47% and a false positive rate of only 0.035%.
Green K, Oddie S. **The value of the postnatal examination in improving child health**. Archives of Disease in Childhood Fetal & Neonatal Edition 2008; 93(5): F389-93. This paper reviews the evidence regarding the effectiveness of a standard newborn examination in improving infant health. It considers number of examinations (repeated examinations are of benefit for pre term or unwell babies), timing of examinations (which need to be done after 24 hours to improve the chances of detecting congenital heart disease), who performs the examination, detecting congenital heart disease, hip dysplasia, congenital cataracts and cleft lip and palate. The authors concluded that the neonatal examination is highly valued by parents and professionals and probably improves the health of some infants significantly. They also considered that additional screening e.g. by pulse oximetry may be justified.

Knowles R, Griebsch I, et al. **Newborn screening for congenital heart defects: A systematic review and cost-effectiveness analysis**. Health Technology Assessment 2005; 9(44): 1-152.

In the U.K. as in New Zealand, current screening policy is clinical examination of babies at birth and six weeks. This identifies less than half of the babies with heart disease who have not been previously identified either antenatally or because of symptoms. Babies whose heart disease is detected by screening do not always receive timely management. Pulse oximetry and echocardiography are alternative screening strategies with better detection rates (both given as approx. 70% compared with 32% for clinical examination alone). Pulse oximetry is regarded as promising although further evaluation is needed while echocardiography is stated to be very expensive.

Other Relevant Publications

Lisowski LA, Verheijen PM, et al. **Congenital heart disease in pregnancies complicated by maternal diabetes mellitus. An international clinical collaboration, literature review, and meta-analysis**. Herz 2010; 35(1): 19-26.

This study which was a multi-centre retrospective clinical study also included a meta-analysis and a literature review. It investigated the incidence and distribution of congenital structural heart defects in the children of mothers with type 1 diabetes and the effect of peri-conception glycaemic control (as measured by HbA1c). It found that among the offspring of diabetic mothers there was an increased frequency of transposition of the great arteries, persistent truncus arteriosus, visceral heterotaxia and single ventricle. This suggested that the teratogenic effect occurred very early in pregnancy (before 8 weeks) highlighting the importance of poor glycaemic control in the first trimester as a cause of foetal heart disease.

DOWN SYNDROME

Introduction

Down Syndrome is the most common (non sex-linked) chromosomal anomaly in live born babies, with the diagnosis usually being made in-utero, or at the time of birth. Children with Down Syndrome have a range of clinical features including reduced growth (height ~ 3rd percentile), slow cognitive development, low muscle tone and joint laxity, and an increased risk of a number of medical conditions (e.g. congenital heart disease, thyroid dysfunction, cataracts, hearing problems), which may affect their quality of life [20]. Approximately 95% of children with Down Syndrome have an extra chromosome 21 (trisomy 21), with the remaining 5% having either translocations (3%) or mosaicism (2%). In mosaicism, some cells have 46 chromosomes and some have 47, leading to a milder clinical presentation and intelligence often approaching the normal range [21].

In New Zealand, approximately 90 babies each year are born with Down Syndrome [6], with the National Screening Unit recently releasing a set of guidelines for maternity providers, which outline recommended best practice in the area of antenatal screening. The Guidelines recommend that women presenting in their first trimester be offered a nuchal translucency scan, plus a blood test measuring two maternal serum markers (pregnancy-associated plasma protein A and beta-human chorionic gonadatrophin (βhCG)), and that women presenting later in pregnancy be offered a blood test measuring four serum markers (βhCG, Alpha-fetoprotein, unconjugated oestriol, and inhibin A) [6].

The Ministry of Health has also released a set of guidelines on the clinical assessment and management of children and young people with Down Syndrome [20]. These Guidelines outline a range of clinical and support services which children and young people may require at different stages of their development, including:

1. Parental counselling at the time of birth and ongoing support thereafter.
2. Lactation consultant / speech-language therapist support for the establishment of breastfeeding, as well as the ongoing monitoring of feeding, nutrition and growth.
3. Identification and management of other congenital anomalies and medical conditions (e.g. CVS defects, cataracts, hearing problems), with ongoing coordination of care and anticipatory monitoring (e.g. thyroid function, ongoing hearing and vision screening).
4. Access to early intervention and disability support services (e.g. physiotherapists, speech-language, occupational and neurodevelopmental therapists, Child Disability Allowance) and Specialist Education Services.

The following section uses information from the National Minimum Dataset to review the number of hospital births where Down Syndrome was evident at the time of birth.

Data Source and Methods

Definition

1. Babies with Down Syndrome Evident at the Time of Birth

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions with Event Type = Birth and Down Syndrome (ICD-10-AM Q90) listed in any of the first 15 diagnoses

Denominator: All Hospital Admissions with Event Type = Birth

Notes on Interpretation

The analysis includes all admissions recorded in the National Minimum Dataset where the Event Type was listed as a Birth (Note: Only one birth event is allowed per NHI number, with admissions for babies being born prior to hospital admission, or being readmitted shortly after discharge being listed as a routine inpatient event). Thus the analysis does not include babies born prior to hospital admission, babies born at home, or babies whose Down Syndrome was overlooked at the time of initial hospital discharge, but who re-presented shortly thereafter.

For a list of the ICD-10-AM codes used to assign Other Chromosomal Anomalies and co-existing Congenital Anomalies see **Appendix 8.**

Indicator Category Ideal B

New Zealand Distribution and Trends

Chromosomal Anomalies Evident at Birth

In New Zealand during 2005-2009, Down Syndrome was the most frequent chromosomal anomaly identified at the time of birth, accounting for 88.3% of chromosomal anomalies during this period. Such figures may significantly underestimate the prevalence of chromosomal anomalies however, as in the absence of karyotyping, many anomalies (e.g. sex chromosome anomalies) may be undetectable by routine newborn examination **(Table 16)**.

Babies with Down Syndrome and Other Congenital Anomalies

In New Zealand during 2005-2009, 51.9% of babies with Down Syndrome evident at the time of birth had one or more co-existing cardiovascular anomalies, with the most frequent being atrial septal defects and patent ductus arteriosus, followed by ventricular septal defects and atrioventricular septal defects. A smaller proportion had anomalies of other organ systems (**Table 17**).

New Zealand Trends

In New Zealand during 2000-2009, on average 53 babies per year were identified as having Down Syndrome at the time of birth, with numbers fluctuating during this period **(Figure 9)**.

Distribution by Maternal Age

In New Zealand during 2005-2009, while the highest absolute numbers of babies with Down Syndrome were born to women aged 35-39 years, Down Syndrome rates rose exponentially with maternal age, with the highest rates being seen in babies whose mothers were 40+ years. Such differences likely arise because of the small number of women giving birth after 40+ years (**Figure 10**).

Table 16. Chromosomal Anomalies Evident at Birth, New Zealand Hospital Births 2005-2009

Chromosomal Anomaly	Number: Total 2005-2009	Number: Annual Average	Anomalies per 100,000 Births*
New Zealand			
Down Syndrome	264	52.8	88.3
Edwards and Patau Syndromes	43	8.6	14.4
Monosomies / Autosomal Deletions / Rearrangements	28	5.6	9.4
Turners Syndrome	12	2.4	4.0
Sex Chromosome Anomalies Male Phenotype	32	6.4	10.7
Other Chromosome Anomalies	10	2.0	3.3
Total Chromosomal Anomalies	389	77.8	130.1

Source: National Minimum Dataset: Numerator: Hospital Admissions with Event Type = Birth and a Chromosomal Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth; * Anomalies per 100,000 Births refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly.

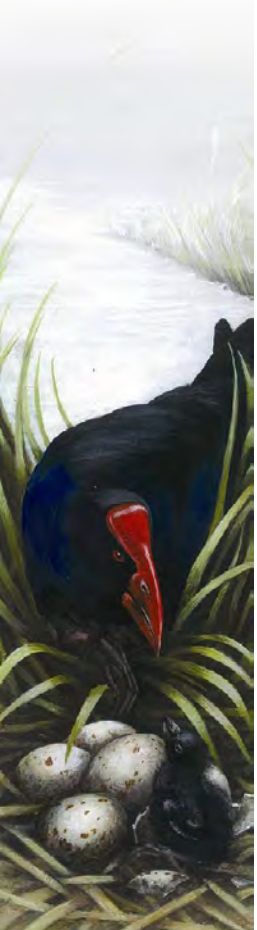
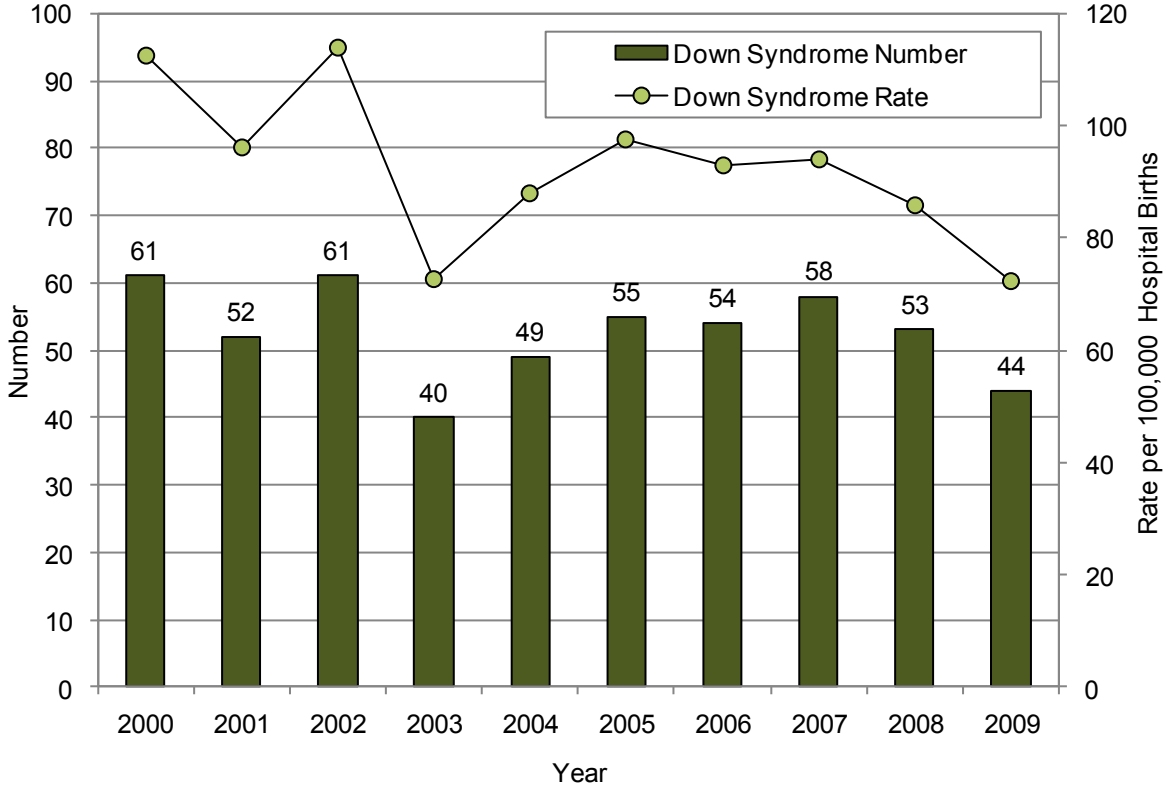


Table 17. Babies with Down Syndrome who also had Other Congenital Anomalies Evident at Birth, New Zealand Hospital Births 2005-2009

Other Congenital Anomaly	Number: Total 2005-2009	% of Babies with Down Syndrome
Babies with Down Syndrome (n=264)		
One or more Malformations of Nervous System	<5	s
One or more Malformations of Eye, Ear, Face and Neck	11	4.2
One or more Malformations of Circulatory System*	137	51.9
One or more Malformations of Respiratory System	<5	s
One or more Other Malformations of Digestive System	13	4.9
One or more Malformations of the Genital Organs	9	3.4
One or more Malformations of the Urinary System	<5	s
One or more Malformations of the Musculoskeletal System	14	5.3
One or more Other Congenital Malformations	10	3.8
* Babies with Down Syndrome and a Circulatory System Anomaly (n=137)		
One or more Malformationss Cardiac Chambers / Connections	<5	s
Ventricular Septal Defect	30	11.4
Atrial Septal Defect	68	25.8
Atrioventricular Septal Defect	27	10.2
Tetralogy of Fallot	8	3.0
One or more Pulmonary / Tricuspid Valve Malformations	<5	s
One or more Aortic / Mitral Valve Malformations	<5	s
One or more Other Heart Malformations	14	5.3
Patent Ductus Arteriosus	61	23.1
One or more Malformations Great Arteries (Excluding PDA)	<5	s
One or more Other Circulatory Malformationss	17	6.4

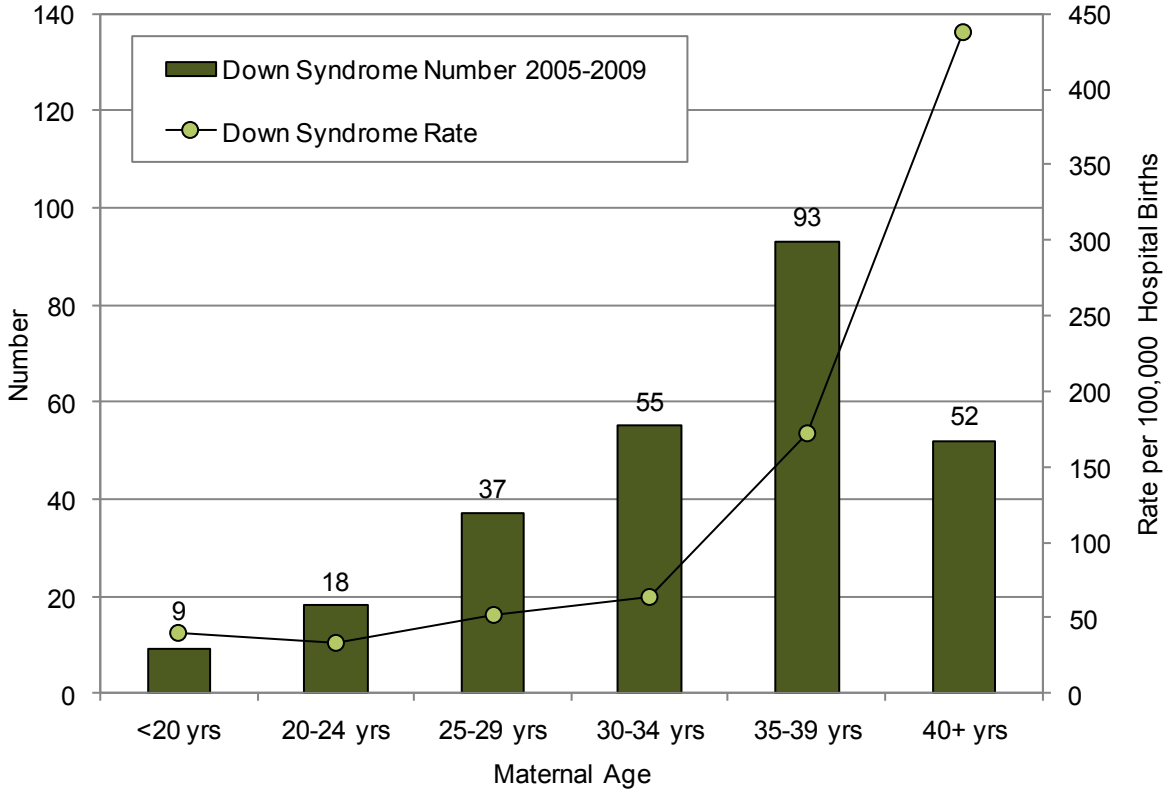
Source: National Minimum Dataset: Numerator: Hospital Admissions with Event Type = Birth and Down Syndrome listed in any of the first 15 diagnoses, plus another Congenital Anomaly listed in first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth and Down Syndrome listed in any of the first 15 diagnoses. Note: Numbers and percentages do not sum to 100%, as some babies have more than one malformation of each of the systems listed.

Figure 9. Babies with Down Syndrome Evident at Birth, New Zealand Hospital Births 2000-2009

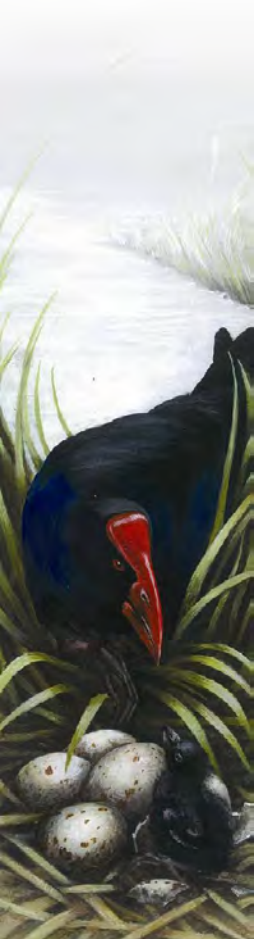


Source: National Minimum Dataset; Numerators: Hospital Admissions with Event Type = Birth and Down Syndrome listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth

Figure 10. Babies with Down Syndrome Evident at Birth by Maternal Age, New Zealand Hospital Births 2005-2009



Source: National Minimum Dataset; Numerators: Hospital Admissions with Event Type = Birth and Down Syndrome listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth



Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

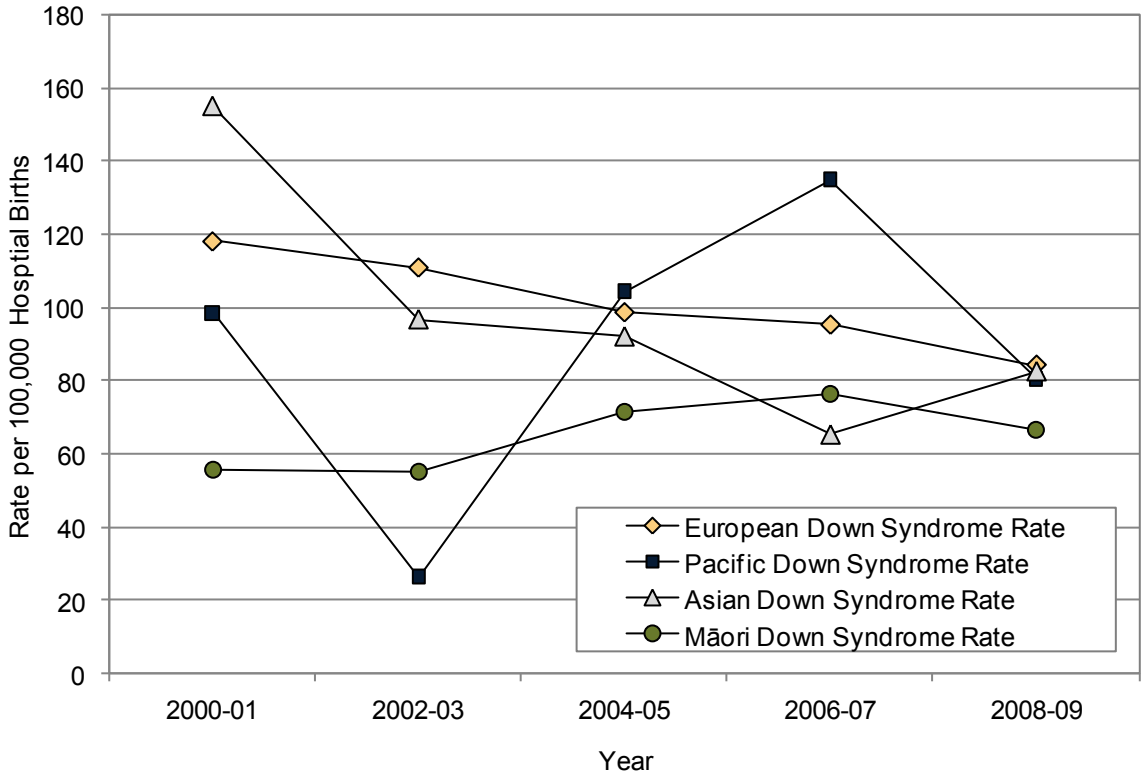
In New Zealand during 2005-2009, there were no statistically significant socioeconomic, ethnic or gender differences in the proportion of babies being identified with Down syndrome at the time of birth. Rates were *significantly* higher for older women however, with rates for those aged 40+ years being 11.0 (95% CI 5.4-22.3) times higher than for those in their teenage years (**Table 18**). During 2000-2009, rates were generally lower for Māori than for European babies (**Figure 11**).

Table 18. Babies with Down Syndrome Evident at Birth by Prioritised Ethnicity, NZ Deprivation Index, Gender and Maternal Age, New Zealand Hospital Births 2005-2009

Variable	Number of Babies: Total 2005-2009	Rate per 100,000 Hospital Births	Rate Ratio	95% CI
Down Syndrome				
Prioritised Ethnicity				
Māori	45	68.8	0.74	0.53 - 1.03
Pacific	34	106.3	1.14	0.79 - 1.65
European	153	93.1	1.00	
Asian	23	83.3	0.89	0.58 - 1.39
NZ Deprivation Index				
Decile 1-2	49	117.6	1.00	
Decile 3-4	40	87.5	0.74	0.49 - 1.13
Decile 5-6	38	70.5	0.60	0.39 - 0.92
Decile 7-8	61	93.1	0.79	0.54 - 1.15
Decile 9-10	73	84.6	0.72	0.50 - 1.03
Gender				
Female	116	79.8	1.00	
Male	148	96.4	1.21	0.95 - 1.54
Maternal Age				
<20 Years	9	39.8	1.00	
20-24 Years	18	33.8	0.85	0.38 - 1.89
25-29 Years	37	51.7	1.30	0.63 - 2.69
30-34 Years	55	64.4	1.62	0.80 - 3.28
35-39 Years	93	172.0	4.33	2.18 - 8.57
40+ Years	52	437.6	11.01	5.43 - 22.33

Source: National Minimum Dataset; Numerators: Hospital Admissions with Event Type = Birth and Down Syndrome listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth.
Note: Rate per 100,000 refers to number of babies with Down Syndrome.

Figure 11. Babies with Down Syndrome Evident at Birth by Prioritised Ethnicity, New Zealand Hospital Births 2000-2009



Source: National Minimum Dataset; Numerators: Hospital Admissions with Event Type = Birth and Down Syndrome listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with Down Syndrome. Ethnicity is Prioritised.

Taranaki Distribution and Trends

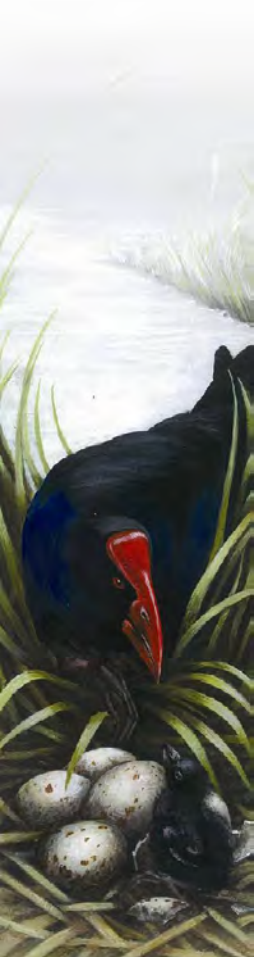
Taranaki Distribution

In Taranaki during 2005-2009, 12 babies were identified with Down Syndrome at the time of birth, with this equating to 2.4 births per year. A smaller number were identified as having Edwards or Patau Syndromes, or other chromosomal anomalies (**Table 19**).

Table 19. Babies with Chromosomal Anomalies Evident at Birth, Taranaki Hospital Births 2005-2009

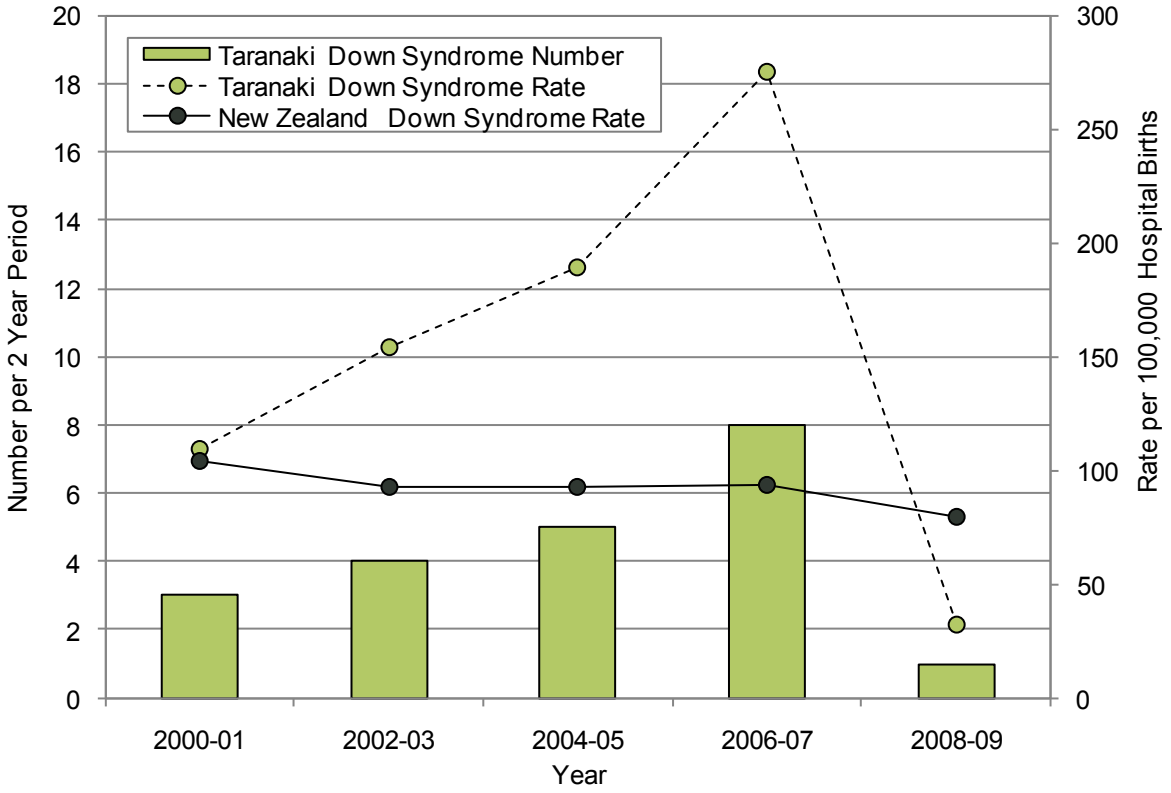
Chromosomal Anomaly	Number: Total 2005-2009	Number: Annual Average	Number of Anomalies per 100,000 Births*
Taranaki			
Down Syndrome	12	2.4	163.4
Edwards and Patau Syndromes	<5	s	s
Sex Chromosome Anomalies Male Phenotype	<5	s	s
Total Chromosomal Anomalies	17	3.4	231.5

Source: National Minimum Dataset: Numerator: Hospital Admissions with Event Type = Birth and a Chromosomal Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. * Anomalies per 100,000 Births refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly.



In Taranaki during 2005-2009, the proportion of babies with Down Syndrome identified at birth was *significantly* higher than the New Zealand average (RR 1.85 95% CI 1.04 – 3.30), although there was considerable year to year variability during 2000-2009 (**Figure 12**).

Figure 12. Babies with Down Syndrome Evident at Birth, Taranaki vs. New Zealand Hospital Births 2000-2009



Source: National Minimum Dataset: Numerators: Hospital Admissions with Event Type = Birth and Down Syndrome listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Numbers are per 2 year period.

Summary

In New Zealand during 2005-2009, Down Syndrome was the most frequent chromosomal anomaly identified at the time of birth, accounting for 88.3% of chromosomal anomalies during this period. Overall, 51.9% of babies with Down Syndrome had one or more co-existing cardiovascular anomalies, with the most frequent being atrial septal defects and patent ductus arteriosus. While the highest absolute numbers of babies with Down Syndrome were born to women aged 35-39 years, Down Syndrome rates rose exponentially with maternal age, with the highest rates being seen in babies whose mothers were 40+ years. There were no statistically significant socioeconomic, ethnic or gender differences in the proportion of babies with Down syndrome during this period although during 2000-2009, rates were generally lower for Māori than for European babies.

In Taranaki during 2005-2009, 12 babies were identified with Down Syndrome at the time of birth, with this equating to 2.4 births per year. A smaller number were identified as having Edwards or Patau Syndromes, or other chromosomal anomalies. During this period, the proportion of babies with Down Syndrome identified at birth was *significantly* higher than the New Zealand average (RR 1.85 95% CI 1.04 – 3.30), although there was considerable year to year variability during 2000-2009.

Local Policy Documents and Evidence Based Reviews Relevant to the Diagnosis and Management of those with Down Syndrome and Other Chromosomal Anomalies

In New Zealand a number of policy documents and literature reviews consider the antenatal diagnosis and management of children and young people with Down Syndrome. These are summarised in **Table 20**, along with a range of other reviews, which consider these issues in the overseas context. In addition, **Table 3** on **Page 26** considers antenatal and newborn screening in more general terms.

Table 20. Local Policy Documents and Evidence Based Reviews Relevant to the Antenatal Diagnosis and Management of those with Down Syndrome and Other Chromosomal Anomalies

New Zealand Policy Documents and Publications
National Screening Unit. **Guidelines for maternity providers offering antenatal screening for Down syndrome and other conditions in New Zealand**. Wellington: National Screening Unit, 2009. These guidelines are intended to inform maternity providers of recommended best practice in antenatal screening for Down syndrome. Women who present in the first trimester are to be offered a nuchal translucency scan plus a blood test that measures two maternal serum markers and women who present later in pregnancy are to be offered a blood test that measures four serum markers. The guidelines state that providers of screening are required to provide accurate and non-directional information to women and to offer unconditional acceptance of and support for whatever choice a woman makes about screening. They also state that "Maternity providers have a contractual obligation under the Primary Maternity Services Notice 2007, issued pursuant to section 88 of the New Zealand Public Health and Disability Act 2000, to provide services within screening initiatives endorsed by the Ministry of Health, including antenatal screening for Down syndrome and other conditions." The Ministry of Health has also published 3 patient information leaflets on screening for Down syndrome: • First trimester Combined Screening • Second Trimester Maternal Serum Screening • Increased chance. These, and the guidelines, can be found at: http://www.nsu.govt.nz/health-professionals/3391.asp
Antenatal Down Syndrome Advisory Group. **Antenatal Down Syndrome Screening in New Zealand 2007**. Wellington: National Screening Unit, 2007. URL: http://www.moh.govt.nz/moh.nsf/indexmh/antenatal-down-syndrome-screening-in-nz-2007?Open This report reviewed the main issues relating to antenatal screening for Down syndrome and considered possible screening options. The members of the advisory group agreed that the opportunistic screening practice current in 2007 was unsafe, inequitable, not in accord with international best practice and resulted in women unnecessarily being referred for invasive diagnostic tests (chorionic villus sampling and amniocentesis) which have a risk of miscarriage. The members of the group were not able to agree on the best way to proceed with screening. A large majority wished to continue to offer screening and to improve the quality and safety of screening tests by means of a nationally organised screening programme. They offered suggestions on the best practice screening methods in particular situations. A minority of group members did not support the introduction of a national screening programme as they felt it would imply an intention to reduce the incidence of Down syndrome. They considered that the best option was to recommend additional funding for disability support services.
Stone P, Austin D. **Report to the National Screening Unit Assessment of Antenatal Screening for Down Syndrome in New Zealand**. Wellington: Ministry of Health, 2006. URL: http://www.nsu.govt.nz/files/ANNB/assessment-antenatal-screening-down-syndrome.pdf This report provides a detailed analysis of the situation regarding antenatal screening for Down syndrome in New Zealand in 2006, which the authors regarded as being unsatisfactory and inconsistent with international evidence and best practice. It includes a literature review from which the authors were able to draw some conclusions to guide future screening practice in New Zealand. It presents the recommendations from discussions with a working group consisting of representatives of consumer and professional organisations and the results of a postal survey of health practitioners. The authors provide a list of recommendations including establishing a working party to develop and implement a screening programme suitable for New Zealand.

O'Connell R, Stephenson M, Weir R. **Screening strategies for antenatal Down syndrome screening**. Christchurch: New Zealand Health Technology Assessment (NZHTA). 2006;253p.

This literature review was performed at the request of the Ministry of Health to assist with assessing options for antenatal Down syndrome screening and determining whether or not New Zealand should have a national antenatal screening programme. The review appraised the international evidence on screening technologies and strategies. Key results of the literature review are presented under the following headings: Accuracy of screening methods, Difficulties in implementing any screening strategies, Uptake of invasive testing following receipt of screening results, Changes in the rate of invasive testing with the introduction of a screening programme and Rates of foetal loss associated with invasive testing procedures.

Ministry of Health. **The Clinical Assessment and Management of Children, Young People and Adults with Down Syndrome: Recommended Clinical Practice**. Wellington: Ministry of Health, 2001. URL: http://www.moh.govt.nz/moh.nsf/by+unid/4BA4A3A3EEE25F14CC256AE90078EA60?Open

This document provides information and guidance on the medical management of Down Syndrome throughout the lifespan as well as on therapy, education, vocational and social support for people with Down Syndrome and their families. Part 1 provides a general overview of Down Syndrome including the major clinical features, incidence, genetics and a brief Māori perspective. Part 2 provides recommendations for care at the various stages of life.

International Guidelines and Systematic and Other Reviews

The Down's Syndrome Medical Interest Group. URL: http://www.dsmig.org.uk/ accessed 29/10/2010.

The Down's Syndrome Medical Interest Group (DSMIG) is a network of doctors from the UK and Republic of Ireland who have a specialist interest in Down's syndrome. The DSMIG has produced evidence based surveillance guidelines for cardiac disease, thyroid dysfunction, hearing and vision disorders, growth and cervical spine instability as well as number of other useful publications. Also on their website is a library of relevant publications from the medical literature.

European Down Syndrome Association. URL: http://www.edsa.eu/index.html accessed 29/9/2010.

Useful publications on this website include:

- EDSA Essentials 2 Health Care Guidelines for People with Down Syndrome
- EDSA Essentials 3 The Person with Down Syndrome: Orientations for Families

National Collaborating Centre for Women's and Children's Health. **Antenatal care: Routine care for the healthy pregnant woman**. London: RCOG Press, 2008. URL: http://www.nice.org.uk/nicemedia/live/11947/40145/40145.pdf

Section 9.2 of this publication covers screening for Down syndrome and reviews published studies relevant to the diagnostic value and effectiveness screening methods, women's views and psychosocial aspects, and health economics. The recommendations for Down syndrome screening are essentially the same as those in New Zealand.

American Academy of Pediatrics, Committee on Genetics. **Health supervision for children with Down syndrome**. Pediatrics 2001; 107(2): 442-9.

These guidelines are aimed at the paediatrician caring for a child with Down syndrome. They also offer advice on counselling pregnant women who have been given a prenatal diagnosis of Down syndrome.

Bondy CA, for The Turner Syndrome Consensus Study Group. **Care of girls and women with Turner syndrome: A guideline of the Turner Syndrome Study Group**. Journal of Clinical Endocrinology & Metabolism 2007; 92(1): 10-25.

These guidelines are the result of a meeting of the Turners Syndrome Consensus Study Group (multidisciplinary panel of experts with relevant clinical and research experience) that met in Maryland in April 2006. The group used peer reviewed published information as the basis for its recommendations and expert opinion where evidence was lacking. The guidelines cover genetic, cardiological, auxological, psychological, gynaecological, and general medical concerns.

Kornman LH, Nisbet DL, et al. **Preconception and antenatal screening for the fragile site on the X-chromosome**. Cochrane Database of Systematic Reviews 2009(1).

Fragile X is the commonest inherited cause of mental retardation. The authors of this review found that there have been no randomised trials to indicate whether there is any additional benefit to be gained from routine pre-conception or antenatal screening for fragile X carrier status over that from testing only women thought to be at increased risk (due to family history of either fragile X and/or other undiagnosed mental illness/impairment).

Other Relevant Publications and Websites

Down Syndrome Education International. URL: http://www.downsed.org/en/gb/default.aspx accessed 29/9/2010.

Down Syndrome Education International is a UK-based charity that works to improve education for young people with Down syndrome through scientific research and global information and advice services. It publishes the journal Down Syndrome Research and Practice.

NEURAL TUBE DEFECTS

Introduction

Neural Tube Defects (NTDs) are congenital malformations which result from abnormal closure of the neural tube between the 3rd and 4th week of gestation. They can result in structural defects anywhere along the neuroaxis, from the developing brain to the sacrum. NTDs are generally divided into two groups:

1. Those affecting cranial structures i.e. anencephaly and encephalocele
2. Those affecting spinal structures i.e. spina bifida

Cranial malformations are generally the most clinically obvious and are often incompatible with life. In contrast, spina bifida can range from a severe open defect leading to muscle weakness, loss of skin sensation and problems with bowel and bladder control, to defects that are less easily detected [22]. Associated central nervous system anomalies, hydrocephalus and later scoliosis or kyphosis, may further complicate the clinical picture.

While advances in neurosurgical, urologic and medical care have allowed many children with spina bifida to survive with virtually intact cognitive skills, specialised medical and surgical care is necessary to ensure that children achieve independent mobility. For younger children, the ability to walk is usually influenced by the degree of paralysis arising from the spinal cord lesion, although as children get older, the amount of energy required for walking and the slow speeds achieved may lead to an increasing reliance on a wheelchair for day to day mobility [23].

The aetiology of NTDs is complex and generally thought to arise from a combination of genetic and environmental factors. While a number of chromosomal / genetic disorders have been associated with NTDs, many result in in-utero death, making their overall contribution to defects evident at the time of birth less than might otherwise be expected. Further, while the effects of maternal age on NTDs is thought to be small, a number of studies have suggested that folic acid supplementation prior to / at conception may reduce the risk of NTDs and as a consequence, there has been significant recent debate regarding the supplementation of New Zealand's food supply with folic acid, with one Ministry of Health publication [24] outlining four possible approaches:

1. An education campaign making women aware of the benefits of folate consumption
2. Considering mandatory fortification of either bread or flour
3. Continuing to recommend folic acid supplements to women planning pregnancy, whether fortification remains voluntary or becomes mandatory
4. Making 400mg folic acid tablets available to women planning pregnancy as a registered medicine.

The same publication also recommended continuing monitoring of neural tube defects, expanding the reporting of terminations of pregnancy to include the type of neural tube defect involved, and monitoring of the folate status and folic acid intake of New Zealanders [24].

The following section uses information from the National Minimum Dataset to review the number of hospital births where neural tube defects were identified at the time of birth.

Data Source and Methods

Definition

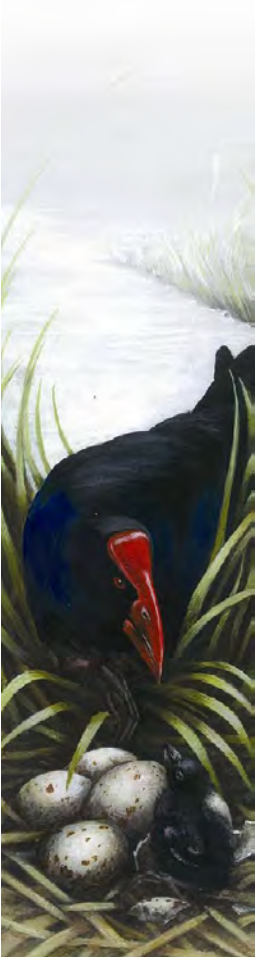
1. Babies with Neural Tube Defects Evident at the Time of Birth

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions with Event Type = Birth and Anencephaly (ICD-10 Q00), Encephalocele (ICD-10 Q01), or Spina Bifida (ICD-10 Q05) listed in any of the first 15 diagnoses.

Denominator: All Hospital Admissions with Event Type = Birth



Notes on Interpretation
The analysis includes all admissions recorded in the National Minimum Dataset where the Event Type was listed as a Birth (Note: Only one birth event is allowed per NHI number, with admissions for babies being born prior to hospital admission, or being readmitted shortly after discharge being listed as a routine inpatient event). Thus the analysis does not include babies born prior to hospital admission, babies born at home, or babies whose neural tube defect was overlooked at the time of initial hospital discharge, but who re-presented shortly thereafter.
For a list of the ICD-10 codes used to define other anomalies of the Nervous System see **Appendix 8.**

Indicator Category Ideal B

New Zealand Distribution and Trends

New Zealand Distribution

In New Zealand during 2005-2009, a total of 80 neural tube defects were evident at the time of birth, with this equating to 16 anomalies per year. Neural tube defects accounted for 20.4% of all nervous system anomalies during this period. (Note: The unit of analysis in this table was the number of anomalies identified, rather than the number of babies with one or more anomalies (**Table 21**)).

New Zealand Trends

In New Zealand during 2000-2009 on average, 13.3 babies per year had one or more neural tube defects evident at the time of birth, with large year to year fluctuations being evident during this period (**Figure 13**).

Distribution by Maternal Age

In New Zealand during 2005-2009, neural tube defects evident at the time of birth were highest amongst babies born to teenage women, and lowest amongst those born to women 30+ years (**Figure 14**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2005-2009, neural tube defects evident at the time of birth were *significantly higher* for Māori babies than for European babies. Rates were also *significantly higher* for those living in the most deprived (NZDep Decile 9-10) areas, and for babies born to teenage mothers (vs. mothers aged 20-39 years (**Table 22**)).

Table 21. Nervous System Anomalies Evident at Birth, New Zealand Hospital Births 2005-2009

Congenital Anomaly	Number: Total 2005-2009	Number: Annual Average	Number of Anomalies per 100,000 Births[1]
New Zealand			
Anencephaly (NTD)[2]	10	2.0	3.3
Encephalocele (NTD)[2]	10	2.0	3.3
Microcephaly	61	12.2	20.4
Congenital Hydrocephalus	71	14.2	23.8
Other Brain Malformations	150	30.0	50.2
Spina Bifida (NTD)[2]	60	12.0	20.1
Other Spinal Cord Malformations	10	2.0	3.3
Other CNS Malformations	21	4.2	7.0
Total Malformations of Nervous System	393	78.6	131.5

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Nervous System Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Anomalies per 100,000 Births refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly; Note 2: NTD denotes Neural Tube Defect

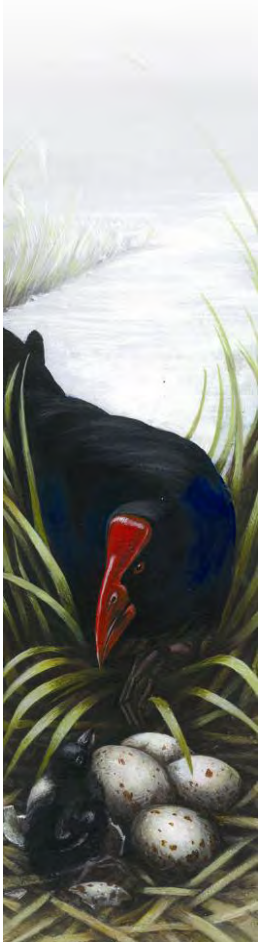
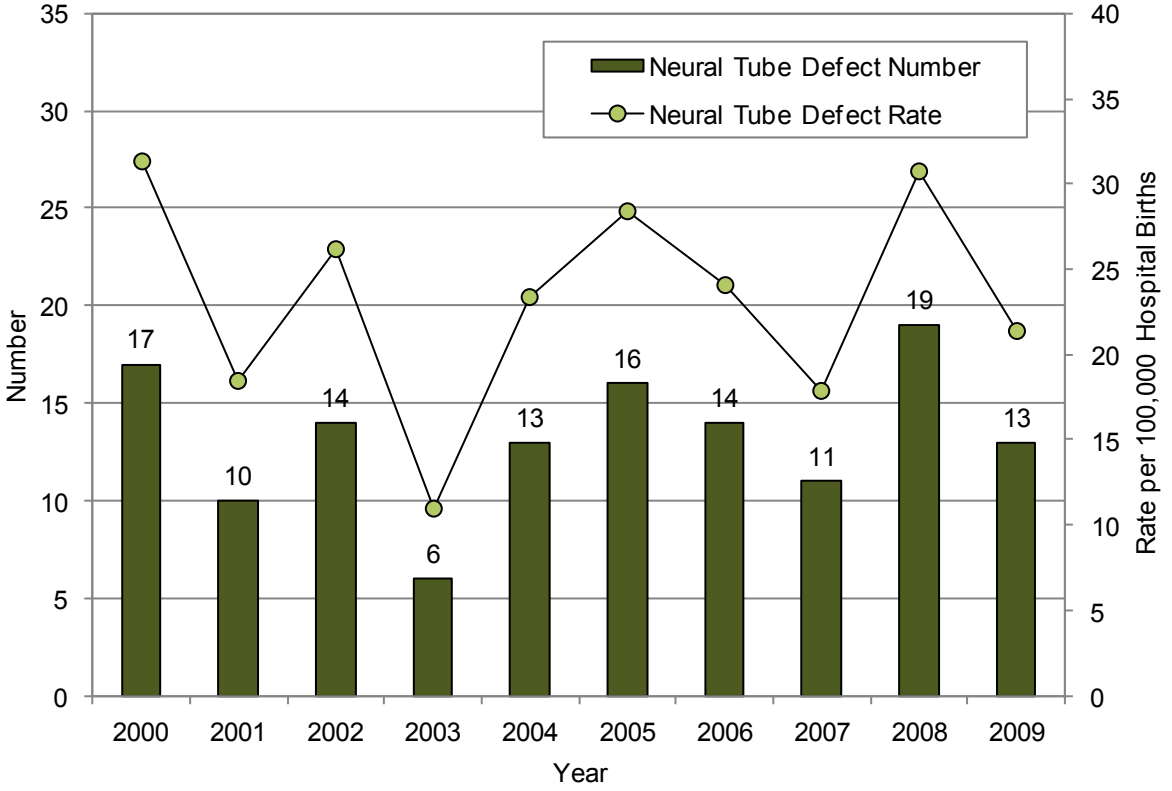
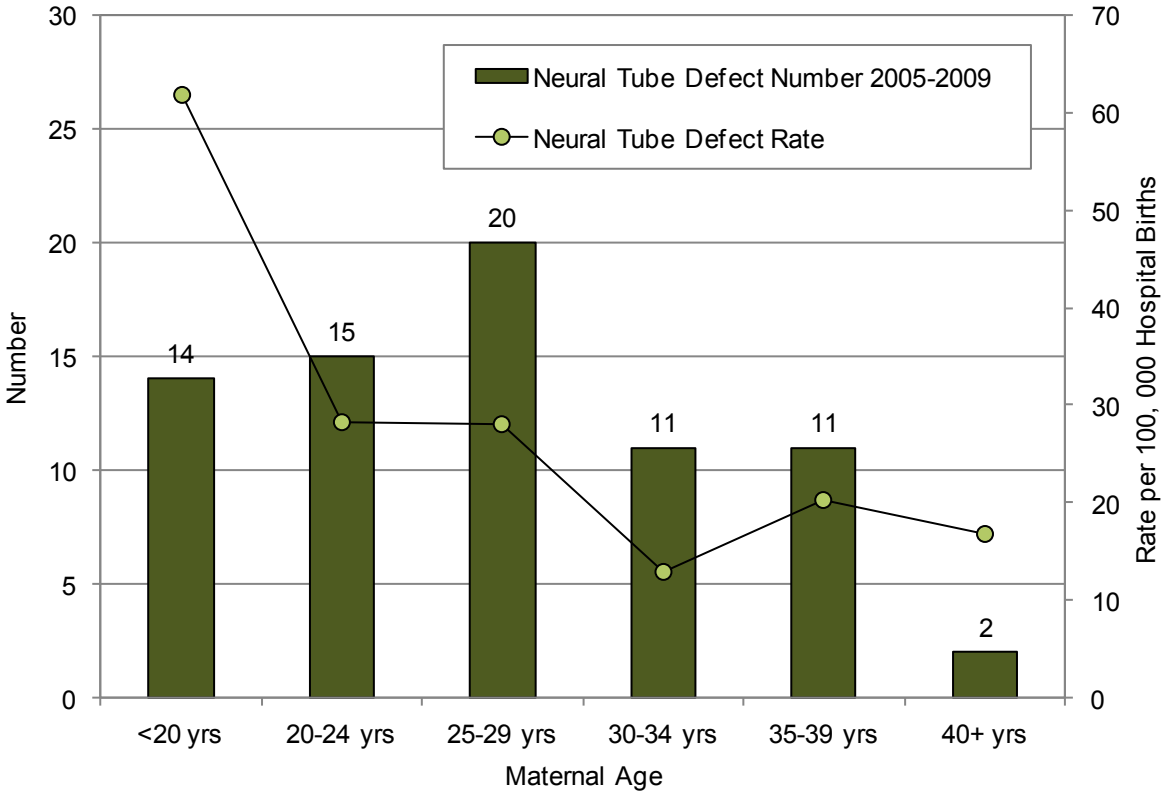


Figure 13. Babies with Neural Tube Defects Evident at Birth, New Zealand Hospital Births 2000-2009



Source: National Minimum Dataset; Numerators Hospital Admissions with Event Type = Birth and a Neural Tube Defect listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with one or more Neural Tube Defects.

Figure 14. Distribution of Babies with Neural Tube Defects Identified at Birth by Maternal Age, New Zealand Hospital Births 2005-2009



Source: National Minimum Dataset; Numerators: Hospital Admissions with Event Type = Birth and a Neural Tube Defect listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note: Rate per 100,000 refers to number of babies with one or more Neural Tube Defects.

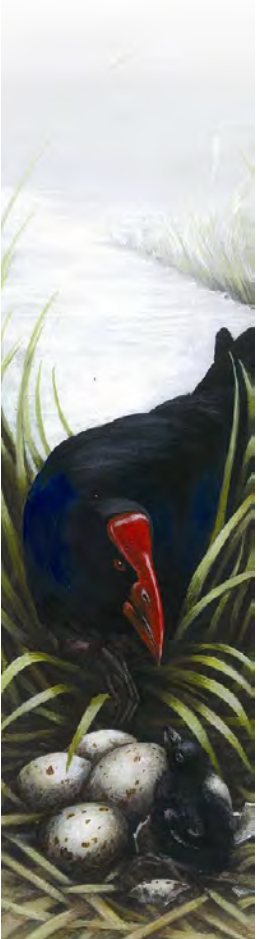


Table 22. Babies with Neural Tube Defects Evident at Birth by Prioritised Ethnicity, NZ Deprivation Index, Gender and Maternal Age, New Zealand Hospital Births 2005-2009

Variable	Number of Babies: Total 2005-2009	Rate per 100,000 Births[1]	Rate Ratio	95% CI
Neural Tube Defects				
Prioritised Ethnicity				
Māori	31	47.4	2.88	1.72 - 4.83
Pacific	6	18.8	1.14	0.47 - 2.76
European	27	16.4	1.00	
Asian	5	18.1	1.10	0.42 - 2.86
NZ Deprivation Index				
Decile 1-2[2]	4	9.6	1.00	
Decile 3-4	8	17.5	1.82	0.55 - 6.05
Decile 5-6	12	22.3	2.32	0.75 - 7.19
Decile 7-8	15	22.9	2.39	0.79 - 7.19
Decile 9-10	33	38.3	3.98	1.41 - 11.25
Gender				
Female	37	25.4	1.00	
Male	36	23.5	0.92	0.58 - 1.46
Maternal Age				
<20 Years	14	61.8	1.00	
20-24 Years	15	28.2	0.46	0.22 - 0.94
25-29 Years	20	27.9	0.45	0.23 - 0.89
30-34 Years	11	12.9	0.21	0.09 - 0.46
35-39 Years	11	20.3	0.33	0.15 - 0.72
40+ Years	<5	s	s	s

Source: National Minimum Dataset; Numerators: Hospital Admissions with Event Type = Birth and a Neural Tube Defect listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Rate Ratios are unadjusted. Note 1: Rate per 100,000 Births refers to number of babies with one or more Neural Tube Defects. Note 2: NZ Deprivation Index decile rate ratios should be interpreted with caution due to the small numbers in the reference category.

Taranaki Distribution and Trends

Taranaki Distribution

In Taranaki during 2005-2009, a total of 3 neural tube defects were evident at the time of birth, with these accounting for 21.4% of all nervous system malformations during this period (**Table 23**). When the number of babies with one or more NTDs, rather than the total number of NTDs was taken into account, the numbers were the same, with 3 Taranaki babies having a neural tube defect evident at birth, equating to 0.6 babies per year, and a rate that was not *significantly* different from the New Zealand average (RR 1.67 95% CI 0.53 – 5.31).

Table 23. Nervous System Anomalies Evident at Birth, Taranaki Hospital Births 2005-2009

Congenital Anomaly	Number: Total 2005-2009	Number: Annual Average	Number of Anomalies per 100,000 Births[1]
Taranaki			
Anencephaly (NTD)[2]	<5	s	s
Congenital Hydrocephalus	<5	s	s
Other Brain Malformations	5	1.0	68.1
Spina Bifida (NTD)[2]	<5	s	s
Other Spinal Cord Malformations	<5	s	s
Other CNS Malformations	<5	s	s
Total Malformations of Nervous System	14	2.8	190.6

Source: National Minimum Dataset; Numerator: Hospital Admissions with Event Type = Birth and a Nervous System Anomaly listed in any of the first 15 diagnoses; Denominator: All Hospital Admissions with Event Type = Birth. Note 1: Anomalies per 100,000 Births refers to total number of anomalies rather than number of babies, as some babies have more than one anomaly. Note 2: NTD denotes Neural Tube Defect.

Summary

In New Zealand during 2000-2009 on average, 13.3 babies per year had one or more neural tube defects evident at the time of birth, with large year to year fluctuations being evident during this period. During 2005-2009, neural tube defects identified at birth were *significantly higher* for babies born to teenage mothers (vs. mothers aged 20-39 years). Rates were also *significantly higher* for Māori babies than for European babies, and for those living in the most deprived (NZDep Decile 9-10) areas.

In Taranaki during 2005-2009, a total of 3 neural tube defects were evident at the time of birth, with these accounting for 21.4% of all nervous system malformations during this period. When the number of babies with one or more NTDs, rather than the total number of NTDs was taken into account, the numbers were the same, with 3 Taranaki babies having a neural tube defect evident at birth, equating to 0.6 babies per year, and a rate that was not *significantly* different from the New Zealand average (RR 1.67 95% CI 0.53 – 5.31).

Local Policy Documents and Evidence Based Reviews Relevant to Folic Acid Supplementation and the Prevention and Management of Neural Tube Defects

In New Zealand a number of policy documents and literature reviews consider folic acid supplementation and the prevention of Neural Tube Defects. These are summarised in **Table 24**, along with a range of reviews which consider these issues in the overseas context. In addition, **Table 3** on **Page 26** considers antenatal and newborn screening in general.

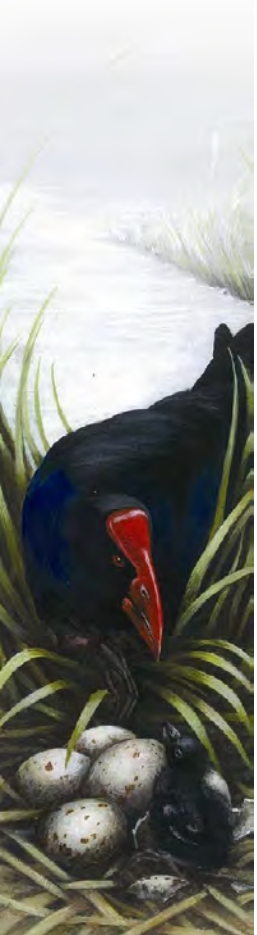


Table 24. Local Policy Documents and Evidence Based Reviews Relevant to Folic Acid Supplementation and the Prevention and Management of Neural Tube Defects

New Zealand Policy Documents and Publications
Ministry of Health. **Folic Acid and Iodine**. Wellington: Ministry of Health, 2010. URL: http://www.healthed.govt.nz/uploads/docs/HE4147.pdf This short pamphlet provides advice for mothers regarding taking folic acid when planning to become pregnant and during pregnancy and also on taking iodine supplements when pregnant and breastfeeding.
Ministry of Health. **Eating for Healthy Pregnant Women/Ngā Kai Totika mā te Wahine Hapū.** Wellington: Ministry of Health, 2010. URL: http://www.healthed.govt.nz/resources/eatingforhealthypregnantwomenngaka.aspx Page 16 of this healthy food guideline for pregnant women covers the recommendations for folic acid.
Ministry of Health. **Improving Folate Intake in New Zealand: Policy Implications** Wellington: Ministry of Health, 2003. URL: http://www.moh.govt.nz/moh.nsf/pagesmh/2482?Open This publication provides background information on the benefits of folic acid and reviews the current policy situation regarding folic acid in New Zealand, Australia, Canada, the U.K. and the U.S. It considers four policy options for improving folate status in women of childbearing age: • Increasing dietary folate intake • Consumption of folic acid supplements (status quo) • Voluntary fortification of staple food products with folic acid (status quo) • Mandatory fortification of staple food products with folic acid. The key recommendations were: • An education campaign to make women aware of the benefits of increased folate consumption • Considering mandatory fortification of either bread or flour • Continuing to recommend folic acid supplements to women planning pregnancy whether fortification remains voluntary or becomes mandatory • Making 400mg folic acid tablets available to women planning pregnancy as a registered medicine • Continuing monitoring of neural tube defects, improved reporting of terminations of pregnancy to include the type of neural tube defect involved and monitoring of the folate status and folic acid intake of New Zealanders.
International Guidelines and Systematic and Other Reviews
Spina Bifida Foundation of Victoria. **Spina bifida continence management**. Australian Family Physician 2001;30 (Suppl 2). URL: http://www.racgp.org.au/Content/NavigationMenu/ClinicalResources/RACGPGuidelines/SpinaBifidaContinenceManagement/20020107spinabifida.pdf These guidelines are to assist general practitioners to help young people and adults with spina bifida to manage their own continence. Once children leave paediatric services their general practitioner usually becomes their contact with the health system so it is important that he or she is well informed about day to day treatment issues and the complications indicating need for specialist referral.
Lumley J, Watson L, et al. **Periconceptional supplementation with folate and/or multivitamins for preventing neural tube defects**. Cochrane Database of Systematic Reviews 2009(1). Based on a review of four randomised or quasi-randomised trials involving 6425 women which addressed periconceptional supplementation with folate and/or multivitamins, the authors of this review concluded that periconceptional folate supplementation (but not multivitamins alone) has a strong protective effect against neural tube defects (relative risk 0.28, 95% confidence interval 0.13 to 0.58). They stated that information about the benefits of folate should be made more widely available through both the health and education systems. They stated that the risks and benefits of fortifying basic foods (such as flour or bread) remain unresolved.
National Collaborating Centre for Women's and Children's Health. **Antenatal care: Routine care for the healthy pregnant woman**. London: RCOG Press, 2008. URL: http://www.nice.org.uk/nicemedia/live/11947/40145/40145.pdf Section 9.1 of this publication covers screening for structural anomalies and reviews studies relating to the use of ultrasound and serum screening (alpha-fetoprotein, AFP) for this purpose. Second trimester ultrasound seemed in general to show high specificity but poor sensitivity for identifying foetal structural anomalies but the actual values varied considerably depending on the centre and the particular anomaly. There were only a few high quality studies looking at first trimester ultrasound. It was reported to have high specificity and positive likelihood ratio but (as reported by a single centre in the U.K.) moderate sensitivity and negative likelihood ratio. There was good evidence that routine, rather than selective, ultrasound before 24 weeks resulted in improved detection of foetal anomalies which led to higher termination rates of affected pregnancies. There were two studies identified that investigated maternal serum alpha-fetoprotein (AFP) as a screening test for neural tube defects. One found that maternal AFP had good diagnostic value in both predicting and ruling out anomalies while the other found it to have less diagnostic value than a routine ultrasound. There was no evidence on the value and effectiveness of a combination of routine ultrasound and maternal AFP screening.

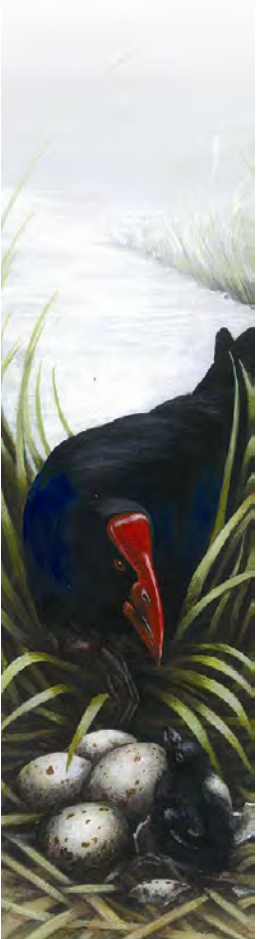
CYSTIC FIBROSIS

Introduction

Cystic fibrosis (CF) is one of the most common genetic diseases in European populations, with the outlook for those affected improving steadily in the past two decades, largely as a result of earlier diagnosis, more aggressive treatment, and the provision of care in specialised centres [25]. In the US, the projected life expectancy for those with CF has increased from 31 years to 37 years over the past decade, while in the UK a model predicting that a child born with CF today will typically live to be 50 years of age, is seen as being realistic [25].

Cystic fibrosis is caused by a mutation in a gene that encodes cystic fibrosis transmembrane conductance regulator protein (CFTR), which occurs in many epithelial and blood cells. Although CFTR functions mainly as a chloride channel, it has many other regulatory roles, and a number of hypotheses have been put forward as to how CFTR dysfunction leads to cystic fibrosis [25]. The *Low Volume Hypothesis* suggests that epithelial sodium and chloride channel dysfunction leads to excess sodium and water reabsorption, resulting in dehydration of airway surfaces, a reduction in the lubricating layer between the epithelium and mucus, the compression of cilia, and the loss of normal ciliary and cough clearance of mucus. The *High Salt Hypothesis* suggests that in the absence of functional CFTR, excess sodium and chloride are retained in airway surface liquids, disrupting the function of antibiotic molecules, and allowing bacteria that are normally cleared by the airways to persist in the lungs. Another hypothesis suggests that CF arises from disregulation of host inflammatory responses, with support for this coming from the abnormally high concentrations of inflammatory mediators seen in patients with CF. Finally, alterations of bacterial attachment are seen as playing a role, with the rapid, self limiting response seen when *Pseudomonas aeruginosa* binds to CFTR being lost, leading to a failure to eliminate *Pseudomonas aeruginosa* from the airways. At the same time, there is also increased attachment of other bacteria to epithelial surfaces.

By whatever mechanism, CFTR dysfunction results in around 15% of infants with CF being born with meconium ileus, an obstructive condition secondary to inspissated material in the small and large bowel. In addition, 85-90% of infants develop pancreatic insufficiency, with typical signs being greasy stools, abdominal bloating and poor weight gain. While the lungs of children with CF are normal in appearance at birth, they quickly become infected and inflamed. Typically infants with cystic fibrosis are rapidly colonised with *Haemophilus influenzae* or *S. aureus* or both, with *P. aeruginosa* soon becoming the predominant organism in the airway. Chronic airway infection may then progress to bronchiectasis, gas trapping and hypoxaemia [25].



In terms of diagnosis, newborn screening usually relies on a heel prick blood spot to measure immunoreactive trypsinogen (IRT), with a very high IRT concentration suggesting pancreatic injury consistent with (but not specific to) cystic fibrosis. In older children and adults, a diagnosis is made when a clinical history characteristic of cystic fibrosis is accompanied by biochemical and genetic markers of CFTR dysfunction. This typically includes a sweat test, with a diagnosis being made if the concentration of chloride in sweat is >60 mmol/l, or if intermediate (30-59 mmol / l) if an infant is < 6 months of age, or in older individuals (40-59 mmol/l) if two CFTR mutations are also identified [25].

In terms of management, research suggests that centres which see patients more frequently, obtain more cultures, and use more oral and intravenous antibiotics achieve better lung function than centres with less aggressive approaches to care [25]. A range of other therapies are also available, with a number of these being included in the table of evidence based reviews which appears at the end of this section. In order to assess the impact CF has on health service demand, the following section uses the National Minimum Dataset and Mortality Collection to review hospitalisations and mortality in children and young people with cystic fibrosis.

Data Source and Methods

Definition

1. Hospital Admissions and Mortality for Children and Young People with Cystic Fibrosis

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions for Children and Young People Aged 0-24 Years with Cystic Fibrosis (ICD-10-AM E84) in any of the first 15 diagnoses.

Denominator: Statistics New Zealand Estimated Resident Population

2. National Mortality Collection

Numerator: Mortality for Children and Young People Aged 0-24 Years with Cystic Fibrosis (ICD-10-AM E84) listed as either the main underlying cause of death, or as a contributory cause of death.

Denominator: Statistics New Zealand Estimated Resident Population

Notes on Interpretation

Unless otherwise specified, this analysis focuses on hospital admissions and mortality for children and young people who had cystic fibrosis listed in any of the first 15 diagnoses, or as a main underlying or contributory cause of death (rather than on the subset where cystic fibrosis was listed only as the primary diagnosis or main underlying cause of mortality). The rationale for this wider focus was the need to highlight the full spectrum of health issues experienced by children and young people with cystic fibrosis, and their consequent requirement for acute health services. For example, during 2005-2009, around 85% of hospitalisations for children and young people with cystic fibrosis had cystic fibrosis listed as the primary diagnosis, but a significant minority were admitted for infectious and respiratory diseases, digestive system problems or for other reasons. Further a review of the secondary diagnoses of those admitted with a primary diagnosis of cystic fibrosis indicated that a significant proportion of such admissions were for infections or respiratory or digestive system complications. The presence of a small number of events in patients with cystic fibrosis which were unrelated to the diagnosis of CF itself however, may slightly overinflate the impact cystic fibrosis has on acute service demand. If no mention of cystic fibrosis was made in any of the first 15 diagnoses however, these cases were not included (even if the patient had been assigned a cystic fibrosis related code on a previous admission).

Indicator Category Proxy B

New Zealand Distribution and Trends

Hospital Admissions by Diagnosis

Primary Diagnosis: In New Zealand during 2005-2009, 84.6% of hospital admissions for children and young people with cystic fibrosis (i.e. cystic fibrosis listed in any of the first 15 diagnoses) had cystic fibrosis listed as the primary diagnosis, with the remainder having a variety of infectious and respiratory diseases, digestive system problems and other issues listed as the primary reason for admission (**Table 25**)

Secondary Diagnosis: Of hospitalised children and young people who had cystic fibrosis listed as the primary reason for their admission during 2005-2009, the vast majority had a secondary diagnosis listed, with additional diagnoses including a range of infectious (e.g. pseudomonas, *staphlycoccus aureus*, aspergillosis), respiratory (e.g. bronchiectasis, pneumonia) and other (e.g. diabetes and pancreatic problems) complications (**Table 26**).

Mortality from Cystic Fibrosis

In New Zealand during 2003-2007, a total of 24 children and young people had cystic fibrosis listed as the main underlying cause of death. None however had cystic fibrosis listed as an additional contributory cause.

Distribution by Age

In New Zealand during 2005-2008, hospital admissions in children and young people with cystic fibrosis were relatively evenly distributed across the age range, although a peak in admissions was evident during early adolescence. Mortality however, was more common amongst those in their late teens and early twenties (**Figure 15**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2005-2009, hospital admissions for children and young people with cystic fibrosis were similar for males and females, and no marked social gradients were evident (with rates being highest for those living in average NZDep decile areas, and *significantly* lower for those in the most deprived (decile 10) areas). Admissions however,

were *significantly* higher for European > Māori > Pacific and Asian children and young people (**Table 27**). Similar ethnic differences were seen during 2000-2009 (**Figure 16**).

Table 25. Hospital Admissions in Children and Young People Aged 0-24 Years with Cystic Fibrosis by Primary Diagnosis, New Zealand 2005-2009

Primary Diagnosis	No. Total 2005-2009	No. Annual Average	Rate per 100,000 Population	% of Admissions in those with CF
Cystic Fibrosis (E84)	2,547	509.4	33.75	84.56
Respiratory System Diseases (J00-J99)	111	22.2	1.47	3.69
Factors Influencing Health Service Contact (Z00-99)	92	18.4	1.22	3.05
Diseases Digestive System (K00-K93)	56	11.2	0.74	1.86
Complications Surgical Medical Care (T80-T88)	53	10.6	0.70	1.76
Infectious and Parasitic Diseases (A00-B99)	36	7.2	0.48	1.20
Other Diagnoses	117	23.4	1.55	3.88
Total	3,012	602.4	39.91	100.00

Source: Numerator: National Minimum Dataset, Primary diagnosis for children and young people with Cystic Fibrosis listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population.

Table 26. Secondary Diagnoses in Children and Young People Aged 0-24 Years Hospitalised with Cystic Fibrosis as a Primary Diagnosis, New Zealand 2005-2009

Secondary Diagnosis	Total Admissions 2005-2009	% of Those With CF as Primary Diagnosis
Bronchiectasis (J47)	247	9.70
Acute Upper Respiratory Infections (J00-J06)	70	2.75
Influenza and Pneumonia (J10-J18)	62	2.43
Other Respiratory System Diseases (Remainder J20-J99)	598	23.48
Pseudomonas Infections (B965)	305	11.97
Staphlycoccus aureus infections (B954-958)	209	8.21
Aspergillosis (B44)	170	6.67
Other Mycobacterial Infections (A31)	15	0.59
Other Infectious and Parasitic Diseases (Remainder A00-B99)	135	5.30
Other Diseases Pancreas (K86)	92	3.61
Other Diseases Digestive System (Remainder K00-K93)	66	2.59
Factors Influencing Health Service Contact (Z00-99)	85	3.34
Non-Insulin Dependent Diabetes (E11)	38	1.49
Cystic Fibrosis (E84)	25	0.98
Complications Surgical Medical Care (T80-T88)	24	0.94
Insulin Dependent Diabetes (E10)	20	0.79
Other Diagnoses	153	6.01
No Secondary Diagnosis Listed	233	9.15
Total	2,547	100.0

Source: Numerator: National Minimum Dataset, Secondary diagnosis for children and young people with Cystic Fibrosis listed as their primary diagnosis. Denominator: Statistics NZ Estimated Resident Population.

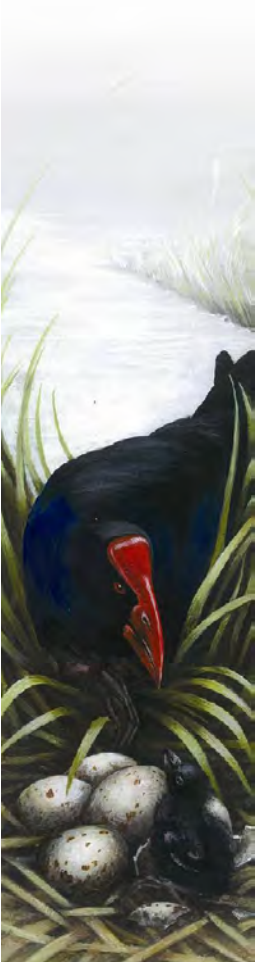
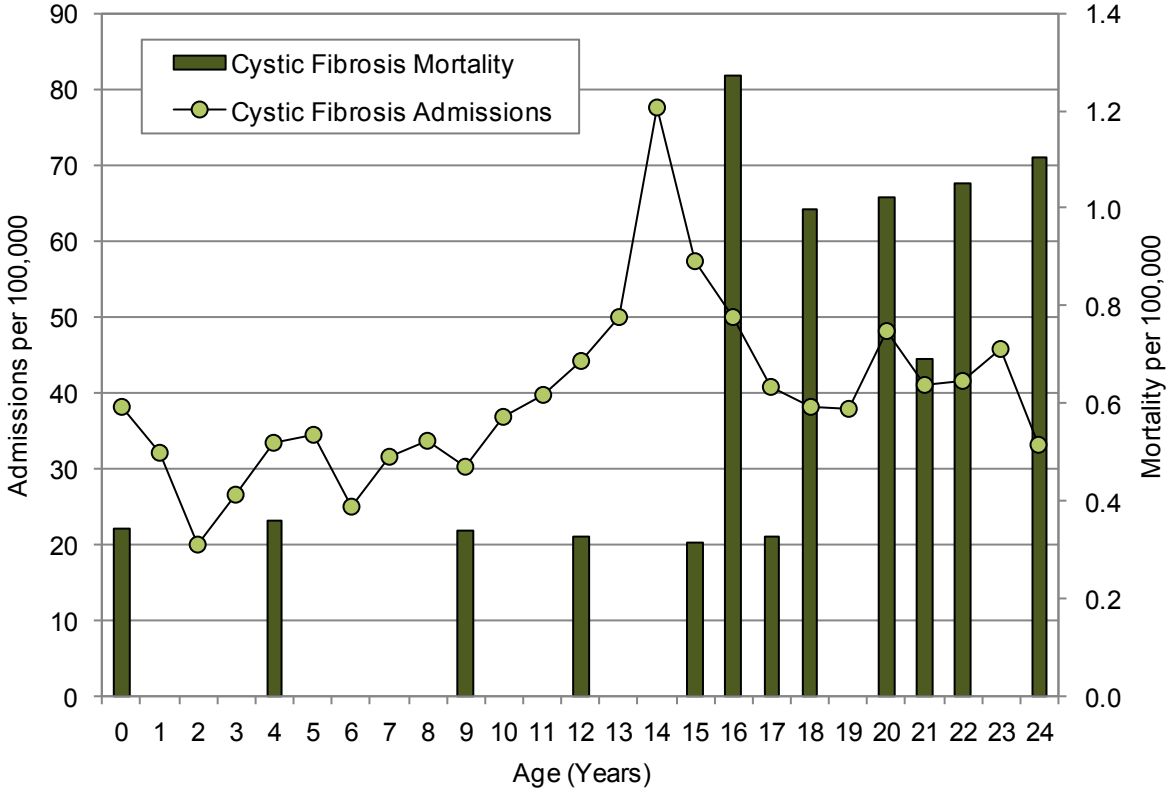


Figure 15. Hospital Admissions (2005-2009) and Mortality (2003-2007) for New Zealand Children and Young People with Cystic Fibrosis by Age



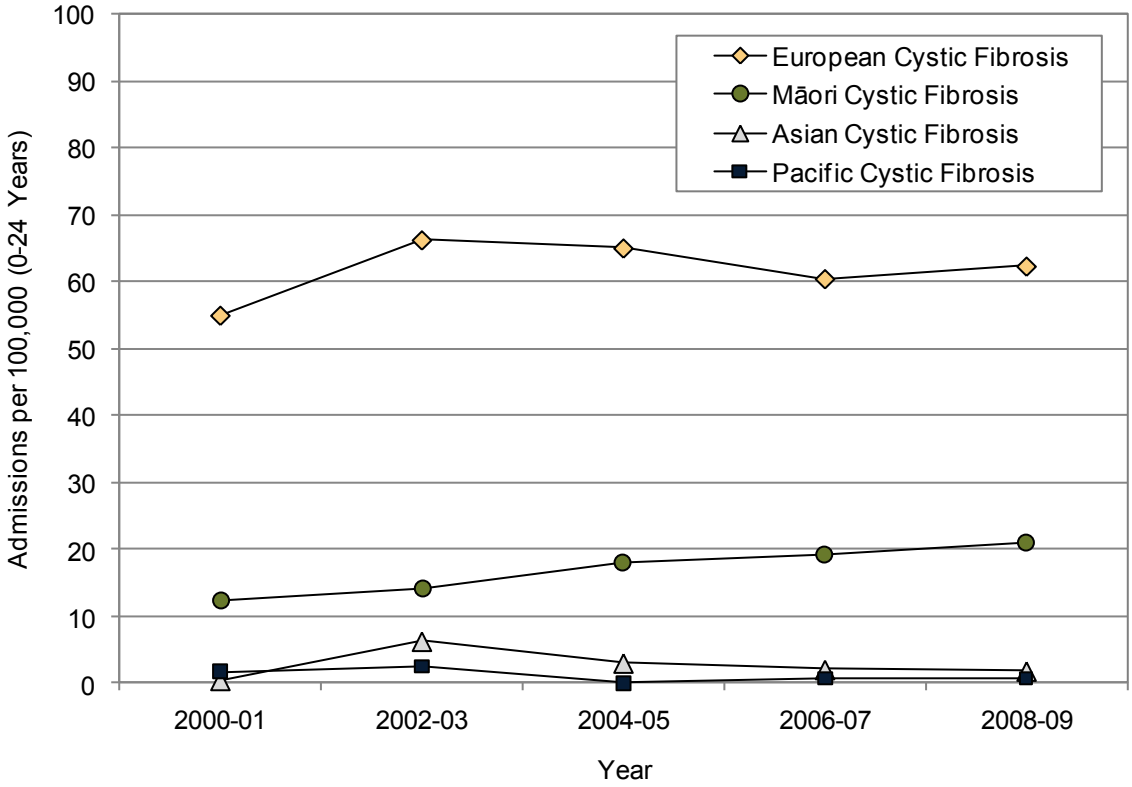
Source: Numerator Admissions: National Minimum Dataset, Hospital Admissions for children and young people with Cystic Fibrosis listed in any of the first 15 diagnoses; Numerator Mortality: National Mortality Collection, Deaths with Cystic Fibrosis listed as the main underlying or a contributory cause of death. Denominator: Statistics NZ Estimated Resident Population.

Table 27. Hospital Admissions for Children and Young People Aged 0-24 Years with Cystic Fibrosis by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2005-2009

Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
Cystic Fibrosis							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	31.5	1.00		Decile 1-2	33.0	1.00	
Decile 2	34.5	1.10	0.91 - 1.32	Decile 3-4	48.3	1.47	1.30 - 1.65
Decile 3	36.9	1.17	0.98 - 1.41	Decile 5-6	39.8	1.21	1.06 - 1.36
Decile 4	58.8	1.87	1.59 - 2.20	Decile 7-8	53.1	1.61	1.43 - 1.80
Decile 5	38.8	1.23	1.03 - 1.48	Decile 9-10	25.8	0.78	0.69 - 0.89
Decile 6	40.6	1.29	1.08 - 1.53	Prioritised Ethnicity			
Decile 7	57.4	1.82	1.55 - 2.15	Asian	2.1	0.03	0.02 - 0.05
Decile 8	49.4	1.57	1.33 - 1.85	European	61.1	1.00	
Decile 9	31.8	1.01	0.85 - 1.21	Māori	20.0	0.33	0.29 - 0.37
Decile 10	19.9	0.63	0.52 - 0.77	Pacific	0.6	0.01	0.00 - 0.03
Gender							
Female	39.9	1.00		Male	40.0	1.00	0.93 - 1.08

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Cystic Fibrosis listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Rate is per 100,000 population. Rate ratios are unadjusted.

Figure 16. Hospital Admissions for Children and Young People Aged 0-24 Years with Cystic Fibrosis by Prioritised Ethnicity, New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Cystic Fibrosis listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised.

Taranaki Distribution and Trends

Taranaki Distribution and Trends

In Taranaki during 2005-2009, a total of 10 individual children and young people were admitted to hospital with cystic fibrosis listed in any of the first 15 diagnoses. Admission rates per 100,000 population were *significantly* lower than the New Zealand average (RR 0.75 95% CI 0.58-0.98) (**Table 28**)). Admission rates increased during the early 2000s, reached a peak in 2002-03 and then declined, with rates during the early 2000s being similar to the New Zealand average, while rates during the mid-late 2000s were lower (**Figure 17**).

Table 28. Hospital Admissions for Children and Young People Aged 0-24 Years with Cystic Fibrosis, Taranaki vs. New Zealand 2005-2009

DHB	Total No. Individuals 2005-2009		Total No. Admissions 2005-2009	Average No. Admissions per Individual per Year	Admission Rate per 100,000 Total Population	Rate Ratio	95% CI
	(A)*	(B)*					
Cystic Fibrosis							
Taranaki	10	10	55	1.10	30.0	0.75	0.58 - 0.98
New Zealand	364		3,012	1.65	39.9	1.00	

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Cystic Fibrosis listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population.
*Note: (A): Each individual only counted once in DHB in which they first reside (i.e. DHB total = NZ total);
(B): Each individual counted once in each DHB in which they reside (i.e. the sum of DHB totals exceeds New Zealand total). Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

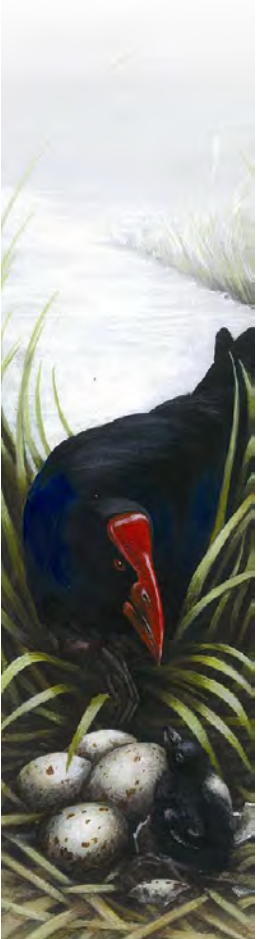
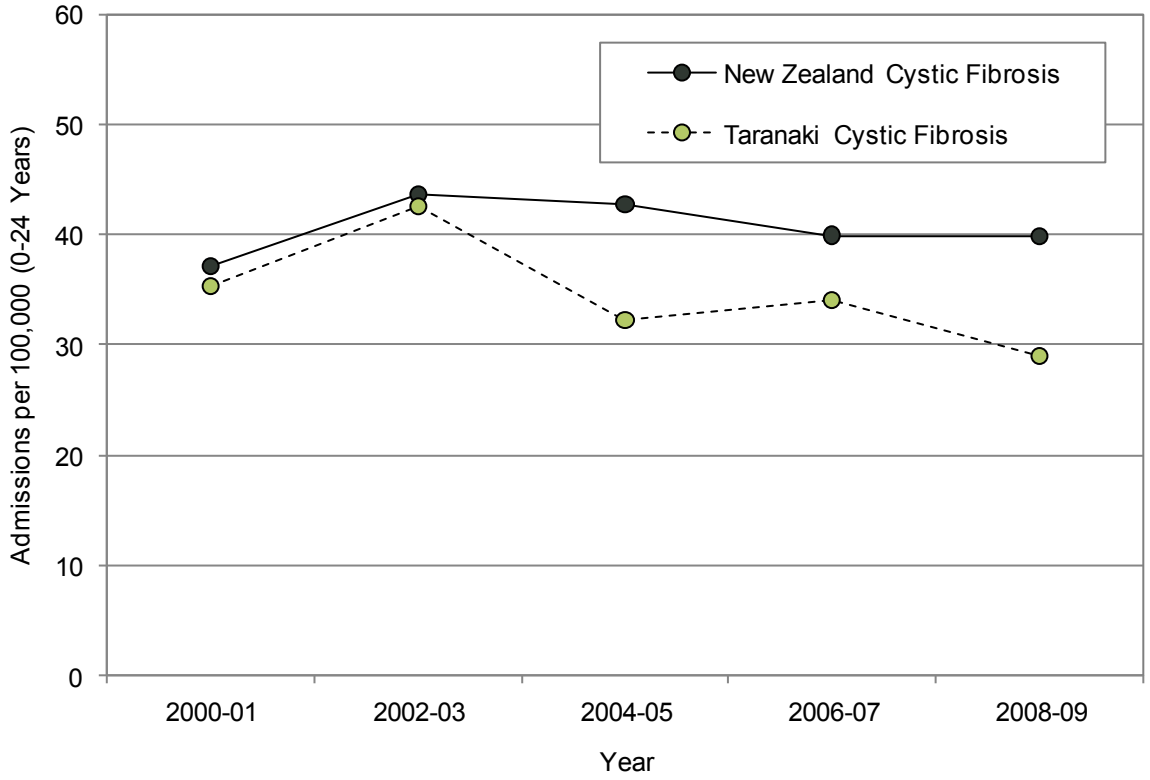


Figure 17. Hospital Admissions for Children and Young People Aged 0-24 Years with Cystic Fibrosis, Taranaki vs. New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Cystic Fibrosis listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Summary

In New Zealand during 2005-2009, 84.6% of hospital admissions for children and young people with cystic fibrosis had cystic fibrosis listed as the primary diagnosis. Of those with cystic fibrosis as the primary diagnosis, the vast majority also had a secondary diagnosis, with these including a range of infectious (e.g. pseudomonas, staphlycoccus aureus, aspergillosis), respiratory (e.g. bronchiectasis, pneumonia) and other (e.g. diabetes) complications. During this period, hospital admissions were similar for males and females, and no marked social gradients were evident (with rates being highest for those living in average NZDep decile areas, and *significantly* lower for those in the most deprived (decile 10) areas). Admissions however, were *significantly* higher for European > Māori > Pacific and Asian children and young people.

In Taranaki during 2005-2009, a total of 10 individual children and young people were admitted to hospital with cystic fibrosis listed in any of the first 15 diagnoses. Admission rates per 100,000 population were *significantly* lower than the New Zealand average (RR 0.75 95% CI 0.58-0.98). Admission rates increased during the early 2000s, reached a peak in 2002-03 and then declined, with rates during the early 2000s being similar to the New Zealand average, while rates during the mid-late 2000s were lower.

Policy Documents and Evidence Based Reviews Relevant to the Diagnosis and Management of Cystic Fibrosis

In New Zealand there is a paucity of policy documents outlining optimal care for children and young people with cystic fibrosis, although a document entitled *Standards of Care for Cystic Fibrosis in New Zealand* is due to be released shortly. A range of Guidelines and Evidence Based Reviews have been published overseas however, and these are summarised in **Table 29** below.

Table 29. Policy Documents and Evidence Based Reviews Relevant to the Diagnosis and Management of Cystic Fibrosis

International Guidelines
Bell SC, Robinson PJ. **Cystic Fibrosis Standards of Care, Australia**. Sydney: Cystic Fibrosis Australia, 2008. URL: http://www.cysticfibrosis.org.au/projects/standardsofcare/ These guidelines are the first such guidelines to be published in Australia. The ten chapters cover facilities and staffing, services, newly diagnosed children, newly diagnosed adolescents and adults, outpatient care, inpatient care, home therapy, transition care, outreach services and care, transplantation and end of life care and the role of the CF organisations. Each chapter includes a literature review and provides guidelines for clinical care as well as specifying the requirements for facilities, staffing and services. Where evidence from the literature is referred to, it is graded according to the National Health and Medical Research Council guidelines.
Cystic Fibrosis Trust. **Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the U.K. 2001.** Kent: Cystic Fibrosis Trust, 2001. URL: http://www.cftrust.org.uk/aboutcf/publications/consensusdoc/ These U.K. guidelines cover all aspects of the management of Cystic Fibrosis. They discuss the implementation of a 2-tier model of care with patients receiving some of their care from a CF clinic at their local hospital and some from a specialist centre (typically having 100+ patients). The functions, facilities and staff requirements for each type of service are specified. The recommendations in the guidelines are accompanied by a grading of the evidence on which they are based. (The grading system used is based on that of the U.S. Agency for Healthcare Policy and Research.) The appendices contain summaries of the guidelines for physiotherapy, dietetic management and the provision of psychological services for patients with cystic fibrosis. The U.K. Cystic Fibrosis trust also produces guidelines on Antibiotic treatment, Methicillin-resistant *Staphylococcus aureus*, Bone mineralisation, Pseudomonas infection, the Burkholderia cepacia Complex, CF-related diabetes, and Nursing, Physiotherapy and Nutritional management.
Guidelines from the American Cystic Fibrosis Foundation. URL: http://www.cff.org/treatments/CFCareGuidelines/ These guidelines are produced under the direction of the CFF Guidelines Steering Committee, the members of which represent various stakeholders including the different health disciplines providing care for people with CF as well as members of the CF community. The recommendations in the guidelines are informed by the systematic reviews performed by investigators at The Johns Hopkins University who perform explicit assessment of evidence and grade it according to the grading system developed by the U.S. Preventive Services Task Force. Flume PA, Mogayzel J, et al. **Cystic Fibrosis pulmonary guidelines: Pulmonary complications: Haemoptysis and pneumothorax.** American Journal of Respiratory & Critical Care Medicine 2010: Mar 18 Flume PA, Mogayzel Jr PJ, et al. **Cystic Fibrosis pulmonary guidelines: Treatment of pulmonary exacerbations.** American Journal of Respiratory & Critical Care Medicine 2009; 180(9):802-8. Flume PA, Robinson KA, et al. **Cystic Fibrosis pulmonary guidelines: Airway clearance therapies.** Respiratory Care 2009; 54(4): 522-37. Borowitz D, Robinson KA, et al. **Cystic Fibrosis Foundation evidence-based guidelines for management of infants with Cystic Fibrosis.** Journal of Pediatrics 2009; 155(6 Suppl): S73-93. Borowitz D, Parad RB, et al. **Cystic Fibrosis Foundation practice guidelines for the management of infants with Cystic Fibrosis Transmembrane Conductance Regulator-Related Metabolic Syndrome during the first two years of life and beyond.** Journal of Pediatrics 2009; 155(6 Suppl): S106-16. Farrell PM, Rosenstein BJ, et al. **Guidelines for Diagnosis of Cystic Fibrosis in Newborns Through Older Adults: Cystic Fibrosis Foundation Consensus Report.** Journal of Pediatrics 2008; 153(2):S4-S14. Stallings VA, Stark LJ, et al. **Evidence-Based practice recommendations for nutrition-related management of children and adults with Cystic Fibrosis and pancreatic insufficiency: Results of a systematic review.** Journal of the American Dietetic Association 2008; 108(5): 832-9. LeGrys VA, Yankaskas JR, et al. **Diagnostic sweat testing: The Cystic Fibrosis Foundation guidelines.** Journal of Pediatrics 2007; 151(1): 85-9. Comeau AM, Accurso FJ, et al. **Guidelines for implementation of Cystic Fibrosis newborn screening programs: Cystic Fibrosis Foundation workshop report.** Pediatrics 2007; 119(2): e495-518. Flume PA, O'Sullivan BP, et al. **Cystic Fibrosis pulmonary guidelines: Chronic medications for maintenance of lung health**. American Journal of Respiratory & Critical Care Medicine 2007; 176(10): 957-69. Cantin AM, White TB, et al. **Antioxidants in Cystic Fibrosis. Conclusions from the CF Antioxidant Workshop, Bethesda, Maryland, November 11-12, 2003.** Free Radical Biology & Medicine 2007; 42(1): 15-31. Aris RM, Merkel PA, et al. **Guide to bone health and disease in Cystic Fibrosis**. Journal of Clinical Endocrinology & Metabolism 2005; 90(3): 1888-96. Yankaskas JR, Marshall BC, et al. **Cystic Fibrosis adult care: Consensus Conference report.** Chest 2004; 125(1 Suppl): 1S-39S.

Saiman L, Siegel J. **Infection control recommendations for patients with Cystic Fibrosis: Microbiology, important pathogens, and infection control practices to prevent patient-to-patient transmission.** Infection Control & Hospital Epidemiology 2003; 24(5 Suppl): S6-52.

Stevens DA, Moss RB, et al. **Allergic bronchopulmonary aspergillosis in Cystic Fibrosis-State of the art: Cystic Fibrosis Foundation Consensus Conference**. Clinical Infectious Diseases 2003; 37 Suppl 3: S225-64.

Borowitz D, Baker RD, et al. **Consensus report on nutrition for pediatric patients with Cystic Fibrosis.** Journal of Pediatric Gastroenterology & Nutrition 2002; 35(3): 246-59.

Moran A, Hardin D, et al. **Diagnosis, screening and management of Cystic Fibrosis related diabetes mellitus: A Consensus Conference report.** Diabetes Research & Clinical Practice 1999; 45(1): 61-73.

Sokol RJ, Durie PR. **Recommendations for management of liver and biliary tract disease in Cystic Fibrosis. Cystic Fibrosis Foundation Hepatobiliary Disease Consensus Group.** Journal of Pediatric Gastroenterology & Nutrition 1999; 28 Suppl 1: S1-13.

Yankaskas JR, Mallory GB, Jr. **Lung transplantation in Cystic Fibrosis: Consensus Conference statement.** Chest 1998; 113(1): 217-26.

Borowitz D, Grand RJ, et al. **Use of pancreatic enzyme supplements for patients with Cystic Fibrosis in the context of fibrosing colonopathy**. Consensus Conferences: Cystic Fibrosis Foundation, 1995.

Kerem E, Conway S, et al. **Standards of care for patients with Cystic Fibrosis: A European consensus**. Journal of Cystic Fibrosis 2005; 4(1): 7-26. URL: http://www.ecfs.eu/publications/consensus_reports

This concise (20 page) publication aims to provide a consensus on standards of care for CF patients in Europe. It is the result of the 2004 European Consensus Conference organized by the European Cystic Fibrosis Society which took place in Artimino in Italy, and involved 36 experts in Cystic Fibrosis. It details the necessary infrastructure for a CF centre (serving a minimum of 50 patients), the minimum standards for routine evaluation and assessment of patients, the management of complications and the documentation of results in a standard database. The appendix covers a series of 35 “important questions” the answers to which include a grading of the evidence on which they are based. A table explains the grading system used.

The European Cystic Fibrosis Society (which publishes the Journal of Cystic Fibrosis) has also published 2 sets of guidelines and a number of consensus documents which have been developed at meetings of leading workers (typically with about 30 participants) in the particular topics. These publications do not discuss the details of research studies but all the information and recommendations contained in them are very well referenced.

Castellani C, Southern KW, et al. **European best practice guidelines for Cystic Fibrosis neonatal screening.** Journal of Cystic Fibrosis 2009; 8(3): 153-73.

Heijerman H, Westerman E, et al. **Inhaled medication and inhalation devices for lung disease in patients with Cystic Fibrosis: A European consensus.** Journal of Cystic Fibrosis 2009; 8(5): 295-315.

Mayell SJ, Munck A, et al. **A European consensus for the evaluation and management of infants with an equivocal diagnosis following newborn screening for Cystic Fibrosis.** Journal of Cystic Fibrosis 2009; 8(1): 71-8.

Castellani C, Cuppens H, et al. **Consensus on the use and interpretation of Cystic Fibrosis mutation analysis in clinical practice.** Journal of Cystic Fibrosis 2008; 7(3): 179-96.

Edenborough FP, Borgo G, et al. **Guidelines for the management of pregnancy in women with Cystic Fibrosis.** Journal of Cystic Fibrosis 2008; 7 Suppl 1: S2-32.

Doring G, Elborn JS et al. **Clinical trials in Cystic Fibrosis.** Journal of Cystic Fibrosis 2007; 6(2): 85-99.

Malfroot A, Adam G, et al**. Immunisation in the current management of Cystic Fibrosis patients.** Journal of Cystic Fibrosis 2005; 4(2): 77-87.

Doring G, Hoiby N. **Early intervention and prevention of lung disease in Cystic Fibrosis: A European consensus.** Journal of Cystic Fibrosis 2004; 3(2): 67-91.

Sinaasappel M, Stern M, et al. **Nutrition in patients with Cystic Fibrosis: A European consensus.** Journal of Cystic Fibrosis 2002; 1(2): 51-75.

Doring G, Conway SP, et al. **Antibiotic therapy Against Pseudomonas aeruginosa in Cystic Fibrosis: A European consensus.** European Respiratory Journal 2000; 16(4): 749-67.

Cochrane Reviews With Good Evidence For Clinical Decision Making

Jones AP, Wallis C. **Dornase Alfa for Cystic Fibrosis.** Cochrane Database of Systematic Reviews 2010(3).

This review considered 15 trials with a total of 2469 participants lasting up to 2 years. The authors found evidence that therapy with dornase alfa over a 1-month period is associated with improved lung function for patients with cystic fibrosis (compared to placebo, no treatment or treatment with hypertonic saline). In addition, one trial found that this improvement lasted 6 months and one trial found that in children FEV1 was significantly improved after 2 years and that there was a non-significant reduction in the risk of infective exacerbations. The only adverse reactions that were found with increased frequency in the RCTs were rash and voice alteration.

Southern KW, Merelle MM, et al. **Newborn screening for Cystic Fibrosis.** Cochrane Database of Systematic Reviews 2009(1):CD001402

This review considered whether early detection of Cystic Fibrosis via newborn screening results in improved clinical outcomes (by preventing or reducing irreversible organ damage), and greater quality of life and survival. The authors found two suitable randomised controlled trials and analysed the data from one of them (the 1998 Wisconsin trial). In this trial 650,341 neonates were screened for CF and the results of screening were withheld from half the families and investigators until the children were 4 years old to provide the control group (unless the parents requested the results). There were benefits for the screened group in improved growth and nutrition but the effect of screening on long-term pulmonary function was confounded by other factors. Screening was found to be cheaper than traditional diagnosis.

Johansen HK, Gotzsche PC. **Vaccines for preventing infection with Pseudomonas aeruginosa in Cystic Fibrosis.** Cochrane Database of Systematic Reviews 2009(1).

The authors reviewed 3 trials with 483, 476 and 37 patients. No data was published from one of the larger trials and both the other 2 trials found that vaccination did not decrease the risk of getting a chronic infection. The authors concluded that these vaccines cannot be recommended.

Cheng K, Ashby D, et al. **Oral steroids for Cystic Fibrosis.** Cochrane Database of Systematic Reviews 2009(1).

Based on a review of 4 RCTs with a total of 378 participants, the authors found that low dose oral corticosteroids (at a prednisolone-equivalent dose of 1 to 2 mg/kg alternate days) appeared to slow the progression of lung disease. They note that this benefit should be weighed against the adverse effects of steroid treatment including cataracts and growth retardation.

Lands LC, Stanojevic S. **Oral non-steroidal anti-inflammatory drug therapy for lung disease in Cystic Fibrosis.** Cochrane Database of Systematic Reviews 2009(1).

Based on a review of four RCTs with a total of 287 participants (aged five to 39 years and followed up for a maximum period of four years) the authors concluded that “High-dose ibuprofen can slow the progression of lung disease in people with CF, especially in children, which suggests that strategies to modulate lung inflammation can be beneficial for people with CF.”

Wark P, McDonald VM. **Nebulised hypertonic saline for Cystic Fibrosis.** Cochrane Database of Systematic Reviews 2009(1).

The authors reviewed 12 trials (442 participants, aged 6 to 46 years) and found that treatment with nebulised 7% Hypertonic Saline (HS) for 48 weeks produced a small improvement in FEV1 at four weeks but that this was not sustained at 48 weeks (this was the primary outcome measure of the only long-term trial). Despite finding that HS did not improve lung function long term the authors noted that it was inexpensive and safe and its use resulted in improved quality of life and reduced pulmonary exacerbations.

Ryan G, Mukhopadhyay S, et al. **Nebulised anti-Pseudomonal antibiotics for Cystic Fibrosis.** Cochrane Database of Systematic Reviews 2009(1).

This review considered 14 trials (randomised or quasi-randomised trials) with a total of 1100 participants. The authors concluded that inhaled anti-Pseudomonal antibiotic treatment improves lung function but that trials of longer duration are needed to see if the benefit is maintained and to investigate the development of antibiotic resistant organisms. They noted that the most studied nebulised anti-Pseudomonal antibiotic is Tobramycin and they considered that there was insufficient evidence to guide the choice of drug or dose regimens.

OTHER DISABILITIES

IN DEPTH TOPIC:
DISABILITY, DISABILITY SUPPORT SERVICES AND TRANSITIONS TO ADULT CARE

DISABILITY, DISABILITY SUPPORT SERVICES AND TRANSITIONS TO ADULT CARE

Introduction

In New Zealand it is difficult to estimate the number of children and young people with disabilities, or the nature and extent of their disabilities, as the result of a longstanding paucity of data. Nevertheless, these children and young people require a range of health and disability support services in order to reach their full potential, and it is undesirable that a paucity of data should preclude them featuring prominently in prioritisation, planning and resource allocation decisions.

The following section provides a brief overview of disability, disability support services and issues with transition to adult care. It begins by briefly defining disability, before considering (based on a mix of local and overseas data) the most common conditions leading to disabilities in New Zealand children and young people. New Zealand's historical approaches to service delivery are then reviewed, before an overview is provided of New Zealand's current disability support services. A final section considers the transition of young people with disabilities from paediatric to adult care, some of the difficulties inherent with this transition, and a range of overseas models which consider how this transition might be improved. Issues for medically fragile and technology dependent children and young people are considered in a separate section commencing on **Page 137**.

Disability Definitions and Local Prevalence Estimates

Definitions

In New Zealand while a range of definitions are available, within the health sector it is the Government's definition of disability which determines eligibility for Ministry of Health (MoH) funded Disability Support Services via Needs Assessment and Service Coordination (NASC) agencies. The Government definition states that: "*A person with a disability is someone who has been assessed as having a physical, psychiatric, intellectual, sensory, or age related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required*" [26].

MoH funded Disability Support Services are primarily designed to meet the needs of those <65 years of age who have been assessed as having a physical, intellectual and / or sensory impairment or disability. MoH funding is also available to support those with neurological conditions that result in permanent disabilities, developmental disabilities (e.g. autism), and physical, intellectual or sensory disabilities that co-exist with other health conditions and / or injuries. Services for people with psychiatric or age related (65+ years) disabilities however, are traditionally delivered via DHB funding [26].

Prevalence Estimates

In terms of service planning, the paucity of information on the number of children and young people in New Zealand with disabilities who are likely to meet the criteria outlined above, makes it very difficult for the health sector to undertake any long term planning, or to consider the optimal configuration of services which would best meet the needs of disabled children and young people, both now and on into the future.

When considering the available data, in 2001 the Household Disability Survey estimated that 11% of New Zealand children (0-14 yrs) had a disability. While little information was available on the precise nature of these disabilities, in general terms they included chronic health problems, sensory impairments, psychiatric or psychological problems, intellectual disabilities, speech, learning and developmental problems, and the need for special education or technical equipment. Of those with a disability, 41% had a disability which

had existed from birth, 33% had a disability caused by a disease / illness and 3% had a disability which resulted from an injury [14].

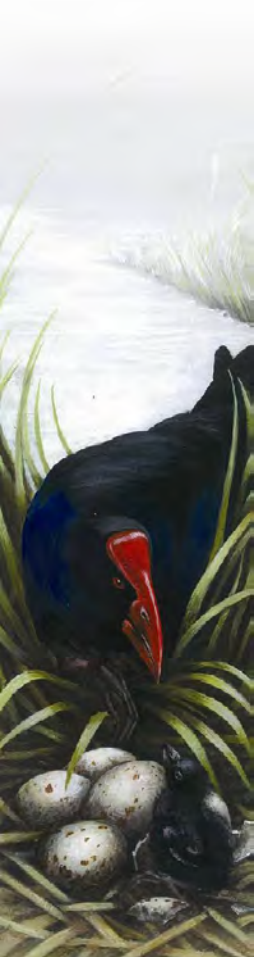
The classifications used in the Household Disability Survey however make it very difficult to determine the aetiology, or likely clinical course of the conditions leading to disabilities in New Zealand children and young people, and as a consequence, provide few insights into potential pathways for prevention, or service requirements over the life course. While there is little research in the New Zealand context, overseas reviews have considered these issues in more detail. In one recent review, neurodevelopmental disabilities in children and young people were defined as "*those arising from a diverse group of chronic disorders beginning at any time in the developmental process (from conception, birth and growth, through to 22 years of age), and whose impact lasted through the life course*". Collectively, these disorders were thought to arise from deficits in the developing brain due to genetic, prenatal, perinatal, metabolic and other factors [27], with some of the most important including: autism spectrum disorders; genetic / chromosomal disorders (e.g. Down Syndrome), metabolic disorders; neuromuscular disorders; cerebral palsy; neural tube defects; sensory impairments; intellectual and learning disabilities; disabilities associated with chronic diseases; and traumatic brain and spinal cord injuries.

With prevention and early intervention being critically important for mitigating the significant personal and socioeconomic costs associated with childhood disabilities [27], a review of these conditions in the New Zealand context may assist the health sector to consider key prevention and early intervention points for each condition, as well as future strategies to reduce disabilities in New Zealand children and young people as a whole. The following section thus briefly reviews the available New Zealand data on the prevalence of each of the conditions outlined above, with links being provided (data permitting) to later sections of this report, which consider these conditions in more detail (Note: injuries and permanent hearing loss will be reviewed in next year's report).

New Zealand Prevalence Estimates for Conditions Commonly Causing Disability

In New Zealand, while there is a paucity of high quality routinely collected data on the prevalence of conditions leading to disabilities in children and young people, a range of more limited local data and overseas estimates are available. These include:

- **Metabolic Disorders**: In New Zealand, while there is no routinely collected data on the number of children and young people with metabolic disorders, Newborn Metabolic Screening identifies a small number of babies each year with specific metabolic disorders, and these are considered in more detail on **Page 24**.
- **Congenital Anomalies**: In New Zealand there is little recent data on the prevalence of congenital anomalies at the time of birth, although the Plunket National Child Health Study estimated an overall prevalence of 4.3% in 1990-1991 [13]. Similarly, the 2001 Household Disability Survey estimated that of the 11% of children (0-14 yrs) with a disability, 41% had a disability which had existed from the time of birth [28]. Further information on the number of babies with congenital anomalies identified at the time of birth is presented in the *Congenital Anomalies Evident at Birth* Section on **Page 28**.
- **Down Syndrome**: In New Zealand the prevalence of Down Syndrome at the time of birth has been static in recent years, with earlier estimates of 0.82 per 1,000 in 1980-82 and 0.94 per 1,000 in 1989-91 [29] being very similar to the estimates of 0.92 per 1,000 derived from the birth admission dataset in 2004-05 [30]. Further information on the number of babies with Down Syndrome identified at birth is presented in the *Down Syndrome* Section on **Page 49**.
- **Neural Tube Defects (NTDs):** In New Zealand over the past two decades, there has been a dramatic decline in the number of babies born with NTDs. During 1996-2006, approximately 12 babies each year were identified as having spina bifida and 4 as having anencephaly or an encephalocele at birth, although the general downward trend meant that the numbers in the latter part of this period may have been lower [30]. Further information on the number of babies with neural tube defects identified at birth is presented in the *Neural Tube Defects* Section on **Page 58**.



- **Intellectual and Learning Disabilities**: While there is no routinely collected data on the prevalence on intellectual disability in New Zealand, a range of overseas estimates are available. While estimates vary widely depending on the definition used and the population surveyed, it is usually assumed that approximately 3% of the population have an IQ of <68, with 80-90% of these being classified as having mild mental retardation and 5% being severely or profoundly impaired [31]. Other estimates suggest that 3-4 per 1,000 have an IQ in the <50 range [32]. Limited information on hospitalisations for children and young people with intellectual disabilities is presented in the *Developmental Delays and Intellectual Disabilities* Section on **Page 101**.
- **Cerebral Palsy**: While there is no routinely collected data on the prevalence of cerebral palsy in New Zealand, overseas research suggests that the prevalence may have risen over time, from around 1.5 per 1,000 live births in the 1960s to around 2.5 per 1,000 in the 1990s, with the proportion of low birth weight babies increasing during this period, possibly as the result of increased survival amongst very premature babies [33]. Further information on hospitalisations for children and young people with Cerebral Palsy is presented in the *Cerebral Palsy* Section on **Page 114**.
- **Autism Spectrum Disorders**: At present there is no routine information on the prevalence of Autism or Asperger's Syndrome in New Zealand, although a recent estimate from the Statistics NZ Household Disability survey suggested that 2,100 New Zealand children may have Autism or Asperger's Syndrome (personal communication Phillipa Clark 2006) giving a prevalence of 24.8 per 10,000. Similarly, a recent estimate from the Nelson Marlborough Region suggested a prevalence of 46 per 10,000, with 56% having Autism, 30% having Asperger's Syndrome and 14% having a non specified Pervasive Developmental Disorder [34]. Overseas, some estimates (based on parental report) have placed the prevalence as high as 110 per 10,000 [35]. Further information on hospitalisations for children and young people with Autism is presented in the *Autism and Other Pervasive Developmental Disorders* Section on **Page 124**.
- **Sensory Impairments**: While information on the number of children with permanent hearing losses may soon become available from the Newborn Hearing Screening Programme, notification data from the New Zealand Deafness Notification database suggests that approximately 135-170 babies (2-3 /1000) in New Zealand each year will be identified as having a permanent congenital hearing loss [10]. In addition, during 2006, information from the Vision Education Agency suggested that a total of 1,323 children and young people in New Zealand required educational support as a result of a visual impairment, with enrolments being spread across the educational spectrum from early childhood to secondary school level [30]. Permanent hearing loss in children and young people will be considered in more detail in next year's report.
- **Disabilities Associated with Chronic Conditions**: A range of chronic conditions can lead to disability in this age group, with issues such as asthma, bronchiectasis and rheumatic fever being considered in previous reports. The current report considers hospital admissions and mortality for children and young people with Diabetes (**Page 153**), Epilepsy (**Page 166**), and Cancer (**Page 176**), with a more detailed review on issues for Medically Fragile Children being provided on Page 135.

While the information presented above provides only a very limited snapshot of the conditions leading to disabilities in New Zealand children and young people, the available data does suggest that a significant number of children and young people each year are likely to require health and disability support services as a result of their impairments. The following section thus reviews New Zealand's historical approaches to the provision of disability support services and the impact this has had on the lives of children and young people with disabilities and their families, before considering the services currently available in the New Zealand context.

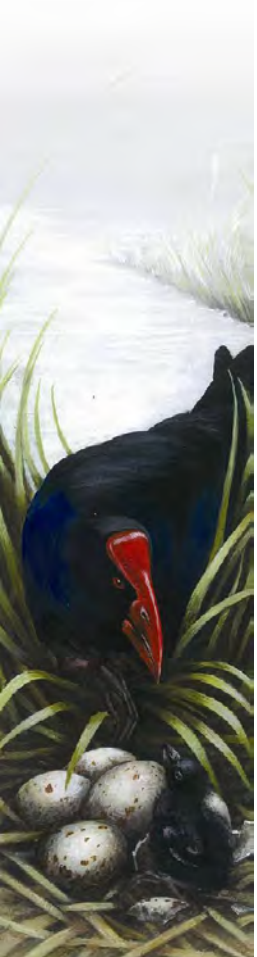
Historical Approaches to the Provision of Disability Support Services in New Zealand

In understanding New Zealand's current approaches to the provision of services for children and young people with disabilities, it is worthwhile briefly reviewing New Zealand's historical approaches to service delivery and how these have changed over time. While much of the detail of New Zealand's current model is unique, changing approaches to service delivery over time have occurred in a manner consistent with international trends, with a review by the National Health Committee in the early 2000s suggesting that these changes can be divided into five main stages [36]:

Charitable Aid (1840-1910)
In the early 1800s, social services were provided by charitable organisations who focused on helping the poor, the sick and children. By the 1840s the Government had begun to take on a role in the provision of social services, with the late 1800s seeing the public sector becoming the major provider of welfare services, via its support of charitable organisations. In this era, the roles of Government and voluntary organisations became established, with the voluntary sector deciding on the services it would provide, and the Government providing grants to support specific services. The Hospitals and Charitable Institutions Act 1885 established Hospital and Charitable Aid Boards, with these Boards taking over the role of dispensing charitable aid and hospital and asylum care, although most disabled people still continued to live at home. In the late 19th century, hospitals became more treatment focused and there were calls for state funded „homes for incurables' [36].

Era of Institutional Services (early 1900s to 1970)
In the early 1900s, a range of legislation was introduced which affected services for people with disabilities. This included the 1907 Education Amendment Act, which introduced compulsory education for „defective or epileptic' children. In 1908 a Government school for „mentally retarded' boys was opened in Otago, with a similar school opening in Nelson in 1916. In 1914, the new Education Act consolidated previous provisions, established special classes for „backward children' and instituted compulsory notification of all „mentally defective children'. Eligibility for special classes was determined by IQ tests [36].

During this period, adults with an intellectual disability had the choice of living at home with no government support, or in one of the publicly funded psychiatric institutions (Seaview in Hokitika, Seacliff near Dunedin, Tokanui near Hamilton and Kingseat in Auckland). In 1929, Templeton Farm and School, New Zealand's first psychopaedic hospital was opened, providing residential care and a school for children with disabilities. The Kimberly Centre in Levin was opened several years later [36].



By the late 1930s, many children and young people with disabilities were housed in public psychiatric or psychopaedic institutions, with most being situated in the country away from major population centres. During the 1950s and 1960s, parents were encouraged to place children with disabilities in these psychopaedic institutions, with significant numbers being admitted as young children, and then losing all contact with their families. Anecdotal reports suggest that some parents were told that it disturbed their children when they came and went, and that they needed to accept that their children were receiving the best possible care. During this era, institutionalisation and segregation were the underpinning philosophies, with services being provided in a custodial and medical framework, where people who were seen as being sick or vulnerable were segregated from society. The end of this era came gradually, with a shift to the concept of "normalisation" and a growing dissatisfaction with institutional care [36].

During this period, despite the social pressure to place their children in institutions and the lack of assistance for those not doing so, a number of parents chose to keep their children at home. In 1949, the Intellectually Handicapped Children's' Parents Association (IHCPA) (later the IHC), was formed by a group of parents wanting an educational facility for children with disabilities not receiving state support. By the end of the 1960s, the IHC had

established 15 Children's Day Care Centres and 11 Occupational Groups, and a number of residential homes. A range of other residential facilities and schools were also established by other providers during this period, to meet the needs of children and young people with disabilities, and the number of special work settings for adults with intellectual disabilities increased dramatically. Sheltered workshops became the most common "work" for intellectually disabled young people during this period [36].

Deinstitutionalisation and Shift Towards Community Based Services (1970s-1980s)
By the late 1960s, "normalisation" had begun to underpin service delivery, with changing views about placing children in institutions leading to more people with disabilities living in the community, either with their families or in smaller residential facilities. A Royal Commission on Psychopaedic Hospitals in 1972 resulted in funding being diverted from expanding long-stay psychopaedic hospitals to providing community beds. In 1975, the Disabled Persons' Community Welfare Act provided people with disabilities with a legislative entitlement to funding for specific services (e.g. respite care, personal assistance, travel costs, equipment, home alterations). If a person met the entitlement criteria they received the services, whereas if they did not, they received nothing [36].

During the 1970s there was also a significant emphasis on increasing the provision of community services for people with disabilities, with further funding being granted for the building of residential facilities, which were commonly clusters of units on a single site. At this time IHC was the major provider, with their main focus being on residential care and services such as sheltered workshops. The model however was similar to that operating previously, with voluntary sector organisations deciding on the services they would provide (based on their own organisational philosophy) and the government assisting with grants. As a result, providers often drove Government policy in the area of disability services, with the overall trend during the period being a move towards deinstitutionalisation and people being supported at home, or living in group homes and working in sheltered workshops. While these homes and workshops were located in the community, services were often still provided in segregated settings [36].

Public Sector Reform (Late 1980s and 1990s)
During the late 1980s and 1990s New Zealand underwent significant public sector reform, with government departments being contracted for specific outputs as part of their performance agreements. This focus on outputs resulted in a dramatic shift in the Government's approach to funding social services, with contracting for outputs being a major change from the previous policy of providing 75% salary subsidies to voluntary sector agencies. Standards were introduced, and once an organisation had shown they could meet the required standard, a contract was negotiated which specified the services to be provided, along with the performance measures against which they had to report. Many providers were opposed to these changes, as they created a significant administrative burden, and in addition, because they were required to provide (and be evaluated on), the total service, even if the contract only funded a portion of their work. Further, providers often needed to negotiate a range of contracts with different agencies, in order to provide the integrated services they had provided previously, with the changes also creating a number of problems for service users, with people no longer receiving all of their services from one agency. The previous legislative entitlement to services was also replaced by a person's entitlements being determined by a Needs Assessment, followed by a service coordination process, which allowed access to services to be tailored to an individual's needs [36].

During the late 1980s and 1990s, a number of large institutions (including Kingseat, Templeton and Cherry Farm) were progressively closed, with more than 10,000 people moving into the community during 1990-1999. Many moving out of psychopaedic institutions had high level needs. At the same time, many young people with disabilities who had never been institutionalised began to leave mainstream schools and look for adult services. This placed a significant strain on service providers and resulted in a number entering into agreements with regional health authorities (RHAs) to develop new services, although there was often limited funding available for such new enterprises. Overall, the

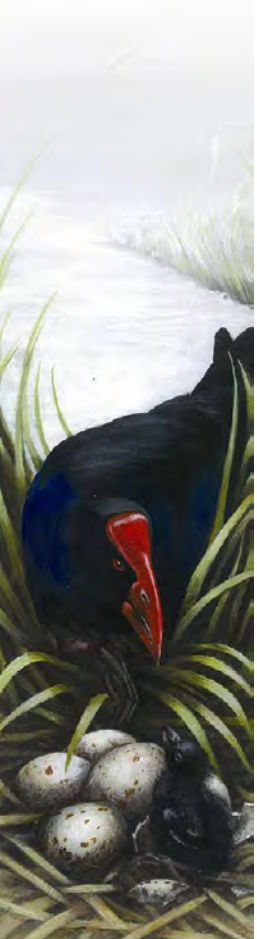
changes of the 1980s and 1990s led to a “silo” approach to policy development, with the Ministries of Health, Education, and Social Policy all having responsibility for different aspects of disability policy. The absence of an overall strategic framework was seen by many as contributing to a lack of coherence and leadership in the sector [36].

Current Structures and the NZ Disability Strategy (2000s)
Until 1999 there was no Minister or Government agency with overarching responsibility for disability issues, and silos in policy development and service delivery often led to disabled people experiencing gaps in service coverage, duplication of assessment, and confusion as to who was responsible for which services. In 1999 the portfolio of Minister for Disability Issues was established, with the New Zealand Disability Strategy, which provided an overarching framework for the direction of the disability sector, being launched in 2001. In July 2002 the Office for Disability Issues was established within the Ministry of Social Development with a view to leading strategic whole of government disability policy development, overseeing the implementation of the New Zealand Disability Strategy, and supporting the Minister of Disability Issues in her role. The theme emerging during this phase was that of community membership, and an approach that emphasised the development of supports which enhanced inclusion and quality of life [36].

Current Disability Support Services

In New Zealand, in addition to the overarching role of the Office of Disability Issues as outlined above, a range of Government and Non-Government Agencies are involved in the provision of services to those with disabilities, with the Ministry of Health being responsible for the provision of Disability Support Services, the Ministry of Social Development being responsible for income support, vocational services and Family and Community Services, Housing NZ Corporation providing housing assistance, and the Ministry of Education providing Special Education and educational supports to disabled students. The following section briefly reviews the services provided by these main Government Agencies, before considering some of the issues (both in New Zealand and overseas) associated with the current model, which relies heavily on informal caregivers (including family members) to care for children and young people with disabilities in their own homes.

Disability Support Services Provided by the Ministry of Health
The Ministry of Health is responsible for the planning and funding of disability support services, administering the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, and providing policy advice to the Minister of Health. The Ministry funds a number of disability support services which assist families caring for children and young people with disabilities. Access to almost all of these services is via Needs Assessment and Service Co-ordination (NASC) Agencies, who accept children with significant intellectual, physical or sensory disabilities, or with autism spectrum disorders. NASC Agencies work on the basis of assessed need and the equitable sharing of available resources, with needs assessments being designed to identify the disability support needs of children and young people and their caregivers. The NASC agency also acts as a budget manager for the pre-purchased packages of service, allocating them according to preset eligibility criteria. Most NASC agencies are able to use a small amount of their allocated budget-holding to purchase discretionary services not covered by pre-purchased contracts [37].



The need for support services is usually reviewed annually (or more often at parental request) and if there is a significant change in needs (e.g. school entry), a new needs assessment is carried out. Some of the services available via NASC include disability information advisory services, home based services such as personal care and home help, residential services, supports for carers in the home, respite care in specialist facilities, supported independent living services, special equipment and housing alterations (see text box below). Unfortunately not all types of support service are available in all regions and entitlements may vary with the age of the child [20], with not all children with a disability qualifying for a NASC assessment.

The Ministry of Health funds a range of Disability Support Services for people with disabilities and their families. Eligibility is determined via a NASC agency assessment, with these services including:

Home and Community Support Services

Home and Community Support Services provide assistance for disabled people living at home and include household management and personal care. Household management may include help with preparing a meal, doing the washing, or essential house cleaning, while personal care may include assistance with eating or drinking, getting dressed, showering, or getting up in the morning. Eligibility is restricted to those <65 years who are disabled and are Community Service Cardholders (or their parents are Cardholders if <16 years) [38].

Service providers are contracted by the Ministry, with the NASC being able to provide information on local service availability. While clients are offered the choice between available providers in areas where more than one provider is available, in some areas (e.g. rural areas) there may only be one service provider. Once a selection is made, the NASC agency sends client information to the service provider, who contacts the client and an individual plan is made, outlining the supports required, and when the services are to be delivered.

Individualised Funding (IF) lets disabled people directly manage the resources they are allocated by NASC agencies for home and community support services, with clients being able to choose caregivers and service delivery plans, employ their own care providers, and manage the payment for services, thereby allowing the disabled person increased choice and control over their support services. Currently the Ministry contracts a single agency to help manage payment arrangements and support people on the Scheme [39].

Respite Services

Respite services are available to individuals with a disability and their caregivers and family, and are intended to allow the main caregiver to take a short break from their caregiving duties. Respite care usually occurs in a community setting, and is intended to be short term and intermittent, with the frequency and amount of respite care available being based on an individual assessment of the disabled person's needs and the availability of services in the community [40].

Carer Support

Carer support is a subsidy funded by the MoH which is designed to help the unpaid full-time carers of disabled people to take a break from their care giving role. The number of hours or days of funding available is determined by the NASC agency (based on the needs of the carer and disabled person). Carer support is able to be paid to friends, family, or neighbours, or for more formal care to e.g. rest homes. It cannot be used when the full time caregiver is at work, by a parent or partner of the disabled person, for convalescence after hospital discharge, or if the support carer lives at the same address as the full time carer [41].

Community Residential Support Services

Community residential support services are available to those <65 years who have a long term disability not covered by ACC. The services are designed to assist those with disabilities to live in the community, with the MoH entering into agreements with residential service providers to provide residential support in a home-like setting for up to 24 hours a day. This support may include assistance with shopping, preparing and cooking meals, housework, assistance with personal cares (e.g. eating and drinking, getting dressed and showering), and going out. Services are provided in a range of community settings such as small or large homes, and groups of small homes or flats, with paid staff being available to assist residents with everyday activities. For those on a benefit, a portion of the costs associated with the residential support services is paid for by a deduction from the benefit, with the left over portion (called a Personal Allowance) being set aside for personal needs (e.g. shampoo, magazines). The MoH pays the remaining costs associated with the provision of the residential services [42].

Child Development Services

Child Development Services are multidisciplinary allied health and community based services. They focus on early intervention for pre-school children who have disabilities, or who are not achieving developmental milestones. The service provides specialist assessment, intervention and management with a view to ensuring good rehabilitation / habilitation results for children who have an intellectual, sensory or physical disability [43].

Equipment and Modifications

The MoH also provides financial support to assist disabled people access necessary equipment including wheelchairs, shower stools, walking frames, mobility aids (e.g. walking sticks), communication devices and hearing aids. Assistance with housing modifications (e.g. handrails, ramps, level access showers) and car modifications (e.g. van hoists, hand controls) is also available, although some of the cost of these modifications may need to be met by the disabled person themselves. All equipment (except hearing aids) is provided by service providers on loan, with the equipment needing to be returned once it is no longer required. In order to qualify for assistance, the person's disability must be likely to persist for at least 6 months, it must limit the ability to carry out some everyday activities safely, and the disability must not be covered by ACC [44].

Additional Services

Additional services are available for people with intellectual disabilities who have high and complex needs, and those who require behavioural support services, or community day activity programmes, with more detailed information being available on the MoH website http://www.moh.govt.nz/moh.nsf/indexmh/disability-fundedservices

Disability Supports Provided by the Ministry of Social Development

The Ministry of Social Development is responsible for the provision of income support for people with disabilities and their families, and in addition provides vocational support for those wishing to enter the workforce. A range of supports are available, with the main ones being listed in the text box below.

Income Supports Available to Children and Young People with Disabilities and their Families

Child Disability Allowance

The Child Disability Allowance is a non-taxable, non-income or asset tested payment made to the main carer of a child or young person who has a serious disability, in recognition of the extra care required [45]. To be eligible for this allowance, the carer must:

- Be a New Zealand citizen or permanent resident who usually lives in New Zealand
- Care for a child or young person who has a serious disability or medical condition

In addition, the child or young person must:

- Be < 18 years of age and be dependent on the person caring for them
- Need constant care and attention for at least 12 months because of their disability

When applying for a Child Disability Allowance, the medical practitioner who provides the ongoing care for the child or young person must complete a medical certificate. This certificate asks the practitioner to consider:

- Whether the child or young person has a serious disability (e.g. physical, sensory, mental health, intellectual, developmental, or chronic medical condition)
- Whether they require frequent attention in connection with bodily functions as a result of their disability that is in excess of that required by someone of the same age
- Whether they require attention or supervision that is substantially in excess of that required by someone of the same age
- Whether regular care and supervision is required to avoid substantial danger to themselves or others
- Whether such care is required for a period exceeding 12 months

Further, the practitioner is asked to comment on when the child or young person's disability should next be assessed (e.g. 1 year, 2 years, 5 years, or never). As at 1 October 2010, the weekly rate was $43.81.

Disability Allowance

The Disability Allowance is available for people who have a disability and require assistance with everyday tasks or ongoing medical care. Carers can apply on behalf of a child if the child is aged 18 years or less and are financially dependent, with the Allowance assisting carers to meet any additional costs the child may have as a result of their disability. In order to receive a Disability Allowance a client or their child must [46]:

- Meet an income test
- Have a disability which is likely to last for at least 6 months
- Have ongoing additional costs associated with that disability
- Be a New Zealand citizen or permanent resident, and be resident in New Zealand

The allowance is income tested, with a maximum weekly amount of $56.98 / week (as at 1 October 2010). The amount available depends on the extra costs incurred as a result of the disability. Extra costs that may be covered include: doctor's, specialists and hospital fees that are not already subsidised, prescription fees, travel to appointments, heating, and medical alarm rental and monitoring. Claimants need to provide some proof (e.g. receipts) of costs incurred, as well as a declaration from their doctor that they need them for their disability.

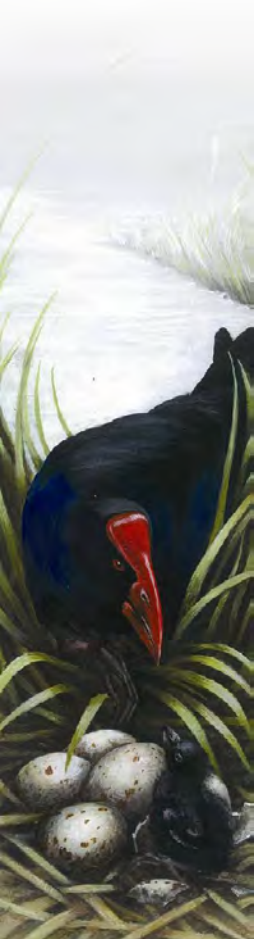
Invalid's Benefit

Once a young person with a disability turns 16 years of age, they may become eligible to receive an Invalid's Benefit. To be eligible for an Invalid's Benefit, people need to be 16+ years of age and unable to work 15+ hours a week because of a sickness, injury or disability which is expected to last at least 2 years OR their life expectancy is <2 years and they are unable to regularly work 15+ hours a week OR they are blind with a specified level of visual impairment. A doctor's certificate is required and an applicant must be a New Zealand citizen or permanent resident and have lived in New Zealand for 10 years or more ([47]). The amount available depends on the individual's circumstances, and ranges from $219.39 – $363.52 per week, if not in hospital.

Domestic Purposed Benefit – Care of Sick or Infirm (DPB-CSI)

The DPB-CSI is available to people caring for someone at home who requires full-time care. This includes parents who provide full-time care and attention for high needs dependent child; and care for children who would otherwise require extended care services or residential disability care. In this context, *„full-time care and attention'* is defined as: "*the person will require 24-hour access to care and attention. This does not mean the carer is expected to give 24-hour care, but they must be available if required. The level of care and attention must be over and above the ordinary care and attention required by someone of the same age*". A carer can be away from the home for a few hours a day, and still be considered to be providing full-time care, if arrangements are made for the supported person's care and their safety is not compromised. The carer's absence can be for a number of reasons including part-time employment or study. The carer must provide the care and attention at home, with the home being that of the supported person or the carer [48].

The amount available depends on family circumstances, and ranges from $219.39 - $363.52 per week before tax, as at 1 October 2010.



Community Services Card

The Community Services Card assists with the costs of health care. It can decrease the cost of prescriptions, fees for after hours doctor appointments, visits to see a doctor who is not the child's regular doctor, glasses for children <16 years, emergency dental care provided by hospitals and approved dental contractors, travel and accommodation, and home help. The card can be used for dependent children if they are <18 years of age. It is income tested, and provided to low-middle income individuals or families. It is also automatically issued for anyone receiving a Child Disability Allowance, Domestic Purposes Benefit, or Invalids Benefit.

Mainstream Employment Programme

The Mainstream Employment Programme is a partnership between Work and Income, disability employment experts, employers and those with disabilities. It provides a package of subsidies, training, and other support to assist people with significant disabilities to get work in the State sector. Assistance includes:

- A 100% salary subsidy for the first year of employment, plus 50% of salary for the second year
- Funding for external training for participants and their supervisors
- Funding to meet participants' adaptive technology or specialised assistance costs
- An advice and referral service for employers and Mainstream participants
- Follow-up support for participants and their direct supervisors

Participants are not expected to be 'job-ready' when they start but are trained on the job, with pay being comparable to that of others performing similar duties. After two years, it is expected that participants will be better equipped to compete for advertised vacancies.

Other Supports

Information on a range of other supports available to assist young people with disabilities enter the workforce is available from the Work and Income website http://www.workandincome.govt.nz/

Disability Support Provided by the Ministry of Education

In New Zealand, most disabled children with special education needs attend regular schools, although a small number may attend a Special School or a Residential Special School [49]. Special Schools are state schools providing specialist teaching and services for students with special education needs, with the curriculum being the same as in state schools, but with adaptations being made to meet students' needs. At present there are 28 day special schools across New Zealand, and as well as a base school, many have satellite classes at regular schools, which allow students to receive specialist teaching, at the same time as being integrated into the regular school environment. In addition, 8 residential special schools provide support for students who are deaf or hearing impaired, blind or vision impaired, or who have severe behaviour needs, or other educational needs coupled with an underlying intellectual impairment. Access to these special schools is via the Ministry of Education, Special Education (GSE) district offices [49].

Under the Education Act 1989, all children from age 5 are able to attend their local school until the end of the school year in which they turn 19. Students with a Section 9 Agreement (an agreement between a parent and the Secretary of Education for a student to enrol at a Special Education Facility) or who are in the Ongoing and Reviewable Resourcing Schemes (ORRS- see below) can stay at school until the age of 21. To do so, a student must have been attending either a special school or a special unit which provides a programme designed to meet their needs. During the early 2000s, 60% of ORRS students who left school did so at age 21 [36] and while overseas research suggests that age-appropriate post-secondary education for students with disabilities may have significant advantages, in New Zealand one factor contributing to the trend to stay in school until age 21 is the lack of appropriate services outside of the education sector to meet the needs of disabled young people with high levels of need [36].

Educational Supports Available to Children and Young People with Disabilities

The Government announced a Review of Special Education in August 2009. The aim of the review was to ensure that policies and processes were fair, consistent, reached those most in need, made the best use of government funding, and that parents had choices. The Government is currently considering what changes it will make to special education in response to submissions received in the review, with the services outlined below reflecting current practice at the time of writing.

The Ongoing and Reviewable Resourcing Schemes (ORRS)

ORRS [50] provides specialist assistance for students with the highest need for special education (≈1% of the school population), with around 7000 students receiving assistance at any one time. For students to be eligible they must meet at least one of nine criteria, with significant educational needs that arise from either extreme or severe difficulty with any of the following: 1) Learning; 2) Hearing; 3) Vision; 4) Mobility; 5) Language Use and Social Communication; OR moderate to high difficulty with learning combined with any two of: 1) Hearing; 2) Vision; 3) Mobility; 4) Language Use and Social Communication.

ORRS funding is managed by the Ministry of Education: Special Education, which must balance the priorities for all the children in the Schemes and remain within budget, with the funds being used to purchase:

a) Specialist and therapist expertise (e.g. physiotherapists, occupational therapists, speech language therapists, psychologists)
b) Additional teaching time (including teachers with specialist tertiary qualifications in the areas of learning, vision or hearing).
c) Teacher aide time for children who need support with personal care and / or to engage in the curriculum
d) Consumable items (e.g. tape, disposable gloves)

All students entering the ORRS programme must have an Individual Education Plan (IEP), which spells out the child's special education needs, the goals the team plans to achieve, and the resources required to achieve these goals. In addition, all students are assigned to one of two levels of need: very high or high (including combined moderate ongoing needs). The information in the IEP is then used to allocate specialists' time and funds to pay teacher aides to support the child at school, with children with very high needs receiving a greater amount of therapy and special programmes than those deemed only to have high needs [50].

Duration of need is also taken into account, with students entering ORRS as part of one of two schemes [50]:

The Reviewable Resourcing Scheme (RRS) is for students who meet edibility criteria at the time of application, but whose long term need for assistance is unclear. Students receive intensive specialist programmes for 3 years from the year they enter the scheme, with schools being directed to use resources most intensively early on, and then gradually reduce them over the 3-year period. At the end of 3 years, students with ongoing high or very high needs may be eligible for the Ongoing Resourcing Scheme.

The Ongoing Resourcing Scheme (ORS) is for students with high or very high needs at the time of application and where it is clear they will continue to require the highest level of specialist support.

ORRS Extension: In 2010 the ORRS were extended to include an additional 400 students who had just missed out on receiving the ORRS. The new programme is called ORRS Extension and is an interim approach to expand the ORRS while the Government undertakes the Review of Special Education. Students who receive ORRS Extension will continue to receive support until they leave school [51] .

Travel Assistance

Assistance to travel between home and the nearest school is provided by the Ministry of Education: Special Education to students who need transport for mobility or safety reasons. Assistance may be in the form of a vehicle allowance, a place in a taxi or minibus, or a total mobility vehicle [52].

Assistive Technology

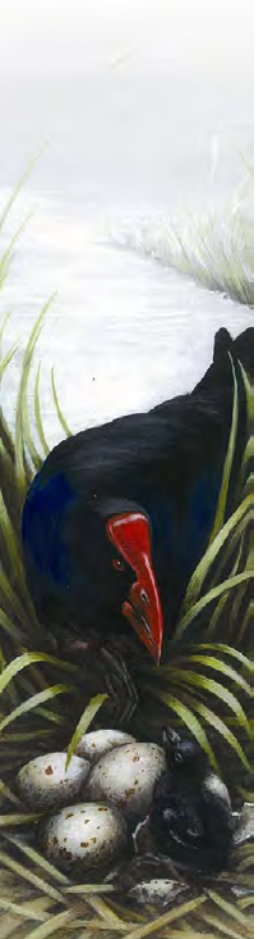
Assistive technology support (including computers, vision equipment, specialised seating, tables and hearing devices), is available to students who require technology or equipment to remove barriers to learning, or to raise their achievement at school. Applications are via the Ministry of Education: Special Education [53].

Intersectoral Support: The High and Complex Needs Unit

The High and Complex Needs (HCN) Unit is an interagency unit which supports staff from a range of sectors including health, disability, education and Child, Youth and Family. It aims to assist these agencies to better identify, plan and meet the needs of children and young people with high and complex needs. The Unit provides tools, resources and information to support interagency working and, if required, funding for the purchase of additional services [54], with 70-100 children and young people nationally receiving funding from the HCN Unit each year.

To be accepted for funding, a child or young person must be <21 years of age, and have high and complex needs. For example, challenging behaviour such as suicidal and risk taking activities or aggression; living in care, or a specialised placement; mental health diagnoses including autism, attention deficit disorder, conduct disorder; prior experience of sexual, or physical abuse, or parental mental illness; or a number of very high needs associated with disabilities. By definition, the needs of these children are complex and cannot be met by a single sector, with the interventions funded by the HCN Unit being in addition to those provided by other agencies. To access funding a child or young person must be accessing all locally available services, with senior managers in each sector needing to decide if more can be done within existing services, before an application can be made.

Once an application is accepted, the HCN Unit becomes responsible for funding locally developed and managed Interagency Plans, which support children and young people access the right mix and types of services. A service coordinator, contracted by the lead agency is responsible for the case coordination required to develop implement, monitor and review the plan, with each individual's plan being approved for a year at a time, although further renewals are possible. The HCN then covers the costs of those elements of the interagency plan that cannot be met through existing services [54].



Family Impacts of Caring for Children and Young People with Disabilities & the Role of Disability Support Services

In New Zealand during the past 2-3 decades, the move away from institutional care has led to the majority of disabled children and young people living in the community and their care becoming increasingly the domain of family members [55]. Such shifts have significant resource implications if the transition to home based care is to be sustainable, with access to appropriate support services being crucial for families coping with the demands of caring for a child or young person with a disability in their homes. The following section briefly reviews some of the findings from overseas research, regarding the impact supporting a child or young person with a disability has on families, before considering the available literature on these impacts in the New Zealand context.

Overseas Research on Family Impacts of Caring for a Child with a Disability and the Role of Disability Support Services

Deinstitutionalisation and a move towards home based care for children and young people with disabilities has also occurred in many other developed countries, with a number of studies considering the impacts of caring for a child or young person with a disability on families, particularly when the care is provided in the context of inadequately resourced or poorly coordinated disability support systems.

In the UK, two studies [56] [57] reviewing the impact on families of caring for preschool age children with disabilities noted higher levels of parental stress, and problems associated with fragmented sleep, particularly if the child had a co-existing sleeping problem. In terms of physical stress, lifting and associated back strain were one of the biggest problems, with housing also being an issue, particularly if children had behavioural problems which precluded them from sharing a room with siblings, mobility issues (e.g. walking frames in small units), or problems with escaping from the house. Additional strain was often put on parental relationships, with some commenting that the majority of support was targeted at mothers, with mothers and fathers also often adjusting to their child's disability over different timeframes. Further employment opportunities were reduced for some, as a result of difficulties in accessing after hours and holiday care, or the need to take additional time off at short notice, which in turn impacted on the financial resources available to the family. The impact on siblings was variable, with some missing out on quality time with their parents, while others became more understanding. Access to services, fragmentation of services, and difficulties in knowing what services were available were also common themes, with many parents spending a great deal of time trying to find the most appropriate supports for their children. Many mothers expressed positive feelings about their children however, with none in these two UK studies wishing to have them cared for anywhere else but in the home, but many noting that they would like additional supports to assist them to do so [56] [57].

In Ireland, a review of families' views on the provision of supports for disabled young people transitioning into adulthood also noted considerable caregiver frustration at the fragmentation of service delivery, an inability to find out what services were available, and a reluctance by services to act unless there was a crisis, with parents going to considerable lengths to advocate on behalf of their disabled children. Further, concerns were expressed about the availability of respite care, with parents of young people with the highest needs often finding it the most difficult to find the type of respite care their families needed, as well as the lack of appropriate post-secondary school educational and training opportunities [58]. Similar views were expressed in a Welsh study which interviewed mothers of young people with intellectual disability about their dealings with the professional and service worlds. Mothers reported that often these encounters were based on conflict and they felt that their capabilities as mothers were under scrutiny. Mothers accepted advocacy for their children as something they were prepared to do, but were hesitant to advocate for their own needs and aspirations, for fear of being seen as selfish and because they felt that doing so would undermine their credibility as advocates for their children [59].

Another theme emerging from research involving mothers of adolescents with intellectual disabilities was the observation that while most mothers were looking forward to increased freedom as their children grew up, mothers of children with disabilities often found their lives becoming more and more restricted, particularly if the child's siblings left home and they lost the babysitters that had made it possible for them to go out. Lack of appropriate post school services also meant that some mothers faced having to stay at home with their disabled adult son or daughter. Some mothers felt that this role should be valued and that they would be lost if their child left home, while others felt that their own aspirations were frustrated [60].

In Australia, a literature review by the Australian Institute of Health and Welfare on these issues identified a number of common themes including [55]:

Family Structure: Higher proportions of disabled children and young people were found to live in single parent families, and while the reasons for this were unclear, the authors noted that some had attributed this to the stresses associated with raising a disabled child, while others had suggested that once socioeconomic factors were taken into account, rates of divorce were no different between couples with and without disabled children.

Family Socioeconomic Position: Higher proportions of disabled children were found to live in low income families and the authors noted that while some research suggested that families living in financial hardship had a higher number of risk factors for childhood disability, other studies had found that families with disabled children had significant out-of-pocket costs directly related to their children's special needs, as well as more indirect time costs associated with caring for their children. Such costs were particularly significant for families with medium to low incomes and for single parents, whose care commitments may have prevented them from taking up or staying in employment.

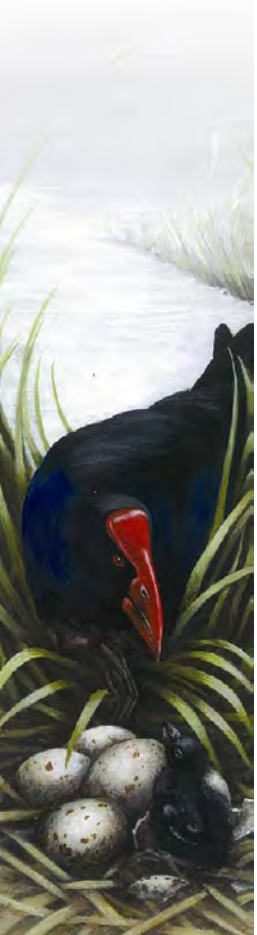
Effects on Parents: The authors found that for many parents, caring for a child with a disability could be stressful, with a number of studies noting that mothers caring for children with conditions such as autism, and physical and learning disabilities, had higher rates of stress and depression. Sole parents were particularly vulnerable to stress, as a result of their dual role as primary caregiver and primary bread-winner.

Role of Social and Material Support: In explaining why some parents experienced less stress than others when caring for children and young people with disabilities, the authors suggested that the availability of socioeconomic resources might play a role. In addition, the presence of social and material support (e.g. emotional support, access to services, early interventions, respite care, equipment services and family support programmes) were thought to be crucial in ensuring parental wellbeing.

Effects on Siblings: Evidence regarding the effects that childhood disability had on siblings was mixed. At the positive end of the spectrum, some siblings reported enhanced self-esteem, empathy, maturity and a sense of responsibility. At the more negative end of the spectrum, some expressed concerns about having to take on higher levels of caregiving and household responsibility (particularly if financial resources were limited, or family size was small resulting in greater caregiving responsibilities), less attention from parents and the restrictions a disabled family member placed on their social life.

Positive Effects: The authors noted that there was much less research into the more positive effects caring for a disabled child had on families (e.g. strengthening family relationships and the positive emotional bonds parents developed with their children).

Similar themes were identified in a literature review prepared for the National Health Committee (NHC) [61], as a background to its review of informal caregivers in New Zealand, as well as in studies from other developed countries including the UK, and the USA [62] [63] [64]. Such research has led to a range of overseas policy documents and Government strategies being developed [65] [66] [67] [68] [69] which outline the guiding principles and service delivery models required to address these issues. The following section considers whether similar issues have been identified in the New Zealand context.



New Zealand Research on the Family Impacts of Caring for a Child with a Disability and the Role of Disability Support Services

In New Zealand there have been a number of reviews of the adequacy of our disability support services, and a number of reports have also considered their impacts on children and young people with disabilities and their families.

Just Surviving Report

Just Surviving [70], commissioned by the Health Funding Authority and Child Youth and Family in 2000, considered the factors that led families to seek permanent „out of family' care for their children. The authors, following a series of focus groups with the family caregivers of children with very high support needs, noted that for most families, a combination of factors had brought them to this point over time. These included:

- Carers being ground down emotionally and / or physically
- Carers ageing or their health becoming compromised (e.g. back injuries)
- The child getting bigger and harder to manage (physically, emotionally or behaviourally) as they got older
- The availability of support reducing as children got older
- The needs of other family members (siblings, ageing parents, unwell spouses)
- Parental separation / new partners not accommodating the needs of the child

In general, the pattern was that over time, as the child's needs increased and the parent's capacity to meet these needs decreased, situations arose that were no longer sustainable, with a final event (e.g. death of a family member) often triggering the out of home placement, but usually not being the sole reason for it. A number of parents said that if they had had high quality support they would have been able to cope better and for longer, although few envisaged that they would be able to continue to care for their child indefinitely (i.e. even with optimal support, the need for permanent out of home care would not have been eliminated in the longer term). All families however, wanted to maintain an ongoing relationship with their child, and for the child to be in close proximity.

The authors noted that parents often expressed a sense of guilt at out of home placement, particularly if the child was not receiving the best of care in their new environment:

"It used to be pretty good there. But now there are fewer residents and fewer staff...and they are all crowded together. His face is always covered in scratches. I visit every month but now, every time I see him I wish I hadn't, and I cry for the next week"

For some however, such placements were necessary for the safety of other family members, with some families living in constant tension as a result of behavioural issues:

"*It wasn't so bad when he was...younger. He gets frustrated very suddenly and lashes out at whoever is closest. Recently our 3 year-old had had a black eye and our 1 year-old has been thrown against the wall. I've got to think of their safety now*".

Another common theme was a lack of adequate remuneration for support workers, with families being unable to access appropriately qualified people to provide the support they required. High support worker turnover, inflexible hours of assistance and the disruption of having a support worker in the home were also common issues raised, with many parents also being unable to access respite care, due to problems with caregivers being able to manage the child's difficult behaviour, or the complexity of their medical conditions.

"*We told them what he's like. We warned them that his room would need to be secured before he came. They didn't listen to us and within half an hour he had shredded the curtains, smashed the furniture and broken the windows*".

In general, the consensus of those interviewed was that supports for families needed to be improved, with the highest priority areas being access to adequate respite care, support for parents themselves (in addition to that provided to their children), around the clock

emergency support for crises (e.g. another child becoming unwell) and for short term (e.g. caregiver going to hospital) and longer term (e.g. caregiver dying) emergency planning.

2006 Household Disability Survey and Other Surveys

The 2006 Household Disability Survey [71] reinforced some of the concerns regarding respite care and support. In this survey, 4% of parents of an estimated 3,300 disabled children had received home support from a government agency in the past 12 months (including help with the disabled person's personal care or with housework), with 56% of children with an intellectual disability receiving this support. During this period, the caregivers of 17% of all disabled children required respite care or carer support, with 40% of those requiring respite care receiving some free respite care, 46% receiving help from a government agency to pay for care and 15% paying for the respite care themselves. Of those requiring respite care 43% did not get some or all of the care they required, with the most common reasons given being that care was too expensive, or that they did not know how to access it.

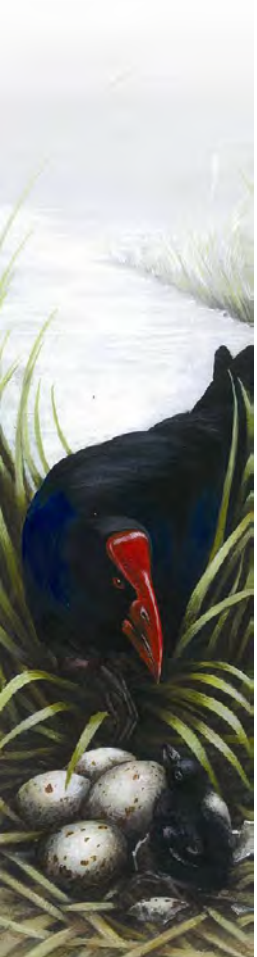
Similarly, a New Zealand survey of 300 informal caregivers of those with disabilities conducted in 2007-2008 [72] found that 85% were suffering from stress, and that 89% of those aged 30-39 years showed signs of depression. Issues identified by caregivers included the adverse impacts that caregiving had on their lifestyles, health and financial situations, a lack of information and assistance and the fact that respite care was inadequate (with difficulties finding age appropriate facilities and the small amount of money paid to respite workers). Overall, 0.7% of caregivers of those <65 years were happy with the support received, with caregivers wanting more financial assistance, information, reliable support workers, flexible respite, and greater recognition of their roles.

In terms of the paid workforce, a survey of home-based and residential healthcare providers was undertaken in 2004, which provided information on 17,910 paid caregivers (health care assistants, caregivers and home health aides) working in residential homes, long term care settings, and private homes. The survey found that 94% of the workforce was female, most were aged between 40 and 50 years, and that their mean hourly pay was $10.90 (minimum wage at the time $10.00) [73]. The turnover was 29% in residential care and 39% in the community. While most providers recognised the need for training, the providers often felt that their paid caregivers were not adequately trained, with training being poorly attended (with the main reasons cited for non attendance being funding, secondary employment, family, staff turnover, low pay and few incentives). The authors raised concerns regarding the vulnerability of this workforce, given the ongoing trend towards the care of people with disabilities in the community.

NHC Reports: To Have and Ordinary Life and How Should We Care for the Carers

In the early 2000s the National Health Committee (NHC) undertook a review of the lives of adults with intellectual disabilities receiving Government funded services [37]. This review involved a series of background literature reviews, coupled with interviews with people with intellectual disabilities (10 focus groups), their families (3 focus groups), caregivers and service providers, policy makers, and consumer and carer organisations. The NHC found that although New Zealand has sought to move away from institutionally based services, much of this had involved removing bricks and mortar, rather than providing non-institutional services and that service purchase and provision had failed to keep up with international practice. Further, the nature of the support provided tended to be custodial and constrictive, rather than actively moving towards community membership. To a large extent, the NHC felt that this resulted from the limited range of services that were contracted for, the disability workforce being undervalued, a lack of understanding about the potentials of adults with disabilities, and the narrow focus of assessment and planning processes. The NHC identified three priorities for action in areas where it believed that the most significant changes were required [37]:

1. **Refocusing Needs Assessment, Service Coordination and Service Purchasing**: While NASC was not the focus of the review, the NHC noted that many people raised concerns about variations in the approaches taken by different NASC agencies across



the country, with many also expressing frustrations about the lack of long-term planning for support, linked with the inability of the NASC process to acknowledge developmental goals, and the lack of flexibility to fund non-standard options of support (e.g. laundry service rather than home help), or to acknowledge needs in areas where services were not generally purchased (e.g. cultural services). While the NHC believed that the NASC concept was a good one and a crucial tool in the implementation of the NZ Disability Strategy, they noted that the current model was constrained by its focus on allocating and rationing pre-purchased existing services and that a fundamental review of the NASC service model was required. Changes needed to include an emphasis on strategic assessment and planning for life, with services being designed to meet the individuals changing support and development needs over time.

2. **Moving Away From a Custodial Ownership Model of Service Delivery**: The NHC noted that in many instances, providers owned the houses in which disabled people lived, provided the services in these houses, were ascribed the resident's benefits and controlled their personal income. The NHC recommended that people with disabilities have full tenancy protection and access to full benefit and housing entitlements, so that the cost of accommodation could be disentangled from the funding of service provision.
3. **Addressing the Neglect of Basic Health Needs**: The NHC noted that many adults with disabilities endured prolonged suffering from treatable health conditions, yet received inadequate medical management, with the review also discovering some disturbing prescribing practices. The NHC thus recommended that addressing the neglect of the health needs of adults with disabilities be awarded a high priority.

In March 2010 the NHC released a further report entitled "*How Should We Care for the Carers, Now and Into the Future*?" [74]. The report reviewed the role of informal carers within the disability sector. In this context, it defined an *'informal carer'* as someone caring for *'a friend, family member or neighbour who because of sickness, frailty or disability, couldn't manage everyday living without help or support'*. The NHC noted that many carers felt that the supports and services available to them were complex and fragmented, and the system was difficult to navigate, particularly where multiple agencies were involved and that there was a lack of quality choices in the services, particularly for respite care. As a result, the NHC made a series of recommendations to the Ministry of Health, with a number focusing on the need for joint working between the MoH and DHBs to develop service specifications and contracts which:

- Improve national consistency in the services available for informal carers and require that an acceptable level of respite care be available in every locality
- Give service providers more flexibility to tailor services to an individual's or family's needs (e.g. through increased use of discretionary funds)
- Provide incentives to deliver quality services that focus on outcomes, and improve carers' health and wellbeing
- Develop a programme of regular evaluation of services for informal carers, separate from the evaluation and monitoring of individual service providers
- Widen the eligibility for individualised funding and develop multiple options for the level of management of the funding by the individual or their family
- Actively support the development of new models of community-based care for people with high support needs, to ensure there is an acceptable level of service available in every locality, and culturally appropriate models of community-based and long-term respite care.

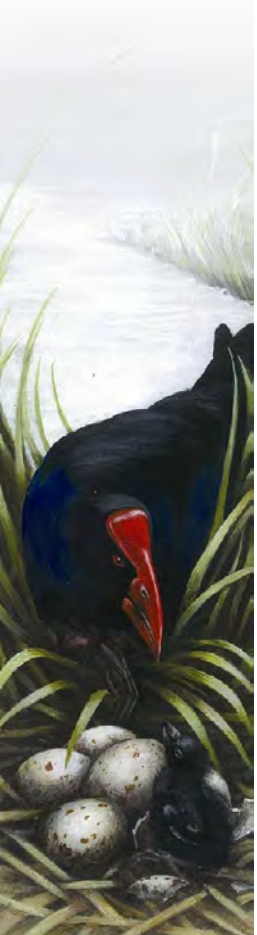
Themes Arising from the NZ Literature and the Social Services Select Committee Inquiry into the Quality of Care and Service Provision for People with Disabilities

When considered collectively, the research above highlights a number of recurring themes:

1. **Carer Burnout**: The reliance on family members to provide care for children and young people with often complex medical conditions or behavioural problems, and the consequent impact this had on families' and caregivers' health and wellbeing was a recurring theme, coupled with a lack of adequate respite care and reliance on a poorly paid support workforce (see below).
2. **Respite Care**: There was a clear need for age appropriate respite care, with those in the greatest need of respite care (e.g. those with older children with significant behavioural issues, or complex medical problems) being the least likely to be able to access the type of care they required.
3. **Poorly Paid and Trained Workforce**: Reliance on a poorly paid workforce, with a high turnover and limited training meant that some families were unable to access the type of support they required to assist them care for their children in their homes.
4. **Inflexibility of Current Model of Service Delivery**: The reliance on NASC agencies to ration pre-purchased packages of services, and a lack of flexibility in service delivery to meet individual needs, coupled with a lack of short, medium and long term planning which took into account the changing needs of the child or young person were of concern. In addition, many adults with disabilities felt that they did not have control over their own living arrangements, including who they lived with and the type of accommodation provided.

During 2005-2006, a number of the above concerns were raised by the media and discussed in Parliament, with two major service providers also being accused of the inappropriate treatment of people with disabilities in their care, and with organisations representing the disabled community publicly expressing dissatisfaction at current service provision. In response, in May 2006 a Social Services Select Committee inquiry into the quality of care and service provision for people with disabilities was announced, and in the ensuing months the Select Committee reviewed approximately 150 submissions, with many echoing the concerns raised above. The Committee [75] found that in many instances the NZ Disability Strategy had not been well implemented, that no one agency was held accountable for the disability sector or the overall provision of disability services, that people with disabilities often felt they had little control over the services they received, and that the funding was relatively inflexible. The Committee also expressed significant concerns about the working conditions of those providing care and support services in the disability sector including concerns regarding low pay, high turnover and a lack of training and career structure. As a result, in 2008, the Social Services Select Committee recommended that the Government [75]:

- Appoint an appropriately funded lead agency with responsibility for disability issues, make this new agency responsible for ensuring the NZ Disability Strategy was effectively implemented, and that if this arrangement did not achieve significant change within 6 years, establish an independent disability commission. Further, they recommended the Government investigate the appointment of an independent disability commissioner, with this commissioner being responsible for considering disability issues in relation to health, education, social development and housing.
- Change the role of NASC agencies to ensure there was no duplication with local area coordination, and that they focused on meeting the needs of individuals rather than those of service providers, with all NASC agencies needing to have a clear separation from service providers. Further, to direct the relevant ministries to ensure that funding was provided in ways that allowed people with disabilities more choice about their day to day living arrangements, and better access to supported independent living and individualised funding. In addition, they recommended that evaluations of disability services focus on quality of life for people with disabilities, rather than on compliance



with minimum standards for audit purposes, with reviewers needing to have the freedom and responsibility to speak to all stakeholders involved in the service (including clients and their families).

- That a strategy be established for improving training, pay rates and working conditions for the caring and support workforce, including a structured career pathway, a skills based pay system, values based training for all staff, and consistent and appropriate work conditions.

In its response to the Inquiry's findings, the Government [76] noted that for the majority of recommendations, further work would be required before it could make any decisions regarding the steps it would take, as the recommendations were wide ranging and had significant implications for a range of government agencies and disabled people. Further, in some cases their response would also be affected by the need to consider the results of consultation before making any decisions. In other cases however, the Government had already implemented several responses consistent with the recommendations, or was expanding existing work programmes so they were consistent with the recommendations (e.g. expanding access to individualised funding, scoping a range of projects to look at different residential options). Of note, the recent announcement by the Minister of Disability Issues regarding the intention to create a Disability Rights Commissioner role within the Human Rights Commission is one step towards implementing these recommendations, as is the New Zealand Carers Strategy and 5 Year Action Plan, released by the Ministry of Social Development in 2008 [77].

Conclusions

While it is beyond the scope of this review to make formal recommendations as to the roles DHBs might play while some of the more structural issues associated with the disability sector are worked out, it is suggested that at the very minimum, DHBs review the availability of respite care and associated supports for the caregivers of children and young people with disabilities in their regions, and familiarise themselves with the recommendations made in *Just Surviving* [70], *To Have and Ordinary Life* [37], *How Should We Care for the Carers, Now and Into the Future*?" [74] and the *Social Services Select Committee Inquiry into the Quality of Care and Service Provision for People with Disabilities [75]*, with a view to considering whether any of these recommendations can be implemented locally in the short to medium term.

In addition, a further issue of concern in the international literature, and one which has not been touched on above, is the transitions of children and young people with disabilities from paediatric to adult care. The following section considers some of the issues associated with such transitions, as well as possible service models which might assist children and young people with disabilities to transition to adult services in a planned and coordinated manner.

Transitions from Paediatric to Adult Health Care for Young People with Disabilities

Introduction

Each year a large number of young adults with disabilities graduate from special or mainstream schools, around the same time as they transition from paediatric to adult health services. Research suggests that during these transitions, the quality of young people's health may decline, and in particular that a large number of medical and psychological conditions may go undetected, as well as a range of social and financial problems [78]. Further, many young adults with disabilities require care from a range of healthcare providers, and coordination may become more difficult as young people transition to an entirely new set of services, many of which are unfamiliar with their medical conditions and social context [78]. The following section thus considers the barriers to effective healthcare transitions for young people with disabilities, before reviewing the literature for effective models of transition planning and care. Examples of effective transition service elements are sought, before the key principles which govern effective

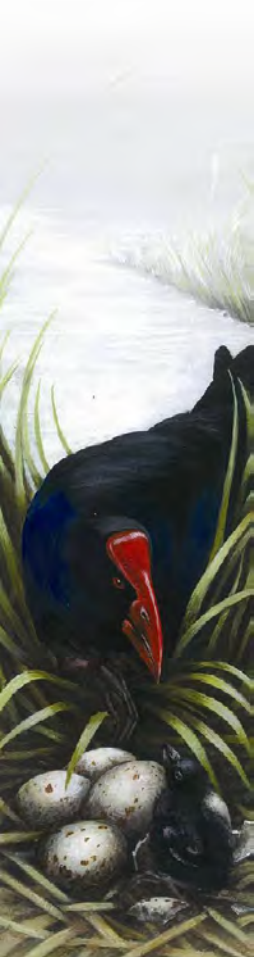
care are reviewed. The section concludes by asking DHBs to consider how they might ensure effective service transitions for young people with disabilities in their regions.

Barriers to Transition

In the literature, a number of barriers have been identified to effective healthcare transitions. One review suggested that some of these barriers may stem from the fact that recent improvements in the care of children with chronic conditions may not be sustained during the transition from child to adult services. While in part, the authors of this review felt that this may be attributed to a paucity of adult services in some areas, they suggested it might also reflect a failure to integrate care effectively during the transition, with a number of young people becoming dislocated from services at this point in their life course [79]. As a consequence, paediatric providers were often seen as being reluctant to refer adolescents to an adult provider, believing there was a scarcity of available adult specialists in the area, with some also being reluctant to terminate longstanding professional relationships with young people and their families. Similarly some young people and their families were seen as being unwilling to transfer to adult care given the strong relationships developed with their paediatrician, with some also feeling more comfortable with family-centred paediatric services than person-centred adult services. Others suggested that not all young people may be developmentally ready to assume greater responsibility for their own care [80], with some feeling that an arbitrary age point which assumes that chronological age alone indicates readiness for transfer, potentially disregarding the complexity of adolescent development [79]. In addition, for young people who have multiple providers (e.g. those with intellectual learning disabilities) each agency (e.g. health, education) may have different rules and practices governing the transition process [79]. Finally, it may be difficult to find an adult health provider with experience in paediatric conditions, particularly in rural or remote areas [78].

While much of the research above comes from the UK and the USA, a recent Australian study [78] interviewing young adults (16-25 years) with predominantly intellectual disabilities, their caregivers, and their health service providers, found similar concerns. The authors noted that while all acknowledged the supportive and coordinating role of the paediatrician, once this role had ended, communication problems between service providers often became an issue, with many carers feeling they lacked the knowledge or support to manage a young person with a disability [78]. Paediatricians often saw their role as one of case coordination, monitoring and supervision, plus the provision of support and guidance for young people, especially in areas such as healthcare management and family issues, and many expressed concerns that there was no equivalent role in adult services. General practitioners also acknowledged the value of this role, with some noting that they would be unable to take on such a role as they lacked knowledge of services and resources. Some GPs stated that they felt ill equipped to deal with specific complex disabilities and thus often just focused on the specific medical problem that was the reason for the consultation.

The authors also found that the health system relied heavily on carers to shoulder the overall burden of care for young people, with these carers often playing a central role in coordinating and communicating between services. As the child grew older and the availability of services decreased, carers often had problems dealing with new issues such as adolescent sexuality. Carers also expressed a desire for information about the services available to them, often stating that they had found out about services by accident. In addition, they highlighted the need for support services that could be accessed in a crisis. Finally, with the multiplicity of organisations involved in service delivery to this group of young adults, there was often a lack of communication and coordination between them, with services often being delivered as a reaction to a crisis situation, rather than being pro-active in preventing problems arising in the first place [78].



Transition Models of Care

While there have been a number of studies exploring problems arising during the transition process, there is a paucity of evidence in the current literature regarding optimal models for effective transition planning and service delivery. Before considering the available

models however, it is worthwhile considering the definition of „*transition*', and distinguishing between it and a transfer of care, with the latter being a single event, occurring when a young person moves into a new health care setting. In contrast, a transition is an anticipated, coordinated process, often defined as "*the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult orientated healthcare systems, with the goal being to provide comprehensive and developmentally appropriate care in a coordinated and uninterrupted manner* [81]".

In a review of the literature on transition care from the 1980s-early 2000s (n=43 studies) Betz et al [82] found that the majority of research during this period had been descriptive, with researchers exploring concepts such as the best age for transition, issues faced by young people and their caregivers as young people grew older, and barriers to effective service delivery. There were few randomised trials of service delivery models, or even research utilising comparison groups. The authors concluded that better evidence regarding effective models of transition planning and service delivery was required so that in future, the provision of transition services could be based on standards of practice and pathways of care which were derived from evidence based practices.

In a similar review undertaken at around the same time, While et al [79], identified 5,319 items in the literature relating to youth transitions to adult care, of which 126 were thought to make a contribution to knowledge regarding good practice. Of these 35% were descriptive, 34% were user accounts, 17% were reviews and 14% (n=18) were evaluations. These evaluations included studies which attempted to assess the process or the outcome of interventions, although it was felt by the authors that only three had strong external validity. As a result of the paucity of high quality evidence, the authors attempted to identify common themes in the core principles and practices presented in these studies that related to the way services worked with parents and young people during the transition process. This resulted in the development of four models of care, which were differentiated by their organisational philosophies, the capacities of young people to take on responsibility for the management of their own condition, and the extent to which the model of care assisted them to do so. The four main models to emerge were [79]:

1. **Direct Transition Model**: In this model, continuity is achieved when the young person is transferred to adult care safely and efficiently, with the emphasis being on good channels of communication and information sharing between services both horizontally (i.e. all of the agencies involved in care within the relevant age band) and vertically (i.e. from paediatric to adult services). No consideration is given however, to addressing young people's developmental needs, or assisting families' transition to greater youth autonomy. Such a model was seen as being adequate when the young person's condition did not adversely impact on their ability to function in an adult environment (e.g. uncomplicated diabetes).
2. **Sequential Transition Model**: This transition model recognises the fact that the young person's needs are changing and that they will require some preparation if they are to adjust to adult care successfully. Thus allowances are made for a more sequential transition, with either an extension of paediatric services (which are distinct from child focused services), or a joint sharing between paediatric and adult services. Such a model is most appropriate when the young person themselves is likely to increasingly take on responsibility for their own care, and should allow the young person to prepare for adult based care, and to become an „expert" in their own condition (e.g. cystic fibrosis). This may involve a redefining of the family's role and allowing the young person increasing autonomy in making decisions about their care [82].

   One example of such a transition model was a programme established for adolescents with cystic fibrosis. Adolescents entered the programme at age 17, and were jointly seen (1-4 times) by their paediatric specialist and an adult medical pulmonary fellow for a period of one year. Once the young person was transferred to adult services, the adult medical pulmonary fellow continued their care for a year under the supervision of an adult pulmonologist, before the adult pulmonologist assumed full responsibility for

their care. During the transition, a social worker from the paediatric team assisted with the coordination of medical services, and provided ongoing psychosocial support, with educational and vocational anticipatory guidance aimed at assisting adolescents achieve independence being provided by both adult and paediatric providers [80].

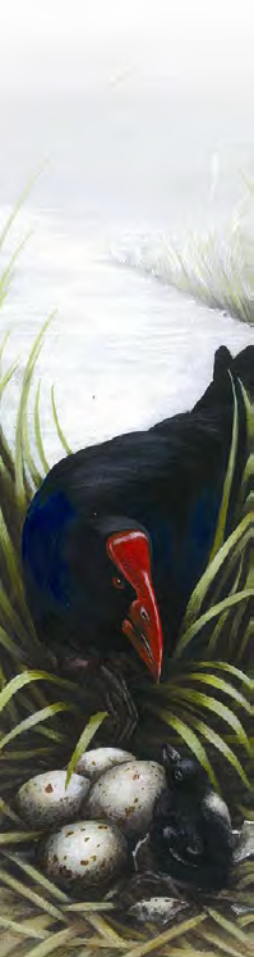
3. **Professional Transition Model**: This model is particularly relevant for young people with a short life expectancy, or where expertise is heavily concentrated within one service (e.g. HIV). It focuses on maximising young people's access to expertise within the specialist area, and on ensuring that professionals working within the specialty are able to respond effectively to the young person's health needs. No emphasis is placed on personal development however, or on assisting families with their role transitions.
4. **Developmental Transition Model**: This model recognises that some young people will need additional help to acquire the skills and support systems necessary to access adult care effectively (e.g. those with physical or intellectual disabilities). The focus is thus on personal development during the transition, and on assisting young people to acquire the skills necessary to negotiate the adult service environment, accompanied by assistance to families to help redefine their roles in a manner which accommodates the young person's ongoing personal development and progress towards autonomy.

The in-depth topic *Models of Care for Medically Fragile Children* (commencing page 135), considers specific examples of Transition Models 1-3, which relate predominantly to young people with medical conditions (e.g. diabetes, cystic fibrosis) where no additional supports to attain age appropriate developmental milestones are required. The section which follows however considers some possible service elements relevant to Model 4, which may be of value when assisting young people, who as a result of additional intellectual or physical disabilities, may require additional supports to transition to adult services.

Transition Model Service Elements

The international literature describes a range of service elements which have been proposed, trialled, or implemented overseas to assist young people with disabilities and additional developmental needs transition to adult service. In a review of these service elements for the NHS in the UK, Forbes et al [83] identified the most common approaches taken, as well as the degree to which the literature supported the effectiveness of each element. (Note: With few RCTs available, levels of support were based on an assessment of available studies, many of which were descriptive or observational in nature, and the reader must bear this in mind when considering the author's conclusions below.) In this review, service elements commonly implemented or suggested included:

1. **Transition Workers**: Transition workers were found in a range of settings including education, social services and health, with their main roles being the planning of transitional care, making connections between child and adult services, and coordinating care across a range of services. While some worked solely in this capacity, in other cases the role was undertaken by a member of a larger team (e.g. a specialist nurse). At the micro-level, tasks included co-ordinating packages of care for individual clients and ensuring that they attended their appointments and accessed services appropriately, while at the macro level they also acted to facilitate greater cooperation between agencies. Advocacy was another key role, and involved ensuring that young people were properly represented in the transition process, and were able to maximise their full potential. The authors noted that the use of transition workers was supported by a moderate amount of evidence, that they were likely to be beneficial in most settings, and that they were of particular utility when there were complex needs, vulnerable young people, and multiple services involved. Providing a dedicated worker was seen as being costly however, and it was felt important that the role was supported by all of the agencies involved.
2. **Transition Teams**: Transition teams were also found in a range of contexts, ranging from a single service or institution, to multidisciplinary teams working in the community. Their roles were similar to those of transition workers, with such teams being of particular value in the context where young people had multiple disabilities and



learning difficulties. Such teams were further subdivided into multidisciplinary review panels, which coordinated resources to develop and approve transition plans, and the teams providing the actual interventions, which assisted young people through their transition. The authors noted that the use of such teams was supported by some evidence, and that they were thought to be beneficial in most settings, although they also entailed a major investment.

3. **Transitional (Adolescent) Services**: Adolescent services have evolved in response to increasing recognition that young people require a different approach to service delivery than that required by children or adults. They provide care by linking young people with available services, or by providing specialist services that are designed to cater to the emotional and physical needs of young people as they develop. Services usually involve clinics or care (inpatient) facilities staffed by people with specialist knowledge and skills in working with young people. The focus is often on preparing the young person (+/- their families) for adult life, including the care and management of their own condition. The authors noted there was moderate evidence that such services were beneficial in assisting young people to transition to adult care, although the costs of service establishment needed to be taken into account.

4. **Using Primary Care to Bridge the Transition**: It has been suggested that continuity might be enhanced by using primary care to support transitions, as primary care practitioners are likely to be involved with young people on both sides of the transition. An emphasis on greater management in primary care, supported by specialists as required, was suggested as one way to reduce discontinuity, as while the specialist providing the support might change, the base from which the care was delivered would not. Unfortunately, the authors noted that this model was weakly supported by the available literature and its potential to benefit continuity had not been established. While evidence from older age groups suggested that primary care could provide effective management for many chronic health conditions, the extent to which this could be extended to children and adolescents was untested, as most remained within the domain of specialist care. The authors noted that if child and adolescent provision was to be extended to primary care, this would require careful management to ensure that the quality and sensitivity of care provision were not diluted.

5. **Interagency Liaison and Agreements**: A commonly cited transition issue is the lack of liaison between different agencies. In this context, inter-agency liaison can be regarded as a continuum, ranging from communication, through co-operation, to formal collaboration agreements. Liaison may range from maintaining communication between the parties involved (e.g. via a transition coordinator who takes responsibility for information sharing), through to more formal co-operation (e.g. joint outpatient clinics, holding interdisciplinary meetings to facilitate referrals), to joint teams with shared responsibilities and decision making (with these relationships being cemented by shared contractual obligations and service level agreements). In terms of the evidence, the authors noted there was a moderate level of support in the literature that such approaches were beneficial, with formal agreements being thought essential where complex needs and multi-service provision were involved.

6. **Joint Organisational Planning**: This element involves bringing together stakeholders from various agencies to consider, develop and review practices aimed at improving continuity for defined groups of young people. Interagency and professional forums may support this process, together with the development of shared targets and mission statements. The authors noted that the benefits of such approaches had not been fully evaluated, although they seemed an intuitively useful way of ensuring service continuity. Potential limitations included difficulties in achieving consensus if services were unable to resource the same level of care as that available in paediatric settings.

Principles Governing Effective Transitions

Whatever the mix of service elements selected however, a number of key principles underpin transition planning and service delivery. In developing best practice guidelines for such transitions in Canada, Stewart [84] outlined a number of such governing principles

which reflected a move away from a sole focus on health service transitions, to a more holistic model of transition planning which attempted to assist young people to maximise their potential across a range of adult roles (educational, vocational, access to healthcare). Some of the key principles underpinning such transitions included:

- The need for effective intersectoral collaboration and communication at the service delivery level, with transfer between paediatric and adult service systems starting early and involving all services working together with young people and their families.
- Service providers working together to build the individual's capacity in the areas of problem solving, decision making and an understanding of their own abilities, as well as being in control of their lives and directing others to provide supports.
- The need for community facilitators who are funded intersectorally and whose role it is to support young people and their families in planning for transition and navigating all of the systems and resources. Such a person should be not affiliated with any one service system but rather should be seen as being part of the community.
- A single access point for information, resources, networks and supports across the lifespan, with community facilitators (above) potentially being based at such an access point, and with all services providing information about the resources they are able to provide in an accessible and easy to understand manner.

In the New Zealand context, a number of policy documents have also been developed which provide guidance in this area. The main ones are briefly summarised below.

The Royal Australasian College of Physicians. **Transition to Adult Health Services for Adolescents with Chronic Conditions**. Sydney 2005, Royal Australasian College of Physicians http://www.racp.edu.au/index.cfm?objectid=D7FAA370-0B87-808A-90C36BD48C54B2D8.

This position statement outlines a number of principles for successful transition to adult care. They suggest that health services need to be: developmentally appropriate and inclusive of the young person's family; holistic and address a range of concerns such as normal growth and development, mental health, sexuality and risk taking behaviours; and flexible and able to tailor the transition process to the young person's needs. They also suggest that transitions are optimised when a specific health care provider takes responsibility for helping the young person and their family through the transition, with active case management, general practitioner engagement, and close communication between paediatric and adult services being important.

The position statement also makes a number of recommendations regarding transitions to adult care:

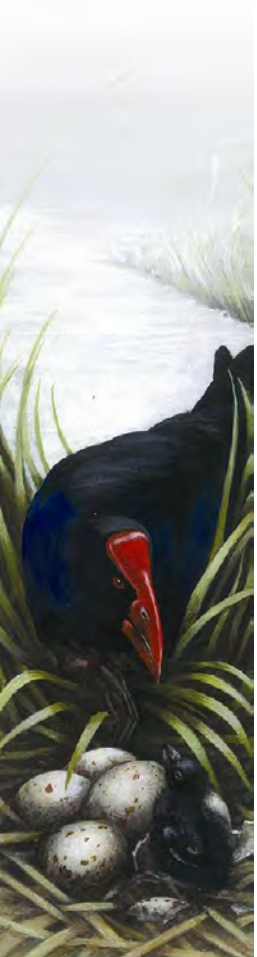
1. All young people with a chronic illness or disability should have a health care provider who takes specific responsibility for the transition to adult healthcare. This includes the coordination of community, primary, speciality and allied health services, as well as the development of up-to date written transition plans, in collaboration with young people and their families.
2. Additional care needs to be taken of vulnerable young people without family support, or in State care.
3. The adult service provider should accept responsibility for active case management and follow up once the young person has left the paediatric service.
4. The development of a portable, accessible, medical summary would facilitate the smooth collaboration and transfer of care between health professionals.
5. Affordable, comprehensive and continuous health care should be accessible to young people with chronic conditions throughout adolescence.
6. All young people with a chronic illness should have a primary care provider. Further, the same standards of primary and preventive health care should be accessible to young people with chronic conditions, with a focus on wellness that takes into account their biological, psychological, vocational and educational needs.
7. Careful consideration needs to be paid to confidentiality and informed consent, with confidentiality needing to be maintained as young people engage with different health professionals and providers.

Paediatric Society of New Zealand. **Meeting the Care and Support Needs of Young People with Complex and Chronic Health and Disability Needs as they Approach Adulthood**. Wellington 2005 Paediatric Society of New Zealand http://www.paediatrics.org.nz/index.asp?pageID=2145878337

In this position statement, the Paediatric Society notes that many young people with chronic health problems and disabilities have problems that are complex and require input from a range of providers. Further, that many of these young people have difficulty accessing coordinated care and expertise (with many having problems which are too complex or rare to be adequately managed by a general practitioner alone).

The Paediatric Society thus recommends that:

1. Systems of care be developed that meet the needs of these children and young people, with these systems recognising the high costs involved in providing care for those with complex and chronic health and disability support needs.



2. Funding should support the best local solutions for continuity of holistic care, and might include the development of adolescent transition services, initiatives within primary care, the funding of paediatric services up until the 18th birthday and the development of adult medicine and rehabilitation services with a special interest in young people with high health and disability needs.
3. National networks be developed to meet the needs of young people with complex and chronic health and disability support needs.

Waikato DHB. **Youth** Transition **Standards of Care**. Hamilton 2010 Waikato DHB
http://www.waikatodhb.govt.nz/files/Policies/Admin-Clinical/Youth%20Transition%202791%20Jul%202010.pdf

This document, developed by the Waikato DHB, outlines best practice in the transition of young people from paediatric to adult healthcare. It outlines the need for: all services involved in the transitional care of young people to establish effective communication systems and processes; the early identification of young people who will require additional transitional support; an identified key worker who will be responsible for coordinating the transition process; the use of a youth heath assessment tool and other youth health transition resources by all services; an individualised transition plan which has been developed and agreed with the young person and their families; services actively supporting young people to engage with primary care and community based providers; the timing of the transfer of care being determined by the stage of preparedness of the young person and their caregivers; and that all DHB services have processes which ensure that no young person is lost to follow up at any stage of their transition to adult care.

The Background Literature Review which informed this Standard of Care is also available from the Waikato DHB website http://www.waikatodhb.govt.nz/page/pageid/2145839490

Mockford A. **2010 Youth Transition Project: From Paediatric to Adult Healthcare Literature Review Final Background Report.** Hamilton, Waikato DHB p1-51
http://www.waikatodhb.govt.nz/file/fileid/34268

The Literature Review considers barriers to transitions, the risks associated with poor transition, the benefits of a good transition, what young people say they want, and the key elements of any effective youth health transition model. The review also contains links to a number of pre-existing transition programs including:

Great Ormond Street Children's Hospital, "Getting Ready" Program in London, UK
http://www.ich.ucl.ac.uk/clinical_information/care_pathways/AdolescentTransitionICP.pdf
http://www.ich.ucl.ac.uk/gosh_families/information_sheets/transition/transition_families.html

Toronto SickKids "Go2Go" Model, Canada
www.sickkids.ca/good2go

"On TRAC" Transition Programme- British Columbia Children's Hospital, Vancouver Canada
http://www.bcchildrens.ca

"Getting Connected" Greater Metropolitan Clinical Taskforce (GMCT), Sydney, Australia
http://www.health.nsw.gov.au/gmct/transition/index.asp

Children's Hospital at Westmead, Sydney, Australia
http://www.chw.edu.au/site/directory/entries/transition.htm

Royal Children's Hospital, Melbourne, Australia
http://www.rch.org.au/transition/index.cfm?doc_id=8143

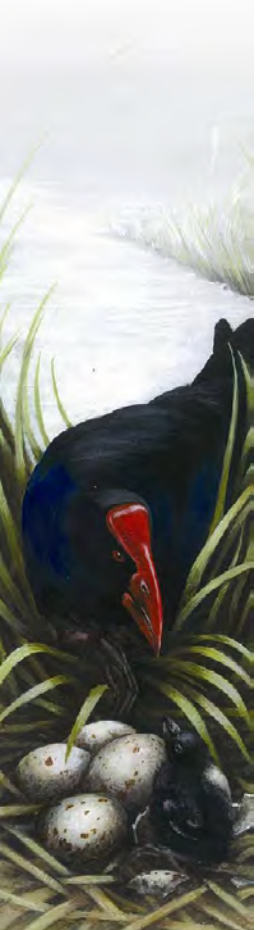
The ACT Transition Care Pathway UK
http://www.act.org.uk/page.asp?section=115&sectionTitle=ACT%27s+transition+care+pathway

Transitions: In Conclusion

While from a health service planning perspective, there is a paucity of evidence-based transition models in the current literature, the same literature does highlight a range of issues inherent to adolescent healthcare transitions, as well as a number of service elements which have been trialled (if not fully evaluated) elsewhere. Further, a range of principles provide guidance on the overall approaches which should be taken. At both the DHB and Ministry of Health levels, it is thus recommended that service funders and planners review the services available to young people with chronic conditions and disabilities, and consider whether any of the problems associated with transition care (as outlined above) are likely to occur in their own jurisdictions. Further, service planners and funders are urged to consider whether any of the service elements outlined above might be of value in improving continuity of care at this key point in young peoples' life course.

In Conclusion

The above review has highlighted a range of areas where New Zealand may need to improve service delivery for children and young people with disabilities and their families. While in many cases high quality evidence from randomised control trials is lacking, there is nevertheless sufficient information to be able to direct future initiatives in the areas of greatest need, which include access to respite care, continuity and coordination between services and the adequate resourcing of the caregivers (both paid and informal) who care for children and young people with disabilities. Attention to ongoing quality improvement in these areas will ensure that over time, the health sector will be able to better direct its efforts to meet the needs of some of the most vulnerable children and young people in our society.



DEVELOPMENTAL DELAYS AND INTELLECTUAL DISABILITIES

Introduction

Global developmental delay is usually defined as *a significant delay in two or more developmental domains including gross or fine motor, speech / language, cognitive, social / personal and activities of daily living*. While delays in some children (especially if mild) are transient, for many they may signal future intellectual disability [85]. A number of definitions are also in current use for intellectual disability, with the American Association on Mental Retardation (AAMR) 1992 definition being the most frequently used within the United States and the ICD-10 definition being more frequently used elsewhere. The AAMR's definition defines mental retardation with reference to 3 domains: intelligence (IQ), adaptive behaviour and systems of supports (although more recently the term intellectual disability is being increasingly used in preference to mental retardation) [85]. In general, developmental delays are diagnosed in children <5 years of age, with intellectual disabilities not usually being diagnosed until children are at least 5 years, when standardized measures of developmental skills (including IQ) become more reliable [85].

The prevalence of intellectual disabilities is estimated at 1-3% [85] with the aetiology of global developmental delay and intellectual disabilities being highly variable. In general, exogenous causes (e.g. teratogen exposure, infection) are implicated in 19-45% of cases, with 17-47% being thought to have a genetic cause [86]. In terms of clinical evaluation, the American Academy of Paediatrics [86] recommends that all infants and young children be screened for developmental delays as part of their routine care, with those identified as having a delay being referred for further evaluation. Ideally such an evaluation should include a full clinical history, a 3-generation family history, a dysmorphologic examination, a neurological examination, chromosomal analysis, molecular genetic testing (e.g. for fragile X and other syndromes), computed tomography +/- magnetic resonance brain imaging, and targeted studies for metabolic disorders [86].

In terms of their health needs, children and young people with developmental delays and intellectual disabilities require a variety of personal health and disability support services. Personal health needs include routine well child care (e.g. immunisation, monitoring of growth and development), as well as the management of conditions more common in children with delays (e.g. seizure disorders, vision and hearing problems). Early intervention programmes for infants and toddlers assist in nurturing children's development, while tailored educational programmes during the preschool and school years may facilitate learning, positive self-esteem, social competence and adaptive living skills [23]. During adolescence, issues related to sexuality, vocational training and community living become more prominent [31], with the National Advisory Committee on Health and Disability (NHC) [37] emphasising the need for planning for adulthood to start by the time a young person is 14 years. The NHC notes that people with intellectual disabilities are a heterogeneous group and recommends that services become more flexible and focussed on the individual and his or her needs. The NHC also highlights the need for meaningful post school activity for young adults who have been through mainstream school settings.

The section which follows uses the National Minimum Dataset to review hospital admissions for children and young people with any mention of a developmental delay or intellectual disability in any of the first 15 diagnoses.

Data Source and Methods

Definition

1. Hospital Admissions for Children and Young People with Developmental Delays
2. Hospital Admissions for Children and Young People with Intellectual Disabilities

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions for Children and Young People Aged 0-24 Years with Developmental Delays (ICD-10-AM R62) or Intellectual Disabilities (ICD-10-AM Mental Retardation F70-79) in any of the first 15 diagnoses.

Denominator: Statistics New Zealand Estimated Resident Population

Notes on Interpretation

Unless otherwise specified, this analysis focuses on hospital admissions for children and young people who had developmental delays, or intellectual disabilities listed in any of the first 15 diagnoses (rather than on the subset of admissions where these diagnoses were listed only as the primary diagnosis). The rationale for this wider focus was the fact that the majority of children and young people with developmental delays or intellectual disabilities were not hospitalised primarily as a result of these conditions, but rather for a range of other diagnoses, some of which may have been associated with the delay or intellectual disability (e.g. autism, congenital anomalies), and some of which were unrelated. For example, during 2005-2009, only 23.6% of hospitalisations for children and young people with developmental delays had the delay listed as the primary diagnosis, with 15.5% being admitted for respiratory infections / diseases, and 8.9% for epilepsy or convulsions. If no mention was made of developmental delays or intellectual disabilities in any of the first 15 diagnoses however, these cases were not included (even if the patient had been assigned one of these diagnoses on a previous admission).

Further, as many children and young people with developmental delays or intellectual disabilities are managed predominantly in the outpatient or primary care setting (e.g. in contrast to cystic fibrosis where frequent hospitalisation often occur), it is likely that the analysis of hospital admission data presented in this section significantly underestimates the number of children and young people with developmental delays or intellectual disabilities. The rationale for the methodology used however, was the absence of other more reliable sources of information on children and young people with these diagnoses, and the importance of this group of children and young people in paediatric practice.

Indicator Category Bookmark B

New Zealand Distribution and Trends

New Zealand Distribution by Primary Diagnosis

In New Zealand during 2005-2009, 23.6% of hospitalisations for children and young people with developmental delays (i.e. a developmental delay listed in any of the first 15 diagnoses) had the developmental delay listed as the primary diagnosis. A further 15.5% had respiratory infections and diseases listed as the primary diagnosis, while 8.9% were admitted primarily for epilepsy or convulsions (**Table 30**). Similarly, during 2005-2009 only 7.2% of hospitalisations for children and young people with intellectual disabilities had their intellectual disability listed as the primary diagnosis, with 14.7% being admitted for dental caries or other oral health issues, and 13.1% for epilepsy or convulsions (**Table 31**).

Distribution by Age

In New Zealand during 2005-2009, hospitalisations for children and young people with developmental delays were highest during the first year of life, with rates dropping away rapidly thereafter. In contrast, hospitalisations for children and young people with intellectual disabilities were relatively infrequent during the first two years of life, but increased gradually during childhood and early adolescence. In numerical terms, the number of hospitalisations for children and young people with developmental delays (n=5,961 hospitalisations) was higher than for those with intellectual disabilities (n=2,221 hospitalisations) during this period (**Figure 18**).

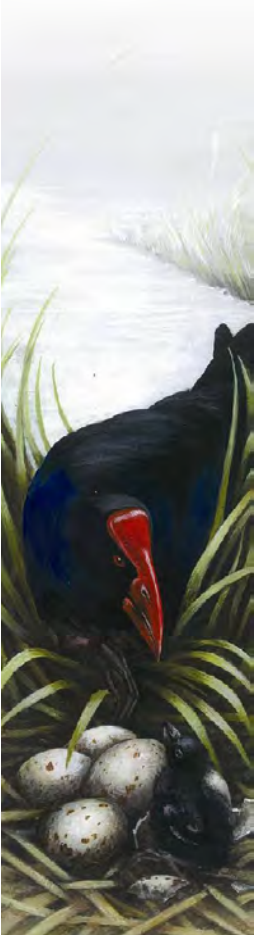


Table 30. Hospital Admissions for Children and Young People 0-24 Years with Developmental Delays by Primary Diagnosis, New Zealand 2005-2009

Primary Diagnosis	Number: Total 2005-2009	Number: Annual Average	Rate per 100,000 Population	% of Admissions in those with Developmental Delay
Developmental Delay				
Developmental Delay (R62)	1,404	280.8	18.6	23.6
Respiratory Infections and Diseases (J00-J99)	925	185.0	12.3	15.5
Epilepsy and Status Epilepticus (G40-G41)	386	77.2	5.1	6.5
Unspecified Convulsions (R568)	142	28.4	1.9	2.4
Infectious and Parasitic Diseases (A00-B99)	291	58.2	3.9	4.9
Congenital Anomalies Cardiovascular System (Q20-Q28)	260	52.0	3.4	4.4
Congenital Anomalies Nervous System (Q00-Q07)	56	11.2	0.7	0.9
Other Congenital and Chromosomal Anomalies (Remainder Q00-Q99)	219	43.8	2.9	3.7
Gastro-Oesophageal Reflux (K21)	122	24.4	1.6	2.0
Feeding Difficulties (R633)	120	24.0	1.6	2.0
Dental Caries and Oral Health Issues (K00-K14)	109	21.8	1.4	1.8
Injuries (S00-T35, T66-T79)	100	20.0	1.3	1.7
Cerebral Palsy (G80)	31	6.2	0.4	0.5
Other Diagnoses	1,796	359.2	23.8	30.1
Total	5,961	1,192.2	79.0	100.0

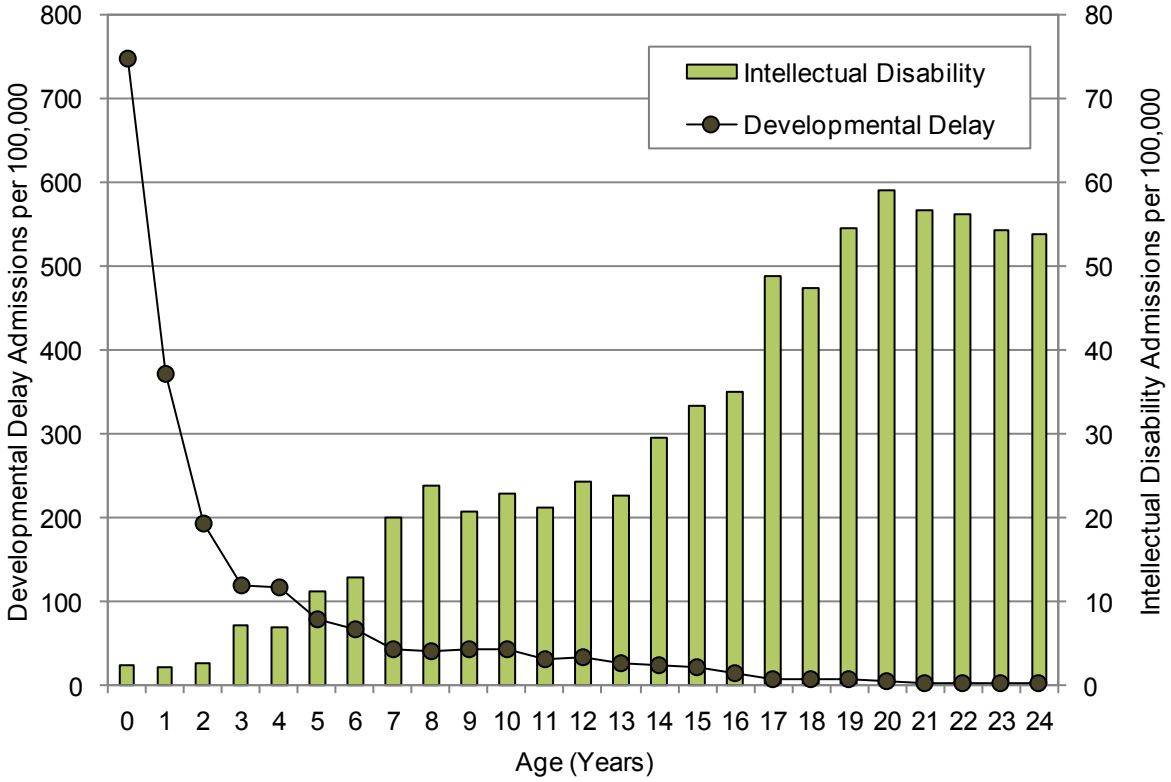
Source: Numerator: National Minimum Dataset: Hospital admissions by primary diagnosis for children and young people with a Developmental Delay listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Table 31. Hospital Admissions for Children and Young People 0-24 Years with Intellectual Disabilities by Primary Diagnosis, New Zealand 2005-2009

Primary Diagnosis	Number: Total 2005-2009	Number: Annual Average	Rate per 100,000 Population	% of Admissions in those with Intellectual Disability
Intellectual Disability				
Intellectual Disabilities (ICD-10 Mental Retardation F70-F79)	160	32.0	2.1	7.2
Dental Caries and Oral Health Issues (K00-K14)	326	65.2	4.3	14.7
Epilepsy and Status Epilepticus (G40-G41)	250	50.0	3.3	11.3
Unspecified Convulsions (R568)	41	8.2	0.5	1.8
Schizophrenia, Schizotypal and Delusional Disorders (F20-F29)	177	35.4	2.3	8.0
Pervasive Developmental Disorders including Autism (F84)	49	9.8	0.6	2.2
Other Mental and Behavioural Disorders (Remainder F00-F99)	225	45.0	3.0	10.1
Respiratory Infections and Diseases (J00-J99)	155	31.0	2.1	7.0
Injuries (S00-T35, T66-T79)	119	23.8	1.6	5.4
Congenital and Chromosomal Anomalies (Q00-Q99)	50	10.0	0.7	2.3
Contraceptive Management (Z30)	38	7.6	0.5	1.7
Infectious and Parasitic Diseases (A00-B99)	33	6.6	0.4	1.5
Constipation (K590)	25	5.0	0.3	1.1
Cerebral Palsy (G80)	16	3.2	0.2	0.7
Other Diagnoses	557	111.4	7.4	25.1
Total	2,221	444.2	29.4	100.0

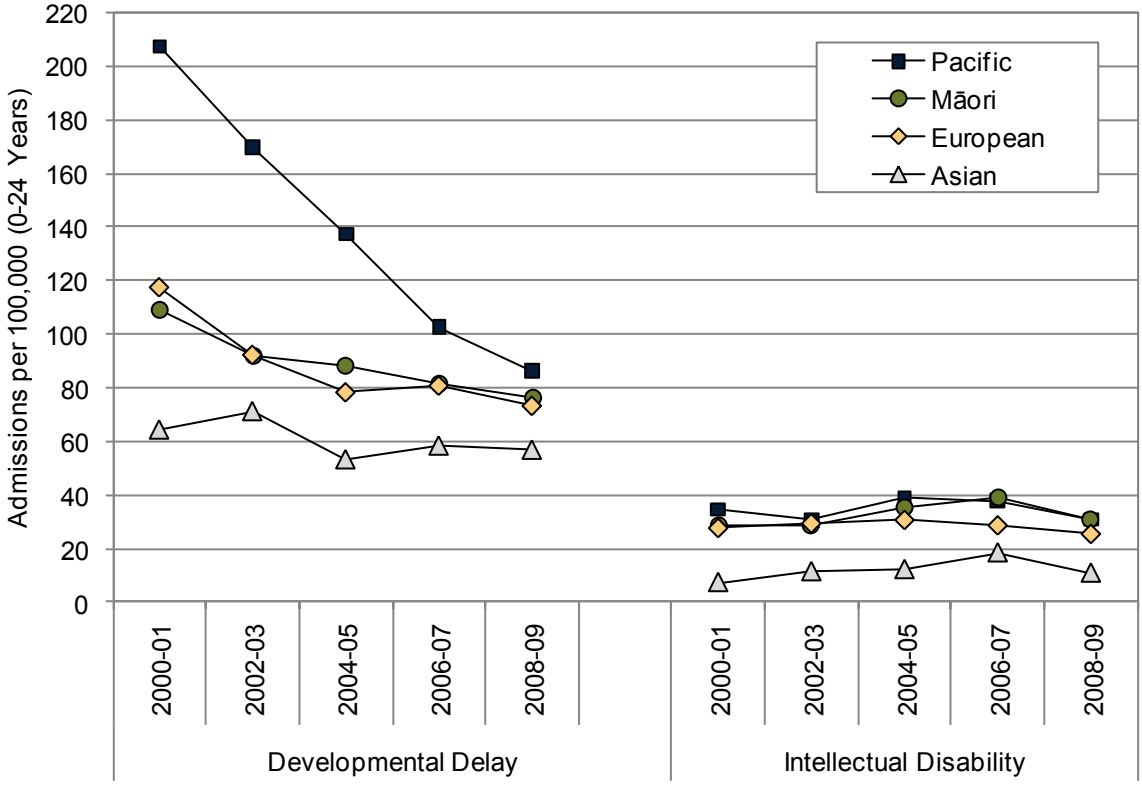
Source: Numerator: National Minimum Dataset: Hospital admissions by primary diagnosis for children and young people with an Intellectual Disability listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Figure 18. Hospital Admissions for Children and Young People with Developmental Delays or Intellectual Disabilities by Age, New Zealand 2005-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with a Developmental Delay or an Intellectual Disability listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Figure 19. Hospital Admissions for Children and Young People Aged 0-24 Years with Developmental Delays or Intellectual Disabilities by Ethnicity, New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with a Developmental Delay or an Intellectual Disability listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised.

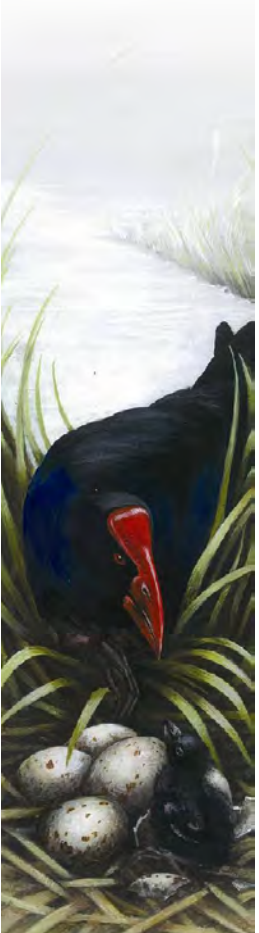
Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2005-2009, hospitalisations for children and young people with developmental delays were *significantly* higher for males, Pacific > Māori and European > Asian children and young people and those living in average-more deprived (NZDep deciles 5-10) areas. Similarly, hospitalisations for children and young people with intellectual disabilities were *significantly* higher for males, Pacific and Māori > European > Asian children and young people and those living in average-more deprived (NZDep deciles 5-10) areas (**Table 32**). Similar ethnic differences were seen during 2000-2009, although hospitalisations for European and Māori children and young people with intellectual disabilities were more similar during the early 2000s (**Figure 19**).

Table 32. Hospital Admissions for Children and Young People Aged 0-24 Years with Developmental Delays or Intellectual Disabilities by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2005-2009

Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
Developmental Delay							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	51.1	1.00		Decile 1-2	50.2	1.00	
Decile 2	49.3	0.96	0.83 - 1.12	Decile 3-4	55.6	1.11	1.00 - 1.23
Decile 3	55.3	1.08	0.93 - 1.25	Decile 5-6	69.7	1.39	1.26 - 1.53
Decile 4	55.9	1.09	0.95 - 1.26	Decile 7-8	89.0	1.77	1.62 - 1.94
Decile 5	70.9	1.39	1.21 - 1.59	Decile 9-10	110.2	2.20	2.01 - 2.39
Decile 6	68.7	1.34	1.17 - 1.54	Prioritised Ethnicity			
Decile 7	90.0	1.76	1.54 - 2.00	Asian	57.4	0.75	0.68 - 0.82
Decile 8	88.1	1.72	1.52 - 1.96	European	76.9	1.00	
Decile 9	105.8	2.07	1.83 - 2.34	Māori	80.5	1.05	0.98 - 1.12
Decile 10	114.5	2.24	1.99 - 2.53	Pacific	99.3	1.29	1.19 - 1.40
Gender							
Female	73.2	1.00		Male	84.6	1.16	1.10 - 1.22
Intellectual Disability							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	18.4	1.00		Decile 1-2	13.7	1.00	
Decile 2	9.1	0.50	0.37 - 0.67	Decile 3-4	20.1	1.47	1.22 - 1.76
Decile 3	20.4	1.11	0.87 - 1.42	Decile 5-6	25.6	1.87	1.56 - 2.23
Decile 4	19.9	1.08	0.85 - 1.38	Decile 7-8	37.4	2.73	2.31 - 3.21
Decile 5	25.0	1.36	1.08 - 1.72	Decile 9-10	42.4	3.09	2.63 - 3.62
Decile 6	26.1	1.42	1.14 - 1.78	Prioritised Ethnicity			
Decile 7	31.3	1.71	1.37 - 2.12	Asian	13.9	0.50	0.41 - 0.60
Decile 8	42.7	2.32	1.90 - 2.85	European	28.0	1.00	
Decile 9	41.8	2.28	1.86 - 2.78	Māori	36.9	1.32	1.20 - 1.45
Decile 10	43.0	2.34	1.92 - 2.86	Pacific	34.9	1.25	1.09 - 1.44
Gender							
Female	25.1	1.00		Male	33.6	1.34	1.23 - 1.45

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with a Developmental Delay or an Intellectual Disability listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Rates are per 100,000. Rate Ratios are unadjusted.



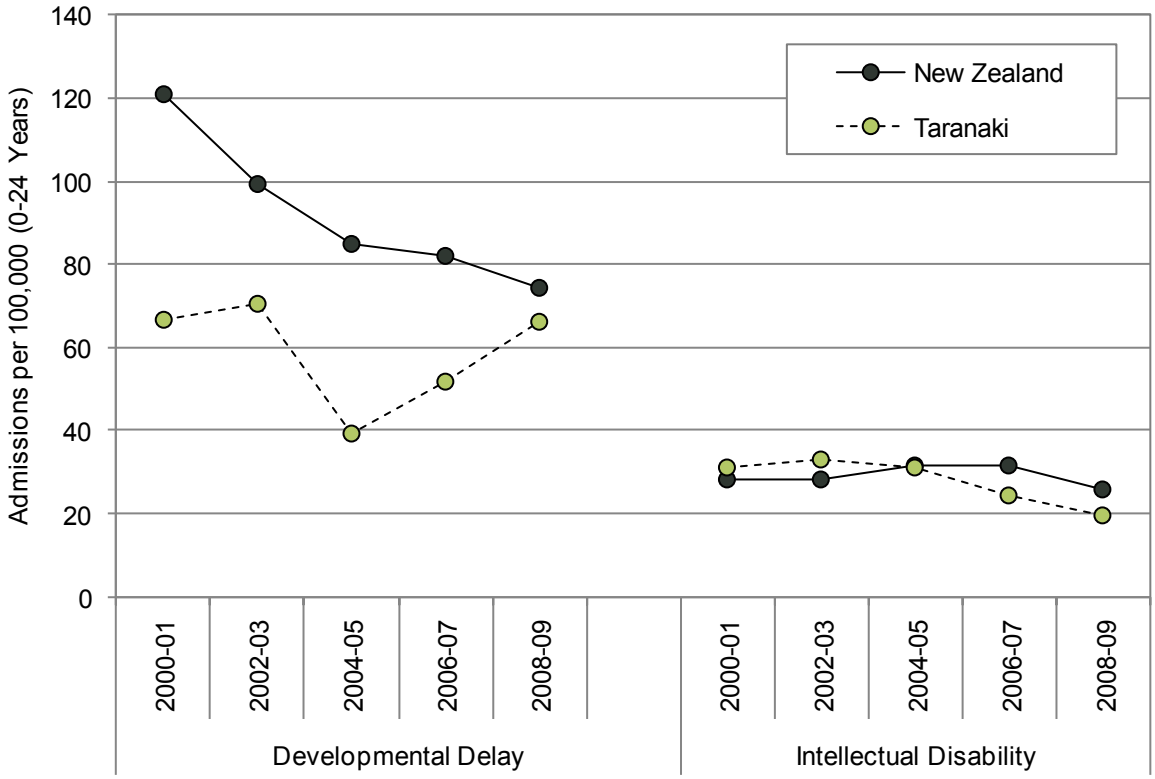
Taranaki Distribution and Trends

Table 33. Hospital Admissions for Children and Young People Aged 0-24 Years with Developmental Delays or Intellectual Disabilities, Taranaki vs. New Zealand 2005-2009

DHB	Total Number Individuals 2005-2009		Total Admissions 2005-2009	Average Admissions per Individual per Year	Admission Rate per 100,000 Total Population	Rate Ratio	95% CI
	(A)*	(B)*					
Developmental Delay							
Taranaki	74	76	103	0.27	56.3	0.71	0.59 - 0.87
New Zealand	3,696		5,961	0.32	79.0	1.00	
Intellectual Disabilities							
Taranaki	32	32	47	0.29	25.7	0.87	0.65 - 1.16
New Zealand	1,260		2,221	0.35	29.4	1.00	

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with a Developmental Delay or an Intellectual Disability listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population. *Note: (A): Each individual only counted once in DHB in which they first reside (i.e. DHB total = NZ total); (B): Each individual counted once in each DHB in which they reside (i.e. the sum of DHB totals exceeds New Zealand total). Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

Figure 20. Hospital Admissions for Children and Young People Aged 0-24 Years with Developmental Delays or Intellectual Disabilities, Taranaki vs. New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with a Developmental Delay or an Intellectual Disability listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population.

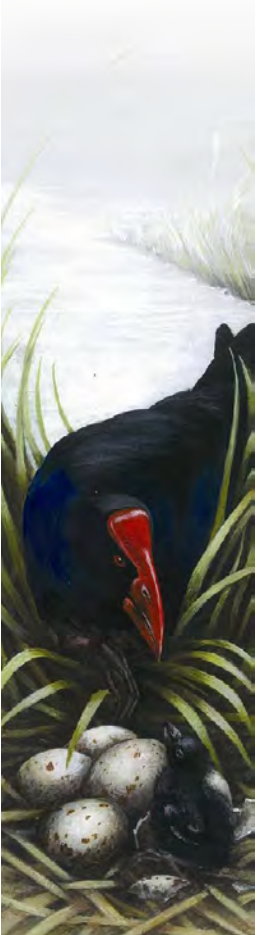
Taranaki Distribution and Trends

In Taranaki during 2005-2009, a total of 76 individual children and young people were admitted to hospital with a developmental delay listed in any of the first 15 diagnoses. Admission rates per 100,000 population were *significantly* lower than the New Zealand average (RR 0.71 95% CI 0.59 – 0.87). In addition, 32 individual children and young people were admitted to hospital with an intellectual disability listed in any of the first 15 diagnoses, although admission rates per 100,000 population were not *significantly* different from the New Zealand average (RR 0.87 95% CI 0.65 – 1.16) (**Table 33**). Similar differences were seen during 2000-2009 (**Figure 20**).

Summary

In New Zealand during 2005-2009, 23.6% of hospitalisations for children and young people with developmental delays had the developmental delay listed as the primary diagnosis. A further 15.5% had respiratory infections and diseases listed as the primary diagnosis, while 8.9% were admitted primarily for epilepsy or convulsions. Similarly, only 7.2% of hospitalisations for children and young people with intellectual disabilities had their intellectual disability listed as the primary diagnosis, with 14.7% being admitted for dental caries or other oral health issues, and 13.1% for epilepsy or convulsions. Hospitalisations for those with developmental delays were highest during the first year of life, with rates dropping away rapidly thereafter. In contrast, hospitalisations for those with intellectual disabilities were relatively infrequent in the first two years of life, but increased during childhood and the early teens. Hospitalisations for those with developmental delays were *significantly* higher for males, Pacific > Māori and European > Asian children and young people and those living in average-more deprived (NZDep deciles 5-10) areas, while hospitalisations for those with intellectual disabilities were *significantly* higher for males, Pacific and Māori > European > Asian children and young people and those living in average-more deprived (NZDep deciles 5-10) areas.

In Taranaki during 2005-2009, a total of 76 individual children and young people were admitted to hospital with a developmental delay listed in any of the first 15 diagnoses. Admission rates per 100,000 population were *significantly* lower than the New Zealand average (RR 0.71 95% CI 0.59 – 0.87). In addition, 32 individual children and young people were admitted to hospital with an intellectual disability listed in any of the first 15 diagnoses, although admission rates per 100,000 population were not *significantly* different from the New Zealand average (RR 0.87 95% CI 0.65 – 1.16).



Local Policy Documents and Evidence Based Reviews Relevant to Children and Young People with Intellectual Disabilities and Developmental Delays

In New Zealand a number of policy documents are relevant to children and young people with intellectual disabilities. These are summarised in **Table 34,** along with a range of international reviews which consider aspects of the non-pharmacological management and care of children and young people with these diagnoses. In addition, **Table 43** on **Page 130** considers the diagnosis and management of Autism and Other Pervasive Developmental Disorders. Note: The effectiveness of various medications for the management of behavioural issues and epilepsy in those with developmental delays and intellectual disabilities is beyond the scope of this review.

Table 34. Local Policy Documents and Evidence Based Reviews Relevant to Children and Young People with Intellectual Disabilities and Developmental Delays

New Zealand Health Policy Documents and Publications
Ministry of Health. **Living with Intellectual Disability in New Zealand: Key Results on Intellectual Disability From the 2001 Household Disability Survey and the 2001 Disability Survey of Residential Facilities**. Wellington: Ministry of Health, 2005. URL: http://www.moh.govt.nz/moh.nsf/by+unid/D359AB374BD30DA8CC257019007C5B14?Open Pages 12 – 22 cover the results relevant to children. They provide some basic information about children with intellectual disability in New Zealand as reported by their parents or caregivers. The self-reporting probably contributes to the % of children being reported as having an intellectual disability (2%) being higher than the % of adults (1%).
National Advisory Committee on Health and Disability. **To Have an 'Ordinary' Life - Kia Whai Oranga 'Noa'**. Wellington, 2003. URL: http://www.nhc.health.govt.nz/moh.nsf/indexcm/nhc-ordinary-life?Open This report highlights the barriers that people with intellectual disabilities face to having a life like that of other New Zealanders. It emphasises the need for planning for adulthood to start by the time a young person reaches the age of 14. It notes that people with intellectual disabilities are a very heterogeneous group and recommends that services become more flexible and focussed on the individual and his or her needs. It highlights the need for meaningful post school activity for young adults who have been through mainstream school settings. They and their parents expect something better than repetitive activities in large groups with other disabled people with no opportunity for individual skill development.
Ministry of Health. **A Guide to the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003**. Wellington: Ministry of Health, 2004. URL: http://www.moh.govt.nz/moh.nsf/0/47B3BFB016FE6B86CC256F08000EC36F/$File/idccrguidelines-intellectualdisability.pdf These guidelines outline key aspects of the application and operation of the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 („the IDCCR Act') which authorises the provision of compulsory care and rehabilitation to individuals with an intellectual disability who have been charged with, or convicted of, an imprisonable offence. Other publications relating to this Act can be found on the Ministry website: http://www.moh.govt.nz/idccr#guidelines
New Zealand Special Education Policy Documents and Publications
Ministry of Education. **The Review of Special Education 2010 Public Response Summary**. Wellington: Ministry of Education, 2010. URL: http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/SuccessForAll.aspx In August 2009 the government announced a year long review of special education, the key aims of which were "to ensure that policies and processes are fair, consistent, reach those most in need, provide choices for families and make the best use of Government funding." The public were invited to contribute to the review by responding to a discussion document that featured a wide-ranging series of questions on special education. More than 2000 replies were received from individuals, groups and organisations and the results are summarised in the 215 pages of the above document. Each section covers one of the ten questions, and summarises the key themes of the responses and presents a representative sample of the responses. The discussion document that contains the questions that the public responded to can be found at: http://www.minedu.govt.nz/theMinistry/Consultation/ReviewOfSpecialEducation/DiscussionDocument2010.aspx.
Education Review Office. **Including Students with High Needs.** Wellington: Education Review Office, 2010. URL: http://www.ero.govt.nz/National-Reports/Including-Students-with-High-Needs-June-2010 This is the report on an Education Review Office (ERO) evaluation of how well schools included students with high needs. The evaluation included 30 secondary schools and 199 primary schools. ERO noted that about 3% students have significant physical, sensory neurological, psychiatric, behavioural or intellectual impairment. The evaluation found that about half the schools in the study showed inclusive practice, 30% had "pockets of inclusive practice" and 20% had few inclusive practices. Schools that provided good models for inclusive practice were stated to be those that had an "ethical, committed, innovative, informed and coordinated approach to including students with high needs".
Alliston L. **Principles and practices in early intervention: A literature review for the Ministry of Education**. Wellington: Research New Zealand, 2007. This literature review, which was commissioned by the Ministry of Education, reviews studies illustrating effective and/or evidence-based principles and practices for early intervention aimed at children from birth to six years of age with special education needs, particularly those principles and practices linked to improved child outcomes.
Meyer LH, Evans IM. **Literature review on intervention with challenging behaviour in children and youth with developmental disabilities**. Wellington: Victoria University of Wellington College of Education, 2006. This Ministry of Education contracted literature review on severe challenging behaviour in children and young people with developmental disabilities focuses on effective educational and support services for children and young people whose challenging behaviour is associated with a diagnosis of developmental delay, severe learning difficulties, severe traumatic brain injury, intellectual disability, and/or autistic spectrum disorder.

Wylie C. **Picking up the pieces: Review of Special Education 2000 - He Tātaritanga Mō te Mātauranga Motuhake 2000**. Wellington: Education Counts, Ministry of Education, 2000. URL: http://www.educationcounts.govt.nz/ data/assets/pdf_file/0018/15336/10605-wylie-review---download.pdf

All aspects of special education policy are covered in this review of Special Education, which was the result of extensive consultation with schools, parents, other educators, disability organisations and service providers and the review of more than1000 submissions. Chapter 13 covers intersectoral issues regarding health and education.

Systematic and Other Reviews from the International Literature

Mayo-Wilson E, Montgomery P, et al. **Personal assistance for children and adolescents (0-18) with intellectual impairments**. Cochrane Database of Systematic Reviews 2008(3): CD006858.

This review defined personal assistance as paid support of at least 20 hours per week which is given to children and adolescents to enable them to participate in mainstream activities. It might include help with bathing, dressing, getting around during the day, going shopping or participating in sport and leisure activities. The reviewers identified one study (with 1002 participants) which met their criteria by assigning participants at random to receive either personal assistance or usual care. This study (by Carlson et al below) suggested that some people and their informal caregivers prefer this form of assistance. They recommend further research to address the following questions: (i) what are the additional benefits of personal assistance over those of other services, (ii) how do the costs of personal assistance compare to those of other services and (iii) which kinds of personal assistance are best for particular people?

Carlson BL, Foster L, et al. **Effects of Cash and Counselling on personal care and well-being**. Health Services Research 2007; 42(1 Pt 2): 467-87.

This study aimed to evaluate a new model of consumer directed care which gave people with disabilities (or their parents in the case of children) an allowance to direct and purchase their own services as Cash and Counselling consumers. Participants were randomly assigned to receive either the new service or the usual Medicaid services. The study found that Cash and Counselling consumers were more likely to receive paid care, had greater satisfaction with their care and had fewer unmet needs than the control group, except among the elderly in Florida where only a few treatment group members actually received the allowance. Further information about the programme can be found at: http://www.cashandcounseling.org/ and also at http://www.bc.edu/schools/gssw/nrcpds/cash-and-counseling.html

Hassiotis AA, Hall I. **Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with learning disabilities**. Cochrane Database of Systematic Reviews 2008(3): CD003406.

Outwardly-directed aggressive behaviour is a relatively common part of problem behaviours in people with learning disabilities and can be both long term and a cause of social exclusion. There is little evidence from methodologically sound clinical trials on the efficacy of cognitive behavioural and behavioural interventions in dealing with such behaviour. This review reported on four small heterogeneous studies in which most of the participants had mild learning disability or borderline intelligence. The review authors considered that these studies indicated that cognitive behavioural techniques (such as modified relaxation, assertiveness training with problem solving, and anger management) do have the potential to reduce outwardly directed aggression in adults with learning disabilities. They note that behavioural therapies, although expensive, are often considered to be preferable to the use of antipsychotic drugs which have significant side-effects. They recommend further research.

Balogh R, Ouellette-Kuntz H, et al. **Organising health care services for persons with an intellectual disability**. Cochrane Database of Systematic Reviews 2008(4): CD007492.

There are significant disparities in health between people with intellectual disability and the general population. This review identified 8 studies investigating interventions for mental health problems in people with an intellectual disability but none which focussed on physical problems. The authors state: “There is an urgent need for high quality research to identify optimal health services for persons with an intellectual disability and concurrent physical problems.”

Beavis J, Kerr M, et al. **Non-pharmacological interventions for epilepsy in people with intellectual disabilities**. Cochrane Database of Systematic Reviews 2007(4): CD005502.

Seizures in people with intellectual disability are often complex and refractory to drug treatment, so there is interest in a variety of non pharmacological interventions which could be used as well as or instead of drugs. These include surgery, special diets, psychological interventions to reduce stress, yoga and acupuncture. The authors of this review found that there have been no RCTs of non pharmacological treatments for epilepsy in people with intellectual disabilities but state that such studies are needed.

Spittle AJ, Orton J, et al. **Early developmental intervention programs post hospital discharge to prevent motor and cognitive impairments in preterm infants**. Cochrane Database of Systematic Reviews 2007(2): CD005495.

Compared to full term infants, infants born pre-term are at increased risk for cognitive and motor impairments. This review aimed to investigate the effectiveness of early developmental intervention post hospital discharge in improving motor and cognitive function in infants born <37 weeks gestation with no major congenital abnormalities. The authors reviewed 16 heterogeneous studies with 2379 randomised patients, (6 of which were RCTs with strong methodological quality). They concluded that early intervention programmes have a positive influence on cognitive outcomes in the preschool years but that this effect was not sustained into the school years. They found that there was little evidence of an effect on motor outcomes at any stage as only one study (out of 13) reported an improvement in motor function in infancy, no studies reported on motor outcomes at preschool age, and the only study reporting on motor outcomes at school age found no difference between the children who had received early intervention and those who had not.

Montgomery P, Bjornstad G, et al. **Media-based behavioural treatments for behavioural problems in children**. Cochrane Database of Systematic Reviews 2006(1): CD002206.

While cognitive behavioural treatments have been shown to be effective for behavioural problems in children, access to professional therapists is limited and expensive. This review considered the effects of providing information on managing problem behaviour to parents via media such as booklets, DVDs or computer programmes. It reported on 11 randomised or quasi-randomised controlled trials of media-based behavioural treatments for behaviour problems in children involving 943 children. Two of the studies involved children with learning disabilities. The authors considered that such an approach was likely to be effective and economical at least for moderate cases and was worth consideration. They suggested it could also be the first stage of a stepped care approach to more complex cases. They found insufficient evidence to recommend one method of media based intervention over another.

Klassen TP, Kiddoo D, et al. **The effectiveness of different methods of toilet training for bowel and bladder control**. Evidence Report/Technology Assessment No 147. Rockville, MD: Agency for Healthcare Research and Quality U.S. Department of Health and Human Services, 2006.

This review aimed to review toilet training methods including those for patients with special needs. It included 26 observational studies and eight controlled trials approximately half of which looked at healthy children and the other half at mentally or physically disabled children. For mentally disabled children, individual training was better than group methods, relaxation techniques were better than conventional techniques, and the Azrin and Foxx method and a behaviour modification method were better than no training. (The Azrin and Foxx method is a parent-oriented method that emphasizes structured behavioural endpoint training which is aimed at eliciting a specific chain of independent events by teaching the component skills of toilet training.)

Centre for Reviews and Dissemination. **The effectiveness of different methods of toilet training for bowel and bladder control**. Database of Abstracts of Reviews of Effects 2010(3).

The CRD reviewers of this paper stated it was a well conducted review and that the results were likely to be reliable.

Schlosser R, Lee D. **Promoting generalization and maintenance in augmentative and alternative communication: A meta-analysis of 20 years of effectiveness research**. Augmentative and Alternative Communication 2000; 16(4): 208-226.

Alternative and augmentative communication involves using methods other than speech to serve a communication function such as making a request (e.g. by giving someone a picture of what you want). The authors of this review used statistical methods to pool the results from 56 studies involving people aged between 5 and 25 with a variety of disabilities associated with impaired communication, including mental retardation and autism, in a variety of settings. They concluded that alternative and augmentative communication interventions were effective in terms of behaviour change, generalisation and (to a lesser extent) maintenance. (Generalisation is the use of the communication behaviour with different people and in different settings from those in initial training, maintenance is the persistence of the communication behaviour beyond the training period.) This review is somewhat technical but it does offer an entry point to the literature on this topic.

Centre for Reviews and Dissemination. **Promoting generalization and maintenance in augmentative and alternative communication: A meta-analysis of 20 years of effectiveness research**. Database of Abstracts of Reviews of Effects 2010(3).

The CRD reviewers considered that this review addressed a well-defined question and involved a very thorough literature review. They stated that it was unclear whether or not it was appropriate to pool the results of all the interventions given the range of ages and disabilities of the participants in the various studies, but that overall it was a fairly good review and the authors' conclusions were valid.

Other Relevant Publications

HM Treasury and the Department for Education and Skills. **Aiming High for Disabled Children: Better Support for Families**. London: HM Treasury and the Department for Education and Skills, May 2007. URL: http://www.dcsf.gov.uk/everychildmatters/826

This review sets out the U.K. government's plans for improving service provision for disabled children and their families. It lists three priority areas: (i) access and empowerment, (ii) responsive services and timely support and (iii) improving quality and capacity.

Power A. **'It's the system working for the system': Carers' experiences of learning disability services in Ireland**. Health & Social Care in the Community 2009; 17(1): 92-8.

This paper reports on a qualitative study from Ireland which interviewed 25 family carers of young people with learning disabilities and six representatives from national care organisations. It discusses some of the important issues for young people leaving school, in particular day care, special vocational training schemes and respite care; and the difficulties faced by parents in attempting to access suitable services for their adult child. Many parents wish their children to get a "real job" and avoid a lifetime of benefit dependency but supported employment is not readily available. There were problems with respite care for adults. The staff are very poorly paid and the work is challenging leading to high staff turnover and difficulty in recruiting and retaining suitable staff. Due to the nature of their disability many people with learning disabilities feel uncomfortable, nervous or confused with changes in care setting, diet or personnel. Often there is no recognition of the additional difficulties associated with a learning disability such as behavioural issues or other health problems and this can result in people with these difficulties being excluded from respite facilities even though it is their families that are most in need of respite. Caregivers felt that occupational and day service providers tended to prefer to accept the least disabled "clients" yet were geared to providing activities related to basic living skills.

Todd S, Jones S. **Looking at the future and seeing the past: The challenge of the middle years of parenting a child with intellectual disabilities**. Journal of Intellectual Disability Research 2005; 49(6): 389-404.

This paper reports on the results of interviews with 48 mothers of adolescents with intellectual disabilities. It reviews some of the literature and discusses some important issues. While most mothers of adolescents are looking forward to increased freedom as their children grow up, mothers of children with disabilities may find their lives becoming more challenging. In their work with mothers of young children with disabilities the authors had found that mothers aimed for a life that was "an ordinary family life" but as their children grow up parents' lives become more and more restricted compared to those of other parents with whom they now have little in common. When siblings leave home parents may lose the reliable sitters that made it possible for them go out. Lack of appropriate post school services may mean that mothers may face having to stay at home with their disabled adult son or daughter. Some mothers felt that this role should be valued and rewarded and that they would be lost if their child left home while others felt that their own aspirations were frustrated.

Davies J. **First Impressions: Emotional and practical support for families of a young child with a learning disability: A guide for practitioners and service commissioners**. London: The Mental Health Foundation, 2005. URL: http://www.learningdisabilities.org.uk/EasySiteWeb/getresource.axd?AssetID=14903&type=full&servicetype=Attachment

This report was commissioned to look at the emotional and practical needs of families who have a small child (aged up to five) with a learning disability. It found that there was a considerable variation in the amount of support and information families received depending on both where they lived and on the professionals involved. Some families got good help but others had to fight for a diagnosis in the first place and were then left to cope more or less on their own. The report includes accounts from families of their experiences, conclusions from a literature review on the topic and recommendations from an expert panel on the First Impressions advisory committee. It provides some good practice case studies and offers recommendations for improving practices and reducing stress for families.

Rees S, Cullen C, et al. **Learning Disabilities**. In: Stevens A, Rafferty J, Mant J, Simpson S, eds. Health Care Needs Assessment, First Series. 2 ed. Vol. 2. Abingdon, UK: Radcliffe, 2004. URL: http://www.hcna.bham.ac.uk/documents/HCNA_Vol2_chap17sh_6L.pdf

This very comprehensive publication addresses the social and health care needs of people with learning disabilities. (In the U.K. this is the preferred term for intellectual disability.) It emphasises the importance of considering health, social and education needs together, as well as the needs of the whole family. It covers categories of people with learning disabilities, prevalence and incidence, availability and effectiveness of services, models of care, target setting and information and research needs.

Meijer MM, Carpenter S, et al. **European manifesto on basic standards of health care for people with intellectual disabilities**. Journal of Policy and Practice in Intellectual Disabilities 2004; 1(1): 10-15.

This manifesto was the outcome of a conference organized by the Netherlands Society of Physicians for Persons with Intellectual Disabilities (NVAVG) and the European Association of Intellectual Disability Medicine (MAMH), in collaboration with the Erasmus Medical Center's Department of Specialist Training for Physicians for People with Intellectual Disabilities. It outlines the core elements of adequate health care for people with intellectual disabilities and offers guidance for European nations regarding addressing deficiencies in this area.

Robinson A, Richdale A. **Sleep problems in children with an intellectual disability: Parental perceptions of sleep problems and views of treatment effectiveness**. Child Health, Care and Development 2004; 30(2): 139-50.

This paper reports on two studies (with 149 and 243 participants) in which the parents of children aged between 3 and 18 years with a variety of disabilities completed questionnaires on the sleep problems of their children. Sleep problems were found to be common (25.5% and 36.2%) and to persist for many years (on average 6-9 years) but many parents did not seek treatment, and if they did, the advice and treatment received was very variable in its effectiveness. Behavioural treatment was not found to be any more effective than other treatments.

Redmond B, Richardson V. **Just getting on with it: Exploring the service needs of mothers who care for young children with severe / profound and life-threatening intellectual disability**. Journal of Applied Research in Intellectual Disabilities 2003; 16(3): 205-218.

This paper from Ireland reports on interviews with 17 mothers of children aged under 4 years with severe or profound intellectual disability, some of whom also had complex medical life-limiting conditions. It found that although caring for their children was complex and stressful the mothers wanted to care for their children care for at home. The mothers reported that gaining information on available services was a haphazard process and that the services offered were mostly unreliable, uncoordinated and difficult to access. The mothers wanted services in their own homes which would enable them to take short breaks or engage in part time employment.

Todd S, Jones S. **„Mum's the word!' Maternal accounts of dealings with the professional world**. Journal of Applied Research in Intellectual Disabilities 2003; 16: 229-244.

This paper from Wales reports on interviews with 30 mothers of young people with intellectual disability about their dealings with the professional and service worlds. Often these encounters were based on conflict and the mothers felt that their capabilities as mothers were under scrutiny. Mothers accepted advocacy for their children as something they were prepared to do but were hesitant to advocate for their own needs and aspirations for fear of being seen as selfish, and because they felt that doing so would undermine their credibility as advocates for their children.

Department of Health (U.K.). **Valuing People: A new strategy for learning disability for the 21st century: A white paper**. London: Department of Health (U.K.), 2001.

This white paper, which was the first major new initiative for 30 years, set out the U.K. Government's vision for people with a learning disability across a range of services. It is based on four key principles of rights, independence, choice, and inclusion. It covers a range of issues including health, housing and employment. Chapter 3 sets out proposals for maximizing opportunities for disabled children and supporting the transition of young people into adult life.

Routledge M, Sanderson H. **Valuing people: A new strategy for learning disability for the 21st century: Planning with people towards person centred approaches: Guidance for implementation groups**. London: Department of Health (U.K.), 2002. URL: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009374

This guidance document is intended to assist partnership boards in developing their local frameworks for person-centred planning as required by *Valuing people*. The eight chapters are entitled: Introduction; What is Person Centred Planning?; A Framework for Person Centred Planning; Empowering People with Learning Disabilities and their Families; The Role of Specialist Professionals; Person Centred Planning and Service Providers; Implementing Person Centred Planning; and Evaluating Person Centred Planning. The appendices contain details on a large number of useful resources.

The U.K. Department of Health funded a two and a half year research programme by the Norah Fry Research Centre at the University of Bristol to examine the outcomes of this strategy and to provide advice on good practice in learning disability services. The report produced as a result of this programme is:

"**Making Valuing People Work: Strategies for change in services for people with learning disabilities**", by Rachel Fyson and Linda Ward, published by The Policy Press and available from Marston Book Services, PO Box 269, Abingdon, Oxon OX14 4YN.

The latest UK government strategy for people with learning disabilities is:

Valuing people now: A new three-year strategy for people with learning disabilities (2009) which can be found at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377

U.S. Public Health Service. **Closing the Gap: A national blueprint for improving the health of individuals with mental retardation. Report of the Surgeon General's Conference on Health Disparities and Mental Retardation**. Washington DC, 2001. URL: http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=mretard

This report from the U.S. Surgeon General presents the national blueprint for improving the health of persons with mental retardation. It recognises that these people and their families often face enormous obstacles to achieving basic health care. At the Surgeon General's National Conference on Health Disparities and Mental Retardation in 2001 in Washington work groups developed a series of action steps, organised under six broad goals, to address this problem.

CEREBRAL PALSY

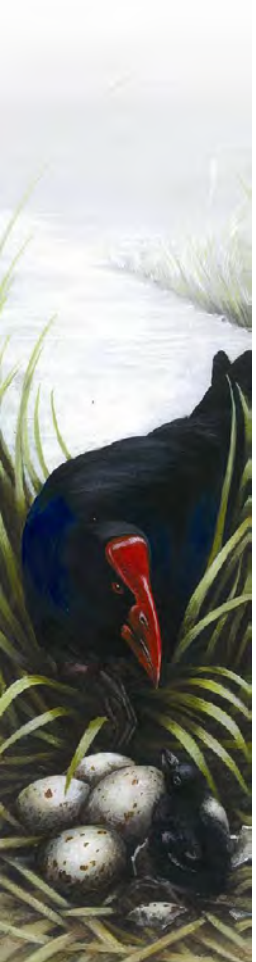
Introduction

Cerebral palsy refers to a group of disorders of movement or posture arising from a non-progressive insult to the central nervous system during early development. The insult may occur prior to, during or shortly after birth and while being non-progressive, its physical consequences can evolve over time [87]. The clinical presentation may also vary, with one Australian study [87] noting that of children with cerebral palsy in one cohort, ~ 84% had predominantly spastic cerebral palsy (characterised by weakness, increased muscle tone, overactive reflexes and a tendency to contractures), 8.3% had predominantly dyskinetic cerebral palsy (characterised by involuntary movements which disappear during sleep) and 6.6% had predominantly ataxic cerebral palsy (characterised by problems with coordination, gait and rapid movements of the distal extremities) [23]. In addition, while cerebral palsy refers solely to the motor impairment, features such as seizures, intellectual impairment and learning disabilities are also common [23].

Depending on their degree of motor impairment, children and young people with cerebral palsy require a variety of personal health care and disability support services, with the overall aim being to ensure a team approach which achieves the highest possible functioning within the family and community contexts. Physical and occupational therapy are beneficial in the management of motor impairments, with proper positioning and handling being necessary to minimise the difficulties associated with posture, trunk control and feeding. Passive and active exercises to stretch tight tendons may also be necessary to maintain normal alignment of bone, joint and soft tissue and to prevent contractures. Medical and surgical procedures may be necessary to correct contractures that do not respond to physiotherapy and to re-establish motor balance between opposing muscle groups, with innovations in this area evolving rapidly. In addition, a variety of equipment (e.g. walkers and standing frames, motorised wheel chairs, feeding tubes, computers to augment communication) and additional supports (e.g. speech therapy, medications, ophthalmology referrals, tailored educational programmes, respite care) may be required to meet the needs of children and their caregivers [88].

While there is no routinely collected data on the prevalence of cerebral palsy in New Zealand, overseas research suggests that the prevalence may have risen over time, from around 1.5 per 1,000 live births in the 1960s to around 2.5 per 1,000 in the 1990s, with the proportion of low birth weight babies increasing during this period, possibly as the result of increased survival amongst very premature babies [33]. With ½ of all cerebral palsy cases occurring in infants of normal birth weight however, and with asphyxiation at birth accounting for only a small percentage of cases, research has now turned to other exposures during pregnancy and immediately after birth (e.g. intrauterine infection / inflammation and perinatal coagulation disorders) as possible causes [89].

The following section reviews hospital admissions for children and young people with any mention of cerebral palsy in any of the first 15 diagnoses, as well as mortality for children and young people with cerebral palsy listed as either the main underlying cause of death, or as a contributory cause.



Data Source and Methods

Definition

1. Hospital Admissions and Mortality for Children and Young People with Cerebral Palsy

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions for Children and Young People Aged 0-24 Years with Cerebral Palsy (ICD-10-AM G80) in any of the first 15 diagnoses.

Denominator: Statistics New Zealand Estimated Resident Population

2. National Mortality Collection
Numerator: Mortality for Children and Young People Aged 0-24 Years with Cerebral Palsy (ICD-10-AM G80) listed as either the main underlying cause of death, or as a contributory cause.
Denominator: Statistics New Zealand Estimated Resident Population

Notes on Interpretation
Unless otherwise specified, this analysis focuses on hospital admissions and mortality for children and young people who had cerebral palsy listed in any of the first 15 diagnoses, or as a main underling or contributory cause of death (rather than on the subset of admissions or deaths where cerebral palsy was listed only as the primary diagnosis or main underlying cause of mortality). The rationale for this wider focus was the need to highlight the full spectrum of health issues experienced by children and young people with cerebral palsy, and their consequent requirement for health services. For example, during 2005-2009, only 5% of acute or arranged hospitalisations for children and young people with cerebral palsy had cerebral palsy listed as the primary diagnosis, with e.g. 10.8% being admitted for epilepsy or seizures. Similarly 42.4 % of admissions were from the waiting list, with a significant proportion being for orthopaedic procedures. The presence of a small number of hospital admissions in patients with cerebral palsy which were unrelated to their cerebral palsy (e.g. acute upper respiratory infections) however, may slightly overinflate the impact cerebral palsy has on acute service demand (see **Table 35** and **Table 36** to assess the likely contribution such conditions made to hospitalisation rates). If no mention of cerebral palsy was made in any of the first 15 diagnoses however, these cases were not included (even if the patient had been assigned a cerebral palsy related code on a previous admission).

Indicator Category Bookmark B

New Zealand Distribution and Trends

Distribution by Primary Diagnosis and Procedure

Acute and Arranged Admissions: In New Zealand during 2005-2009, only 4.98% of acute and arranged hospital admissions in children and young people with cerebral palsy (i.e. any mention of cerebral palsy in their first 15 diagnoses) had cerebral palsy listed as their primary diagnosis, with 10.8% of admissions being for epilepsy or convulsions and 14.5% being for respiratory infections / diseases collectively. Overall, acute and arranged admissions made up 57.6% of admissions for children and young people with cerebral palsy during this period (**Table 35**).

Waiting List Admissions: During the same period, 42.4% of admissions in children and young people with cerebral palsy were from the waiting list, with orthopaedic procedures accounting for 46.8% of waiting list admissions, and for 19.8% of all admissions in children and young people with cerebral palsy. Dental procedures and the insertion of gastrostomy tubes and buttons made a smaller contribution (**Table 36**).

Distribution by Age

Admissions and Mortality: In New Zealand during 2005-2009, hospital admissions for children and young people with cerebral palsy increased during infancy, reached a peak at 3-4 years of age, and thereafter gradually declined. In contrast, mortality was more evenly distributed across the age range, with a total of 72 children and young people aged 0-24 years dying from cerebral palsy during 2003-2007 (**Figure 21**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2005-2009, hospital admissions for children and young people with cerebral palsy were *significantly* higher for males and those living in average-more deprived (NZDep deciles 4-10) areas. Admission rates were similar for Māori, Pacific and European children and young people, but *significantly* lower for Asian children and young people (**Table 37**). Similar ethnic differences were seen during 2000-2009 (**Figure 22**).

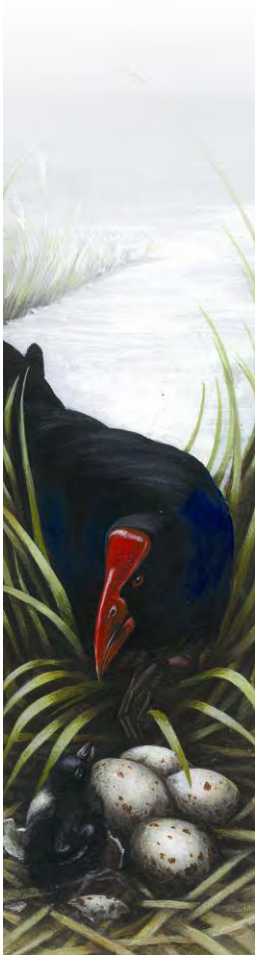


Table 35. Hospital Admissions in Children and Young People Aged 0-24 Years with Cerebral Palsy by Admission Type and Primary Diagnosis, New Zealand 2005-2009

Primary Diagnosis	Number: Total 2005-2009	Number: Annual Average	Rate per 100,000 Population	% of Admissions in those with Cerebral Palsy
Acute and Arranged Admissions by Primary Diagnosis				
Epilepsy, Status Epilepticus, Convulsions (G40-41, R56)	589	117.8	7.80	10.83
Cerebral Palsy (G80)	271	54.2	3.59	4.98
Influenza and Pneumonia (J10-J18)	202	40.4	2.68	3.72
Pneumonitis due to Food and Vomit (J690)	158	31.6	2.09	2.91
Acute Upper Respiratory Infections (J00-J06)	137	27.4	1.82	2.52
Other Respiratory Infections and Diseases (J20-J99)	292	58.4	3.87	5.37
Constipation (K590)	84	16.8	1.11	1.54
Other Diseases Digestive System (K00-K93)	166	33.2	2.20	3.05
Infectious and Parasitic Diseases (A00-B99)	161	32.2	2.13	2.96
Respite Care (Z755)	25	5.0	0.33	0.46
Other Factors Influencing Health Service Contact (Z00-Z99)	113	22.6	1.50	2.08
Complications of Surgical and Medical Care (T80-T88)	90	18.0	1.19	1.66
Other Diagnoses	846	169.2	11.21	15.56
Total Acute and Arranged Admissions	3,134	626.8	41.52	57.64
Total Waiting List Admissions	2,303	460.6	30.51	42.36
Total Admissions in those with Cerebral Palsy	5,437	1,087.4	72.03	100.00

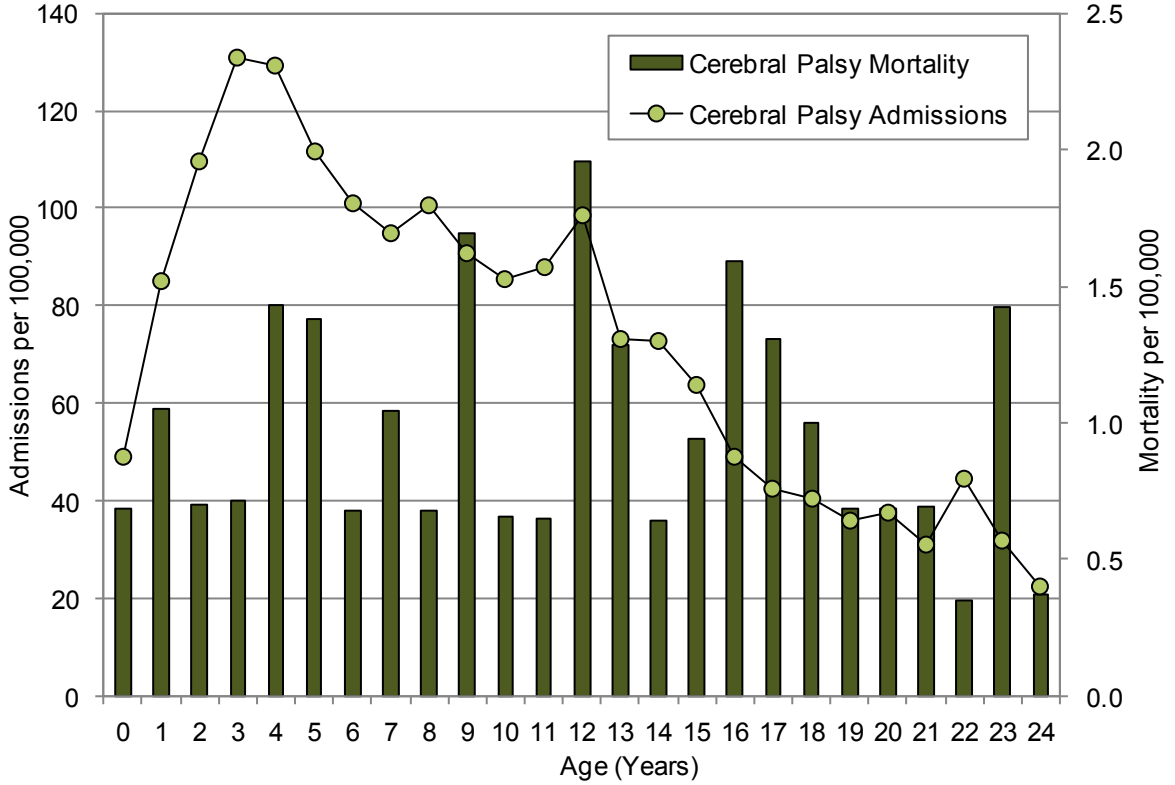
Source: Numerator: National Minimum Dataset, Acute and Arranged Admissions by primary diagnosis for children and young people with Cerebral Palsy listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population.

Table 36. Hospital Admissions in Children and Young People Aged 0-24 Years with Cerebral Palsy by Admission Type and Primary Procedure, New Zealand 2005-2009

Primary Procedure	Number: Total 2005-2009	Number: Annual Average	Rate per 100,000 Population	% of Admissions in those with Cerebral Palsy
Waiting List Admissions by Primary Procedure				
Injection into Joints or Other Synovial Cavities	487	97.4	6.45	8.96
Lengthening of Tendons	165	33.0	2.19	3.03
Osteotomy of Distal Femur	104	20.8	1.38	1.91
Anterior Release Hip Contracture (Unilateral)	101	20.2	1.34	1.86
Sequestrectomy of Femur	64	12.8	0.85	1.18
Open Tenotomy (Incision of Tendon)	49	9.8	0.65	0.90
Anterior Spinal Fusion, 1 Level	48	9.6	0.64	0.88
Removal of Pin, Screw or Wire	28	5.6	0.37	0.51
Other Procedures on Musculoskeletal System	32	6.4	0.42	0.59
Injection or Infusion of Therapeutic Substance	281	56.2	3.72	5.17
Tooth Extraction	94	18.8	1.25	1.73
Tooth Filling	56	11.2	0.74	1.03
Removal Dental Plaque or Stain	55	11.0	0.73	1.01
Other Dental Procedures	16	3.2	0.21	0.29
Insertion Percutaneous Endoscopic Gastrostomy (PEG) Tube	42	8.4	0.56	0.77
Insertion Percutaneous Non-Endoscopic Gastrostomy Button	27	5.4	0.36	0.50
Fundoplasty (Abdominal Approach)	38	7.6	0.50	0.70
Tonsillectomy and / or Adenoidectomy	28	5.6	0.37	0.51
Insertion of Intrauterine Device	24	4.8	0.32	0.44
MRI Brain	24	4.8	0.32	0.44
Other Procedures	459	91.8	6.08	8.44
No Procedure Listed	81	16.2	1.07	1.49
Total Waiting List Admissions	2,303	460.6	30.51	42.36
Total Acute and Arranged Admissions	3,134	626.8	41.52	57.64
Total Admissions in those with Cerebral Palsy	5,437	1,087.4	72.03	100.00

Source: Numerator: National Minimum Dataset, Waiting list admissions by primary procedure for children and young people with Cerebral Palsy listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population

Figure 21. Hospital Admissions (2005-2009) and Mortality (2003-2007) in New Zealand Children and Young People with Cerebral Palsy by Age



Source: Numerator Admissions: National Minimum Dataset, Hospital Admissions for children and young people with Cerebral Palsy listed in any of the first 15 diagnoses. Numerator Mortality: National Mortality Collection, Children and young people with Cerebral Palsy as the main underlying or contributory cause of death. Denominator: Statistics NZ Estimated Resident Population.

Table 37. Hospital Admissions for Children and Young People Aged 0-24 Years with Cerebral Palsy by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2005-2009

Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
Cerebral Palsy							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	46.8	1.00		Decile 1-2	48.1	1.00	
Decile 2	49.4	1.06	0.91 - 1.23	Decile 3-4	57.5	1.20	1.08 - 1.33
Decile 3	53.3	1.14	0.98 - 1.33	Decile 5-6	64.8	1.35	1.22 - 1.49
Decile 4	61.3	1.31	1.14 - 1.51	Decile 7-8	85.1	1.77	1.61 - 1.94
Decile 5	68.4	1.46	1.27 - 1.69	Decile 9-10	91.7	1.91	1.74 - 2.09
Decile 6	61.8	1.32	1.15 - 1.52	Prioritised Ethnicity			
Decile 7	86.9	1.86	1.62 - 2.13	Asian	30.0	0.39	0.35 - 0.45
Decile 8	83.5	1.79	1.57 - 2.04	European	76.4	1.00	
Decile 9	87.5	1.87	1.64 - 2.13	Māori	72.4	0.95	0.89 - 1.01
Decile 10	95.8	2.05	1.80 - 2.33	Pacific	81.9	1.07	0.98 - 1.17
Gender							
Female	61.7	1.00		Male	82.0	1.33	1.26 - 1.40

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Cerebral Palsy listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Rates are per 100,000. Rate Ratios are unadjusted.

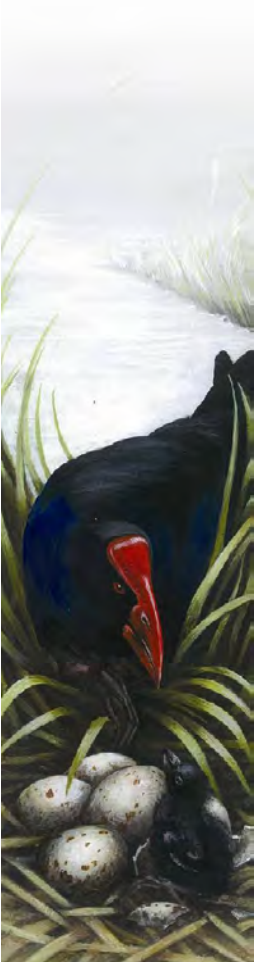
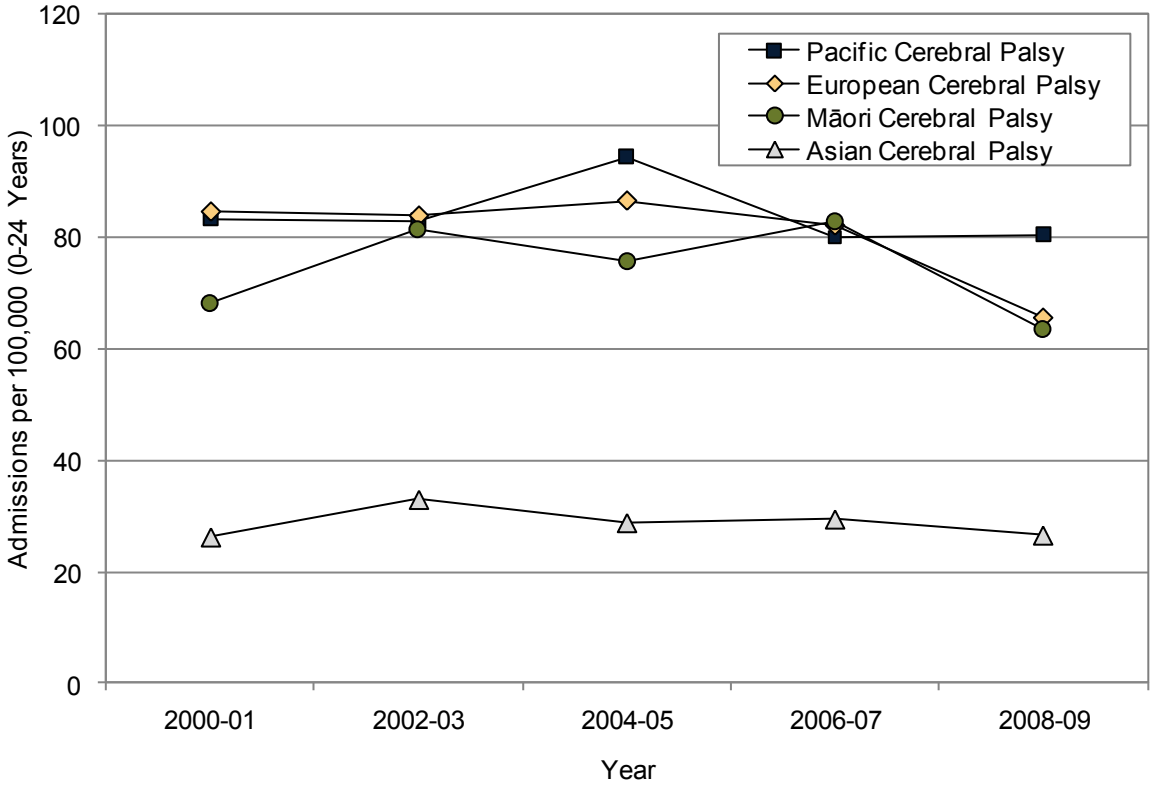


Figure 22. Hospital Admissions in Children and Young People Aged 0-24 Years with Cerebral Palsy by Prioritised Ethnicity, New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Cerebral Palsy listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised.

Taranaki Distribution and Trends

Taranaki Distribution and Trends

In Taranaki during 2005-2009, a total of 36 individual children and young people were admitted to hospital with cerebral palsy listed in any of the first 15 diagnoses. Admission rates per 100,000 population were *significantly* lower than the New Zealand average (RR 0.62 95% CI 0.50 – 0.77) (**Table 38**). Similar differences were seen during 2000-2009 (**Figure 23**).

Table 38. Hospital Admissions for Children and Young People Aged 0-24 Years with Cerebral Palsy, Taranaki vs. New Zealand 2005-2009

DHB	Total Number Individuals 2005-2009		Total Admissions 2005-2009	Average Annual Admissions per Individual	Admission Rate per 100,000 Total Population	Rate Ratio	95% CI
	(A)*	(B)*					
Cerebral Palsy							
Taranaki	35	36	82	0.46	44.8	0.62	0.50 - 0.77
New Zealand	1,664		5,437	0.65	72.0	1.00	

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Cerebral Palsy listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population. *Note: (A): Each individual only counted once in DHB in which they first reside (i.e. DHB total = NZ total); (B): Each individual counted once in each DHB in which they reside (i.e. the sum of DHB totals exceeds New Zealand total). Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

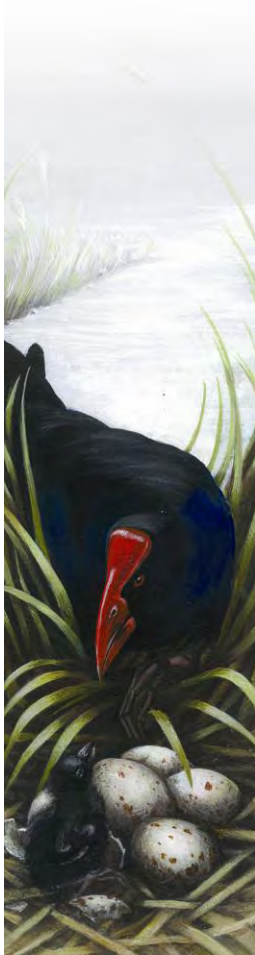
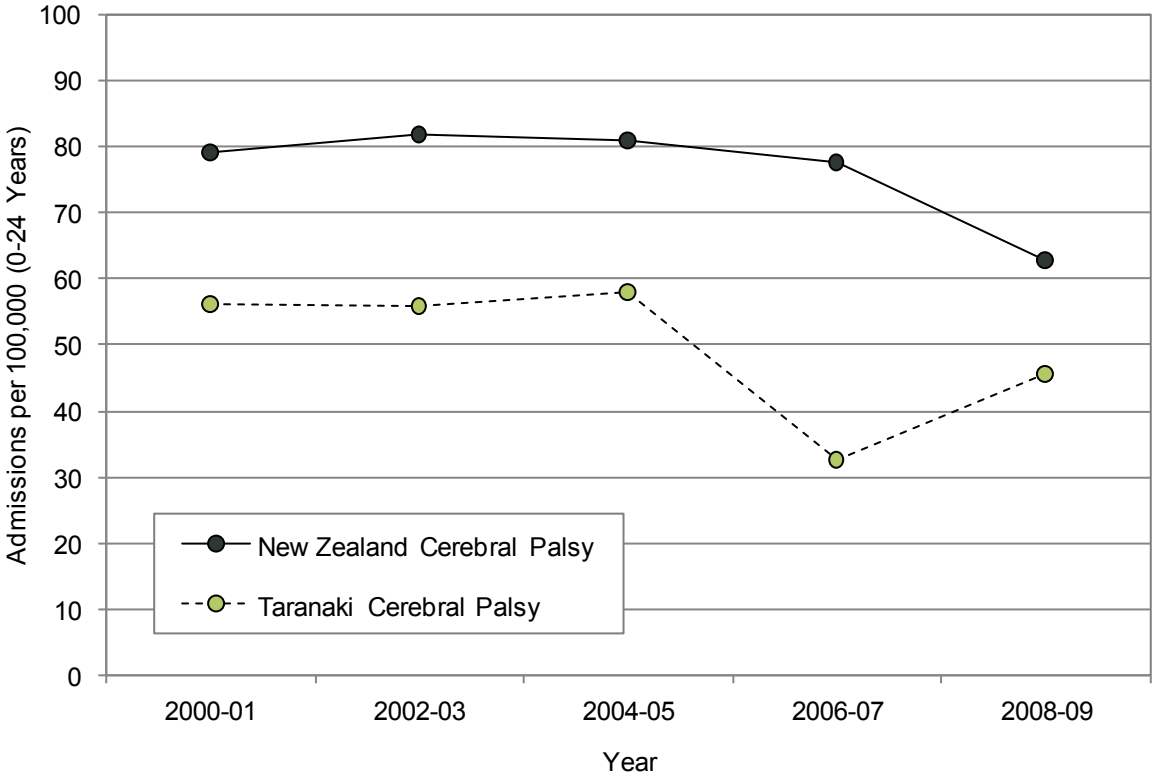


Figure 23. Hospital Admissions in Children and Young People Aged 0-24 Years with Cerebral Palsy, Taranaki vs. New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Cerebral Palsy listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Summary

In New Zealand during 2005-2009, only 4.98% of acute and arranged hospital admissions for children and young people with cerebral palsy had cerebral palsy listed as their primary diagnosis, with 10.8% of admissions being for epilepsy or convulsions and 14.5% being for respiratory infections / diseases. Overall, acute and arranged admissions accounted for 57.6% of admissions, while 42.4% were from the waiting list. Orthopaedic procedures accounted for 46.8% of waiting list admissions, and for 19.8% of all admissions in children and young people with cerebral palsy. During this period, hospital admissions were significantly higher for males and those living in average-more deprived (NZDep deciles 4-10) areas. Admission rates were similar for Māori, Pacific and European children and young people, but significantly lower for Asian children and young people.

In Taranaki during 2005-2009, a total of 36 individual children and young people were admitted to hospital with cerebral palsy listed in any of the first 15 diagnoses. Admission rates per 100,000 population were *significantly* lower than the New Zealand average (RR 0.62 95% CI 0.50 – 0.77). Similar differences were seen during 2000-2009.

Policy Documents and Evidence Based Reviews Relevant to the Management of Children and Young People with Cerebral Palsy

In New Zealand there is a paucity of policy documents which focus on managing the health needs of children and young people with cerebral palsy, although a number of reviews have considered these issues in the overseas context. These are considered in **Table 39**. In addition, **Table 34** on **Page 109** considers the health and educational needs of children and young people with developmental delays and intellectual disabilities.

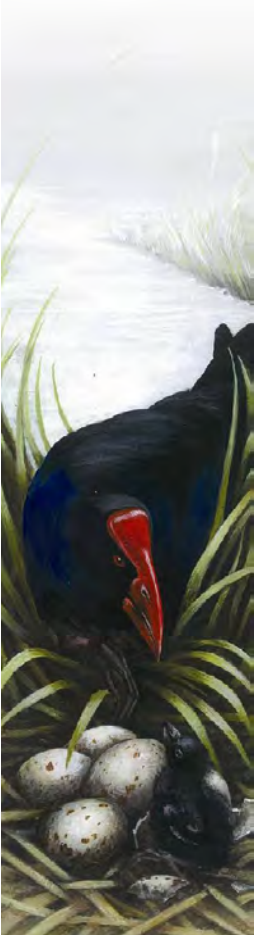


Table 39. Policy Documents and Evidence Based Reviews Relevant to the Management of Children and Young People with Cerebral Palsy

International Guidelines and Useful Websites
American Academy for Cerebral Palsy and Developmental Medicine http://www.aacpdm.org/index.php This organisation describes itself as "A global leader in the multidisciplinary scientific education of health professionals and researchers dedicated to the well-being of people with childhood-onset disabilities." It provides scientific information for health professionals and promotes excellence in research and services. It publishes the journal **Developmental Medicine & Child Neurology.** The following evidence reports can be found on the website http://www.aacpdm.org/publications/outcome/ : • A systematic review of the effectiveness of aerobic exercise interventions for children with cerebral palsy • A systematic review of the effects of casting on equinus in children with cerebral palsy • Effects of therapy for children with CP following botulinum toxin-A injections • Effects of Conductive Education for Cerebral Palsy • Effects of Intrathecal Baclofen for Spastic and Dystonic Cerebral Palsy • Effects of Neurodevelopmental Treatment (NDT) for Cerebral Palsy • Effects of Gastrostomy Feeding in Children with Cerebral Palsy • Effect of Surgical Adductor Releases for Hip Subluxation in Cerebral Palsy
CanChild Centre for Childhood Disability Research http://www.canchild.ca/en/ CanChild is a research and educational centre based at McMaster University in Ontario Canada, which conducts health services and systems research on child health issues that will make a difference for children and youth with physical, developmental and communication needs, and their families. It provides evidence-based information to improve the lives of children and youth with disabilities and their families. Information about Cerebral Palsy including reviews of the evidence for various forms of therapy can be found at: http://www.canchild.ca/en/childrenfamilies/cerebralpalsy.asp
Heinen F, Desloovere K, et al. **The updated European Consensus 2009 on the use of Botulinum toxin for children with cerebral palsy**. European Journal of Paediatric Neurology 2010; 14(1): 45-66. This guideline was produced by an interdisciplinary group consisting of both clinical experts in the field of movement disorders and experienced Botulinum toxin users. It summarises the current understanding regarding the use of Botulinum toxin in the treatment of children with Cerebral Palsy (CP). It is based on both published and practice-based evidence. Data from 36 institutions in 9 European countries were pooled to establish a clinical evidence base. In part 2 of the guideline there are Gross Motor Function Measure (GMFM) and Gross Motor Function Classification System (GMFCS) based Motor Development Curves. These provide a graphical framework showing how to treat the motor disorders in children with CP. These curves are intended to facilitate communication between parents, therapists and medical doctors regarding: (1) achievable motor function, (2) realistic goal-setting and (3) treatment perspectives.
Ashwal S, Russman BS, et al. **Practice parameter: Diagnostic assessment of the child with cerebral palsy: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society**. Neurology 2004; 62(6): 851-63. URL: http://www.neurology.org/cgi/content/abstract/62/6/851 The authors of this practice parameter considered the available evidence relevant to the assessment of the child suspected of having cerebral palsy (CP). Their recommendations, based on a 4-tiered classification of evidence (Level A is the most reliable) are: an MRI should be performed in preference to a CT (Level A); the routine use of metabolic and genetic studies is not justified (Level B) but they should be considered if the clinical history or findings on neuroimaging do not reveal a specific structural abnormality or if there are additional and atypical features in the history or clinical examination (Level C). An underlying genetic or metabolic aetiology should also be considered if a brain malformation is detected. Due to the incidence of cerebral infarction in children with hemiplegic CP, testing for coagulation disorders should be considered although the evidence is insufficient to indicate precisely which tests should be used. (Level B). Unless there are features suggestive of epilepsy or a related syndrome an EEG is not recommended (Level A). Screening for the deficits commonly associated with CP including mental retardation, vision and hearing impairments, speech and language disorders and oral-motor dysfunction should be included in the initial assessment (Level A).
Cooley WC, Committee on Children With Disabilities. **Providing a primary care medical home for children and youth with cerebral palsy**. Pediatrics 2004; 114(4): 1106-13. This clinical report highlights the value of a primary care medical home, which can initiate, coordinate and monitor the many services and personnel required by children with cerebral palsy and their families. These include paediatric medical and surgical care, various therapists and community developmental and educational teams. Families need to form a reliable long-term alliance with the medical home for information, support and advocacy. The report provides background information on cerebral palsy and a brief review of the care issues specific to cerebral palsy. Some of the information is specific to the American context but the general principles are widely applicable.

Systematic and Other reviews from the International Literature
Katalinic OM, Harvey LA, et al. **Stretch for the treatment and prevention of contractures**. Cochrane Database of Systematic Reviews 2010(9): CD007455. Contractures are a common complication of neurological conditions, including cerebral palsy and musculoskeletal conditions. This review aimed to determine the effect of stretch in reducing contractures. The authors of the review identified 35 relevant studies (RCTs and controlled clinical trials, both published and unpublished) with a total of 1391 participants, none of which lasted longer than 7 months. They concluded that stretch does not have clinically important benefits for joint mobility in people who have, or are at risk of getting, contractures as a result of neurological or non-neurological conditions. In addition, stretch was found to have little or no effect on pain, spasticity, activity limitation, participation restriction or quality of life.
Hoare BJ, Wallen MA, et al. **Botulinum toxin A as an adjunct to treatment in the management of the upper limb in children with spastic cerebral palsy** (UPDATE). Cochrane Database of Systematic Reviews 2010(1): CD003469. The authors of this review identified ten RCTs which compared Botulinum toxin A (BoNT-A) or BoNT-A injection plus occupational therapy with other types of treatment (including no treatment or placebo) for managing upper limb spasticity in children with cerebral palsy. They found that there was good evidence to support the use of BoTN-A as an adjunct in the management of upper limb spasticity however, they stated that it should not be used alone but in combination with planned occupational therapy. Further research is needed to determine the children most likely to respond, long term outcomes, the most effective dosages, dilution, volumes and timing of BoTN-A injections as well as the most effective adjunct therapies, their frequency and intensity.
Simpson DM, Gracies JM, et al. **Assessment: Botulinum neurotoxin for the treatment of spasticity (an evidence-based review): Report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology**. Neurology 2008; 70(19): 1691-8. In the parts of this review relevant to children the authors considered the evidence relating to the use of Botulinum toxin (BoTN) for the treatment of spasticity in various muscle groups. Articles included in the review were classified as Class I through IV using the AAN guideline process. (Class I trials are randomized, controlled clinical trials with masked or objective outcome assessment in a representative population.) There were six class I trials with 376 participants investigating the use of BoTN in children. The authors concluded that the use of BoTN injections in gastrocnemius-soleus muscles is established as effective in the treatment of spastic equinus in patients with CP (four Class I studies). They stated that the evidence for the use of BoTN in treating adductor spasticity and for pain control in children undergoing adductor-lengthening surgery was insufficient (one Class I study each) but stated that such treatment should be considered. They also stated that BoTN should be considered as a treatment option for upper extremity spasticity although this was supported only by two Class II studies and one Class III study.
Verschuren O, Ketelaar M, et al. **Exercise programs for children with cerebral palsy: A systematic review of the literature**. American Journal of Physical Medicine & Rehabilitation 2008; 87(5): 404-17. This review considered all kinds of exercise programmes which focussed on cardiovascular fitness (aerobic or anaerobic capacity) and/or lower-extremity muscle strength in children with cerebral palsy (CP). It aimed to determine what studies have been done on these programmes, what were the measures used in the studies to assess the effectiveness of the programmes and what was the methodological quality of the studies. The authors identified 20 studies which they considered to be of low methodological quality. However, they noted that it appeared that children with CP may benefit from improved exercise programmes that focus on cardiovascular fitness, lower extremity muscle strength or a combination of both. They also stated that there is a need to evaluate exercise programmes in terms of their efficacy in improving the daily activity and participation level of children with CP and increasing their self-competence or quality of life rather than just according to measures based on the International Classification of Function, Disability and Health body function and activity level. Centre for Reviews and Dissemination. **Exercise Programs for Children with Cerebral Palsy: A Systematic Review of the Literature.** [Abstract 12008103807] Database of Abstracts of Reviews of Effects 2009(3). URL: http://www.crd.york.ac.uk/CRDWeb/ShowRecord.asp?ID=12008103807 The CRD reviewers of the above paper considered that the authors' conclusions were appropriately cautious given the quality of the evidence and that their conclusions were likely to be reliable.
Doyle LW, Crowther CA, et al. **Magnesium sulphate for women at risk of preterm birth for neuroprotection of the fetus**. Cochrane Database of Systematic Reviews 2009(1): CD004661. Based on a review of five RCTs involving 6145 babies the authors of this review found that antenatal magnesium sulphate given to women at risk of preterm birth led to a substantial reduction in the risk of cerebral palsy for their child. (Relative risk (RR) 0.68, 95% confidence interval (CI) 0.44-0.85.) They also found that the rate of substantial gross motor dysfunction was significantly reduced. (RR 0.61, 95% CI 0.44-0.85, 4 trials 5980 infants.) They did not find a significant effect on mortality or on other neurological impairments or disabilities in the first few years of life. The use of magnesium sulphate was associated with maternal side effects including flushing, sweating, nausea, vomiting headaches and palpitations but not with major maternal complications.

National Institute for Health & Clinical Excellence. **Selective Dorsal Rhizotomy for Spasticity In Cerebral Palsy**. National Institute for Health & Clinical Excellence, 2006. URL: http://www.nice.org.uk/nicemedia/live/11220/31555/31555.pdf

Selective dorsal rhizotomy (SDR) is a major surgical procedure on the lower spine in which some of the small rootlets of the spinal sensory nerves are cut. After the procedure patients require 3-12 months of intensive physiotherapy and patients who were able to walk prior to surgery may need to learn to walk again. According to this brief guidance document selective dorsal SDR is safe but there is evidence that it is of only limited efficacy. The available evidence reviewed included a meta-analysis of three RCTs comparing physiotherapy and SDR with physiotherapy alone which found that physiotherapy plus SDR produced an additional 4% improvement in gross motor function compared with physiotherapy alone. Two non-randomised studies and two case series are also discussed briefly. Further details of the evidence on which this document is based can be found is given in the publication „Interventional procedure overview of selective dorsal rhizotomy for spasticity in cerebral palsy', February 2006, which is available from: www.nice.org.uk/IP318overview

Pennington L, Goldbart J, et al. **Speech and language therapy to improve the communication skills of children with cerebral palsy**. Cochrane Database of Systematic Reviews 2004(2): CD003466.

This review included 11 studies, seven of which evaluated treatment given directly to children and four of which investigated the effects of training for communication partners. Studies were selected for inclusion if they were experimental studies containing an element of control. Methodological flaws prevented definite conclusions being drawn about the effectiveness of therapy and maintenance of communication skills was not thoroughly investigated in the studies. The authors concluded that firm evidence for the benefit of speech language therapy for children with cerebral palsy has not been demonstrated however, they noted positive trends in communication with therapy and did not recommend any change in practice.

Steultjens EM, Dekker J, et al. **Occupational therapy for children with cerebral palsy: A systematic review**. Clinical Rehabilitation 2004; 18(1): 1-14.

This review reports on 17 studies including seven RCTs, one of which was considered to be of high quality. The authors found that there was insufficient evidence for the efficacy of occupational therapy in all intervention categories because of the low methodological quality of the studies. They stated that this may be due to the difficulties of conducting efficacy research in children with cerebral palsy and they recommended that further research should critically reflect on issues of methodology.

Sleigh G, Sullivan PB, et al. **Gastrostomy feeding versus oral feeding alone for children with cerebral palsy**. Cochrane Database of Systematic Reviews 2004(2):CD003943.

Children with cerebral palsy can have significant disability in the areas of sucking, chewing and swallowing which puts them at risk of under nutrition and of aspirating food into the lungs. The authors of this review aimed to assess the benefits or harms that may occur as result of feeding by gastrostomy or jejeunostomy tube compared to oral feeding alone. They found that there have been no randomised controlled trials addressing this issue and that there is therefore no reliable evidence from which to draw conclusions about benefits or otherwise of this technique. The authors provide a brief review of other (non-RCT) studies on this topic and of the difficulties and costs for both parents and the health services associated with gastrostomy feeding.

Other Relevant Publications

Gough M. **Continuous postural management and the prevention of deformity in children with cerebral palsy: An appraisal**. Developmental Medicine & Child Neurology 2009; 51(2): 105-10.

Continuous postural management programmes are common practice for children with cerebral palsy (CP) in Gross Motor Function Classification System levels IV and V. They aim to prevent musculoskeletal deformity. There is a lack of evidence to support this practice and it is possible that those children with CP who are most likely to develop deformity may be those least able to comply with a continuous postural management programme. These programmes are demanding for the child and his or her family both in time and discomfort, and the implications of this are discussed within the framework of the International Classification of Functioning, Disability and Health. It is suggested that there should be a shift in the focus of the use of postural management away from an emphasis on body structure and towards the environment and participation of the child with CP.

Raina P, O'Donnell M, et al. **The health and well-being of caregivers of children with cerebral palsy**. Pediatrics 2005; 115(6): e626-36.

This paper reports on a study of the families of 488 children with cerebral palsy in Ontario, Canada. It found that the psychological and physical health of caregivers, who were primarily mothers, was strongly influenced by both child behaviour and caregiving demands. The support of extended family, friends and neighbours was less important than that provided by the immediate family working closely together. The authors state that their study supports the use of biopsychosocial frameworks that are family centred rather than simply technical and short-term rehabilitation interventions that are focused primarily on the child. They also suggest that providing parents with cognitive and behavioural strategies to manage their child's behaviours may have the potential to improve caregiver health.

AUTISM AND OTHER PERVASIVE DEVELOPMENTAL DISORDERS

Introduction

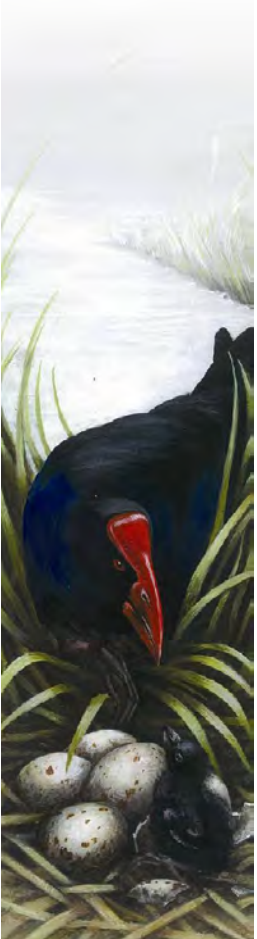
Pervasive Developmental Disorders comprise a group of developmental disorders characterised by poor or absent communication, social isolation and unusual behaviours. They include Autism, Asperger Syndrome, Pervasive Developmental Disorder NOS, Rett Syndrome and Childhood Disintegrative Disorder. Of these, autism is most studied and is characterised by severe difficulties with social interaction and communication and with behaviours and interests that are restricted or stereotyped. Onset is usually <3 years, with delayed language development being a common reason for presentation. Many children with autism never speak, or if they do so their language often has unusual intonation, echolalia (a repetition of what is said) or pronoun reversal. Other features include impaired eye gaze, a lack of social reciprocity, limited or absent peer relationships and difficulties in developing imaginative play. Children are often pre-occupied with non-functional features of objects, such as taste or smell and stereotyped movements are often present (e.g. hand flapping or finger flicking) [90].

Early intervention improves outcomes for children with autism. Management is primarily educational. While programmes vary in nature, the overall aims of treatment are usually to foster growth in areas of communication, cognition and self help skills, as well as to reduce problem behaviours which interfere with learning. Programmes often draw on procedures from special education and behavioural psychology. Occasionally pharmacological treatments are used to manage problem behaviours and to enhance children's participation in educational programmes. Over time a large number of alternative treatments have also been put forward, although evidence for the efficacy of many is often limited or non-existent [90].

At present the cause of autism remains unknown, although higher rates of seizures, persistent primitive reflexes and cognitive disability suggest central nervous system involvement. A genetic basis is also likely, as recurrence rates in families are high, but the mode of transmission remains unknown [90]. While there have been reports of large increases in Autism Spectrum Disorders over the past 40 years (estimates in the 1960s of ~4 per 10,000 contrast with more recent estimates of 30-60 per 10,000), some of these differences are likely due to increased ascertainment and a broadening of the diagnostic concept to include a greater number of children with normal IQs [91].

At present there is no routine information on the prevalence of Autism or Asperger Syndrome in New Zealand, although a recent estimate from the Statistics NZ Household Disability survey suggested that 2,100 NZ children may have Autism or Asperger Syndrome (personal communication Phillipa Clark 2006) giving a prevalence of 24.8 per 10,000. Similarly, a recent estimate from the Nelson Marlborough Region suggested a prevalence of 46 per 10,000, with 56% having Autism, 30% having Asperger Syndrome and 14% having a non specified Pervasive Developmental Disorder [34]. Overseas, some estimates (based on parental report) have placed the prevalence as high as 110 per 10,000 [35].

The following section uses the National Minimum dataset to review hospital admissions for children and young people with any mention of Autism or Other Pervasive Developmental Disorders in any of the first 15 diagnoses.



Data Source and Methods

Definition

1. Hospital Admissions for Children and Young People with Autism and Other Pervasive Developmental Disorders

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions for Children and Young People Aged 0-24 Years with Autism and Other Pervasive Developmental Disorders (ICD-10-AM F84) in any of the first 15 diagnoses.

Denominator: Statistics New Zealand Estimated Resident Population

Notes on Interpretation

Unless otherwise specified, this analysis focuses on hospital admissions for children and young people who had autism or other pervasive developmental disorders listed in any of the first 15 diagnoses (rather than on the subset of admissions where autism or other pervasive developmental disorders were listed only as the primary diagnosis). The rationale for this wider focus was the fact that the majority of children and young people with pervasive developmental disorders were not hospitalised primarily as a result of their pervasive developmental disorder per se, but rather for a range of other diagnoses, some of which were potentially more likely as a result of their pervasive developmental disorder, and some which were unrelated. For example, during 2005-2009, only 12.1% of hospitalisations for children and young people with autism or other pervasive developmental disorders had these diagnoses listed as the primary diagnosis, with 20% being admitted for dental caries or other oral health related problems, and 10% for epilepsy or convulsions. If no mention of pervasive developmental disorders was made in any of the first 15 diagnoses however, these cases were not included (even if the patient had been assigned a pervasive developmental disorder related code on a previous admission).

Further, as many children and young people with autism and other pervasive developmental disorders are managed predominantly in the outpatient or primary care setting (e.g. in contrast to cystic fibrosis where frequent hospitalisation often occur), it is likely that the analysis of hospital admission data presented in this section significantly underestimates the number of children and young people with autism or other pervasive developmental disorders. The rationale for the methodology used however, was the absence of other more reliable sources of information on children and young people with these diagnoses.

Indicator Category Bookmark B

New Zealand Distribution and Trends

Distribution by Primary Diagnosis

In New Zealand during 2005-2009, autism or other pervasive developmental disorders were listed as the primary diagnosis in only 12.1% of hospitalisations for children and young people with pervasive developmental disorders (i.e. with these conditions listed in any of the first 15 diagnoses). Of this 12.1%, 61.9% had childhood autism listed as the primary diagnosis, while 34.0% had pervasive developmental disorder NOS and 4.2% had other pervasive developmental disorders listed as the primary diagnosis. Overall, 20.2% of admissions in children and young people with pervasive developmental disorders were for dental caries or other oral health problems, while a further 9.9% were for epilepsy or convulsions (**Table 40**).

Distribution by Age

Admissions and Mortality: In New Zealand during 2005-2009, hospital admissions for children and young people with pervasive developmental disorders increased rapidly during the preschool years, reached a peak at 4-6 years of age and then declined (**Figure 24**). During 2003-2007, one death occurred where the main underlying cause of death was listed as a pervasive developmental disorder, with this young person being in their late teens.

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2005-2009, hospital admissions for children and young people with pervasive developmental disorders were *significantly* higher for males and for European than for Māori, Pacific or Asian children and young people. No consistent socioeconomic gradients were evident however, with admission rates being similar for those living in the most and least deprived NZDep areas (**Table 41**). Similar ethnic differences were seen during 2000-2009 (**Figure 25).**

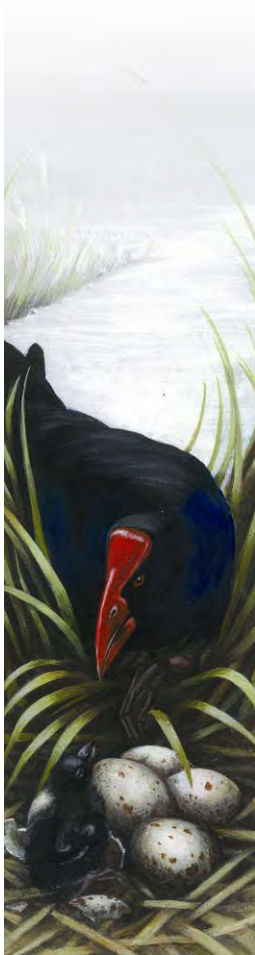
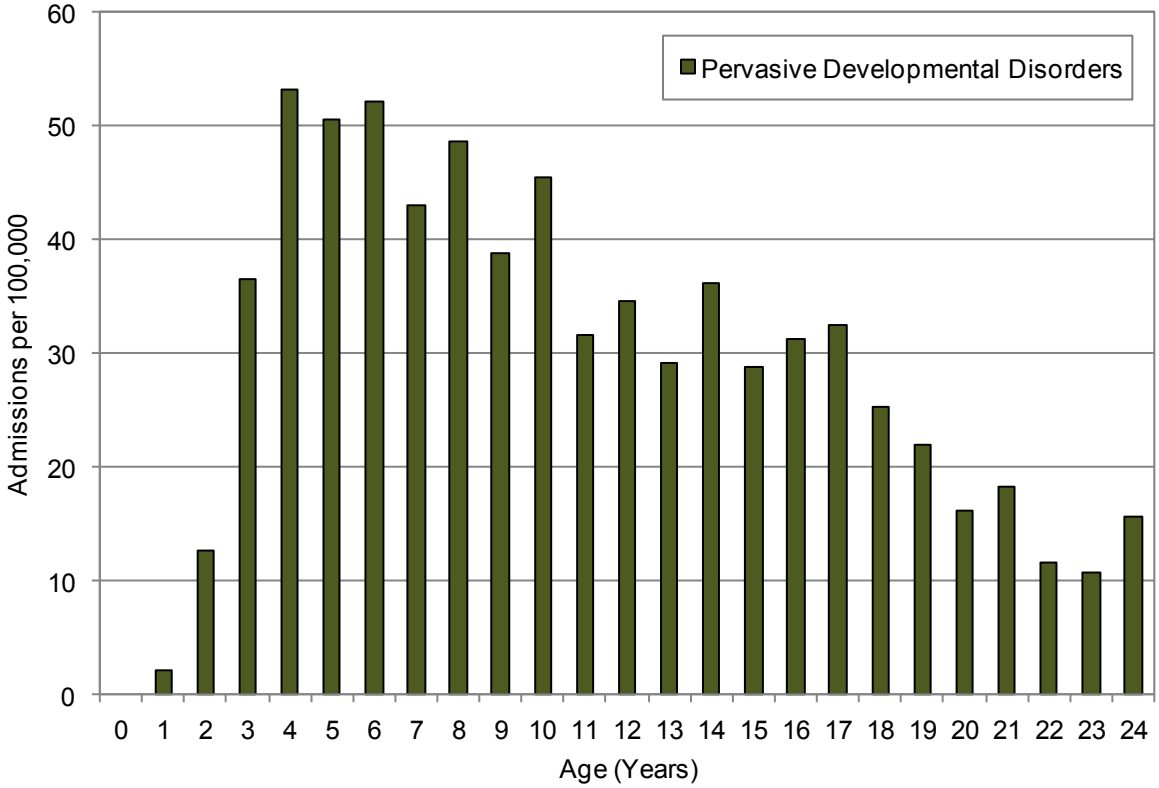


Table 40. Hospital Admissions for Children and Young People Aged 0-24 Years with Autism or Other Pervasive Developmental Disorders by Primary Diagnosis, New Zealand 2005-2009

Primary Diagnosis	Number: Total 2005-2009	Number: Annual Average	Rate per 100,000 Population	% of Admissions in those with Autism or Other Pervasive Developmental Disorders
Autism and Other Pervasive Developmental Disorders				
Childhood Autism (F840)	164	32.8	2.2	7.5
Pervasive Developmental Disorder NOS (F849)	90	18.0	1.2	4.1
Other Autism and Other Pervasive Developmental Disorders (F848)	11	2.2	0.1	0.5
Total Autism and Other Pervasive Developmental Disorders	265	53.0	3.5	12.1
Other Diagnoses				
Dental Caries (K02)	352	70.4	4.7	16.1
Other Dental and Oral Health Issues (K00-K01, K03-K14)	89	17.8	1.2	4.1
Epilepsy and Status Epilepticus (G40-G41)	155	31.0	2.1	7.1
Unspecified Convulsions (R568)	62	12.4	0.8	2.8
Respiratory Infections and Diseases (J00-J99)	105	21.0	1.4	4.8
Schizophrenia, Schizotypal and Delusional Disorders (F20-F29)	60	12.0	0.8	2.7
Mood Disorders (F30-39)	56	11.2	0.7	2.6
Other Mental and Behavioural Disorders (Remainder F00-F99)	87	17.4	1.2	4.0
Constipation (K590)	50	10.0	0.7	2.3
Infectious and Parasitic Diseases (A00-B99)	44	8.8	0.6	2.0
All Other Diagnoses	865	173.0	11.5	39.5
Total Other Diagnoses	1,925	385.0	25.5	87.9
Total	2,190	438.0	29.0	100.0

Source: Numerator: National Minimum Dataset: Hospital Admissions by primary diagnosis for children and young people with Autism or Other Pervasive Developmental Disorders listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Figure 24. Hospital Admissions for Children and Young People with Autism or Other Pervasive Developmental Disorders by Age, New Zealand 2005-2009



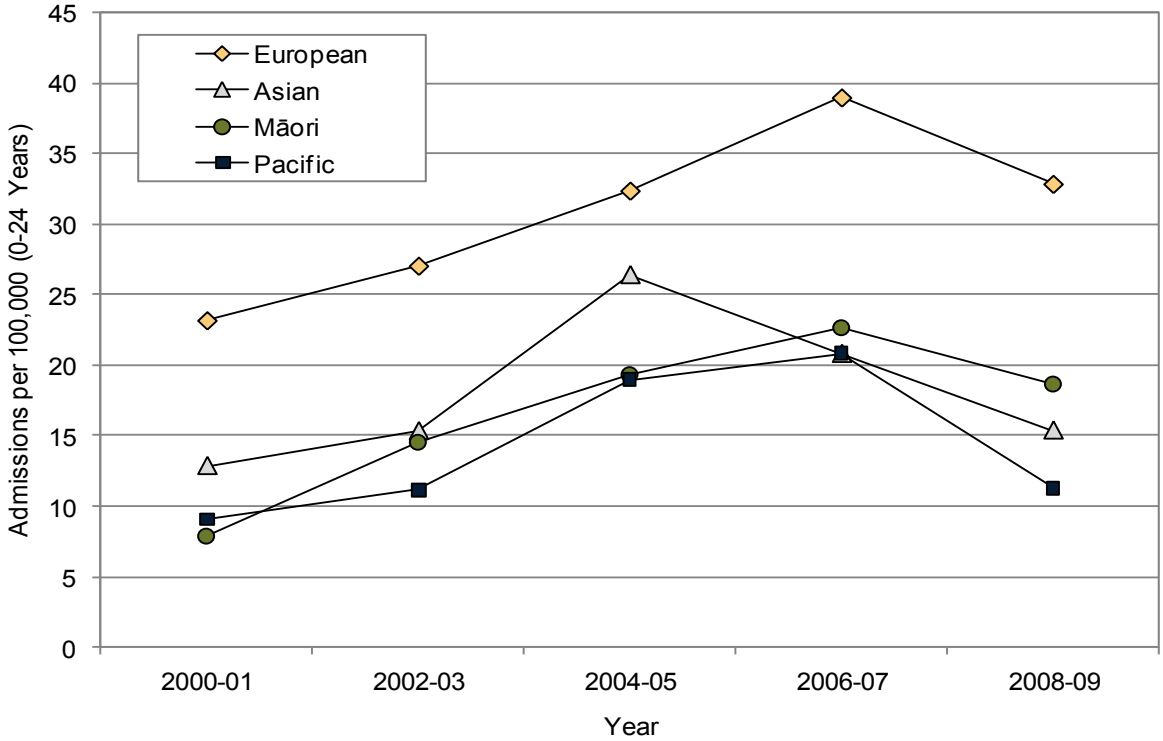
Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Autism or Other Pervasive Developmental Disorders listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Table 41. Hospital Admissions for Children and Young People Aged 0-24 Years with Autism or Other Pervasive Developmental Disorders by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2005-2009

Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
Autism and Other Pervasive Developmental Disorders							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	26.1	1.00		Decile 1-2	24.8	1.00	
Decile 2	23.5	0.90	0.73 - 1.11	Decile 3-4	27.0	1.09	0.94 - 1.26
Decile 3	30.6	1.17	0.96 - 1.44	Decile 5-6	29.1	1.17	1.02 - 1.36
Decile 4	23.8	0.91	0.74 - 1.12	Decile 7-8	35.5	1.43	1.25 - 1.64
Decile 5	30.0	1.15	0.94 - 1.41	Decile 9-10	26.6	1.07	0.94 - 1.23
Decile 6	28.3	1.08	0.89 - 1.32	Prioritised Ethnicity			
Decile 7	31.9	1.22	1.01 - 1.49	Asian	19.5	0.55	0.47 - 0.65
Decile 8	38.5	1.48	1.23 - 1.77	European	35.4	1.00	
Decile 9	30.5	1.17	0.97 - 1.41	Māori	20.2	0.57	0.51 - 0.64
Decile 10	22.8	0.87	0.72 - 1.07	Pacific	16.3	0.46	0.38 - 0.56
Gender							
Female	13.2	1.00		Male	44.2	3.34	3.02 - 3.69

Source: Numerator National Minimum Dataset, Hospital Admissions for children and young people with Autism or Other Pervasive Developmental Disorders listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Rates are per 100,000. Rate Ratios are unadjusted.

Figure 25. Hospital Admissions for Children and Young People Aged 0-24 Years with Autism or Other Pervasive Developmental Disorders by Prioritised Ethnicity, New Zealand 2000-2009



Source: Numerator National Minimum Dataset, Hospital Admissions for children and young people with Autism or Other Pervasive Developmental Disorders listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised

Taranaki Distribution and Trends

Taranaki Distribution and Trends

In Taranaki during 2005-2009, a total of 34 individual children and young people were admitted to hospital with autism or other pervasive developmental disorders listed in any of the first 15 diagnoses. Admission rates per 100,000 population were not *significantly* different from the New Zealand average (RR 0.87 95% CI 0.65 – 1.16) (**Table 42**). During 2000-2009, while there were some year to year variations, overall admission rates for those with autism in Taranaki remained relatively static, while rates nationally increased. Thus while rates were initially higher than the New Zealand average during the early 2000s, by 2004-2009, rates were similar to the national average (**Figure 26**).

Table 42. Hospital Admissions for Children & Young People Aged 0-24 Years with Autism or Other Pervasive Developmental Disorders, Taranaki vs. New Zealand 2005-2009

DHB	Total Number Individuals 2005-2009		Total Admissions 2005-2009	Average Admissions per Individual per Year	Admission Rate per 100,000 Total Population	Rate Ratio	95% CI
	(A)*	(B)*					
Autism and Other Pervasive Developmental Disorders							
Taranaki	34	34	46	0.27	25.1	0.87	0.65 - 1.16
New Zealand	1,335		2,190	0.33	29.0	1.00	

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Autism or Other Pervasive Developmental Disorders listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. *Note: (A): Each individual only counted once in DHB in which they first reside (i.e. DHB total = NZ total); (B): Each individual counted once in each DHB in which they reside (i.e. the sum of DHB totals exceeds New Zealand total). Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

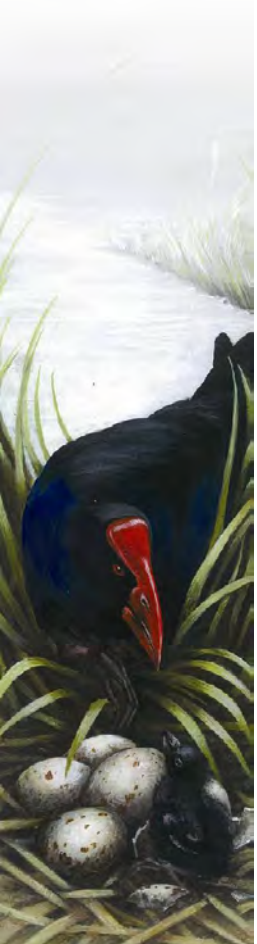
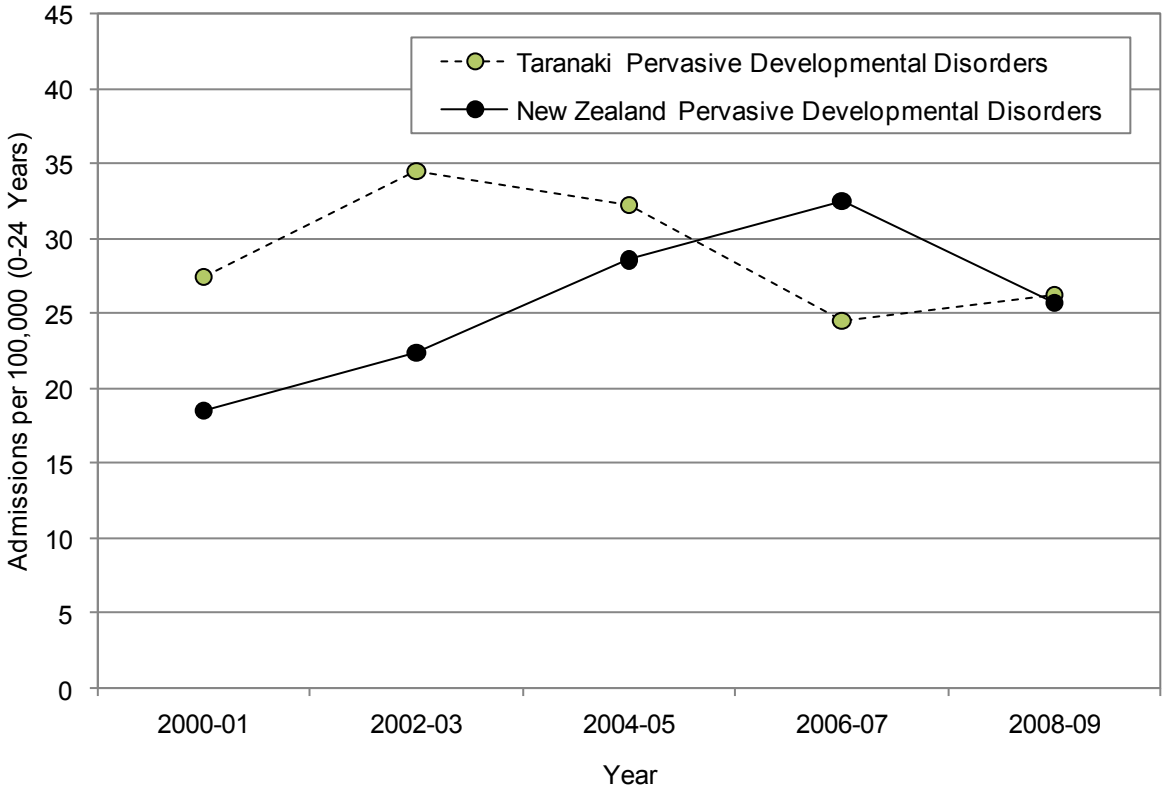


Figure 26. Hospital Admissions for Children and Young People Aged 0-24 Years with Autism or Other Pervasive Developmental Disorders, Taranaki vs. New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Autism or Other Pervasive Developmental Disorders listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Summary

In New Zealand during 2005-2009, autism or other pervasive developmental disorders were listed as the primary diagnosis in only 12.1% of hospitalisations for children and young people with pervasive developmental disorders. Of this 12.1%, 61.9% had childhood autism listed as the primary diagnosis, while 34.0% had pervasive developmental disorder NOS and 4.2% had other pervasive developmental disorders listed. Overall, 20.2% of admissions in children and young people with pervasive developmental disorders were for dental caries or other oral health problems, while a further 9.9% were for epilepsy or convulsions. Hospital admissions were *significantly* higher for males and for European than for Māori, Pacific and Asian children and young people. No consistent socioeconomic gradients were evident however, with admission rates being similar for those living in the most and least deprived NZDep areas.

In Taranaki during 2005-2009, a total of 34 individual children and young people were admitted to hospital with autism or other pervasive developmental disorders listed in any of the first 15 diagnoses. Admission rates per 100,000 population were not *significantly* different from the New Zealand average (RR 0.87 95% CI 0.65 – 1.16). During 2000-2009, while there were some year to year variations, overall admission rates for those with autism in Taranaki remained relatively static, while rates nationally increased. Thus while rates were initially higher than the New Zealand average during the early 2000s, by 2004-2009, rates were similar to the national average.

Policy Documents and Evidence Based Reviews Relevant to the Management of Pervasive Developmental Disorders

In New Zealand, the NZ Autism Spectrum Guideline provides advice on the management of children and young people with pervasive developmental disorders and this is briefly considered in **Table 43**, along with a range of international guidelines and reviews which consider these issues in the overseas context. In addition, **Table 34** on **Page 109** considers the health and educational needs of children and young people with developmental delays and intellectual disabilities.

Table 43. Local Policy Documents and Evidence Based Reviews Relevant to the Management of Pervasive Developmental Disorders

Ministry of Health and Ministry of Education Policy Documents and Reviews
Ministries of Health and Education. **New Zealand Autism Spectrum Disorder Guideline**. Wellington: Ministry of Health, 2008. URL: http://www.moh.govt.nz/moh.nsf/indexmh/nz-asd-guideline-apr08 This guideline provides evidence-based information for all those involved in providing services for people with autism spectrum disorder and their families including health, disability and education professionals. The eight parts of the guideline cover Diagnosis and initial assessment of Autism Spectrum Disorder (ASD); Support for individuals, families and carers; Education for learners with ASD; Treatment and management of ASD; Living in the community; Professional learning and development; Māori perspectives and Pacific peoples' perspectives. The information on Applied Behaviour Analysis should be read in conjunction with the supplementary paper on Applied Behaviour Analysis (also available on the website) which revised some of the recommendations in the guideline.
New Zealand Guidelines Group. **Synthesis of recently published secondary literature on applied behaviour analysis for the New Zealand Autism Spectrum Disorder Living Guideline Group**. Wellington: New Zealand Guidelines Group, 2009.URL: http://www.nzgg.org.nz/download/files/Synthesisofrecentlypublishedsecondaryliteratureonappliedbehaviouranalysisaspublished.pdf This report considers secondary research evidence published since December 2007 (the cut off point used in the two reviews below) which related to the effectiveness of interventions based on the principles of Applied Behaviour Analysis (ABA) for people with ASD. Twelve review articles met the reviewer's criteria, ten of which reported on ABA-based interventions and two which reported on evaluations of the Picture Exchange Communication System (PECS). The reviews tended to include the same studies and to overlap with earlier reviews. Of the four reviews regarded as being of high quality, two found tentative evidence of benefit and two found that there was inadequate evidence of benefit. The four reviews regarded as being of good quality found ABA interventions to be generally beneficial but limitations in the evidence base were noted. The remaining four reviews, including the two on PECS were not regarded as providing reliable conclusions from the evidence base but may be of interest as narrative critiques. Mudford O, Blampied N, et al. **Technical review of published research on applied behaviour analysis interventions for people with autism spectrum disorder**. Wellington: Ministry of Education, 2009. URL: http://www.educationcounts.govt.nz/publications/special_education/61210/1 This review was one of two using different methodological approaches which were commissioned by the Ministry of Education. (The other is the one below.) It used data from existing analyses of peer-reviewed publications previously collected by the National Autism Center National Standards Project (NSP) based in the USA and also from any additional New Zealand publications considered to meet the criteria set out by the Ministries of Health and Education. It found that overall there was strong evidence that behavioural interventions based on the principles of Applied Behaviour Analysis produced beneficial effects for people with ASD, very little evidence that they were ineffective and no evidence that they were harmful. New Zealand Guidelines Group. **The effectiveness of applied behavioural analysis interventions for people with autism spectrum disorder. Systematic review**. Wellington: New Zealand Guidelines Group, 2008. URL: http://www.educationcounts.govt.nz/publications/special_education/61791/1 This review considered the evidence from 21 systematic reviews or evidence-based guidelines, and 20 primary studies (8 RCTs, one quasi randomised study, three cohort studies and eight non-randomised experimental studies). It found that there was consistent evidence that interventions based on the principles of Applied Behaviour Analysis can produce beneficial outcomes for young children with Autism Spectrum Disorders and that such interventions appear to be more promising than standard care or other approaches in education and in managing problem behaviour in young children.
International Guidelines
Myers SM, Johnson CP. **Management of children with autism spectrum disorders**. Pediatrics 2007; 120(5): 1162-82. URL: http://aappolicy.aappublications.org/cgi/reprint/pediatrics;120/5/1162 This clinical report from the American Academy of Pediatrics reviews the educational strategies and associated therapies that are the primary treatments for children with ASD. It aims to assist paediatricians in educating parents and helping them to choose empirically supported interventions for their children. It also covers important healthcare issues including management of associated medical problems, pharmacologic and non-pharmacologic intervention for challenging behaviours or coexisting mental health conditions, and use of complementary and alternative medical treatments.

Scottish Intercollegiate Guidelines Network. **Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders: A national clinical guideline**. Edinburgh: Scottish Intercollegiate Guidelines Network, 2007. URL: http://www.sign.ac.uk/pdf/sign98.pdf

This Scottish guideline aims to provide the evidence base and recommendations to inform clinical service provision, in particular assessment, diagnosis and clinical intervention. It considers the evidence for working in partnership with children and young people and with their parents and carers. It also considers the evidence relating to how multidisciplinary and multiagency working can best address the needs of people with ASD at all levels of care provision. It considers educational interventions which may influence clinical outcomes but does not examine the broad range of educational and social opportunities offered to children and young people with ASD which may add value to their lives and promote social inclusion.

Systematic and Other Reviews

Millward C, Ferriter M, et al. **Gluten- and casein-free diets for autistic spectrum disorder**. Cochrane Database of Systematic Reviews 2008(2): CD003498.

There have been reports of high levels of peptides in the urine and cerebrospinal fluid of people with autism and there are theories that peptides from gluten and casein are a cause of some of the problems associated with autism. This review aimed to determine the effectiveness of gluten and/or casein free diets in improving behaviour, and cognitive and social functioning of people with autism. The authors identified only two small RCTs with a total of 35 participants and they concluded that although gluten- and casein-free diets are a popular complementary therapy there is poor evidence for their efficacy. They state that further high quality research is needed.

Gold C, Wigram T, et al. **Music therapy for autistic spectrum disorder**. Cochrane Database of Systematic Reviews 2006(2): CD004381.

This review identified three small studies with a total of 24 participants which the authors considered to have limited applicability to clinical practice. However, they considered that the studies indicated that music therapy may help to improve the communication skills of children with autistic spectrum disorder.

Nye C, Brice A. **Combined vitamin B6-magnesium treatment in autism spectrum disorder**. Cochrane Database of Systematic Reviews 2005(4): CD003497.

The authors of this review identified only three small randomised studies (with a total of 33 participants) which assessed the efficacy of combined vitamin B6 and magnesium in treating social, communication, and behavioural difficulties in children or adults with autism. As a result they were unable to make any recommendations regarding the use of B6-Mg as a treatment for autism.

Sinha Y, Silove N, et al. **Auditory Integration Training and Other Sound Therapies for Autism Spectrum Disorders**. Cochrane Database of Systematic Reviews 2009(1): CD003681.

Auditory integration therapy (AIT) involves listening to music modified by filtering and modulation and is aimed at improving abnormal sound sensitivity in people with behavioural disorders including autism. The authors of this review identified six heterogeneous RCTs of AIT (with a total of 171 participants aged between 3 and 39 years). Four of these had fewer than 20 participants. Three studies found that AIT had no benefit over control conditions and three small studies reported improvements for the AIT group based on total mean scores for the aberrant behaviour checklist. There were no adverse effects reported. The authors concluded that further research is needed.

Diggle T, McConachie HR, et al. **Parent-mediated early intervention for young children with autism spectrum disorder**. Cochrane Database of Systematic Reviews 2003(1): CD003496.

This review aimed to determine the extent to which parent-mediated early intervention has been shown to be effective in the treatment of children with autistic spectrum disorder aged between 1 and 7 years. The reviewers identified only two studies, both with small numbers of participants, which were either randomised or quasi-randomised. The two studies were not directly comparable. The authors stated that their review had little to offer in the way of implications for practice and noted that there are barriers to the implementation of large scale RCTs in this field, particularly equipoise (the need to offer equivalent services for the two arms of a trial).

Other Relevant Publications

Bevan-Brown J. **Māori perspectives of autistic spectrum disorder**. Wellington: Ministry of Education, 2004. URL: http://www.educationcounts.govt.nz/publications/special_education/5479

This study reported on interviews with the parents and whānau of 19 Māori children with ASD who shared their experiences of raising their children. It includes information on significant areas of unmet needs.

OTHER CHRONIC MEDICAL CONDITIONS

IN DEPTH TOPIC:
MODELS OF CARE FOR MEDICALLY FRAGILE CHILDREN

MODELS OF CARE FOR MEDICALLY FRAGILE AND TECHNOLOGY DEPENDENT CHILDREN

Introduction

Advances in medical care in recent decades have led to a dramatic increase in the number of technology dependent children [92]. Some children who as recently as 20 years ago, may not have survived, are now able to live into adulthood. For example, life expectancy for children with serious congenital abnormalities has improved, as have survival rates and the quality of life for children with cancer and cystic fibrosis [93]. In addition, advances in neonatal care have led to the increasing survival of extremely preterm and very low birth weight infants.

The terms „medically fragile' and „technology-dependent' are both used to describe this sub-population of chronically ill children who have special health needs, and who are dependent on technology for survival. While a range of definitions are available, an oft-cited definition is that of Wagner et al [94], who define technology dependent children as those who "*…need both a medical device to compensate for the loss of a vital bodily function and substantial ongoing nursing care to avert death or further disability*." Similarly, in their study of technology dependence, Feudtner et al [95] classified participants as being technology-dependent if "*the failure or withdrawal of the technology would likely have adverse health consequences sufficient to require hospitalization*", with technology-dependence in this context including both devices and medications.

As might be inferred from these definitions, technology-dependent children are a heterogeneous group, with this heterogeneity spanning a number of dimensions including:

- Cause (congenital, genetic, illness or accident-related)
- Age at onset of the dependency (from (premature) birth through to adolescence)
- Duration of dependency (months for the respiratory system of a premature infant to mature, to years while awaiting corrective surgery, to lifelong)
- Presence and severity of associated disabilities
- Frequency of using technology (continuous – mechanical ventilation, daily – peritoneal dialysis, intermittent – intravenous antibiotics for cystic fibrosis) [93].

In addition, Feudtner et al [95] consider dependence on technology to be a multidimensional construct, with varying degrees of severity, as illustrated below.

Dimension	Milder End of Spectrum	More Severe End of Spectrum
Failure Consequence	Minor Morbidity	Immediate Death
Failure Likelihood	Unlikely (crutches)	Likely (CSF shunts)
Maintenance / Repair	Insubstantial (pills)	Substantial (machines)
Duration	Fleeting (minutes)	Permanent (years)
Hindrance	No Limitations	Bed-Bound (ventilated)
Burden of Care	Negligible	Extreme (majority of daily labour)
System Reliance	Autonomous (MDI)	Reliant (dialysis)
Cost	Cheap	Expensive
Consensus	Everyone Agrees	Dispute Over Appropriate Use

Source: Feudtner et al [95] CSF cerebrospinal fluid; MDI metered dose inhaler

While there is little research in the New Zealand context, in the United Kingdom the conditions most frequently associated with technology dependency are cancer, CNS disorders, heart disease, cystic fibrosis, asthma, premature lung disease, renal disease, digestive system disorders (particularly oesophageal atresia), alimentary disorders, and foetal environmental and developmental defects [93]. Technological supports to assist children with these conditions include oxygen, tracheostomies, gastrostomies, suction, and

intravenous or pump feeding [96]. In addition, there has been a move away from long-term institutional care with early hospital discharge now being actively encouraged. There has also been an increase in the number of portable technical devices available, particularly those which can be accommodated in domestic settings and operated by trained lay people [93] [97].

The increase in survival of medically fragile children, coupled with advances in medical technology, have allowed an increasing number of children and young people to live at home, while at the same time being dependent on complex medical technology [93] [97]. Such changes have major implications however, for the health services providing the technical support which allows these children and young people to live at home, as well as for their families and caregivers, who in the current era of de-institutionalisation, are being required to take on an increasingly complex role in the care of their children. With this in mind, the following section reviews models of care for medically fragile and technology dependent children. It begins by providing a brief overview of informal caregivers in New Zealand, the current support services available to them, and some of the problems families and caregivers encounter when caring for medically fragile and technology dependent children and young people. Models of care and health service provision are then reviewed, before issues associated with transitions to adult care are considered in more detail.

Informal Caregivers in New Zealand

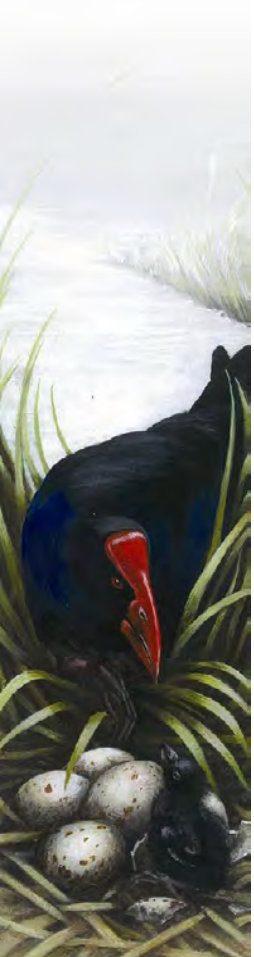
The New Zealand health system, like most, relies on family caregivers to assist people with disabilities or chronic illness to live at home. These „informal caregivers' are unpaid, and are usually family or friends who support people with disabilities or illness. At the time of the 2006 Census, there were approximately 420,000 informal caregivers in New Zealand [77]. In terms of the levels of support provided to these informal caregivers, a 2007-2008 survey found that the vast majority of informal caregivers had signs of stress (85%), and 89% of those aged 30-39 showed signs of depression. Problems identified included a lack of financial assistance; the need for flexible and reliable respite; the difficulty of being in paid employment; poor information about assistance and how to access it; and lack of recognition about their caregiving role. Caregivers of younger people has particular problems with respite care, such as the difficulty in finding appropriate age-related facilities, and the small amount of money that is paid to respite workers [72]. Overall, 0.7% of caregivers of people under 65 years of age were happy with the level of support they received.

In response to these and other concerns, the Ministry of Social Development, as part of a wider Government process, developed the New Zealand Carers' Strategy [77], which outlines the Government's vision for informal caregivers in New Zealand. The objectives of the Strategy are to [77]:

- Provide information
- Protect the health and wellbeing of carers
- Enable carers to take a break
- Provide financial support for carers
- Provide training and pathways to employment for carers.

The underpinning principles which guide the strategy are to [77]:

- Acknowledge and respond to the diversity of needs and aspiration of carers
- Enable family focused support to be in place for carers when they need it
- Enable carers to have choices and the autonomy to develop and sustain their personal, family and community support systems; and ensure that formal supports are reliable and are able to provide real support to carers
- Acknowledge that the needs of carers, family, whānau, or aiga and the person being supported are often intertwined



The Strategy takes a whole-of-government approach, with commitments from the Ministries of Social Development and Health, the Department of Labour, and the Accident Compensation Corporation. The following actions were identified as priorities for 2010:

Objective	Action	Responsibility
Provide information	Carers consulted about their information needs and the findings used to update *„A Guide for Carers'* and the Carers' Website	Ministry of Social Development
Protect the health and wellbeing of carers	Work across Government to develop a wellbeing and learning programme for informal carers	ACC in conjunction with Carers NZ
	Update informal carers' training requirements	Ministry of Health
	Improve mechanisms for providing informal carers of people with mental illness or addiction with supports in the health sector through revised specifications for those services	Ministry of Health
Enable carers to take a break	Increase the flexibility and reliability of respite care for informal carers	Ministry of Health
	Increase residential respite services for older people	Ministry of Health
	Provide additional assistance with recruiting relief carers	Ministry of Health
Provide financial support for carers	Access to income support for families with high and complex needs continues to be improved through information, training and awareness raising	Ministry of Social Development
	Research undertaken to better understand cumulative effect of means-testing on work incentives for households with caring responsibilities	Ministry of Social Development
Provide training and pathways to employment for carers	Encourage and support employers to recognise carers' skills and needs	Department of Labour
	Investigate ways to support carers into employment	Department of Labour

Source: The New Zealand Carers' Strategy [77]

It is hoped that this intersectoral approach supported by both government and a number of Non-Governmental Organisations (NGOs) will support carers and enable them to continue to provide care.

Current Support Services

In addition to strategies to improve support for informal caregivers as outlined above, a range of supports are available to children and young people with significant medical problems who meet eligibility criteria. Those fitting the Government's definition of disability[1] are able to apply for Ministry of Health-funded Disability Support Services (DSS) via a Needs Assessment and Service Coordination (NASC) agency. The range of Ministry of Health-funded DSS for people who have been assessed as meeting the criteria for a physical, intellectual or sensory disability, or a combination of these are outlined in more detail on **Page 82.** In addition, the Ministry will also fund DSS for people with certain neurological conditions that cause permanent disabilities, certain developmental disabilities in children and young people such as autism, and for those with physical, intellectual or sensory disabilities that co-exist with a health condition and / or an injury.

While anyone who fits the definition of disability may apply for DSS, there are a number of funding exclusions which are relevant to those with chronic medical conditions, or with disabilities arising from injuries. Funding of DSS for people with psychiatric and age-related disability was devolved to District Health Boards (DHBs) in 2002. Those who have cover under the Injury, Prevention, Rehabilitation and Compensation Act 2001 are also excluded from Ministry funding. Furthermore, the Ministry does not usually fund DSS for

[1] The Government definition of a person with a disability is: "A person with a disability is someone who has been assessed as having a physical, psychiatric, intellectual, sensory, or age related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required".

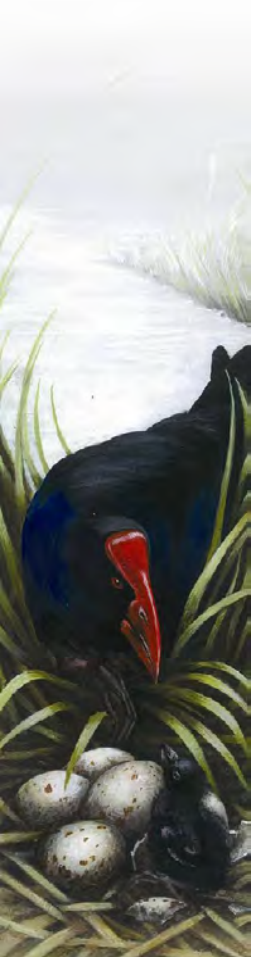
people with „personal health' conditions, such as asthma or diabetes [98]. This may well preclude some medically fragile children and youth from obtaining funding through Disability Support Services.

In addition to DSS, there are a range of other potential supports available. The Ministry of Social Development provides income support for those with disabilities or significant chronic medical problems (**Page 84**), the Ministry of Education provides a range of supports for children with high or very high needs (**Page 85**) and the High and Complex Needs Unit **(Page 86**) provides additional resources for children whose needs are too complex to be met by any one agency. The Ministry of Health also provides additional funding to Primary Health Organisations through the Care Plus programme. This is for people who require high levels of care or have high needs because of chronic conditions or terminal illness. There is also funding available from DHBs for transport to enable people to access specialist health and disability support services [99].

Problems Encountered when Caring for Medically Fragile Children at Home

As previously discussed, advances in medical technology have significantly improved the survival of premature babies, and children with serious congenital abnormalities. Similarly, the prognosis and quality of life for children with illnesses such as cancer and cystic fibrosis has also improved [93]. As the number of medically fragile and technology dependent children has increased however, a desire to promote family functioning, to enhance normal child development and to decrease the costs and the burden on the health care system, has seen these children increasingly being cared for at home, rather than in a hospital setting [100]. While home care is the preferred option for many families, the available literature suggests that such models of care also create a number of challenges for families caring for medically fragile children in their homes, as well as for the health services who support them to do so.

While there is little research in the New Zealand context (the available New Zealand literature is considered at the end of this section), a number of reviews have considered these issues overseas. In one such review, Parker et al [101] noted that the practice of caring for medically fragile children at home was increasing, despite the weakness of the research base associated with this model of care. In evaluating the available evidence, Parker et al [101] conducted a systematic review of the cost and effectiveness of home care for paediatric populations, including children who were both acutely and chronically ill. In their review they considered four main outcomes: service use, clinical outcomes, costs, and impacts on the family, with the findings of this review, along with those of other researchers, being briefly summarised below.



Service Use

In their review, Parker et al [101] found that for very low birth weight (VLBW) babies, home care was associated with higher levels of hospital admission than the literature had previously suggested. It was theorised that earlier discharge caused higher levels of anxiety in parents, leading to equivalent or greater use of hospital services following discharge, either by means of increased re-admission and / or the greater use of the emergency department.

Costs

Parker et al [101] examined the studies reporting cost comparisons for home-based versus hospital care. The only studies in their review that commented on this were for very low birth weight babies. The authors found that the costs to the hospital appeared to be reduced by a substantial amount. However, none of the studies reported on all relevant cost data. There was a tendency to comment on cost savings by hospitals, but not the costs of intervention programmes, the costs of community-based or home-based care, or the costs to the family.

Glendinning et al [93] also examined the costs associated with caring for technology-dependent children living at home in the UK. They found that the total service costs of

caring for each child varied with the technology the child was using and with local patterns of service use, but that such costs might be as high as £150,000 per child per year. The costs incurred were spread across a range of agencies and groups including:

- The Health Authority
- The Local Authority
- The Department of Social Security
- Families

Costs that were incurred by the health system when medically fragile children were cared for at home included the costs of specialists, physiotherapists, occupational therapists, nurses, social workers, dieticians, equipment, consumables, and drugs. There were also the costs of home help services, housing adaptations, respite care, transport, telephones, special support in schools, insurance to cover equipment in the house, electricity to run equipment, and removal of clinical waste from homes. Costs to families that needed to be taken into consideration were the loss of parental income and lost opportunities for promotion. The authors made the comment that accurate data on the number and costs of technology-dependent children was vital for adequate service planning, with it being necessary to ensure that children were not kept in hospital any longer than was necessary (as occurred when community-based services were not available). Furthermore, accurate data was crucially important because of the very high direct and indirect costs of caring for technology-dependent children at home.

Research also suggested that the burden of costs borne by families was not shared evenly in society. In a US analysis of health service use and health care expenditures for children with disabilities and chronic conditions, it was noted that the financial burden of childhood disability continued to be shared unevenly, with low-income families being particularly vulnerable to burdensome expenses. The authors concluded that further efforts were needed to protect these high-risk children and their families [102].

Clinical Outcomes

Although there are various models of care for children who are technology-dependent, there is little evidence on outcomes arising from different models. In their meta-analysis, Parker et al [101] found there was a suggestion of slight advantage in home care for very low birth weight (VLBW) babies. VLBW babies receiving home care had slightly improved physical function and mental function outcomes, but this did not reach statistical significance.

Impacts on Families

It is well documented in the literature that families of medically fragile children face enormous stresses. These multidimensional stresses are interrelated so intimately that even a small incident can have a major impact [103]. In their systematic review, Parker et al [101] did not find any assessment of the impact of home care on family members. Likewise, there was no examination of parents' quality of life or satisfaction with the services provided. Rehm and Bradley [104] however, undertook two field studies examining family experiences in raising children who were medically fragile and developmentally delayed or disabled. Their article identified some of the stressors that families face including: social isolation; the need for constant vigilance to maintain the child's well being; scarcity of competent respite or alternative caregivers; employment and financial strains; loss of privacy (with multiple people coming to the house); altered family dynamics, including strains between spouses and parents and children; and sleep deprivation caused by anxiety over complications that might arise while parents are asleep. The authors grouped stressors into four broad categories: role conflict (primarily with health care providers); financial burdens; care burdens; and independence / isolation of the child and family. The literature on these four areas is considered below.

Role Conflict

A number of researchers have examined the perceived role conflict for parents of children who are technology-dependent. Kirk and Glendinning [105] conducted interviews with parents of 24 technology-dependent children, and with 44 health, social and other

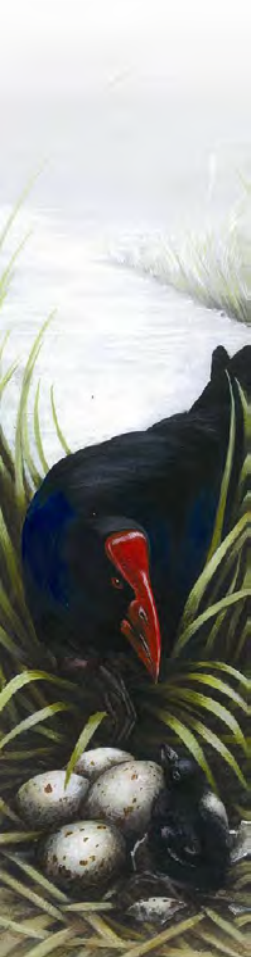
professionals. They found that some parents felt that the emotional aspects of caregiving were neglected by professionals. Professional tended to emphasise only the acquisition of technical competencies when teaching parents. One area of particular parental concern was undertaking clinical procedures on their children that could be painful (e.g. inserting a nasogastric tube).

Care Burdens

Kirk et al [105] describe the significant burden of care on some of these families. Because of the nature of their children's illnesses, parents reported that relatives and friends often could not help with childcare unless they had been trained. Parents therefore relied on formal services to provide a break from caring. However, both professionals and parents described how accessing such support was one of the biggest problems families faced. Parents participating in the study found that the usual short-term care or home-based support services were frequently inappropriate because of the child's particular nursing needs. Consequently, home care workers were often specially recruited and trained to support families at home (and at times, to support the child at school), by providing a regular break during the day and / or overnight.

Likewise Kuster and Merkle [100] found that parents were frequently taking on a large burden of care, with parents often undertaking the responsibility for care that would otherwise have been provided by skilled nurses within a hospital environment. The authors noted that both the physical burden and psychosocial stress associated with caring for a medically fragile child at home had the potential to impact on the physical and emotional health of the parent(s).

One of the ways to relieve such burdens of care for families is to provide respite care. In her reflections on setting up and maintaining a respite service for chronically sick or disabled children, Beale [106] noted an initial gap in respite provisions to children who were dependent on technology. Once set up, the respite service was in high demand, and it became necessary to create a dependency rating scale to prioritise families most in need. The service was expensive, but Beale noted that various agencies were becoming more aware of the growing need for respite care. To reduce the cost, support workers were employed within the service. These workers were trained to do specific tasks and their competency tested over time in particular aspects of care. Beale recommend regular audit of such services, training, updating, monitoring and re-training staff, publicising the service, and having clear referral, admission and discharge policies.



In paediatric clinical care, there is often a focus on providing medical treatment and tests, performing procedures and monitoring the well-being of the affected child. There is often little consideration of parents as a target for intervention, with a view to both benefiting the child indirectly, and to caring for the parents themselves. Tong et al [107] conducted a systematic review of interventions for informal caregivers of patients with chronic kidney disease. There was no high quality evidence about the effect of information or support interventions on the physical or psychosocial well-being of caregivers. However, the authors made a number of recommendations including:

- That strategies to improve intrapersonal well-being should aim to increase parental confidence in being able to manage the child and decrease parental anxiety.
- The health care team should provide opportunities for parents to express their feelings and concerns.
- Parents should be trained and equipped to deliver care in the home, and be made aware of, and prepared for, the role adjustment that they may experience.

The authors also commented that professional instruction for health care personnel can reduce the disparity between professional and parent perceptions of each other. Professionals' awareness of the value of caregiver „expertise' can improve the interaction between parents and staff [107].

Independence / Isolation of the Child and Family

In their evaluation of dyadic peer support for caregiving parents of children with chronic lung disease, Nicholas and Keilty [108] described how family caregivers were highly

committed to their child's needs and well-being. However, they often denied their own need for support and self-care, resulting in a population of parents at considerable risk for isolation and high caregiver burden. The authors noted that the delegation of extraordinary patient care to parents (usually mothers) was often at significant personal cost, including personal well-being, and that this deserved a careful review at the clinical, structural, societal, and ideological levels. They also noted that adequate resources to effectively support care giving parents and their ill children were crucial to their quality of life.

In their longitudinal study of factors predicting adjustment in mothers caring for medically fragile infants, Miles et al [109] collected data on 67 mothers of infants with serious life-threatening illnesses requiring hospitalisation and the use of technology for survival. They examined distress using a depression scale, and growth using a personal developmental impact rating scale. They found that 45% of the mothers at discharge and 36% of the mothers at 12 months had scores at or above the risk score for serious depression. Three mothers were rated on the personal developmental impact scale as having a definite negative developmental change. Their findings support previous research that found mothers of chronically ill children are at risk for emotional distress. They also found evidence of developmental growth in mothers despite the distress associated with caring for a medically fragile infant. The authors noted that while depressive symptoms and personal developmental impacts were moderately correlated, these outcomes had different patterns of prediction. Distress tended to be influenced by maternal characteristics such as a personal sense of mastery, maternal education, satisfaction with family, and maternal illness-related distress; hospital environmental stress; and worry about child's health. Growth was influenced by characteristics of the child's illness, cognitive development, and technology; maternal illness-related distress; hospital environmental stress and worry about the child's health; and level of maternal role attainment, identity, and competence. The severity of the child's continuing health problems also affected maternal growth. Mothers whose infants had a multisystem diagnosis had more negative developmental impacts at six months. Similarly, mothers whose children had lower mental development and more technology at an early age had more negative developmental impact ratings at 16 months. There was a higher risk for depression in mothers with less education and less perceived control. The authors' findings support the charge to develop interventions to help mothers of critically ill infants during hospitalisation and after discharge.

Other Outcomes and Aspects of Service Delivery

In their study on developing services to support parents caring for a technology-dependent child at home, Kirk and Glendinning [105] interviewed parents of technology-dependent children, as well as health, social care and other professionals in the UK. The authors found that parents were often confused about who was responsible for various aspects of care. Compounding this, even professionals themselves were sometimes unclear about their responsibilities. Both GPs and nurses were at times unsure whether GPs or hospital consultants were medically responsible for children while at home. There was poor communication on the hospital-community interface, and between hospitals. Few families had a designated person to ensure communication and coordination between services. The authors also noted that transferring responsibility for the provision of clinical care was rarely negotiated with parents before discharge. Although parents had a strong desire to care for their child at home, parental choices were constrained to some extent by the lack of alternatives to parental caregiving. Most striking from the study was that most families lacked a designated key worker to coordinate care. This is despite it being long advocated by a number of independent researchers and government reports. The study highlighted the need for clear lines of accountability and communication in the care of medically fragile children, particularly when their parents were caring for them at home.

Other studies have identified a range of other problems. Watson et al [110] found a number of barriers to care for children with disabilities and complex health needs. They identified discharge planning; the provision and funding of equipment; and liaison between acute and community health professionals as areas where there were frequently problems. In their literature review on caring for technology-dependent children at home, Wang and Barnard [111] also found that, among other things, having children dependent on

technology being cared for at home resulted in altered relationships between the child, parents, siblings, professionals and society. Similarly, in her review of health care policy for medically fragile children, Mentro [92] highlighted a number of problems with US system. These included stringent eligibility requirements, capitated care plans, payments not covering the complete cost, difficulty working out eligibility for children with uncommon disorders or unusual symptoms, and complicated paperwork. While some of these problems are particular to the US, a number of them apply to New Zealand as well.

New Zealand Research

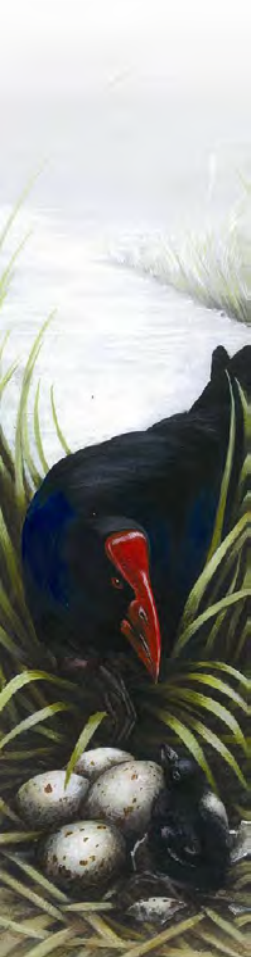
In the New Zealand context, there are few studies which consider the needs of families with technology-dependent children. One study to do so however, a qualitative analysis of the needs of eight families with technology-dependent children in Counties Manukau, found similar issues to those identified above [96]. Issues raised by the caregivers interviewed included the need for high quality information about their children's medical condition, particularly at the time of diagnosis; empathy and being listened to by staff; the need for continuity of care; and the importance of individual case coordination, advocacy and cultural support, particularly when a range of services were involved.

Transitions from hospital to home, and between services were seen as being important and potentially stressful times, with one parent noting "...*he was in hospital for nine months... the actual day coming home was quite different because we had no nurses to back us up and it was just me and my partner the day we came home... it was quite frightening*." Impacts on family dynamics were also significant, with one parent noting "*I've had a lot of hard times... my children's father and I separated due to a combination of factors, one of those factors being that we have a child that has high medical needs*...." Others also had difficulties accessing support from the extended family, with one parent noting " *Most of our family, they're too scared to look after him*". The author concluded that access to high quality and culturally appropriate support, care coordination, and adequate respite care, were all important in protecting caregivers' health and sustaining the family's ability to care for their child [96].

Further Areas for Research

While the above research has highlighted a number of important areas of concern, there are also a number of challenges, as well as areas where further research might inform future improvements in the care of technology-dependent children. Feudtner et al [95] identified three specific challenges to further research. Firstly, there was no consensus definition of "technology-dependency", either as a yes / no option, or as gradations of a technology-dependency classification scheme. They noted that the intrinsic worth of any definition needs to be based on its ability to be used readily, reliably, accurately, and consistently for research purposes; and whether the definition when applied enables the subsequent analysis to advance a research agenda that ultimately maximizes patient, family, and public well-being. Secondly, they noted that methods to assess the burden of care, both quantitatively as well as qualitatively, needed to be developed. Without such measures, evaluations of technology were seen as being likely to underestimate the indirect costs borne by families and care providers, and the broader consequences to society. Thirdly, better assessment of the value that children, parents, and others place on quality of life was seen as being essential, not only for cost-utility analyses, but also to enable children and parents to make better-informed decisions when presented with options of care. It was also seen as important to investigate how these evaluations change over time with increased exposure to the technology and the quality of life that it supports. The authors consider that addressing these areas would enable:

1. The incidence and prevalence of technology-dependence to be documented
2. The impact of technology-dependency on patients' and families' physical, psychosocial and financial well-being throughout the course of an illness to be assessed
3. Health-care providers and agencies that care for technology-dependent children to be identified, and the economic ramifications of providing such care to be explored



4. The care that technology-dependent patients require to be evaluated in terms of how it affects the health-care system as well as schools, social services, and parental employers
5. Specific interventions and management techniques that conceivably influence the burden of technology-dependent care to be tested.

The authors concluded that such research could then be used to inform: individual and population-level needs assessment and planning; the development of techniques to lessen the burden of, and to increase the safety and efficacy of technology-dependence; and policies to promote high-quality care for these vulnerable patients and their families [95].

Others suggest that another neglected area of research, was research into the views of the children themselves. Vickers and Maynard [112] make the comment that no-one has really undertaken research to ask the children involved what they think about technology (such as inserting a gastrostomy). In addition, another area with a paucity of data is the academic and social outcomes of technology-dependent children. Rehm and Rohr [113] discuss the lack of empirical data on school activities or academic and social outcomes specifically for children who are medically fragile/technology-dependent (MFTD). Information about these children is frequently subsumed in the health and education literature within the general population of children with disabilities. The authors believe it is essential that nurses and health-care providers understand how families in such extraordinary circumstances use available resources, and that they identify unmet family needs. As education is an essential part of childhood for all children, it is important to understand the special health needs of children who are MFTD, as they create a unique set of circumstances for families, caregivers, and educators.

In conclusion, the expansion of home based care for medically fragile and technology dependent children has occurred, in the context of a paucity of cost effectiveness data, upon which to build a sound evidence base. As a consequence, it is critically important to build evaluation components into any new services as they are established, as well as to review the effectiveness of existing models of health care provision. Further, hospital care has changed markedly over the last 30 years, and has become more age-appropriate and less damaging to children. Careful analysis thus needs to be undertaken to determine which children, with which conditions, and for which treatments are better at home than in hospital, with a view to informing future policy in this area. Further, the evaluative literature on the costs of home care usually examine the cost to the health service, although the available descriptive literature tells us there are costs to the family, both long and short term that also should not be ignored [101]. Thus overall, it appears that the development of appropriate community-based services has not kept pace with the medical and technological advances that now allow children with complex, intensive needs to be discharged from hospital [93]. Finally, there is a need to recognise that parents are just that – parents first and foremost, *not* nurses or care workers, and that they may need support in developing and sustaining a parenting role with their child [105].

Models of Care

"*Advances in medicine have resulted in more children surviving conditions that were once considered to be life threatening. This is often reflected in an increased demand for all levels of care, from primary care to community and educational services, to special health care services required by children with chronic conditions"* American Academy of Pediatrics 2005

With the available literature suggesting that there are a number of problems inherent with current models of care for medically fragile and technology dependent children, the question thus arises, as to what a more appropriate model of care might look like. With a paucity of local research in this area, the following section considers the available overseas literature which has reviewed these issues.

Central to most contemporary models of care for medically fragile children is the recognition that coordination of care is critically important. In 1992, the American Academy

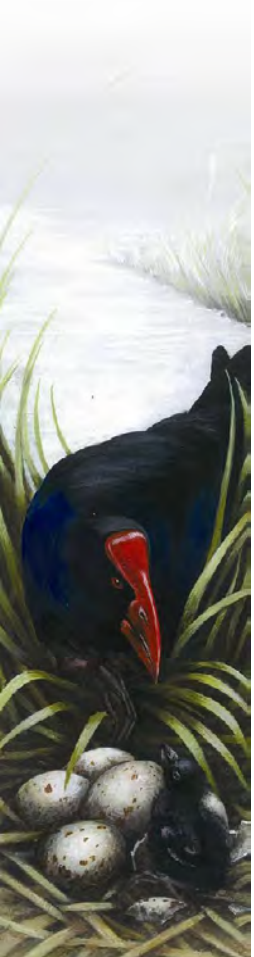
of Pediatrics developed the concept of a „medical home' in a position statement [114]. The term was initially used to describe a place where all of the medical information about a particular patient was kept, but this has now evolved to a broader approach to care. The seven original components of the Medical Home were that care should be accessible, continuous, comprehensive, family-centred, coordinated, compassionate and culturally effective [115]. The goal was to have all children with special health care needs receiving regular ongoing care within a medical home [114].

Overseas, coordinated care is particularly important, as in many countries there is no single entry point to gain access to systems of health care, social services, education, public health services, and home services [116]. This view is backed up by a number of studies that have shown significant benefits related to implementation of care coordination models. Benefits included reduced hospital admissions, reduced length of hospital stay, reduced emergency department visits, improved patient satisfaction, and enhanced opportunities for outcome-based clinical process improvement [116], with the overarching goals of care coordination being to [116]:

- Develop an anticipatory / proactive plan for appropriate services for the child and family, integrating the recommendations of multiple professionals and service systems
- Assist the family in accessing needed services and resources
- Facilitate communication among multiple professionals
- Avoid duplication of services and unnecessary costs
- Optimise the physical and emotional health and well-being of the child, and
- Improve the child's and family's quality of life.

All those involved with children with special needs (health, education, social services) need to work cooperatively to develop effective care coordination models. These should take into account the continuum of health, education, and social services in order to improve the quality of care for children with special health needs. Any barriers to care coordination that may exist need to be addressed and overcome (for example, cultural, language, educational, economic, transport etc).

In developing such a model of care, Harrigan et al [117] conducted an integrative review of the literature relating to medically fragile children. They found that the stressors that families looking after technology-dependent children face include issues with home care professionals, respite care, finances and limited community resources. However, children cared for in hospitals often experience sub-optimal quality outcomes. Community-based paediatric care services may be a means of reducing family stress, improving physiological developmental outcomes and decreasing cost. Case management may significantly reduce parental stress, and at the same time improve the quality of life for the children. The authors developed a model of care for use that relates to improving health outcomes for medically fragile children. Their recommendations are that:



- A case manager (in a community-based setting) should be assigned to each child.
- Educated professional providers should arrange and provide paediatric care at a specialty facility.
- Each child should have an individualised care plan defined by their individual needs.
- Families should be educated before the child's discharge. The case manager should provide support and education as needed following a scheduled assessment.

The authors also noted that merely because complex life-support systems can be placed in the home, this does not always mean that they should be [117].

Watson et al [110] also examined the literature on different approaches to joint working, when caring care for children with complex health care needs. They considered multidisciplinary, interdisciplinary and transdisciplinary ways of working. They defined multidisciplinary as being where individual professionals in a single agency worked together to support a child with complex health needs. Interdisciplinary approaches occurred where individual professionals from different agencies separately assessed the

needs of children and their families, and then met to discuss their findings and set goals. Transdisciplinary working was seen as a holistic approach where the focus of service delivery was the child and family, with assessment starting with the needs and wishes of the child and family, rather than existing service provision, or the roles of individual professionals. The transdisciplinary approach was seen as placing the child and family at the centre of care, and involved designing a package of support that met their demands and lifestyle, rather than the other way around. Vital in this approach was the „primary provider', whose role was funded by multiple agencies, and who offered advice on, designed, and delivered a programme of care which supported the physical, cognitive, and social development of both the child and the family. With this model of care, families were seen as equal partners who set the goals for delivering and measuring the quality of the services they received. Transdisciplinary methods are also known as „multidisciplinary collaboration'. While the authors do not advocate for one method to be used at all times, they highlighted some components the felt were necessary for good practice in joint working:

- Good joint work should involve multiple agencies
- Multi-agency work involves two, three or four-way arrangements of service delivery and funding
- Service delivery should focus on the child and family
- Partnering with families is key
- Commitment from services/professionals is vital
- A single pathway for families (e.g. via a primary provider, key worker or service co-ordinator), is important.

Working together, or joint working, is thus a continuum that includes transdisciplinary, interdisciplinary, and multidisciplinary working. Research suggests that a transdisciplinary model is likely to offer the most benefits for children and their families, however, Watson et al note that there is a paucity of research on the subject. One example of such joint working is reviewed in the text box below:

Example of a Model of Care - Special Needs Programme

In the US, a children's hospital and Medical College partnered together to establish a Special Needs Programme (SNP) [118]. The programme was a tertiary care-primary care partnership model for children and youth with special health care needs. Patients were potentially eligible regardless of diagnosis, rather than the programme being disease-specific. The target children and youth were those who had special health care needs, who were also medically complex and fragile. Criteria were developed to determine „complexity' and „fragility'. „Complexity' related to the number of specialists involved in care and number of organ systems involved. „Fragility' was based on the number of hospital admissions and clinic visits, length of hospital admissions; or dependence on technology or presence of home nursing. These were used to determine if patients were eligible for enrolment into the programme.

The programme was two-tiered, with about 30% of patients assigned an SNP paediatric nurse case manager and an SNP physician. The remainder were assigned only an SNP paediatric nurse case manager, who liaised closely with primary care physicians. Patients assigned an SNP physician generally had more frequent and longer hospitalisations, and had disputed or uncertain diagnoses.

The paediatric nurse case managers were available weekdays from 8am-6pm, and were the single point of contact at the Children's Hospital for patients, families, primary care physicians and community resources. The paediatric nurse case managers' roles included preparing a plan for care, facilitating communication among specialists and primary care, attending appointments, and often advocating for the child and family. They usually spent 10-20 hours per patient for the first month, then 2-6 hours a month after that. The average case load for an SNP paediatric nurse case manager was 30-35 patients.

The SNP physicians were able to be contacted 24 hours a day, seven days a week. When each patient enrolled, they performed a detailed history and physical examination, reviewed the medical record, and synthesized the child's problems in a comprehensive clinical care coordination summary. The summaries were reviewed with the family, primary care physician, and specialists. The SNP physicians frequently arbitrated in disputes about competing diagnoses and therapies. The SNP physician saw patients electively in the clinic and urgently in the emergency department. They also occasionally made home visits or held joint appointments in the primary care physicians' office. They facilitated admissions by reviewing the patient's case in detail with the admitting team and coordinating care during the inpatient stay by attending rounds with the primary team and communicating with specialists. Occasionally, patients were admitted to the SNP service itself. During hospitalisations, SNP physicians remained in close contact with the primary care physician, thus providing them with a presence at the tertiary care centre. The SNP physicians generally spent 8 to 20 hours initially

considering and synthesizing the child's condition and preparing the clinical care coordination summary. Subsequently, they spent two to four hours each month depending on the level of medical complexity and fragility of the patient. The average case load for an SNP physician was 25 to 30 patients.

Comparing data prior to enrolment and post enrolment showed that there was a striking decrease in the number of hospitalisations and number of days spent in hospital. There was also a decrease in the tertiary centre charges and payments made after enrolment in the programme. There was a significant increase in the number of outpatient and ED visits per patient, with no change in short-stay admissions (<23 hours). This resulted significant monetary savings. The authors attribute the success of the SNP to:

(1) partnership with the child's family and primary care physician,

(2) being familiar with the child's condition,

(3) close involvement with the child and family during hospital admissions, and

(4) proactive outpatient care [118].

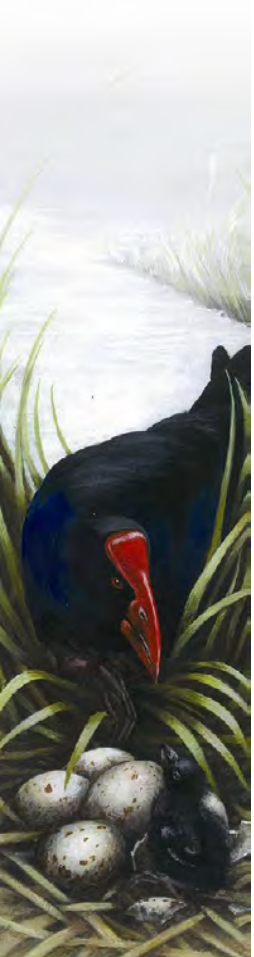
Transitions to Adult Care for Children and Young People with Chronic Conditions

In addition to models of service delivery for medically fragile children, issues often arise as children grow older, and must transition from paediatric to adult care. The planned transition of care from child-centred to adult orientated services can be a complex process, and one that requires a great deal of input in order to ensure that patients transition smoothly, and continue to engage with services appropriately [119].

There are a number of features of adolescence which make transitions from paediatric to adult services more complicated than transitions outside of this age group. Not only are there the pragmatic elements of transfer of care from one service to another, but there are also additional complexities that result from the unique stage of life at which these transitions occur. In this context, Weissberg-Benchell et al [120] reviewed the phases of development from childhood to „emerging adulthood', and noted the importance of recognising the phases of development in planning transition care from paediatric to adult services. They noted that patients aged 18-24 years, in the period of „emerging adulthood' have unique needs, with this being a time during which youths are increasingly responsible for themselves and the decisions that they make. However, it is also a time when they have often left home and have less structure in their daily routine, with the authors noting two key themes. The first is that the developmental period following high school represents a distinct period with unique demands separate from adolescence. The second is that for a subgroup of high-risk adolescent patients, there is continuity between the adherence and control problems associated with adolescence, and with the post-adolescent years. The goal of effective transition is to provide developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.

Psychological theories suggest that transition should be undertaken towards emerging adulthood, rather than young adult status [119]. A major imperative of the clinician is to ensure that the transitioning patient continues to follow up with regular medical visits [120], as poor attendance is likely to be associated with poor adherence to treatment and increased risk of acute and long-term complications, including increased mortality [119].

In terms of models of care during the transition process, While et al [79] examined the literature around effective transitions to adult services, and identified four overlapping models of transition care. These models are not intended to be mutually exclusive, with their relevance varying with the needs of the young people for whom the services are to be provided [79]. The 4 models are briefly reviewed in the text box below, with the third model (Developmental Transition Model) being reviewed in more detail in the in-depth topic on disability and disability support services on **Page 94**.



Direct Transition Model
Continuity is achieved in this model when the individual in question is transferred to adult care safely and efficiently. The emphasis for this model is on structural factors, such as good communication and information sharing, with a focus on relationships between the services. Such structures are considered horizontally (between multiple services within each age band structure) and vertically (from child to adult). This approach is generally adequate when the disease has a minimal impact on the young person's ability to develop normally.

Sequential Transition Model
Using this model, services and care are arranged recognising that the young person's needs are changing and that they require some preparation if they are to successfully adjust to adult care. Services are usually either contracted as an extension of child services, or jointly between adult and paediatric providers, and have the features of being flexible, with longitudinal continuity. This model is particularly important when the roles and responsibilities of the young person are likely to change significantly. The service structure and care is distinct from paediatric care, and allows the young person to rehearse and prepare for adult-based care. This model can be used for conditions like diabetes.

Developmental Transitional Model
This model assumes that the young person will require help to acquire the skills and support systems necessary to use adult care effectively. It uses principles of the sequential model, with an active focus on personal growth and development. This model is particularly relevant for vulnerable young people and those with physical disabilities and learning difficulties.

Professional Transition Model
The aim of this model is to develop relational or personal continuity between the young person and the professional caring for them. This is particularly important for conditions with a short life expectancy or where expertise are concentrated within one service (for example, cystic fibrosis or HIV/AIDS) [79].

In the context of medically fragile children, much of the literature around transition to adult services comes from studies of patients with diabetes and cystic fibrosis who are transitioning to adult care. These two conditions will be used to highlight some of the difficulties, concerns and recommendations around these transitions.

Diabetes Mellitus (DM)

Adolescence is a time when achieving good glycaemic control can be difficult as, among other reasons, adolescents are less likely to adhere to prescribed care [121]. A study in Waikato of people under 26 years of age with diabetes (Type I and II) found that there was a non-significant trend for adolescents (aged 15-19 years) to have the worst control (as measured by HbA1c) [122]. Epidemiological studies show that intensive treatment during adolescence does not necessarily set the stage for optimal glucose control during young adulthood. Research suggests that a high level of family support was the strongest predictor of adherence to the diabetes regimen. This underscores the vital importance of considering behavioural, developmental and social issues in the evaluation and care of the young adult patient with diabetes [120].

De Beaufort et al [123] conducted a survey to evaluate how diabetes health care providers managed the transition from paediatric to adult diabetes services. They sent out a questionnaire to members of the International Society for Pediatric and Adolescent Diabetes. They had a 16% response rate. The responses showed a marked variation in the age at which patients were seen by adult services. Half of the centres had a structured transition programme; 44% of centres suggested transition between the ages of 18 and 25 years. One centre had no age limit. Usually the transition was initiated by the paediatric unit. Different approaches to transition were used, including phone contact, letters, joint clinics at either the paediatric or adult site, cross-over meetings with the paediatric and adult team, and group transfer. Of those who completed the survey, 90% recommended that transition planning should begin at least one year prior to transfer. Larger centres generally reported utilising more than one method to assist successful transition. With diabetes, youth who drop out of care may miss some opportunities for expert self-management education and coaching, and complication surveillance, as well as the early detection of problems. There is a risk that those who do not transition to adult services will resurface in the medical system only when serious problems occur – problems which may have been averted.

Cystic Fibrosis (CF)

With advances in medical care, many patients with CF are now living into their fourth decade. Approximately half of all people living with CF currently are over the age of 18 years. Despite some research and initiatives, the best way to facilitate a successful transfer from paediatric to adult CF care remains unclear [124]. Kerem et al [125] also comment that while there are various models for how to manage the transition of care, in their opinion, none are optimal. There is a dearth of literature on best practice for

managing the transition of care in CF, despite much research on concerns, needs, and experiences of patients, families and staff using cross-sectional or before and after surveys [126]. Given that there is very limited medical literature to guide practice, there is considerable variation in practice between countries, and probably between centres [126].

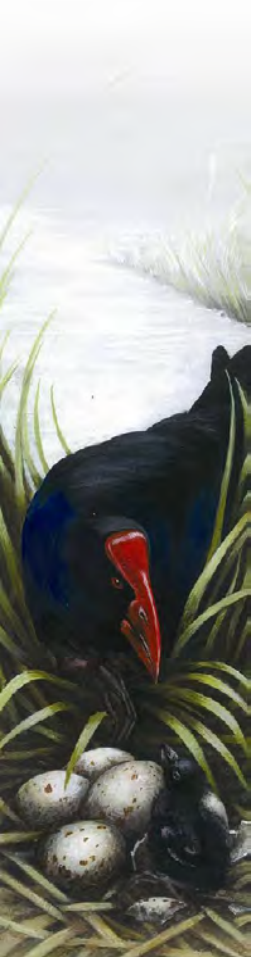
With the epidemiology of CF changing, there is a critical need to design health systems to preserve the achievements of paediatric medical care into adulthood. Central to this is a patient and family-centred transition process. If the adult-oriented health services are unable to accommodate an individual's needs at transfer, even a willing and prepared patient is unlikely to be successful. Likewise, if paediatricians do not trust the adult services to care adequately for their patients, this adds a further barrier to the transition of care [124].

As with diabetes, care for patients with CF needs to anticipate developmental changes in the early adult years relating to decision-making, relationships, employment, and taking on the increasing responsibility for self-managing aspects of their medical care. As CF is usually diagnosed before one year of age, children and their families have opportunities to develop skills and knowledge that will assist them in self-management well before adolescence [124].

Transition Principles

Whatever the model used, the transition from a paediatric to an adult service should not involve a sudden unanticipated transfer but rather be an organised process of preparation and adaptation. The process should be a component of a high quality service and must involve both teams of carers [119]. There is a growing body of literature providing guidance on the underlying principles and practices which underpin successful transition planning and implementation. These include:

- Transition of care needs to be individualised to meet the specific needs of the individual and their families [121] [127].
- A joint clinic with members of both paediatric and adult teams working together to facilitate a smooth transition process for adolescents and their parents [119].
- Staff in paediatric and adult services should meet regularly to discuss individuals who plan to transfer within the next year [126].
- Ongoing liaison between the two services is vital. Ideally, this involves the appointment of a liaison person who is able to move between the two services to aid with the transition of the young person [119] [127].
- The timing and provision of services should be discussed well in advance with the young person and their family. It is best if there is flexibility around the age of transition to meet the needs of individual patients, rather than the needs of the clinic [119] [127] [128].
- The transition should occur at a time when the individual's health is relatively stable, and should be coordinated with other life transitions [128].
- Young people should be allowed sufficient time to familiarise themselves with the practicalities of transition, as this has been shown to improve clinic attendance [128].
- The services themselves should be flexible enough to meet the needs of the range of young people they will need to cater for [121].
- The services should be appropriate for both chronological age and stage of development [121] [128].
- Clear plans about the transition should be developed and documented [128] [120]. A summary of the young person's medical notes including indices of control, co-morbidities and results of screening should be provided [119].
- Written transition plans should be updated annually [120].
- Educational material should be provided to facilitate the transition process [126].



- Transition programmes should be able to address common concerns that young people have, such as growth and development, sexuality, mood and other mental health disorders [121].
- Good communication and cooperation between all members of the paediatric and adult teams is essential [119] [125] [126].
- The primary care team looking after the individual concerned must be kept informed of the transition arrangements, including having full access to care records [127] [126].
- Mechanisms should be in place to ensure that young people are not lost to follow-up [119].
- Patients and their families should have the opportunity to ask questions of relevant staff from both services [126].
- There should be an evaluation phase following transition to ensure that transition took place in a timely fashion and that continuing appointments have been made [121].

Diabetes-specific

- Young people who are preparing for transition should be aware that some aspects of diabetes control, such as targets for short term control and screening for complications, may change as they enter adult services [128].
- The adult service should ensure long term follow-up of their patients who have developed diabetes as children or adolescents, as there is evidence showing that they are prone to poor glycaemic control and long term morbidities [119]

Cystic Fibrosis-specific

- All CF centres ought to have a transition programme that prepares children and adolescents to transfer to an adult CF centre [126].
- Ensure continuity between services by adopting the same treatment and diagnosis protocols, tailored to specific age groups [125].
- Where patients are being managed in a centre, infection control policies between the adult and paediatric units should be shared [125].
- The transition process should begin as early as possible by allowing developmentally appropriate involvement in self-care. For example, young children can learn how to administer their pancreatic enzymes, mix aerosols, or become more active in airway-clearance therapies [124].
- A transition programme should permit the assessment of the optimum time for transfer to the adult centre. For example, transition at a younger age may be appropriate for some individuals who are judged mature enough for transfer to adult care. Delayed transfer may be indicated in patients who are progressing through the terminal stage of their disease [126].

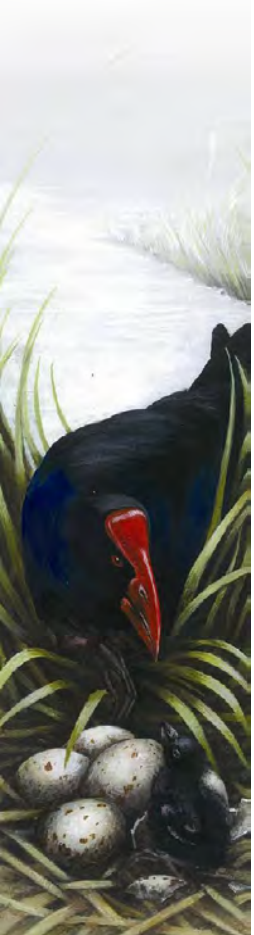
While it is recognised that the transition from paediatric to adult CF services is complex and multifaceted, there is scant empirical research beyond the descriptions of perceptions and experience. As more patients with CF reach the point where they require transition, the need for a comprehensive evidence-based approach increases [124].

Conclusion

Advances in medical care and the increased survival of medically fragile children have resulted in a growing number of technology dependent children living in the community. While being cared for at home is the preferred option for the majority of these children and their families, there are a number of issues that still need to be worked through, if families are to be supported to care for their children effectively. Prior to a decision about discharging a medically fragile child home, parents need to be actively involved in discussions about how the child's care will be managed. There is a need for a clear plan for the child's ongoing medical care, including documentation of roles and responsibilities. It is also preferable that someone other than the parents take the role of care coordinator. Further, parents need to be supported financially, both by providing a safety net through benefits, and by enabling parents to be in paid employment, if they so choose. It is also

important that the costs of care are not transferred to parents. Parents also need to be supported emotionally, with one way of doing so being the adequate provision of respite care. Further, ongoing research is required to adequately evaluate current models of care, as ideally occurs with any new service or programme.

There is also scant research on effective models for transition from paediatric to adult care. Transition often occurs at a time when adolescents are undergoing a number of changes in their life roles and responsibilities, and at a time when there is less structure in general in their lives. It is important that there is a seamless transition from one service to another, so as to ensure that the gains made in the paediatric years are not lost through an individual being lost to follow up. There are a number of underlying principles and practices which underpin such successful transitions, and these should be considered when examining the effectiveness of existing services, as well as when planning new services. Finally, there is a need to recognise that parents are just that – parents first and foremost, *not* nurses or care workers, and that they may need support in developing and sustaining a parenting role with their child [105].



DIABETES

Introduction

Overseas research suggests that the incidence of Type I diabetes is increasing in the paediatric population [129]. National and regional incidence studies during the past three decades have indicated that similar trends may also be occurring in New Zealand. During 1968-1972, a review of hospital admission data suggested an annual incidence (new cases per year) of 8.9 per 100,000 for those 0-15 years [130]. In Auckland during 1977-1984, registry data suggested rates of 9.3 per 100,000 [131], while a Canterbury audit during 1982-1990 suggested rates of 12.8 per 100,000 [132]. In contrast, active national surveillance over a two year period during 1999-2000 found an annual incidence of 17.9 per 100,000, with rates being 4.5 times higher amongst European children [129].

This same review also noted that while the incidence of Type 1 diabetes had doubled in New Zealand during the past three decades, the geographical (South Island > North Island) and ethnic (European > Māori) differences highlighted in previous reports had persisted [129]. In contrast, prevalence estimates (existing cases at a single point in time) based on a recent Christchurch review suggested that 227 per 100,000 of those aged 0-24 years had Type 1 diabetes, with rates being 274 per 100,000 in Europeans and 81 per 100,000 in Māori. The same report also noted a two to threefold rise in the prevalence of Type 1 diabetes since similar estimates were made in 1988 [133].

Active surveillance during 1999-2000 also suggested a number of risk factors for Type 1 Diabetes including [129]:

1. Age: 21% of new Type 1 diabetics were <5 years of age, with a median age of diagnosis of 9.5 years for males and 9.0 years for females and the peak incidence being between 9-11 years.
2. Ethnicity: Māori, Pacific and Asian children all had significantly lower rates of Type 1 diabetes than European children, with the incidence for Māori being 5.6 per 100,000, as compared to 21.7 per 100,000 for non-Māori children.
3. Family History: While there were no significant differences in diabetes incidence by gender, 8.8% of cases had a first degree relative with Type I diabetes.

At a population level, increases in the number of children and young people with Type 1 diabetes have significant implications for service delivery, with optimal long term outcomes requiring intensive management by the patient, their family and their health professional team [133]. It has been suggested that if the increases highlighted above continue at their current pace, new models of service delivery may be required in both paediatric and adult secondary care services [133]. In addition, with estimates of 1:500 school children having Type 1 diabetes, this has implications for health policy planning in schools as well, with most secondary schools likely to have at least one child with diabetes [133]. In the longer term, such increases may also signal increases in microvascular (e.g. retinopathy and nephropathy) and macrovascular disease (e.g. coronary heart disease, stroke and peripheral vascular disease) as the current generation of children and young people with Type 1 diabetes reach adulthood [134].

The following section uses the National Minimum Dataset to review hospital admissions for children and young people with any mention of insulin dependent or non-insulin dependent diabetes in any of the first 15 diagnoses.

Data Source and Methods

Definition

1. Hospital Admissions and Mortality for Children and Young People with Insulin Dependent Diabetes
2. Hospital Admissions and Mortality for Children and Young People with Non-Insulin Dependent Diabetes

Data Source

1.National Minimum Dataset

Numerator: Hospital Admissions for Children and Young People Aged 0-24 Years with Insulin Dependent Diabetes (ICD-10-AM E10) or Non-Insulin Dependent Diabetes Mellitus (ICD-10-AM E11) in any of the first 15 diagnoses.

Denominator: Statistics New Zealand Estimated Resident Population

2. National Mortality Collection

Numerator: Mortality for Children and Young People Aged 0-24 Years with Insulin Dependent Diabetes (ICD-10-AM E10) or Non-Insulin Dependent Diabetes Mellitus (ICD-10-AM E11) listed as either the main underlying cause of death, or as a contributory cause of death.

Denominator: Statistics New Zealand Estimated Resident Population

Notes on Interpretation

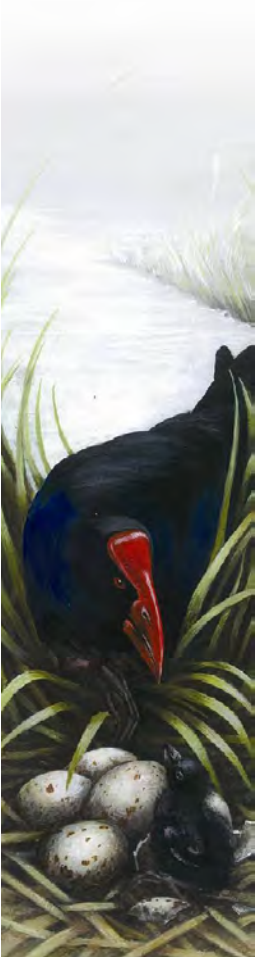
Unless otherwise specified, this analysis focuses on hospital admissions and mortality for children and young people who had diabetes listed in any of the first 15 diagnoses, or as a main underling or contributory cause of death (rather than on the subset where diabetes was listed only as the primary diagnosis or main underlying cause of mortality). The rationale for this wider focus was the need to highlight the full spectrum of health issues experienced by children and young people with diabetes, and their consequent requirement for acute health services. For example, during 2005-2009, around 2/3 of such hospitalisations for children and young people with IDDM were for diabetes related diagnoses such as ketoacidosis, but the remaining 1/3 were for other diagnoses, a proportion of which may have been more likely because of the diabetes (e.g. some types of infection), or because management may have been more complicated in diabetic patients (e.g. acute gastroenteritis). The presence of a small number of events in diabetic patients which were unrelated to their diabetes however, may slightly overinflate the impact diabetes has on acute service demand (see **Table 44** and **Table 45** to assess the likely contribution such conditions made to hospitalisation rates). If no mention of diabetes was made in any of the first 15 diagnoses however, these cases were not included (even if the patient had been assigned a diabetes related code on a previous admission).

Indicator Category Proxy B

New Zealand Distribution and Trends

Hospital Admissions by Primary Diagnosis

Insulin Dependent Diabetes: In New Zealand during 2005-2009, 67.5% of hospital admissions for children and young people with IDDM (i.e. any mention of IDDM in their first 15 diagnoses) were for diabetes related diagnoses, with ketoacidosis accounting for 30.2% and IDDM without complications for 27.9% of admissions during this period. A further 32.5% of hospitalisations were for diagnoses other than diabetes, with gastroenteritis, injuries and poisoning, and respiratory diseases being the most common reasons for non-diabetes related hospitalisations in patients with IDDM (**Table 44**).



Non-Insulin Dependent Diabetes: In New Zealand during 2005-2009, 17.8% of hospital admissions for children and young people with NIDDM (i.e. any mention of NIDDM in their first 15 diagnoses) were for diabetes related diagnoses, with NIDDM without complications accounting for 5.6% of admissions during this period. The remaining 82.2% were for non-diabetes related diagnoses, with cystic fibrosis (17.98% of admissions) and pregnancy and childbirth (10.2% of admissions) being the leading causes of non-diabetes related hospitalisations in patients with NIDDM (**Table 45**).

Mortality from Diabetes

Main Underlying Cause of Death: In New Zealand during 2003-2007, a total of 9 children and young people aged 0-24 years had IDDM listed as their main underlying cause of death, while one death had NIDDM listed as the main underlying cause, and in a further case the type of diabetes was unspecified. Of those dying from IDDM, 44.4% had diabetic ketoacidosis listed as the primary diabetic complication, with the remainder resulting from circulatory, renal or other specified diabetic complications.

Contributory Causes of Death: In addition, during 2003-2007 a further 3 children and young people aged 0-24 years had IDDM listed as a contributory cause of death, while one

had NIDDM listed as a contributory cause, and 5 had other specified or unspecified types of diabetes listed as contributory causes. The main underlying causes of death for those listed with diabetes as a contributory cause included cancer, injuries, cystic fibrosis and other medical conditions.

Table 44. Hospital Admissions for Children and Young People Aged 0-24 Years with Insulin Dependent Diabetes by Primary Diagnosis, New Zealand 2005-2009

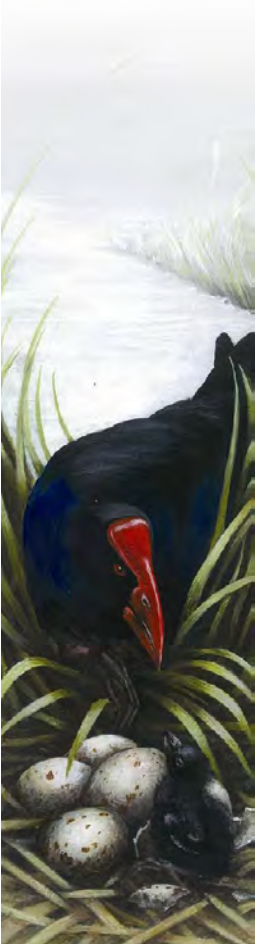
Primary Diagnosis	Number of Admissions Total 2005-2009	Number of Admissions Annual Average	Rate per 100,000	% of Admissions in those with IDDM
New Zealand				
Diagnoses other than IDDM*	2,672	534.4	35.4	32.5
IDDM with Ketoacidosis	2,483	496.6	32.9	30.2
IDDM without Complications	2,300	460.0	30.5	27.9
IDDM with Other Specified Complications	585	117.0	7.8	7.1
IDDM with Neurological Complications	54	10.8	0.7	0.7
IDDM with Ophthalmic Complications	48	9.6	0.6	0.6
IDDM with Coma	37	7.4	0.5	0.4
IDDM with Unspecified Complications	29	5.8	0.4	0.4
IDDM with Renal Complications	21	4.2	0.3	0.3
New Zealand Total	8,229	1,645.8	109.0	100.0
*Conditions Contributing to Diagnoses other than IDDM				
Gastroenteritis (A00-A09, K52, R11)	461	92.2	6.1	5.6
Injury and Poisoning (S00-T79, T90-T98)	251	50.2	3.3	3.1
Diseases of Respiratory System (J00-J99)	245	49.0	3.2	3.0
Pregnancy Childbirth Post Partum (O00-O99)	190	38.0	2.5	2.3
Skin Infections (L00-L08)	130	26.0	1.7	1.6
Viral Infection Unspecified Site (B34)	110	22.0	1.5	1.3
Abdominal and Pelvic Pain (R10)	107	21.4	1.4	1.3
Cystic Fibrosis (E84)	89	17.8	1.2	1.1
Other Infectious Diseases (A10-B99)	51	10.2	0.7	0.6
Complications Medical Surgical Care (T80-88)	48	9.6	0.6	0.6
All Other Diagnoses	990	198.0	13.1	12.0
Total Diagnoses other than IDDM	2,672	534.4	35.4	32.5

Source: Numerator: National Minimum Dataset, Primary Diagnosis for Children and Young People with IDDM listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Table 45. Hospital Admissions for Children and Young People Aged 0-24 Years with Non-Insulin Dependent Diabetes by Primary Diagnosis, New Zealand 2005-2009

Primary Diagnosis	No. of Admissions Total 2005-2009	No. of Admissions Annual Average	Rate per 100,000	% of Admissions in those with NIDDM
Non-Insulin Dependent Diabetes				
Diagnoses other than NIDDM*	1,042	208.4	13.81	82.2
NIDDM Without Complications	71	14.2	0.94	5.60
NIDDM with Other Specified Complications	55	11	0.73	4.34
NIDDM With Unspecified Complications	47	9.4	0.62	3.71
NIDDM with Ketoacidosis	24	4.8	0.32	1.89
NIDDM with Renal Complications	14	2.8	0.19	1.10
NIDDM with Ophthalmic Complications	9	1.8	0.12	0.71
NIDDM with Coma	<5	s	s	s
NIDDM with Neurological Complications	<5	s	s	s
New Zealand Total	1,268	253.6	16.80	100.00
*Conditions Contributing to Diagnoses other than NIDDM				
Cystic Fibrosis (E84)	228	45.6	3.02	17.98
Pregnancy Childbirth Post Partum (O00-99)	129	25.8	1.71	10.17
Diseases of Respiratory System (J00-J99)	69	13.8	0.91	5.44
Injury and Poisoning (S00-T79 T90-T98)	64	12.8	0.85	5.05
Skin Infections (L00-L08)	45	9	0.60	3.55
Cardiovascular Diseases (I00-I99)	42	8.4	0.56	3.31
Abdominal and Pelvic Pain (R10)	42	8.4	0.56	3.31
Mental Health Issues (F00-F19, F21-F99)	32	6.4	0.42	2.52
Schizophrenia (F20)	31	6.2	0.41	2.44
Gastroenteritis (A00-A09 K52 R11)	16	3.2	0.21	1.26
Other Infectious Diseases (A10-B99)	23	4.6	0.30	1.81
Neoplasms (C00-D48)	29	5.8	0.38	2.29
Complications Medical Surgical Care (T80-88)	29	5.8	0.38	2.29
All Other Diagnoses	263	52.6	3.48	20.74
Total Diagnoses other than NIDDM	1,042	208.4	13.81	82.18

Source: Numerator: National Minimum Dataset, Primary Diagnosis for children and young people with NIDDM listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

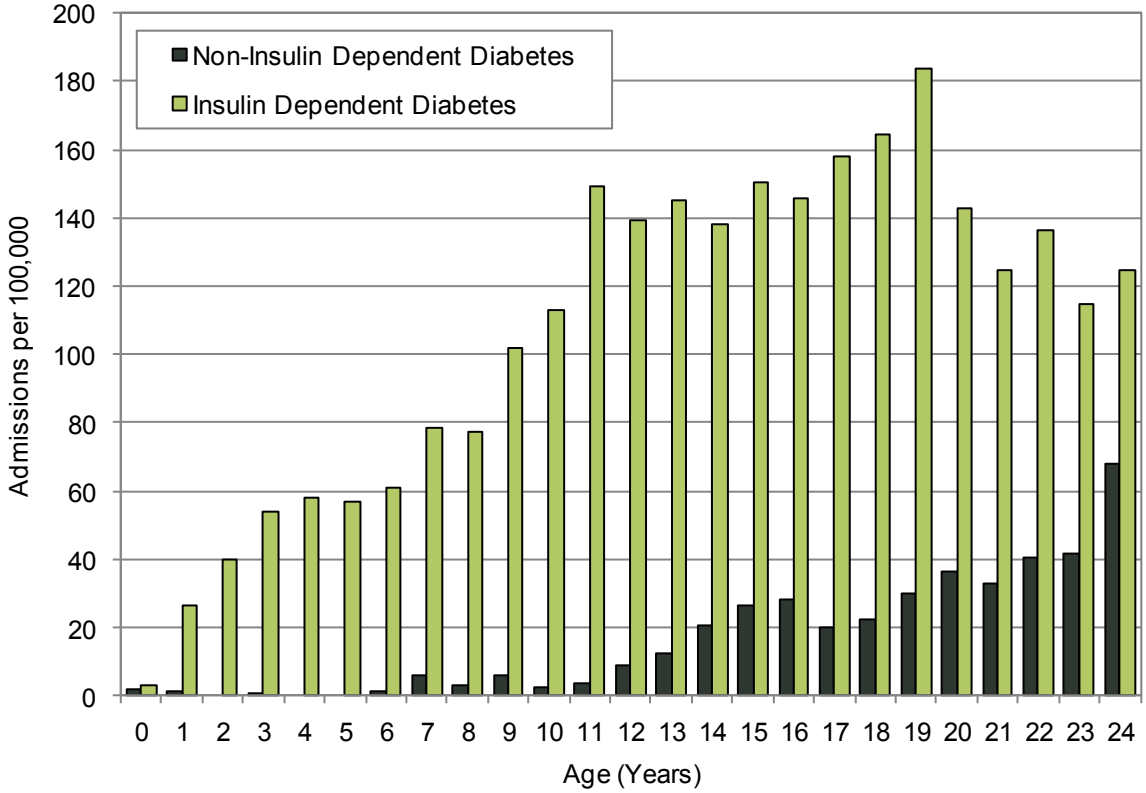


Distribution by Age

IDDM and NIDDM: In New Zealand during 2005-2009, hospitalisations for children and young people with IDDM increased during childhood, reached a peak amongst those in their late teens and then declined a little during the early 20s. In contrast, hospitalizations for NIDDM were infrequent during childhood, but increased gradually thereafter (**Figure 27**). During 2003-2007, all of those dying with IDDM or NIDDM were over 12 years of age, with IDDM deaths being reasonably evenly distributed across the teens and early twenties.

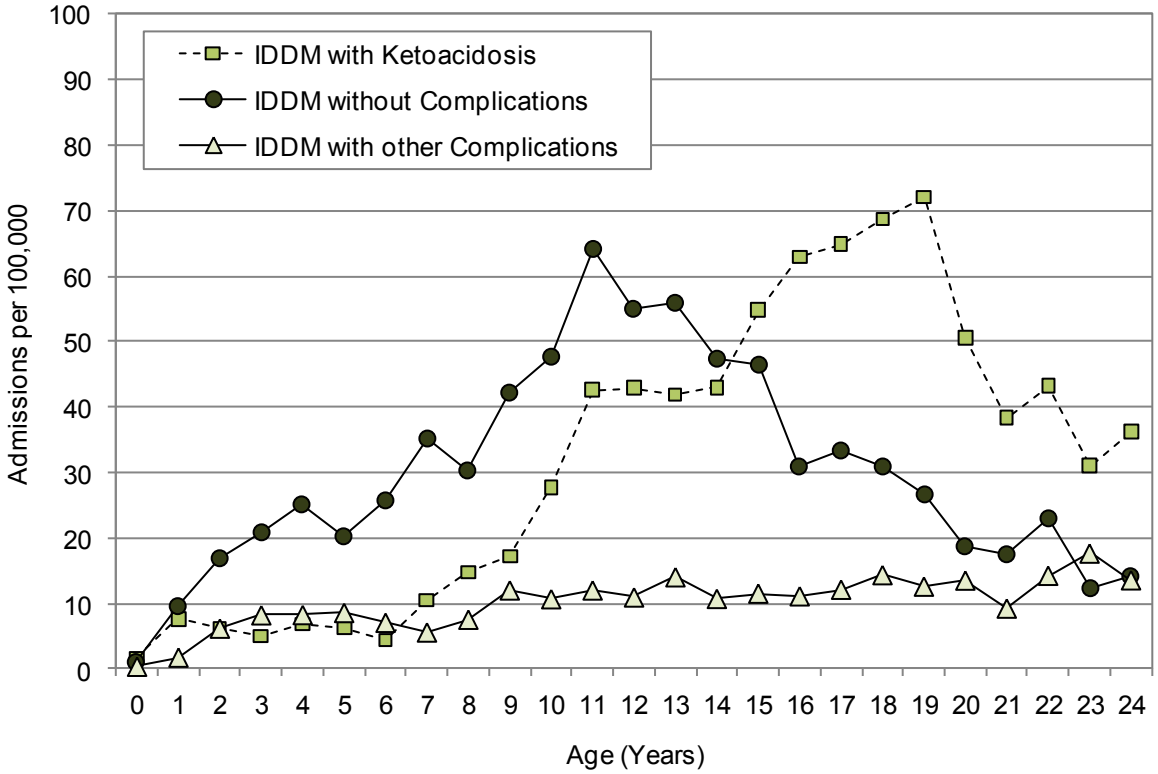
IDDM Complications: In New Zealand during 2005-2009, hospitalisations for children and young people with uncomplicated IDDM increased during childhood, reached a peak at 11 years of age and then declined. In contrast, hospitalisations for ketoacidosis in those with IDDM were relatively infrequent during early childhood, but then increased rapidly, reaching a peak amongst those in their late teens (**Figure 28**).

Figure 27. Hospital Admissions for Children and Young People with Insulin Dependent and Non-Insulin Dependent Diabetes by Age, New Zealand 2005-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with IDDM or NIDDM listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Figure 28. Hospital Admissions for Children and Young People with Insulin Dependent Diabetes by Age and Presence of Diabetic Complications, New Zealand 2005-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with IDDM listed in any of the first 15 diagnoses and a Diabetes related Primary Diagnosis. Denominator: Statistics NZ Estimated Resident Population

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2005-2009, hospitalisations for children and young people with IDDM (i.e. IDDM listed in any of the first 15 diagnoses) were *significantly* higher for females, European > Māori and Pacific > Asian children and young people, and those in average-more deprived (NZDep Decile 3-10) areas. In contrast, hospitalisations for children and young people with NIDDM were *significantly* higher for females, Pacific > Māori > European > Asian children and young people, and those in average-more deprived areas (**Table 46**). Similar ethnic differences were seen during 2000-2009 (**Figure 29**).

Table 46. Hospital Admissions for Children and Young People Aged 0-24 Years with Insulin Dependent and Non-Insulin Dependent Diabetes by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2005-2009

Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
Insulin Dependent Diabetes							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	78.1	1.00		Decile 1-2	73.4	1.00	
Decile 2	68.7	0.88	0.78 - 1.00	Decile 3-4	93.4	1.27	1.17 - 1.38
Decile 3	88.7	1.14	1.01 - 1.28	Decile 5-6	123.4	1.68	1.56 - 1.82
Decile 4	97.7	1.25	1.12 - 1.40	Decile 7-8	132.0	1.80	1.67 - 1.94
Decile 5	132.2	1.69	1.52 - 1.89	Decile 9-10	108.2	1.47	1.37 - 1.59
Decile 6	115.9	1.48	1.33 - 1.65	Prioritised Ethnicity			
Decile 7	133.6	1.71	1.54 - 1.90	Asian	12.6	0.09	0.07 - 0.11
Decile 8	130.6	1.67	1.51 - 1.85	European	141.7	1.00	
Decile 9	121.9	1.56	1.41 - 1.73	Māori	80.8	0.57	0.54 - 0.61
Decile 10	94.6	1.21	1.09 - 1.35	Pacific	70.8	0.50	0.45 - 0.55
Gender							
Female	125.9	1.00		Male	92.7	0.74	0.70 - 0.77
Non-Insulin Dependent Diabetes							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	9.0	1.00		Decile 1-2	8.6	1.00	
Decile 2	8.3	0.91	0.64 - 1.31	Decile 3-4	11.1	1.28	1.01 - 1.62
Decile 3	7.3	0.81	0.56 - 1.18	Decile 5-6	13.6	1.57	1.25 - 1.97
Decile 4	14.5	1.60	1.17 - 2.19	Decile 7-8	19.4	2.24	1.81 - 2.77
Decile 5	16.2	1.79	1.31 - 2.46	Decile 9-10	26.1	3.02	2.47 - 3.69
Decile 6	11.3	1.26	0.90 - 1.74	Prioritised Ethnicity			
Decile 7	17.0	1.89	1.39 - 2.56	Asian	3.7	0.26	0.18 - 0.37
Decile 8	21.3	2.36	1.77 - 3.15	European	14.3	1.00	
Decile 9	25.1	2.78	2.10 - 3.68	Māori	22.9	1.61	1.41 - 1.83
Decile 10	27.1	3.00	2.27 - 3.96	Pacific	33.4	2.35	2.01 - 2.74
Gender							
Female	21.0	1.00		Male	12.8	0.61	0.54 - 0.68

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with IDDM or NIDDM listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Rate is per 100,000 population.

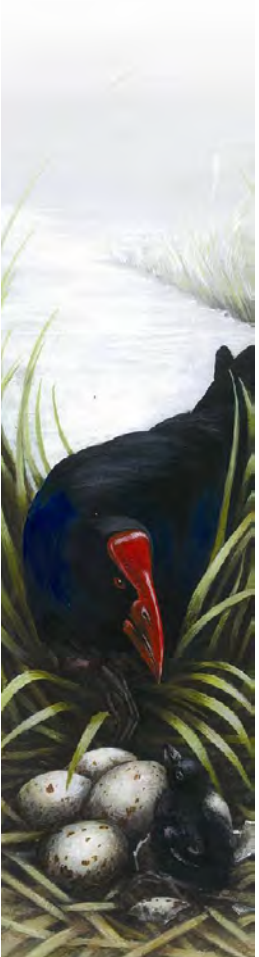
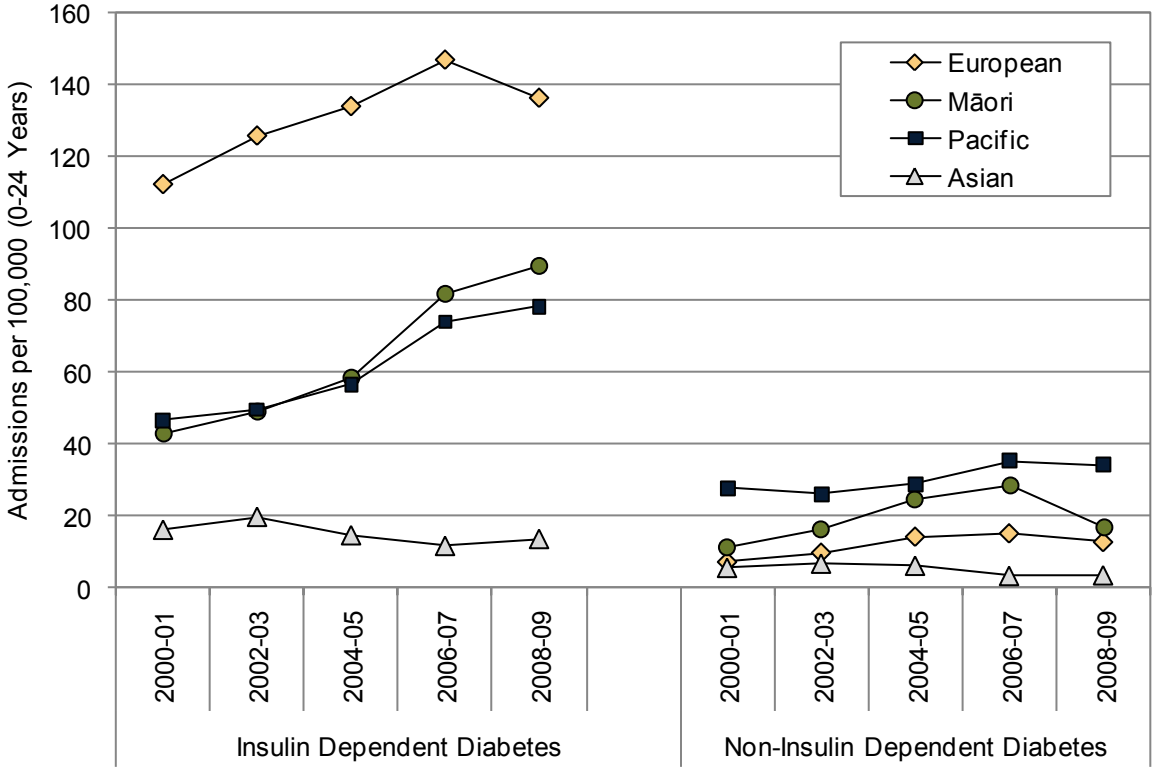


Figure 29. Hospital Admissions for Children and Young People Aged 0-24 Years with Insulin Dependent and Non-Insulin Dependent Diabetes by Ethnicity, New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with IDDM or NIDDM listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised.

Taranaki Distribution and Trends

Taranaki Distribution

In Taranaki during 2005-2009, a total of 76 individual patients were admitted to hospital with Insulin Dependent Diabetes listed in any of the first 15 diagnoses, while a further 12 individual patients were admitted with Non-Insulin Dependent Diabetes listed in any of the first 15 diagnoses. When hospitalisations per 100,000 population were considered, rates for IDDM in Taranaki were similar to the New Zealand average (RR 0.98 95% CI 0.85 – 1.13), while rates for NIDDM were *significantly* lower (RR 0.55 95% CI 0.34 – 0.89 (**Table 47**)).

Taranaki Trends

In Taranaki hospital admissions for children and young people with IDDM increased during the early-mid 2000s, reached a peak in 2006-07 and then declined, while admissions for those with NIDDM were more static (**Figure 30**).

Distribution by Primary Diagnosis

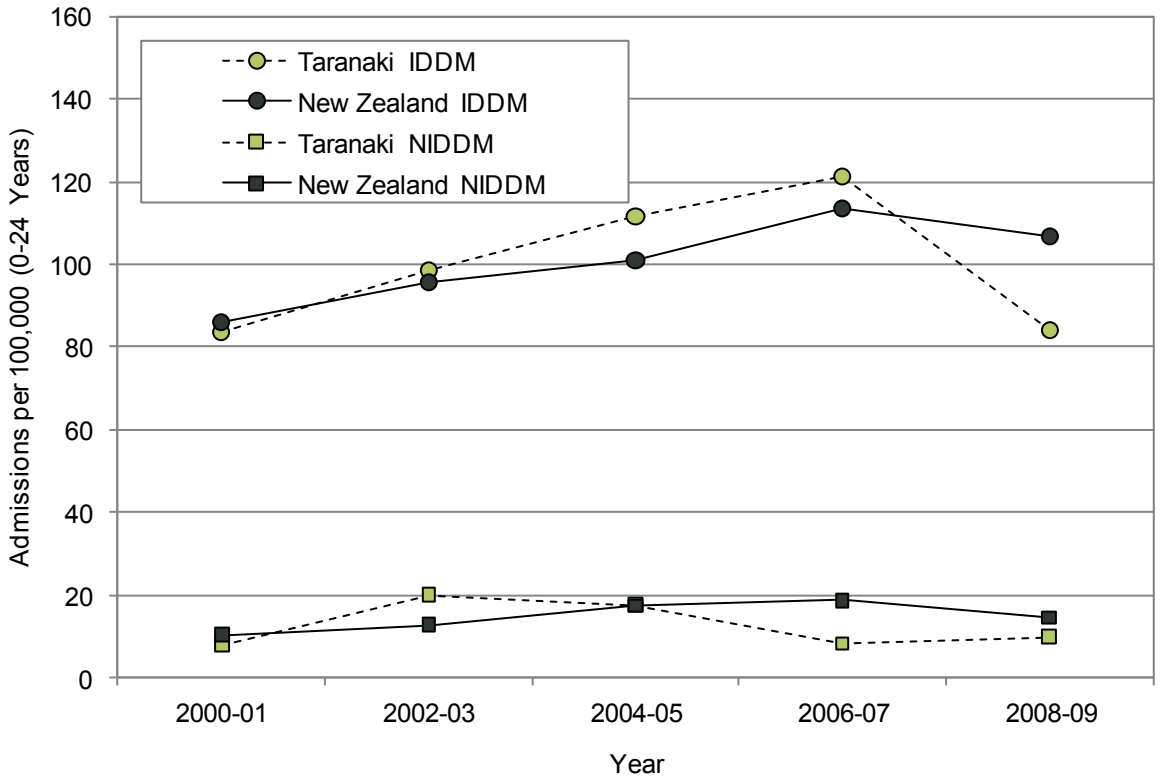
In Taranaki during 2005-2009, just under ¾ of hospital admissions in children and young people with IDDM (i.e. IDDM listed in any of their first 15 diagnostic codes) were for diabetes related diagnoses, with ketoacidosis accounting for 33.3% of admissions during this period. A further 27.2% of admissions were for IDDM without further complications (**Table 48**).

Table 47. Hospital Admissions for Children and Young People Aged 0-24 Years with Insulin Dependent and Non-Insulin Dependent Diabetes, Taranaki vs. New Zealand 2005-2009

DHB	Total Number Individuals 2005-2009		Total Admissions 2005-2009	Average Admissions per Individual per Year	Admission Rate per 100,000 Total Population	Rate Ratio	95% CI
	(A)*	(B)*					
Insulin Dependent Diabetes							
Taranaki	72	76	195	0.51	106.5	0.98	0.85 - 1.13
New Zealand	2,805		8,229	0.59	109.0	1.00	
Non-Insulin Dependent Diabetes							
Taranaki	11	12	17	0.28	9.3	0.55	0.34 - 0.89
New Zealand	600		1,268	0.42	16.8	1.00	

Source: Numerator: National Minimum Dataset: Individuals refers to total number of unique individuals with IDDM or NIDDM listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population. *Note: (A): Each individual only counted once in DHB in which they first reside (i.e. DHB total = NZ total); (B): Each individual counted once in each DHB in which they reside (i.e. the sum of DHB totals exceeds New Zealand total). Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

Figure 30. Hospital Admissions for Children and Young People Aged 0-24 Years with Insulin Dependent and Non-Insulin Dependent Diabetes, Taranaki vs. New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with IDDM or NIDDM listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population.

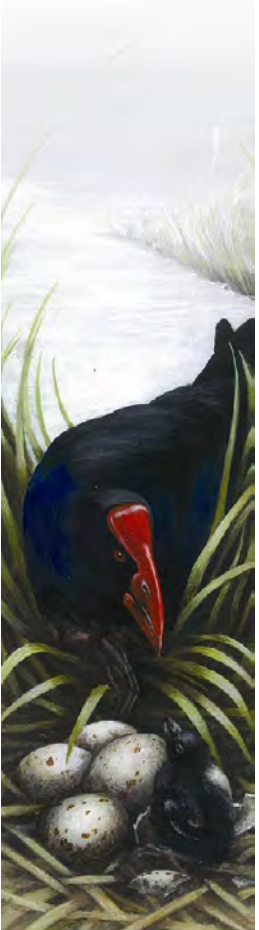


Table 48. Hospital Admissions for Children and Young People Aged 0-24 Years with Insulin Dependent Diabetes by Primary Diagnosis, Taranaki 2005-09

Primary Diagnosis	No. of Admissions: Total 2005-2009	No. of Admissions: Annual Average	Rate per 100,000	% of Admissions in those with IDDM
Taranaki Insulin Dependent Diabetes				
IDDM with Ketoacidosis	65	13.0	35.5	33.3
Diagnosis other than IDDM	55	11.0	30.0	28.2
IDDM without Complications	53	10.6	29.0	27.2
IDDM with other Specified Complications	13	2.6	7.1	6.7
IDDM with Unspecified Complications	<5	s	s	s
IDDM with Neurological Complications	<5	s	s	s
IDDM with Ophthalmic Complications	<5	s	s	s
Taranaki Total	195	39.0	106.5	100.0

Source: Numerator: National Minimum Dataset, Hospital Admissions by primary diagnosis for children and young people with IDDM listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population.

Summary

Insulin Dependent Diabetes: In New Zealand during 2005-2009, 67.5% of hospitalisations for children and young people with IDDM were for diabetes related diagnoses, with ketoacidosis accounting for 30.2%, and IDDM without complications for 27.9% of admissions. A further 32.5% were for non-diabetes diagnoses, with gastroenteritis, injuries, and respiratory diseases being the leading causes. Admissions increased during childhood, reached a peak in those in their late teens and then declined during the early 20s. Admissions were *significantly* higher for females, European > Māori and Pacific > Asian children and young people, and those in average-more deprived (NZDep Decile 3-10) areas.

In Taranaki during 2005-2009, a total of 76 individual patients were admitted to hospital with Insulin Dependent Diabetes listed in any of the first 15 diagnoses. When hospitalisations per 100,000 population were considered, rates for IDDM in Taranaki were similar to the New Zealand average (RR 0.98 95% CI 0.85 – 1.13).

Non-Insulin Dependent Diabetes: In New Zealand during 2005-2009, 17.8% of hospitalisations for children and young people with NIDDM were for diabetes related diagnoses, with NIDDM without complications accounting for 5.6% of admissions. The remaining 82.2% were for other diagnoses, with cystic fibrosis (17.98%) and pregnancy and childbirth (10.2%) being the leading causes. Hospitalisations were infrequent during childhood but increased gradually thereafter. Admissions were *significantly* higher for females, Pacific > Māori > European > Asian children and young people, and those in average-more deprived areas.

In Taranaki during 2005-2009, a total of 12 individual patients were admitted with Non-Insulin Dependent Diabetes listed in any of the first 15 diagnoses. When hospitalisations per 100,000 population were considered, rates for NIDDM in Taranaki were *significantly* lower than the New Zealand average (RR 0.55 95% CI 0.34 – 0.89).

Local Policy Documents and Evidence Based Reviews Relevant to the Management of Type 1 Diabetes

In New Zealand a small number of policy documents are relevant to the management of children and young people with Type 1 Diabetes and these are reviewed in **Table 49,** along with a range of guidelines and reviews which consider these issues in the overseas context.

Table 49. Local Policy Documents and Evidence Based Reviews Relevant to the Management of Type I Diabetes in Children and Young People

Ministry of Health Policy Documents and Reviews
Campbell S, Suebwongpat A, et al. **Systematic review update and economic evaluation for the New Zealand setting: Subcutaneous insulin pump therapy**. Christchurch: Health Services Assessment Collaboration, University of Canterbury, 2008. URL: http://www.hsci.canterbury.ac.nz/documents/Subcutaneous_Insulin_Pump.pdf This systematic review update was performed at the request of the Ministry of Health and considers the question "Is subcutaneous insulin pump therapy effective, safe, and cost-effective compared with multiple daily injections?" The update was based on the NHS technology assessment report [135] which informed the National Institute for Health and Clinical Excellence (NICE) recommendations for the use of continuous subcutaneous insulin infusion (CSII) in diabetes [136]. It concludes that compared to multiple daily injections, CSII produces a modest improvement in glycosylated haemoglobin levels in all patient groups assessed, including children, (which could be expected to result in a reduction in long term complications although as yet there have not been trials of long enough duration to show this). Based on the studies identified in this update there is limited evidence to support the contention that CSII produces a reduction in the incidence of severe hypoglycaemic events and improved quality of life (due to greater flexibility of lifestyle). The reviewers estimated that "if every patient who changed from MDI to CSII therapy was able to avoid one severe hypoglycaemic attack every two years (i.e. an improvement of 0.5 events per annum), the incremental cost per severe hypoglycaemic event avoided would be approximately $6,000. The total incremental cost associated with the introduction of CSII compared to MDI for a patient with Type 1 diabetes is approximately $16,000 over six years (the approximated life of the pump)."
Ministry of Health. **National Diabetes Retinal Screening Grading System and Referral Guidelines 2006**. Wellington: Ministry of Health, 2008. URL: http://www.moh.govt.nz/moh.nsf/by+unid/06E1C5F9A7E9BD45CC257257006E0E4A?Open These detailed guidelines aim to achieve a nationally consistent approach to classifying and referring people with significant diabetic retinopathy using eye screening photographs for review by an ophthalmologist. They also aim to provide standards against which to compare images for the purposes of measuring and monitoring grading and referrals, for comparison, training, and quality assurance purposes and to help ensure consistency between different clinicians seeing the same patient at different times. It is recommended that children have their first screening at puberty or five years after diagnosis, whichever is the earlier and that thereafter they should be screened two-yearly unless any abnormality is detected. All pregnant women should be screened in their first trimester of pregnancy and if no abnormality is found, continue with their two-yearly screening.
Ministry of Health. **Our Children's Health: Key Findings on the Health of New Zealand Children**. Wellington: Ministry of Health, 1998. URL: http://www.moh.govt.nz/moh.nsf/ea6005dc347e7bd44c2566a40079ae6f/ea72c39ba892a43a4c25666d007d37c1?OpenDocument While now somewhat dated, pages 197-202 of this document provide a good summary of insulin-dependent diabetes mellitus (IDDM) in children in New Zealand covering incidence, mortality and morbidity, prevalence, age, gender and ethnicity and changes in these statistics over time. It compares the incidence in New Zealand to that in other countries noting that it is similar to that in Australia, the US and the UK but lower than that in Scandinavia. There is a brief discussion of risk factors including genetics, nutrition and viruses.
Guidelines from the International Literature
International Society for Pediatric and Adolescent Diabetes. **ISPAD Clinical Practice Consensus Guidelines 2009 Compendium**. Pediatric Diabetes 2009; 10(Suppl. 12): 1-210. These guidelines from the International Society for Pediatric and Adolescent Diabetes (ISPAD) build on the national guidelines developed in Australia, Britain, Canada and the United States. The authors state: "We have used the American Diabetes Association grading system for grading evidence. Whenever possible, the reference for a statement or recommendation has been included, but as the reader will see, a vast majority of the recommendations and suggestions do have the grade E (Expert consensus or clinical experience) (p 1)". This is a very large compendium of information covering all aspects of child and adolescent diabetes. Education is recognised as being of central importance in clinical management. The increasing use of intensive therapy and insulin pumps (in countries where this is affordable) in all age groups necessitates better education for successful therapy.

British Society for Paediatric Endocrinology and Diabetes. **BSPED Recommended DKA Guidelines 2009**. 2009. URL: http://www.bsped.org.uk/professional/guidelines/index.htm

These guidelines provide a concise but detailed guide for the doctor treating a child with suspected diabetic ketoacidosis in an emergency room setting. They were originally produced by a working group of the British Society of Paediatric Endocrinology and Diabetes. They have been modified in the light of the ESPE/LWPES consensus statement on diabetic ketoacidosis in children and adolescents (Archives of Disease in Childhood, 2004, 89: 188-194) and the guidelines produced by the International Society for Pediatric and Adolescent Diabetes (Pediatric Diabetes, 2007: 8: 28–43). They provide links to where the evidence base for the guidelines can be found but do not include them.

AACE Clinical Guidelines Task Force. **American Association of Clinical Endocrinologists medical guidelines for clinical practice for the management of diabetes mellitus**. Endocrine Practice. 2007; 13(Suppl 1) (May/June).

These American guidelines provide a concise set of recommendations for glycaemic management in diabetes including a summary of the pharmacokinetics of the different types of insulin. Each of the recommendations is accompanied by a grading of the evidence base on which it is based.

Australian Paediatric Endocrine Group. **Clinical Practice Guidelines: Type 1 diabetes in children and adolescents**. 2005. URL: http://www.chw.edu.au/prof/services/endocrinology/apeg/

These comprehensive guidelines from the Australian Paediatric Endocrine Group (APEG) are aimed at health professionals caring for children and adolescents with type 1 diabetes, and replace the previous 1996 APEG Handbook. They are evidence-based according to NHMRC levels of scientific evidence. They cover background information, all aspects of the medical management of paediatric diabetes, special situations such as illness, surgery and travelling, lifestyle issues, psychosocial issues, complications and foot and dental care.

National Institute for Clinical Excellence. **Type 1 diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults**. London: National Institute for Clinical Excellence, 2004. URL: http://www.evidence.nhs.uk/search.aspx?t=diabetes

This clinical guideline from the National Institute for Clinical Excellence (NICE) in the UK offers evidence-based advice on the diagnosis of type 1 diabetes in children, young people and adults. It also covers the care and treatment that should be available in the NHS, including transition to adult care. The section on children covers diagnosis and initial management, ongoing management, complications and associated conditions, psychological and social issues and continuity of care.

National Collaborating Centre for Women's and Children's Health. **Type 1 diabetes: Diagnosis and management of type 1 diabetes in children and young people - evidence tables**. London: RCOG Press, 2004. URL: http://guidance.nice.org.uk/CG15/Guidance/Children/EvidenceTables/pdf/English

This document provides summary tables detailing the research studies on which the parts of the NICE guidelines dealing with children and young people were based. For each study the tables give brief information on the population studied, interventions, outcomes, results and design along with comments from the document authors and their assessment of the evidence level.

Systematic and Other Reviews from the International Literature Relevant to the Non-Pharmacological Management of Type 1 Diabetes

Thomas D, Elliott EJ. **Low glycaemic index, or low glycaemic load, diets for diabetes mellitus**. Cochrane Database of Systematic Reviews 2009(1): CD006296.

These reviewers investigated the effects of low glycaemic index, or low glycaemic load, diets on glycaemic control in people with diabetes. They found 11 relevant randomised controlled trials involving 402 participants. They found a significant decrease in HbA1c (weighted mean difference -0.5%) in the low GI groups in both the parallel and the cross-over trials. One study found significantly fewer episodes of hypoglycaemia in the low GI group compared to the high GI group and another found that there were significantly fewer hypoglycaemic episodes per month in the low GI group compared to a measured carbohydrate exchange diet. There were no studies which reported on mortality, morbidity or costs. The authors concluded that: "A low-GI diet can improve glycaemic control in diabetes without compromising hypoglycaemic events".

Clar C, Waugh N, et al. **Routine hospital admission versus out-patient or home care in children at diagnosis of type 1 diabetes mellitus**. Cochrane Database of Systematic Reviews 2007(2):CD004099.

This review of seven studies (only one of which was considered to be of high quality) involving a total 298 patients in the outpatient/at home group concluded that "Due to the generally low quality or limited applicability of the studies identified, the results of this review are inconclusive. On the whole, the data seem to suggest that where adequate out-patient/home management of type 1 diabetes in children at diagnosis can be provided, this does not lead to any disadvantages in terms of metabolic control, acute diabetic complications and hospitalisations, psychosocial variables and behaviour, or total costs."

Armour TA, Norris SL, et al. **The Effectiveness of Family Interventions in People With Diabetes Mellitus: A Systematic Review**. Diabetic Medicine 2005; 22(10): 1295-305.

This review based on a meta analysis of 19 randomised controlled trials suggests that family-based interventions may be effective in improving diabetes-related knowledge and glycaemic control (as indicated by glycated haemoglobin levels).

Loveman E, Royle P, et al. **Specialist nurses in diabetes mellitus**. Cochrane Database of Systematic Reviews 2003(2): CD003286.

This review considers the evidence for benefits the of diabetes specialist nurses or nurse case managers in diabetes on the metabolic control of patients with type 1 and type 2 diabetes mellitus. The review considered six studies comparing the effects of the involvement of specialist nurse care on outcomes for people with diabetes with usual care in hospital clinics or primary care with no input from specialist nurses. Of these studies, five were randomised controlled trials and one was a controlled clinical trial. There were a total of 1382 participants. There were no differences in the glycosylated haemoglobin (HbA1c) between the intervention groups the control groups over a 12-month follow up period. One study showed a significant reduction in HbA1c in the presence of the diabetes specialist nurse/nurse case manager at six months and one found significant differences in episodes of hypoglycaemia and hyperglycaemia between the intervention and control groups. In the studies that looked at emergency admissions and quality of life there were no significant differences found between groups. There were no studies assessing BMI, mortality, long-term diabetic complications, adverse effects, or costs. The authors point out that there are a number of difficulties in assessing complex interventions such as specialist nurses because of the multiple roles that they perform. They highlight the need for further research to investigate the issue and also to look at the cost-benefit considerations.

National Institute for Clinical Excellence. **Guidance on the use of patient-education models for diabetes**. Technology Appraisal 60. London: National Institute for Clinical Excellence, 2003. URL: http://www.nice.org.uk/download.aspx?o=TA060guidance

This document provides a general overview of the issues involved in the management of diabetes but puts particular emphasis on patient education. The authors reviewed the available evidence, which for type 1 diabetes consisted of two randomised controlled trials (RCTs) and two controlled clinical trials (CCTs). Only one study (an RCT with 37 patients) looked at education alone (and found no benefit from it), the others looked at education and intensified insulin treatment together. In general, intensified insulin treatment (including patient education) results in small improvements in HbA1c levels and fewer incidences of ketoacidosis and hospitalisations, but at a cost of more frequent severe hypoglycaemic events. The results from the study of Dose Adjustment for Normal Eating (DAFNE) programme in the UK showed similar results although it did not meet the reviewers' criteria for inclusion in the systematic review as there was a concurrent control group only for the first six months. The authors found two published economic evaluations, both from the USA, and both of limited applicability and generalisability. The authors concluded that there is insufficient evidence currently available to recommend a specific type of education or provide guidance on the setting for, or frequency of, sessions. However they recommended that structured patient education be made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on a formal, regular assessment of need, and that the education should be provided by a multidisciplinary team, including at least a diabetes specialist nurse and a dietician with help from other disciplines such as podiatry being beneficial.

Other Relevant Publications

Department of Health Diabetes Policy Team. **Making Every Young Person with Diabetes Matter: Report of the Children and Young People with Diabetes Working Group**. London: Department of Health, 2007. URL: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073674

This British report from the Children and Young People with Diabetes Working Group (which involved a wide range of stakeholders, including Diabetes UK, healthcare professionals, policy makers, purchasers and users of care) aimed to identify what needs to be done to improve care for children and young people with diabetes and to ensure that standards are met. It considers issues relating to the provision of services including commissioning and provision of services, workforce, audit and information technology.

Krebs J. **Expert Opinion of the use of long-acting insulin analogues**. New Zealand Society for the Study of Diabetes, 2008. URL: http://www.nzssd.org.nz/healthprofs/expertopinion.html

In this Expert Opinion from the New Zealand Society for the Study of Diabetes, the author compares the current situation regarding the use of the long acting insulin glargine in New Zealand with that in other countries. He makes a plea for the ability to use detemir (another long acting insulin), and the expansion of the criteria for the use long acting insulin (currently restricted through special authority to those with type 1 diabetes meeting criteria for hypoglycaemia) to include certain patients where compliance with other regimens is doubtful, where injections are given by carers, or similar situations.

Footnote: Some changes in this area have occurred according to a media release from Pharmac (16th August, 2010) http://www.pharmac.govt.nz/2010/08/16/Enhance%20access%20to%20diabetes%20treatments.pdf

- Widening access to the long-acting insulin glargine (Lantus);
- Funding a new rapid-acting insulin glulisine (Apidra);
- Widening access to blood ketones testing strips (Optium); and
- Widening access to the diabetes treatment acarbose (Glucobay).

New Zealand Society for the Study of Diabetes. **NZSSD Position Statement on Insulin Pump Therapy**. NZ Society for the Study of Diabetes, 2008. URL: http://www.nzssd.org.nz/position_statements/insulinpump.html

In this position statement the members of the executive of the NZSSD offer their recommendations on who should be eligible for Insulin Pump therapy and how such therapy should be administered.

Fisher LK. **The selection of children and adolescents for treatment with continuous subcutaneous insulin infusion (CSII)**. Pediatric Diabetes 2006; 7 Suppl 4: 11-14.

This paper aims to review what has been learned about the characteristics of patients (and their families) that are necessary for successful use of insulin pumps in diabetes therapy. It provides a list required motivational and treatment factors and states that “Children should be considered for CSII after diabetes management skills have been perfected, and where there exists understanding by both the child (at his/her level) and the parent as to what pump treatment can and cannot accomplish.”

EPILEPSY AND STATUS EPILEPTICUS

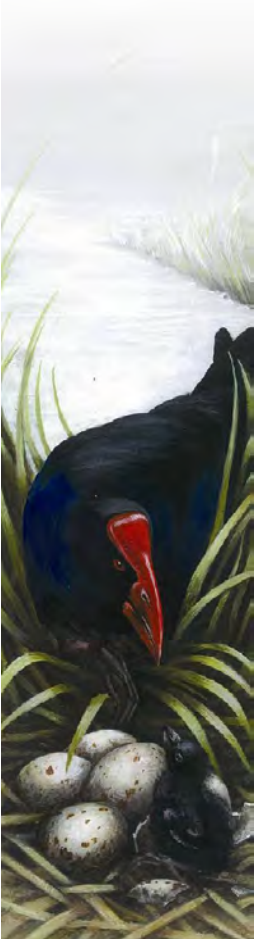
Introduction

Epilepsy is the most common serious neurological illness in children and young people. It is a cause of significant morbidity for those affected and has significant resource implications for the health care system. In developed countries, it is generally accepted that the incidence (number of new cases) of epilepsy is 50 per 100,000 per year, while the prevalence (existing cases at any point in time) is 5-10 per 1,000 [137]. In the year ending June 2009, PHARMAC estimated that the New Zealand health sector spent $25.9 million on anti-epilepsy medications [138].

Despite its significant impact, epilepsy is not an entity in itself, but rather a symptom complex arising from a variety of different processes. Causes vary with age, with congenital, developmental and genetic conditions being most commonly associated with the development of epilepsy in childhood, while head trauma, central nervous system infections and tumours may lead to epilepsy at any age [137]. In addition, in a proportion of cases, the underlying cause for the epilepsy is unknown [139]. In developed countries, it had been consistently shown that despite an overall good prognosis for seizure control, those with epilepsy have a 2-3 fold increase in risk of mortality compared to those without epilepsy, with most deaths being directly related to the epilepsy itself [140]. In addition, a recent audit of epilepsy related deaths in the UK found that 59% of deaths during childhood could have potentially or probably been avoided given sufficient attention to appropriate drug management, access to specialist care, or adequate investigations [140].

The appropriate management of status epileptics is thus of prime importance. Convulsive status epilepticus has been defined as more than 30 minutes of continuous seizure activity, or two or more sequential seizures without full recovery of consciousness between seizures, although a revised definition (based on the indication to commence treatment) has recommended defining status epilepticus as seizures of 5 minutes or more in children older than 5 years of age [141]. Status epilepticus is associated with significant mortality, with estimates of 3% in paediatric population data, and as high as 32% in patients with refractory status epilepticus in the paediatric intensive care setting. Morbidity following status epilepticus includes the development of focal neurological deficits, cognitive impairment and behavioural problems [141]. The management of status epilepticus is time critical, with longer seizure durations being associated with greater brain injury and poorer outcomes. As a result, a set of Australasian practice guidelines has recently been released, which outline the optimal management of status epilepticus in the emergency department setting [141].

The following section uses the National Minimum Dataset to review hospital admissions in children and young people with any mention of epilepsy or status epilepticus in any of the first 15 diagnoses.



Data Source and Methods

Definition

1. Hospital Admissions and Mortality for Children and Young People with Epilepsy or Status Epilepticus

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions for Children and Young People Aged 0-24 Years with Epilepsy (ICD-10-AM G40) or Status Epilepticus (ICD-10-AM G41) in any of the first 15 diagnoses.

Denominator: Statistics New Zealand Estimated Resident Population

2. National Mortality Collection

Numerator: Mortality in Children and Young People Aged 0-24 Years with Epilepsy (ICD-10-AM G40) or Status Epilepticus (ICD-10-AM G41) listed as either the main underlying cause of death, or as a contributory cause of death.

Denominator: Statistics New Zealand Estimated Resident Population

Notes on Interpretation
Unless otherwise specified, this analysis focuses on hospital admissions and mortality for children and young people who had epilepsy or status epilepticus listed in any of the first 15 diagnoses, or as a main underling or contributory cause of death (rather than on the subset where these diagnoses were listed only as the primary diagnosis or main underlying cause of mortality). The rationale for this wider focus was the need to highlight the full spectrum of health issues experienced by children and young people with epilepsy and their consequent requirement for acute health services. For example, during 2005-2009, around 70.5% of hospitalisations for children and young people with epilepsy or status epilepticus had these conditions listed as their primary diagnosis, but a significant minority were admitted for infectious and respiratory diseases, pregnancy related issues or for injuries. Further a review of the secondary diagnoses of those admitted with a primary diagnosis of epilepsy or status epilepticus indicated that while infections or respiratory diseases contributed to a significant proportion of such admissions, a number of children had other underlying conditions (e.g. cerebral palsy, developmental delay, congenital anomalies of the CNS) which may have increased their risk of developing epilepsy. The presence of a small number of events in patients with epilepsy which were unrelated to the epilepsy itself however, may slightly overinflate the impact epilepsy has on acute service demand. If no mention of epilepsy or status epilepticus was made in any of the first 15 diagnoses, these cases were not included (even if the patient had been assigned an epilepsy related code on a previous admission). Note: Children and young people with febrile convulsions or convulsions NOS were not included in the analysis (unless they also had a diagnosis of epilepsy or status epilepticus), on the basis that for many, such seizures are one off events which do not lead to a subsequent diagnosis of epilepsy.

Indicator Category Proxy B

New Zealand Distribution and Trends

Distribution by Cause

Primary Diagnosis: In New Zealand during 2005-2009, 70.5% of all hospital admissions in children and young people with epilepsy or status epilepticus (i.e. these diagnoses mentioned in any of the first 15 diagnoses), were for epilepsy related diagnoses, with generalised idiopathic epilepsy (27.3%) and unspecified epilepsy (21.1%) making the greatest contribution. A further 29.5% of admissions were for conditions unrelated to epilepsy, with respiratory infections and diseases, pregnancy and childbirth, and injuries making the largest contributions in this category (**Table 50**).

Secondary Diagnosis: During the same period, secondary diagnoses for children and young people admitted with epilepsy or status epilepticus as a primary diagnosis, tended to fall into two main categories: conditions which may have increased the risk of the child or young person developing epilepsy (e.g. cerebral palsy, congenital anomalies of the nervous system); and acute concurrent illnesses such as respiratory infections and otitis media (**Table 51**).

Distribution by Age

In New Zealand during 2005-2009, hospital admissions for epilepsy and status epilepticus were highest during the first five years of life, with rates declining during mid-late childhood, but increasing again during the mid-late teens. In contrast, during 2003-2007 mortality was more frequent amongst those in their teens and early 20s, although a smaller number of deaths also occurred during childhood. During this period, a total of 57 children and young people died of epilepsy or status epilepticus (**Figure 31**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2005-2009, hospital admissions for epilepsy or status epilepticus were *significantly* higher for males, Māori and Pacific > European > Asian children and young people and those living in average-more deprived (NZDep deciles 3-10) areas (**Table 52**). Similarly, during 2000-2009, admissions were consistently lower for Asian than for Māori, Pacific and European children and young people (**Figure 32**).

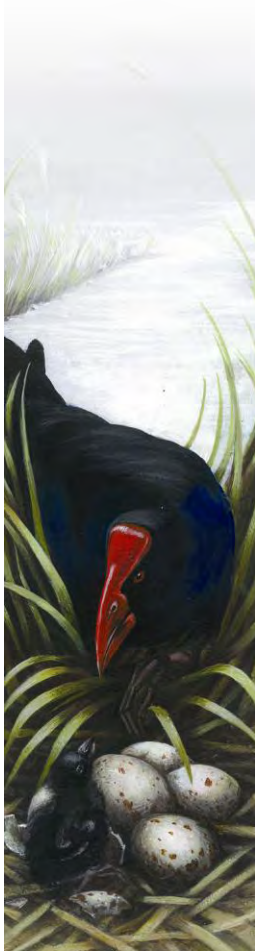


Table 50. Hospital Admissions in Children and Young People Aged 0-24 Years with Epilepsy or Status Epilepticus by Primary Diagnosis, New Zealand 2005-2009

Primary Diagnosis	Number of Admissions Total 2005-2009	Number of Admissions Annual Average	Rate per 100,000 Population	% of Admissions in those with Epilepsy / Status Epilepticus
Epilepsy or Status Epilepticus				
Generalised: Idiopathic (G403)	2,480	496.0	32.9	27.3
Unspecified Epilepsy (G409)	1,913	382.6	25.3	21.1
Status Epilepticus: Grand Mal (G410)	674	134.8	8.93	7.42
Status Epilepticus: Complex Partial (G412)	477	95.4	6.32	5.25
Focal: Symptomatic with Simple Partial Seizures (G401)	336	67.2	4.45	3.70
Generalised: Other (G404)	331	66.2	4.39	3.65
Other Epilepsy (G408)	131	26.2	1.74	1.44
Special Epileptic Syndromes (G405)	53	10.6	0.70	0.58
Status Epilepticus: Petit Mal (G411)	11	2.2	0.15	0.12
Total Epilepsy or Status Epilepticus	6,406	1,281.2	84.9	70.5
Other Diagnoses				
Respiratory Infections and Diseases (J00-J99)	480	96.0	6.36	5.29
Pregnancy, Childbirth, Puerperium (O00-O99)	231	46.2	3.06	2.54
Injuries (S00-T35, T66-T79)	227	45.4	3.01	2.50
Infectious and Parasitic Diseases (A00-B99)	187	37.4	2.48	2.06
Dental and Oral Health (K00-K14)	168	33.6	2.23	1.85
Unspecified Convulsions (R568)	43	8.6	0.57	0.47
All Other Diagnoses	1,339	267.8	17.7	14.7
Total Other Diagnoses	2,675	535.0	35.4	29.5
Total	9,081	1,816.2	120.3	100.0

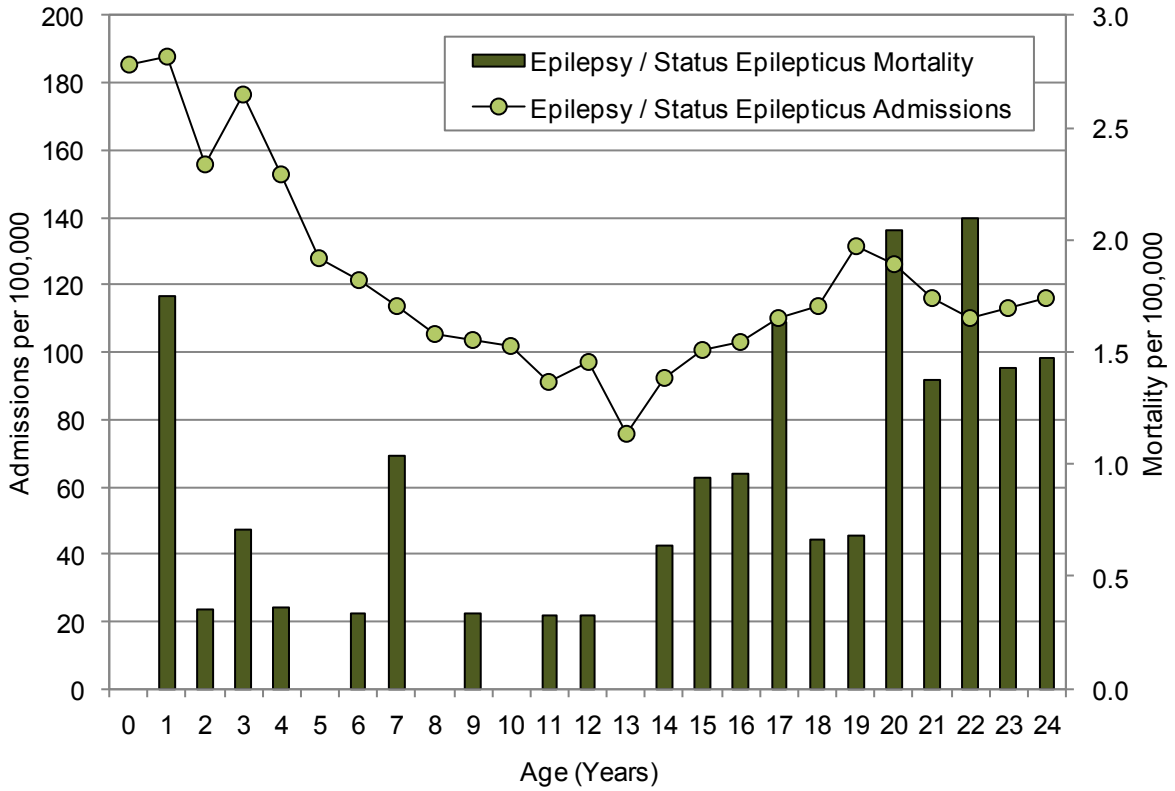
Source: Numerator: National Minimum Dataset, Hospital Admissions by primary diagnosis for children and young people with Epilepsy or Status Epilepticus listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Table 51. Secondary Diagnosis in Children and Young People Aged 0-24 Years Hospitalised with Epilepsy or Status Epilepticus as a Primary Diagnosis, New Zealand 2005-2009

Secondary Diagnosis	Number of Admissions Total 2005-2009	Number of Admissions Annual Average	% Admissions in those with Epilepsy / Status Epilepticus as Primary Diagnosis
Those with Epilepsy or Status Epilepticus as a Primary Diagnosis			
Respiratory Infections and Diseases (J00-J99)	324	64.8	5.06
Cerebral Palsy (G80)	301	60.2	4.70
Epilepsy or Status Epilepticus (G40-G41)	45	9.0	0.70
Other Diseases of Nervous System (G00-G99)	303	60.6	4.73
Non Compliance with Treatment (Z911)	267	53.4	4.17
Injuries (S00-T35, T66-T79)	195	39.0	3.04
Congenital Anomalies Nervous System (Q00-Q07)	123	24.6	1.92
Other Congenital Anomalies (Q10-Q99)	174	34.8	2.72
Developmental Delay (R62)	171	34.2	2.67
Infectious and Parasitic Diseases (A00-B99)	158	31.6	2.47
Mental Retardation (F70-F79)	108	21.6	1.69
Pervasive Developmental Disorders (including Autism) (F84)	92	18.4	1.44
Fever of Unknown Origin (R50)	54	10.8	0.84
Otitis Media (H65-H67)	52	10.4	0.81
Other Diagnoses	1,284	256.8	20.04
No Secondary Diagnosis	2,755	551.0	43.01
Total	6,406	1,281.2	100.00

Source: Numerator: National Minimum Dataset, Hospital Admissions by secondary diagnosis for children and young people with Epilepsy or Status Epilepticus listed as their primary diagnosis. Denominator: Statistics NZ Estimated Resident Population.

Figure 31. Hospital Admissions (2005-2009) and Mortality (2003-2007) for New Zealand Children and Young People with Epilepsy or Status Epilepticus by Age



Source: Numerator Admissions: National Minimum Dataset, Hospital Admissions for children and young people with Epilepsy or Status Epilepticus listed in any of the first 15 diagnoses; Numerator Mortality: National Mortality Collection, Deaths with Epilepsy or Status Epilepticus listed as the main underlying or a contributory cause of death. Denominator: Statistics NZ Estimated Resident Population.

Table 52. Hospital Admissions for Children and Young People Aged 0-24 Years with Epilepsy or Status Epilepticus by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2005-2009

Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
Epilepsy or Status Epilepticus							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	76.3	1.00		Decile 1-2	79.6	1.00	
Decile 2	82.8	1.08	0.96 - 1.22	Decile 3-4	93.7	1.18	1.09 - 1.28
Decile 3	98.6	1.29	1.15 - 1.45	Decile 5-6	96.6	1.21	1.12 - 1.32
Decile 4	89.3	1.17	1.04 - 1.31	Decile 7-8	140.2	1.76	1.64 - 1.89
Decile 5	101.1	1.32	1.18 - 1.49	Decile 9-10	160.7	2.02	1.88 - 2.17
Decile 6	92.9	1.22	1.09 - 1.36	Prioritised Ethnicity			
Decile 7	134.4	1.76	1.58 - 1.96	Asian	48.1	0.39	0.36 - 0.44
Decile 8	145.1	1.90	1.72 - 2.10	European	121.8	1.00	
Decile 9	157.1	2.06	1.86 - 2.27	Māori	140.1	1.15	1.10 - 1.21
Decile 10	164.3	2.15	1.95 - 2.38	Pacific	136.8	1.12	1.05 - 1.21
Gender							
Female	115.9	1.00		Male	124.6	1.08	1.03 - 1.12

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Epilepsy or Status Epilepticus listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Rate is per 100,000 population.

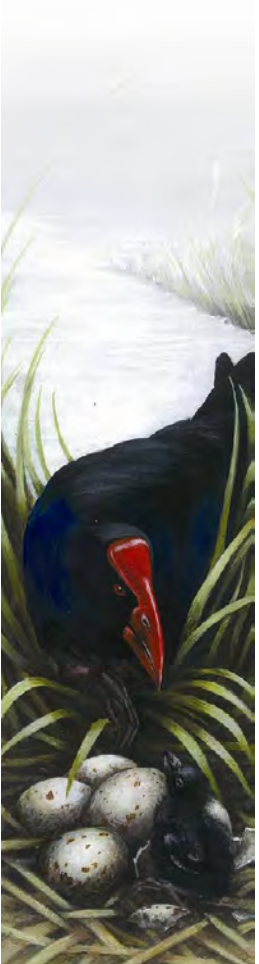
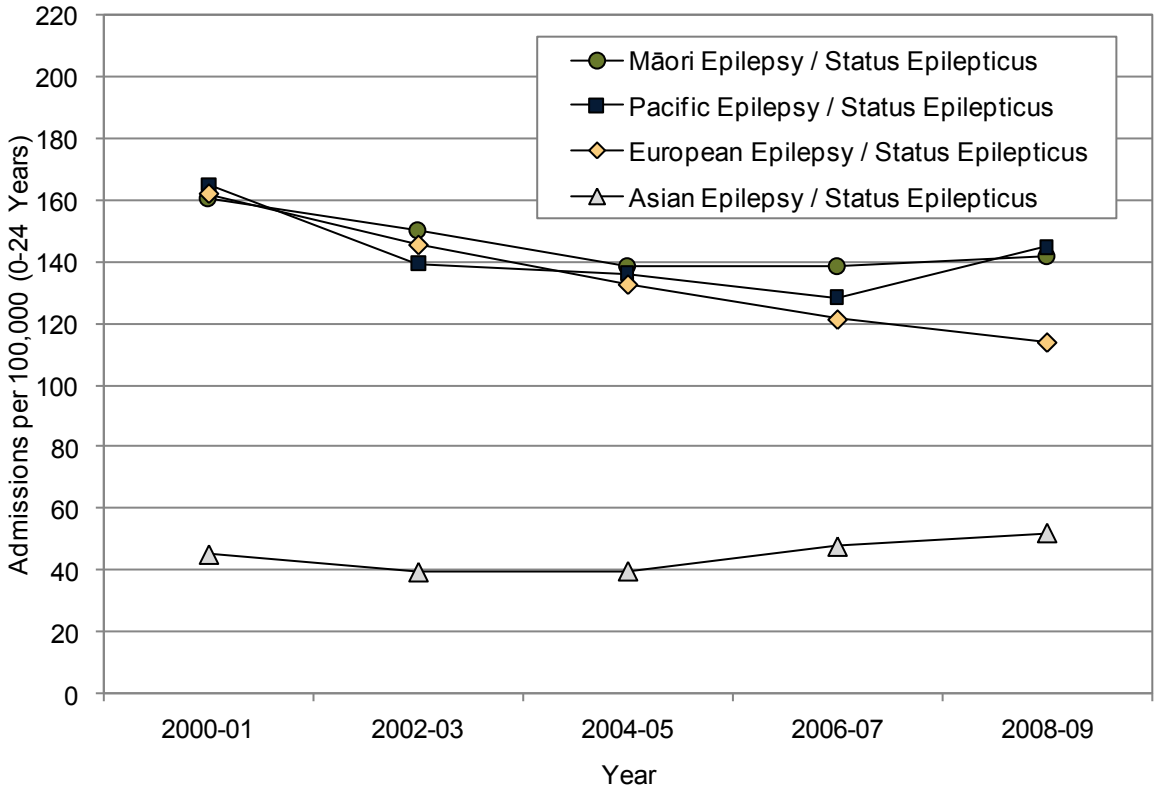


Figure 32. Hospital Admissions for Children and Young People Aged 0-24 Years with Epilepsy or Status Epilepticus by Ethnicity, New Zealand 2000-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Epilepsy or Status Epilepticus listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised.

Taranaki Distribution and Trends

Taranaki Distribution and Trends

In Taranaki during 2005-2009, a total of 99 individual children and young people were admitted with a diagnosis of epilepsy or status epilepticus, with hospital admission rates per 100,000 population being similar to the New Zealand average (RR 1.07 95% CI 0.94 – 1.21) (**Table 53**). Similar patterns were seen during 2000-2009 (**Figure 33**).

Table 53. Hospital Admissions for Children and Young People Aged 0-24 Years with Epilepsy or Status Epilepticus, Taranaki vs. New Zealand 2005-2009

DHB	Total Number Individuals 2005-2009		Total Admissions 2005-2009	Average Admissions per Individual per Year	Admission Rate per 100,000 Total Population	Rate Ratio	95% CI
	(A)*	(B)*					
Epilepsy and Status Epilepticus							
Taranaki	94	99	235	0.47	128.4	1.07	0.94 - 1.21
New Zealand	3,925		9,081	0.46	120.3	1.00	

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Epilepsy or Status Epilepticus listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. *Note: (A): Each individual only counted once in DHB in which they first reside (i.e. DHB total = NZ total); (B): Each individual counted once in each DHB in which they reside (i.e. the sum of DHB totals exceeds New Zealand total). Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

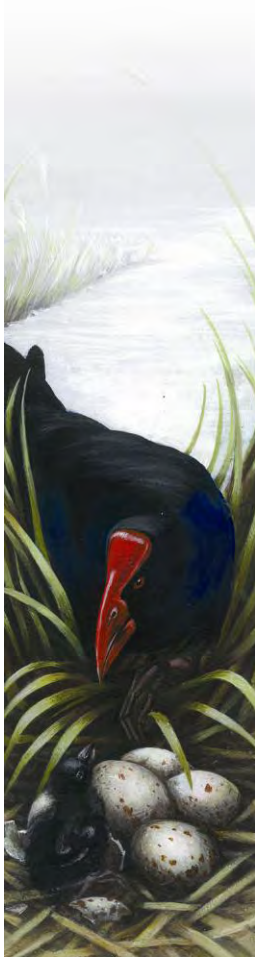
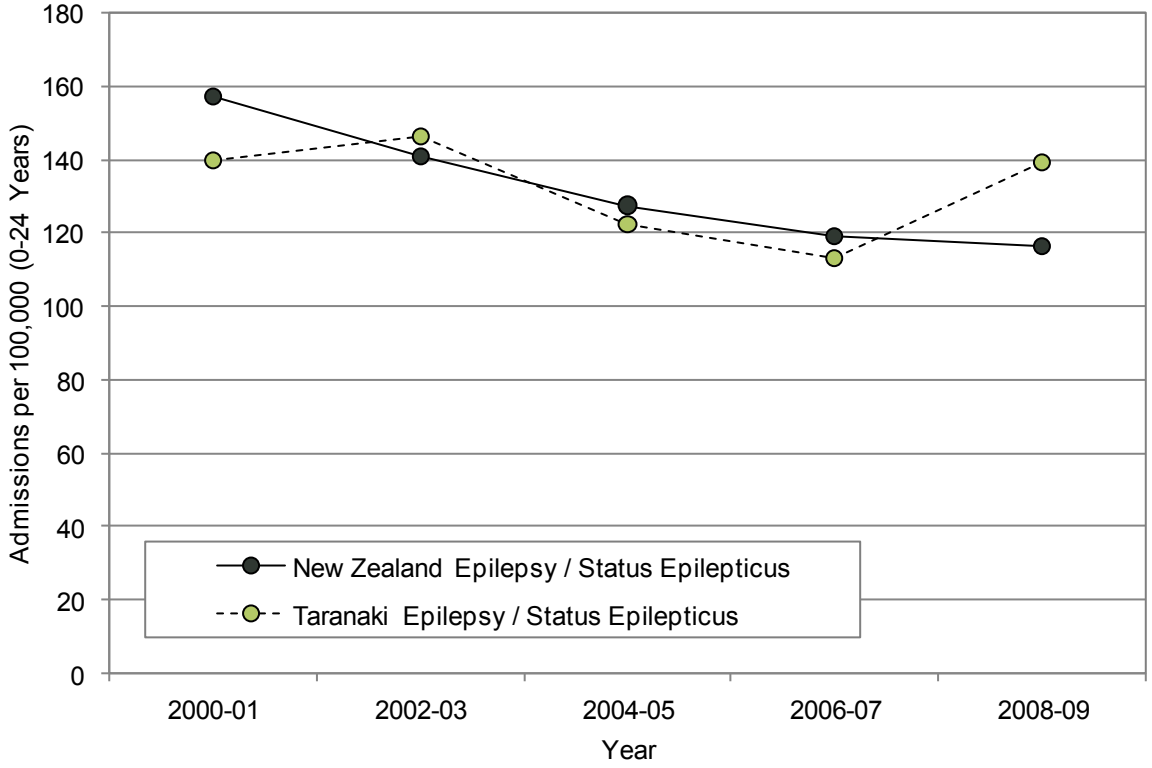


Figure 33. Hospital Admissions for Children and Young People Aged 0-24 Years with Epilepsy or Status Epilepticus, Taranaki vs. New Zealand 2000-2009



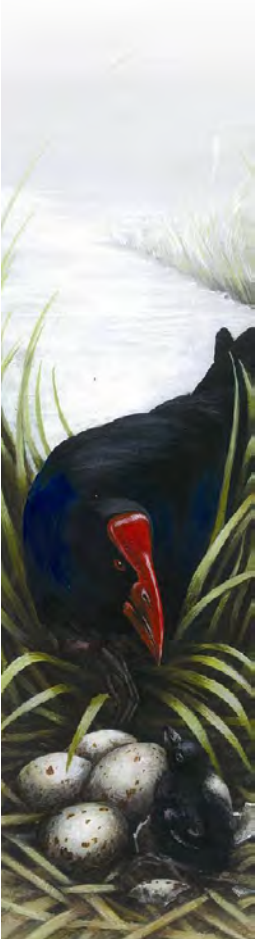
Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Epilepsy or Status Epilepticus listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population.

Summary

In New Zealand during 2005-2009, 70.5% of hospital admissions in children and young people with epilepsy or status epilepticus were for epilepsy related diagnoses, with generalised idiopathic epilepsy (27.3%) and unspecified epilepsy (21.1%) making the greatest contribution. A further 29.5% of admissions were for conditions unrelated to epilepsy, with respiratory infections and diseases, pregnancy and childbirth, and injuries making the largest contributions. Secondary diagnoses for those admitted with epilepsy or status epilepticus as a primary diagnosis, fell into two main categories: conditions which may have increased the risk of developing epilepsy (e.g. cerebral palsy, congenital anomalies of the nervous system); and acute concurrent illnesses such as respiratory infections and otitis media.

During 2005-2009, admissions were highest during the first five years of life, with rates declining during mid-late childhood, but increasing again during the mid-late teens. Mortality was more frequent for those in their teens and early 20s, with a total of 57 children and young people dying from epilepsy or status epilepticus during 2003-2007. Hospital admissions were also *significantly* higher for males, Māori and Pacific > European > Asian children and young people and those in average-more deprived (NZDep deciles 3-10) areas.

In Taranaki during 2005-2009, a total of 99 individual children and young people were admitted with a diagnosis of epilepsy or status epilepticus, with hospital admission rates per 100,000 population being similar to the New Zealand average (RR 1.07 95% CI 0.94 – 1.21). Similar patterns were seen during 2000-2009.



Policy Documents and Evidence Based Reviews Relevant to the Diagnosis or Management of Epilepsy or Status Epilepticus

In New Zealand, a recently released Australasian practice guideline outlines recommended best practice in the emergency management of status epilepticus. This guideline, along with a range of other international guidelines and evidence based reviews is briefly summarised in **Table 54.** (Note: It was beyond the scope of this review to consider publications which explored the efficacy of individual drugs in the management of epilepsy, with the focus of the table below being on broader management principles).

Table 54. Policy Documents and Evidence Based Reviews Relevant to the Diagnosis or Management of Epilepsy or Status Epilepticus

International Guidelines
Gaillard WD, Chiron C, et al. **Guidelines for imaging infants and children with recent-onset epilepsy.** Epilepsia 2009; 50(9): 2147-53. These guidelines are the result of a review by the Subcommittee for Pediatric Neuroimaging of the International League Against Epilepsy (ILAE), which examined published series reporting the use of computed tomography (CT) and magnetic resonance imaging (MRI) for the evaluation of children with new-onset seizure(s). The reviewers reported that nearly 50% of imaging studies in these children were abnormal and they provide details on the findings on imaging (or lack of them) and their diagnostic, prognostic and management implications for particular types of epilepsy. They recommend imaging, preferably with MRI if this is available, (because of the lack of radiation and its superior resolution and versatility), when localisation-related epilepsy is known or suspected, when there is doubt about the epilepsy classification, or when there is suspicion of an epilepsy syndrome with remote symptomatic cause.
Riviello JJ, Jr., Ashwal S, et al. **Practice parameter: Diagnostic assessment of the child with status epilepticus (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society**. Neurology 2006; 67(9): 1542-50. The recommendations in this practice parameter are based on a review of the relevant literature and follow the evidence grading system of the American Academy of Neurology. They cover the indications for use of routine laboratory studies, blood cultures, lumbar puncture, measurement of anti-epileptic drug levels, toxicology and metabolic studies and EEG and neuroimaging with CT or MRI.
Scottish Intercollegiate Guidelines Network. **Diagnosis and management of epilepsies in children and young people**. Edinburgh: Scottish Intercollegiate Guidelines Network, 2005. These Scottish guidelines are aimed at health care professionals involved in the diagnosis and management of childhood epilepsies. They do not cover issues relating to babies less than one month of age, non-epileptic seizures, surgical treatments or reproductive issues. (These last are addressed in the adult guidelines.) There is an evidence grading system for the research evidence on which the guidelines are based and each recommendation in the guidelines is accompanied by a grade reflecting the strength of the evidence on which it is based.
National Institute for Clinical Excellence. **The epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care**. Clinical Guidance 20. London: National Institute for Clinical Excellence, 2004. URL: http://guidance.nice.org.uk/CG20/NICEGuidance/pdf/English These guidelines provide concise recommendations for dealing with all aspects of epilepsy. All the recommendations in the guideline are followed by a grading for the evidence on which they were based. Along with the general guidelines for epilepsy there is specific information on epilepsy in young people and people with learning disabilities. There are no references included in this publication. This is an abbreviated version of the full guideline (see below).
Stokes T, Shaw EJ, Juarez-Garcia A, et al. **Clinical Guidelines and Evidence Review for the Epilepsies: Diagnosis and management in adults and children in primary and secondary care**. London: Royal College of General Practitioners, 2004. URL: http://guidance.nice.org.uk/CG20/Guidance This comprehensive 397-page publication provides best practice advice on the diagnosis, treatment and management of the epilepsies in children and adults. It aims to cover all the important issues and base its recommendations on the published evidence that supports them, with explicit links to the evidence. It also aims to consider the perspectives of the person with epilepsy and their family and/or carers and to indicate areas of uncertainty requiring further research. It is intended to be used by all healthcare professionals dealing with people with epilepsy, healthcare commissioning and provider organisations as well as people with epilepsy and their carers. It includes a large number of references.

National Institute for Clinical Excellence. **Vagus nerve stimulation for refractory epilepsy in children**. London National Institute for Clinical Excellence, 2004. URL: http://guidance.nice.org.uk/IPG50/Guidance/pdf/English

This brief publication states that the current evidence regarding the safety and efficacy of vagus nerve stimulation for refractory epilepsy in children is apparently adequate to support the use of this procedure. The evidence base for this document is contained in: *Interventional procedure overview of vagus nerve stimulation for refractory epilepsy in children (second consultation)* which is available from: http://www.nice.org.uk/guidance/index.jsp?action=download&o=30905

Hirtz D, Berg A, et al. **Practice parameter: Treatment of the child with a first unprovoked seizure: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society**. Neurology 2003;60(2):166-75.

This practice parameter provides evidence-based recommendations based on a review of the published literature relevant to the question of whether or not to treat a child or adolescent who has experienced their first unprovoked seizure. The evidence grading system of the American Academy of Neurology is used. The authors concluded that the majority of children who have a first seizure will have few if any recurrences and that treatment with anti-epileptic drugs is not indicated (Level B recommendation) but that such treatment may be considered in circumstances where the benefits of reducing the risk of a second seizure outweigh the possible psychosocial and pharmacological side effects (Level B).

Systematic and other Reviews from the International Literature

Levy RG, Cooper PP. **Ketogenic diet for epilepsy**. Cochrane Database of Systematic Reviews 2009(1): CD001903.

The ketogenic diet is a high fat, low carbohydrate diet which is used mainly by children who continue to have seizures despite drug treatment. The authors found that there is no reliable evidence from randomised controlled trials to support the use of these diets for people with epilepsy although there are large observational studies, some of which are prospective, which suggest an effect in reducing seizure frequency. They considered that a ketogenic diet is a possible option for people with epilepsy who do not achieve satisfactory outcomes despite taking multiple anti-epileptic drugs.

Winterbottom JB, Smyth RM, et al. **Preconception counselling for women with epilepsy to reduce adverse pregnancy outcome**. Cochrane Database of Systematic Reviews 2008(3): CD006645.

It is recommended practice that women with epilepsy receive counselling about the risks associated with pregnancy due to the effects of both seizures and drug treatment on the mother and baby. This review aimed to assess the evidence concerning the effectiveness of preconception counselling for women with epilepsy. The authors found that that “There is no evidence to inform the content, methods of delivery or effectiveness of preconception counselling to improve pregnancy outcomes for women with epilepsy and their offspring”. They recommend the undertaking of well designed studies to evaluate preconception counselling.

Beavis J, Kerr M, Marson AG. **Non-pharmacological interventions for epilepsy in people with intellectual disabilities**. Cochrane Database of Systematic Reviews 2007(4): CD005502.

Seizures in people with intellectual disability are often complex and refractory to drug treatment, so there is interest in a variety of non-pharmacological interventions which could be used as well as, or instead of, drugs. These include surgery, special diets, psychological interventions to reduce stress, yoga and acupuncture. The authors of this review found that there have been no RCTs of non-pharmacological treatments for epilepsy in people with intellectual disabilities but state that such studies are needed.

Other Relevant Publications

Babl FE, Sheriff N, et al. **Emergency management of paediatric status epilepticus in Australia and New Zealand: Practice patterns in the context of clinical practice guidelines**. Journal of Paediatrics & Child Health 2009; 45(9): 541-6.

This paper reports on a study that reviewed clinical practice guidelines and reported physician practice concerning the management of paediatric status epilepticus in the largest Australian (n=9) and New Zealand (n=2) paediatric emergency departments within the Paediatric Research in Emergency Departments International Collaborative (PREDICT) network. There were seven different guidelines in use in ten of the sites and one site didn’t have a guideline. Initial management of seizure was similar at all sites with benzodiazepines being the first line strategy, consistent with Advanced Paediatric Life Support (APLS) guidelines. There was more variation in the second and third line strategies used for persistent seizures. The authors noted that there is a lack of evidence comparing the efficacy of different second and third line agents and regarding the use or non-use of rapid sequence intubation and that this is reflected in the variations in practice. They considered that further research in this area would be beneficial.

Salpekar JA, Dunn DW. **Psychiatric and psychosocial consequences of pediatric epilepsy**. Seminars in Pediatric Neurology 2007; 14(4): 181-8.

This is a comprehensive review with 107 references. Children and adolescents with epilepsy are significantly more likely than children with other chronic illnesses to have psychiatric and behavioural problems. It is suspected that there may be an underlying neurological cause for this which adds to the psychosocial stress associated with chronic illness. This review is an attempt to assess what evidence there is about psychiatric and psychosocial co-morbidity in children and adolescents with epilepsy and to address ways to manage it.

Plioplys S, Dunn DW, et al. **10-year research update review: Psychiatric problems in children with epilepsy**. Journal of the American Academy of Child & Adolescent Psychiatry 2007; 46(11): 1389-402.

The authors of this review searched the literature published from1996 to 2007 on psychopathology in children with epilepsy and they report on those studies that are clinically relevant to mental health professionals. They note that psychopathology in children with epilepsy is the result of complex interactions between CNS, cognitive, linguistic and family variables. They state that the effect of seizures on psychopathology is different for cognitively normal children (those with "idiopathic epilepsy") compared to those who have symptomatic epilepsy resulting from a known or suspected CNS disorder for example cerebral palsy, mental retardation or autism. There is a discussion of ADHD, affective and anxiety disorders, psychosis and autistic spectrum disorders in children with epilepsy.

Rodenburg R, Meijer AM, et al. **Family factors and psychopathology in children with epilepsy: A literature review**. Epilepsy & Behavior 2005; 6(4): 488-503.

This article uses a social interactional and ecologic framework to review studies that either (1) compared family factors in children with epilepsy with those in children from other groups such as healthy children, children with a chronic illness or siblings, or (2) examined the relationships between particular family factors and child psychopathology. The authors found that compared to families in control groups, families with a child with epilepsy have worse outcomes on the whole range of family factors including having poorer quality parent-child relationships, more depression in mothers and problems with family functioning. They found significant associations between psychopathology in children with epilepsy and distinct family factors particularly parental psychological control, parental attributions about epilepsy and family members' satisfaction with family relationships.

CANCER

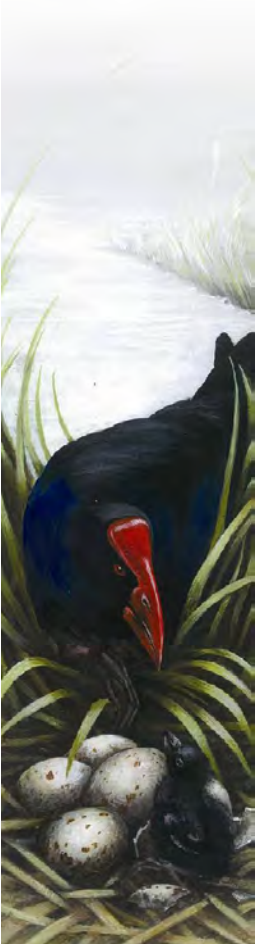
Introduction

In New Zealand leukaemias, tumours of the central nervous system, lymphomas and bone tumours are the most common forms of cancer in children aged 10-14 years, accounting for 70% of all newly diagnosed cancers in this age group. For young people aged 15-19 years, melanomas, lymphomas, leukaemias, germ cell tumours and bone tumours are the most common cancers, and again account for around 70% of all newly diagnosed cancers in this age group. For those aged 20-24 years melanomas, germ cell tumours, lymphomas and leukaemias make the greatest contribution [142].

When compared to other developed countries, the overall rate of cancer in New Zealand adolescents and young people is slightly higher, with this difference entirely explained by an excess burden of malignant melanoma in the New Zealand population. Within New Zealand, while no socioeconomic differences in cancer incidence (as assessed by the NZDep Index) were found in one recent review [142], rates were lower for Māori than for Non Māori, although these differences were reduced in older young people once the lower rate of melanoma in Māori was taken into account. In terms of cancer survival, a review of all children diagnosed with cancer in New Zealand during 1990-1993 suggested that Māori and Pacific children had the same survival rates as non-Māori non Pacific children for all cancers, as well as for acute lymphoblastic leukaemia more specifically [143].

Known risk factors for childhood cancer overseas include a wide range of familial and genetic syndromes. Studies on the links between genetic factors and the environment however have been more inconsistent. In addition, few solely environmental risk factors have been established, although ionising radiation and infective agents have been implicated in a number of specific situations [144]. Thus, from a population health perspective further research is necessary before sound evidence based primary prevention strategies can be developed which address the incidence of childhood cancer in this country. In terms of reducing the impact of childhood cancer once it has developed however, while treatment is very successful in preventing death in the majority of cases, families of children newly diagnosed with cancer can still expect multiple hospital admissions, treatments with severe side effects, and significant disruption to many aspects of their everyday life [145]. Thus ensuring the equitable access to specialist health services, family support and the reimbursement of travel / associated costs remains of considerable importance in reducing the burden cancer places on the families of children and young people in this country.

The following section uses data from the New Zealand Cancer Registry and the National Mortality Collection to review the incidence of, and mortality from, cancer in New Zealand children and young people.



Data Source and Methods

Definition

1. Cancer Registry Notifications for Children and Young People Aged 0-24 Years
2. Cancer Deaths for Children and Young People Aged 0-24 Years

Data Source

1. New Zealand Cancer Registry

Numerator: Cancer Registry Notifications for children and young people aged 0-24 years with cancer site being assigned using ICD-10-AM as follows: Carcinoma in Situ of Cervix (D06), Melanoma in Situ (D03), Hodgkin's Disease (C81), Non-Hodgkin's Lymphomas (C82-C85), Acute Myeloid Leukaemia (C920), Other Myeloid Leukaemias (C921-C929), Acute Lymphoblastic Leukaemia (C910), Other Neoplasms Lymphoid and Haematopoietic Tissues (Remainder C81-C96). Malignant Neoplasms of the: Brain (C71); Testis (C62); Melanoma of Skin (C43); Bone and Cartilage (C40-41); Kidney (Excluding Renal Pelvis (C64); Adrenal Gland (C74); Ovary (C56); Thyroid (C73); Cervix (C53); Retina (C692), Other Malignant Neoplasms (Remainder C00-C97), Other In Situ Neoplasms (Remainder D00-D09), Benign or of Uncertain Behaviour (D10-D48).

Denominator: Statistics New Zealand Estimated Resident Population

2. National Mortality Collection
Numerator: Cancer Deaths in children and young people aged 0-24 years with the main underlying cause of death in the ranges outlined above.
Denominator: Statistics New Zealand Estimated Resident Population

Notes on Interpretation
For the majority of analyses, and for all national and regional totals, rates per 100,000 children and young people aged 0-24 years have been used. For cancers of the testis however, rates are per 100,000 males aged 0-24 years, while for cancers of the ovaries rates are per 100,000 females 0-24 years. For carcinoma in situ and malignant cancers of the cervix, the numerator includes all women aged 0-24 years (there was only one case <15 years), while the denominator includes any women 15-24 years.

Indicator Category Ideal B

New Zealand Distribution by Cancer Type

Table 55. Cancer Registry Notifications for Children and Young People Aged 0-24 Years by Cancer Type, New Zealand 2003-2007

	Total No. 2003-2007	Annual Average	Rate per 100,000	% of Total
Cancer Registry Notifications, New Zealand				
Cancers of Lymphoid and Haematopoietic Tissues				
Acute Lymphoblastic Leukaemia	205	41.0	2.78	5.26
Non-Hodgkin's Lymphomas	93	18.6	1.26	2.39
Hodgkin's Disease	90	18.0	1.22	2.31
Acute Myeloid Leukaemia	39	7.8	0.53	1.00
Other Lymphoid and Haematopoietic Neoplasms	31	6.2	0.42	0.80
Other Myeloid Leukaemias	24	4.8	0.33	0.62
Cancers of Reproductive Organs				
Carcinoma in Situ of Cervix	2,353	470.6	160.98	60.41
Malignant Neoplasm of Testis	116	23.2	3.08	2.98
Malignant Neoplasm of Ovary	24	4.8	0.66	0.62
Malignant Neoplasm of Cervix	17	3.4	1.16	0.44
In Situ or of Uncertain Behaviour				
Other In Situ Neoplasms	33	6.6	0.45	0.85
Benign or of Uncertain Behaviour	23	4.6	0.31	0.59
Melanoma and Melanoma in Situ				
Malignant Melanoma of Skin	150	30.0	2.03	3.85
Melanoma in Situ	79	15.8	1.07	2.03
Other Cancers				
Other Malignant Neoplasms	275	55.0	3.72	7.06
Malignant Neoplasm of Brain	125	25.0	1.69	3.21
Malignant Neoplasms Bone and Cartilage	84	16.8	1.14	2.16
Malignant Neoplasm of Thyroid	52	10.4	0.70	1.34
Malignant Neoplasm of Kidney (Excl. Renal Pelvis)	37	7.4	0.50	0.95
Malignant Neoplasm of Retina	24	4.8	0.33	0.62
Malignant Neoplasm of Adrenal Gland	21	4.2	0.28	0.54
New Zealand Total	3,895	779.0	52.76	100.00

Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 0-24 years, except for cancers of the testis (per 100,000 males 0-24 years), ovary (per 100,000 females 0-24 years) and cervix (per 100,000 females 15-24 years).

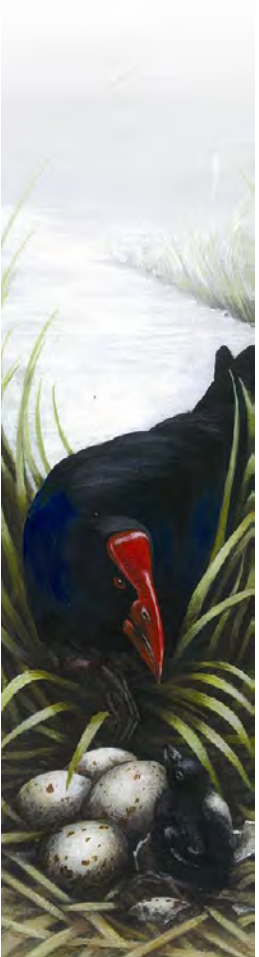
NZ Cancer Registry Notifications: In New Zealand during 2003-2007, carcinoma in situ of the cervix was the most frequent reason for a notification to the NZ Cancer Registry in children and young people aged 0-24 years, and accounted for 60.4% of notifications in this age group. Acute lymphoblastic leukaemia was the second leading reason for notification, followed by malignant melanomas of the skin (**Table 55**).

Cancer Mortality: In New Zealand during 2003-2007, cancers of the brain were the leading cause of cancer mortality in children and young people, followed by acute lymphoblastic leukaemia (**Table 56**).

Table 56. Cancer Deaths for Children and Young People Aged 0-24 Years by Cancer Type, New Zealand 2003-2007

	Total No. 2003-2007	Annual Average	Rate per 100,000	% of Total
Cancer Deaths, New Zealand				
Cancers of Lymphoid and Haematopoietic Tissues				
Acute Lymphoblastic Leukaemia	44	8.8	0.60	14.7
Acute Myeloid Leukaemia	18	3.6	0.24	6.0
Non-Hodgkin's Lymphomas	13	2.6	0.18	4.3
Hodgkin's Disease	6	1.2	0.08	2.0
Other Myeloid Leukaemias	<3	s	s	s
Other Lymphoid and Haematopoietic Neoplasms	11	2.2	0.15	3.7
All Other Cancers				
Malignant Neoplasm of Brain	58	11.6	0.79	19.4
Malignant Neoplasms Bone and Cartilage	41	8.2	0.56	13.7
Malignant Neoplasm of Adrenal Gland	11	2.2	0.15	3.7
Malignant Neoplasm of Testis	8	1.6	0.21	2.7
Malignant Melanoma of Skin	6	1.2	0.08	2.0
Malignant Neoplasm of Kidney	<3	s	s	s
Malignant Neoplasm of Thyroid	<3	s	s	s
Malignant Neoplasm of Cervix	<3	s	s	s
Malignant Neoplasm of Ovary	<3	s	s	s
Benign or of Uncertain Behaviour	9	1.8	0.12	3.0
Other Malignant Neoplasms	67	13.4	0.91	22.4
New Zealand Total	299	59.8	4.05	100.0

Source: Numerator: National Mortality Collection; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 0-24 years, except for Cancers of the Testis (per 100,000 males 0-24 years), Ovary (per 100,000 females 0-24 years) and Cervix (per 100,000 females 15-24 years).



Cancers of the Lymphoid and Haematopoietic Tissues

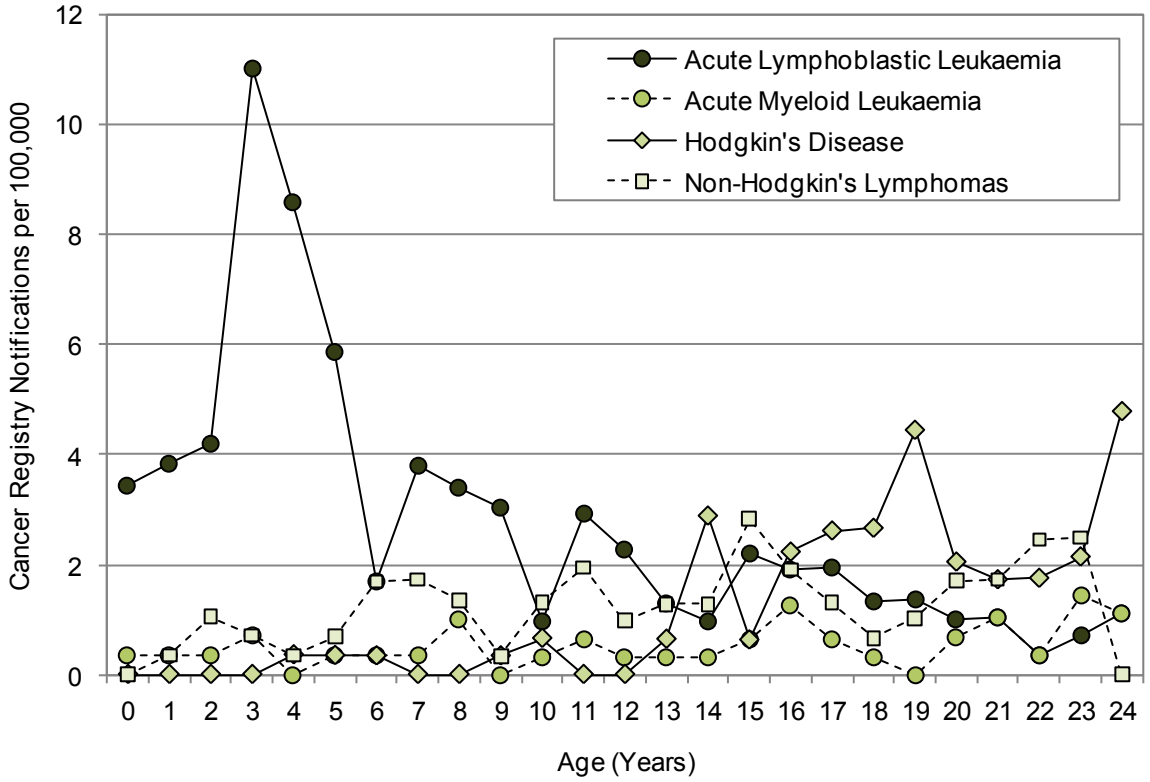
Distribution by Age

In New Zealand during 2003-2007, NZ Cancer Registry notifications for acute lymphoblastic leukaemia increased during infancy, reached a peak at 3 years of age and then declined, with the highest rates being seen in those aged 2-5 years. In contrast, notifications for Hodgkin's disease were more frequent amongst those in their late teens and early twenties (**Figure 34**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2003-2007, there were no significant ethnic, gender or socioeconomic (as measured by NZ Deprivation Index quintile) differences in NZ Cancer Registry notifications for acute lymphoblastic leukaemia (**Table 57**).

Figure 34. Cancer Registry Notifications for Children and Young People with Selected Cancers of the Lymphoid and Haematopoietic Tissues by Age, New Zealand 2003-2007



Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population.

Table 57. Cancer Registry Notifications for Children and Young People Aged 0-24 Years with Acute Lymphoblastic Leukaemia by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2003-2007

Variable	Notifications: Total Number 2003-2007	Notifications per 100,000	Rate Ratio	95% CI
Acute Lymphoblastic Leukaemia				
NZ Deprivation Index Decile				
Decile 1-2	31	2.35	1.00	
Decile 3-4	39	2.91	1.24	0.77 - 1.98
Decile 5-6	43	3.15	1.34	0.84 - 2.12
Decile 7-8	41	2.65	1.13	0.71 - 1.80
Decile 9-10	50	2.76	1.18	0.75 - 1.84
Gender				
Female	111	3.06	1.00	
Male	94	2.50	0.82	0.62 - 1.07
Prioritised Ethnicity				
Asian	20	2.61	0.95	0.59 - 1.53
European	117	2.75	1.00	
Māori	39	2.37	0.86	0.60 - 1.24
Pacific	21	3.28	1.19	0.75 - 1.90

Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 0-24 years. Ethnicity is Level 1 Prioritised. Rate Ratios are unadjusted.

Malignant Melanoma and Melanoma in Situ

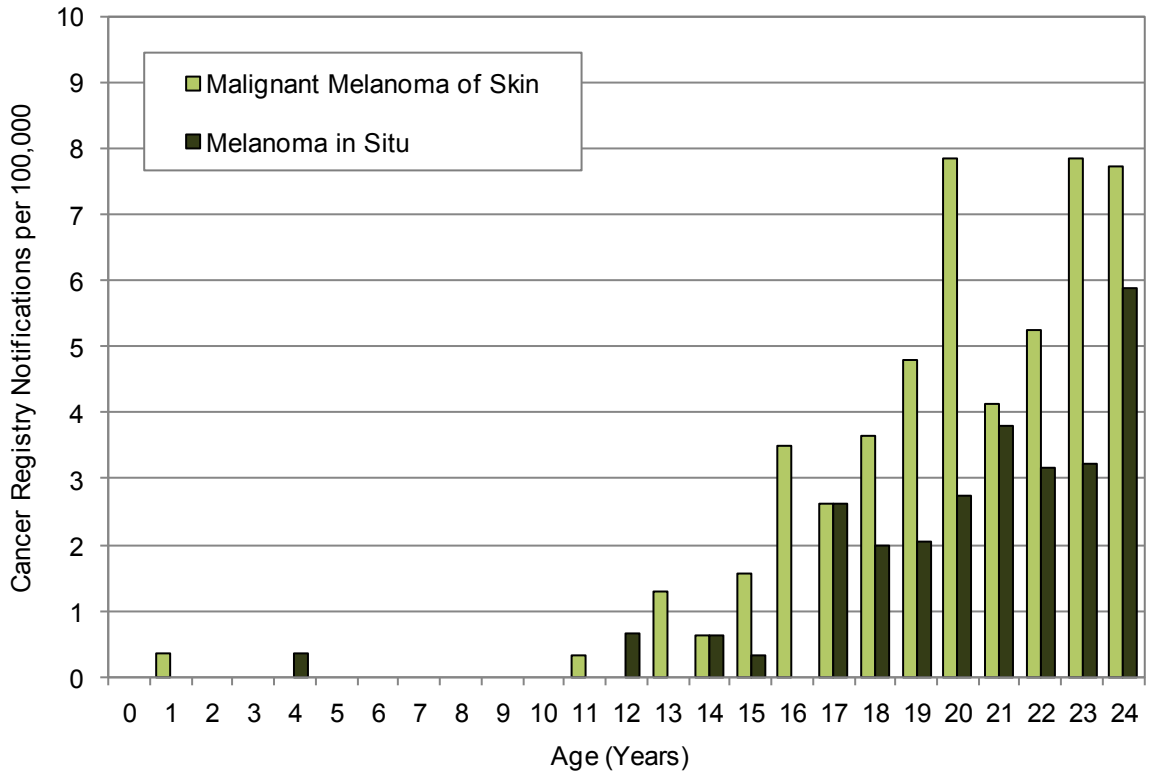
Distribution by Age

In New Zealand during 2003-2007, NZ Cancer Registry notifications for malignant melanoma and melanoma in situ were infrequent during childhood but increased during adolescence, with the highest rates being seen in those in their late teens and early twenties **(Figure 35**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2003-2007, NZ Cancer Registry notifications for malignant melanoma and melanoma in situ were *significantly* higher for European than for Māori, children and young people. Numbers were too small for Asian and Pacific children and young people to undertake a valid comparison. Rates were also *significantly* higher for females and those living in the least deprived (NZDep deciles 1-2) areas, when compared to those living in the most deprived (NZDep deciles 9-10) areas (**Table 58**)

Figure 35. Cancer Registry Notifications for Children and Young People with Malignant Melanoma or Melanoma in Situ by Age, New Zealand 2003-2007



Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population.

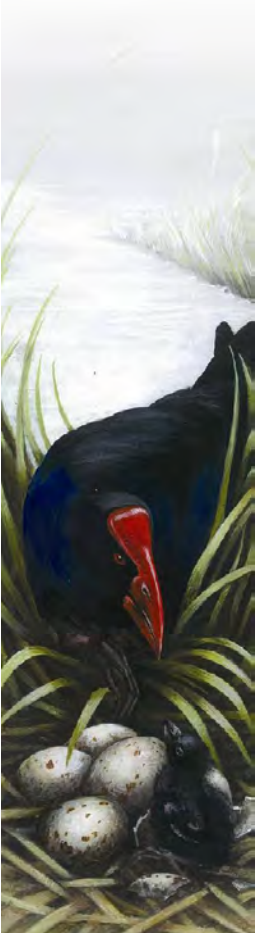


Table 58. Cancer Registry Notifications for Children and Young People Aged 0-24 Years with Malignant Melanoma or Melanoma in Situ by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2003-2007

Variable	Notifications: Total Number 2003-2007	Notifications per 100,000	Rate Ratio	95% CI
Malignant Melanoma and Melanoma in Situ				
NZ Deprivation Index Decile				
Decile 1-2	51	3.87	1.00	
Decile 3-4	42	3.14	0.81	0.54 - 1.22
Decile 5-6	45	3.29	0.85	0.57 - 1.27
Decile 7-8	49	3.17	0.82	0.55 - 1.21
Decile 9-10	42	2.32	0.60	0.40 - 0.90
Gender				
Female	134	3.70	1.00	
Male	95	2.53	0.68	0.52 - 0.89
Prioritised Ethnicity				
Asian	<5	s	s	s
European	197	4.63	1.00	
Māori	8	0.49	0.11	0.05 - 0.21
Pacific	<5	s	s	s

Source: Numerator: NZ Cancer Registry, Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 0-24 years. Ethnicity is Level 1 Prioritised.

Cancer of the Testis

Distribution by Age

In New Zealand during 2003-2007, NZ Cancer Registry notifications for cancers of the testis were infrequent during childhood but increased during adolescence, with the highest rates being seen in those in their late teens and early twenties (**Figure 36**).

Distribution by Prioritised Ethnicity and NZDep Index Decile

In New Zealand during 2003-2007, no significant socioeconomic gradients were seen in NZ Cancer Registry notifications for cancers of the testis, with notification rates also being similar for Māori and European children and young people. Small numbers however prevented comparisons for Pacific and Asian children and young people (**Table 59**).

Cancers of the Cervix and Ovaries

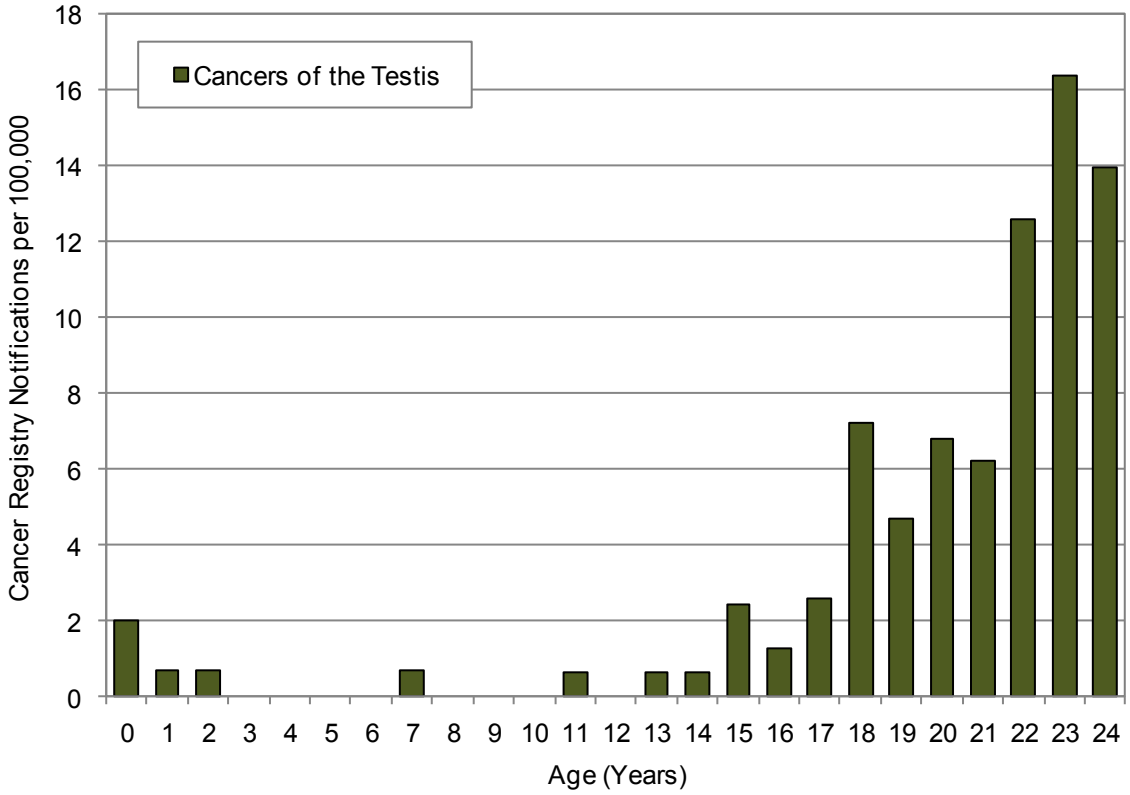
Distribution by Age

In New Zealand during 2003-2007, NZ Cancer Registry notifications for carcinoma in situ of the cervix were relatively infrequent during early adolescence, but increased rapidly thereafter, with the highest rates being seen amongst those in their early twenties. Similarly, the vast majority of notifications for cancer of the cervix were for those in their early twenties. Notifications for cancers of the ovaries occurred from 11 years of age onwards (**Figure 37**).

Distribution by Prioritised Ethnicity and NZDep Index Decile

In New Zealand during 2003-2007, NZ Cancer Registry notifications for carcinoma in situ of the cervix were *significantly* higher for European > Māori > Pacific and Asian women. Rates were *significantly* lower for those in the least deprived (NZDep deciles 1-2) areas, when compared to those living in average-more deprived (NZDep deciles 3-10) areas (**Table 60**).

Figure 36. Cancer Registry Notifications for Males Aged 0-24 Years with Cancers of the Testis, New Zealand 2003-2007



Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 males.

Table 59. Cancer Registry Notifications for Males Aged 0-24 Years with Cancers of the Testis by NZ Deprivation Index Decile and Prioritised Ethnicity, New Zealand 2003-2007

Variable	Notifications: Total Number 2003-2007	Notifications per 100,000	Rate Ratio	95% CI
Cancers of the Testis				
NZ Deprivation Index Decile				
Decile 1-2	13	1.92	1.00	
Decile 3-4	21	3.05	1.59	0.80 - 3.18
Decile 5-6	27	3.85	2.01	1.04 - 3.90
Decile 7-8	24	3.06	1.60	0.81 - 3.14
Decile 9-10	31	3.42	1.79	0.93 - 3.41
Prioritised Ethnicity				
Asian	<5	s	s	s
European	74	3.40	1.00	
Māori	33	3.96	1.16	0.77 - 1.76
Pacific	<5	s	s	s

Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 males 0-24 years. Ethnicity is Level 1 Prioritised.

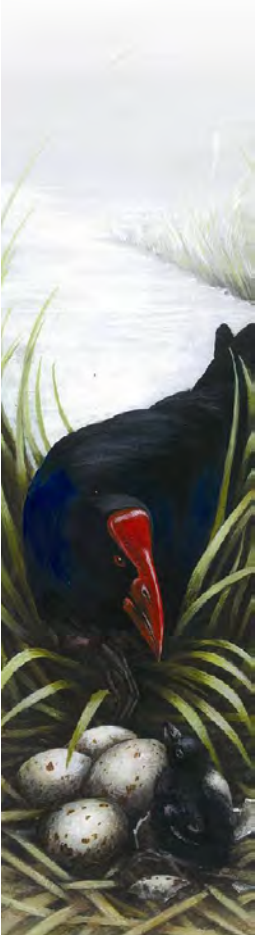
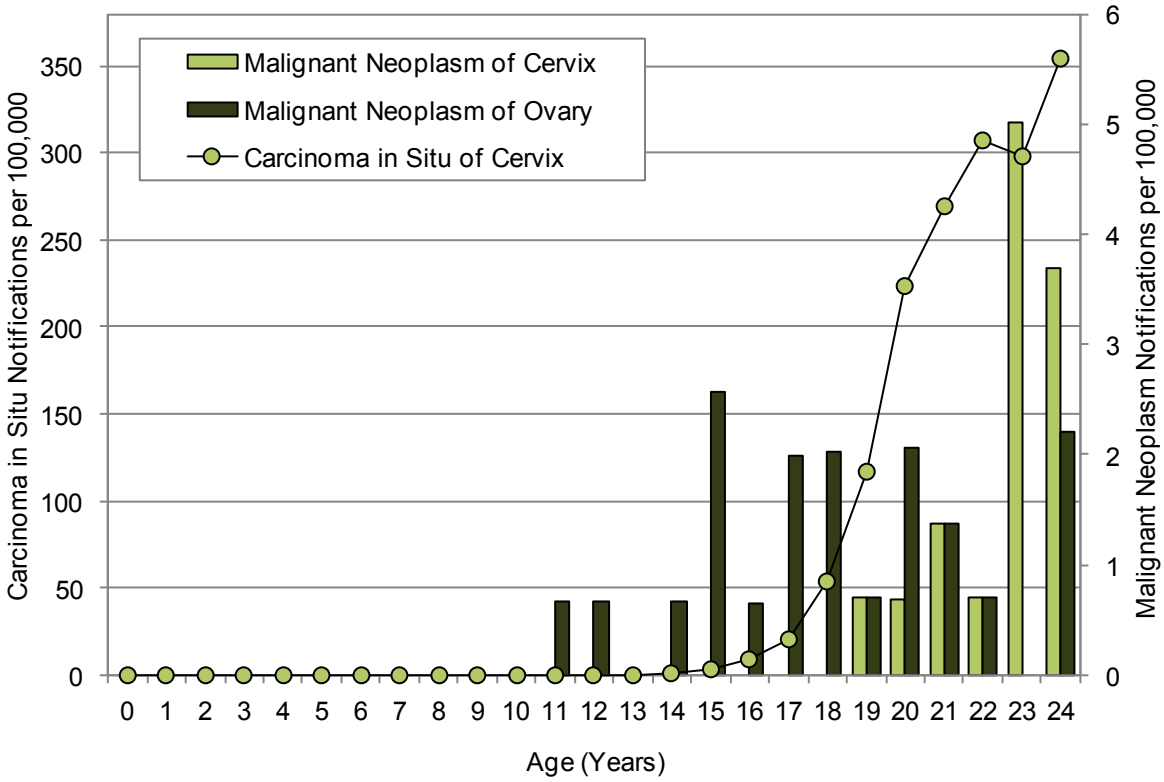


Figure 37. Cancer Registry Notifications for Females Aged 0-24 Years with Cancer and Carcinoma in Situ of the Cervix and Cancer of the Ovary by Age, New Zealand 2003-2007



Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 females.

Table 60. Cancer Registry Notifications for Females Aged 15-24 Years with Carcinoma in Situ of the Cervix by NZ Deprivation Index Decile and Prioritised Ethnicity, New Zealand 2003-2007

Variable	Notifications: Total Number 2003-2007	Notifications per 100,000	Rate Ratio	95% CI
Carcinoma in Situ of the Cervix				
NZ Deprivation Index Decile				
Decile 1-2	277	115.64	1.00	
Decile 3-4	383	152.93	1.32	1.13 - 1.54
Decile 5-6	503	189.20	1.64	1.41 - 1.89
Decile 7-8	600	188.79	1.63	1.42 - 1.88
Decile 9-10	585	150.96	1.31	1.13 - 1.51
Prioritised Ethnicity				
Asian	44	22.01	0.11	0.08 - 0.15
European	1,694	201.04	1.00	
Māori	438	152.01	0.76	0.68 - 0.84
Pacific	46	39.83	0.20	0.15 - 0.27

Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 females 15-24 years. Ethnicity is Level 1 Prioritised. Rate Ratios are unadjusted.

Other Cancers

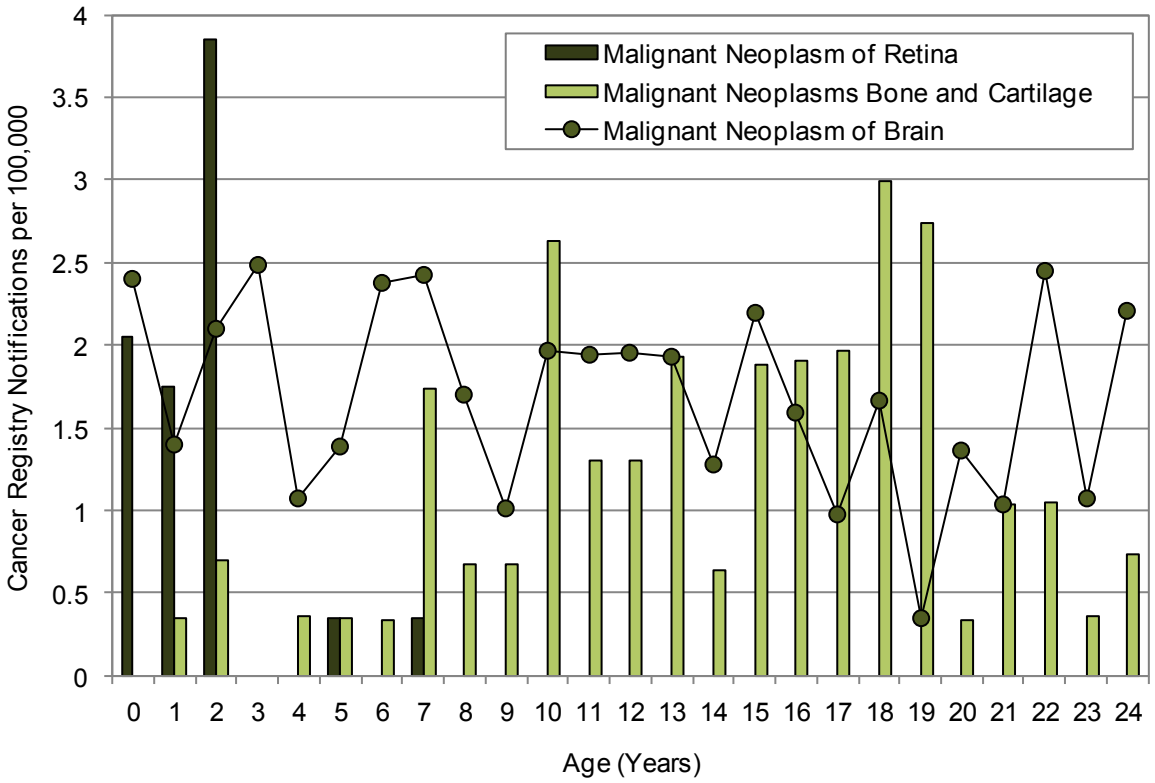
Distribution by Age

In New Zealand during 2003-2007, NZ Cancer Registry notifications for cancers of the retina were more frequent for those under three years of age, while cancers of the brain were more evenly distributed throughout childhood and adolescence, and cancers of the bone and cartilage were more common after 6 years of age (**Figure 38**). Similarly, notifications for cancers of the kidney and adrenal were more common amongst those under 8 years of age, while notifications for cancers of the thyroid were more frequent amongst those in their late teens and early twenties (**Figure 39**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

In New Zealand during 2003-2007, there were no significant socioeconomic (as measured by NZ Deprivation index quintile), ethnic or gender differences in NZ Cancer Registry notifications for cancers of the brain, although small numbers prevented valid comparisons for Asian children and young people (**Table 61**).

Figure 38. Cancer Registry Notifications for Children and Young People with Cancers of the Brain, Retina and Bone and Cartilage by Age, New Zealand 2003-2007



Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population.

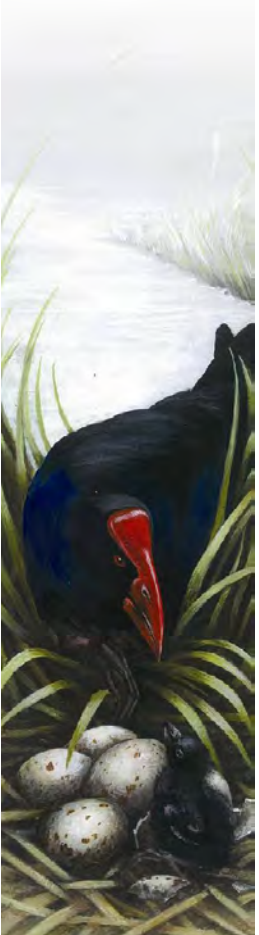
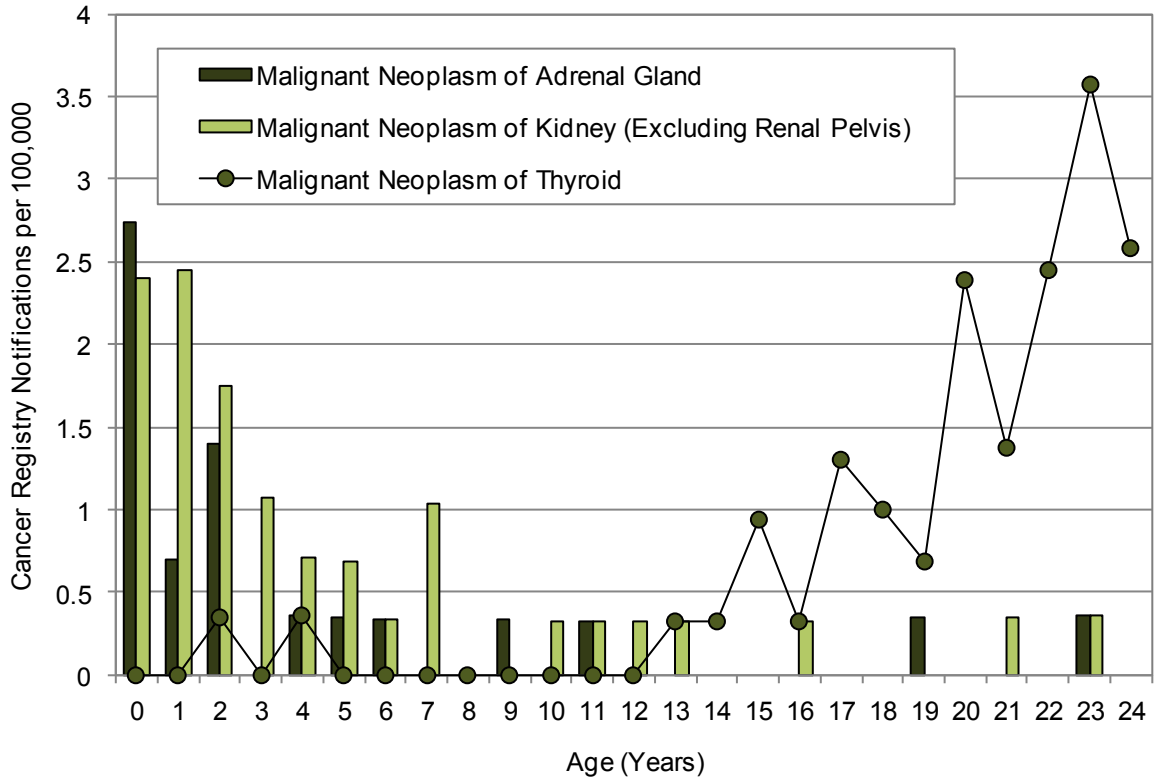


Figure 39. Cancer Registry Notifications for Children and Young People with Cancers of the Kidney, Adrenal Gland and Thyroid by Age, New Zealand 2003-2007

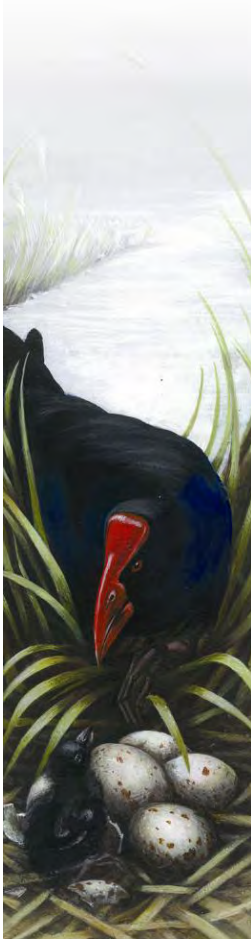


Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population.

Table 61. Cancer Registry Notifications for Children and Young People Aged 0-24 Years with Cancers of the Brain by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2003-2007

Variable	Notifications: Total No. 2003-2007	Notifications per 100,000	Rate Ratio	95% CI
Cancers of the Brain				
NZ Deprivation Index Decile				
Decile 1-2	19	1.44	1.00	
Decile 3-4	14	1.05	0.73	0.36 - 1.45
Decile 5-6	22	1.61	1.12	0.60 - 2.06
Decile 7-8	31	2.00	1.39	0.79 - 2.46
Decile 9-10	36	1.99	1.38	0.79 - 2.41
Gender				
Female	64	1.77	1.00	
Male	61	1.62	0.92	0.65 - 1.30
Prioritised Ethnicity				
Asian	<5	s	s	s
European	80	1.88	1.00	
Māori	26	1.58	0.84	0.54 - 1.31
Pacific	13	2.03	1.08	0.60 - 1.94

Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 0-24 years. Ethnicity is Level 1 Prioritised. Rate Ratios are unadjusted.



Taranaki Distribution

Distribution by Cancer Type

NZ Cancer Registry Notifications: In Taranaki during 2003-2007, carcinoma in situ of the cervix was the most frequent reason for a notification to the NZ Cancer Registry in children and young people aged 0-24 years, and accounted for 50.5 % of notifications in this age group. Acute lymphoblastic leukaemia was the second leading reason for notification, followed by malignant melanomas and cancers of the brain (**Table 62**).

Cancer Mortality: During the same period, cancers of the brain were the leading cause of cancer mortality in Taranaki children and young people (**Table 63**).

Table 62. Cancer Registry Notifications for Children and Young People Aged 0-24 Years by Cancer Type, Taranaki 2003-2007

Cancer	Total No. 2003-2007	Annual Average	Rate per 100,000	% of Total
Cancer Registry Notifications, Taranaki				
Cancers of Lymphoid and Haematopoietic Tissues				
Acute Lymphoblastic Leukaemia	9	1.8	4.85	8.41
Hodgkin's Disease	3	0.6	1.62	2.80
Non-Hodgkin's Lymphomas	<3	s	s	s
Other Lymphoid and Haematopoietic Neoplasms	<3	s	s	s
Cancers of Reproductive Organs				
Carcinoma in Situ of Cervix	54	10.8	165.31	50.47
Malignant Neoplasm of Testis	4	0.8	4.18	3.74
Malignant Neoplasm of Ovary	<3	s	s	s
In Situ or of Uncertain Behaviour				
Other In Situ Neoplasms	<3	s	s	s
Benign or of Uncertain Behaviour	<3	s	s	s
Melanoma and Melanoma in Situ				
Malignant Melanoma of Skin	6	1.2	3.24	5.61
Other Cancers				
Other Malignant Neoplasms	15	3.0	8.09	14.02
Malignant Neoplasm of Brain	6	1.2	3.24	5.61
Malignant Neoplasms Bone and Cartilage	4	0.8	2.16	3.74
Taranaki Total	107	21.4	57.72	100.00

Source: Numerator: NZ Cancer Registry; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 0-24 years, except for Cancers of the Testis (per 100,000 males 0-24 years), Ovary (per 100,000 females 0-24 years) and Cervix (per 100,000 females 15-24 years).

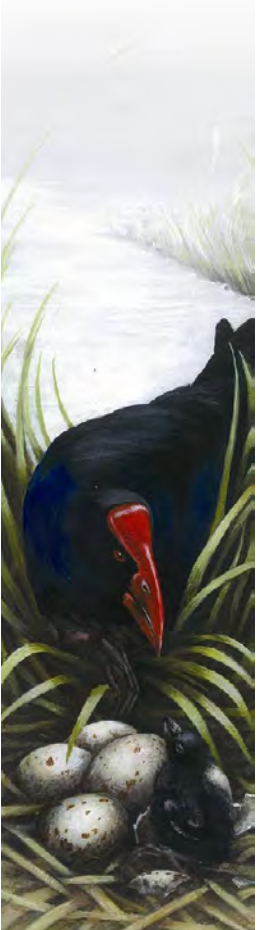


Table 63. Cancer Deaths for Children and Young People Aged 0-24 Years by Cancer Type, Taranaki 2003-2007

Cancer	Total No. 2003-2007	Annual Average	Rate per 100,000	% of Total
Cancer Deaths, Taranaki				
Malignant Neoplasm of Brain	5	1.0	2.70	50.0
Other Cancers	5	1.0	2.70	50.0
Taranaki Total	10	2.0	5.39	100.0

Source: Numerator: National Mortality Collection; Denominator: Statistics NZ Estimated Resident Population. Rates are per 100,000 0-24 years, except for Cancers of the Testis (per 100,000 males 0-24 years), Ovary (per 100,000 females 0-24 years) and Cervix (per 100,000 females 15-24 years).

Summary

In New Zealand during 2003-2007, carcinoma in situ of the cervix was the most frequent reason for a notification to the NZ Cancer Registry in children and young people aged 0-24 years, and accounted for 60.4% of notifications in this age group. Acute lymphoblastic leukaemia was the second leading reason for notification, followed by malignant melanomas of the skin. During the same period, cancers of the brain were the leading cause of cancer mortality in New Zealand children and young people, followed by acute lymphoblastic leukaemia.

In Taranaki during 2003-2007, carcinoma in situ of the cervix was the most frequent reason for a notification to the NZ Cancer Registry in children and young people aged 0-24 years, and accounted for 50.5 % of notifications in this age group. Acute lymphoblastic leukaemia was the second leading reason for notification, followed by malignant melanomas and cancers of the brain. Cancers of the brain were also the leading cause of cancer mortality in Taranaki children and young people.

Local Policy Documents and Evidence Based Reviews Relevant to the Diagnosis or Management of Cancer in Children and Young People

In New Zealand, a small number of policy documents are relevant to the management of children and young people with cancer and these are reviewed in **Table 64**, along with a range of international guidelines and reviews which consider these issues in the overseas context. Note: The efficacy of particular therapeutic agents in the management of specific types of cancer in children and young people is beyond the scope of this review, with the focus of the table below being on broader management principles only.

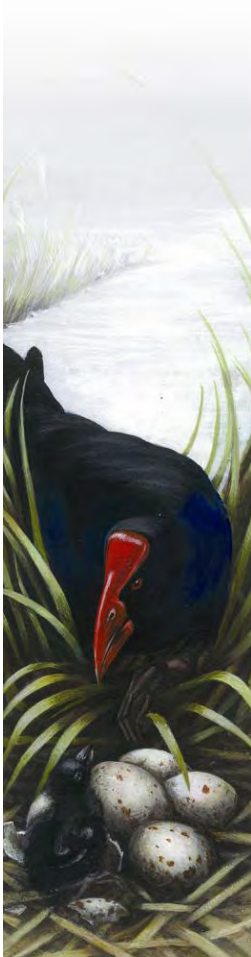


Table 64. Local Policy Documents and Evidence Based Reviews Relevant to the Diagnosis or Management of Cancer in Children and Young People

New Zealand Policy Documents and Other Publications
Ministry of Health. **Cancer Projections: Incidence 2004-2008 to 2014-2018**. Wellington: Ministry of Health, 2010. URL: http://www.moh.govt.nz/moh.nsf/indexmh/cancer-projections-incidence-2004-08-to-2014-18 Page 11 of this document gives observed and projected rates for childhood cancer in general for males and females by age group and page 12 gives similar information for childhood leukaemia, although male and female data are combined.
New Zealand Guidelines Group. **Suspected Cancer in Primary Care: Guidelines for investigation, referral and reducing ethnic disparities**. Wellington: New Zealand Guidelines Group, 2009. URL: http://www.moh.govt.nz/moh.nsf/indexmh/suspected-cancer-primary-care-guidelines This document aims to help primary care practitioners make timely and appropriate referrals by alerting them to signs and symptoms that should raise the suspicion of cancer. Chapter 14 deals with cancer in children and young people. General recommendations are presented first, followed by specific recommendations for the most common childhood cancers: leukaemia, lymphoma, brain and central nervous system tumours, neuroblastoma, Wilms' tumour, soft tissue sarcoma, bone sarcoma and retinoblastoma.
Moore AS, Shaw PJ, et al. **Haemopoietic stem cell transplantation for children in Australia and New Zealand, 1998-2006: A report on behalf of the Australasian Bone Marrow Transplant Recipient Registry and the Australian and New Zealand Children's Haematology Oncology Group**. Medical Journal of Australia 2009; 190(3): 121-5. This paper reports on an analysis of the paediatric data from the Australasian Bone Marrow Transplant Recipient Registry over the period 1998-2006. Over this period there were 522 autologous haemopoietic stem cell transplants (HSCT) (41% of the total) and 737 allogenic procedures (59%). Statistics on donor characteristics, age of patients, indications for HSCT and transplant-related mortality are provided. The authors state that local trends in the indications for HSCT, the selection of donors and transplant related mortality mirror those of contemporary international practice.
Williams G. **Cancer among New Zealand Adolescents and Young People 1988-2002: An occasional paper**. Wellington: Ministry of Health, 2006. URL: http://www.moh.govt.nz/moh.nsf/pagesmh/1630 This paper describes in detail the pattern of cancer incidence and survival among New Zealand adolescents and young people (those aged 10 -24 years). It notes that while cancer in New Zealand adolescents and young people generally follows a pattern similar to that in other developed countries, there is a higher incidence of melanoma. Young Māori have a lower cancer incidence overall but worse survival than non- Māori.
Heath JA, Stern CJ. **Fertility preservation in children newly diagnosed with cancer: Existing standards of practice in Australia and New Zealand**. Medical Journal of Australia 2006; 185(10): 538-41. This paper reports on the results of a cross-sectional survey of all paediatric oncology services in Australia and New Zealand in December 2005, which aimed to establish the extent to which sperm, oocyte and gonadal tissue collection and storage is offered to children newly diagnosed with cancer. The results of the survey suggested that there were inconsistencies between centres in the way fertility preservation methods were offered (if they were offered at all) to child cancer patients. The authors suggest that because of this and because of the unresolved medical, legal and ethical issues involved the development of guidelines would be helpful.
Monteith SJ, Heppner PA, et al. **Paediatric central nervous system tumours in a New Zealand population: A 10-year experience of epidemiology, management strategies and outcomes**. Journal of Clinical Neuroscience 2006; 13(7): 722-9. This paper reports on an analysis of 166 cases of paediatric central nervous system tumours which presented to Auckland City and Starship Children's Hospital, New Zealand, between 1995 and 2004. It provides statistics on patient characteristics, presentation, diagnosis, treatment and outcomes.
Children's Cancer Research Group University of Otago Christchurch http://www.uoc.otago.ac.nz/research/ccrg/index.htm This website provides information on the activities of the Children's Cancer Research Group including brief outlines of their research projects.
International Guidelines
Children's Oncology Group. **Long term follow-up guidelines for survivors of childhood, adolescent and young adult cancers, Version 3.0**. Arcadia, CA: Children's Oncology Group, 2008. URL: www.survivorshipguidelines.org Long-term survivors of childhood cancer have greatly increased risks for a number of conditions in later life, including cardiac and pulmonary complications and second cancers, because of the treatment they have received for their original cancer. These risk-based, exposure-related clinical practice guidelines provide information for healthcare providers that are intended to increase awareness of the late effects of cancer treatment and to standardise follow up care for paediatric cancer survivors throughout their lives. Recommendations in the guidelines are graded according to the quality of the studies that provide the evidence base for the recommendations.

National Cancer Peer Review - National Cancer Action Team. **Manual for Cancer Services 2008: Children's cancer measures**. London: NHS National Cancer Action Team, 2008. URL: http://www.cquins.nhs.uk/download.php?d=Gateway_12770_Childrens_Cancer_Measures_Nov_09.pdf

This manual incorporates the recommendations contained in the NICE guidance below. It is written for the specific purpose of being used to assess a service against it when a peer review visit is taking place. For this reason the measures are specified in such a way as to be specific, measureable, verifiable, achievable, clear and unambiguous, encouraging of quality improvement, and related to previous standards. It sets out the characteristics services should have with the intention of assisting those involved in planning, commissioning, organising, and providing cancer services to identify gaps in service provision and check the appropriateness and quality of existing services.

National Collaborating Centre for Cancer. **Improving Outcomes in Children and Young People with Cancer**. London: National Institute for Health and Clinical Excellence, 2005. URL: http://www.nice.org.uk/nicemedia/live/10899/28876/28876.pdf

These guidelines are intended primarily for the commissioners of services. They are evidence-based and the stated aim of the guidance is that age-appropriate, safe and effective services should be provided as locally as possible, not that local services should be provided as safely as possible. It is recognised that there is a need for an integrated approach to services and a sustainable balance between centralisation and decentralisation. The information in these guidelines is organised under three broad chapter headings: Background, The Care Pathway and Service Organisation.

National Institute for Health and Clinical Excellence. **Referral guidelines for suspected cancer**. London: National Institute for Health and Clinical Excellence, 2005. URL: http://www.nice.org.uk/nicemedia/live/10968/29814/29814.pdf

Pages 45-52 of this publication cover referral indications in children and young people seen in primary care with a history, symptoms or signs that may indicate the presence of cancer. Recommendations are accompanied by a grade indicating the strength of the evidence on which they are based. Appendix E provides the recommendations in the form of algorithms for practitioners to follow. This publication is an abbreviated version of the full guidance, which includes the references to the literature and discussion of key studies, and can be found in several parts at: http://guidance.nice.org.uk/CG27/Guidance. Part 2, pages 284-411 cover cancer in children.

Scottish Intercollegiate Guidelines Network. **Long term follow up of survivors of childhood cancer: A national clinical guideline**. Edinburgh: Scottish Intercollegiate Guidelines Network, 2004. URL: http://www.sign.ac.uk/pdf/sign76.pdf

This guideline covers the late effects, both expected and unexpected, that may be experienced by young people who have survived childhood cancer. It is aimed at primary care staff who have young cancer survivors as patients and at the secondary care and follow up clinic staff who usually have responsibility for this area of care. It covers five key areas: growth, puberty and fertility, cardiac problems, thyroid function and neurodevelopment and psychological health. It does not cover secondary malignancy, or renal, respiratory or liver dysfunction, or vision and hearing problems.

American Academy of Pediatrics Section on Hematology/Oncology. **Position statement: Guidelines for the pediatric cancer center and role of such centers in diagnosis and treatment**. Pediatrics 1997; 99(1): 139-41.

The purpose of this statement is to provide an outline of the personnel and facilities required to provide state-of-the-art care for children and young people with cancer. It stresses the need for specialist paediatric haematologists/oncologists and paediatric subspecialty consultants to oversee the care of these patients, and the need for initial management and much of follow up care to occur at a tertiary centre with appropriate facilities and equipment.

Systematic and Other Reviews from the International Literature

Phillips RS, Gopaul S, et al. **Antiemetic medication for prevention and treatment of chemotherapy induced nausea and vomiting in childhood**. Cochrane Database of Systematic Reviews 2010(9):CD007786.

Based on a review of 28 studies which examined a variety of anti-emetics the authors of this review concluded that 5-HT_3 antagonists (e.g. ondansetron, granisetron or tropisetron) with additional dexamethazone are effective for patients who are to receive highly emetogenic chemotherapy. The additional benefits of steroids such as dexamethazone in reducing vomiting have to be weighed against their in vitro effect of reducing chemotherapy sensitivity. The authors considered that the state of knowledge regarding anti-emetic medications for child cancer patients is incomplete and that further research should address nausea as well as vomiting because patients find it more distressing and use a holistic approach taking into account the views of patients and their families.

Wakefield CE, McLoone J, et al. **The psychosocial impact of completing childhood cancer treatment: A systematic review of the literature**. Journal of Pediatric Psychology 2010; 35(3): 262-74.

The authors of this review identified19 articles reporting on research examining the psychological functioning of children who had recently completed treatment for cancer. Of these studies, four utilised qualitative methodology, 13 used quantitative methodology and two utilised mixed methods. The end of treatment can be associated with complex psychological issues. On the positive side, children may experience high self-worth, good behavioural conduct, and improved mental health and social behaviour. On the negative side, there may be lower levels of psychological well-being; decreased mood, liveliness, self esteem, motor and physical functioning; increased anxiety; problem behaviours and sleeping difficulties. The authors recommend further research addressing the psychological needs of these children.

Jones L, Watling RM, et al. **Nutritional support in children and young people with cancer undergoing chemotherapy**. Cochrane Database of Systematic Reviews 2010(7): CD003298.

Either cancer itself or the treatment for it can cause malnutrition. This review aimed to determine the effects of any kind of parenteral (delivered into a vein) or enteral (delivered into the gut, usually via a tube) nutritional support in children and young people undergoing chemotherapy for cancer. The authors of this review identified eight small RCTs in children undergoing chemotherapy which they considered to be of low quality. One small trial compared parenteral nutrition to enteral nutrition and found that it significantly increased weight, serum albumin, and protein and calorie intake. One trial compared peripheral parenteral and enteral nutrition with central parenteral nutrition and found significantly less weight gain and energy intake in the peripheral nutrition group but significantly greater serum albumin. The authors concluded that there is limited evidence that parenteral nutrition is better than enteral nutrition for well-nourished children and young people undergoing chemotherapy for cancer. They found that for malnourished patients and regarding comparisons between other forms of nutrition the evidence is unclear.

Bishop FL, Prescott P, et al. **Prevalence of complementary medicine use in pediatric cancer: A systematic review**. Pediatrics 2010; 125(4): 768-776.

This review reports on 28 studies with survey data on 3526 children, collected from 1975 to 2005. The studies were heterogeneous and of variable quality. The reported prevalence of complementary medicine use ranged from 6% to 91%. The most popular form of complementary medicine was herbal remedies, followed by diet/nutrition and faith healing. Common reasons cited for the use of complementary medicine were: to help fight or cure the child's cancer, to provide symptomatic relief and to support the use of conventional therapy. The authors of this review state that it is important for paediatricians to be aware that many of their patients are using complementary medicine and for them to encourage open communication with patients and their parents about this. They offer some suggestions for improving the methodology of future research.

Goossen GM, Kremer LC, et al. **Influenza vaccination in children being treated with chemotherapy for cancer**. Cochrane Database of Systematic Reviews 2009(2): CD006484.

Influenza can have severe consequences for children with cancer. This review aimed to assess the efficacy of influenza vaccination in stimulating an immune response and in preventing influenza, and also to determine its adverse effects, in children with cancer. The authors of this review identified one relevant RCT and eight controlled clinical trials (with a total of 708 participants). Five trials compared response to vaccination in children on chemotherapy with response in children with cancer not on chemotherapy and three compared response to vaccination in children on chemotherapy with response in healthy children. The authors concluded that child cancer patients receiving chemotherapy are able to generate an immune response to vaccination although it is weaker than that generated in both children who have completed chemotherapy and healthy children. Only minor side effects (mild local reactions and low grade fever) were reported. No studies reported on infection with influenza infection after vaccination so it is unknown whether vaccination is effective on preventing influenza in child cancer patients although it appears to be safe.

Ranmal R, Prictor M, et al. **Interventions for improving communication with children and adolescents about their cancer**. Cochrane Database of Systematic Reviews 2008(4): CD002969.

The authors of this review report on ten diverse studies with a total of 438 participants. Studies were selected for inclusion in the review because they were randomised or non-randomised controlled trials, or before and after studies. Interventions studied included computer assisted learning, group therapy, art therapy and multifaceted interactive interventions offering support before and during particular procedures, and programmes for school and social reintegration. The authors found that interventions to enhance communication involving children and young people with cancer have not been well assessed and that because of the heterogeneity of the studies and the inherent problems with the design of the individual studies it was difficult to interpret and summarise the findings. They considered that overall there is weak evidence to suggest that interventions may lead to improvements in knowledge and understanding, and in psychological, behavioural and social outcomes.

Lee SJ, Schover LR, et al. **American Society of Clinical Oncology recommendations on fertility preservation in cancer patients**. Journal of Clinical Oncology 2006; 24(18): 2917-31.

This review was performed by an expert panel of the American Society of Clinical Oncology to provide guidance about available methods of fertility preservation and related issue for patients having treatment for cancer. The authors found that although there have been many cohort studies, case series, and case reports there have been few RCTs or definitive trials in this field. The authors state that fertility preservation is often possible in people undergoing treatment for cancer and that to preserve the full range of options it should be considered as early as possible in the treatment process.

Other Relevant Publications and Useful Websites

Royal College of Nursing. **Nutrition in children and young people with cancer**. London: Royal College of Nursing, 2010. URL: http://www.rcn.org.uk/__data/assets/pdf_file/0010/338689/003805.pdf

This publication provides guidance about nutrition for children and young people with cancer. Cancer treatment often involves long periods in hospital and may be associated with nausea and vomiting, mucositis, stomatitis, taste changes, constipation, diarrhoea, pain, fatigue and metabolic abnormalities. In addition, cancer-related psychological factors such as depression, fatigue and anxiety can impair food intake. Suggestions for improving food provision for children with cancer include having a dedicated children's cook to cook to order, providing child-friendly food and protecting dedicated meal times in the ward routine.

Clarke S, Mitchell W, et al. **Care and support needs of children and young people with cancer and leukaemia and their families**. York: Social Policy Research Centre, University of York, 2004.

This is the report on a two year project funded by the charity Cancer and Leukaemia in Childhood which aimed to

- Explore types of psychosocial support service provision within the UK.
- Describe the needs of children and young people with cancer and leukaemia and their parents over the course of the illness and post treatment.
- Compare support provided with parents' and children's/teenagers' views of their support needs, and to develop recommendations for the provision of services by the voluntary sector.

The study used postal surveys of all NHS paediatric oncology treatment centres (excluding Dublin) and key voluntary agencies associated with them; focus group and individual interviews with children, teenagers and parents; and a postal survey of parents and children/young people. The study covers a large number of important issues and includes a comprehensive literature review. It identified areas of unmet need and noted that there was considerable variation from place to place in the services provided.

National Cancer Institute US National Institutes of Health.
http://www.cancer.gov/cancertopics/types/childhoodcancers

This site has a large number of useful resources, grouped into sections on Treatment; Supportive care; Prevention, genetics and causes; Clinical Trials; Cancer Literature; and Related information. There is information for both patients and health professionals. The National Cancer Institute maintains a comprehensive cancer database, PDQ® (Physician Data Query) http://www.cancer.gov/cancertopics/pdq/cancerdatabase which includes peer-reviewed, evidence-based summaries for health professionals on the major types of cancer in children with detailed information on prognosis, staging, and treatment for each disease, and references (with links to the abstracts) to key citations in the literature.

OBESITY, NUTRITION AND PHYSICAL ACTIVITY

OVERWEIGHT AND OBESITY

In New Zealand, there was no consistent national monitoring of body mass index (BMI) in children prior to 2002. However one Hawke's Bay study during 1989-2000 found that the risk of being overweight had increased 2.2 fold in 11-12 year olds, while the risk of being obese had increased 3.8 fold [146]. Similarly a study which measured health and physical activity parameters in 5,579 Christchurch 10-14 year olds between 1991 and 2001 [147] found that during this period, the average weight in boys had increased by 2.9 kg and in girls by 2.1 kg. Further, the proportion of boys who were overweight or obese had increased from 4.2% in 1991 to 7.8% in 2000, while for girls the proportion had increased from 2.0% in 1991 to 11.3% in 2000. In addition, the level of fitness of children had deteriorated, with the time to complete a 550m run increasing by 23.6s for boys and 27.0s for girls. More recently however, the 2006/07 New Zealand Health Survey found that the mean BMI for children aged 5-14 years had not changed since the 2002 National Children's Nutrition Survey, potentially suggesting that the rate of increase in BMI signalled in these earlier studies may have slowed, as it has in adults [148].

Any increases in average BMI remain of concern however, as obesity has been associated with a variety of adverse health outcomes including ischaemic heart disease, stroke, diabetes and cancer [149]. Ischaemic heart disease and diabetes are often preceded by a cluster of cardiovascular risk factors known as the "Metabolic Syndrome", characterised by abdominal adiposity, glucose intolerance, insulin resistance, hypertension and dyslipidaemia [150]. While these adverse risk factor profiles have traditionally been viewed as the domain of adults, recent evidence suggests that the Metabolic Syndrome and Type II diabetes are increasing amongst adolescents [151].

When considering the pathways linking childhood obesity to adverse health outcomes, it remains difficult to determine conclusively whether being obese as a child independently increases the risk of later adverse outcomes, once the effects of adult obesity are taken into account [152]. Despite this uncertainty, there remains strong evidence to suggest that being obese as a child increases the risk of adult obesity, and that adult obesity in turn is linked to the adverse outcomes discussed above. While not all obese children become obese adults, the risk increases with increasing age, severity of obesity and whether the child's parents are also obese. In one study, 19% of obese 1-2 year olds were obese as young adults, as compared to 55% of obese 6-9 year olds and 75% of obese 10-14 year olds, with the risk of remaining obese being elevated nearly 3 fold if either parent was obese [153].

Factors predisposing children to obesity tend to be those which result in a positive energy balance over a relatively long period of time (e.g. a low level of habitual physical activity and variations in body metabolism and insulin sensitivity). In addition, obesity has been shown to run in families, with genetic predisposition being seen as accounting for a significant proportion familial clustering, once the effects of shared environmental conditions are taken into account [154]. In population health terms, while it remains unclear which of these risk factors has made the greatest contribution to the current obesity epidemic, it is likely that interventions which address both sides of the energy equation (e.g. high fat diets, increased portion sizes vs. reductions in the amount of energy expended on transport, housework and leisure time activities) will be necessary, if the current obesity epidemic is to be addressed.

The following section briefly reviews some of the issues associated with the measurement of overweight and obesity in children and young people, before reviewing the distribution of overweight and obesity in New Zealand children and young people using data from the 2006/07 New Zealand Health Survey [148] and the National Survey of Children and Young People's Physical Activity and Dietary Behaviours [155].

Data Sources and Methods

Definitions

Proportion of Children and Young People who are Underweight, Overweight or Obese

Data Sources

The 2006/07 New Zealand Health Survey (NZHS)

The 2006/07 NZHS [148] was a cross sectional survey carried out from October 2006 to November 2007, which collected information on 4,921 children from birth to 14 years, and 12,488 adults aged 15 years and over who lived in private dwellings. The child survey included 3,039 European / Other, 1,983 Māori, 798 Pacific and 742 Asian children, with the final response rate for the child questionnaire being 71%, and for the adult questionnaire being 68%. The primary caregiver, in the case of children aged 0-14 years, answered the questionnaire on the child's behalf. In addition, height and weight measurements were taken on all children aged 2-14 years using standardised equipment and procedures, with waist circumference also being taken if the child was 5+ years of age. The survey results have been weighted to ensure they are representative of New Zealand's resident population living in permanent dwellings [148].

Ethnicity: In the Survey four ethnic groups were reported: Māori, Pacific, Asian and European / Other, with the "Other" category including Middle-Eastern, Latin-American and African ethnic groups. Total response ethnicity was used throughout, with an individual being included in the analysis for each ethnic group to which they affiliated (28.3% of children were assigned to more than one ethnic group). As a result, ethnic groups cannot be directly compared with each other, and thus all interpretations which appear in the text are made with reference to the total population [148].

Age Standardisation: In New Zealand, each ethnic group has its own age structure (e.g. the Māori and Pacific populations have a much higher proportion of individuals <25 years of age) and thus when comparisons are made between different ethnic groups (and also by NZ Deprivation Index decile, which is unevenly distributed by ethnicity), these differences need to be taken into account. Thus, in the sections which follow, all ethnic and NZ Deprivation Index decile specific analyses have been age standardised (to the World Health Organisation (WHO) world population age distribution - see [148] p16 for a more detailed account). All age / gender graphs however use unadjusted rates, so that the underlying prevalence in the New Zealand population can better be ascertained. Where gender comparisons are made in the text however, these have been adjusted for differences in the underlying age distributions of the two gender groupings [148].

Measurement of Overweight and Obesity: International BMI cut-off points were used to classify participants as underweight (or thin in children), normal range, overweight or obese, with the WHO BMI cut off points being used for adults aged 18+ years, while for those aged 2-17 years, BMI cut off points developed by the International Obesity Taskforce were used. These cut off points (see additional technical notes below) are sex and age specific and are designed to coincide with the WHO BMI cut off points for adults at age 18 [156] [157].

The data for the tables and graphs derived from this survey were sourced from
http://www.moh.govt.nz/moh.nsf/indexmh/portrait-of-health#summary

The National Survey of Children and Young People's Physical Activity and Dietary Behaviours in New Zealand: 2008/09 (NZS-CY-PA-DB-2008/09)

The NZS-CY-PA-DB-2008/09 [155] was a nationally representative survey of 2,503 children and young people aged 5-24 years (470 Māori , 239 Pacific, 324 Asian and 1,786 European and Other). Data were collected between September 2008 and May 2009, by means of a face-to-face home visit and a subsequent telephone interview. Height and weight were measured during the home visit, with accelerometers being used to assess the time spent in physical activity over a 7-day period. Data were collected directly from those aged 10+ years, with parents providing proxy responses for children ≤9 years. The overall response rate was 55%, with population weighting being used to ensure that the results were representative of the total population. In contrast to the 2006/07 NZHS however, age standardisation was not undertaken, so none of the data presented have been adjusted for differences in the age structure of different population groups.

Ethnicity: In the Survey four ethnic groups were reported: Māori, Pacific, Asian and European / Other. Total response ethnicity was used throughout, with an individual being included in the analysis for each ethnic group to which they affiliated. As oversampling by ethnic group was not undertaken, the survey is unable to provide reliable estimates by ethnic group and thus any ethnic differences reported should be interpreted with caution.

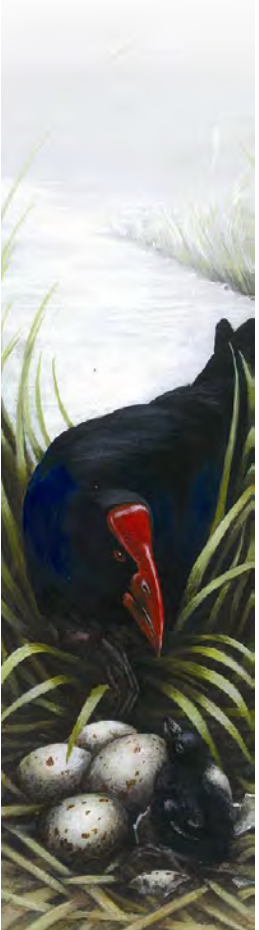
Additional Notes on the Measurement of Overweight and Obesity

Obesity: Obesity is defined as an excess in adiposity or body fat mass. Measures of adiposity in current use include weight, weight for height (e.g. BMI), skin fold thickness (e.g. triceps / sub-scapular) and circumferences / diameters (e.g. waist-hip / waist-thigh ratios, mid-upper arm circumferences), each of which has its own reference standards and cut-points [152]. Of these, the most popular is the Body Mass Index (BMI).

Obesity is often assessed using the Body Mass Index (BMI), calculated using the formula

$$BMI = \text{weight (kg)} / \text{height (m)}^2$$

Using height and weight to assess adiposity is generally viewed as being reliable, reproducible, non-intrusive and cheap, making BMI one of the most popular measures for obesity, both in New Zealand and overseas. In adults, cut-offs are based on mortality risk or other criteria, with those having a BMI of 25-29.9 kg/m2 being traditionally classified as overweight and those with a BMI of 30 kg/m2 or over being seen as obese. Using BMI to assess obesity in children however has a number of drawbacks, including the changes in body composition that occur as part of normal growth and with the onset of puberty, and ethnic differences in body composition for a given BMI [150]. These issues are discussed in more detail below.



Changes in Body Composition with Age: The Need for BMI Percentile Charts

Assessing obesity during childhood and adolescence is more complex than in adults, as both height and body composition change progressively with development. In particular, the proportion of fat mass / total body weight changes significantly during childhood, beginning at around 13-15% in term newborn infants and increasing progressively during the first year of life, to a maximum of 25-26% at 12 months of age. From 12 months to 4-6 years, the proportion of body fat then declines, to a nadir of around 12-16%, before increasing again between the ages of 6-10 years. By early adulthood, the proportion of fat mass is 20-25% for women and 15-20% for men [150]. As a result of these changes, when assessing the level of obesity in an individual child, BMI for age percentile charts are usually used, which extrapolate back the traditional adult cut points of 25-29.9 kg/m2 and ≥30 kg/m2, to the same points on the BMI distribution during the childhood years e.g. a male child with a BMI > 19.3 at the age of 5 years, is on the same point in the percentile charts as an 18 year old with a BMI of >30, and thus will be classified as obese [156]. As New Zealand to date has not developed its own BMI percentile charts for children, overseas standards must be used. Of these, the most popular were developed by the International Obesity Taskforce (see Cole [156] [157]) using pooled survey data from a number of different countries.

Ethnic Differences in BMI

With no BMI for age percentile charts specifically designed for New Zealand use, there remains a significant amount of debate about the appropriateness of the traditional BMI-for-age cut offs for New Zealand children of different ethnic groups. While a number of studies have suggested that, for a given BMI, Māori and Pacific children have a lower percentage of body fat [158] [159] [160], others have argued that while statistical differences may exist, there are no clinically significant ethnic differences in the relationship between BMI and body composition and that a common standard should be used for children of all ethnic groups [160]. Overseas research also suggests that ethnic differences in body composition may increase during puberty, with differences being much less marked amongst children <8 years of age [161]. Similarly, ethnic differences in the onset of puberty may also make utilisation of a common BMI cut off difficult, with puberty on average, occurring earlier amongst Māori and Pacific groups [162]. Such differences need to be kept in mind when interpreting ethnic specific obesity rates calculated using overseas percentile charts, as they may tend to overestimate obesity rates amongst Māori and Pacific children slightly.

Indicator Category: Bookmark B

The 2006/07 New Zealand Health Survey (NZHS)

Underweight, Overweight and Obesity

Age and Gender Differences

In the 2006/07 New Zealand Health Survey, there were no significant gender or age differences in the (unadjusted) prevalence of overweight or obesity in those aged 2-4 years, 5-9 years, 10-14 years, although higher rates of obesity were seen in those aged 15-24 years (compared to some younger age groups) (**Figure 40**).

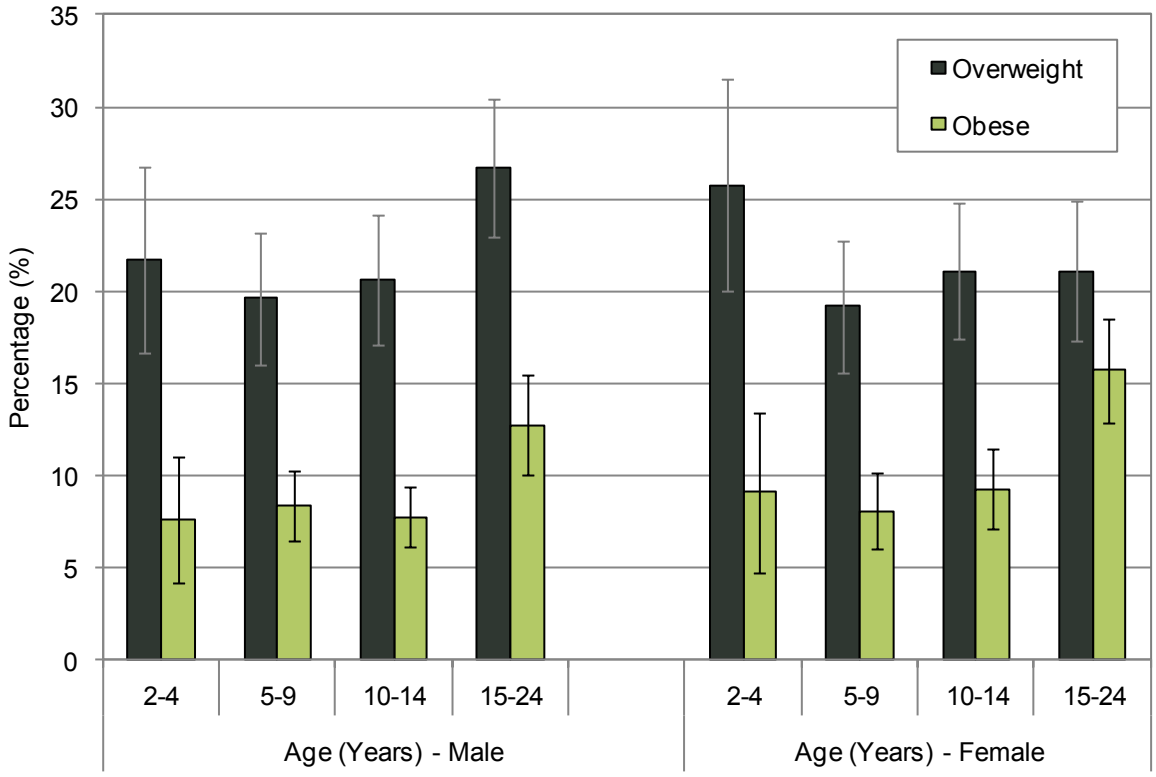
Ethnic Differences

Once standardised for age, Māori children (boys and girls combined) were 1.23 (95% CI 1.09-1.38) times more likely to be overweight and 1.43 (95% CI 1.18-1.67) times more likely to be obese than children in the total population. Similarly Pacific children were 1.50 (95% CI 1.32-1.67) times more likely to be overweight and 2.81 (95% CI 2.32-3.31) times more likely to be obese than those in the total population. In contrast, Asian (RR 0.70 95% CI 0.54-0.86) and European / Other (RR 0.92 95% CI 0.89-0.96) children were *significantly* less likely to be overweight than those in the total population. European / Other children were also *significantly* less likely to be obese (RR 0.67 95% CI 0.58-0.76). For a breakdown of ethnic differences by gender see **Figure 41**.

NZ Deprivation Index Decile

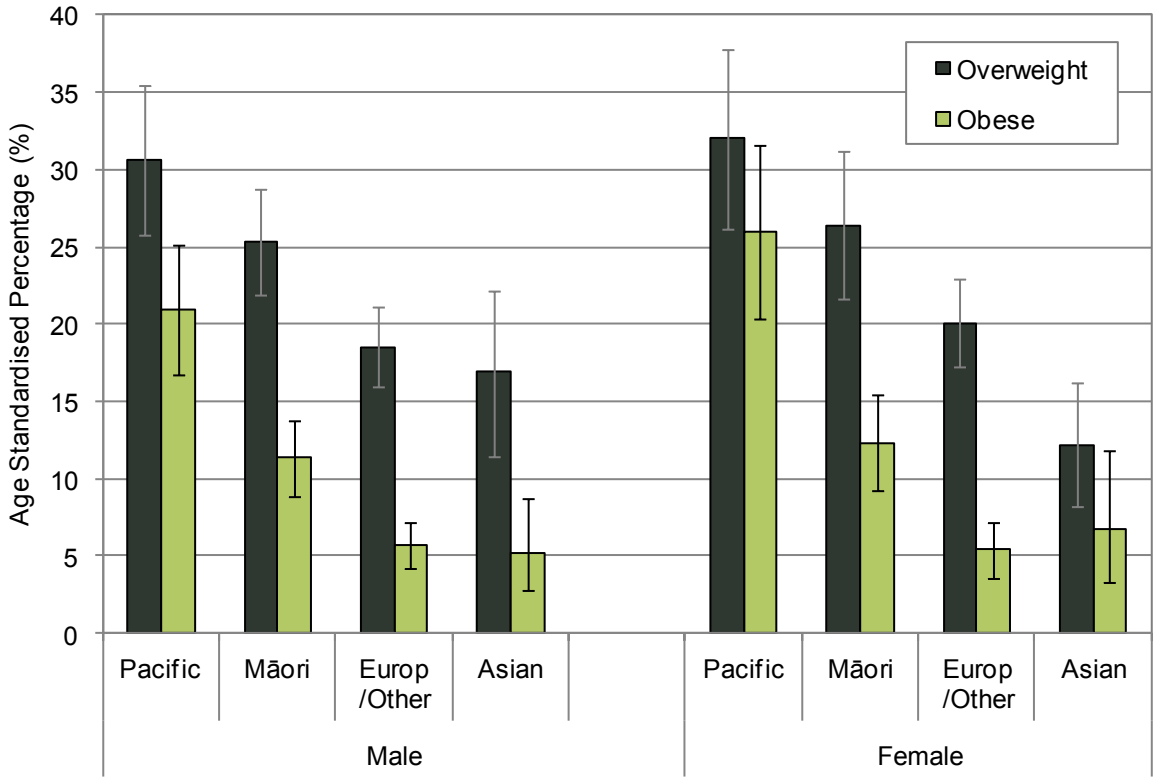
Once standardised for age, children (boys and girls combined) living in the most deprived (NZDep deciles 9-10) areas were *significantly* more likely to be obese than those living in the least deprived–average ((NZDep decile 1-8) areas. Children in the most deprived (NZDep deciles 9-10) areas were also *significantly* more likely to be overweight than those living in more affluent (NZDep deciles 1-4) areas (**Figure 42**).

Figure 40. Proportion of Children and Young People 2-24 Years who were Either Overweight or Obese by Gender and Age, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey

Figure 41. Proportion of Children and Young People 2-14 Years who were Either Overweight or Obese by Gender and Ethnicity, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Ethnicity is Total Response; Rates are Age Standardised

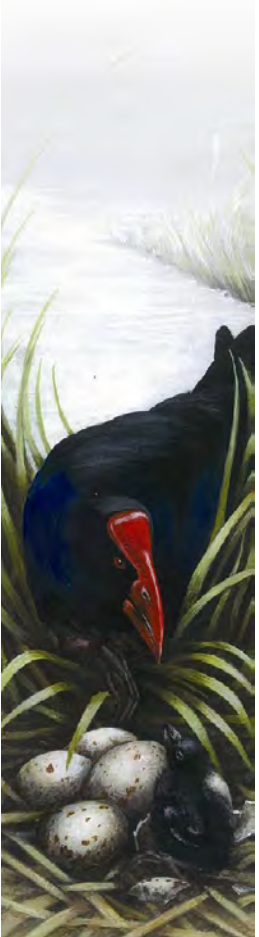
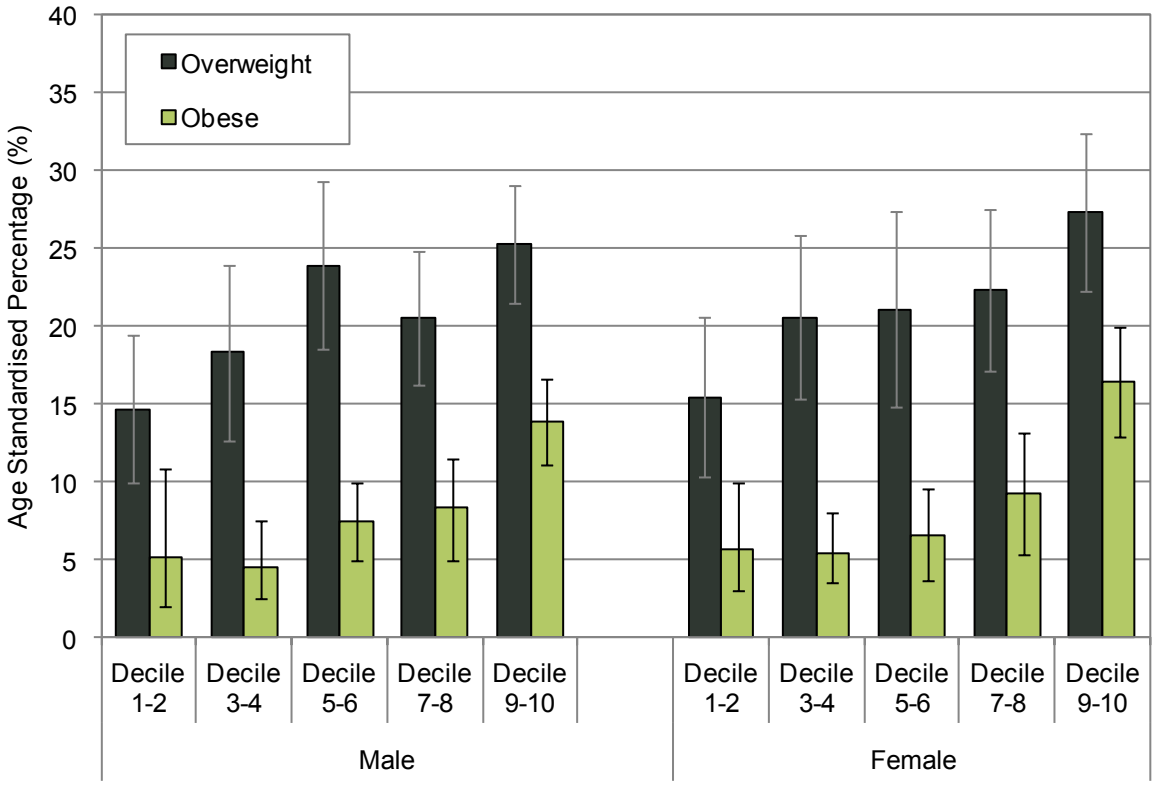
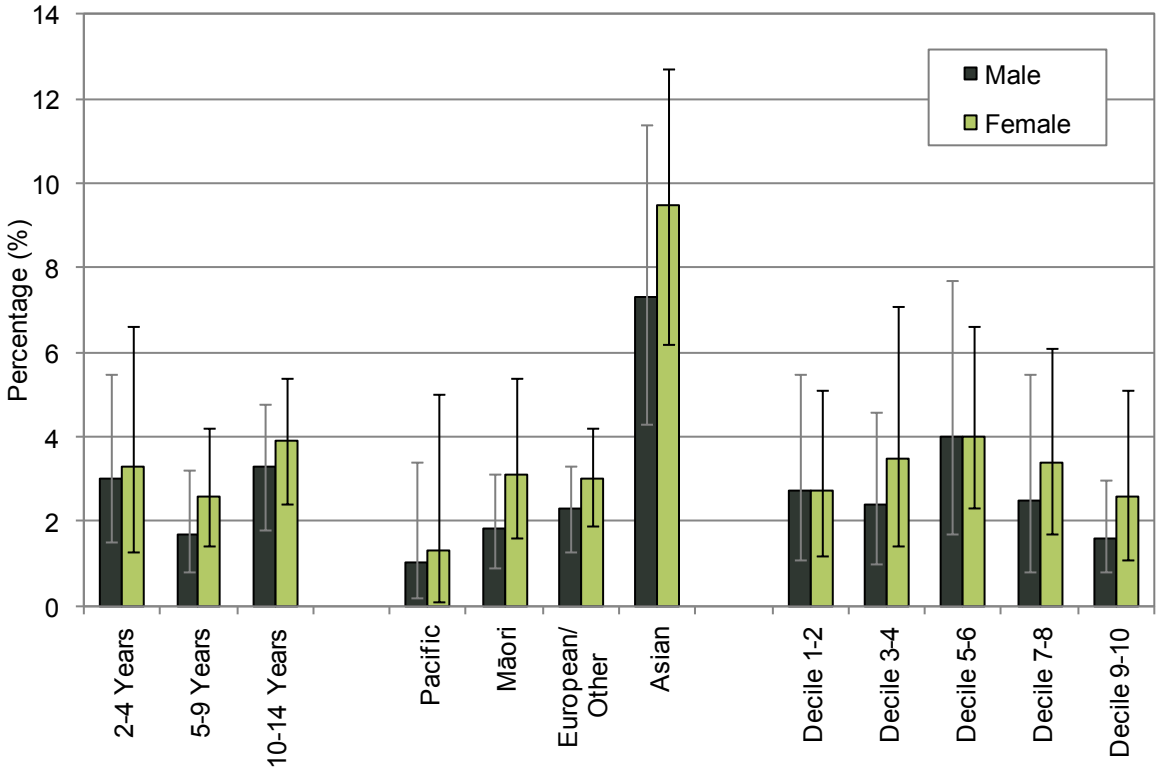


Figure 42. Proportion of Children and Young People 2-14 Years who were Either Overweight or Obese by Gender and NZ Deprivation Index Decile, New Zealand Health Survey 2006/07



Source: 2006/07 New Zealand Health Survey; Rates are Age Standardised

Figure 43. Proportion of Children and Young People 2-14 Years who were Thin by Gender, Age, Ethnicity and NZ Deprivation Index Decile, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Ethnicity is Total Response; Ethnic Specific and NZDep Rates are Age Standardised

Table 65. Prevalence of Obesity in Children Aged 2-14 Years by Region, 2006/07 New Zealand Health Survey

DHB Region	Prevalence (95% CI)
Northland / Tairawhiti / Hawke's Bay / Lakes / Whanganui	8.9 (6.6 - 11.2)
Waitemata	5.9 (3.4 - 8.3) -
Auckland	9.7 (6.6 - 12.9)
Counties Manukau	12.7 (9.4 - 16.0) +
Waikato	9.2 (6.2 - 12.2)
Bay of Plenty / Taranaki / MidCentral	5.2 (3.1 - 7.3) -
Wairarapa / Hutt Valley / Capital and Coast	9.1 (6.0 - 12.2)
Canterbury	6.1 (3.5 - 9.6)
Nelson Marlborough / West Coast / South Canterbury / Otago / Southland	8.2 (4.0 - 12.3)
New Zealand Total	8.3 (7.4 - 9.3)

Source: 2006/07 New Zealand Health Survey: + significantly higher than the national rate; - significantly lower than the national rate; Rates are unadjusted.

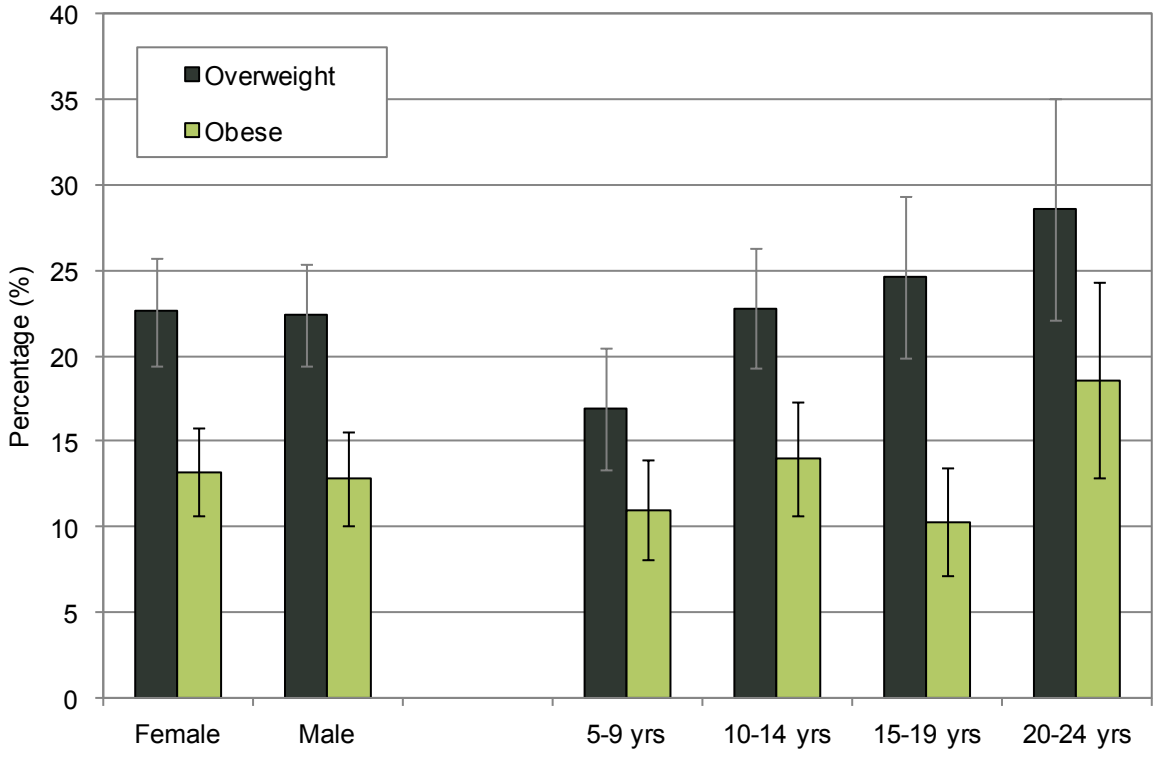
Regional Differences

The prevalence of obesity in children living in Counties Manukau was *significantly* higher than the national rate, while the prevalence of obesity amongst children living in Waitemata and the Bay of Plenty / Taranaki / MidCentral was *significantly* lower (**Table 65**).

National Survey of Children and Young People's Physical Activity and Dietary Behaviours in New Zealand: 2008/09

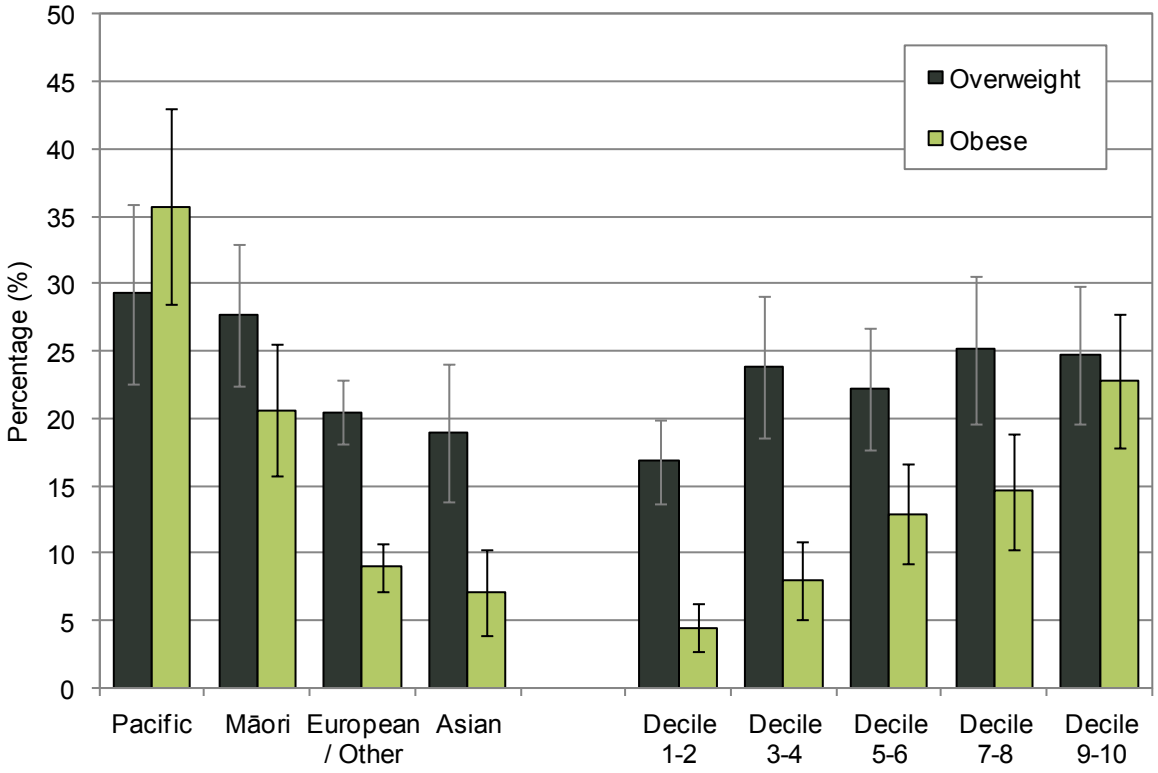
The NZS-CY-PA-DB-2008/09 [155] also measured overweight and obesity in New Zealand children and young people aged 5-24 years.

Figure 44. Proportion of Children and Young People Aged 5-24 Years who were Overweight or Obese by Gender and Age, 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours



Source: 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours

Figure 45. Proportion of Children and Young People Aged 5-24 Years who were Overweight or Obese by Ethnicity and NZ Deprivation Index Decile, 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours



Source: 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours.
Note: Ethnicity is Total Response.

Age and Gender Differences

In the NZS-CY-PA-DB-2008/09 [155], while the overall prevalence of obesity was highest in those aged 20-24 years, there was no clear pattern of increasing obesity in males or females with increasing age. Similarly, there were no significant gender differences in overweight or obesity when those aged 5-24 years were considered as a group (**Figure 44**), although obesity rates for females aged 20-24 years were *significantly* higher than for males in the same age group [155].

Ethnicity and NZ Deprivation Index Decile

The prevalence of obesity varied by (total response) ethnic group, with rates being 35.7% for Pacific and 20.6% for Māori children and young people, as compared to 9.0% for European / Other and 7.1% for Asian children and young people. The prevalence of obesity also increased with increasing NZDep deprivation, with rates for both males and females in the most deprived (NZDep deciles 9-10) areas being *significantly* higher than for those in the least deprived (NZDep decile 1-2) areas [155] (**Figure 45**).

Summary

Overweight and Obesity: In the 2006/07 New Zealand Health Survey, there were no significant gender differences in the prevalence of overweight or obesity in those aged 2-14 years. Adjusted for age, Māori and Pacific children however were *significantly* more likely to be overweight or obese than those in the total population, while Asian and European / Other children were *significantly* less likely to be overweight, and European / Other children were also *significantly* less likely to be obese. Children in the most deprived (NZDep deciles 9-10) areas were *significantly* more likely to be obese than those living in the least deprived-average ((NZDep decile 1-8) areas. Children in the most deprived (NZDep deciles 9-10) areas were also *significantly* more likely to be overweight than those living in more affluent (NZDep deciles 1-4) areas. Similar patterns were identified in the 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours, for those aged 5-24 years.

Local Policy Documents and Evidence Based Reviews Relevant to the Prevention and Management of Overweight and Obesity in Children and Young People

In New Zealand a range of policy documents and reviews consider the prevention and management of overweight and obesity and these are briefly summarised in **Table 66**, along with a range of guidelines and reviews which consider these issues in the overseas context.

Table 66. Local Policy Documents and Evidence Based Reviews Relevant to the Prevention and Management of Overweight and Obesity in Children and Young People

New Zealand Policy Documents and Reviews
Ministry of Health. **Healthy Eating - Healthy Action. Oranga Kai – Oranga Pumau: A strategic framework**. Wellington: Ministry of Health, 2003. URL: http://www.moh.govt.nz/moh.nsf/ea6005dc347e7bd44c2566a40079ae6f/6088a42cfaa9ac6fcc256ce0000dae66?OpenDocument This document sets out the framework for the Healthy Eating – Health Action strategy which aims to encourage people to improve their nutrition and be more physically active, and to reduce the number of people who are obese. These are population health priorities in the New Zealand Health Strategy. It is a planning tool aimed at a variety of sectors and service providers including the Ministry of Health, District Health Boards and the Health Research Council. There are suggestions for action in the key priority areas of lower socioeconomic groups, children, young people and their whānau (including older people), environments, communication and workplace. Ministry of Health. **Healthy Eating – Healthy Action. Oranga Kai – Oranga Pumau: A background**. Wellington: Ministry of Health, 2003. URL: http://www.moh.govt.nz/moh.nsf/ea6005dc347e7bd44c2566a40079ae6f/6f0cb6922a8575b5cc256ce6000d3a6f?OpenDocument This document provides the scientific evidence that underpins the strategy document Healthy Eating – Healthy Action: A strategic framework. It is based on a review of the literature and extensive public consultation. It provides a summary of the issues identified in the areas of nutrition, physical activity, obesity, Māori, and Pacific Peoples. Ministry of Health. **Healthy Eating – Healthy Action: Oranga Kai – Oranga Pumau Implementation Plan: 2004–2010**. Wellington: Ministry of Health, 2004. URL: http://www.moh.govt.nz/moh.nsf/49ba80c00757b8804c256673001d47d0/cd182e2c03925c09cc256ebd0016cf4b?OpenDocument This implementation plan follows on from the HEHA strategy and background paper. It outlines key points from the strategy and provides an integrated policy framework for achieving the objectives of improving nutrition, increasing physical activity and reducing obesity. Tables set out specific desired outcomes, actions to achieve those outcomes, which agencies need to be involved, milestones and progress measures and timeframe/resourcing for the eight objectives of the implementation plan. Ministry of Health. **Healthy Eating – Healthy Action, Oranga Kai – Oranga Pumau: Progress on Implementing the HEHA Strategy 2008**. Wellington: Ministry of Health, 2008. URL: http://www.moh.govt.nz/moh.nsf/indexmh/heha-progress-dec08 This document provides an outline of the HEHA Project Team's progress and a summary of the main work streams the Project Team has undertaken since the release of the 2007 progress report and of the areas it will continue to work on.
Ministry of Health, **Food and Nutrition Guidelines for Healthy Children and Young People (Aged 2–18 Years): A background paper - Draft for Consultation**. Wellington. Ministry of Health 2010. URL http://www.moh.govt.nz/moh.nsf/indexmh/consultation-food-and-nutrition-guidelines?Open This background paper is one of a series of five background papers on food and nutrition, with others targeting infants and toddlers, adults, older people and pregnant and breastfeeding women. It aims to provide up to date, evidence informed policy advice and technical information for health practitioners working with children and young people. The document has been developed by updating and amalgamating the 1997 Food and Nutrition Guidelines for Healthy Children (2-12 years), and the 1998 Food and Nutrition Guidelines for Healthy Adolescents. At the time of writing the document was being circulated for comment, with submissions closing 13th December 2010.
Ministry of Health, Clinical Trials Research Unit. **Clinical Guidelines for Weight Management in New Zealand Children and Young People**. Wellington: Ministry of Health, 2009. URL: http://www.moh.govt.nz/moh.nsf/indexmh/clinical-guidelines-for-weight-management-in-nz-children-and-young-people These guidelines, which are primarily intended for use in primary care and community-based initiatives, aim to provide evidence-based guidance for the management of overweight and obesity in children and young people. They were developed by the Clinical Trials Research Unit at the University of Auckland with advice and guidance from the guidelines Technical Development Group.

Ministry of Health. **Food and Nutrition Guidelines for Healthy Infants and Toddlers (Aged 0–2): A background paper (4th Ed).** Wellington: Ministry of Health, 2008. URL: http://www.moh.govt.nz/moh.nsf/indexmh/0-2-food-and-nutrition-guidelines-may2008

This publication provides a policy base for the implementation of the HEHA strategy in infants and toddlers. It includes evidence-based policy advice on nutrition and physical activity. It aims to provide information on which to base education programmes and resources as well as guidance for health practitioners. It also aims to provide a basis for the preparation of policies to protect, promote and support breastfeeding including those to ensure compliance with the Baby Friendly Hospital Initiative (BFHI) and the Baby Friendly Community Initiative (BFCI) for health care facilities. It identifies health inequalities relating to nutrition and physical activity in order to facilitate targeting.

Ministry of Health. **An Analysis of the Usefulness and Feasibility of a Population Indicator of Childhood Obesity**. Wellington: Ministry of Health, 2006. URL: http://www.moh.govt.nz/moh.nsf/by+unid/365AE9B0C1B24A17CC25718800097D82?Open

This paper provides an analysis of the usefulness and feasibility of an indicator to monitor obesity in children and young people and to monitor the effectiveness of strategies and interventions for the prevention and management of childhood obesity. It was written by Dr Nikki Blair, as part of her advanced training in paediatrics, during a six-month attachment to the Ministry of Health. Although it does not necessarily represent the views of the Ministry of Health, it is intended as a guide for policy and funding decisions concerning the prevention and management of childhood obesity which will assist policy makers in the Ministry of Health and other government departments and also District health Board funders and planners. It used a „Leading for Outcomes' approach, which is a systems-level approach to health care employed by the Clinical Services Directorate of the Ministry of Health. The five chapters cover: Potential indicators of obesity in childhood, Timing of BMI (Body mass index) collection, Ethical considerations, Risks and costs, Practical issues, and The outcomes of monitoring childhood obesity using BMI.

National Health and Medical Research Council, Ministry of Health. **Nutrient reference values for Australia and New Zealand including recommended dietary intakes**. Canberra: Commonwealth Department of Health and Ageing, 2006. URL: http://www.nhmrc.gov.au/publications/synopses/n35syn.htm

This publication is the result of a joint initiative of the Australian National Health and Medical Research Council and the New Zealand Ministry of Health. An expert working party reviewed recommendations from other countries, particularly from the US and Canada, as well as scientific data, information from recent dietary surveys in Australia and New Zealand and research and other information specific to Australian and New Zealand conditions. Each chapter covers one nutrient and provides recommended dietary intakes and upper levels of intake by life stage and gender. A comprehensive list of references is included for each chapter.

Ministry of Health. **Tracking the Obesity Epidemic: New Zealand 1977-2003**. Wellington: Ministry of Health, 2004. URL: http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/e967ef8fec435353cc256f62000c96fd?OpenDocument

This report examines changes in the prevalence of overweight and obesity in the total population from 1977-2003 and for the Māori Population from 1989-2003. It also uses graphical methods to visualise changes in the body mass index (BMI) distribution by age, gender, ethnicity and socioeconomic position. The data on which the report is based are derived from measurements of height and weight of adults aged 15-74 years from four national health and nutrition surveys: 1977 National Diet Survey, 1989 Life in New Zealand Survey, 1997 National Nutrition Survey, and 2002/03 New Zealand Health Survey.

Ministry of Health. **NZ Food, NZ Children: Findings of the 2002 National Children's Nutrition Survey**. Wellington: Ministry of Health, 2003. URL: http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/064234a7283a0478cc256dd60000ab4c?OpenDocument#NZ_Food_NZ_Children

This report provides an overview of the 2002 National Children's Nutrition Survey in which 3275 children participated. The survey involved anthropometric measurements being taken and blood and urine samples being collected at school as well as an interview on the food eaten in the past 24 hours which was done in the children's homes in the presence of a parent or caregiver. The survey data include data on nutrient intakes and their sources, food security, eating patterns, frequently eaten foods, physical activity patterns, dental health, anthropometric measures and selected nutrition-related clinical measures. Various summary documents including separate summaries for the results pertaining to Māori and to Pacific children are also available from the same web page as the main report.

Ministry of Health. **DHB Toolkit: Physical Activity**. Wellington: Ministry of Health, 2003. URL: http://www.moh.govt.nz/moh.nsf/pagesmh/5535?Open

District Health Boards are expected to focus on the priority population health objectives which include improving nutrition, reducing obesity, and increasing levels of physical activity. This toolkit aims to provide DHBs with guidance on the most effective ways they can work to increase physical activity in their region.

Ministry of Health. **DHB Toolkit: Improve Nutrition**. Wellington: Ministry of Health, 2001. URL: http://www.moh.govt.nz/moh.nsf/by+unid/DF0401461EC72B40CC2572340008A1D7?Open

This toolkit provides guidance to DHBs on improving nutrition. Its focus is on the promotion of the Ministry of Health's series of food and nutrition guidelines, the promotion of breast feeding and the introduction of the Baby Friendly Hospital Initiative. It covers the policy context as well as the current status of nutrition and breastfeeding in New Zealand and the targets for food, nutrients and breastfeeding.

Ministry of Health and the University of Auckland. **Nutrition and the Burden of Disease: New Zealand 1997-2011**. Wellington: Ministry of Health, 2003. URL: http://www.moh.govt.nz/moh.nsf/ea6005dc347e7bd44c2566a40079ae6f/7b9c6de0d0ac6483cc256d7a000b58ab?OpenDocument

This study used the comparative risk assessment methodology developed by the World Health Organisation (and used in the *World Health Report 2002*) to estimate the burden of disease that could be attributed to selected nutrition-related risk factors. It also aimed to estimate the burden of disease that could be avoided in 2011 if policy interventions reduced the exposure to these risk factors. The authors concluded that in 1997 40% of all deaths may have been attributable to the combined effects of sub-optimal diet and levels of physical activity, including 85% of the deaths from ischaemic heart disease, 70% of the deaths from stroke, 80% of the deaths from diabetes and 6% of the deaths from cancer. The results of this study confirm that the well known nutrition–related risks of cholesterol and blood pressure along with tobacco smoking are the three major modifiable causes of premature death in New Zealand.

International Guidelines

Scottish Intercollegiate Guidelines Network (SIGN). **Management of obesity. A national clinical guideline.** Edinburgh, Scotland: Scottish Intercollegiate Guidelines Network (SIGN), 2010. URL: http://www.guideline.gov/content.aspx?id=15597

This guideline provides evidence-based recommendations on the prevention and treatment of obesity in clinical settings. The focus of prevention is on primary prevention i.e. interventions for people who are of healthy weight or overweight which aim to prevent them becoming obese. Sections 16-19 are relevant to children and young people.

World Health Organisation. **Population-based prevention strategies for childhood obesity: Report of a WHO forum and technical meeting**. Geneva: World Health Organisation, 2009. URL: http://www.who.int/dietphysicalactivity/childhood/report/en/index.html

This meeting was held to identify priorities for population-based strategies to prevent childhood obesity and also to provide a forum for the sharing of experiences and lessons learned from many different countries. The participants identified guiding principles and areas for action and these are set out in Chapter 4 of the report. The final chapter, Chapter 5 sets out proposed actions for four major stakeholder groups: the World Health Organisation, Member States, nongovernmental organisations, civil society and academia, and the private sector.

In February 2004 the American Medical Association convened an expert committee with representatives from 15 national organisations to produce evidence-based guidelines on the assessment, prevention and treatment of child and adolescent overweight and obesity. The following publications are the result:

Barlow SE, Expert Committee. **Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: Summary report**. Pediatrics 2007; 120(4): S164-92.

Krebs NF, Himes JH, et al. **Assessment of child and adolescent overweight and obesity**. Pediatrics 2007; 120 (4):

Davis MM, Gance-Cleveland B, et al. **Recommendations for prevention of childhood obesity**. Pediatrics 2007; 120 (4): S229-53.

Spear BA, Barlow SE, et al. **Recommendations for treatment of child and adolescent overweight and obesity**. Pediatrics 2007; 120 (4): S254-88.

A brief summary of the above information can be found in:

Rao G. **Childhood obesity: Highlights of AMA Expert Committee recommendations**. American Family Physician 2008; 78(1): 56-63.

The American Academy of Pediatrics has published a number of policy statements relating to nutrition, obesity and physical activity including:

Council on Sports Medicine and Fitness, Council on School Health. **Active healthy living: Prevention of childhood obesity through increased physical activity**. Pediatrics 2006; 117(5): 1834-42.

Krebs NF, Jacobson MS, et al. **Prevention of pediatric overweight and obesity**. Pediatrics 2003; 112(2): 424-30.

In addition, the website http://www.aap.org/obesity/policystatements.html includes policy statements on advertising; television; eating disorders; type 2 diabetes in children; soft drinks in schools; the built environment; and the use and misuse of fruit juice.

National Collaborating Centre for Primary Care, Centre for Public Health Excellence. **Obesity: Guidance on the prevention, identification, assessment and management of overweight and obesity in adults and children**. London: National Institute for Health and Clinical Excellence, 2006. URL: http://guidance.nice.org.uk/CG43/NICEGuidance/pdf/English

These comprehensive evidence-based guidelines cover the prevention, identification, assessment and management of overweight and obesity. As well as covering the clinical management of overweight and obesity within the health system they also address the role of schools, local authorities, employers and the private and voluntary sectors in developing opportunities to enable people to achieve better health.

Lau DC, Douketis JD, et al. **2006 Canadian clinical practice guidelines on the management and prevention of obesity in adults and children**. Canadian Medical Association Journal 2007; 176(Suppl 8): 1-117. URL: http://www.cmaj.ca/cgi/content/full/176/8/S1/DC1

These evidence-based guidelines for the prevention and management of obesity provide recommendations for individuals and populations in regard to the following interventions: screening for obesity (using BMI and waist circumference), screening for obesity-related conditions (e.g. dyslipidaemia, diabetes), screening for psychosocial disorders (e.g. mood disorders, eating disorders), prevention of obesity through both individual and community interventions, dietary interventions, exercise, cognitive behaviour therapy, pharmacotherapy, bariatric surgery, alternative or non-traditional therapy, and health care team support.

National Health and Medical Research Council. **Clinical Practice Guidelines for the Management of Overweight and Obesity in Children and Adolescents**. Canberra: Australian Government Department of Health and Aging, 2003. URL: http://www.health.gov.au/internet/main/Publishing.nsf/Content/obesityguidelines-guidelines-children.htm

These guidelines are the result of a comprehensive review of the available scientific evidence and provide evidence-based guidance on the management of overweight and obesity in Australian children and adolescents. They are intended for the use of general practitioners and allied health practitioners. Evidence-based statements and also practice and research recommendations are accompanied by a grade which reflects the strength of the evidence on which they are based. The grading system used is that of the NHMRC.

Systematic and Other Reviews from the International Literature

Oude Luttikhuis H, Baur L, et al. **Interventions for treating obesity in children**. Cochrane Database of Systematic Reviews 2009(1): CD001872.

This review considered 64 RCTs with 5230 participants. Fifty-four studies reported on lifestyle interventions. Twelve of these related to interventions concerning physical activity and sedentary behaviour, six related to diet, and 36 related to behaviourally orientated treatment programmes. In addition, ten studies studied drug treatments: metformin, orlistat and sibutramine. There were no RCTs on surgery. Meta-analyses of the results of the studies showed that there was a reduction in overweight at 6 and 12 months follow up for lifestyle interventions in children and for lifestyle interventions in adolescents with or without orlistat or sibutramine. The authors considered that the evidence did not favour any one particular type of lifestyle intervention but stated that a combined dietary, physical and behavioural approach is likely to be effective. For adolescents they considered that in addition orlistat or sibutramine should be considered, after weighing up the benefits with the potential adverse effects. The authors stated that the studies included in the review failed to address and measure important psychological or social factors and they provide a list of unanswered questions for further research.

Dobbins M, DeCorby K, et al. **School-based physical activity programs for promoting physical activity and fitness in children and adolescents aged 6-18**. Cochrane Database of Systematic Reviews 2009(1):CD007651.

This review considered 26 studies which met the reviewers' criteria because they were relevant to public health practice, implemented, facilitated, or promoted by staff in local public health units, implemented in a school setting and aimed at increasing physical activity, and also because they reported on outcomes for children and adolescents (aged 6 to 18 years) and used a prospective design with a control group. There was good evidence that school-based physical activity programmes had a positive impact on duration of physical activity, television viewing, VO_2 max, and blood cholesterol. In general, school-based activity programmes had no effect on leisure time physical activity rates, systolic and diastolic blood pressure, body mass index, and pulse rate. The authors recommend ongoing physical activity promotion in schools.

Ekeland E, Heian F, et al. **Exercise to improve self-esteem in children and young people**. Cochrane Database of Systematic Reviews 2004(1): CD003683.

The authors of this review examined 23 RCTs including a total of 1821 children and young people which compared the effects of exercise either alone or as part of a comprehensive programme with no intervention on measures of self esteem. They concluded that although most of the trials were small and only one could be assessed as having a low risk of bias, the results of the trials indicate exercise has positive effects on self esteem in children and young people. They also note that exercise has no known ill-effects and many positive effects on physical health.

Summerbell CD, Waters E, et al. **Interventions for preventing obesity in children**. Cochrane Database of Systematic Reviews 2005(3): CD001871.

This review considered 22 studies (controlled trials), ten of which were classed as being long-term (12 months or more) and 12 of which were short-term (12 weeks to 12 months). Six of the ten long-term studies involved combined dietary education and physical activity and of these six, five found no difference in the overweight status between control and intervention groups and one found improvement for girls but not for boys in the intervention group. Two long-term studies focussed on physical activity alone and one found that a multimedia approach appeared to prevent obesity. Two long-term studies on nutrition education alone found that it was ineffective in preventing obesity. Two out four short-term studies focussed on interventions to increase levels of physical activity found minor reductions in overweight in the intervention group. The eight short-term studies which combined advice on diet and physical activity showed no difference between the intervention and control groups. The authors of this review concluded that although most studied interventions were not effective in preventing obesity nearly all of them resulted in some improvement in diet or physical activity. They stated that there is a need to reconsider the appropriateness of the development, design, duration and intensity of interventions to prevent childhood obesity and also to ensure that all interventions include carefully considered well-designed evaluation which enables adequately powered analysis of what is working (or not) and for whom.

Inge TH, Krebs NF, et al. **Bariatric surgery for severely overweight adolescents: Concerns and recommendations**. Pediatrics 2004; 114(1): 217-23.

This report provides guidance on evaluating very obese adolescents as potential candidates for bariatric surgery. It discusses important considerations including physiological maturity, co-morbidities, psychosocial factors, decisional capacity, family situation and barriers to compliance with treatment goals.

Other Relevant Publications and Useful Websites

American Academy of Pediatrics. **Prevention and treatment of childhood obesity spotlight: Whitehouse Obesity Initiative**. URL: http://www.aap.org/obesity/whitehouse/

The Lets Move initiative is a joint initiative by the American Academy of Pediatrics, the White House, the US Department of Health and Human Services, the US Department of Education and the US Department of Agriculture which aims to reduce the rates of overweight and obesity in American children. The website has a number of useful resources for both professionals and families.

Adolescent Health Research Group. **Youth '07: The Health and Wellbeing of Secondary School Students in New Zealand. Initial Findings**. 2008, Auckland: University of Auckland. URL: http://www.youth2000.ac.nz/publications/reports-1142.htm

This report presents findings from the 9,107 secondary school students who took part in New Zealand's second national youth health and wellbeing survey, conducted in 2007. The findings are compared with those from the first survey conducted in 2001. Page 25 deals with general health issues: the percentage of students accessing various types of health care and the perceived quality of health care (confidentiality, availability, etc). Pages 21-24 deal with Nutrition and Physical activity. Information about body size, nutrition, dietary behaviours, exercise, leisure activities, and the proportion of students unhappy about their weight is presented. Other topics covered in this survey were: Culture and Ethnicity, Home and Families, School, Emotional Wellbeing, Substance Use, Gambling, Sexual Health, Injuries and Violence, Multiple Health-Risk Behaviours and Community.

NUTRITION

Introduction

As rates of childhood obesity have increased, attention has turned towards the environments in which children live and the role dietary and lifestyle changes have played in altering the balance between caloric intake and the amount of energy expended on incidental physical activity. While no time series information is available for New Zealand, serial surveys of nutritional intake in the USA from the mid-1970s to the 1990s have demonstrated a number of strong and consistent trends including a 3-fold increase in the consumption of chips / crackers / pretzels, a 2-fold increase in the consumption of soft drink and a shift towards larger portion sizes [163]. While the proportion of energy derived from fat fell during this period, the proportion derived from carbohydrate increased, with the majority of the increase in per capita calorie intake seen since the mid-1980s being derived exclusively from carbohydrate [163]. In addition, the proportion of food dollars Americans spent on eating out increased, from 33% in 1970 to 47% in 2001, with researchers noting that food consumed away from home was more energy dense and contained more fats and sugars than food prepared at home. Relative price changes also saw increases in the price of fruit and vegetables, while prices for sugar, sweets, soft drinks and fats fell in relative terms [163].

While no comparable time series data is available for New Zealand, information from a number of cross sectional surveys suggests that aspects of the current nutritional environment are not conducive to healthy food choices for New Zealand children. In one survey of 200 primary / intermediate schools, 79% of school canteens offered pies, 57% offered juice and 55% offered sausage rolls. In contrast, filled rolls (the most expensive item) were offered by only 47%, while 30% offered sandwiches and 17% offered fruit [164]. The potential implications this has for disparities in childhood nutritional intake were highlighted by the 2002 National Children's Nutrition Survey, which suggested that Pacific and Māori children were significantly more likely to buy some or most of the food they consumed at school from the school tuckshop and were also more likely to consume pies, hamburgers, and fizzy drinks than European / Other children [165].

The following section thus reviews the distribution and determinants of nutritional intake in New Zealand children and young people using information from two recent national surveys; The 2006/07 New Zealand Health Survey [148] and the National Survey of Children and Young People's Physical Activity and Dietary Behaviours [155].

Data Sources and Methods

Definitions

Proportion of Children and Young People Aged 5-24 Years Achieving Fruit and Vegetable Intake Guidelines

Number of Times Breakfast Was Eaten at Home in the Previous Week in Children Aged 2-14 Years

Number of Fizzy Drinks Consumed in the Previous Week for Children Aged 2-14 Years

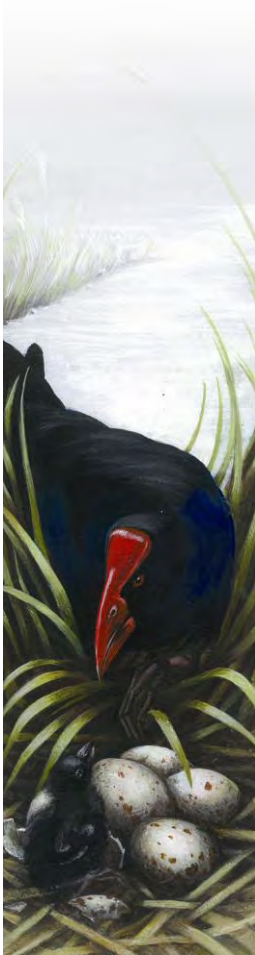
Number of Times Takeaways / Fast Food was Consumed in the Past Week for Children Aged 2-14 Years

Data Sources

The 2006/07 New Zealand Health Survey (NZHS)

The 2006/07 NZHS [148] was a cross sectional survey carried out between October 2006 and November 2007, which collected information on 4,921 children from birth to 14 years, and 12,488 adults aged 15 years and over who lived in private dwellings. The child survey included 3,039 European / Other, 1,983 Māori, 798 Pacific and 742 Asian children, with the final response rate for the child questionnaire being 71%, and for the adult questionnaire being 68%. The primary caregiver, in the case of children aged 0-14 years, answered the questionnaire on the child's behalf. The survey results have been weighted to ensure they are representative of New Zealand's resident population living in permanent dwellings [148].

Ethnicity: In the Survey four ethnic groups were reported: Māori, Pacific, Asian and European / Other, with the "Other" category including Middle-Eastern, Latin-American and African ethnic groups. Total response ethnicity was used throughout, with an individual being included in the analysis for each ethnic group to which they affiliated (28.3% of children were assigned to more than one ethnic group). As a result, ethnic groups cannot be directly compared with each other, and thus all interpretations which appear in the text are made with reference to the total population [148].



Age Standardisation: In New Zealand, each ethnic group has its own age structure (e.g. the Māori and Pacific populations have a much higher proportion of individuals <25 years of age) and thus when comparisons are made between different ethnic groups (and also by NZ Deprivation Index decile, which is unevenly distributed by ethnicity), these differences need to be taken into account. Thus, in the sections which follow, all ethnic and NZ Deprivation Index decile specific analyses have been age standardised (to the World Health Organisation (WHO) world population age distribution - see [148] p16 for a more detailed account). All age / gender graphs however use unadjusted rates, so that the underlying prevalence in the New Zealand population can better be ascertained. Where gender comparisons are made in the text however, these have been adjusted for differences in the underlying age distributions of the two gender groupings [148].

The data for the tables and graphs derived from this survey were sourced from http://www.moh.govt.nz/moh.nsf/indexmh/portrait-of-health#summary

The National Survey of Children and Young People's Physical Activity and Dietary Behaviours in New Zealand: 2008/09 (NZS-CY-PA-DB-2008/09)
The NZS-CY-PA-DB-2008/09 [155] was a nationally representative survey of 2,503 children and young people aged 5-24 years (470 Māori , 239 Pacific, 324 Asian and 1,786 European and Other). Data were collected between September 2008 and May 2009, by means of a face-to-face home visit and a subsequent telephone interview. Height and weight were measured during the home visit, with accelerometers being used to assess the time spent in physical activity over a 7-day period. Data were collected directly from those aged 10+ years, with parents providing proxy responses for children ≤9 years. The overall response rate was 55%, with population weighting being used to ensure that the results were representative of the total population. In contrast to the 2006/07 NZHS however, age standardisation was not undertaken, so none of the data presented have been adjusted for differences in the age structure of different population groups.

Ethnicity: In the Survey four ethnic groups were reported: Māori, Pacific, Asian and European / Other. Total response ethnicity was used throughout, with an individual being included in the analysis for each ethnic group to which they affiliated. As oversampling by ethnic group was not undertaken, the survey is unable to provide reliable estimates by ethnic group and thus any ethnic differences reported should be interpreted with caution.

National Survey of Children and Young People's Physical Activity and Dietary Behaviours in New Zealand: 2008/09

Recommended Fruit and Vegetable Intake

It is recommended that children and young people eat five or more servings of fruit and vegetables each day, with this comprising at least 3 or more servings of vegetables and two or more servings of fruit [155].

Age and Gender Differences

In the NZS-CY-PA-DB-2008/09 [155] there were no significant differences in the proportion of children and young people meeting fruit and vegetable intake guidelines by gender. While the proportion meeting fruit guidelines decreased with increasing age, there were no consistent age related differences in the proportion achieving vegetable intake guidelines, or combined fruit and vegetable intake guidelines (**Figure 46**).

Ethnic and NZ Deprivation Index Decile Differences

In the NZS-CY-PA-DB-2008/09 [155] there were no significant socioeconomic or ethnic differences in the proportion of children and young people achieving fruit intake guidelines. The proportion of Pacific and Asian children and young people achieving vegetable and combined fruit and vegetable intake guidelines was however *significantly* lower than for European / Other children and young people. While children and young people living in the most deprived (NZDep decile 9-10) areas were less likely to achieve vegetable and combined fruit and vegetable intake guidelines, these differences did not reach statistical significance (**Figure 47**).

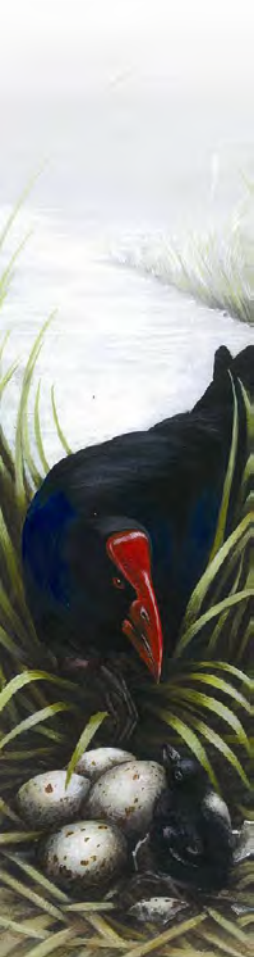
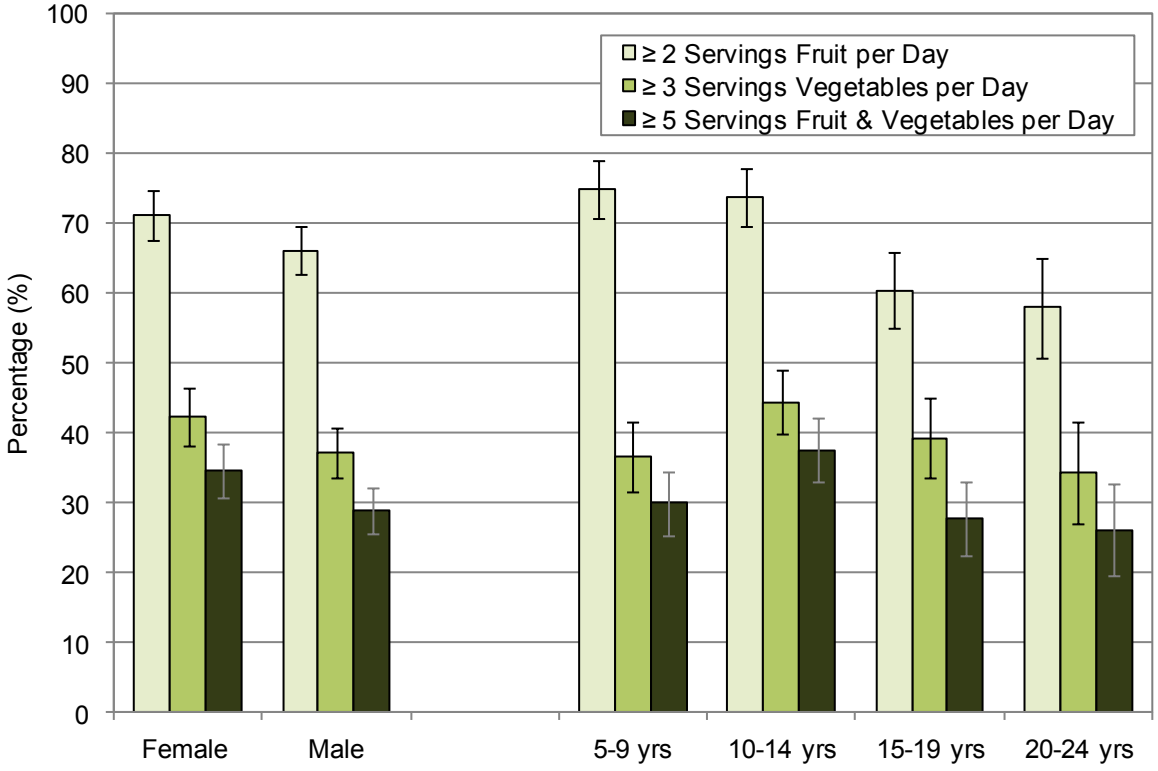
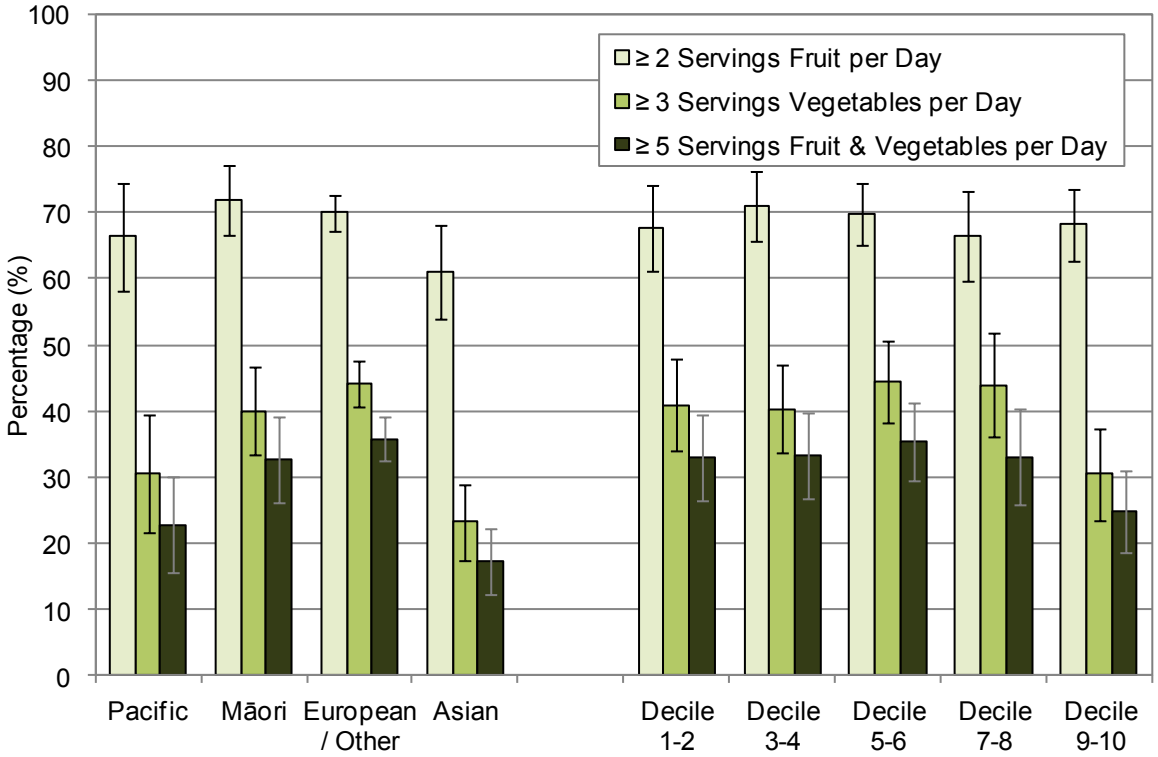


Figure 46. Proportion of Children and Young People Aged 5-24 Years Meeting Guidelines for Fruit and Vegetable Intake by Age and Gender, 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours



Source: 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours

Figure 47. Proportion of Children and Young People Aged 5-24 Years Meeting Guidelines for Fruit and Vegetable Intake by Ethnicity and NZDep Index Decile, 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours



Source: 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours. Ethnicity is Total Response

The 2006/07 New Zealand Health Survey (NZHS)

Breakfast Eaten at Home

Eating breakfast every day is used in the 2006/07 New Zealand Health survey as a proxy for good nutritional intake, as it has been positively associated with an increased intake of vitamins and minerals, better food choices and higher concentration at school [148]. Further, the 2002 National Children's Nutrition Survey [166] showed that children who usually eat breakfast at home have, on average, a lower BMI than those who do not, even once other potentially confounding risk factors are taken into account. Children who do not eat breakfast are also more likely to consume unhealthy snacks such as pies, confectionary and soft drinks [148].

Age and Gender Differences

In the 2006/07 New Zealand Health Survey, once adjusted for age, boys were *significantly* more likely (90.0% 95% CI 88.6-91.5) to have eaten breakfast at home every day in the previous week than girls (85.7% 95% CI 83.8-87.6). The proportion eating breakfast at home decreased with increasing age however, with those aged 10-14 years (80.1% 95% CI 77.7-82.6) being *significantly* less likely to eat breakfast at home every day in the previous week than those aged 2-4 years (95.0% 95% CI 93.5-96.5) and 5-9 years (91.4% 95% CI 89.8-93.0) (**Figure 48**).

Ethnic Differences

Once adjusted for age, Māori (83.6% 95% CI 81.2-86.0) and Pacific (79.3% 95% CI 75.1-83.4) children were *significantly* less likely to have eaten breakfast at home every day in the previous week than the total population, although rates for Asian and European / Other children were similar to the total population rate (**Figure 49**).

NZ Deprivation Index Decile Differences

Once adjusted for age, boys living in the most deprived (NZDep decile 9-10) areas (87.3% 95% CI 84.4-90.1) were *significantly* less likely to have eaten breakfast at home every day in the previous week than boys from the least deprived (NZDep Decile 1-2) areas (93.9% 95% CI 90.8-97.0). No significant differences were seen for girls however (**Figure 50**).

Regional Differences

There were no significant regional differences in the proportion of children who had eaten breakfast at home every day in the previous week.

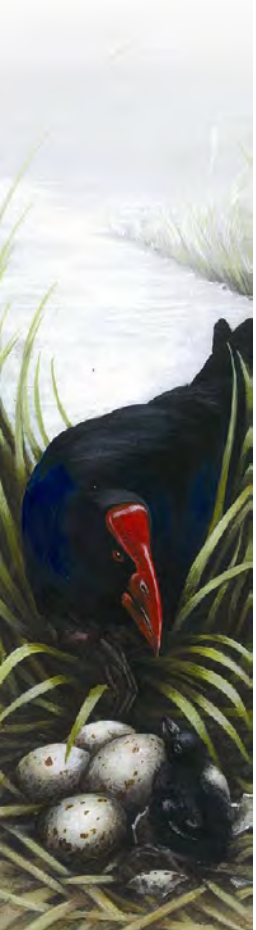
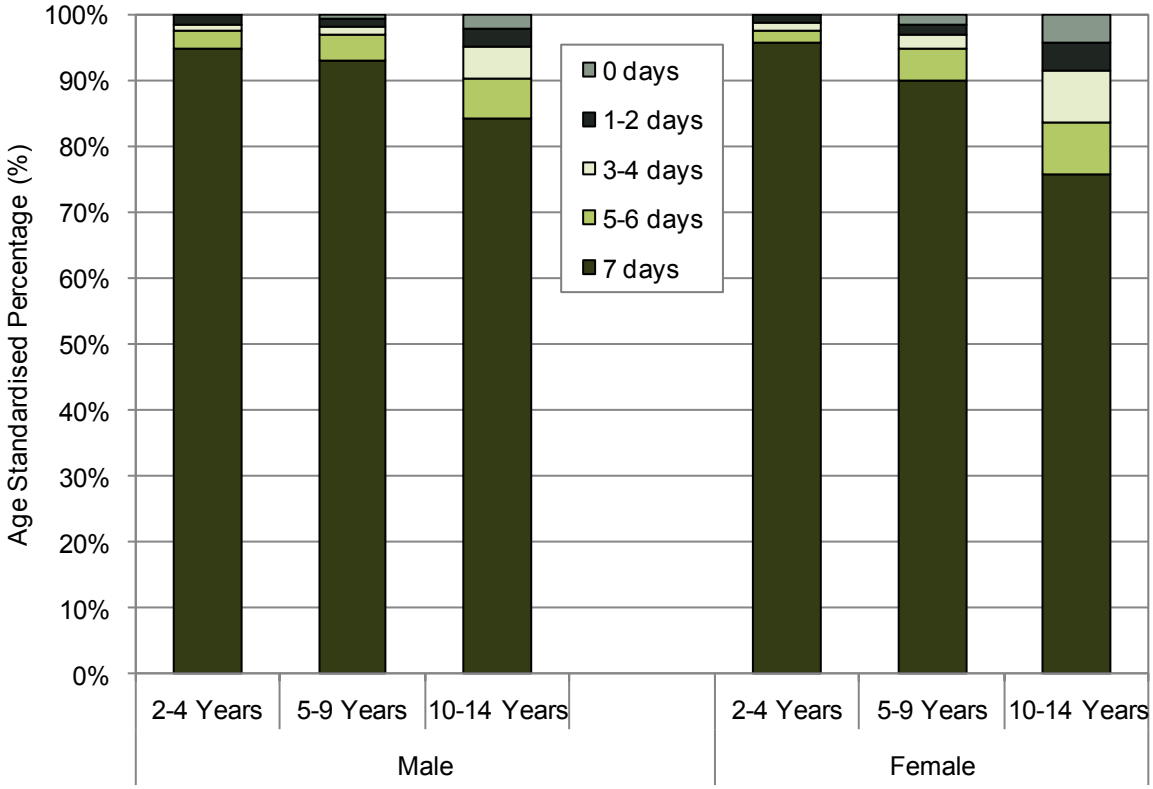
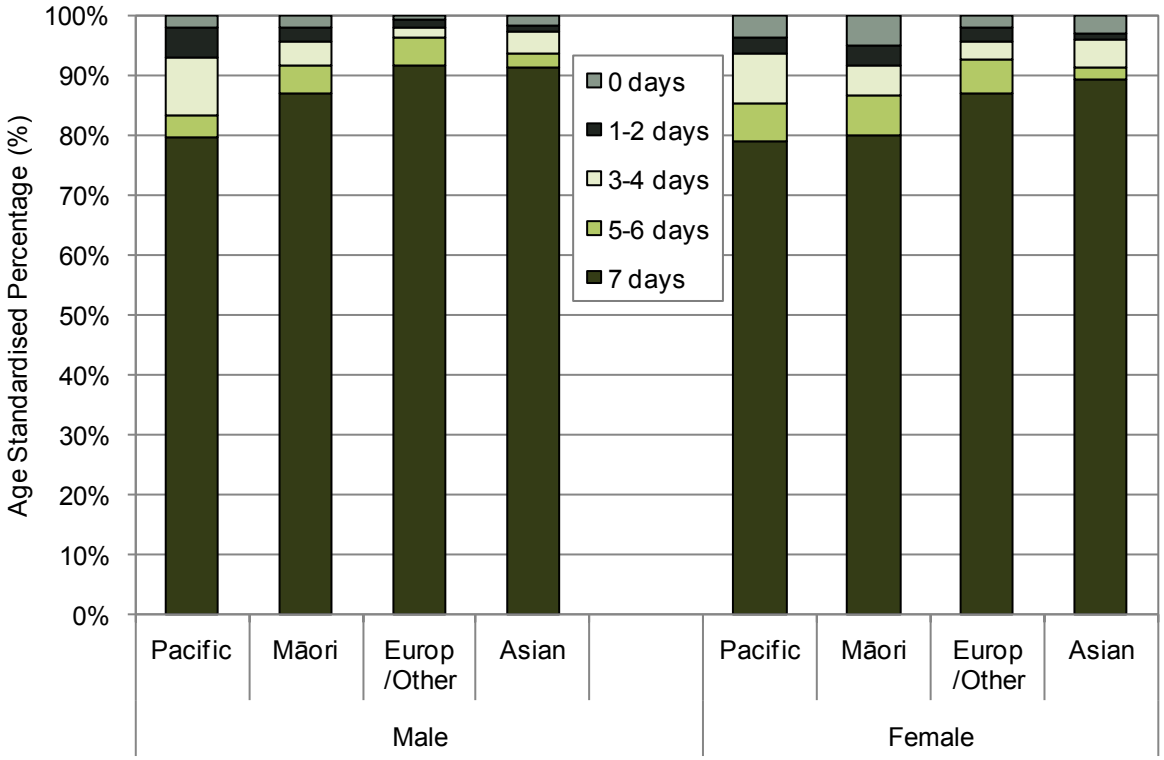


Figure 48. Number of Days Breakfast was Eaten at Home in the Previous Week by Gender and Age, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey

Figure 49. Number of Days Breakfast was Eaten at Home in the Previous Week, Children Aged 2-14 Years by Gender and Ethnicity, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Ethnicity is Total Response; Rates are Age Standardised

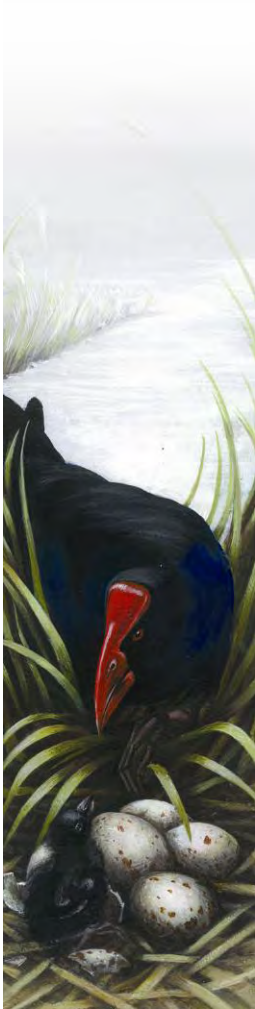
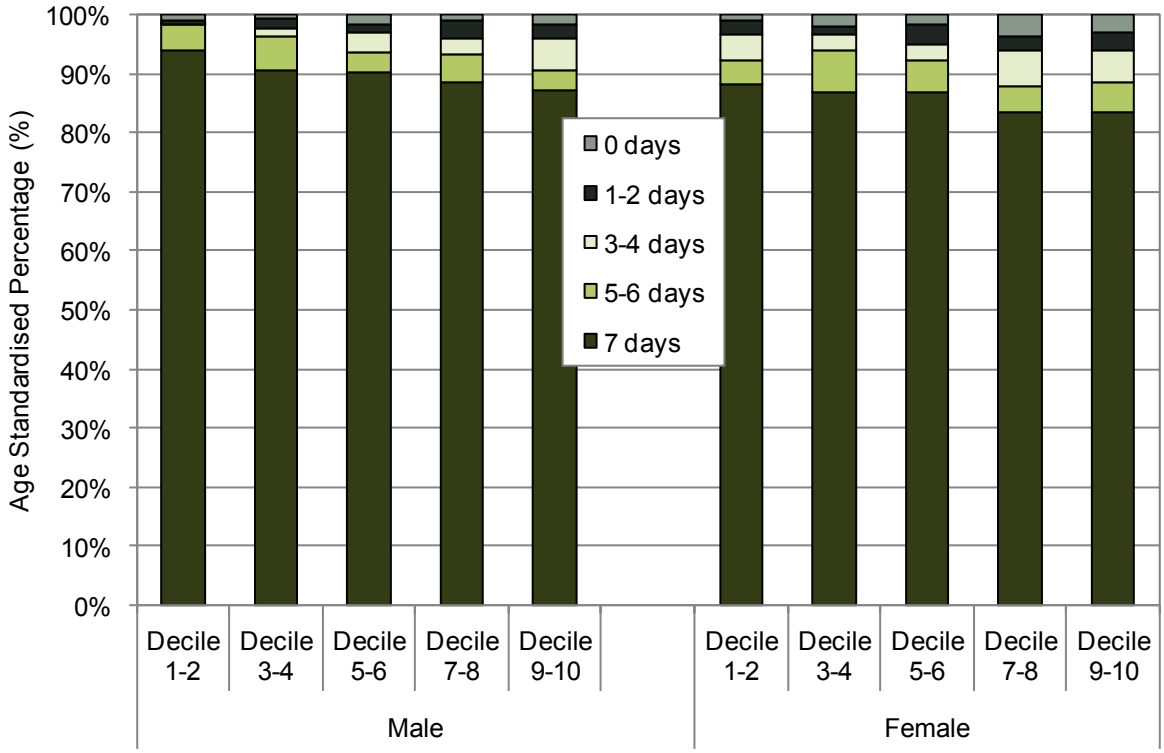


Figure 50. Number of Days Breakfast was Eaten at Home in the Previous Week, Children Aged 2-14 Years by Gender and NZ Deprivation Index Decile, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Rates are Age Standardised

Fizzy Drinks

The consumption of fizzy drinks was included in the 2006/07 New Zealand Health Survey as a result of the strong association between fizzy drinks and an increased risk of obesity and Type 2 diabetes [148], with fizzy drinks being seen as being high in sugar, of little nutritional value and in some studies being seen as replacing more nutritious fluids such as milk in children's diet.

Age and Gender Differences

In the 2006/07 New Zealand Health Survey, once adjusted for age, boys aged 10-14 years (34.2% 95% CI 30.5-38.0) were *significantly* more likely to have consumed 3 or more fizzy drinks in the previous week than girls aged 10-14 years (21.1% 95% CI 17.5-24.6). In addition, children aged 10-14 years (27.8% 95% CI 25.3-30.4) were *significantly* more likely than children aged 2-4 years (13.0% 95% CI 10.2-15.8) to have consumed 3 or more fizzy drinks in the previous week (**Figure 51**).

Ethnic Differences

Once adjusted for age, Māori (RR 1.27 95% CI 1.12-1.42) and Pacific (RR 1.25 95% CI 1.08-1.43) children were *significantly* more likely to have consumed 3 or more fizzy drinks in the previous week than children in the total population. While rates for Asian children were similar to the total population rate, the proportion of European / Other children consuming 3 or more fizzy drinks in the previous week was *significantly* lower than for children in the total population (RR 0.88 95% CI 0.84-0.92) (**Figure 52**).

NZ Deprivation Index Decile Differences

Once adjusted for age, the proportion of children who had consumed 3 or more fizzy drinks in the previous week was *significantly* higher for those in the most deprived (NZDep decile 9-10) areas (26.5 95% CI 23.2-29.9) than for those in the least deprived (NZDep decile 1-2) areas (15.3% 95% CI 11.9-18.7). This association was stronger for girls than for boys, with girls in the most deprived (NZDep decile 9-10) areas being almost twice as likely to have consumed 3 or more fizzy drinks in the previous week than those living in less deprived (NZDep decile 1-6) areas (**Figure 53**).

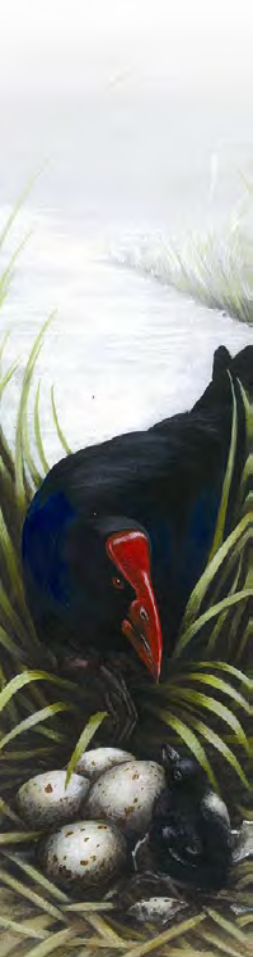
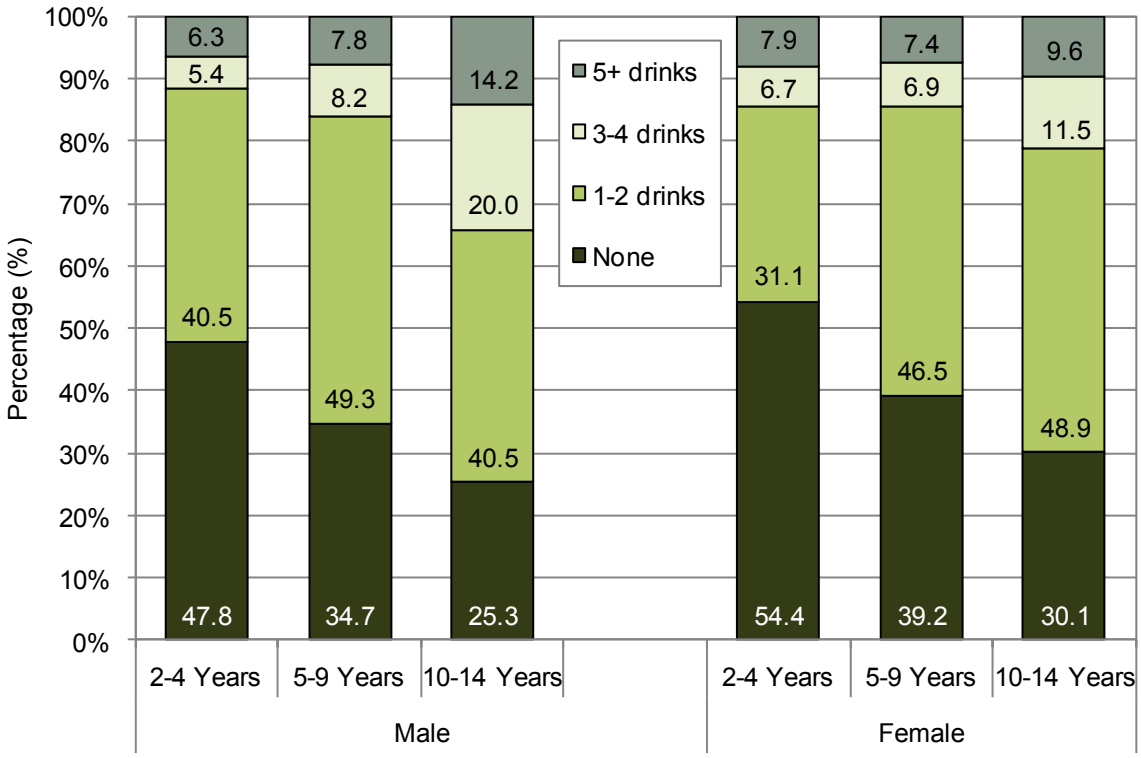
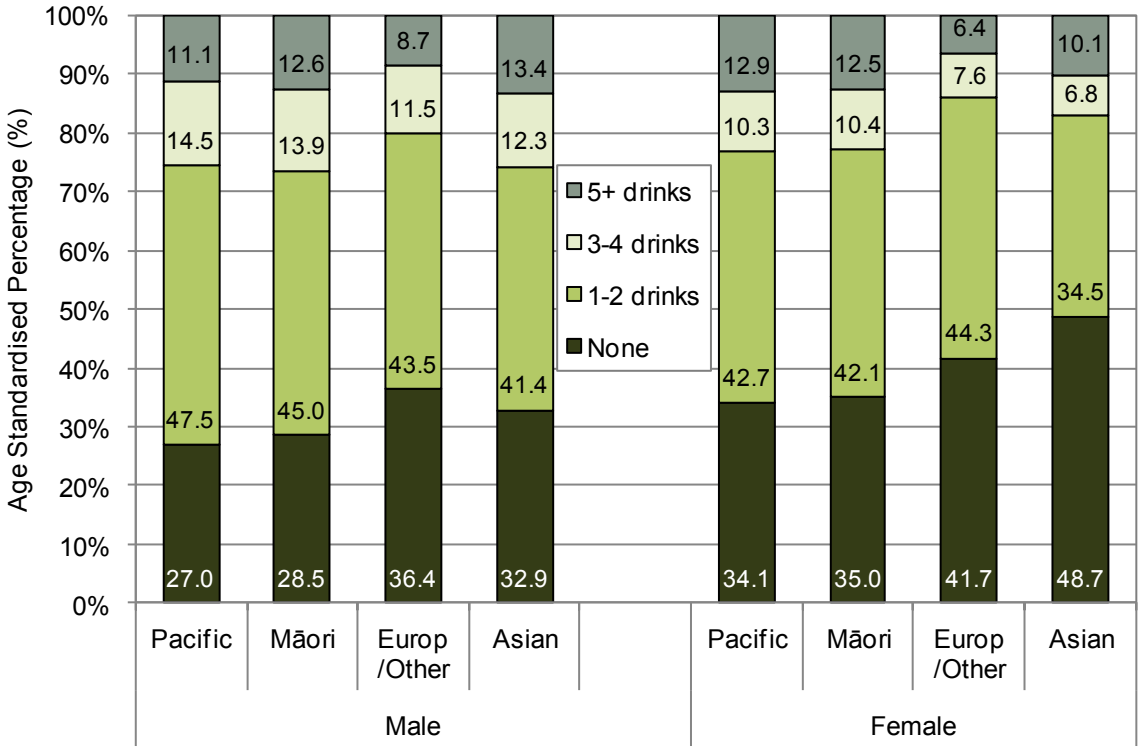


Figure 51. Number of Fizzy Drinks Consumed in the Previous Week for Children Aged 2-14 Years by Gender and Age, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey

Figure 52. Number of Fizzy Drinks Consumed in the Previous Week for Children Aged 2-14 Years by Gender and Ethnicity, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Ethnicity is Total Response; Rates are Age Standardised

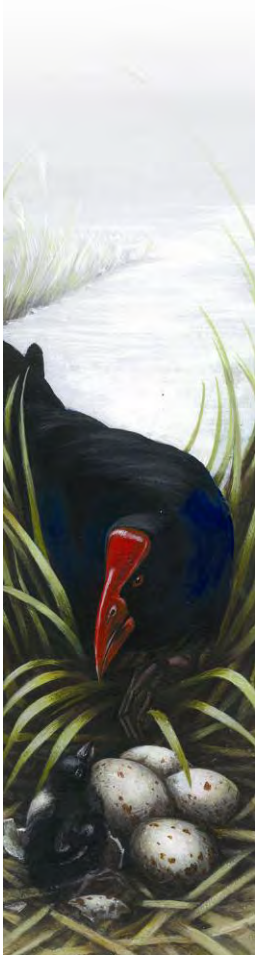
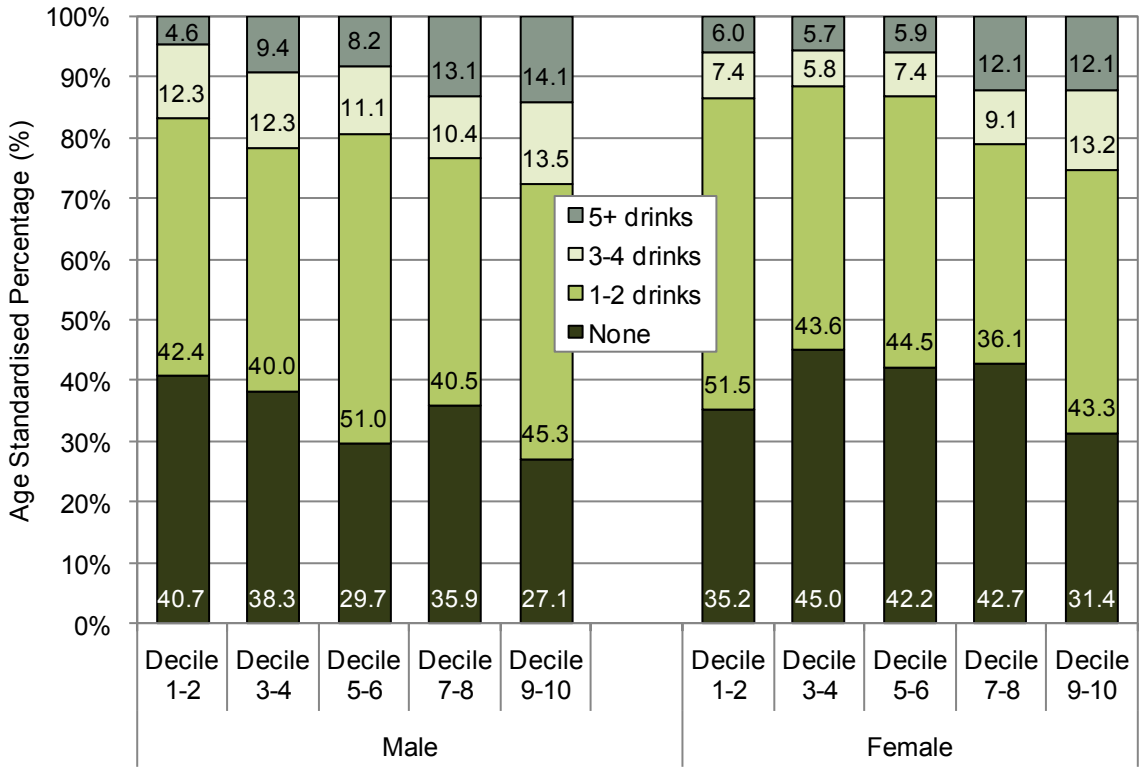


Figure 53. Number of Fizzy Drinks Consumed in the Previous Week for Children Aged 2-14 Years by Gender and NZ Deprivation Index Decile, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Rates Are Age Standardised

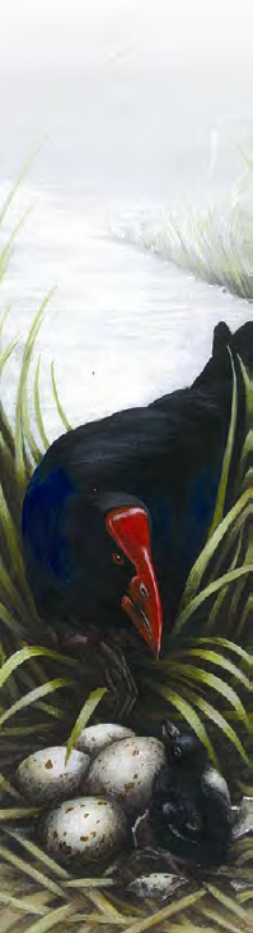
Regional Differences

A *significantly* higher proportion of Counties Manukau children aged 2-14 years had consumed 3 or more fizzy drinks in the previous week than children in the total population, although in Waitemata and the Wairarapa / Hutt Valley / Capital and Coast the proportion was *significantly* lower (**Table 67**).

Table 67. Three or More Fizzy Drinks Consumed in the Past 7 Days for Children Aged 2-14 Years by Region, 2006/07 New Zealand Health Survey

DHB Region	Prevalence (95% CI)
Northland / Lakes / Tairawhiti / Hawke's Bay / Whanganui	20.0 (16.2 - 23.8)
Waitemata	15.1 (11.3 - 18.8) -
Auckland	21.6 (15.7 - 27.6)
Counties Manukau	25.5 (21.3 - 29.8) +
Waikato	19.9 (15.7 - 24.1)
Bay of Plenty / Taranaki / MidCentral	19.4 (14.6 - 24.3)
Wairarapa / Hutt Valley / Capital and Coast	15.2 (10.9 - 19.4) -
Canterbury	19.2 (13.3 - 25.0)
Nelson Marlborough / West Coast / South Canterbury / Otago / Southland	20.4 (14.5 - 26.4)
New Zealand Total	19.6 (18.1 - 21.2)

Source: 2006/07 New Zealand Health Survey: + significantly higher than the national rate; - significantly lower than the national rate; Rates are unadjusted.



Takeaways / Fast Food

Questions on takeaways / fast food were included in the 2006/07 New Zealand Health Survey as a number of studies have suggested that eating fast food more than twice a week is associated with an increased risk of weight gain, overweight and obesity, and in addition because fast food is generally high in fat, salt and sugar and low in fibre [148].

Age and Gender Differences

In the 2006/07 New Zealand Health Survey, once adjusted for age, there were no significant gender differences in the proportion of children aged 2-14 years who had consumed takeaways / fast food three or more times in the past week (boys 8.0% 95% CI 6.5-9.5; girls 6.4% 95% CI 5.1-7.6). Similarly, no significant age differences were evident for those aged 2-4 years, 5-9 years and 10-14 years (**Figure 54**).

Ethnic Differences

Once adjusted for age, Māori (10.1% 95% CI 8.3-12.0) and Pacific (13.9 95% CI 10.4-17.5) children were *significantly* more likely to have consumed takeaways / fast food three or more times in the previous week than children in the total population. Rates for European / Other and Asian children were similar to total population rates (**Figure 55**).

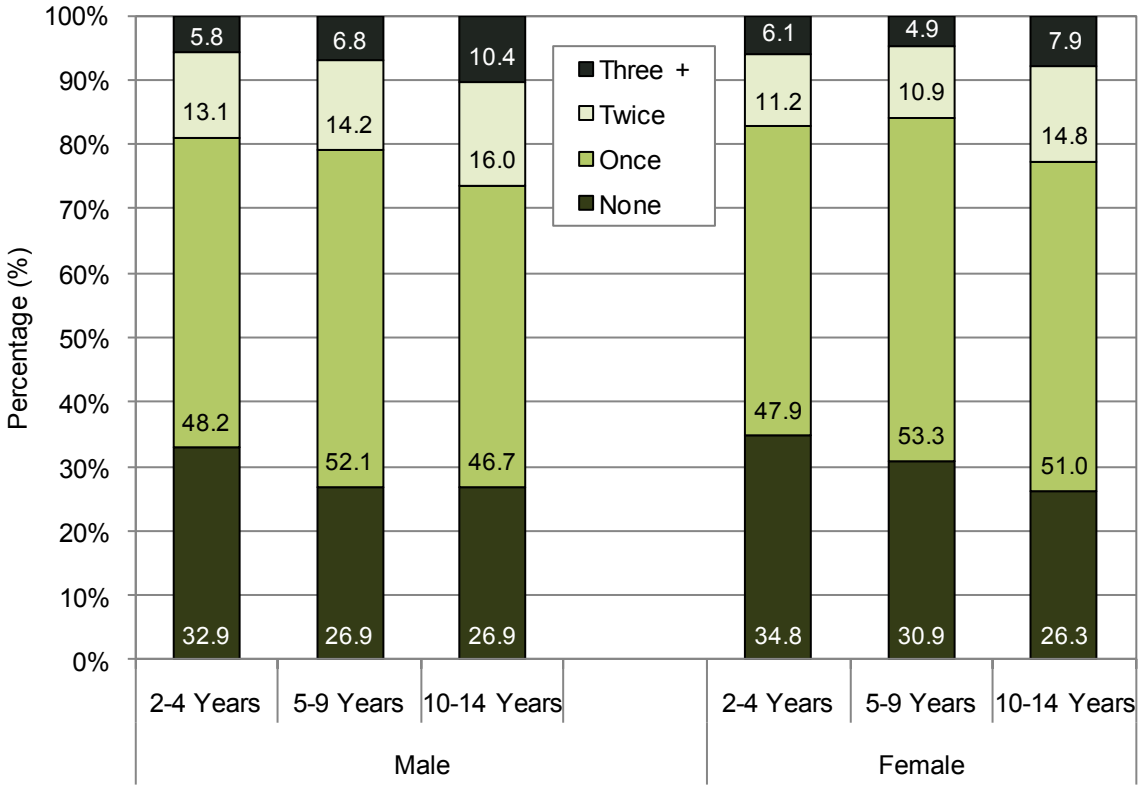
NZ Deprivation Index Decile Differences

Once adjusted for age, children living in the most deprived (NZDep decile 9-10) areas (13.9% 95% CI 11.2-16.6%) were *significantly* more likely to have consumed takeaways / fast food three or more times in the previous week than children living in the least deprived (NZDep deciles 1-2) areas (3.4% 95% CI 1.9-4.9) (**Figure 56**).

Regional Differences

The only significant regional difference in the proportion of children aged 2-14 years who had consumed takeaways / fast food three or more times in the previous week was in Waitemata DHB, where rates were *significantly* lower than those of the total population rate (**Table 68**).

Figure 54. Number of Times Takeaways / Fast Food Consumed in the Previous Week for Children Aged 2-14 Years by Gender and Age, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey

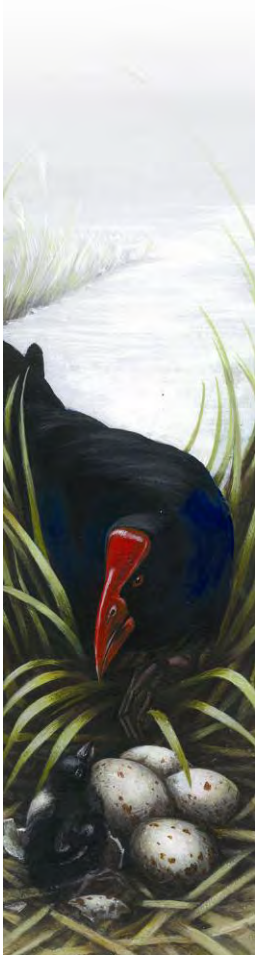
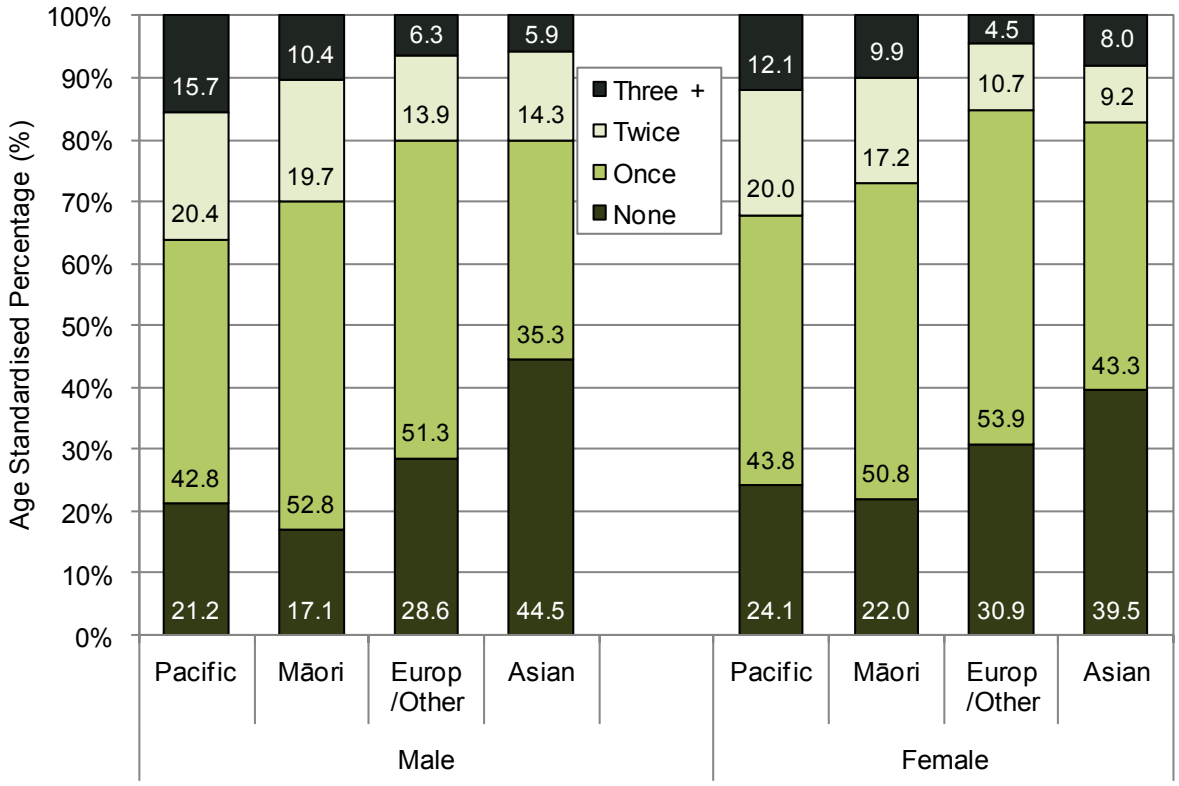
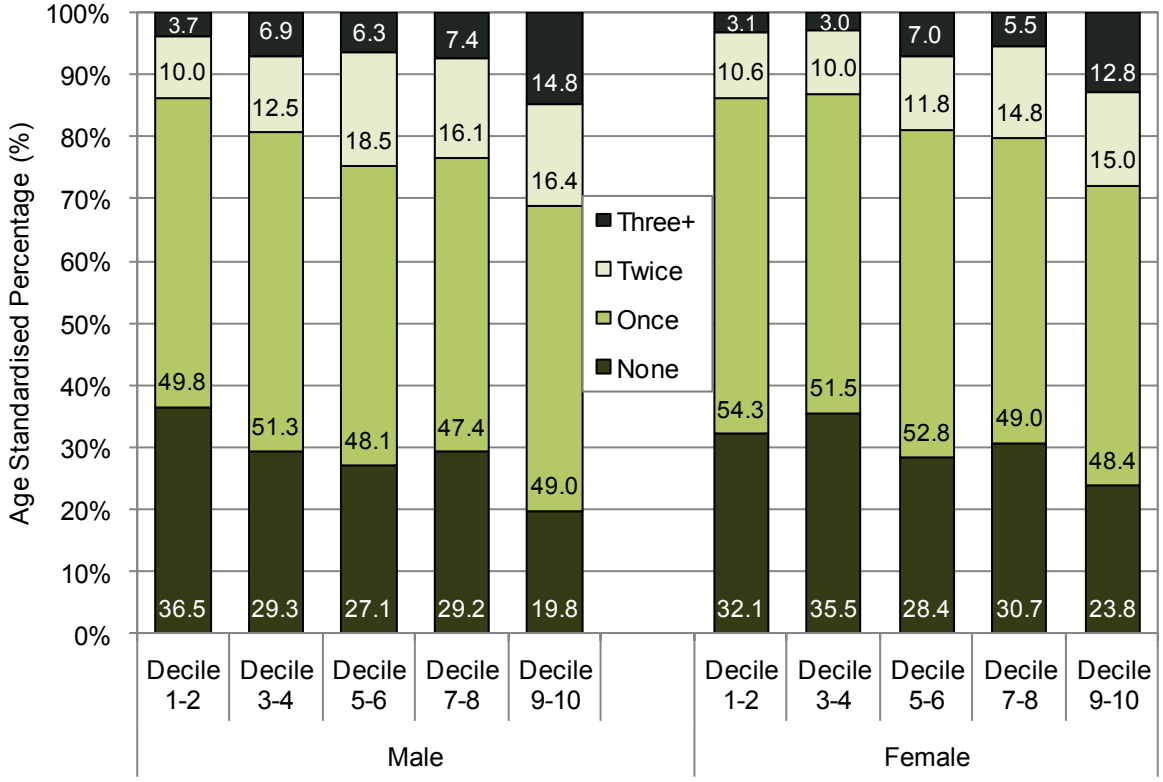


Figure 55. Number of Times Takeaways / Fast Food Consumed in the Previous Week for Children Aged 2-14 Years by Gender and Ethnicity, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Ethnicity is Total Response; Rates are Age Standardised

Figure 56. Number of Times Takeaways / Fast Food Consumed in the Previous Week for Children Aged 2-14 Years by Gender and NZ Deprivation Index Decile, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Rates are Age Standardised

Table 68. Proportion of Children Aged 2–14 Years who had Consumed Takeaways / Fast Food Three or More Times in the Previous Week by Region, 2006/07 New Zealand Health Survey

DHB Region	Prevalence (95% CI)
Northland / Lakes / Tairawhiti / Hawke's Bay / Whanganui	7.5 (5.5 - 9.6)
Waitemata	4.9 (2.9 - 7.8) -
Auckland	6.0 (3.2 - 8.8)
Counties Manukau	10.1 (6.7 - 13.6)
Waikato	6.7 (4.0 - 9.4)
Bay of Plenty / Taranaki / MidCentral	10.4 (6.5 - 14.3)
Wairarapa / Hutt Valley / Capital and Coast	6.4 (3.9 - 8.8)
Canterbury	6.1 (2.6 - 11.9)
Nelson Marlborough / West Coast / South Canterbury / Otago / Southland	5.7 (3.0 - 9.7)
New Zealand Total	7.2 (6.2 - 8.2)

Source: 2006/07 New Zealand Health Survey: + significantly higher than the national rate; - significantly lower than the national rate. Rates are unadjusted.

Summary

Fruit and Vegetable Intake: In the 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours, there were no significant gender, ethnic or socioeconomic differences in the proportion of those aged 5-24 years achieving fruit intake guidelines. The proportion of Pacific and Asian children and young people achieving vegetable intake guidelines however was *significantly* lower than for European / Other children and young people.

Breakfast at Home: In the 2006/07 NZHS, boys were *significantly* more likely to have eaten breakfast at home every day in the previous week than girls. This proportion decreased with increasing age, with those aged 10-14 years being *significantly* less likely to eat breakfast at home every day than those aged 2-4 years. Rates for Māori and Pacific children were *significantly* lower than for the total population. Rates for boys in the most deprived (NZDep decile 9-10) areas were also *significantly* lower than for boys in the least deprived (NZDep Decile 1-2) areas, although no significant differences were seen for girls.

Fizzy Drinks: In the 2006/07 NZHS, boys aged 10-14 years were *significantly* more likely to have consumed 3+ fizzy drinks in the previous week than girls aged 10-14 years. In addition, rates for children aged 10-14 years were *significantly* higher than for children aged 2-4 years. Rates for Māori and Pacific children were *significantly* higher than for the total population, while rates for European / Other children were *significantly* lower. Rates were also *significantly* higher for those in the most deprived (NZDep decile 9-10) areas.

Takeaways / Fast Food: In the 2006/07 NZHS, there were no significant gender or age differences in the proportion of children aged 2-14 years who had consumed takeaways / fast food 3+ times in the past week. Rates for Māori and Pacific children were *significantly* higher than for children in the total population. Rates for children living in the most deprived (NZDep decile 9-10) areas were also *significantly* higher than for children in the least deprived (NZDep deciles 1-2) areas.

Local Policy Documents and Evidence Based Reviews Relevant to Nutrition in Children and Young People

In New Zealand a range of policy documents and reviews consider nutrition as it relates to the prevention and management of overweight and obesity and these are briefly summarised in **Table 66** on **Page 202**, along with a range of guidelines and reviews which consider these issues in the overseas context.

PHYSICAL ACTIVITY

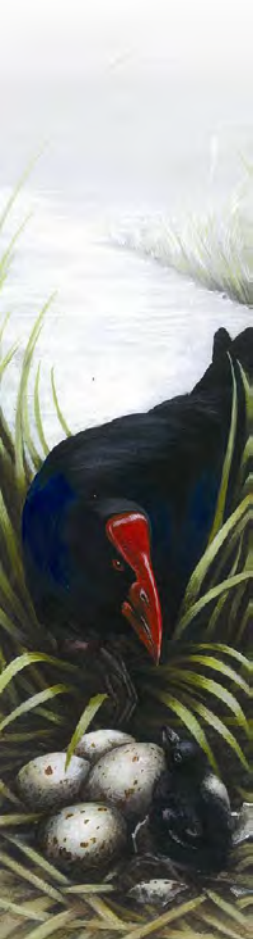
Introduction

The New Zealand Physical Activity Guidelines state that children and young people aged 5-18 years should do 60 minutes or more of moderate-to-vigorous physical activity each day [167]. In this context, moderate physical activity is the equivalent of a brisk walk, and vigorous physical activity is that which causes people to "huff and puff" [155]. Young people aged 18 years or older come under the adult guidelines which recommend 30 minutes of moderate physical activity on most, if not all, days of the week [167].

While declines in the amount of time children and young people spend engaged in physical activity are thought to have contributed significantly to the obesity epidemic, the paucity of longitudinal data makes it difficult to quantify the precise role this has played in the New Zealand context. Overseas evidence for declining physical activity levels comes from a variety of sources, including a Swedish study which noted a significant decrease in energy expenditure (particularly occupational and transport) over the 20th century, with a corresponding increase in sedentary leisure activity (e.g. watching TV, reading) [168]. In the UK, USA and New Zealand, declines in the number of children walking or cycling to school since the early 1970s have been attributed to parental perceptions regarding safety and a reluctance to let children cycle on the road [169] [170, 171]. A local study also suggested that the fitness levels of New Zealand children may be deteriorating, with the time taken for intermediate school children to run 550 metres increasing by 23.6s for boys and 27.0s for girls between 1991 and 2000 [147]. In addition, participation in organised sport has decreased substantially in a number of countries, while the proportion of leisure time children spend on electronic entertainment (e.g. computers, TV) has increased [168].

Not all overseas studies have come to the same conclusion however, with a number of studies exploring leisure time physical activity amongst young people during the 1980s-1990s noting either increases in participation in vigorous activity, or no overall change [168]. In understanding the reasons for these differences however, methodological issues need to be taken into consideration, including the emphasis that different studies place on leisure time physical activity (e.g. sport) vs. total energy expenditure (e.g. housework, walking to school), as well as the potential for questions relating to vigorous activities to become less meaningful as the fitness of a population declines (e.g. the frequency of activities which make you "huff and puff').

The following section explores the available information on physical activity in New Zealand children and young people using information from two recent national surveys: The 2006/07 New Zealand Health Survey [148] and the National Survey of Children and Young People's Physical Activity and Dietary Behaviours [155].



Data Sources and Methods

Definitions

Proportion of Children and Young People Aged 5-24 Years Meeting Physical Activity Guidelines

Transport to and from School for Children Aged 5-14 Years

Proportion of Children and Young People Aged 5-24 Years Meeting Screen Time Guidelines

Number of Hours Television Usually Watched per day for Children Aged 5-14 Years

Data Sources

The 2006/07 New Zealand Health Survey (NZHS)

The 2006/07 NZHS [148] was a cross sectional survey carried out between October 2006 and November 2007, which collected information on 4,921 children from birth to 14 years, and 12,488 adults aged 15 years and over who lived in private dwellings. The child survey included 3,039 European / Other, 1,983 Māori, 798 Pacific and 742 Asian children, with the final response rate for the child questionnaire being 71%, and for the adult questionnaire being 68%. The primary caregiver, in the case of children aged 0-14 years, answered the questionnaire on the child's behalf. The survey results have been weighted to ensure they are representative of New Zealand's resident population living in permanent dwellings [148].

Ethnicity: In the Survey four ethnic groups were reported: Māori, Pacific, Asian and European / Other, with the "Other" category including Middle-Eastern, Latin-American and African ethnic groups. Total response ethnicity

was used throughout, with an individual being included in the analysis for each ethnic group to which they affiliated (28.3% of children were assigned to more than one ethnic group). As a result, ethnic groups cannot be directly compared with each other, and thus all interpretations which appear in the text are made with reference to the total population [148].

Age Standardisation: In New Zealand, each ethnic group has its own age structure (e.g. the Māori and Pacific populations have a much higher proportion of individuals <25 years of age) and thus when comparisons are made between different ethnic groups (and also by NZ Deprivation Index decile, which is unevenly distributed by ethnicity), these differences need to be taken into account. Thus, in the sections which follow, all ethnic and NZ Deprivation Index decile specific analyses have been age standardised (to the World Health Organisation (WHO) world population age distribution - see [148] p16 for a more detailed account). All age / gender graphs however use unadjusted rates, so that the underlying prevalence in the New Zealand population can better be ascertained. Where gender comparisons are made in the text however, these have been adjusted for differences in the underlying age distributions of the two gender groupings [148].

The data for the tables and graphs derived from this survey were sourced from http://www.moh.govt.nz/moh.nsf/indexmh/portrait-of-health#summary

The National Survey of Children and Young People's Physical Activity and Dietary Behaviours in New Zealand: 2008/09 (NZS-CY-PA-DB-2008/09)
The NZS-CY-PA-DB-2008/09 [155] was a nationally representative survey of 2,503 children and young people aged 5-24 years (470 Māori , 239 Pacific, 324 Asian and 1,786 European and Other). Data were collected between September 2008 and May 2009, by means of a face-to-face home visit and a subsequent telephone interview. Height and weight were measured during the home visit, with accelerometers being used to assess the time spent in physical activity over a 7-day period. Data were collected directly from those aged 10+ years, with parents providing proxy responses for children ≤9 years. The overall response rate was 55%, with population weighting being used to ensure that the results were representative of the total population. In contrast to the 2006/07 NZHS however, age standardisation was not undertaken, so none of the data presented have been adjusted for differences in the age structure of different population groups.

Ethnicity: In the Survey four ethnic groups were reported: Māori, Pacific, Asian and European / Other. Total response ethnicity was used throughout, with an individual being included in the analysis for each ethnic group to which they affiliated. As oversampling by ethnic group was not undertaken, the survey is unable to provide reliable estimates by ethnic group and thus any ethnic differences reported should be interpreted with caution.

Physical Activity

National Survey of Children and Young People's Physical Activity and Dietary Behaviours in New Zealand: 2008/09

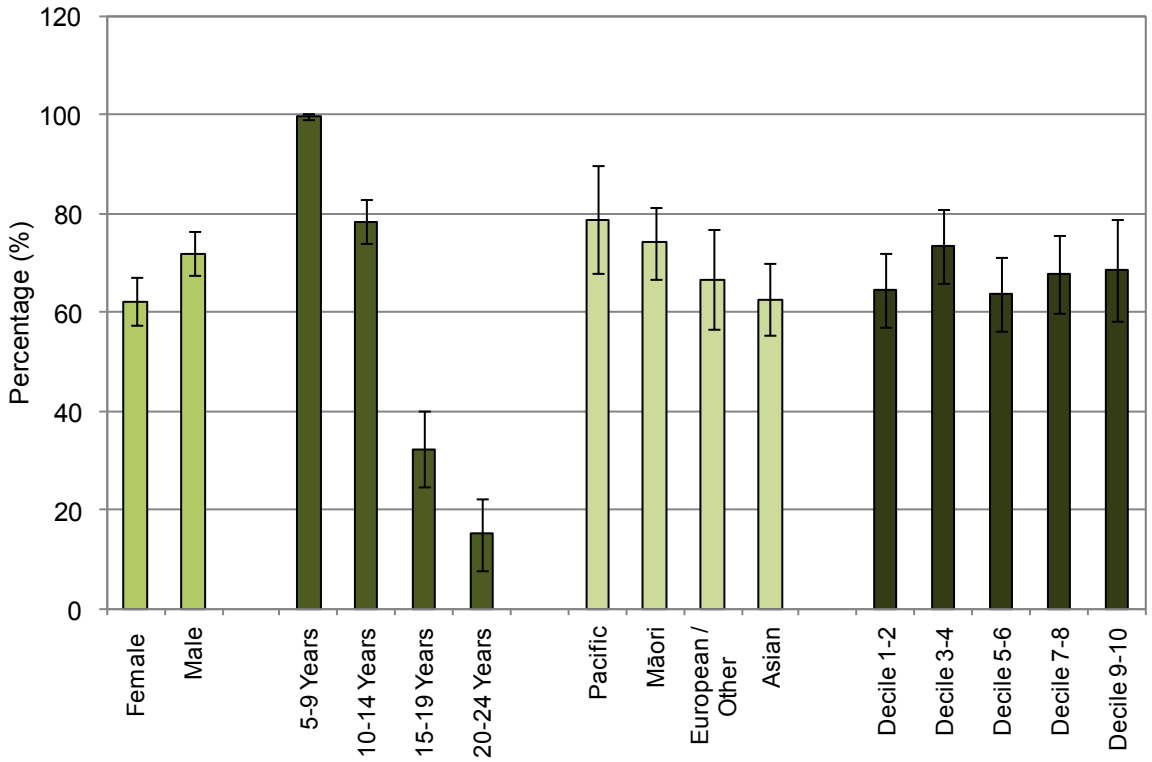
Proportion Meeting Physical Activity Guidelines

The New Zealand Physical Activity Guidelines [167] state that children and young people aged 5-18 years should engage in 60 minutes or more moderate-to-vigorous physical activity each day, while those over the age of 18 years should engage in at least 30 minutes of moderate-intensity physical activity on most if not all days of the week.

Age, Gender, Ethnic and NZ Deprivation Index Decile Differences

In the NZS-CY-PA-DB-2008/09 [155], children and young people wore an accelerometer, which measured their physical activity for seven consecutive days, with the amount of time spent in light, moderate and vigorous physical activity each day being assessed for each participant. Using the all days method (children and young people meeting the guidelines on a minimum of three sampled days), the proportion of children and young people meeting the activity guidelines declined *significantly* with increasing age, with those aged 15-19 years and 20-24 years being *significantly* less likely to meet the guidelines than those aged 5-9 years or 10-14 years. Differences by ethnicity and NZ Deprivation index decile however, did not reach statistical significance (**Figure 57**).

Figure 57. Proportion of Children and Young People Aged 5-24 Years Meeting NZ Physical Activity Guidelines by Age, Gender, Ethnicity and NZDep Index Decile, 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours

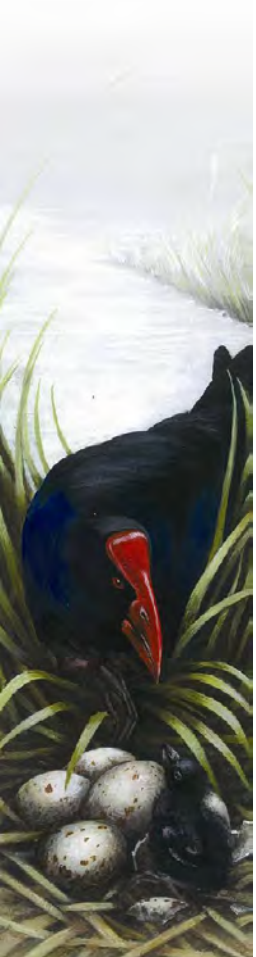


Source: 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours. Ethnicity is Total Response. Analysis undertaken using All Days Method (see text)

The 2006/07 New Zealand Health Survey (NZHS)

Usual Transport To and From School

Questions on active transport to and from school were included in the 2006/07 New Zealand Health Survey as regular physical activity has been associated with lower cholesterol and blood pressure in children, and with improvements in energy balance [148]. In the section which follows, active transport is defined as the use of any form of physical activity (e.g. walk, bike, skate) to get to school, with multiple responses being permitted (e.g. a child who usually walks to the bus stop and then catches the bus to school). Inactive transport includes travelling to school by car or bus, with the caregivers of children who did not usually travel to school by active means being asked what stops this from happening [148].

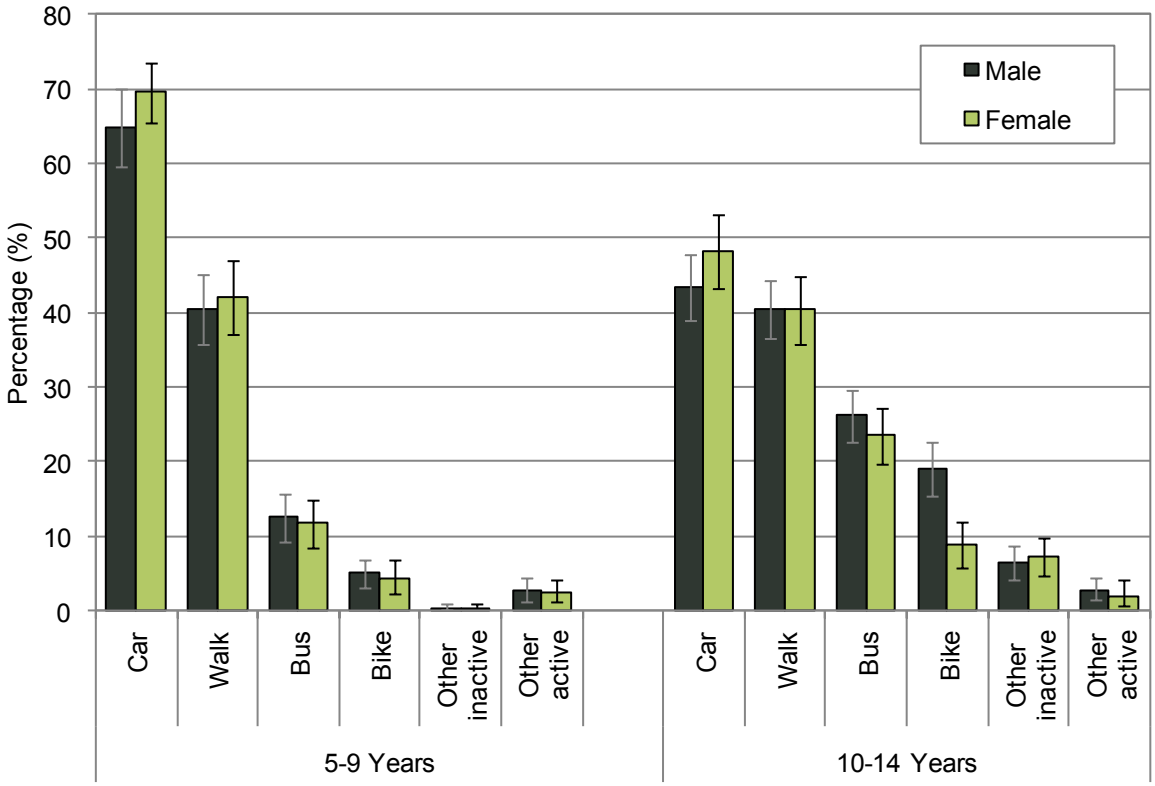


Age and Gender Differences in Means of Transport to School

Private cars were the most common way for children to get to and from school (56.4% 95% CI 54.3-58.6), followed by walking (40.9% 95% CI 38.2-43.5%). There was no significant gender differences in the usual type of transport used to get to and from school with the exception of bicycles, where boys were more likely than girls to cycle to school.

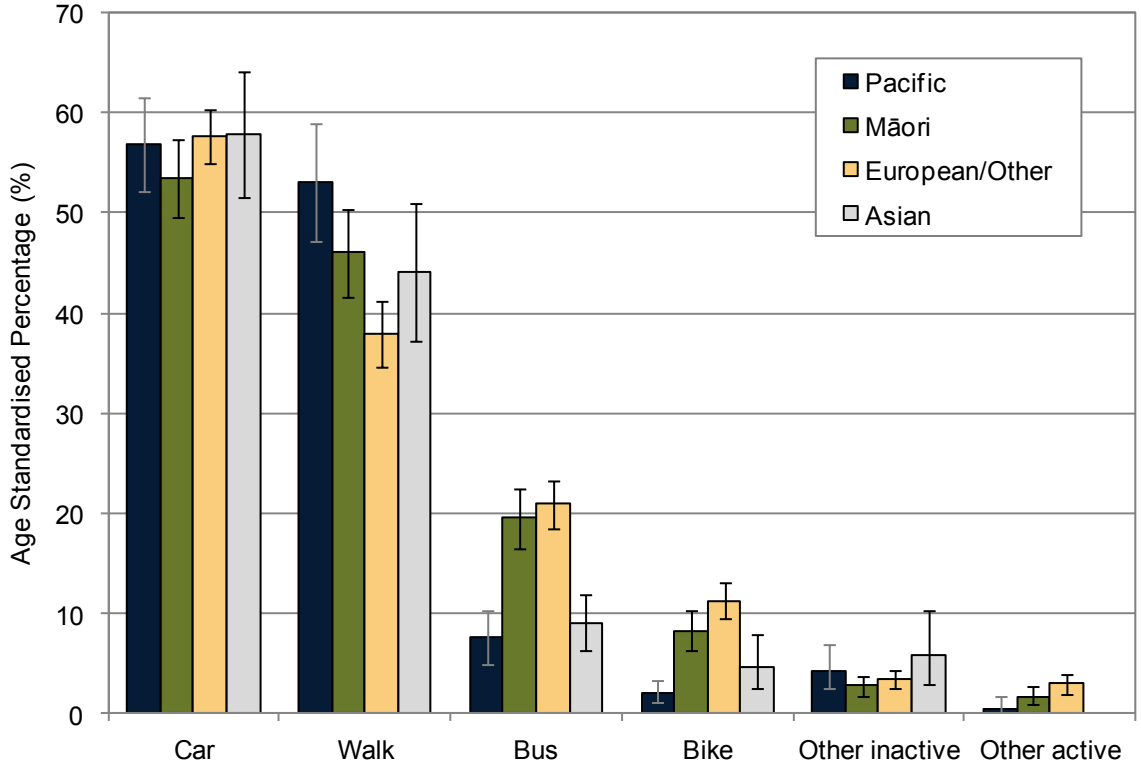
When broken down by age, boys aged 10-14 years (53.7% 95% CI 49.7-57.8) were *significantly* more likely to use active transport to and from school than boys aged 5-9 years (43.6% 95% CI 38.9-48.2), although differences for girls did not reach statistical significance. Within the passive transport category however, the proportion using private cars was *significantly* higher for those aged 5-9 years than for those aged 10-14 years, while the proportion using the bus was *significantly* higher for those aged 10-14 years than for those aged 5-9 years. Within the active transport category, the proportion cycling to school was *significantly* higher for those aged 10-14 years than for those aged 5-9 years, although the proportion walking was similar (**Figure 58**).

Figure 58. Usual Form of Transport to and from School for Children Aged 5-14 Years by Gender and Age, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey. Note: This question allowed multiple responses to totals may exceed 100%

Figure 59. Usual Form of Transport to and from School for Children Aged 5-14 Years by Ethnicity, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Ethnicity is Total Response; Rates are Age Standardised. Note: This question allowed multiple responses to totals may exceed 100%

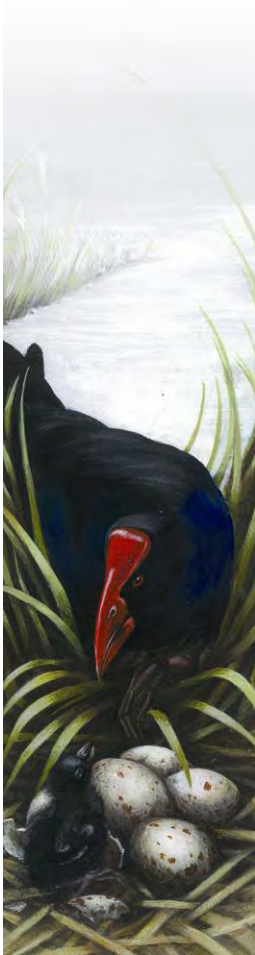
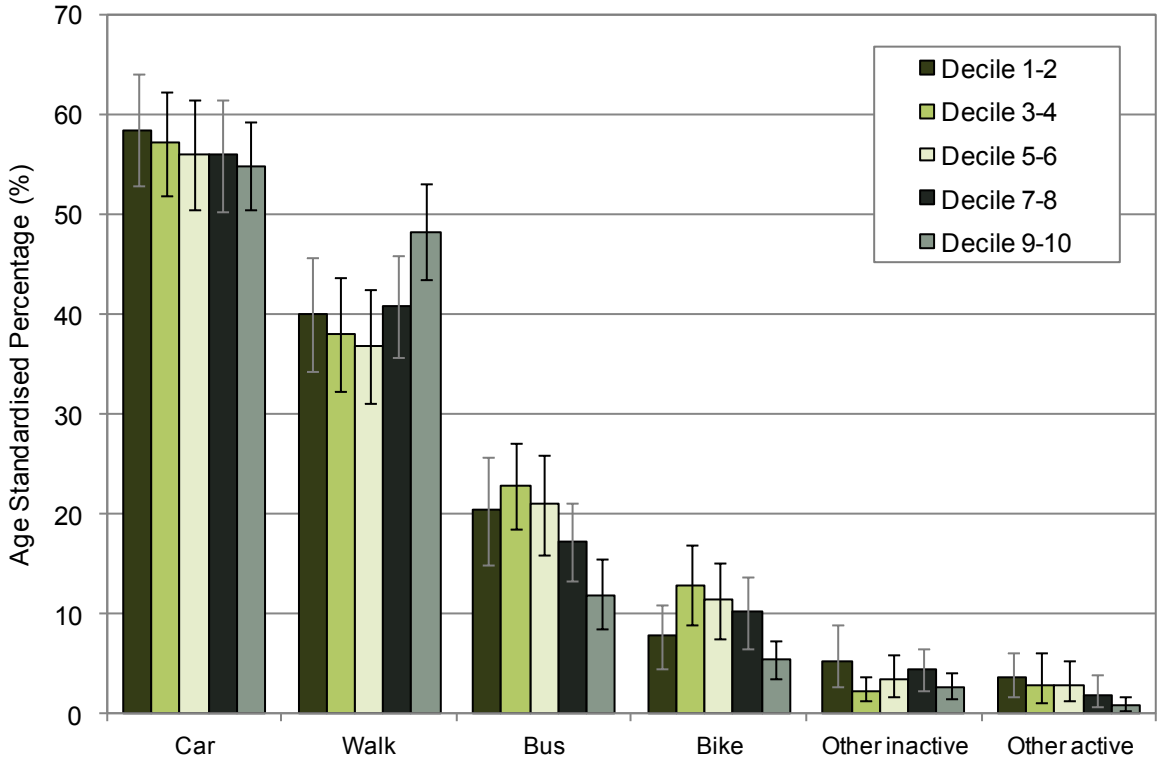


Figure 60. Usual Form of Transport to and from School for Children Aged 5-14 Years by NZ Deprivation Index Decile, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Rates are Age Standardised. Note: This question allowed multiple responses to totals may exceed 100%

Ethnic Differences

Once adjusted for age, Māori (RR 1.16 95% CI 1.05-1.27) and Pacific (RR 1.21 95% CI 1.06-1.36) boys were *significantly* more likely to travel to school by active means, while European / Other boys were *significantly* less likely to travel to school by active means (RR 0.96 95% CI 0.92-0.99) than those in the total population. For girls ethnic differences did not reach statistical significance, with the exception of European / Other girls, who were marginally more likely (RR 1.03 95% CI 1.01-1.05) to not usually use active transport to get to and from school. Transport modalities by ethnicity are reviewed further in **Figure 59**.

NZ Deprivation Index Decile Differences

There were no statistically significant differences by NZDep deprivation in the proportion of children who used active transport modalities to get to and from school, with **Figure 60** considering difference by NZDep in more detail.

Barriers to the Use of Active Transport to Travel to and From School

Parents cited a number of barriers which prevented their children using active transport to travel to and from school. These included the distances being too far, the traffic being too busy, it being too dangerous (for reasons other than traffic), the time it would take, the weather, the child not wanting to, or the child having health conditions which prevented them from doing so (**Figure 61**).

Age and Gender Differences

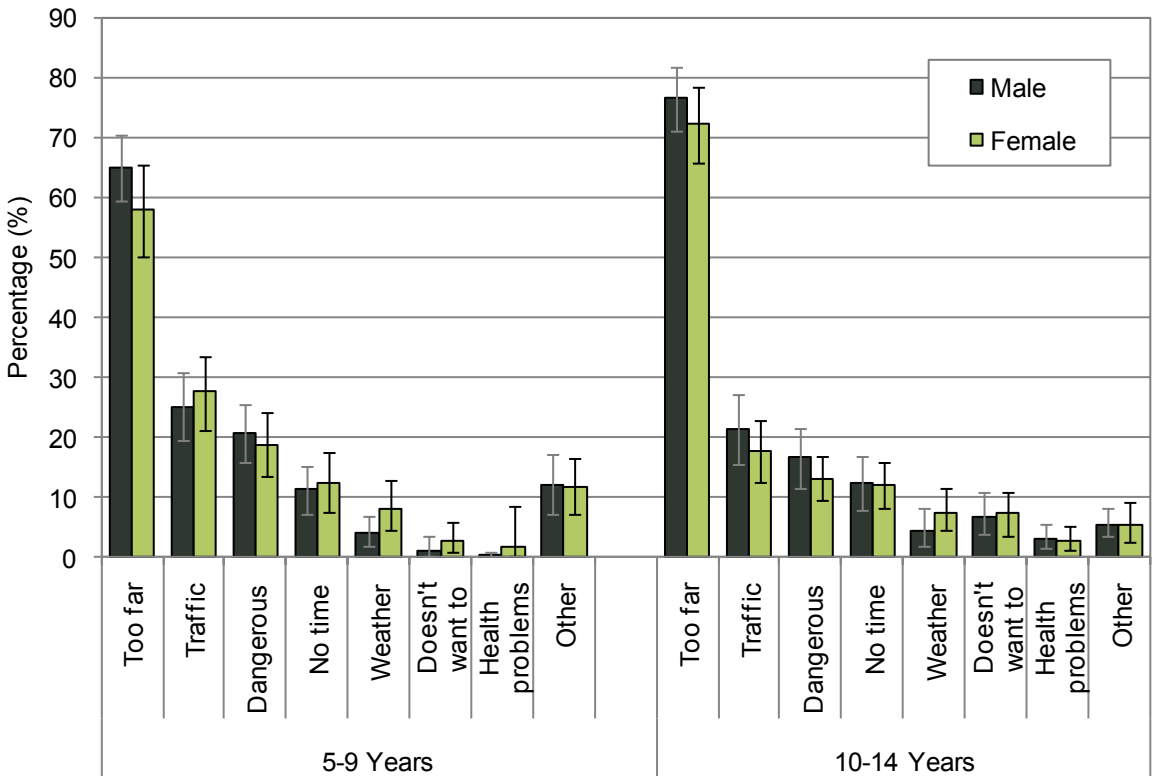
Overall, there were no significant gender differences in the reasons given for children not being able to travel to school by active means, although when broken down by age, the fact that it was too far was more commonly cited for children aged 10-14 years (74.2 95% CI 69.9-78.4) than for children aged 5-9 years (61.4 95% CI 56.4-66.4) (**Figure 61**).

Ethnic Differences

Once adjusted for age, parents of European / Other children were *significantly* more likely to report that traffic (RR1.10 95% CI 1.06-1.15) and a lack of time (RR 1.09 95% CI 1.02-1.15) were barriers to their children travelling to school by active means, than parents in

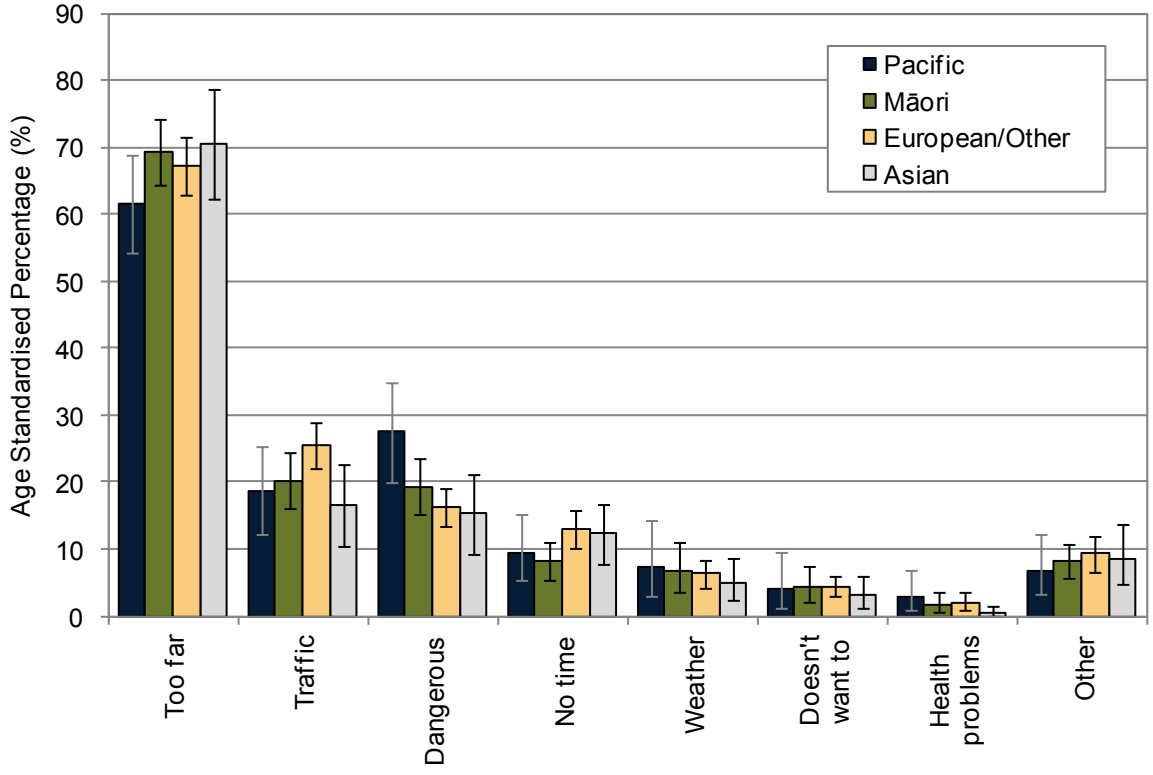
the total population. In contrast, parents of Pacific children (RR 1.59 95% CI 1.17-2.00) were *significantly* more likely to report that it was too dangerous (for reasons other than traffic) for their children to travel to school by active means (**Figure 62**).

Figure 61. Barriers to Using Active Transport to Travel to and From School for Children Aged 5-14 Years by Gender and Age, 2006/07 New Zealand Health Survey



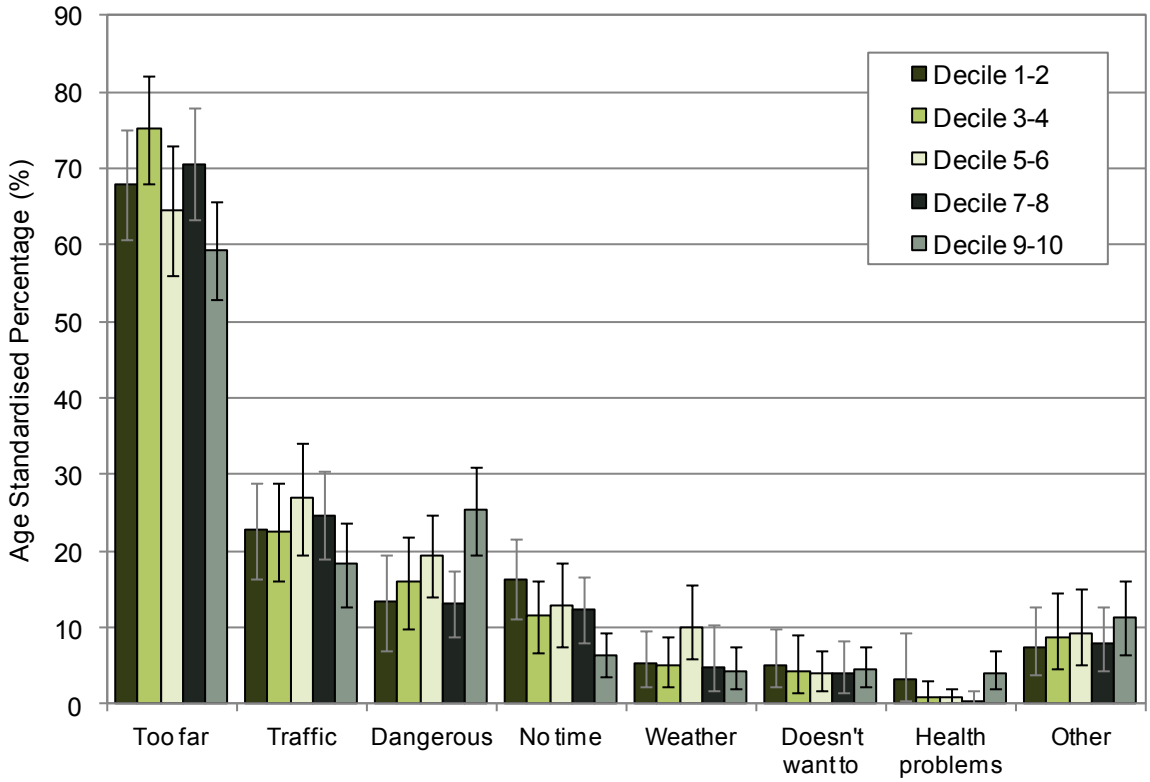
Source: 2006/07 New Zealand Health Survey

Figure 62. Barriers to Using Active Transport to Travel to and From School for Children Aged 5-14 Years by Ethnicity, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Ethnicity is Total Response; Rates are Age Standardised

Figure 63. Barriers to Using Active Transport to Travel to and From School for Children Aged 5-14 Years by NZ Deprivation Index Decile, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Rates are Age Standardised

NZ Deprivation Index Decile Differences

There were no significant differences by NZ Deprivation Index decile in the barriers cited by parents as to why their children were unable to travel to school by active means (**Figure 63**).

Sedentary Time

National Survey of Children and Young People's Physical Activity and Dietary Behaviours in New Zealand: 2008/09

The New Zealand Physical Activity Guidelines [167] state that children and young people aged 5-18 years should spend less than two hours a day (out of school hours) in front of the television, computers and game consoles.

Age, Gender, Ethnic and NZ Deprivation Index Decile Differences

In the NZS-CY-PA-DB-2008/09 [155] children and young people were considered to have met the screen time guidelines if they accumulated less than two hours per day of screen time, averaged over a period of three days. Females were *significantly* more likely to achieve screen time guidelines than males, with those aged 5-9 years also being *significantly* more likely to achieve the guideline than older age groups. There were however, no significant differences by ethnicity or NZDep deprivation (**Figure 64**).

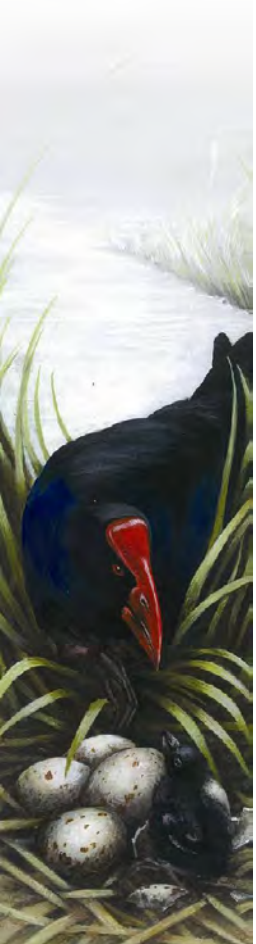
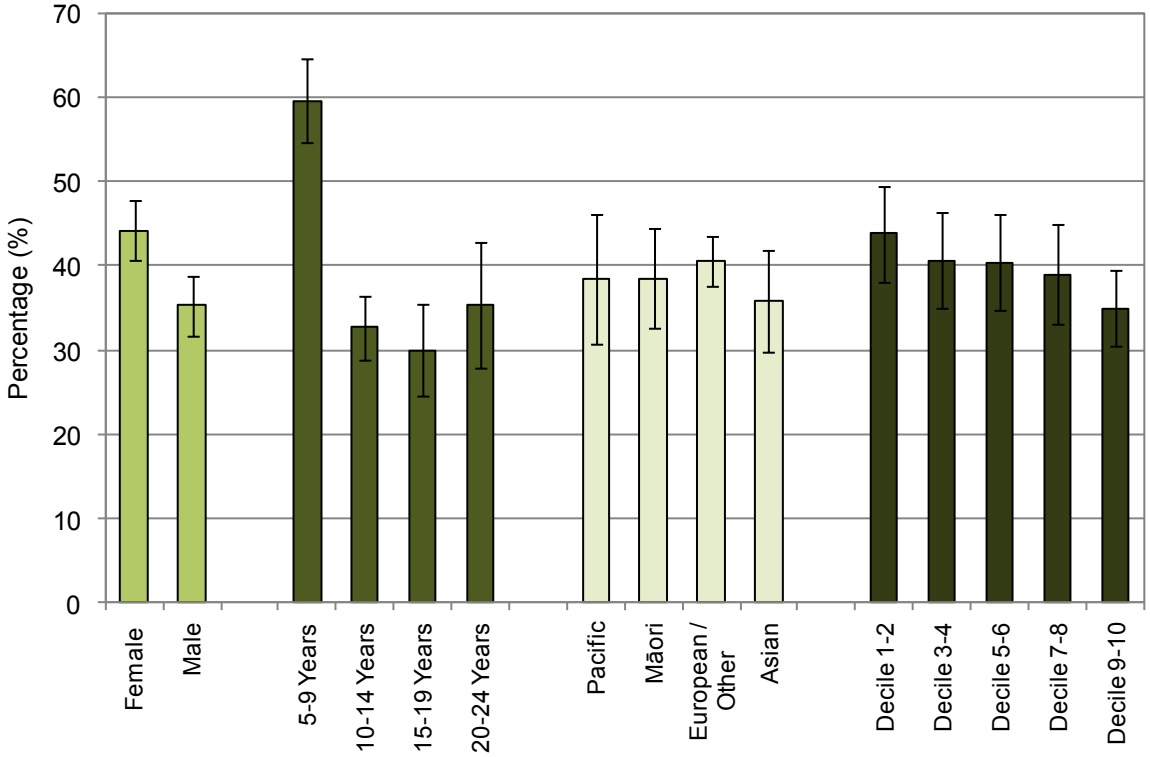


Figure 64. Proportion of Children and Young People Aged 5-24 Years Meeting Screen Time Guidelines by Gender, Age, Ethnicity and NZ Deprivation Index Decile, 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours



Source: 2008/09 National Survey of Children and Young People's Physical Activity and Dietary Behaviours (Three Day Average Method). Ethnicity is Total Response

The 2006/07 New Zealand Health Survey (NZHS)

Number of Hours of Television Watched

The number of hours of television watched was included in the 2006/07 New Zealand Health Survey as television watching is a very sedentary behaviour and time spent watching television displaces opportunities for more physical activities. Television watching also exposes children to advertising which may impact negatively on healthy food choices, with some studies also suggesting that watching two or more hours of television per day in childhood increases the risk of obesity [148].

Age and Gender Differences

Overall, 64.1% (95% CI 62.1-66.2) of children aged 5-14 years usually watched two or more hours of television per day. Once adjusted for age, there were no significant gender differences in the number of hours children usually watched television each day. Children aged 10-14 years (71.8% 95% CI 69.3-74.3) however, were *significantly* more likely to watch television for two or more hours per day than children aged 5-9 years (56.3% 95% CI 53.0-59.7). **Figure 65** reviews the number of hours television was usually watched by age and gender.

Ethnic Differences

Once adjusted for age, Māori children (RR 1.19 95% CI 1.14-1.24) were *significantly* more likely to watch television for two or more hours per day than children in the total population. Rates for Pacific and Asian children were similar to total population rates, while for European / Other children, the proportion was marginally lower (RR 0.97 95% CI 0.96-0.99). **Figure 66** reviews the number of hours television was usually watched by ethnicity.

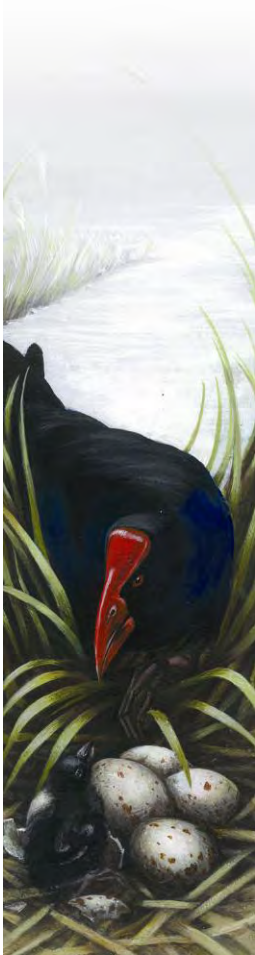
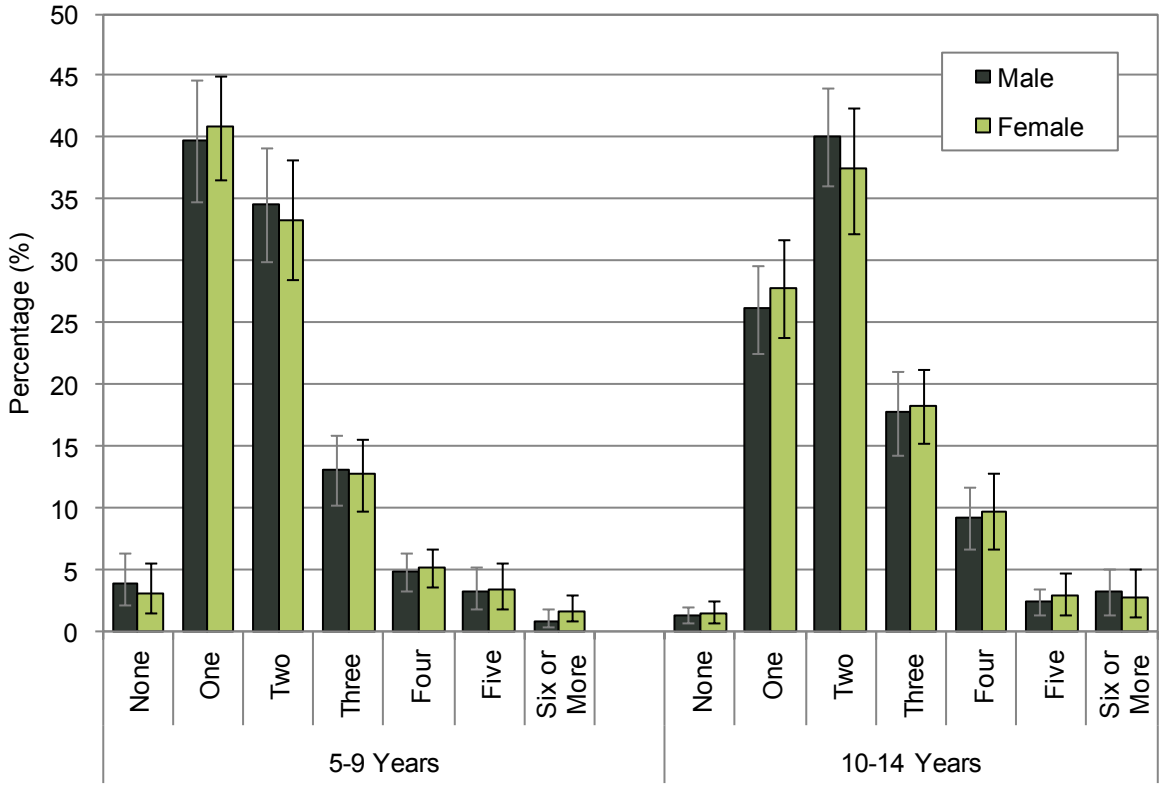
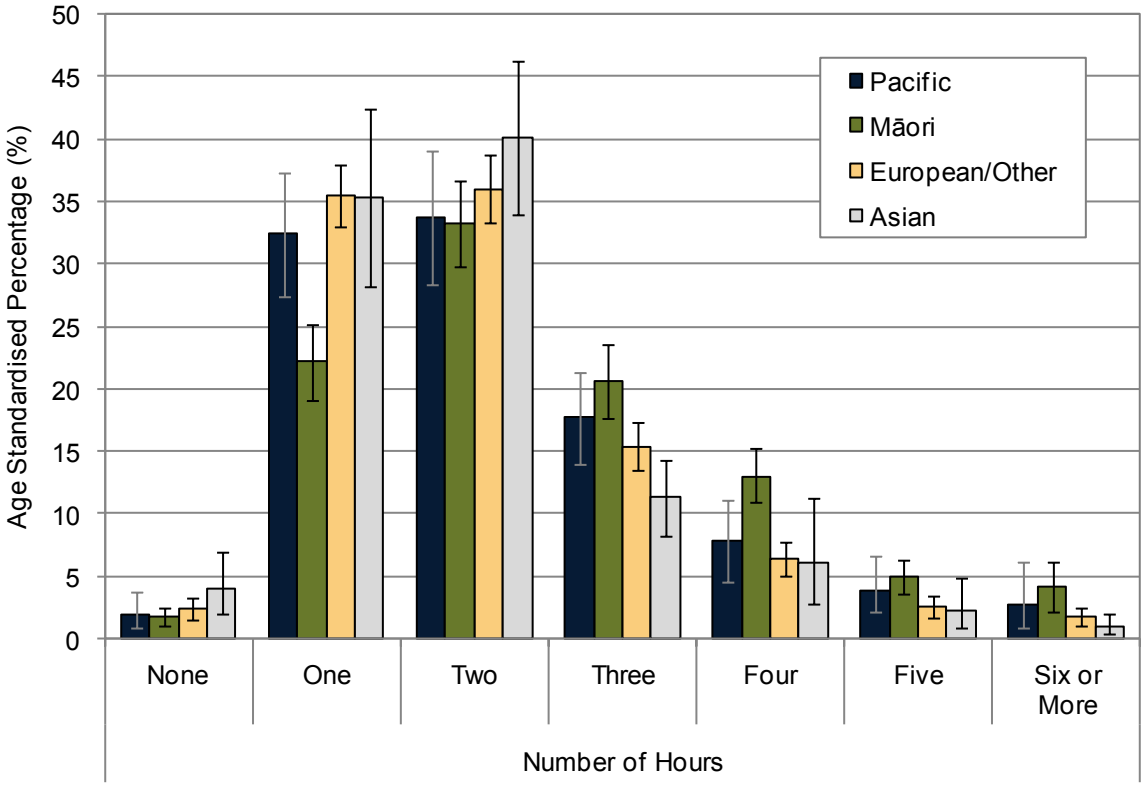


Figure 65. Number of Hours Television Usually Watched per Day for Children Aged 5-14 Years, by Gender and Age-Group, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey

Figure 66. Number of Hours Television Usually Watched per Day for Children Aged 5-14 Years by Ethnicity, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Ethnicity is Total Response; Rates are Age Standardised

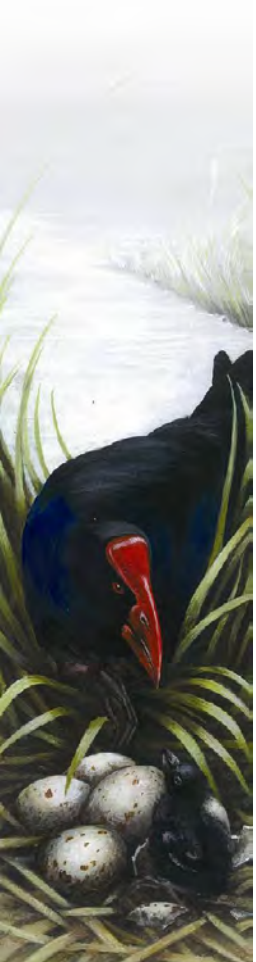
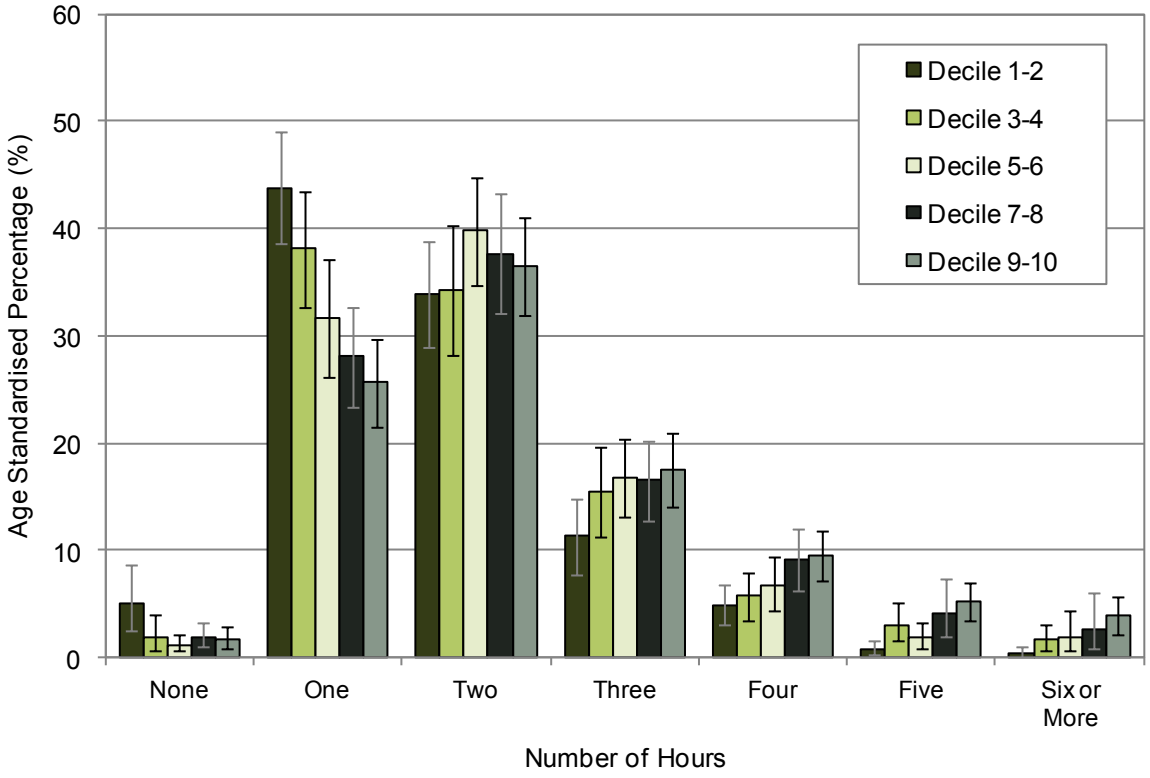


Figure 67. Number of Hours Television Usually Watched per Day for Children Aged 5-14 Years by NZ Deprivation Index Decile, 2006/07 New Zealand Health Survey



Source: 2006/07 New Zealand Health Survey; Rates are Age Standardised

NZ Deprivation Index Decile Differences

Once adjusted for age, children living in the most deprived (NZDep deciles 9-10) areas (72.7% 95% CI 68.4 - 77.0) were *significantly* more likely to watch television for two or more hours per day than children living in the least deprived (NZDep decile 1-2) areas (51.1% 95% CI 46.5 - 55.8). **Figure 67** reviews the number of hours television was usually watched by NZ Deprivation Index decile.

Regional Differences

Children aged 5-14 years in Northland / Lakes / Tairawhiti / Hawke's Bay / Whanganui were *significantly* more likely to watch television for two or more hours per day than children in the total population, while children in Taranaki were *significantly* less likely to watch television for two or more hours per day (**Table 69**).

Table 69. Prevalence of Children Aged 5–14 Years who Usually Watched Two or More Hours of Television per Day by Region, 2006/07 New Zealand Health Survey

DHB Region	Prevalence (95% CI)
Northland / Lakes / Tairawhiti / Hawke's Bay / Whanganui	72.8(68.1 - 77.5) +
Waitemata	59.6 (52.7 - 66.5)
Auckland	62.3 (53.0 - 71.5)
Counties Manukau	57.6 (50.4 - 64.8) -
Waikato	67.0 (60.1 - 73.8)
Bay of Plenty / Taranaki / MidCentral	66.1 (59.6 - 72.6)
Wairarapa / Hutt Valley / Capital and Coast	65.3 (57.7 - 73.0)
Canterbury	58.0 (50.3 - 65.7)
Nelson Marlborough / West Coast / South Canterbury / Otago / Southland	68.6 (61.6 - 75.6)
New Zealand Total	64.1 (62.1 - 66.2)

Source: 2006/07 New Zealand Health Survey: + significantly higher than the national rate; - significantly lower than the national rate; Rates are unadjusted.

Summary

Physical Activity Guidelines: In the 2008/09 Survey of Children and Young People's Physical Activity and Dietary Behaviours [155], the proportion of children and young people meeting the NZ Physical Activity Guidelines (as measured by an accelerometer) declined *significantly* with increasing age. Differences by ethnicity and NZ Deprivation index decile however, did not reach statistical significance.

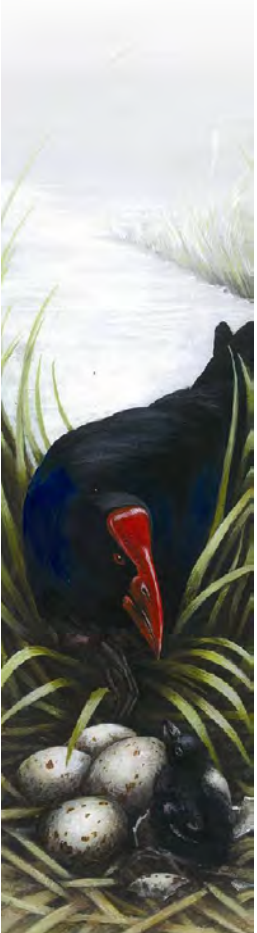
Screen Time Guidelines: In the NZS-CY-PA-DB-2008/09 [155] children and young people aged 5-24 years were considered to have met the screen time guidelines if they had <2 hours per day of screen time. Females were *significantly* more likely to achieve screen time guidelines than males, with those aged 5-9 years also being *significantly* more likely to achieve the guideline than older age groups. There were no significant differences by ethnicity or NZDep deprivation

Travel to School by Active Means: In the 2006/07 NZHS, private cars, followed by walking, were the most common ways for children to get to school. Use of active transport for Māori and Pacific boys was *significantly* higher than for the total population, while European / Other boys were *significantly* less likely to travel to school by active means. For girls ethnic differences did not reach statistical significance. There were no significant differences by NZDep deprivation. Barriers which prevented children using active transport to travel to school included the distances being too far, the traffic being too busy, it being too dangerous and the time it would take.

Television Viewing: In the 2006/07 NZHS, 64.1% of children aged 5-14 years usually watched 2+ hours of television per day. Children aged 10-14 years were *significantly* more likely to watch television 2+ hours per day than those 5-9 years. Rates were *significantly* higher in Māori children and for those in the most deprived (NZDep deciles 9-10) areas.

Local Policy Documents and Evidence Based Reviews Relevant to Physical Activity in Children and Young People

In New Zealand a range of policy documents and reviews consider physical activity as it relates to the prevention and management of overweight and obesity and these are briefly summarised in **Table 66** on **Page 202**, along with a range of guidelines and reviews which consider these issues in the overseas context.



IRON DEFICIENCY ANAEMIA

Introduction

Infants and Preschool Age Children

Iron requirements in the first year of life are greater than at any other time in the life cycle, with infants tripling their birth weight and blood volume during the first year, and requiring between 0.4-0.6 mg of iron a day to maintain their iron stores [172]. Full term infants are born with sufficient iron stores to meet their needs for the first 4-6 months, but after 6 months they become dependent on dietary iron intake from complementary foods, even if they continue to breastfeed [172]. Infants born prematurely however may have had insufficient time to lay down iron stores in-utero, and thus it is recommended that those born <35 weeks gestation, or with a birth weight <1800g receive iron supplementation from 4 weeks of age [172].

In New Zealand, the prevalence of iron deficiency anaemia in those aged 6-23 months is estimated to be 14%, with higher rates being seen in Māori (20%) and Pacific (17%) infants than in European (7%) infants [173]. Risk factors for iron deficiency anaemia in this age group include not receiving iron fortified infant or follow on formula (e.g. receiving only unmodified cow's milk following cessation of breastfeeding) and prolonged (>6 months) breastfeeding [173]. Women breastfeeding after the age of 6 months thus need to be advised that a number of inhibitors in infant foods may impair iron absorption from breast milk, and that a range of foods high in iron (e.g. meat, iron fortified infant cereals) need to be added to the infant's diet in order to prevent iron deficiency. Further, upon cessation of breastfeeding, some infants may require iron-fortified milk formula on into their second year of life, particularly those with large body mass who were smaller at birth, or who were delivered prematurely [173].

Such supplementation is important, as in addition to its haematological manifestations, iron deficiency may impact negatively on the developing brain, with research suggesting that children with iron deficiency anaemia in the first two years of life have poorer achievement at school (as assessed by both cognitive and behavioural measures). Children with current iron deficiency may also not learn as well at school, although treatment of the anaemia usually improves cognitive outcomes in this older age group [172].

Young Women of Reproductive Age

During adolescence, the physiological requirements for iron peak at the time of the pubertal growth spurt, with several processes that accompany puberty in females having a major impact on iron requirements, including sexual maturation, the onset of menarche and increasing erythropoiesis [174]. Further, a range of dietary factors such as poor food selection, low energy intake arising from concerns about body weight, and an interest in vegetarian diets may result in young women failing to meet their physiological iron requirements during this stage of development. Additional factors such as high menstrual losses, blood donations and intense physical exercise may also play a role [174].

In this age group the consequences of iron deficiency anaemia may include impaired cognitive function, poor appetite, impaired mood and growth, and also in the case of pregnancy, an increased risk of fetal growth impairment and preterm birth [174]. The recommended treatment for iron deficiency anaemia is iron supplementation, preferably with slow release ferrous sulphate or equivalent, for at least 6-12 months [174].

With little routinely collected data on the prevalence of iron deficiency anaemia in New Zealand children and young people, the following section uses the National Minimum Dataset to review the number of children and young people admitted to hospital who had any mention of iron deficiency anaemia in any of the first 15 diagnoses. While the figures presented are likely to significantly underestimate the prevalence of iron deficiency anaemia in this age group, the paucity of other routinely collected data sources and the importance of iron deficiency anaemia as a public health issue have led to the use of this data. Thus the figures should not be used as a basis for estimating the underlying

prevalence of iron deficiency anaemia in this age group, but rather to assist in identifying the groups of children and young people who may warrant further attention with regard to their iron status and nutritional intake.

Data Source and Methods

Definition

1. Hospital Admission Rates for Children and Young People with Iron Deficiency Anaemia Listed as a Primary Diagnosis or as a Co-Morbidity
2. Proportion of Hospital Admissions in Children and Young People with Iron Deficiency Anaemia Listed as a Primary Diagnosis or as a Co-Morbidity

Data Source

1. National Minimum Dataset

Numerator: Hospital Admissions for Children and Young People Aged 0-24 Years with Iron Deficiency Anaemia (ICD-10-AM D50) in any of the first 15 diagnoses (birth events in those aged 0 years excluded)

Denominator 1: Statistics New Zealand Estimated Resident Population

Denominator 2: Total Number of Hospital Admissions in Children and Young People Aged 0-24 (birth events in those aged 0 years excluded)

Notes on Interpretation

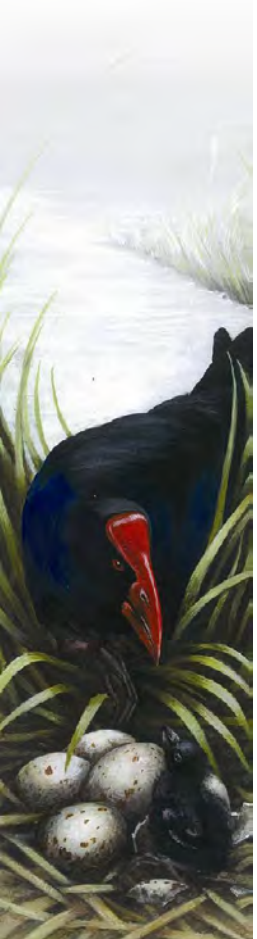
Unless otherwise specified, this analysis focuses on hospital admissions for children and young people who had iron deficiency anaemia listed in any of the first 15 diagnoses (rather than on the subset of admissions where iron deficiency anaemia was listed only as the primary reason for admission). When interpreting the data in this section it is thus important to remember that the majority of children and young people with iron deficiency anaemia were not hospitalised primarily for the management of their anaemia, but rather for a range of other diagnoses, some of which (e.g. excessive menstrual bleeding) may have contributed to the anaemia, and some of which (e.g. acute upper respiratory infections) were likely unrelated.

As only 7.1% of admissions in those aged 0-4 years and 14.8% of admissions in women aged 15-24 years with iron deficiency anaemia (i.e. iron deficiency anaemia listed in any of the first 15 diagnoses) had their anaemia listed as their primary diagnosis, there was some concern that the demographic profiles of those with iron deficiency anaemia (e.g. by age, ethnicity and NZ Deprivation index decile) might merely have reflected the demographic profile of all hospitalisations in this age group. For example, admissions with iron deficiency anaemia may have been more common in those aged 0-4 years, merely because the underlying admission rate in this age group was higher (e.g. as a result of a high burden of infectious and respiratory disease); Similarly an increase in admissions with iron deficiency anaemia in young women aged 15-24 years may have merely reflected the fact that young women increasingly attend hospital for pregnancy related care at this point in the age distribution. In order to address this issue, all of the analyses in this section have been presented in two ways: Firstly admission rates have been presented per 100,000 total population; Secondly, anaemia admissions have been presented as a proportion of all hospital admissions in the relevant age group, (with hospital admissions for births (baby related events) being removed from both the numerator and the denominator in all analyses (due to the relative rarity of iron deficiency anaemia at the time of birth, but the large numerical contribution births make to the hospital admission denominator in the first year of life).

Further, because a review of the data in the section which follows suggested two distinct age peaks for iron deficiency anaemia: one in infants and preschool age children, and another in women aged 15-24 years, the analysis which follows considers each of these groups separately, in order to determine whether the demographic or clinical profiles of these two age groups differed in such a way as to suggest different interventions might be required for each age group.

Finally, as the documentation of iron deficiency anaemia in the National Minimum Dataset relies on a full blood count being taken during the admission, clinical staff documenting the iron deficiency anaemia in the notes, and then clinical coding staff picking up on this diagnosis and listing it as a co-morbidity (where it was not the primary reason for which care was sought), it is likely that the analysis presented in this section significantly undercounts the number of children and young people with iron deficiency anaemia. The rationale for the methodology used however, was the absence of other more reliable data sources, and the importance of iron deficiency anaemia as a public health issue.

Indicator Category Bookmark C



New Zealand Distribution and Trends

Distribution by Primary Diagnosis

In New Zealand during 2005-2009, only 7.1% of hospital admissions in children aged 0-4 years who had iron deficiency anaemia (i.e. iron deficiency anaemia listed in any of the first 15 diagnoses) had their anaemia listed as the primary diagnosis, with 41.1% of admissions being primarily for respiratory infections / diseases and a further 5.8% being for gastroenteritis. In contrast, 14.8% of admissions in women aged 15-24 years with iron deficiency anaemia had their anaemia listed as the primary diagnosis, with 36.1% of admissions being for pregnancy or childbirth, and a further 7.7% being for irregular or excessive uterine bleeding (**Table 70**).

Distribution by Age

Population Rates: In New Zealand during 2005-2009, hospital admissions for children and young people with iron deficiency anaemia were highest in infants during the first two years of life, with a male predominance being evident in this age group. Admissions were lowest for those 5-12 years of age, with rates rising again amongst young women in their teens and early twenties (**Figure 68**).

Proportion of Hospital Admissions: Because of concerns that the age and gender distribution presented above may have merely reflected the distribution of hospital admissions in this age group (as in the majority of cases, iron deficiency anaemia was listed as a contributory diagnosis, with the main reason for admission being for another condition), the same analysis was repeated using the proportion of hospital admissions as the unit of analysis (so that any age and gender peaks in the underlying rate of hospital admissions could be taken into account). When the proportion of hospital admissions was considered, admissions with iron deficiency anaemia were still highest for those in their second year of life and for females aged 15-24 years of age, although the elevation of rates seen in the first year of life was much less marked (**Figure 69**).

Distribution by Prioritised Ethnicity, NZDep Index Decile and Gender

Population Rates: 0-4 Years: In New Zealand during 2005-2009, hospital admissions for children aged 0-4 years with iron deficiency anaemia were *significantly* higher for males, Pacific > Māori and Asian > European children and those living in average-more deprived (NZDep deciles 5-10) areas. **0-24 Years**: For children and young people aged 0-24 years, admissions were *significantly* higher for females, Pacific > Māori > Asian > European children and young people, and those living in average-more deprived (NZDep decile 5-10) areas. **Women 15-24 Years**: Similarly, admissions for women aged 15-24 years were *significantly* higher for Pacific > Māori > European and Asian women and those living in average–more deprived (NZDep decile 5-10) areas (**Table 71**). Similar ethnic differences were seen during 2000-2009 (**Figure 70**).

Proportion of Hospital Admissions: When the unit of analysis was the proportion of hospital admissions, rather than rates per 100,000 population, socioeconomic gradients in each age group, while still being significantly higher for those in the more deprived (NZDep deciles 8-10) areas, were much less marked, potentially suggesting that underlying socioeconomic gradients in admissions for other conditions (e.g. infectious and respiratory diseases) may have contributed to the magnitude of the gradients seen. In addition, rate ratios for Asian women aged 15-24 years (and Asian children and young people aged 0-24 years) became more prominent, potentially suggesting that lower underlying admission rates for Asian women may have initially masked some of the differences seen (**Table 72**, **Figure 71**).

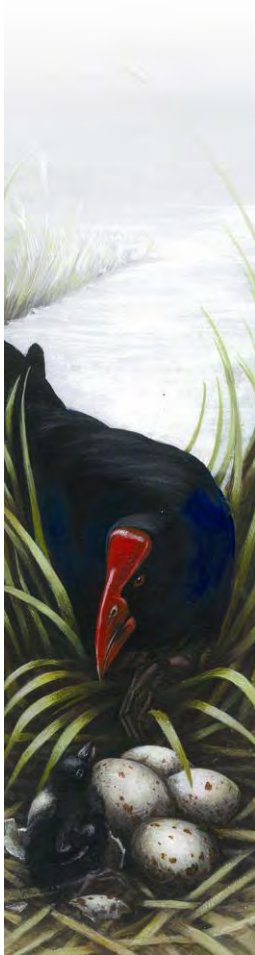
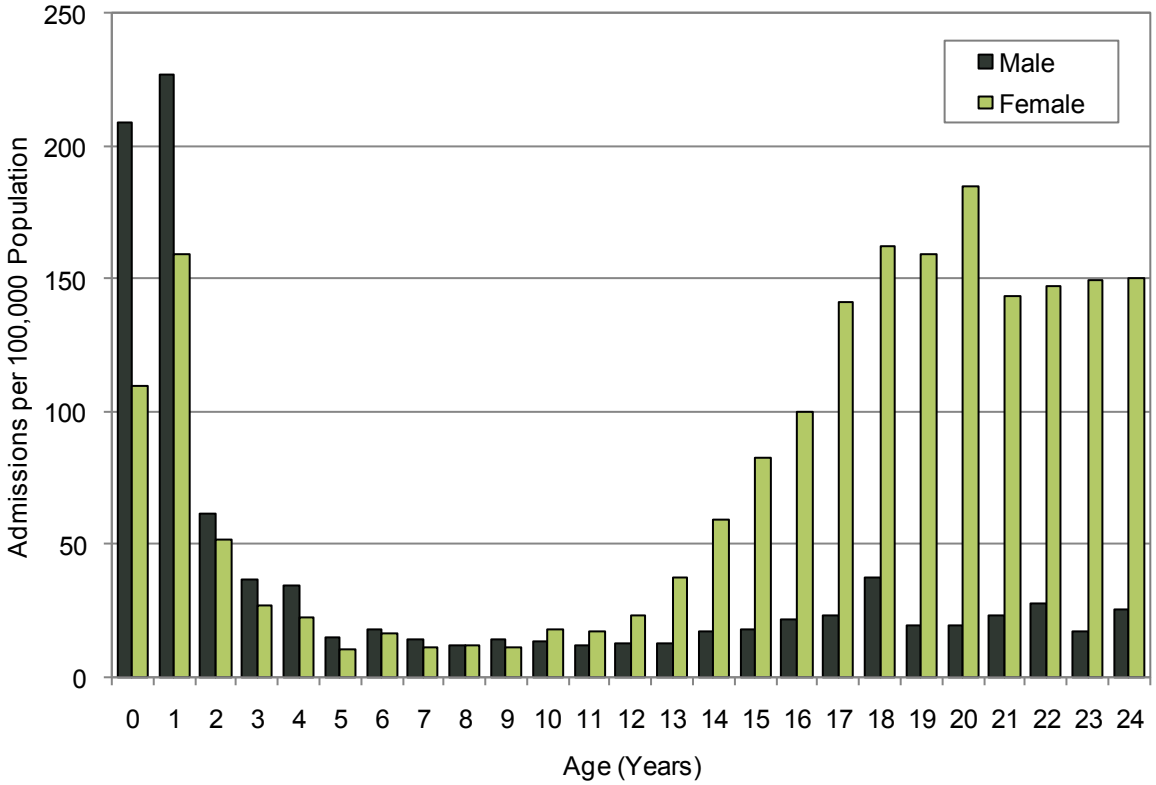


Table 70. Hospital Admissions for Children Aged 0-4 Years and Women Aged 15-24 Years with Iron Deficiency Anaemia by Primary Diagnosis, New Zealand 2005-2009

Primary Diagnosis	Number: Total 2005-2009	Number: Annual Average	Rate per 100,000 Population	% of Admissions in those with Anaemia
Children 0-4 Years				
Iron Deficiency Anaemia (D50)	97	19.4	6.76	7.08
Influenza and Pneumonia (J10-J18)	324	64.8	22.58	23.63
Acute Upper Respiratory Infections (J00-J06)	57	11.4	3.97	4.16
Other Respiratory Infections and Diseases (J20-J99)	182	36.4	12.68	13.27
Gastroenteritis (A00-A09 K52 R11)	80	16.0	5.58	5.84
Viral Infection NOS (B349)	58	11.6	4.04	4.23
Other Infectious and Parasitic Diseases (Remainder A15-B99)	43	8.6	3.00	3.14
Skin Infections (L00-L08)	60	12.0	4.18	4.38
Urinary Tract Infection (N10-N12, N30, N39.0)	40	8.0	2.79	2.92
Febrile Convulsions (R560)	30	6.0	2.09	2.19
Other Diagnoses	400	80.0	27.88	29.17
Total	1,371	274.2	95.54	100.00
Women 15-24 Years				
Iron Deficiency Anaemia (D50)	321	64.2	20.94	14.83
Complications of Labour and Delivery (O60-O75)	316	63.2	20.61	14.60
Anaemia Complicating Pregnancy, Childbirth, Puerperium (O990)	124	24.8	8.09	5.73
Pregnancy with Miscarriage / Abortive Outcome (O00-O08)	94	18.8	6.13	4.34
Complications Predominantly Related to the Puerperium (O85-92)	50	10.0	3.26	2.31
Other Pregnancy, Childbirth, Puerperium (Remainder O00-O99)	198	39.6	12.91	9.15
Excessive / Frequent / Irregular Menstruation (N92)	167	33.4	10.89	7.71
Other Abnormal Uterine and Vaginal Bleeding (N93)	53	10.6	3.46	2.45
Urinary Tract Infection (N10-N12, N30, N39.0)	63	12.6	4.11	2.91
Abdominal and Pelvic Pain (R10)	54	10.8	3.52	2.49
Injuries (S00-T35, T66-T79)	49	9.8	3.20	2.26
Other Diagnoses	676	135.2	44.09	31.22
Total	2,165	433.0	141.21	100.00

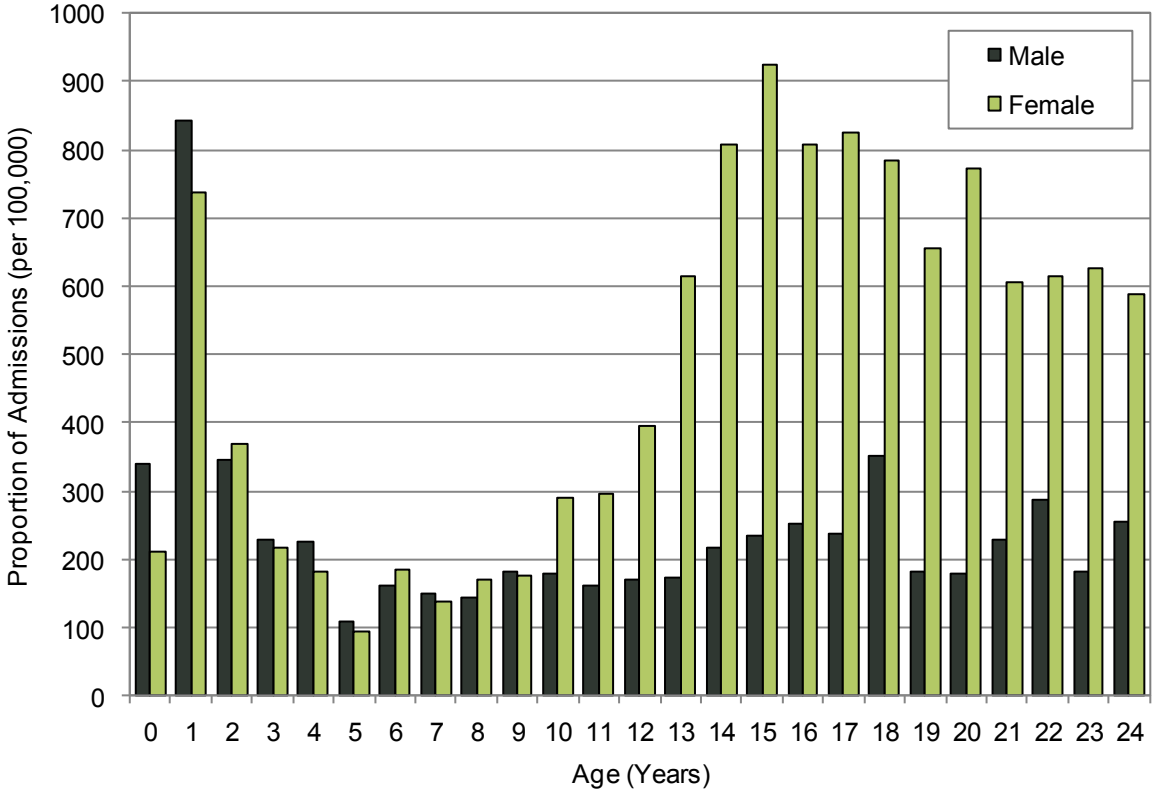
Source: Numerator: National Minimum Dataset, Primary diagnosis for children and young people with Iron Deficiency Anaemia listed in any of the first 15 diagnoses; Denominator: Statistics NZ Estimated Resident Population. Note: Birth Events in those aged 0 years excluded.

Figure 68. Hospital Admissions for Children and Young People with Iron Deficiency Anaemia by Age and Gender, New Zealand 2005-2009



Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Iron Deficiency Anaemia listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Note: Birth Events in those aged 0 years excluded.

Figure 69. Proportion of Hospital Admissions with Iron Deficiency Anaemia in Children and Young People by Age and Gender, New Zealand 2005-2009



Source: National Minimum Dataset; Numerator: Hospital Admissions for children and young people with Iron Deficiency Anaemia listed in any of the first 15 diagnoses. Denominator: Total Admissions in Age Group. Note: Birth Events in those aged 0 years excluded.

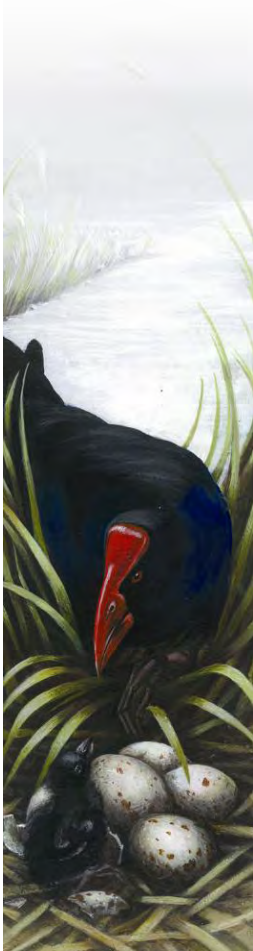


Table 71. Hospital Admissions for Children and Young People Aged 0-24 Years with Iron Deficiency Anaemia by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2005-2009

Iron Deficiency Anaemia: Admissions per 100,000 Population							
Children 0-4 Years							
Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	27.4	1.00		Decile 1-2	33.1	1.00	
Decile 2	38.9	1.42	0.92 - 2.19	Decile 3-4	33.2	1.00	0.74 - 1.36
Decile 3	38.1	1.39	0.90 - 2.16	Decile 5-6	58.7	1.77	1.36 - 2.31
Decile 4	28.8	1.05	0.67 - 1.66	Decile 7-8	88.4	2.67	2.09 - 3.41
Decile 5	48.6	1.78	1.17 - 2.70	Decile 9-10	210.0	6.35	5.07 - 7.95
Decile 6	67.2	2.46	1.67 - 3.62	Prioritised Ethnicity			
Decile 7	71.5	2.61	1.78 - 3.84	Asian	111.9	3.23	2.64 - 3.96
Decile 8	102.4	3.74	2.60 - 5.38	European	34.6	1.00	
Decile 9	176.8	6.46	4.55 - 9.17	Māori	141.6	4.09	3.53 - 4.74
Decile 10	238.9	8.73	6.19 - 12.31	Pacific	288.8	8.35	7.16 - 9.73
Gender							
Female	75.0	1.00		Male	115.2	1.54	1.38 - 1.71
Women 15-24 Years							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	57.2	1.00		Decile 1-2	60.2	1.00	
Decile 2	63.1	1.10	0.80 - 1.52	Decile 3-4	66.1	1.10	0.88 - 1.36
Decile 3	60.6	1.06	0.77 - 1.46	Decile 5-6	102.7	1.71	1.40 - 2.08
Decile 4	71.1	1.24	0.92 - 1.69	Decile 7-8	142.8	2.37	1.98 - 2.84
Decile 5	95.7	1.67	1.25 - 2.24	Decile 9-10	249.9	4.15	3.50 - 4.92
Decile 6	108.7	1.90	1.44 - 2.51	Prioritised Ethnicity			
Decile 7	117.5	2.05	1.56 - 2.70	Asian	73.6	1.19	1.00 - 1.41
Decile 8	163.6	2.86	2.21 - 3.70	European	62.1	1.00	
Decile 9	184.1	3.22	2.50 - 4.14	Māori	272.4	4.39	3.93 - 4.89
Decile 10	330.2	5.77	4.51 - 7.38	Pacific	454.3	7.32	6.50 - 8.24
Children and Young People 0-24 Years							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	23.3	1.00		Decile 1-2	24.8	1.00	
Decile 2	26.2	1.13	0.91 - 1.39	Decile 3-4	29.4	1.19	1.03 - 1.37
Decile 3	31.9	1.37	1.11 - 1.68	Decile 5-6	41.3	1.67	1.46 - 1.91
Decile 4	27.2	1.17	0.95 - 1.44	Decile 7-8	57.8	2.33	2.06 - 2.64
Decile 5	38.5	1.65	1.35 - 2.02	Decile 9-10	114.1	4.60	4.11 - 5.16
Decile 6	43.6	1.87	1.55 - 2.26	Prioritised Ethnicity			
Decile 7	46.7	2.00	1.66 - 2.42	Asian	46.8	1.69	1.51 - 1.89
Decile 8	67.3	2.89	2.42 - 3.44	European	27.7	1.00	
Decile 9	93.6	4.01	3.39 - 4.75	Māori	97.3	3.51	3.26 - 3.78
Decile 10	134.3	5.76	4.89 - 6.79	Pacific	162.4	5.86	5.39 - 6.36
Gender							
Female	81.4	1.00	0.95 - 1.05	Male	37.0	0.46	0.43 - 0.48

Source: Numerator: National Minimum Dataset, Admissions for children and young people with Iron Deficiency Anaemia listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Rate is per 100,000 population. Rate ratios are unadjusted. Birth Events in those aged 0 years excluded.

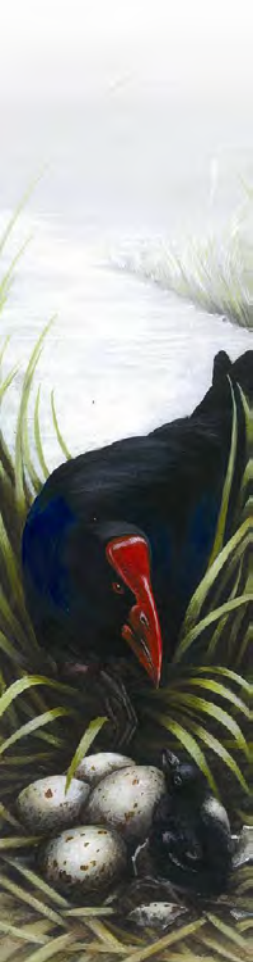
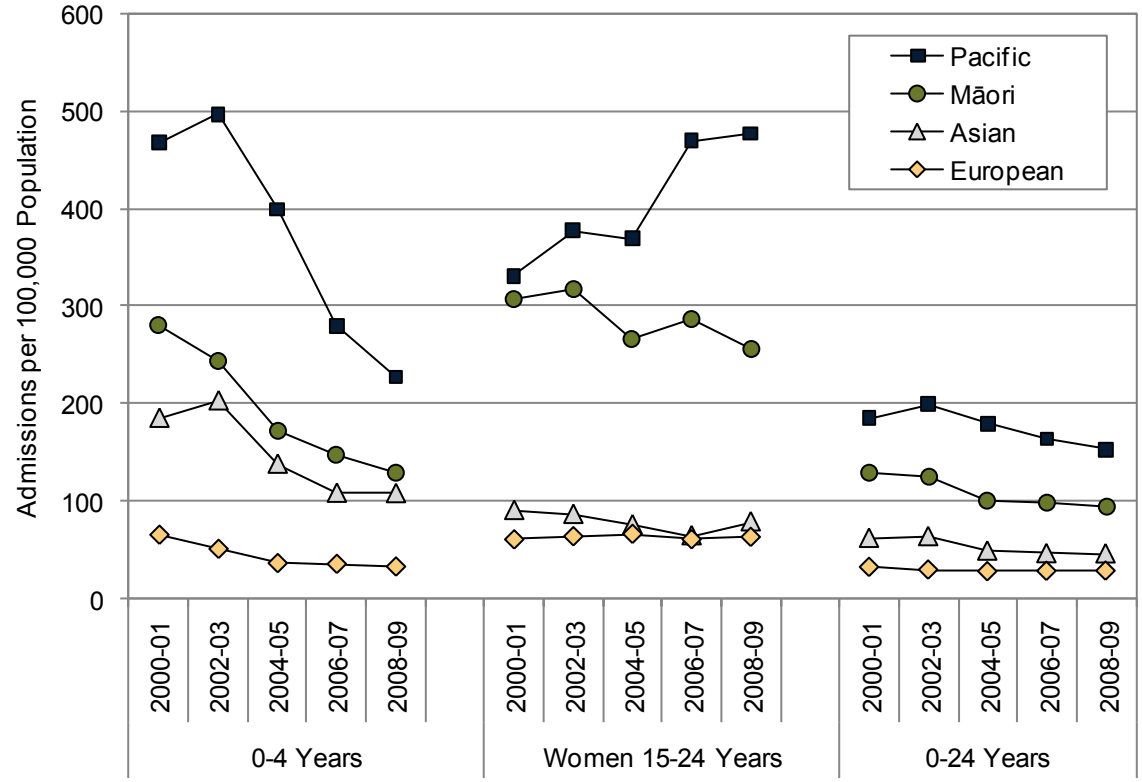


Table 72. Proportion of Hospital Admissions with Iron Deficiency Anaemia in Children and Young People Aged 0-24 Years by NZ Deprivation Index Decile, Prioritised Ethnicity and Gender, New Zealand 2005-2009

Iron Deficiency Anaemia: Proportion of Hospital Admissions (per 100,000)							
Children 0-4 Years							
Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	155.2	1.00		Decile 1-2	188.0	1.00	
Decile 2	221.4	1.43	0.93 - 2.20	Decile 3-4	165.0	0.88	0.65 - 1.19
Decile 3	193.7	1.25	0.80 - 1.94	Decile 5-6	253.0	1.35	1.03 - 1.75
Decile 4	140.4	0.91	0.57 - 1.43	Decile 7-8	332.0	1.77	1.38 - 2.26
Decile 5	209.8	1.35	0.89 - 2.05	Decile 9-10	636.9	3.39	2.70 - 4.24
Decile 6	289.1	1.86	1.27 - 2.74	Prioritised Ethnicity			
Decile 7	283.6	1.83	1.24 - 2.69	Asian	560.7	3.79	3.09 - 4.64
Decile 8	368.5	2.37	1.65 - 3.41	European	148.1	1.00	
Decile 9	530.0	3.42	2.41 - 4.85	Māori	527.3	3.56	3.08 - 4.12
Decile 10	731.4	4.71	3.34 - 6.65	Pacific	837.3	5.66	4.85 - 6.59
Gender							
Female	328.2	1.00		Male	413.6	1.26	1.13 - 1.40
Women 15-24 Years							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	512.3	1.00		Decile 1-2	528.2	1.00	
Decile 2	542.8	1.06	0.77 - 1.45	Decile 3-4	466.0	0.88	0.71 - 1.10
Decile 3	462.7	0.90	0.65 - 1.25	Decile 5-6	537.1	1.02	0.84 - 1.24
Decile 4	468.7	0.91	0.67 - 1.24	Decile 7-8	634.6	1.20	1.00 - 1.44
Decile 5	528.1	1.03	0.77 - 1.38	Decile 9-10	933.4	1.77	1.49 - 2.09
Decile 6	543.9	1.06	0.80 - 1.40	Prioritised Ethnicity			
Decile 7	532.2	1.04	0.79 - 1.37	Asian	1,148.3	3.42	2.88 - 4.06
Decile 8	715.9	1.40	1.08 - 1.81	European	335.9	1.00	
Decile 9	751.7	1.47	1.14 - 1.89	Māori	889.8	2.65	2.38 - 2.95
Decile 10	1,117.0	2.18	1.71 - 2.79	Pacific	1,702.8	5.07	4.50 - 5.70
Children and Young People 0-24 Years							
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	256.4	1.00		Decile 1-2	270.3	1.00	
Decile 2	283.8	1.11	0.90 - 1.37	Decile 3-4	274.2	1.01	0.88 - 1.17
Decile 3	309.2	1.21	0.98 - 1.48	Decile 5-6	312.9	1.16	1.01 - 1.32
Decile 4	244.6	0.95	0.77 - 1.18	Decile 7-8	375.3	1.39	1.23 - 1.57
Decile 5	297.9	1.16	0.95 - 1.42	Decile 9-10	611.6	2.26	2.02 - 2.54
Decile 6	325.2	1.27	1.05 - 1.53	Prioritised Ethnicity			
Decile 7	317.9	1.24	1.03 - 1.50	Asian	665.4	3.17	2.83 - 3.54
Decile 8	420.0	1.64	1.38 - 1.95	European	210.1	1.00	
Decile 9	512.9	2.00	1.69 - 2.37	Māori	571.8	2.72	2.53 - 2.93
Decile 10	704.7	2.75	2.33 - 3.24	Pacific	863.9	4.11	3.79 - 4.46
Gender							
Female	522.9	1.00		Male	290.3	0.56	0.52 - 0.59

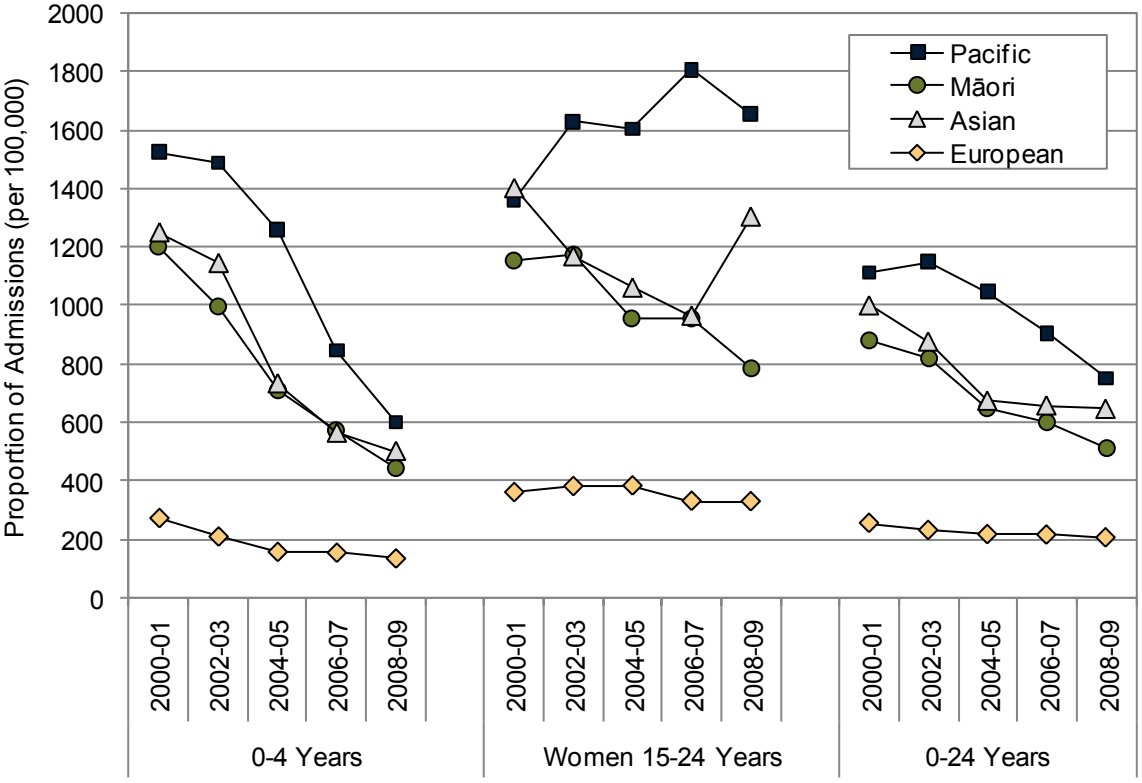
Source: National Minimum Dataset ; Numerator: Admissions for children and young people with Iron Deficiency Anaemia listed in any of the first 15 diagnoses. Denominator: Total Admissions in Age Group. Rate ratios are unadjusted Note: Birth Events in those aged 0 years excluded.

Figure 70. Hospital Admissions for Children and Young People Aged 0-24 Years with Iron Deficiency Anaemia by Prioritised Ethnicity and Age, New Zealand 2000-2009

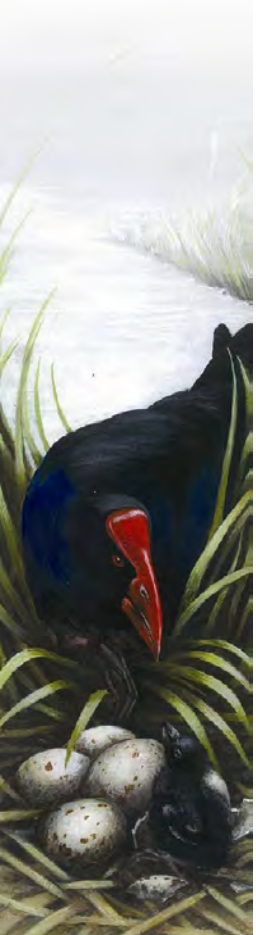


Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Iron Deficiency Anaemia listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Birth Events in those aged 0 years excluded.

Figure 71. Proportion of Hospital Admissions with Iron Deficiency Anaemia in Children and Young People Aged 0-24 Years by Age Group and Ethnicity, New Zealand 2000-2009



Source: National Minimum Dataset; Numerator: Hospital Admissions for children and young people with Iron Deficiency Anaemia listed in any of the first 15 diagnoses. Denominator: Total Admissions in Age Group. Birth Events in those aged 0 years excluded.



Taranaki Distribution

Taranaki Distribution

In Taranaki during 2005-2009, hospital admissions for children aged 0-4 years with iron deficiency anaemia were *significantly* lower than the New Zealand average, while admissions for women aged 15-24 years and children and young people aged 0-24 years were not *significantly* different from the New Zealand average (**Table 73**). These differences persisted, even when the unit of analysis was the proportion of hospital admissions, rather than rates per 100,000 population (**Table 73**). It remains unclear however, whether these differences reflect real differences in the prevalence of iron deficiency anaemia, or differences in the way secondary diagnoses (e.g. iron deficiency anaemia) was recorded in the hospital admission dataset.

Summary

In New Zealand during 2005-2009, 7.1% of hospitalisations in children 0-4 years with iron deficiency anaemia, had their anaemia listed as the primary diagnosis, with 41.1% of admissions being for respiratory infections / diseases. In contrast, 14.8% of admissions in women aged 15-24 years with iron deficiency anaemia had their anaemia listed as the primary diagnosis, with 36.1% of admissions being related to pregnancy or childbirth, and 7.7% being for irregular or excessive uterine bleeding. During this period, admissions were highest in infants during the first two years of life, with a male predominance evident in this age group. Rates were also higher amongst young women in their teens and early twenties. Rates for children aged 0-4 years were *significantly* higher for males, Pacific > Māori and Asian > European children and those living in average-more deprived areas. Similarly for women aged 15-24 years, rates were *significantly* higher for Pacific > Māori > European and Asian women and those living in average–more deprived areas.

When the unit of analysis was the proportion of hospital admissions rather than rates per 100,000 population, while rates were still significantly higher for those in the more deprived (NZDep deciles 8-10) areas, socioeconomic gradients were much less marked, potentially suggesting that underlying socioeconomic gradients in admissions for other conditions (e.g. infectious and respiratory diseases), may have contributed to the magnitude of the gradients seen. In addition, rate ratios for Asian women aged 15-24 years became more prominent, potentially suggesting that lower underlying admission rates for Asian women may have initially masked some of the differences seen.

In Taranaki during 2005-2009, hospital admissions for children aged 0-4 years with iron deficiency anaemia were *significantly* lower than the New Zealand average, while admissions for women aged 15-24 years and children and young people aged 0-24 years were not *significantly* different from the New Zealand average. These differences persisted, even when the unit of analysis was the proportion of hospital admissions, rather than rates per 100,000 population. It remains unclear however, whether these differences reflect real differences in the prevalence of iron deficiency anaemia, or differences in the way secondary diagnoses (e.g. iron deficiency anaemia) was recorded in the hospital admission dataset.

Table 73. Hospital Admissions for Children and Young People Aged 0-24 Years with Iron Deficiency Anaemia by Age, Taranaki vs. New Zealand 2005-2009

DHB	Total Number Individuals 2005-2009		Total Number Admissions 2005-2009	Average Number Admissions per Individual per Year	Admissions per 100,000 Total Population			Proportion of All Hospital Admissions		
	(A)*	(B)*			Rate per 100,000	Rate Ratio	95% CI	Rate per 100,000	Rate Ratio	95% CI
Iron Deficiency Anaemia										
Children 0-4 Years										
Taranaki	14	14	15	0.21	42.7	0.45	0.27 - 0.74	198.1	0.53	0.32 - 0.88
New Zealand	1,204		1,371	0.23	95.5	1.00		376.1	1.00	
Women 15-24 Years										
Taranaki	52	52	58	0.22	173.7	1.23	0.95 - 1.60	668.7	0.96	0.74 - 1.24
New Zealand	1,819		2,165	0.24	141.2	1.00		698.1	1.00	
Children and Young People 0-24 Years										
Taranaki	82	82	92	0.22	50.3	0.85	0.69 - 1.05	354.5	0.85	0.69 - 1.05
New Zealand	3,723		4,440	0.24	58.8	1.00		416.1	1.00	

Source: Numerator: National Minimum Dataset, Hospital Admissions for children and young people with Iron Deficiency Anaemia listed in any of the first 15 diagnoses. Denominator: Statistics NZ Estimated Resident Population. Note: Birth Events in those aged 0 years excluded. *Note: (A): Each individual only counted once in DHB in which they first reside (i.e. DHB total = NZ total); (B): Each individual counted once in each DHB in which they reside (i.e. the sum of DHB totals exceeds New Zealand total). Rate Ratios are compared to New Zealand rates and have not been adjusted for population demographics.

Local Policy Documents and Evidence Based Reviews Relevant to the Prevention and Management of Iron Deficiency Anaemia

In New Zealand a limited range of policy documents and reviews consider the prevention and management of iron deficiency anaemia and these are briefly summarised in **Table 74**, along with a range of guidelines and reviews which consider these issues in the overseas context.

Table 74. Local Policy Documents and Evidence Based Reviews Relevant to the Prevention and Management of Iron Deficiency Anaemia in Children and Young People

New Zealand Policy Documents and Reviews
Ministry of Health. **Food and Nutrition Guidelines for Healthy Infants and Toddlers (Aged 0–2): A background paper (4th Ed).** Wellington: Ministry of Health, 2008. URL: http://www.moh.govt.nz/moh.nsf/indexmh/0-2-food-and-nutrition-guidelines-may2008 This publication provides a policy base for the implementation of the HEHA strategy in infants and toddlers. It includes evidence-based policy advice on nutrition and physical activity. It aims to provide information on which to base education programmes and resources as well as guidance for health practitioners. It also aims to provide a basis for the preparation of policies to protect, promote and support breastfeeding including those to ensure compliance with the Baby Friendly Hospital Initiative (BFHI) and the Baby Friendly Community Initiative (BFCI) for health care facilities. It identifies health inequalities relating to nutrition and physical activity in order to facilitate targeting. Pages 73-77 relate to Iron and Iron deficiency.
Grant CC, Wall CR, et al. **Policy statement on iron deficiency in pre-school-aged children**. Journal of Paediatrics & Child Health 2007; 43(7-8): 513-21. This review was done for the Royal Australasian College of Physicians. It involved a literature review and the development of recommendations in relation to the three areas of: the diagnosis of iron-deficiency anaemia, maternal – infant issues and the prevention of iron deficiency, and the treatment of iron deficiency. It discusses the challenges of obtaining a precise and accurate diagnosis and states that in young children iron deficiency can be defined either by using cut-off values for laboratory measures of iron status or by demonstrating a response to a therapeutic trial of iron supplementation (provided there is not an intercurrent infection). It recommends supplementation with oral iron salts for children who have received a diagnosis of iron deficiency and for all premature and low-birthweight infants.
National Health and Medical Research Council, Ministry of Health. **Nutrient reference values for Australia and New Zealand including recommended dietary intakes**. Canberra: Commonwealth Department of Health and Ageing, 2006. URL: http://www.nhmrc.gov.au/publications/synopses/n35syn.htm This publication is the result of a joint initiative of the Australian National Health and Medical Research Council and the New Zealand Ministry of Health. An expert working party reviewed recommendations from other countries, particularly from the US and Canada, as well as scientific data, information from recent dietary surveys in Australia and New Zealand and research and other information specific to Australian and New Zealand conditions. Each chapter covers one nutrient and provides recommended dietary intakes and upper levels of intake by life stage and gender. A comprehensive list of references is included for each chapter. Pages 187-191 refer to iron.
International Policy Statements and Evidence Based Reviews
Hutton EK, Hassan ES. **Late vs. early clamping of the umbilical cord in full-term neonates: Systematic review and meta-analysis of controlled trials**. JAMA 2007; 297(11): 1241-52. This review considered 15 controlled trials (involving 1912 newborns) comparing late (>2 minutes) versus early (immediately after birth) cord clamping. As a result of a meta-analysis the authors found that between the ages of 2 – 6 months the benefits associated with delayed cord clamping included greater haematocrit levels, greater serum ferritin, greater stored iron and a clinically significant reduction in the risk of anaemia. (Relative risk 0.53, 95% CI 0.40-0.70.) Neonates with delayed clamping did have an increased risk of polycythaemia but the authors stated that this condition appears to be benign.
Martins S, Logan S, et al. **Iron therapy for improving psychomotor development and cognitive function in children under the age of three with iron deficiency anaemia**. Cochrane Database of Systematic Reviews 2001(2): CD001444. The authors of this review identified five RCTs with a total of 180 children with iron deficiency anaemia (IDA) examining the effects of iron therapy on measures of psychomotor development between 5 and 11 days after commencement of therapy. They found that these studies did not provide convincing evidence for the benefits of iron therapy in this situation. The authors also reviewed two studies (with a total of 160 children with IDA) which examined the effects of iron therapy on measures of psychomotor development more than 30 days after commencement of therapy. They considered that the effect of longer term treatment was uncertain but that the results of these studies would be compatible with there being a clinically significant benefit. They recommended further research with long-term follow up.

Other Relevant Publications
Chaparro CM. **Setting the stage for child health and development: Prevention of iron deficiency in early infancy**. Journal of Nutrition 2008; 138(12): 2529-33. This article reviews the prenatal, perinatal and postnatal factors involved in the prevention of iron deficiency anaemia during the first six months of life. Contributing factors to adequate total iron stores at birth include maternal iron status, infant birth weight, gestational age and the timing of umbilical cord clamping. The rate at which birth iron stores are depleted during the first six months of life is influenced by the infant's growth rate, iron intake and iron losses. Premature babies are at risk of anaemia because they start out with lower iron stores and grow at a faster rate post-natally. Cows' milk is a poor source of iron and can cause small amounts of intestinal blood loss (more so in early infancy than later) while breast-feeding protects infants' iron status.
Moy RJ. **Prevalence, consequences and prevention of childhood nutritional iron deficiency: A child public health perspective**. Clinical & Laboratory Haematology 2006; 28(5): 291-8. This article reports on some of the studies that have been done on the prevalence of iron deficiency in children and on some of the difficulties associated with this type of research. The early introduction and excessive consumption of cows' milk is the major cause in the developed world. The article also reports on research on iron deficiency on brain and psychomotor development, and on infections. There is a review of interventions and screening. The authors conclude that the most promising approach for the prevention of iron deficiency at the population level is iron supplementation of essential food items such as infant formula, cereal or fruit juice.
Wharton BA. **Iron deficiency in children: Detection and prevention**. British Journal of Haematology 1999; 106(2): 270-280. This review article covers indications for investigation for anaemia, which investigations to use and the interpretation of the results. Strategies for prevention are reviewed, including screening, health education, fiscal measures and food fortification and supplementation. There is a discussion of iron fortification of infant formula and some of the research on this topic. Fortification of other foods is also discussed. The use of oral iron supplements is not recommended as a preventive measure because they are potentially toxic and compliance is often poor. The author states that targeting of foods for supplementation to those consumed by vulnerable groups would be an effective public health measure.

THE CHILDREN'S SOCIAL HEALTH MONITOR: INTRODUCTION

INTRODUCTION TO THE CHILDREN'S SOCIAL HEALTH MONITOR

In New Zealand, there are currently large disparities in child health status, with Māori and Pacific children and those living in more deprived areas experiencing a disproportionate burden of morbidity and mortality [175]. Such disparities have persisted, despite one of the longest periods of economic growth in recent decades, as well as historically low unemployment rates.

During the past 2 ½ years however, New Zealand's macroeconomic environment has changed rapidly, with current projections being for a significant economic downturn, followed by a slow and fragile recovery [176]. Given that large disparities in health status are evident for socioeconomically vulnerable children, even during periods of economic prosperity, it is possible that as the downturn progresses, and more families become reliant on Government assistance (e.g. unemployment benefits), some of the adaptations families make in order to meet their basic household needs (e.g. house downsizing / increasing the number of occupants to meet rent payments, deferring heating costs to pay for groceries) may result in unintended health consequences for children (e.g. increases in infectious and respiratory diseases, exposure to family conflict).

During 2009, a Working Group made up of health professionals from a range of organisations[2] was formed with a view to developing an indicator set to monitor the impact of the economic downturn on child wellbeing. This indicator set, called the *New Zealand Children's Social Health Monitor* (NZCSHM), was presented for the first time in last year's report. The NZCSHM currently comprises 5 Economic and 4 Health and Wellbeing Indicators, and data on each has been updated in this year's report, with a view to assessing how children, both nationally and locally, are faring in the current economic climate.

Economic Indicators:	Gross Domestic Product (GDP) (**Page 247**)
	Income Inequality (**Page 248**)
	Child Poverty and Living Standards (**Page 252**)
	Unemployment Rates (**Page 262**)
	Children Reliant on Benefit Recipients (**Page 269**)
Health and Wellbeing Indicators:	Hospital Admissions and Mortality with a Social Gradient (**Page 277**)
	Infant Mortality (**Page 290**)
	Injuries Arising from the Assault, Neglect or Maltreatment of Children (**Page 296**)
	Ambulatory Sensitive Hospitalisations (2008 Report)

Note: A more detailed explanation of the rationale for monitoring child health during the economic downturn was presented in last year's report. This was accompanied by a series of evidence based review tables and reviews which considered policies and interventions to address the socioeconomic determinants of child and youth health and the reader is referred to this report for additional information on these issues.

[2] The Paediatric Society of New Zealand, the Population Child Health Special Interest Group of the Royal Australasian College of Physicians, the New Zealand Child and Youth Epidemiology Service, TAHA (the Well Pacific Mother and Infant Service), the Māori SIDS Programme, the Kia Mataara Well Child Consortium, the New Zealand Council of Christian Social Services, and academics from the Universities of Auckland and Otago

THE CHILDREN'S SOCIAL HEALTH MONITOR: ECONOMIC INDICATORS

GROSS DOMESTIC PRODUCT (GDP)

Introduction

Gross Domestic Product (GDP) is defined as "*the total market value of goods and services produced within a given period, after deducting the cost of goods utilised in the process of production*" [177]. GDP is often used as a measure of the size of the economy, with nominal GDP being expressed in current dollar prices, and real GDP being expressed in constant dollar prices (i.e. the dollar value of a particular year, after adjustment for inflation).

Changes in real GDP are often used as a measure of economic growth, or the strength of the economy [177], with a recession typically being defined as two consecutive quarters of negative growth [178]. Recessions are often characterised by high unemployment, stagnant wages and a fall in retail sales, and though usually not lasting longer than a year [178], they may have significant implications for child wellbeing.

New Zealand entered a recession at the end of June 2008 (after 2 consecutive quarters of negative growth), and technically left the recession at the end of June 2009 (although growth in the June quarter (0.1%) was extremely close to zero [179]). Since that time New Zealand has had five consecutive quarters of positive growth, although in the most recent quarter, this growth was only 0.2% [180].

The following section briefly reviews changes in New Zealand's GDP since June 2006.

Data Source and Methods

Definition

Gross Domestic Product (GDP): Percent Change from Previous Quarter

GDP is the total market value of all final goods and services produced in a country in a given year, equal to total consumer, investment and government spending, plus the value of exports, minus the value of imports. A recession is defined as 2 consecutive quarters of negative growth (as measured by GDP).

Data Source

Statistics New Zealand: The New Zealand System of National Accounts. Produced Quarterly

Indicator Category: Ideal B

Notes on Interpretation

Three approaches can be used to calculate GDP:

• *Production Approach*: This method calculates what each separate producer adds to the value of final output, by deducting intermediate consumption from gross output. Value added is summed for all producers.

• *Income Approach*: This approach measures the incomes received by the owners of the factors of production. These represent the returns to the labour and capital employed such as wages and salaries, and profits.

• *Expenditure Approach*: This method sums the values of all final demands, that is, final consumption expenditures (of households, government and private non-profit institutions serving households), changes in inventories, gross capital formation, and net exports.

Conceptually, both the production and expenditure approaches of measuring GDP are the same. However, as each series uses independent data and estimation techniques, some differences between the alternative measures arise. The expenditure approach series has historically shown more quarterly volatility and is more likely to be subject to timing and valuation problems. For these reasons, the production-based measure is the preferred measure for short-term quarter-on-quarter and annual changes [181]

New Zealand Trends

Production Based Measure of GDP

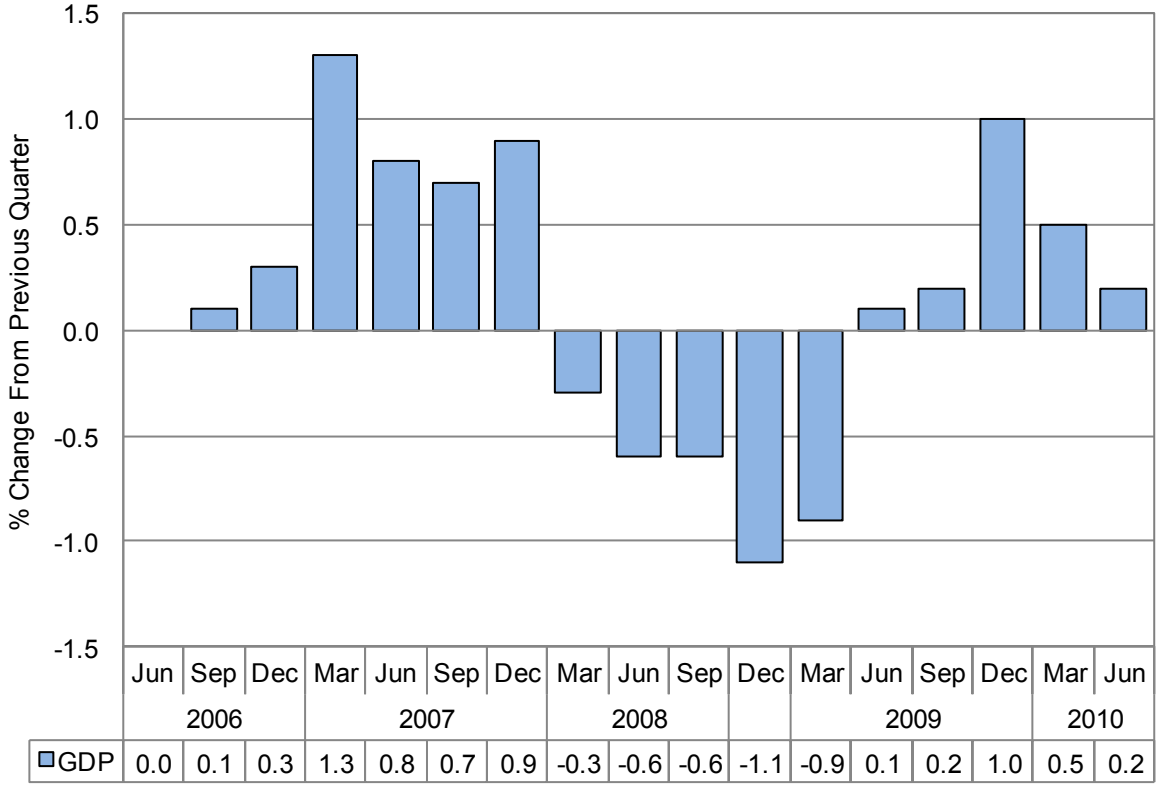
In New Zealand, GDP decreased for 5 consecutive quarters from March 2008-March 2009. GDP has since increased for five consecutive quarters, with economic activity being up 0.2% in the June 2010 quarter, following a 0.5% increase in the March 2010 quarter. Economic activity for the year ending June 2010 was up 0.7% when compared to the year ending June 2009, with this being the first annual increase in economic activity since a 1.5% rise in the year ended September 2008 [180] (**Figure 72**).

During the June 2010 quarter, construction increased by 6.4%, real estate and business services by 0.9%, and retail trade by 1.5%, while manufacturing declined by 4.0% and communication services by 2.6% [180].

Expenditure Based Measure of GDP

The expenditure based measure of GDP, released concurrently with the production based measure, increased by 0.4% in the June 2010 quarter. During this period, household consumption expenditure was flat at 0.0%, with gross fixed capital formation being up 6.2% (mainly from increased investment in residential building), exports being up 1.3% but with inventories being run down by $530 million [180].

Figure 72. Gross Domestic Product (GDP): Percentage Change from Previous Quarter, New Zealand June 2006 to June 2010



	Jun	Sep	Dec	Mar	Jun	Sep	Dec	Mar	Jun	Sep	Dec	Mar	Jun	Sep	Dec	Mar	Jun
	2006			2007				2008				2009				2010	
GDP	0.0	0.1	0.3	1.3	0.8	0.7	0.9	-0.3	-0.6	-0.6	-1.1	-0.9	0.1	0.2	1.0	0.5	0.2

Source: Statistics New Zealand: Seasonally adjusted chain volume series measured in 1995/96 prices

Summary

In New Zealand, GDP decreased for 5 consecutive quarters from March 2008-March 2009. GDP has since increased for five consecutive quarters, with economic activity being up 0.2% in the June 2010 quarter, following a 0.5% increase in the March 2010 quarter. Economic activity for the year ending June 2010 was up 0.7% when compared to the year ending June 2009, with this being the first annual increase in economic activity since a 1.5% rise in the year ended September 2008 [180].

INCOME INEQUALITY

Introduction

There has been much debate in recent years regarding the influence of income inequalities on population health. While it is widely acknowledged that poverty plays a crucial role in shaping health disparities, authors such as Wilkinson and Marmot [182] argue that income inequality itself also plays a role, via its links to psychosocial pathways associated with relative disadvantage. They cite the Whitehall studies of British civil servants, which found that mortality increased in a stepwise manner as relative socioeconomic status decreased, with social gradients being evident even amongst those who were not poor. In addition, they note that while health inequalities exist within societies, there is little association between average income (GDP per capita) and life expectancy across rich countries. Rather, there appears to be a strong correlation between income inequality and mortality. In Wilkinson and Marmot's view, such associations suggest that it is not absolute material deprivation which shapes health at the population level, but rather the effects such inequalities have on psychosocial outcomes such as the degree of control over work, anxiety, depression and social affiliations. In support of this argument, they cite a number of studies which demonstrate social gradients in the lack of control over work, low variety at work and a severe lack of social support, with animal experiments also suggesting that low social status, via its effects on neuroendocrine pathways, leads to atherosclerosis, unfavourable lipid profiles, central obesity, insulin resistance and raised basal cortisol [182].

Others such as Lynch [183] however, would argue that it is not the psychological effects of income inequality which play the greatest role, but rather the lack of material resources (e.g. differentials in access to adequate nutrition, housing and healthcare), coupled with a systematic underinvestment in human, physical, health and social infrastructure (e.g. the types and quality of education, health services, transportation, recreational facilities and public housing available). In Lynch's view, the combination of these negative exposures is particularly important for the health of the most disadvantaged (who have the fewest individual resources), and that in this context, the associations between income inequality and health are not inevitable, but rather are contingent on the level of public infrastructure and resources available. While debate on the precise pathways continues, both sides of the income inequality argument agree, that reducing income inequality by raising incomes for the most disadvantaged, will reduce inequalities and improve population health [184].

The following section explores income inequalities in New Zealand since 1984 using two different measures, the P80/P20 Ratio and the Gini Coefficient.

Definition
1. *Income Inequality as Measured by the P80/P20 Ratio*
2. *Income Inequality as Measured by the Gini Coefficient*

Data Source
Statistics New Zealand Household Economic Surveys (NZHES n=2,800-3,500 households per survey) via Perry 2010 [185].
Note: The P80/P20 Ratio and Gini coefficient are monitored by the Ministry of Social Development using NZHES data [185], which was available 2-yearly from 1982-1998, and 3-yearly thereafter. Since 2007, income data has become available annually through the new HES Incomes Survey. The full NZHES (including expenditure data) however remains 3-yearly. For more detail on methodology used see Perry 2010 [185].

Indicator Category Proxy B

Notes on Interpretation
P80/P20 Ratio: When individuals are ranked by equivalised household income and then divided into 100 equal groups, each group is called a percentile. If the ranking starts with the lowest income, then the income at the top of the 20th percentile is denoted P20 and the income at the top of the 80th percentile is called P80. The ratio of the value at the top of the 80th percentile to the value at the top of the 20th percentile is called the P80/20 ratio and is often used as a measure of income inequality (e.g. a P80/20 ratio of 3.0 indicates that those at the top of the 80th percentile have incomes 3.0x higher than those at the top of the 20th percentile). In general, the higher the ratio, the greater is the level of inequality [185].

Gini Coefficient: The Lorenz curve is a graph with the horizontal axis showing the cumulative % of people in a population ranked by their income. The vertical axis shows the corresponding cumulative % of equivalised disposable household income (i.e. the graph shows the income share of any selected cumulative proportion of the population). The diagonal line represents a situation of perfect equality (i.e. all people having the same income). The Gini coefficient is derived from the Lorenz curve and is the ratio of the area between the actual Lorenz curve and the diagonal (or line of equality), compared to the total area under the diagonal. When the Gini coefficient = 0 all people have the same level of income. When it approaches 1, one person receives all the income (i.e. it is an overall measure of income inequality: the higher the number, the greater the level of inequality) [186]. When comparing changes in income distributions over time, the Gini coefficient is more sensitive to changes in the more dense low-to-middle parts of the distribution, than it is to changes towards the ends of the distribution [185].

New Zealand Trends

Income Inequality: P80/P20 Ratio

In New Zealand during 1984-2009, income inequality as measured by the P80/P20 ratio, was higher after adjusting for housing costs than prior to this adjustment. The most rapid rises in income inequality occurred during 1988-1992. While income inequality also rose during 1994-2004, the rate of increase was slower. During 2004-2009, the P80/P20 ratio fell, a decline in income inequality which Perry attributes largely to the Working for Families package [185] (**Figure 73**).

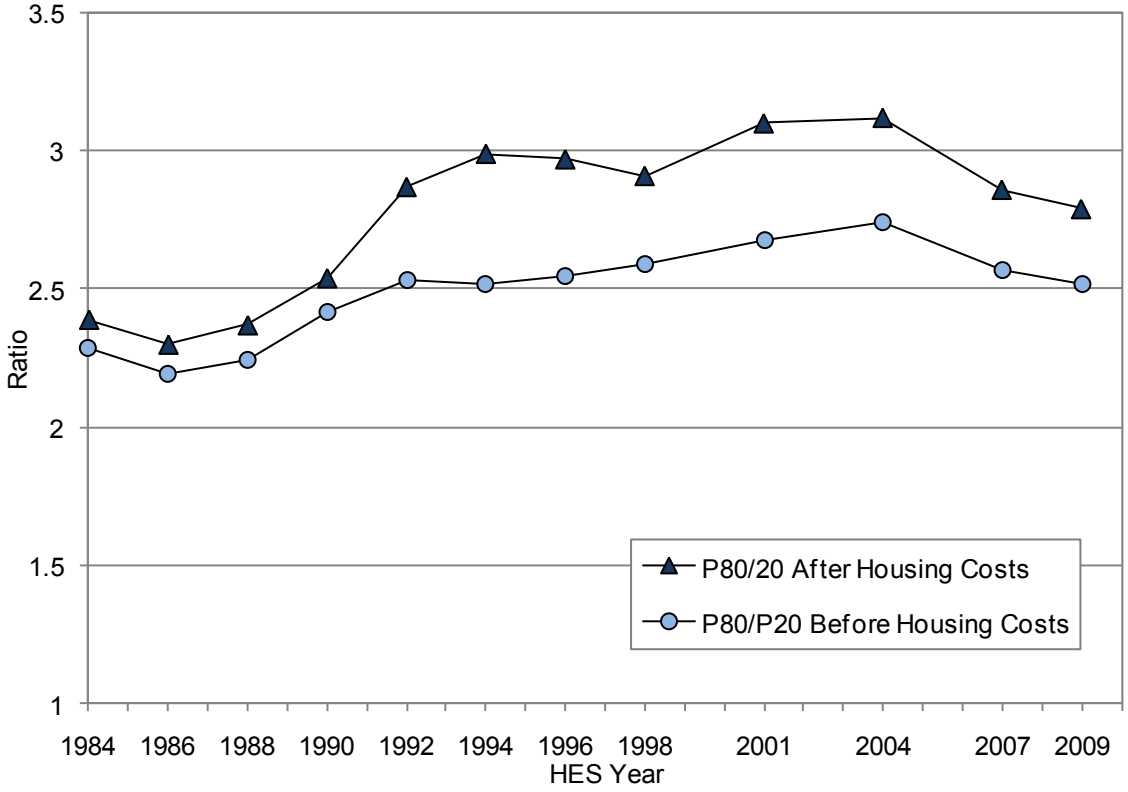
Income Inequality: Gini Coefficient

In New Zealand during 1984-2009, income inequality as measured by the Gini Coefficient, was also higher after adjusting for housing costs than prior to this adjustment. The most rapid rises in income inequality during this period also occurred between the late 1980s and early 1990s. Using both the Before and After Housing Cost measures, the Gini Coefficient declined between 2001-2007, a decline which Perry again attributes to the impact of the Working for Families Package. Perry notes however, that another year's data is required, before it is possible to determine whether the rise in income inequality seen between 2007-2009 is real, or just a statistical fluctuation [185] (**Figure 74**).

Summary

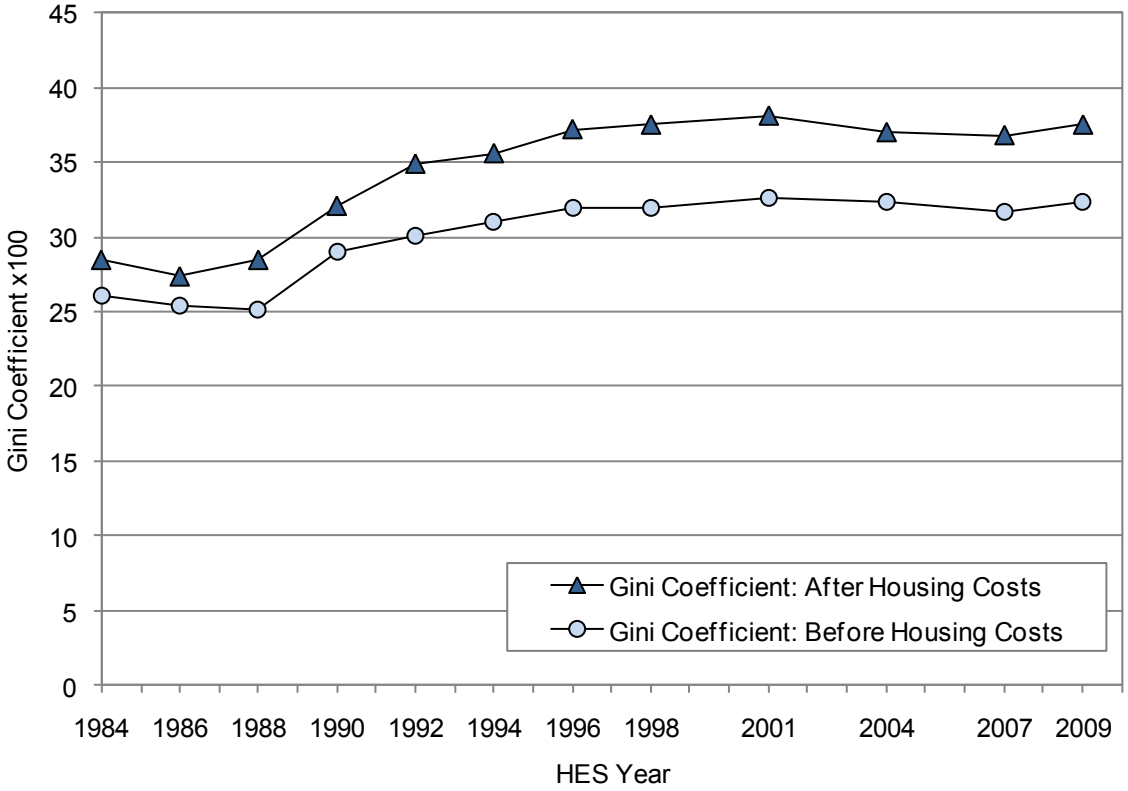
In New Zealand during 1984-2009 income inequality, as measured by the P80/P20 ratio and Gini coefficient, was higher after adjusting for housing costs than prior to this adjustment. The most rapid rises in income inequality occurred between the late 1980s and early 1990s. During the early-mid 2000s however, income inequality declined, a change Perry attributes largely to the Working for Families package. Rises in income inequality were again evident between 2007 and 2009, although another year's data may be required, before it is possible to determine whether this is the beginning of an upward trend, or just a statistical fluctuation [185].

Figure 73. Income Inequality in New Zealand as Assessed by the P80/P20 Ratio for the 1984-2009 HES Years



Source: Perry 2010 [185], derived from Statistics NZ's Household Economic Survey (1984-2009)

Figure 74. Income Inequality in New Zealand as Assessed by the Gini Coefficient for the 1984-2009 HES Years



Source: Perry 2010 [185], derived from Statistics NZ's Household Economic Survey (HES) 1984-2009

CHILD POVERTY AND LIVING STANDARDS

Introduction

High rates of child poverty are a cause for concern, as low family income has been associated with a range of negative outcomes including low birth weight, infant mortality, poorer mental health and cognitive development, and hospital admissions from a variety of causes [187]. Further, the Christchurch Health and Development Study suggests that exposure to low family income during childhood and early adolescence may increase the risk of leaving school without qualifications, economic inactivity, early parenthood and criminal activity. While adjusting for potentially mediating factors (e.g. parental education, maternal age, and sole parent status) reduces the magnitude of these associations somewhat, they do not disappear completely, suggesting that the pathways linking low family income to long term outcomes are complex, and in part may be mediated by other socioeconomic variables [188]. Yet while there is much debate about the precise pathways involved, there is a general consensus that the relationship between poverty and adverse outcomes is non-linear, with the effects increasing most rapidly across the range from partial to severe deprivation [189].

In New Zealand, the Ministry of Social Development has periodically reviewed the socioeconomic wellbeing of families with children using information from two data sources:

1. The New Zealand Household Economic Survey, which can be used to assess the proportion of families with children who live below the income poverty line [185].
2. The New Zealand Living Standards Survey, which uses the Economic Living Standards Index (NZELSI) to assess the proportion of families with children who live in severe or significant hardship [190]

The following section uses information from these two data sources to assess the proportion of New Zealand children living in poverty, or exposed to severe or significant hardship in recent years.

Children Living in Households Below the Poverty Line

Data Source and Methods

Definition

1. *Proportion of children with equivalised disposable household income < 50% or <60% current median*
2. *Proportion of children with equivalised disposable household income < 50% or <60% 2007 median (adjusted for movements in consumer prices)*

Data Source

Statistics New Zealand Household Economic Survey (NZHES n=2,800-3,500 households per survey) via Perry 2010 [185]. Note: Child Poverty measures are reported on by the Ministry of Social Development using NZHES data [185], which was available 2-yearly from 1982-1998, and 3-yearly thereafter. Since 2007, income data has become available annually through the new HES Incomes Survey. The full NZHES (including expenditure data) however remains 3-yearly. For more detail on methodology used see Perry 2010 [185].

Interpretation

Relative poverty measures set a poverty benchmark that rises and falls with changes in national median incomes (i.e. poverty is defined in relation to the incomes of others in society). Constant-value poverty measures select a median at a set point in time (e.g. 2007) and then adjust forward and back in time for changes in consumer prices (i.e. they seek to maintain a constant buying power for the poverty benchmark over time). Most income poverty measures use equivalised disposable household income (i.e. after tax household income adjusted for family size and composition). Both measures can be calculated before or after taking housing costs into account. For more detail on the methodology used see Perry 2010 [185].

Child Poverty Trends Using Different Poverty Measures

Relative Poverty (Compared to Contemporary Median)

Before Housing Costs: In New Zealand, relative child poverty rose rapidly during 1990-1992, a rise which Perry [185] attributes to rising unemployment and the 1991 Benefit Cuts (which reduced incomes for beneficiaries to a greater extent than the median fell during this period). During 1992-1998, relative child poverty rates then declined, a trend which Perry attributes to falling unemployment, occurring in a context where incomes for those around the poverty line rose more quickly than the median. After 1998 however, as economic conditions improved, median incomes again rose, while incomes for many low-income households with children did not, resulting in a rise in relative child poverty up until 2004. From 2004 to 2007 relative poverty rates again declined, a decline which Perry attributes to the roll out of the Working for Families Package. Before housing cost, relative child poverty rates in 2009 were similar to what they were in the 1980s [185] (**Figure 75**).

After Housing Costs: In New Zealand during 1982-2009, while trends in relative child poverty after adjustment for housing costs (AHC), were broadly similar to before housing cost (BHC) measures, one key difference was evident: that AHC child poverty rates in 2009 remained higher than in the 1980s, while BHC measures (for those <60% threshold) were closer to 1980s levels. In addition, during 2007-2009 using the after housing costs measure, child poverty increased from 22% to 25%. Perry [185] attributes these differences to the fact that housing costs in 2009 accounted for a higher proportion of household expenditure for low-income households, than they did in the 1980s (in 1988 16% of households in the bottom income quintile spent >30% of their income on housing; in 2008 this figure was 33%).

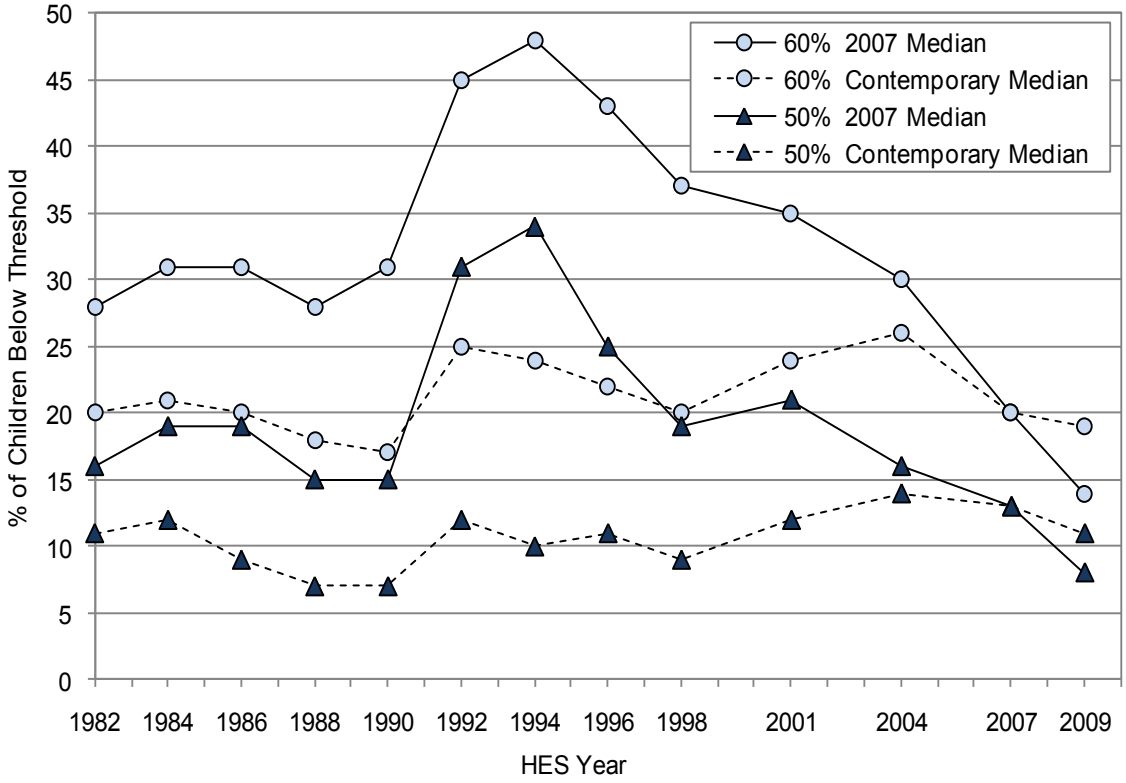
Perry notes however, that the income-related rental policies introduced in 2000, along with later changes to Accommodation Supplements, helped reduce housing expenditure for some low income households, and that these changes contributed to reductions in AHC child poverty during 2001-2007. There were no further policy changes during 2007-2009 however, with maximum rates of assistance remaining fixed, as housing costs continued to increase. As a result, net housing expenditure rose, especially for low income households and this resulted in increases in AHC child poverty rates during 2007-2009 [185] (**Figure 76**).

Fixed Line Poverty (Compared to 2007 Median)

Before Housing Costs: In New Zealand during the late 1980s and early 1990s, fixed line child poverty measures increased markedly, for similar reasons to those outlined above. During 1994-1998 however, child poverty rates declined, a trend which Perry attributes to improving economic conditions and falling unemployment. During 1998-2004, child poverty rates continued to fall, although falls were less rapid for those below the 50% threshold than the 60% threshold. Rates also fell during 2004-2007, although again the rate of decline was less marked for those below the 50% threshold, a difference Perry attributes to greater support from Working For Families for the working poor, than the beneficiary poor [185] (**Figure 75**).

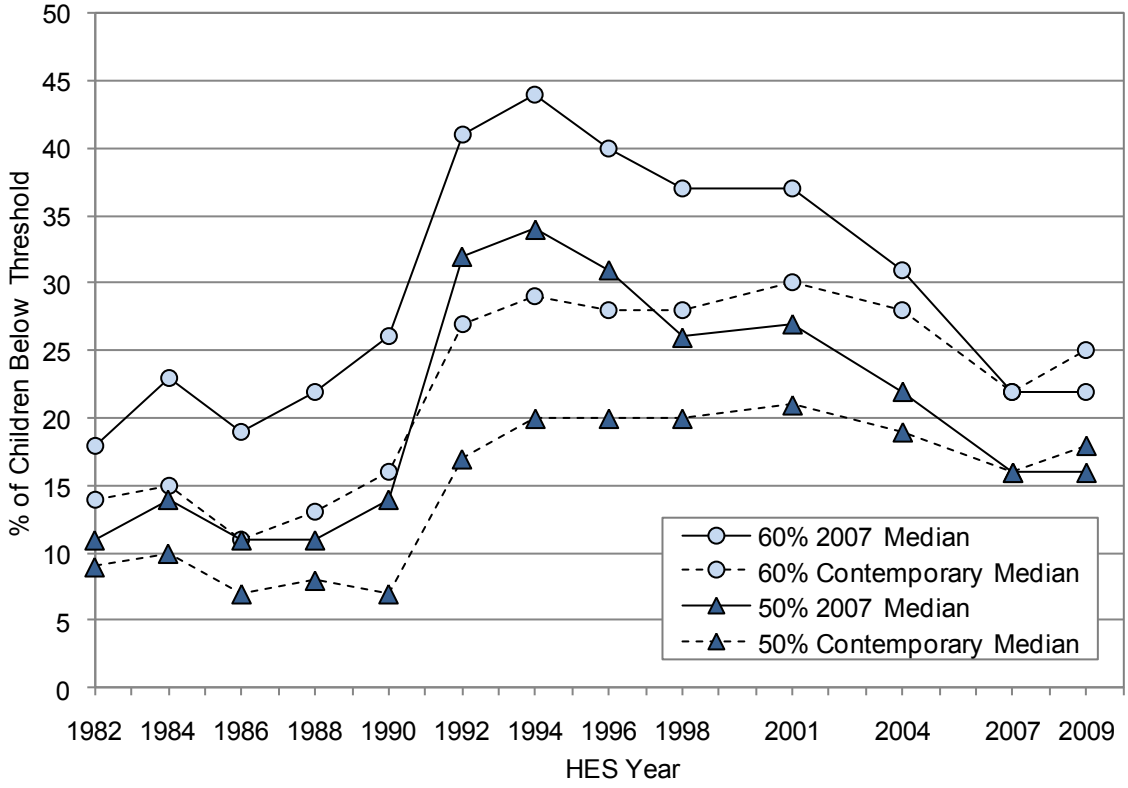
After Housing Costs: In New Zealand during 1982-2008, while trends in fixed line child poverty after adjustment for housing costs (AHC), were broadly similar to before housing cost (BHC) measures, the same key difference seen with relative poverty measures was evident: that AHC child poverty rates in 2009 remained higher than in the 1980s, while BHC measures generally returned to 1980s levels [185] (**Figure 76**).

Figure 75. Proportion of Dependent Children Aged 0-17 Years Living Below the Income Poverty Threshold (Before Housing Costs), New Zealand 1982-2009 HES Years

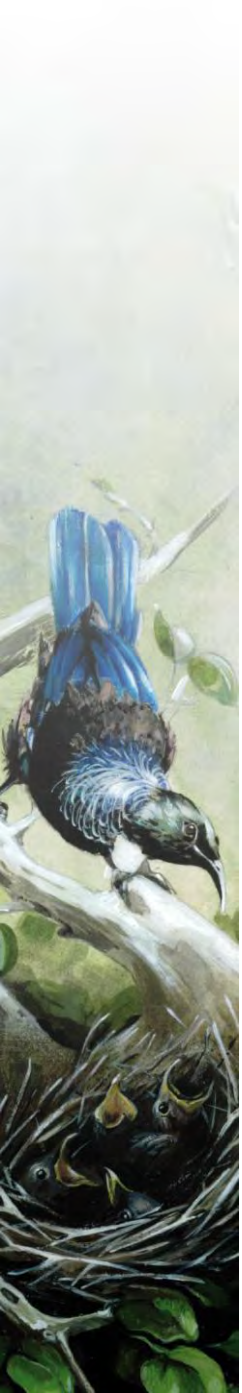


Source: Perry 2010 [185], derived from Statistics New Zealand, Household Economic Survey (HES) 1982-2009

Figure 76. Proportion of Dependent Children Aged 0-17 Years Living Below the Income Poverty Threshold (After Housing Costs), New Zealand 1982-2009 HES Years



Source: Perry 2010 [185], derived from Statistics New Zealand, Household Economic Survey (HES) 1982-2009



Child Poverty Trends: <60% of 2007 Median, After Housing Costs

Child Poverty by Number of Children in Household and Child's Age

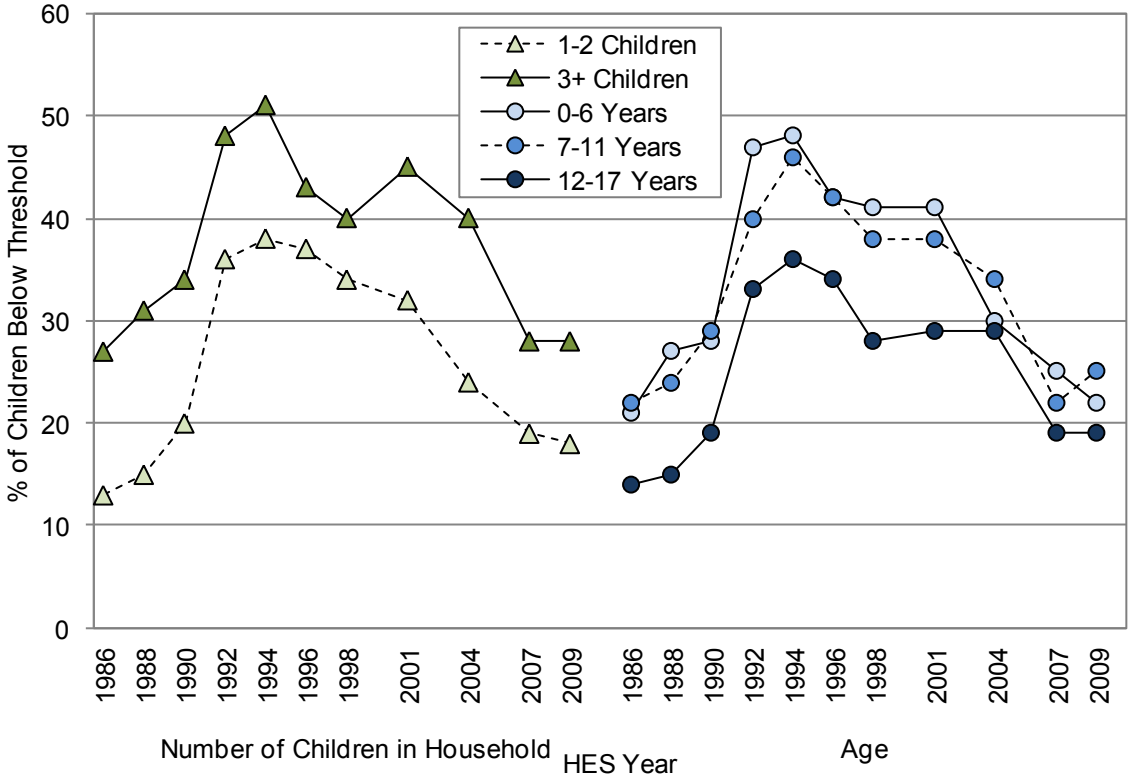
Number of Children: In New Zealand during 1986-2009, child poverty rates for households with 3+ children were consistently higher than for households with 1-2 children (**Figure 77**). (Comment: Perry notes that in 2009, children from these larger households made up 48% of all poor children [185])

Age of Children: In New Zealand during 1986-2001, poverty rates for younger children (0-6 years and 7-11 years) were higher than for older children (12-17 years). Differences after 2001 were less consistent [185] (**Figure 77**).

Child Poverty Trends by Household Type and Work Status of Adults in Household

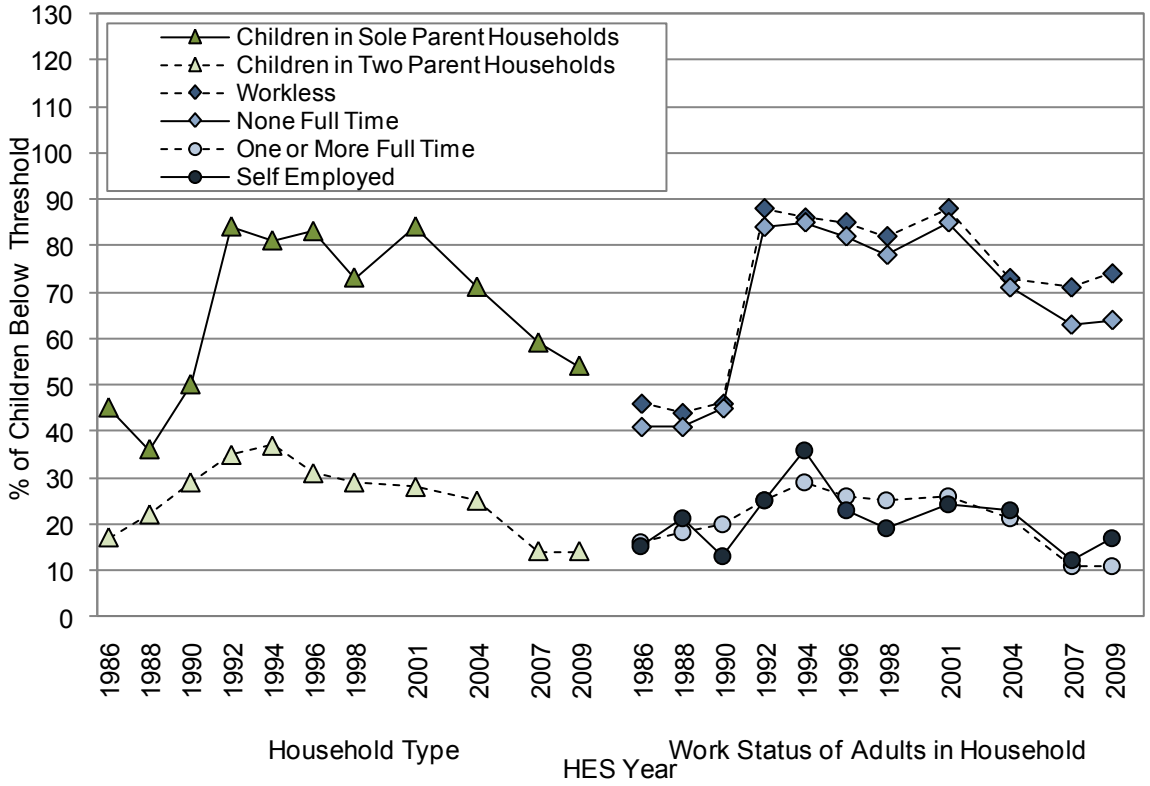
Household Type: In New Zealand, child poverty rates for children in both sole-parent and two-parent households increased rapidly between 1988 and 1992. In absolute terms however, poverty rose most rapidly for children in sole-parent households, with rates reaching a peak of 84% in 1992 (two-parent: rates peaked at 37% in 1994). While rates for both household types declined between 2001 and 2007, during 2007-2009 child poverty rates for those in sole-parent households remained higher than their 1980s levels, while rates for two-parent households were similar (**Figure 78**). (Comment: Perry notes that ≈1/3 sole parent *families* live in wider *households* with other adults, and that children living in these "other" households have significantly lower poverty rates than those living in sole parent households, because of the greater household resources available to them [185]).

Figure 77. Proportion of Dependent Children Living Below the 60% Income Poverty Threshold (2007 Median, After Housing Costs) by Number of Children in Household and Age, New Zealand 1986-2009 HES Years



Source: Perry 2010 [185], derived from Statistics New Zealand, Household Economic Survey (HES) 1986-2009

Figure 78. Proportion of Dependent Children Living Below the 60% Income Poverty Threshold (2007 Median, After Housing Costs) by Household Type and Work Status of Adults in the Household, New Zealand 1986-2009 HES Years



Source: Perry 2010 [185], derived from Statistics New Zealand, Household Economic Survey (HES) 1986-2009

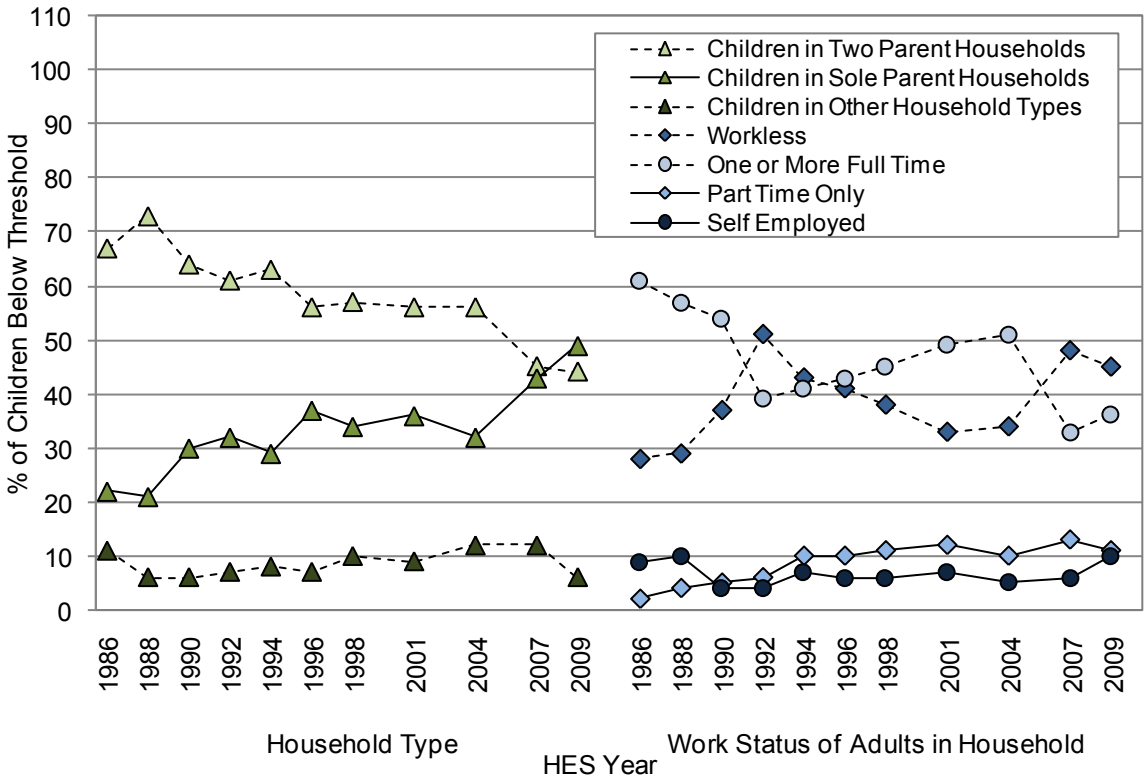
Work Status of Adults in Household: In New Zealand, child poverty rates for children in workless households, or where no adults worked full time, increased rapidly during 1988-1992. Poverty rates for children in these households remained elevated during the 1990s (range 78%-88%), before declining during 2001-2007. Even at their nadir in 2007, poverty rates for children in these households remained much higher than 1980s levels. In contrast, increases in child poverty for households where an adult worked full time, or was self employed, were much less marked, with rates in 2007-2009 being similar to those in the 1980s (**Figure 78**). (Comment: Perry notes that during the 1980s, children in workless households were ≈2x as likely to be in poor households; during 1992-2004 this had risen to ≈ 3-4x higher, and by 2007-2009 it was ≈ 6-7x higher [185]).

Composition of Children Living in Poverty by Household Type and Work Status of Adults in Household

Household Type: In New Zealand during 1988-2009, the proportion of children living in poverty who were from two-parent households declined, while the proportion who were in one-parent households increased. Thus by 2009, 49% of all children living in poverty were in one-parent households, as compared to 21% in 1988 (**Figure 79**).

Work Status of Adults in Household: In New Zealand during 1986, the highest proportion of children living in poverty came from families where at least one adult worked full time. During 1988-1992 however, the proportion of children living in poverty who were from households where at least one adult worked full time declined markedly, while the proportion of children from workless households increased, so that by 1992 children from workless families made the greatest contribution to those living in poverty. During the 1990s however, these trends reversed, so that by 2004 a greater proportion of children living in poverty again came from households where at least one adult worked. Following the introduction of the Working for Families package, these trends reversed yet again. Thus during 2008-2009, the highest proportion of children living in poverty came from workless households (**Figure 79**).

Figure 79. Composition of Dependent Children Living Below the 60% Income Poverty Threshold (2007 Median, After Housing Costs) by Household Type and Work Status of Adults in the Household, New Zealand 1986-2009 HES Years



Source: Perry 2010 [185], derived from Statistics New Zealand, Household Economic Survey (HES) 1986-2009: Note: Totals in each category sum to 100% of children living below poverty line.

Summary: Child Poverty

In New Zealand during 1988-1992, child poverty rates increased markedly, as a result of rising unemployment and the 1991 Benefit cuts. During 1994-1998 however, rates declined, as economic conditions improved and unemployment fell. During 1998-2004, child poverty trends varied, depending on the measure used, but between 2004 and 2007 they again declined, following the roll out of the Working for Families package. For the majority of this period, child poverty rates were higher for younger children (0-11 vs. 12-17 years), larger households (3+ children vs. 1-2 children), sole parent households and households where the adults were either workless, or where none worked full time.

Families with Reduced Living Standards

The Ministry of Social Development has undertaken 3 Living Standards Surveys, in 2000, 2004 and 2008. At the time of writing some preliminary findings from the 2008 Living Standards Survey are available [191], but the full results are yet to be published. In brief, the preliminary analyses from the 2008 Survey suggested that:

1. The proportion of children living in hardship (ELSI Levels 1-2) had fallen from 26% to 19% between 2004 and 2008
2. Most of these gains were for low to middle income working families, with hardship rates for sole parent beneficiary families remaining steady at around 55%
3. Hardship rates for sole parent families were around 4 times those for two parent families (39% vs. 11%)
4. Beneficiary families with dependent children had hardship rates around 5 times those of working families with children (50% vs. 11%), but as there were many times more working families than beneficiary families, half of children in hardship were from working families and half from beneficiary families

5. Sole parent families in work (20%) had hardship rates well below sole parent beneficiary families (54%)
6. Although hardship rates for children had fallen, children remained significantly over represented in the hardship group

It is anticipated that a full analysis of the 2008 Living Standards Survey will be released in the next few months. In the meantime, the key results of the 2004 Living standards survey, as they relate to families with children, are presented below. When interpreting the data in this section, the reader must bear in mind that these findings may not fully reflect the current situation, with any differences likely to be along the lines of the preliminary findings outlined above.

Data Source and Methods

Definition
Distribution of Families with Dependent Children by the NZ Economic Living Standards Index (NZELSI)

Data Source
The Ministry of Social Development's 2004 Living Standards Report [190]

Interpretation
The Economic Living Standard Index (ELSI) uses information on 40 items, which individually have a strong relationship with living standards (e.g. household amenities, personal possessions, access to services, and adequacy of income to meet everyday needs). The 2004 Living Standards Survey used the ELSI to survey a probabilistic sample of New Zealand residents aged 18+ years in March and June 2004. A total of 4,989 respondents answered on behalf of their family units, giving a response rate of 62.2%. The results in this section relate to the living standards of families with dependent children, with the level of analysis being the economic family unit, rather than the individual child. A more detailed discussion of the methodology used and the limitations of this survey can be found in the New Zealand Living Standards 2004 Report [190].

2004 Living Standards Survey

Living Standards by Family Type and Income Source

In the 2004 Living Standards Survey, 30% of all economic family units contained dependent children. While only 10% of family units without children were living in severe or significant hardship, this figure rose to 22% for families with dependent children.

The proportion living in severe or significant hardship also varied with family type and income source, with 42% of sole-parent families being classified as living in severe or significant hardship, as compared to only 14% of two–parent families. Similarly, 58% of families who relied on income tested benefits were classified as living in severe or significant hardship, as compared to 12% of families receiving their income from market sources. Further analysis however, suggested that the difference in living standards between sole and two-parent families was largely due to the former's greater reliance on benefits as their main source of family income [190] (**Figure 80**).

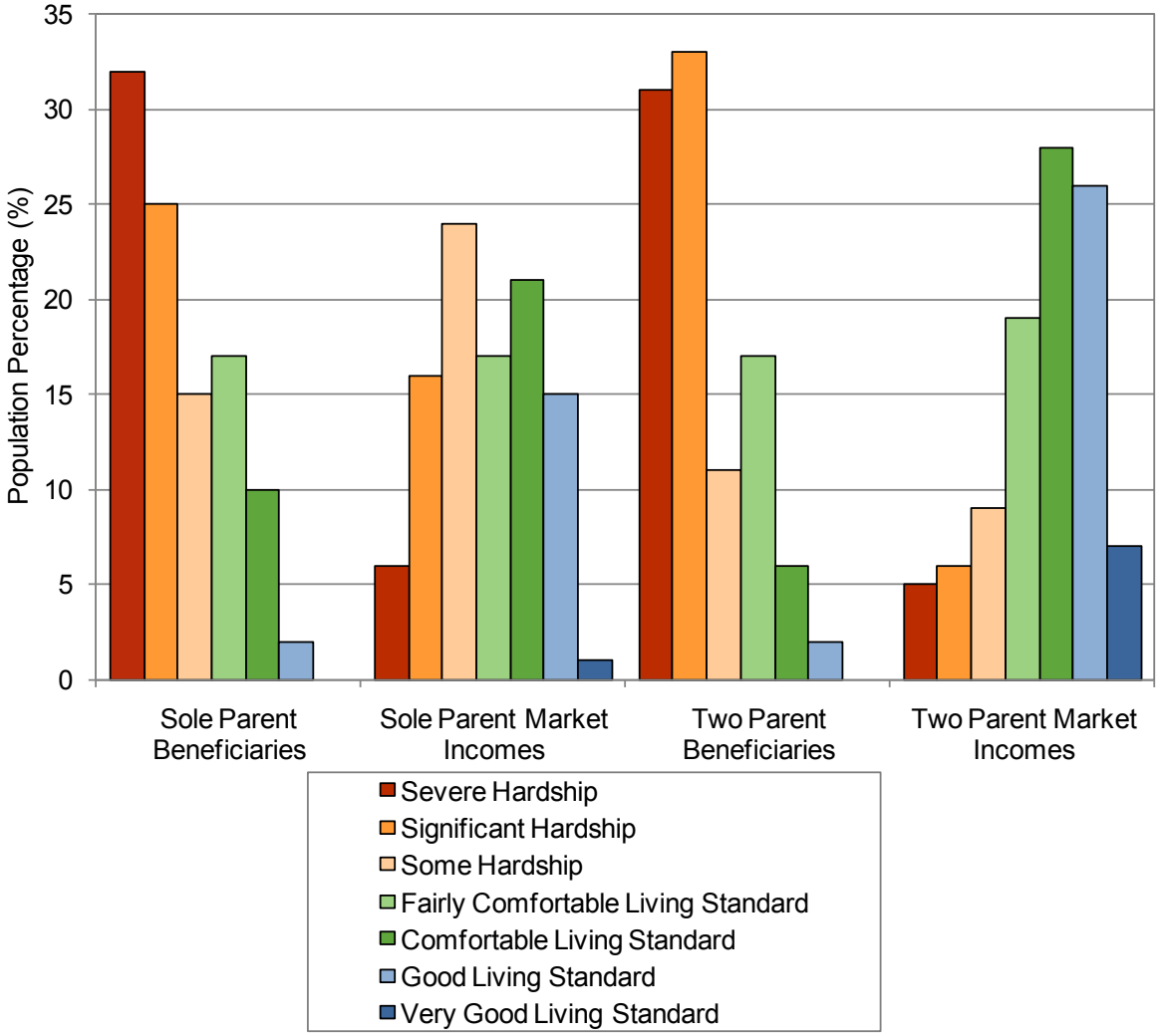
Living Standards by Ethnicity of Family Members

The 2004 Living Standards Survey also noted that European and Other families with dependent children had higher average living standards (37.6 and 38.4 respectively) than Pacific and Māori families with dependent children (25.3 and 31.6 respectively). Of note, 30% of all Pacific families with dependent children in the 2004 Survey reported living in severe hardship, as compared to 20% of Māori families, 8% of European families and 4% of Other families (**Figure 81**).

Constraints Placed on Children's Consumption by their Families Living Standards

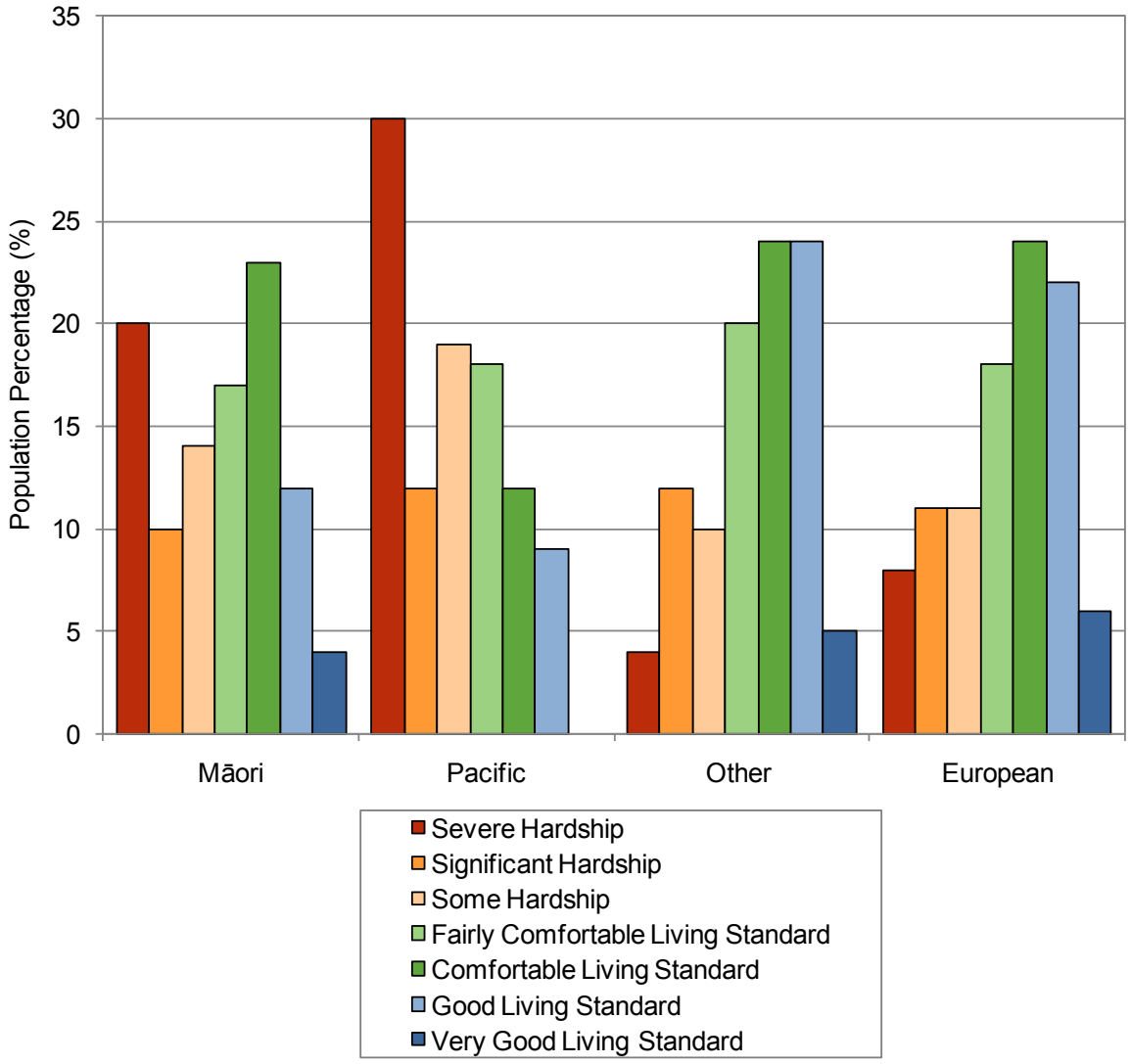
The 2004 Living Standards Survey also explored the constraints placed on children's consumption arising from their families living standards and noted that of children living in severe hardship, 51% had to go without suitable wet weather gear, 38% were unable to have a friend over for a meal, and 34% were unable to have friends over for a birthday party because of the cost. In addition, 46% of parents had postponed a child's doctor's visit and 36% had postponed a child's dentist's visit because of cost, and in 40% of cases children had to share a bed [190] (**Table 75**).

Figure 80. Living Standards Distribution of Families with Dependent Children by Family Type and Income Source, New Zealand Living Standards Survey 2004



Source: NZ Living Standards Survey [190].

Figure 81. Living Standards Distribution of Families with Dependent Children by Family Ethnicity, New Zealand Living Standards Survey 2004



Source: NZ Living Standards Survey [190]; Family Ethnicity is based on total responses to the ethnicity question e.g. if any adult or child specified Pacific as one of their ethnicities, the family is counted as Pacific – thus these ethnic groupings are not mutually exclusive.

Table 75. Constraints on Children's Consumption by their Family's Standard of Living, New Zealand Living Standards Survey 2004

Category	Severe Hardship (Level 1)	Some Hardship (Level 3)	Good / Very Good Living Standards (Level 6 & 7)
Items Not Obtained / Not Participated in Because of Cost (% of Respondents)			
Suitable Wet Weather Clothing for Each Child	51	13	2
A Pair of Shoes in Good Condition	35	5	0
Child's Bike	45	10	1
Play Station or Xbox	37	10	1
Personal Computer	55	23	1
Internet Access	51	23	0
Pay for Childcare	35	15	2
Have Child's Friends Over for a Meal	38	6	0
Enough Room for Child's Friends to Stay the Night	35	9	0
Have Child's Friends to a Birthday Party	34	11	1
Items of Consumption Cut Back on (a Little or a Lot) Because of Cost (% of Respondents)			
Not Gone on School Outings	66	26	0
Not Bought School Books / Supplies	49	19	0
Not Bought Books for Home	61	33	1
Postponed Child's Visit to Doctor Because of Cost	46	20	1
Postponed Child's Visit to Dentist Because of Cost	36	20	1
Child Went Without Glasses	15	10	0
Child Went Without Cultural Lessons	55	40	4
Child's Involvement in Sports Limited	66	40	1
Child Wore Poorly Fitting Clothes or Shoes	65	33	1
Children Share a Bed	40	7	0
Limited Space for Child to Study or Play	72	34	1

Source: NZ Living Standards Survey [190].

Summary: Living Standards

The Ministry of Social Development has undertaken 3 Living Standards Surveys, in 2000, 2004 and 2008. At the time of writing some preliminary findings from the 2008 Living Standards Survey are available [191], which suggest that:

1. The proportion of children living in hardship (ELSI Levels 1-2) has fallen from 26% to 19% between 2004 and 2008
2. Most of these gains were for low to middle income working families, with hardship rates for sole parent beneficiary families remaining steady at around 55%
3. Hardship rates for sole parent families were around 4 times those for two parent families (39% vs. 11%)
4. Beneficiary families with dependent children had hardship rates around 5 times those of working families with children (50% vs. 11%), with half of children in hardship being from working families and half from beneficiary families
5. Sole parent families in work (20%) had hardship rates well below sole parent beneficiary families (54%)
6. Although hardship rates for children had fallen, children remained significantly over represented in the hardship group

UNEMPLOYMENT RATES

Introduction

In the quarter ending December 2009, seasonally adjusted unemployment rates rose to 7.1%, their eighth consecutive quarterly rise. Since this time rates have fluctuated, with rates falling to 6.0% in March 2010, before increasing to 6.8% in June and then falling again to 6.4% in September 2010 [192]. During this period, unemployment rates have been higher for Māori and Pacific people, young people (particularly those 15-19 years) and those without formal qualifications [193]. Such increases are of concern for New Zealand children and young people two reasons:

Firstly, research suggests that children in families where their parents are unemployed have higher rates of psychosomatic symptoms, chronic illnesses and low wellbeing, and that while the magnitude of these associations is reduced once other potentially mediating factors are taken into account (e.g. parents' former occupation, sole parent status, and migrant status), the associations do not disappear completely [194]. Further, research suggests that these negative effects may be mediated via the impact unemployment has on parents' mental health, with the mental distress associated with decreased social status, disruption of roles, loss of self esteem and increased financial strain, all impacting negatively on parents' emotional state [194]. This in turn may lead to non-supportive marital interactions, compromised parenting, and children's internalising (e.g. withdrawal, anxiety, depression) and externalising (e.g. aggressive or delinquent behaviour, substance abuse) behaviour [195].

Secondly, for young people research suggests that unemployment leads to a range of negative psychological outcomes including depression, anxiety and low self esteem, which are in turn associated with adverse outcomes such as heavy tobacco, alcohol and drug use; and higher mortality from suicide and accidents [196]. While social support may reduce the psychological distress associated with unemployment, the type of support provided is important (e.g. while positive support from family and friends decreases psychological distress amongst unemployed youth, parental advice may at times increase distress, as it may be perceived as pressure to find a job [196]). On a more positive note, research also suggests that this psychological distress decreases once young people find permanent employment, or return to further education [196].

The following section uses information from Statistics New Zealand's Quarterly Household Labour Force Surveys, to review unemployment rates during the past two decades.

Data Source and Methods

Definition

Unemployment Rate: The number of unemployed people expressed as a percentage of the labour force.

Data Source

Statistics New Zealand, Household Labour Force Survey (n≈15,000 households). Quarterly Since March 1986 and available on Statistics New Zealand's website www.stats.govt.nz

Indicator Category: Proxy B

Notes on Interpretation

Unemployed refers to all people in the working-age population who during the reference week were without a paid job, were available for work and [197]:

(a) had actively sought work in the past four weeks ending with the reference week, or

(b) had a new job to start within four weeks

Note 1: A person whose only job search method in the previous four weeks has been to look at job advertisements in the newspapers is not considered to be actively seeking work.

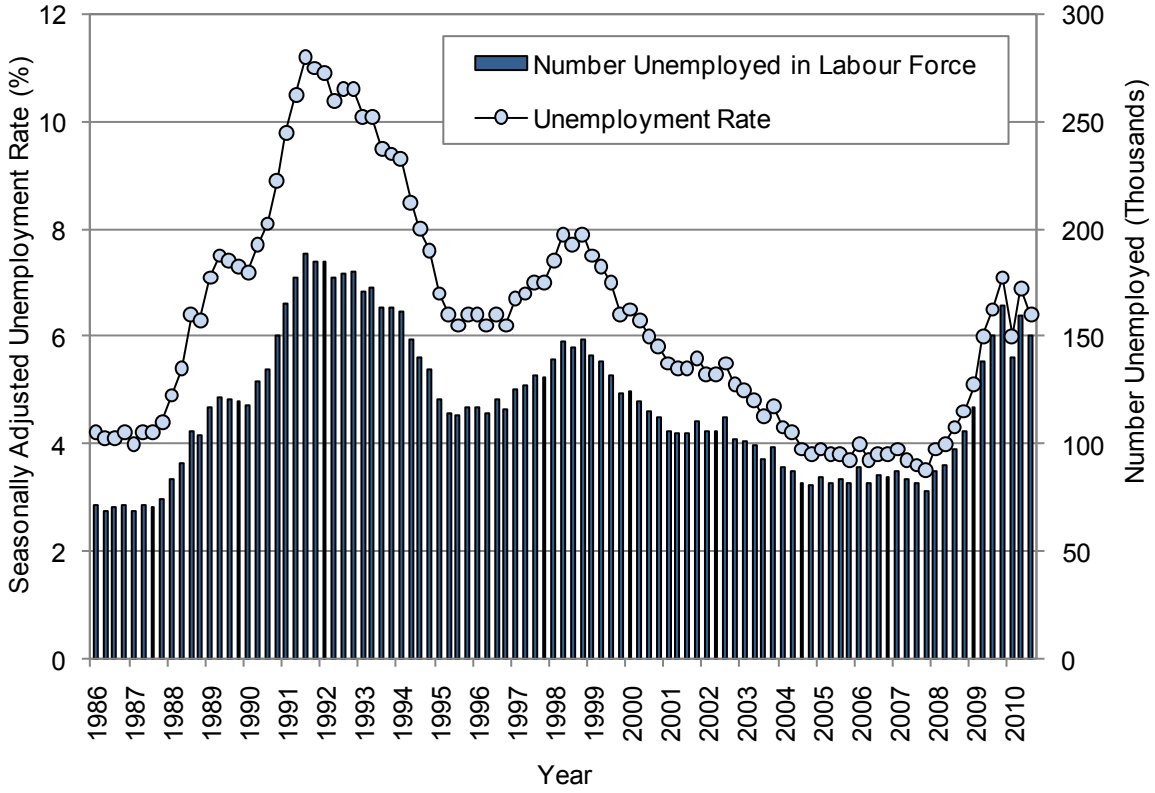
Note 2: Seasonal adjustment makes data for adjacent quarters more comparable by smoothing out the effects of any regular seasonal events. This ensures the underlying movements in time series are more visible. Each quarter, the seasonal adjustment process is applied to the latest and all previous quarters. This means that seasonally adjusted estimates for previously published quarters may change slightly [197].

New Zealand Distribution and Trends

Seasonally Adjusted Unemployment Rates

In the quarter ending September 2010, the seasonally adjusted unemployment rate fell to 6.4%, with seasonally adjusted unemployment numbers decreasing by 10,000 to 150,000 (**Figure 82**). The number of people employed increased by 23,000, with a larger increase being seen for males (1.9%) than for females (0.1%) [192].

Figure 82. Seasonally Adjusted Unemployment Rates, New Zealand Quarter 1 (March) 1986 to Quarter 3 (September) 2010



Source: Statistics New Zealand, Household Labour Force Survey; Rates Have Been Seasonally Adjusted

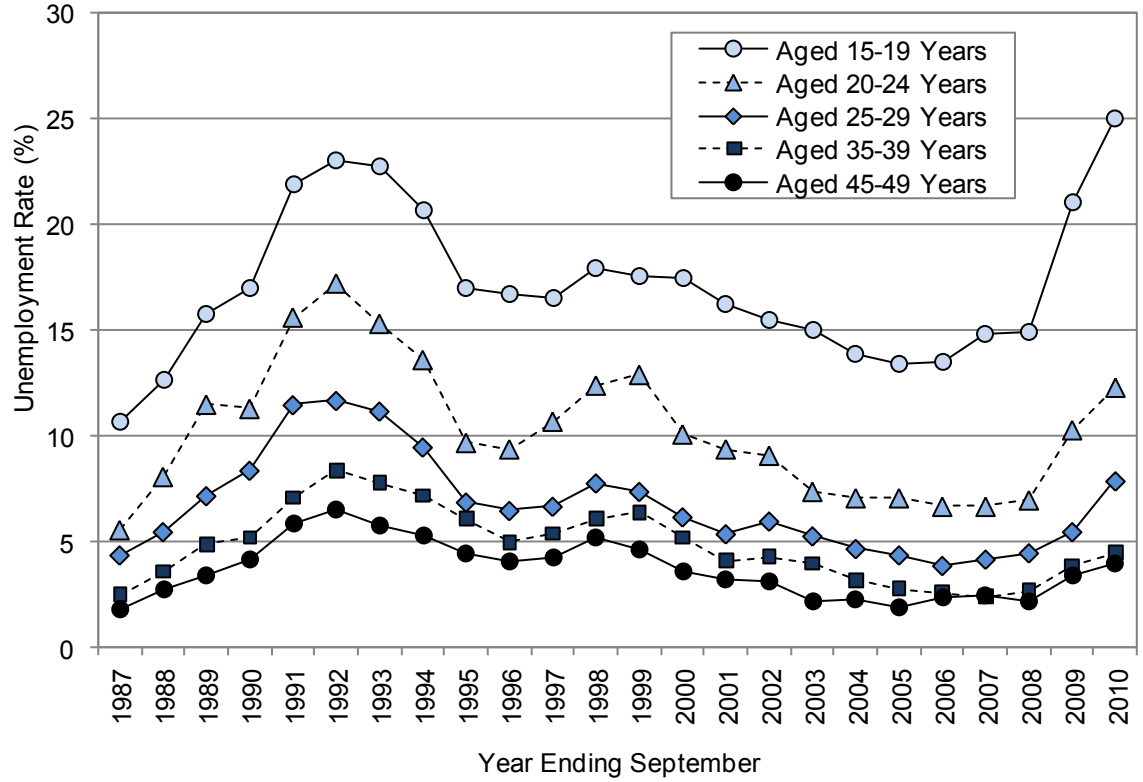
Unemployment Rates by Age

In New Zealand during September 1987-2010, unemployment rates were consistently higher for younger people (15-19 years > 20-24 years > 25-29 years > 35-39 years and 45-49 years). During the year ending September 2010, annual unemployment rates rose to 25.0% for those aged 15-19 years and to 12.3% for those aged 20-24 years (**Figure 83**).

Unemployment Rates by Age and Gender

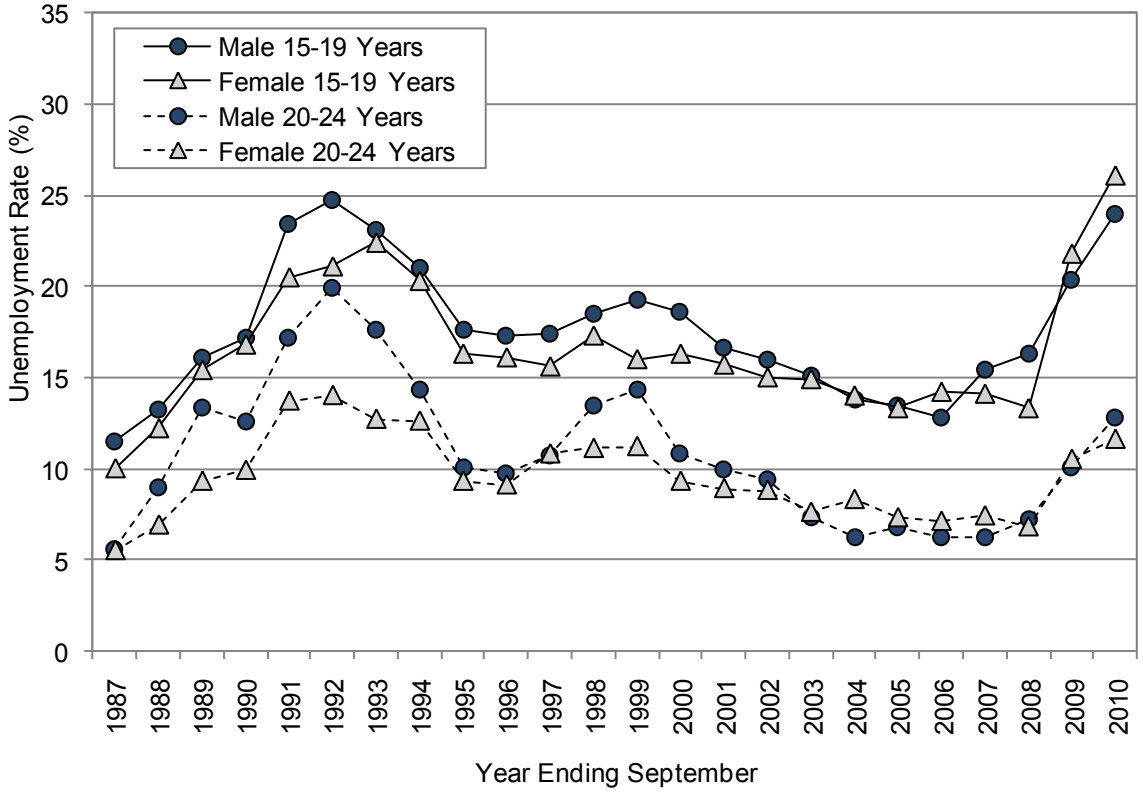
In New Zealand during 1987-2010, there were no consistent gender differences in annual unemployment rates amongst young people aged 15-24 years. During the year ending September 2010, unemployment rates for those aged 15-19 years were 26.1% for females and 24.0% for males, while for those aged 20-24 years, rates were 11.6% for females and 12.8% for males (**Figure 84**).

Figure 83. Annual Unemployment Rates by Age (Selected Age Groups), New Zealand September 1987-2010



Source: Statistics New Zealand Household Labour Force Survey.

Figure 84. Annual Unemployment Rates by Age and Gender in New Zealand Young People Aged 15-24 Years, September 1987-2010



Source: Statistics New Zealand Household Labour Force Survey.

Unemployment Rates by Ethnicity

In New Zealand during 2007(Q4)-2010(Q3) unemployment rates were consistently higher for Māori and Pacific > Asian > European people. While unemployment rates increased for all ethnic groups, in absolute terms, increases were greatest for Māori and Pacific people. Thus by 2010(Q3), unemployment rates were 13.4% for Māori, 13.8% for Pacific, 8.2% for Asian and 4.7% for European people (**Figure 85**).

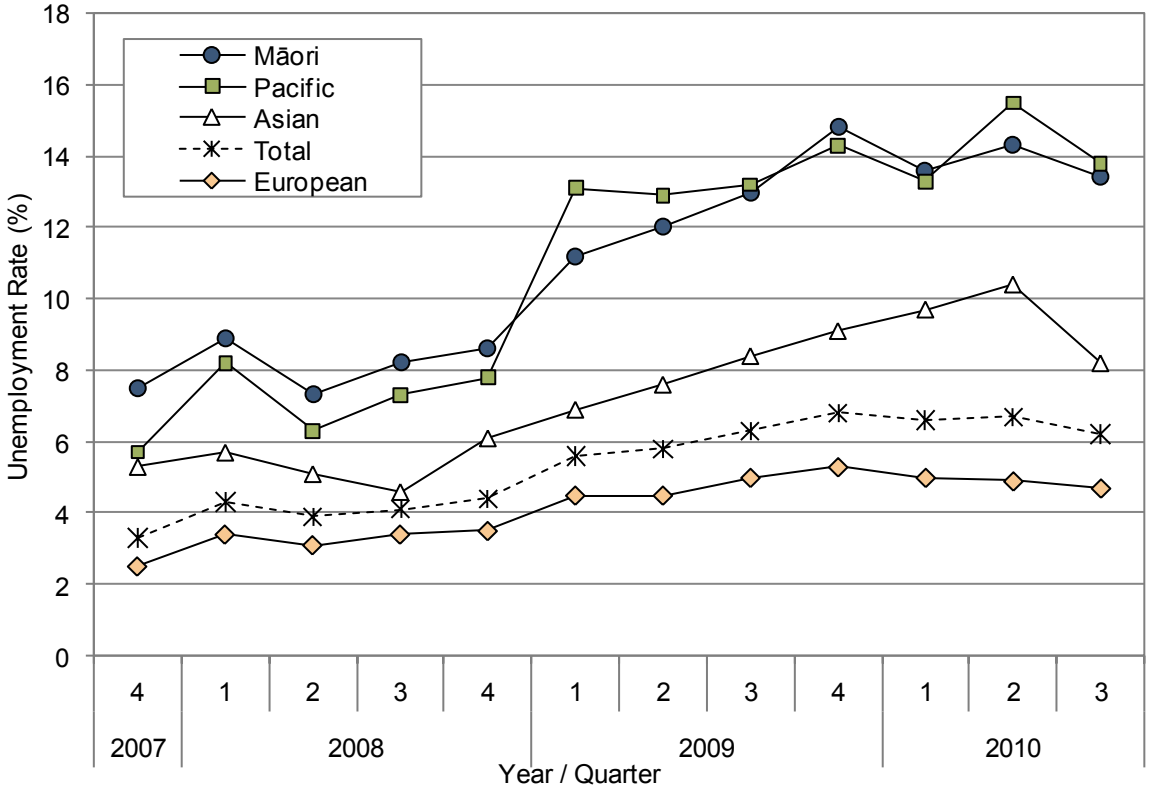
Unemployment Rates by Qualification

In New Zealand during the years ending September 1987-2010, unemployment rates were higher for those with no qualifications > school qualifications, or post school but no school qualifications > both post school and school qualifications. In the year ending September 2010, unemployment rates were 10.6% for those with no qualifications, 8.0% for those with a school qualification, 7.5% for those with post school but no school qualifications and 4.4% for those with both post school and school qualifications (**Figure 86**).

Duration of Unemployment

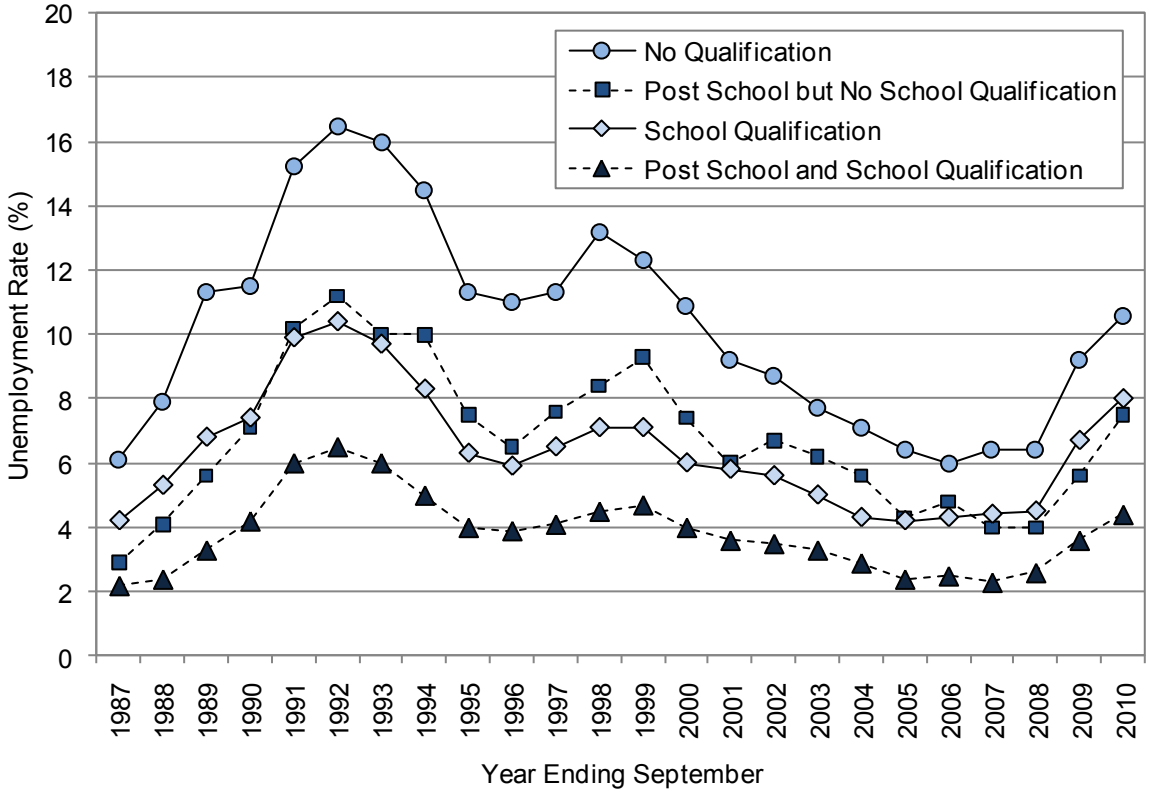
In New Zealand during the years ending September 1987-2010, duration of unemployment varied markedly, and in a manner consistent with prevailing unemployment rates. Thus the highest proportion of people unemployed for 53+ weeks occurred during the early / mid 1990s, when unemployment rates were at their peak, while the highest proportion unemployed for only 1-4 weeks occurred in the mid-2000s, when unemployment rates were at their lowest (**Figure 87**).

Figure 85. Quarterly Unemployment Rates by Total Response Ethnicity, New Zealand Quarter 4 (December) 2007 to Quarter 3 (September) 2010



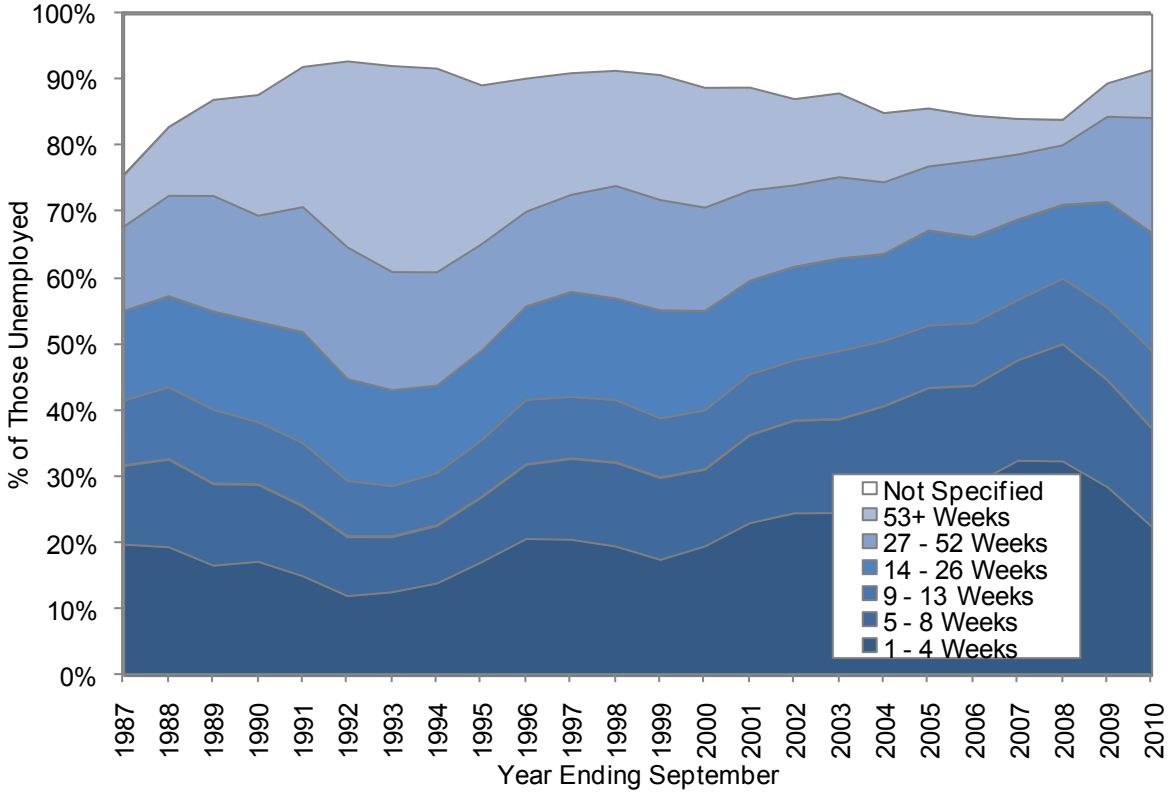
Source: Statistics New Zealand Household Labour Force Survey. Note: Ethnicity is Total Response.

Figure 86. Annual Unemployment Rates by Qualification, New Zealand September 1987-2010



Source: Statistics New Zealand Household Labour Force Survey

Figure 87. Proportion of those Unemployed by Duration of Unemployment, New Zealand September 1987-2010



Source: Statistics New Zealand Household Labour Force Survey

Regional Trends

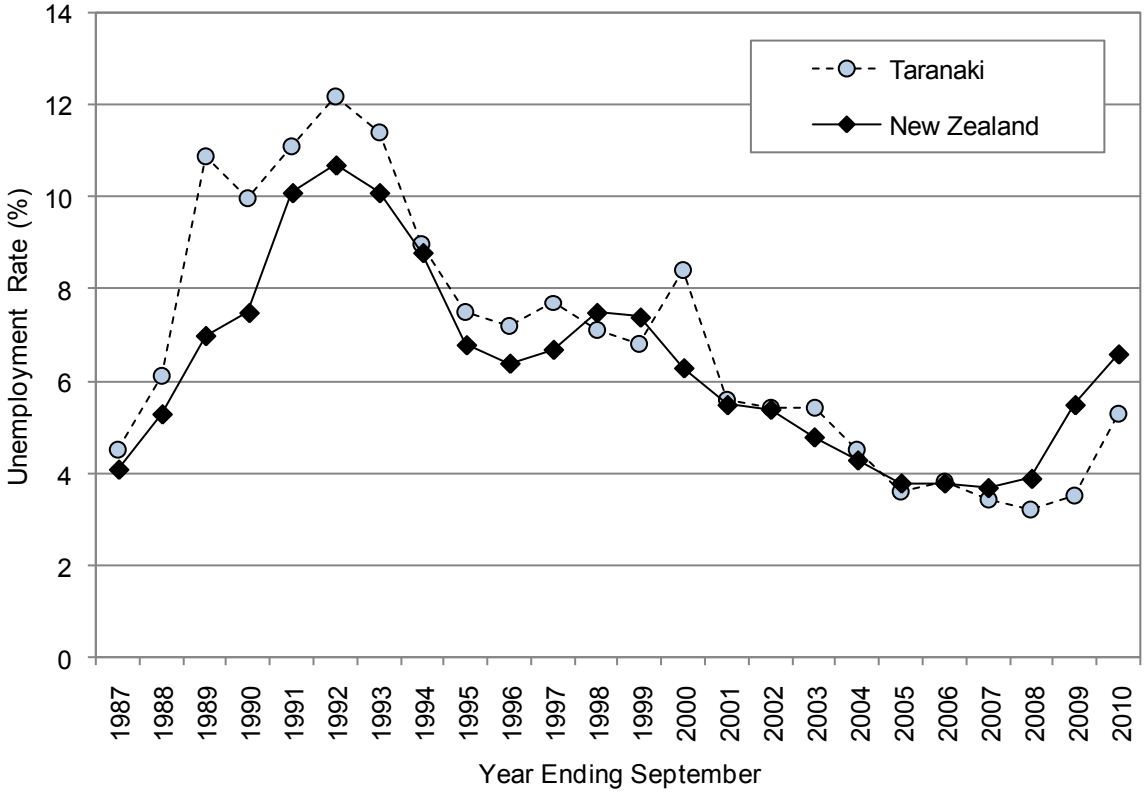
Regional Unemployment Rates: Annual

In Taranaki during the years ending September 1987-2010, unemployment trends were similar to those occurring nationally, with the highest rates being seen in the year ending September 1992, when they peaked at 12.2%. During the 2000s, rates reached their lowest point, at 3.2% in the year ending September 2008, before climbing again to 5.3% in the year ending September 2010 (**Figure 88**).

Regional Unemployment Rates: Quarterly

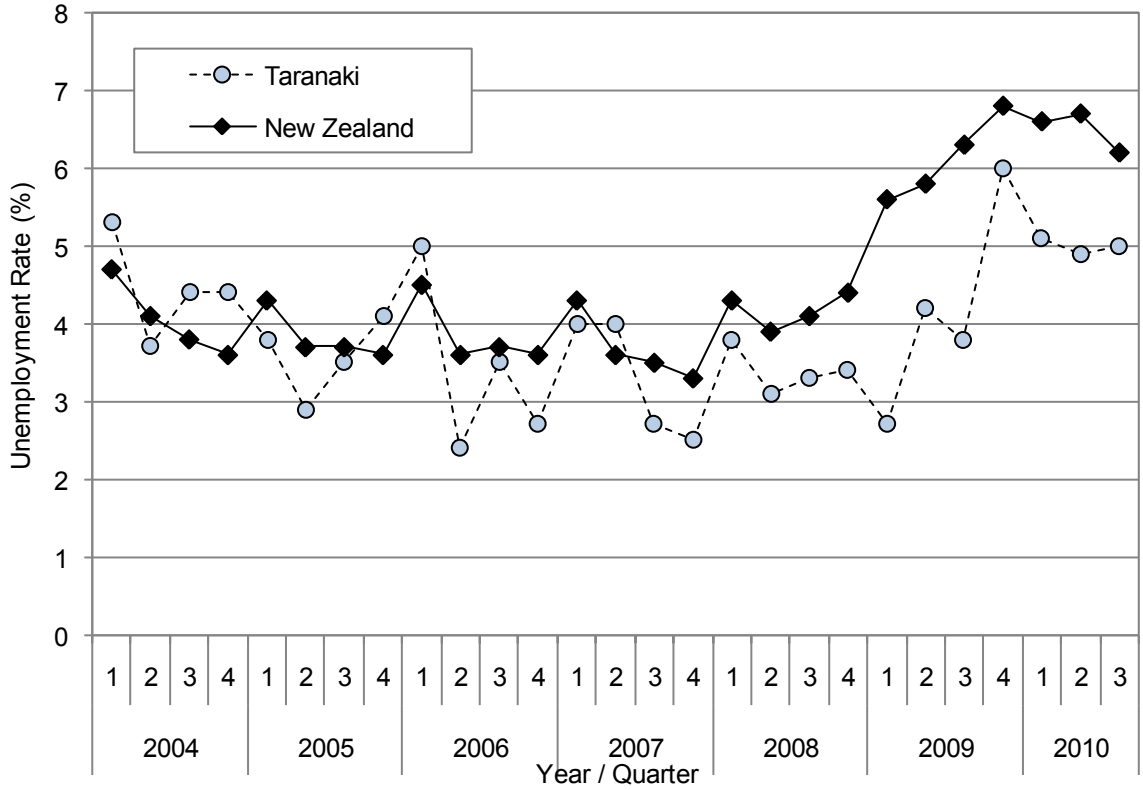
In Taranaki during 2004(Q1)-2009(Q1) unemployment rates fluctuated, but began to rise thereafter, reaching 6.0% by 2009(Q4) before declining again to 5.0% in 2010(Q3). During 2008-2010(Q3), unemployment rates in Taranaki were lower than the New Zealand average (**Figure 89**).

Figure 88. Annual Unemployment Rates by Regional Council, Taranaki Region vs. New Zealand Years Ending September 1987-2010



Source: Statistics New Zealand Household Labour Force Survey.

Figure 89. Quarterly Unemployment Rates by Regional Council, Taranaki Region vs. New Zealand Quarter 1 (March) 2004 to Quarter 3 (September) 2010



Source: Statistics New Zealand Household Labour Force Survey.

Summary

In New Zealand in the quarter ending September 2010, seasonally adjusted unemployment fell to 6.4%, with seasonally adjusted unemployment numbers decreasing by 10,000 to 150,000. During September 1987-2010, unemployment rates were higher for younger people (15-19 years > 20-24 years > 25-29 years > 35-39 years and 45-49 years) and those with no qualifications > school qualifications, or post school but no school qualifications > both post school and school qualifications, although there were no consistent gender differences for young people 15-24 years. During 2007(Q4)-2010(Q3) unemployment rates were higher for Māori and Pacific > Asian > European people. While unemployment rates increased for all ethnic groups, in absolute terms, increases were greatest for Māori and Pacific people.

In Taranaki during the years ending September 1987-2010, unemployment trends were similar to those occurring nationally, with the highest rates being seen in the year ending September 1992, when they peaked at 12.2%. During the 2000s, rates reached their lowest point, at 3.2% in the year ending September 2008, before climbing again to 5.3% in the year ending September 2010. On a quarterly basis, during 2004(Q1)-2009(Q1) unemployment rates fluctuated, but began to rise thereafter, reaching 6.0% by 2009(Q4) before declining again to 5.0% in 2010(Q3). During 2008-2010(Q3), unemployment rates in Taranaki were lower than the New Zealand average.

CHILDREN RELIANT ON BENEFIT RECIPIENTS

Introduction

In New Zealand, children who are reliant on benefit recipients are a particularly vulnerable group. During 2009, 75% of all households (including those with and without children) relying on income-tested benefits as their main source of income were living below the poverty line (housing adjusted equivalent disposable income <60% of 2007 median) [198]. This proportion has increased over the past two decades, rising from 39% of benefit dependent households in 1990, to a peak of 76% in 1994, and then remaining in the low-mid 70s ever since [198], with these trends being attributed to three main factors: cuts in the level in income support during 1991, growth in unemployment (which peaked at 11% in 1991) and escalating housing costs, particularly for those in rental accommodation [199].

The vulnerability of benefit dependent children was further highlighted by the 2000 Living Standards Survey, which noted that even once the level of family income was taken into account, families whose main source of income was Government benefits were more likely to be living in severe or significant hardship and as a consequence, more likely to buy cheaper cuts of meat, go without fruit and vegetables, put up with feeling cold to save on heating costs, make do without enough bedrooms, have children share a bed, postpone a child's visit to the doctor or dentist, go without a computer or internet access and limit their child's involvement in school trips, sports and extracurricular activities [199]. The 2004 Living Standards Survey suggested that the picture may have worsened between 2000 and 2004, with the proportion of benefit dependent families living in severe or significant hardship increasing from 39% in 2000 to 58% in 2004 [190].

The following section reviews the number of children aged 0-18 years who were dependent on benefit recipients during April 2000-2010, using information from the Ministry of Social Development's SWIFTT database. While the number of children reliant on benefit recipients does not correlate precisely with the number living below the poverty line (in 2004 they comprised 60% of those in poverty [200]), in the context of New Zealand's recent rise in unemployment rates, they nevertheless reflect a particularly vulnerable group, who may have higher health needs, and as a consequence, may impact increasingly on future health service demand.

Data Source and Methods

Definition

Children Reliant on a Benefit or a Benefit Recipient by Benefit Type

Data Source

Numerator: Number of Children Aged 0-18 years who were reliant on a Benefit or Benefit Recipient as recorded in the Ministry of Social Development's SWIFTT database

Denominator: NZ Statistics NZ Estimated Resident Population

Notes on Interpretation

Data was provided by the MSD from their SWIFTT database which records information on recipients of financial assistance through Work and Income for 2000-2010. All figures unless stated otherwise, refer to the number of children who were dependent on a benefit or benefit recipient as at the end of April and provide no information on those receiving assistance at other times of the year. Note: New Zealand level trend data is for children 0-18 years, whereas Service Centre Data may also include a very small number (n=5 in 2010) who are aged 19+ years.

To be eligible for a benefit, clients must have insufficient income from all sources to support themselves and any dependents and meet the eligibility criteria for benefits. These are:

Domestic Purposes Benefit – Sole Parent (DPB-SP) and Emergency Maintenance Allowance: This benefit provides income support for sole parents living with their dependent children under 18 years, who meet an income test and are New Zealand citizens or permanent residents. To be eligible, a parent must be 18 years or older OR have been legally married or in a civil union. A 16 or 17 year old sole parent who has never been married may be eligible to receive an Emergency Maintenance Allowance. This emergency benefit can also be paid to sole parents aged 18 and over who do not meet specific criteria for DPB-SP or other benefits.

Unemployment Benefits: Unemployment benefits are available to people who are available for and actively seeking full time work. Clients must be aged 18+ years or 16-17 years and living with a spouse or partner and dependent children. Those receiving unemployment benefits are subject to a full time work test, as are their

spouses or partners if they have no dependent children, or if their youngest dependent child is aged 14+ years. Applicants must have continuously lived in New Zealand for 2 years or more. An Unemployment Benefit-Hardship is available to those who do not meet these criteria but who are not successfully able to support themselves through paid employment or by other means.

Sickness Benefit: To be eligible for a Sickness Benefit people need to be 18 years of age, or 16-17 years of age and either 27+ weeks pregnant or living with a partner and children they support. They must have had to stop working or reduce their hours because of sickness, injury, pregnancy or disability OR, if unemployed or working part time, find it hard to look for or do full time work for the same reasons. To qualify, a person's (and their partner's) income must be below a certain level and they must have a medical certificate, the first of which can last for only up to 4 weeks. For pregnant women, payments may continue for up to 13 weeks after the birth of their child. At least 2 years' residence is required, though a benefit may be granted in cases of hardship.

Invalid's Benefit: To be eligible for an Invalid's Benefit, people need to be 16+ years of age and unable to work 15+ hours a week because of a sickness, injury or disability which is expected to last at least 2 years OR their life expectancy is <2 years and they are unable to regularly work 15+ hours a week OR they are blind with a specified level of visual impairment. A doctor's certificate is required and an applicant must be a New Zealand citizen or permanent resident and have lived in New Zealand for 10 years or more.

Other Benefits: In this section, Other Benefits includes DPB Women Alone and Caring for Sick or Infirm, NZ Superannuation, Veterans and Transitional Retirement Benefit, Emergency Benefits and Widows Benefit, Independent Youth Benefit, Unemployment Benefit Training and Unemployment Benefit Training Hardship, Unemployment Benefit Student Hardship, Orphan's Benefit and Unsupported Child's Benefit.

Indicator Category Ideal B-C

New Zealand Distribution and Trends

Total Number of Children Reliant on a Benefit or Benefit Recipient

In New Zealand, the number of children aged 0-18 years who were reliant on a benefit, or benefit recipient, fell from 280,025 in April 2000, to 211,609 in April 2008, before increasing again to 243,884 in April 2010. A large proportion of this variation was due to changes in the number of in children relying on unemployment benefit recipients, with numbers in this category falling from 49,499 in April 2000, to 5,289 in April 2008, before increasing again to 16,380 in April 2010. Similarly the number of children reliant on DPB recipients fell from 188,216 in April 2000, to 158,173 in April 2008, before increasing again to 177,226 in April 2010 (**Table 76**).

Proportion of All New Zealand Children Reliant on a Benefit Recipient

In New Zealand the proportion of children aged 0-18 years who were reliant on a benefit, or benefit recipient, fell from 25.6% in April 2000 to 18.3% in April 2008, before increasing again to 20.7% in April 2010. A large proportion of the initial decline was due to a fall in the number of children reliant on unemployment benefit recipients (from 4.5% of children in 2000 to 0.5% in April 2008 → to 1.4% in April 2010). While the proportion of children reliant on DPB recipients also fell (17.2% of children in April 2000, to 13.6% in April 2008, to 15.1% in April 2010) (**Figure 90**), the rate of decline was much slower than for unemployment benefits, meaning that in relative terms, the proportion of benefit dependent children reliant on DPB recipients actually increased, from 67.2% of all benefit dependent children in April 2000, to 72.7% in April 2010 (**Table 76**).

Age Distribution

During April 2010, the proportion of children reliant on a benefit, or benefit recipient, was highest amongst those 0-4 years of age. Rates then tapered off rapidly, reaching a plateau in middle childhood (6-9 years). After 10 years of age however, rates again declined, reaching their lowest point at 18 years of age (**Figure 91**).

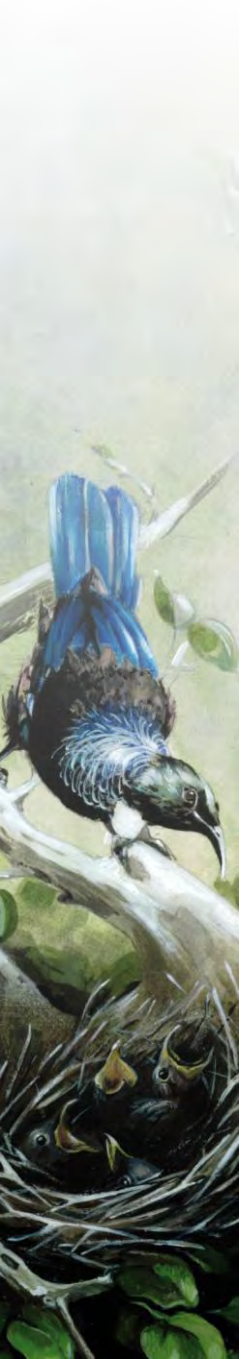
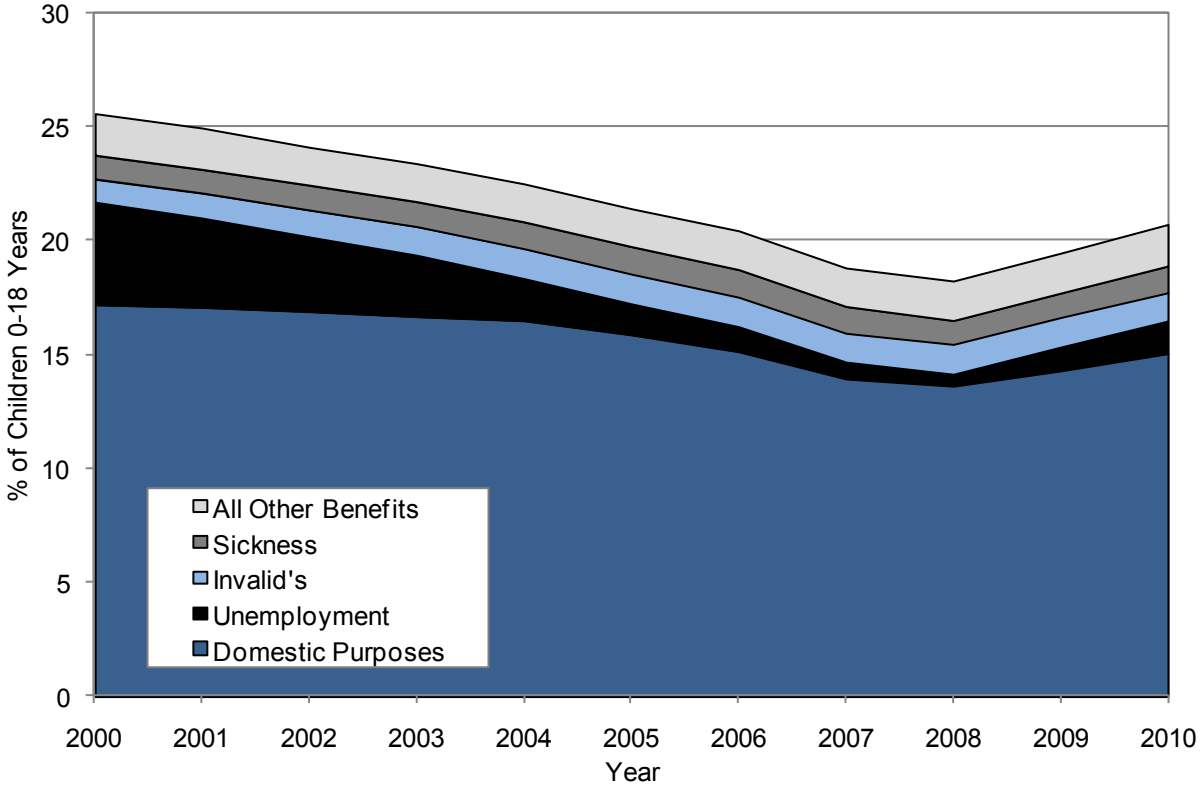
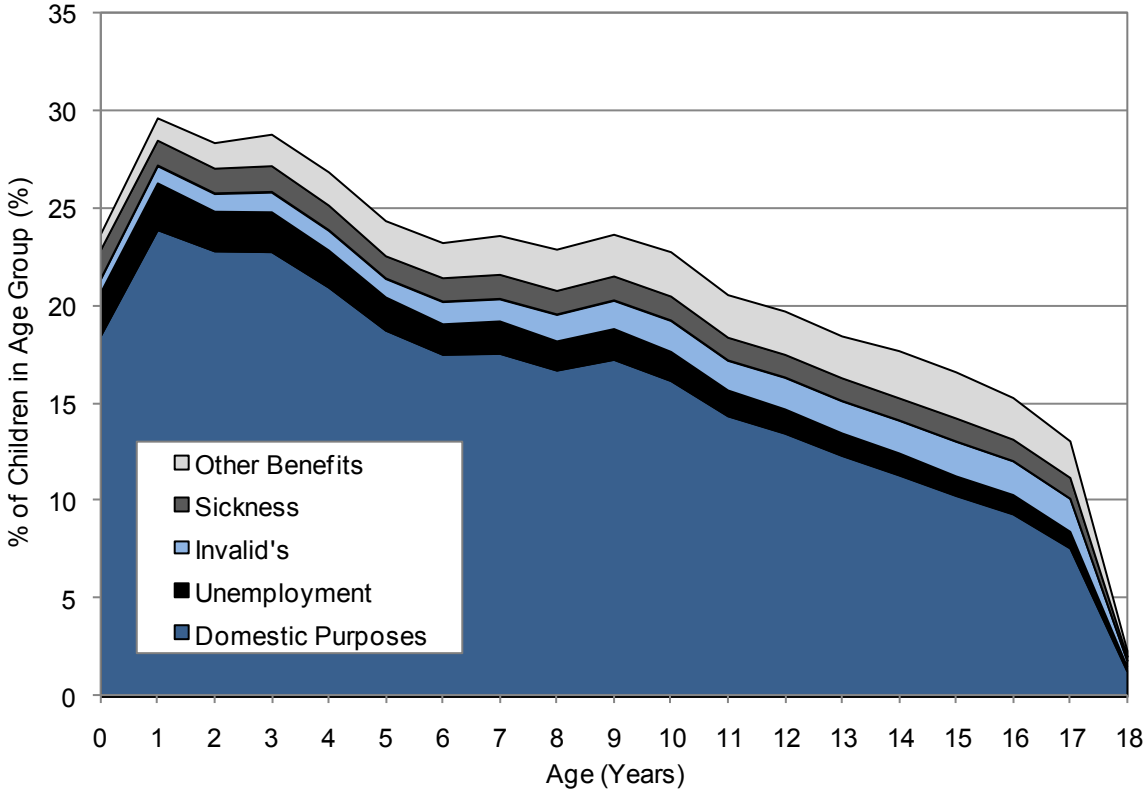


Figure 90. Proportion of All Children Aged 0-18 Years Who Were Reliant on a Benefit or Benefit Recipient by Benefit Type, New Zealand April 2000-2010



Source: Numerator: Ministry of Social Development; Denominator: Statistics NZ Estimated Resident Population; For Composition of Other Benefits, see Methods Section; Non Benefit Assistance not included.

Figure 91. Proportion of All Children Aged 0-18 Years Who Were Reliant on a Benefit or Benefit Recipient by Age and Benefit Type, New Zealand April 2010



Source: Numerator: Ministry of Social Development; Denominator: Statistics NZ Estimated Resident Population; For Composition of Other Benefits, see Methods Section; Non Benefit Assistance not included.

Table 76. Number of Children Aged 0-18 Years Who Were Reliant on a Benefit or Benefit Recipient by Benefit Type, New Zealand April 2000-2010

Year	Domestic Purposes		Unemployment		Invalids		Sickness		All Other Benefits		Total
	Number	%	Number	%	Number	%	Number	%	Number	%	Number
2000	188,216	67.2	49,499	17.7	11,120	4.0	11,295	4.0	19,895	7.1	280,025
2001	187,791	68.5	43,245	15.8	12,122	4.4	11,253	4.1	19,893	7.3	274,304
2002	187,207	70.1	36,342	13.6	13,219	4.9	11,983	4.5	18,346	6.9	267,097
2003	186,184	71.3	30,067	11.5	14,225	5.4	12,119	4.6	18,579	7.1	261,174
2004	185,610	73.3	20,663	8.2	15,053	5.9	13,182	5.2	18,696	7.4	253,204
2005	180,035	74.1	15,134	6.2	15,214	6.3	13,636	5.6	18,783	7.7	242,802
2006	172,995	74.1	12,069	5.2	15,332	6.6	13,797	5.9	19,384	8.3	233,577
2007	160,634	74.2	7,819	3.6	15,247	7.0	13,515	6.2	19,396	9.0	216,611
2008	158,173	74.7	5,289	2.5	15,962	7.5	12,128	5.7	20,057	9.5	211,609
2009	167,142	73.5	11,581	5.1	15,800	6.9	12,482	5.5	20,404	9.0	227,409
2010	177,226	72.7	16,380	6.7	15,116	6.2	13,752	5.6	21,410	8.8	243,884

Source: Ministry of Social Development; *Note: % refers to % of children relying on benefit recipients, rather than % of all children. For Composition of Other Benefits, see Methods Section; Non Benefit Assistance not included.

Table 77. Number of Children Aged 0-18 Years Who Were Reliant on a Benefit or Benefit Recipient by Benefit Type, for Service Centres in the Taranaki Region, April 2007- 2010 (Non-Benefits Excluded)

Year	DPB		Unemployment		Sickness		Invalid's		Other Benefits		Total
	Number	% of Total	Number	% of Total	Number	% of Total	Number	% of Total	Number	% of Total	
2007	3,931	75.9	198	3.8	232	4.5	401	7.7	415	8.0	5,177
2008	3,746	77.1	88	1.8	172	3.5	420	8.6	435	8.9	4,861
2009	3,855	75.7	181	3.6	175	3.4	424	8.3	458	9.0	5,093
2010	4,276	76.5	232	4.2	196	3.5	399	7.1	483	8.6	5,586

Source: Ministry of Social Development; Service Centres include Hawera, New Plymouth, Stratford and Waitara; *Note: % refers to % of children relying on benefit recipients, rather than % of all children; For Composition of *Other Benefits*, see Methods Section; Non Benefit Assistance not included.

Table 78. Number of Children Aged 0-18 Years Who Were Reliant on a Benefit, Benefit Recipient or Other Form of Income Support by Benefit Type, for Service Centres in the Taranaki Region, April 2007- 2010 (Non-Benefits Included)

Service Centre	Year	DPB	Unem-ployment	Sickness	Invalid's	Other Benefits	Non Benefits	Total
Hawera	2007	854	44	40	73	119	165	1,295
	2008	815	36	15	68	95	196	1,225
	2009	787	45	23	91	103	172	1,221
	2010	924	52	22	80	100	157	1,335
New Plymouth	2007	2,156	105	109	225	178	889	3,662
	2008	2,044	25	100	246	222	913	3,550
	2009	2,131	89	108	218	230	865	3,641
	2010	2,301	121	134	205	244	746	3,751
Stratford	2007	432	18	19	51	56	84	660
	2008	408	13	15	48	64	85	633
	2009	426	26	13	54	64	77	660
	2010	434	38	8	53	66	90	689
Waitara	2007	489	31	64	52	62	165	863
	2008	479	14	42	58	54	136	783
	2009	511	21	31	61	61	156	841
	2010	617	21	32	61	73	184	988
Taranaki Total	2007	3,931	198	232	401	415	1,303	6,480
	2008	3,746	88	172	420	435	1,330	6,191
	2009	3,855	181	175	424	458	1,270	6,363
	2010	4,276	232	196	399	483	1,177	6,763

Source: Ministry of Social Development; For Composition of *Other Benefits*, see Methods Section.

Taranaki Distribution and Trends

Total Number of Children Reliant on a Benefit or Benefit Recipient

At the end of April 2010, there were 5,586 children aged 0-18 years who were reliant on a benefit or benefit recipient and who received their benefits from Service Centres in the Taranaki catchment. While the majority of these children were reliant on DPB recipients, increases in the number reliant on DPB and unemployment benefit recipients were evident between April 2008 and April 2010 (**Table 77**, **Table 78**).

Summary

In New Zealand the proportion of children aged 0-18 years who were reliant on a benefit, or benefit recipient, fell from 25.6% in April 2000 to 18.3% in April 2008, before increasing again to 20.7% in April 2010. A large proportion of the initial decline was due to a fall in the number of children reliant on unemployment benefit recipients (from 4.5% of children in 2000 to 0.5% in April 2008 → to 1.4% in April 2010). While the proportion of children reliant on DPB recipients also fell (17.2% of children in April 2000, to 13.6% in April 2008, to 15.1% in April 2010), the rate of decline was much slower than for unemployment benefits, meaning that in relative terms, the proportion of benefit dependent children reliant on DPB recipients actually increased, from 67.2% of all benefit dependent children in April 2000, to 72.7% in April 2010.

At the end of April 2010, there were 5,586 children aged 0-18 years who were reliant on a benefit or benefit recipient and who received their benefits from Service Centres in the Taranaki catchment. While the majority of these children were reliant on DPB recipients, increases in the number reliant on DPB and unemployment benefit recipients were evident between April 2008 and April 2010.

THE CHILDREN'S SOCIAL HEALTH MONITOR: CHILD HEALTH AND WELLBEING INDICATORS

HOSPITAL ADMISSIONS AND MORTALITY WITH A SOCIAL GRADIENT IN CHILDREN

In New Zealand, many child health outcomes exhibit a social gradient, with hospital admissions and mortality from socioeconomically sensitive conditions being several times higher for Māori and Pacific children, and those living in the most deprived areas [175]. Such disparities have persisted, despite one of the longest periods of economic growth in recent decades, as well as historically low unemployment rates.

As earlier sections of this report have demonstrated, New Zealand's macroeconomic environment has changed markedly over the past two years, with rises in unemployment and increases in the number of children reliant on benefit recipients. The impact these changes will have on socially sensitive health outcomes remains unclear however, as international evidence suggests that the effects may vary, not only with the magnitude and duration of any economic downturn, but also as a result of the Government's social policy responses, and the extent to which New Zealand can maintain an effective social safety net (e.g. in housing, health, education, income support) for those most affected. Further, the adaptations families make to their economic circumstances (e.g. cutting back on heating and doctor's visits vs. reductions in cigarettes and takeaways), are also important, with the net impact of such positive / negative adaptations on health outcomes for children being difficult to predict (for a more detailed review of these issues see last year's report).

As predicting the impact of the current economic downturn on child wellbeing is difficult, it would instead seem prudent to monitor a basket of key child health outcomes over time, in order to ensure that any impacts on child health and wellbeing can be identified early, and so that proactive and co-ordinated responses can be put in place, should the need arise. The following section thus uses data from the National Minimum Dataset and the National Mortality collection to review hospital admissions for, and mortality from, the basket of socially sensitive conditions which were presented for the first time in last year's report.

Data Source and Methods

Definition

1. Hospital Admissions for Medical Conditions with a Social Gradient in Children Aged 0-14 Years
2. Injury Admissions with a Social Gradient in Children Aged 0-14 Years
3. Mortality with a Social Gradient in Children Aged 0-14 Years

Data Source

For details of the methodology used to derive these indicators see **Appendix 9**

Numerator:

Hospital Admissions for Medical Conditions with a Social Gradient: Acute and Arranged Hospital Admissions (Waiting List, ACC Cases and neonates <29 days excluded) in children aged 0-14 years with the following ICD-10-AM primary diagnoses: A00-A09 or R11 (Gastroenteritis); A15-A19 (Tuberculosis); A33, A34, A35, A36, A37, A80, B05, B06, B16, B26, B18.0, B18.1, P35.0 or M01.4 (Vaccine Preventable Diseases); A39 (Meningococcal Disease); B34 (Viral Infection of Unspecified Site); E40-E64 or D50-D53 (Nutritional Deficiencies / Anaemias); J00-J03 or J06 (Acute Upper Respiratory Infections); J04 (Croup / Laryngitis / Tracheitis / Epiglottitis); J12, J10.0 or J11.0 (Viral Pneumonia); J13-J16 or J18 (Bacterial / Non-Viral Pneumonia); J21 (Acute Bronchiolitis); J45 or J46 (Asthma); J47 (Bronchiectasis); G00 or G01 (Bacterial Meningitis); A87, G02 or G03 (Viral / Other / NOS Meningitis); G40 or G41 (Epilepsy/ Status Epilepticus); H65, H66 or H67 (Otitis Media); I00-I09 (Rheumatic Fever/Heart Disease); K40 (Inguinal Hernia); L00-L08, H00.0, H01.0, J34.0 or L98.0 (Skin Infections); L20-L30 (Dermatitis and Eczema); M86 (Osteomyelitis); N10, N12, N13.6, N30.0, N30.9 or N39.0 (Urinary Tract Infection); R56.0 (Febrile Convulsions).

Injury Admissions with a Social Gradient: Hospital admissions (emergency department cases, neonates <29 days excluded) in children 0-14 years, with a primary diagnosis of injury (ICD-10-AM S00-T79) and an ICD-10-AM primary external cause code in the following range: V01-V09 (Transport: Pedestrian); V10-V19 (Transport: Cyclist); V40-V79 (Transport: Vehicle Occupant); W00-W19 (Falls); W20-W49 (Mechanical Forces: Inanimate); W50-W64 (Mechanical Forces: Animate); W85-X19 (Electricity / Fire / Burns); X40-X49 (Accidental Poisoning); In order to ensure comparability over time, all injury cases with an Emergency Department Specialty Code (M05-M08) on discharge were excluded.

Mortality with a Social Gradient: All deaths in children 0-14 years, (neonates <29 days excluded) with a main underlying cause of death in the ICD-10-AM medical and injury categories outlined above. In addition post-

neonatal Sudden Unexpected Deaths in Infancy (SUDI) were included, if the child was aged between 29 days and 1 year and their main underlying cause of death was SUDI (ICD-10-AM R95, W75, R99).

Denominator: NZ Statistics NZ Estimated Resident Population

Indicator Category Proxy B-C

Notes on Interpretation (For Further Detail See **Appendix 9**)

Note 1: Hospital admissions in neonates (<29 days) were excluded from both indicators, as these admissions are more likely to reflect issues arising prior to / at the time of birth, (e.g. preterm infants may register multiple admissions as they transition from intensive care (NICU), through special care nurseries (SCBU) to the postnatal ward), and respiratory infections / other medical conditions arising in these contexts are likely to differ in their aetiology from those arising in the community.

Note 2: For medical conditions, only acute and arranged admissions have been included, as Waiting List admissions tend to reflect service capacity, rather than actual health need (e.g. inclusion of these admissions would result in a large number of children with otitis media with effusion (OME) and chronic tonsillitis being included (for grommets and tonsillectomies), whose demographic profile is very different from children attending hospital acutely for similar diseases). For injury admissions however, filtering by admission type could not occur, as a number of DHBs admitted injury cases under (now discontinued) ACC admission codes, making it difficult to distinguish between acute and waiting list admissions in this context. As with other injury data in these reports however, all injury cases with an Emergency Department Specialty Code (M05-M08) on discharge were excluded (see **Appendix 4** for rationale).

Note 3: Hospital admissions were considered to have a social gradient if rates for those in the most deprived (NZDep Decile 9-10) areas were ≥1.8 times higher than for those in the least deprived (NZDep Decile 1-2) areas, or where ethnic differences (Māori, Pacific or Asian vs. European children) met these criteria. In addition, a small number of conditions were included where rates were ≥1.5 times higher, they demonstrated a consistent social gradient, and the association was biologically plausible.

Note 4: When considering the magnitude of social gradients between medical and injury admissions, it must be remembered that these differences are not strictly comparable, as for technical reasons emergency department cases have been removed from injury admissions (and social differences in attendance at the Emergency Department vs. primary care for minor medical conditions may have accounted for some (but not all) of the social gradients in medical admission seen). No such differential filtering occurred for mortality data however, and thus the magnitude of the social differences seen is more readily comparable.

Note 5: 95% confidence intervals have been provided for the rate ratios in this section and where appropriate, the terms significant or not significant have been used to communicate the significance of the observed associations. Tests of statistical significance have not been applied to other data in this section, and thus (unless the terms *significant* or *non-significant* are specifically used) the associations described do not imply statistical significance or non-significance (see **Appendix 1** for further discussion of this issue).

Note 6: SUDI rates are traditionally calculated per 1,000 live births. For this analysis rates for those aged 0-14 years have been calculated, so that the relative contribution SUDI makes to mortality in this age group (as compared to other causes of death) is more readily appreciated. As a result, the SUDI rates in this section are not readily comparable to traditional SUDI mortality rates for those <1 year.

New Zealand Distribution and Trends

Distribution by Cause

Hospital Admissions: In New Zealand during 2005-2009, bronchiolitis, asthma and gastroenteritis made the largest individual contributions to hospitalisations for medical conditions with a social gradient, although infectious and respiratory diseases collectively were responsible for the majority of admissions. Similarly falls, followed by inanimate mechanical forces were the leading causes of injury admissions with a social gradient, although transport accidents as a group also made a significant contribution (**Table 79**).

Mortality: In New Zealand during 2003-2007, SUDI made the single largest contribution to mortality with a social gradient in children aged 0-14 years. This occurred despite the fact that, by definition, all of these deaths occurred during the first year of life. Vehicle occupant related deaths made the second largest contribution, followed by pedestrian injuries and drowning, while bacterial / non viral pneumonia was the leading cause of mortality from medical conditions (**Table 80**).

Table 79. Hospital Admissions for Conditions with a Social Gradient in Children Aged 0-14 Years (excluding Neonates) by Cause, New Zealand 2005-2009

Diagnosis	New Zealand			
	Number: Total 2005-2009	Number: Annual Average	Rate per 1,000	% of Total
Medical Conditions				
Acute Bronchiolitis	24,808	4,961.6	5.57	14.63
Asthma	23,802	4,760.4	5.35	14.03
Gastroenteritis	21,610	4,322.0	4.85	12.74
Acute Upper Respiratory Infections Excl Croup	18,566	3,713.2	4.17	10.95
Viral Infection of Unspecified Site	17,084	3,416.8	3.84	10.07
Bacterial/Non-Viral Pneumonia	15,207	3,041.4	3.42	8.97
Skin Infections	14,401	2,880.2	3.23	8.49
Urinary Tract Infection	6,246	1,249.2	1.40	3.68
Croup/Laryngitis/Tracheitis/Epiglottitis	5,269	1,053.8	1.18	3.11
Epilepsy/ Status Epilepticus	3,932	786.4	0.88	2.32
Otitis Media	3,700	740.0	0.83	2.18
Febrile Convulsions	3,686	737.2	0.83	2.17
Dermatitis and Eczema	2,854	570.8	0.64	1.68
Viral Pneumonia	1,796	359.2	0.40	1.06
Inguinal Hernia	1,548	309.6	0.35	0.91
Osteomyelitis	1,168	233.6	0.26	0.69
Rheumatic Fever/Heart Disease	881	176.2	0.20	0.52
Bronchiectasis	763	152.6	0.17	0.45
Viral / Other / NOS Meningitis	698	139.6	0.16	0.41
Meningococcal Disease	533	106.6	0.12	0.31
Vaccine Preventable Diseases	440	88.0	0.10	0.26
Nutritional Deficiencies/Anaemias	291	58.2	0.07	0.17
Bacterial Meningitis	245	49.0	0.06	0.14
Tuberculosis	72	14.4	0.02	0.04
New Zealand Total	169,600	33,920.0	38.09	100.00
Injury Admissions				
Falls	23,454	4,690.8	5.27	48.05
Mechanical Forces: Inanimate	14,171	2,834.2	3.18	29.03
Transport: Cyclist	3,080	616.0	0.69	6.31
Accidental Poisoning	2,497	499.4	0.56	5.12
Electricity / Fire / Burns	2,026	405.2	0.46	4.15
Transport: Vehicle Occupant	1,294	258.8	0.29	2.65
Mechanical Forces: Animate	1,092	218.4	0.25	2.24
Transport: Pedestrian	1,023	204.6	0.23	2.10
Drowning / Submersion	179	35.8	0.04	0.37
New Zealand Total	48,816	9,763.2	10.96	100.00

Source: Numerator: National Minimum Dataset (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population. Medical Conditions: Acute and Arranged Admissions only; Injury Admissions: Emergency Department Cases removed.

Table 80. Mortality from Conditions with a Social Gradient in Children Aged 0-14 Years (excluding Neonates) by Cause, New Zealand 2003-2007

Diagnosis	New Zealand			
	Number: Total 2003-2007	Number: Annual Average	Rate per 100,000	% of Total
Medical Conditions				
Bacterial/Non-Viral Pneumonia	43	8.6	0.97	29.5
Epilepsy/ Status Epilepticus	18	3.6	0.41	12.3
Meningococcal Disease	17	3.4	0.38	11.6
Viral Pneumonia	14	2.8	0.32	9.6
Bacterial Meningitis	12	2.4	0.27	8.2
Asthma	10	2.0	0.23	6.8
Gastroenteritis	7	1.4	0.16	4.8
Acute Bronchiolitis	6	1.2	0.14	4.1
Other Medical Conditions	19	3.8	0.43	13.0
Total Medical Conditions	146	29.2	3.30	100.0
Injuries				
Transport: Vehicle Occupant	82	16.4	1.85	32.5
Transport: Pedestrian	55	11.0	1.24	21.8
Drowning / Submersion	49	9.8	1.11	19.4
Electricity / Fire / Burns	22	4.4	0.50	8.7
Transport: Cyclist	12	2.4	0.27	4.8
Falls	12	2.4	0.27	4.8
Mechanical Forces: Inanimate	11	2.2	0.25	4.4
Accidental Poisoning	6	1.2	0.14	2.4
Mechanical Forces: Animate	<5	s	s	s
Total Injuries	252	50.4	5.69	100.0
Post Neonatal SUDI				
Post Neonatal SUDI	267	53.4	6.03	100.0
Total	665	133.0	15.01	100.0

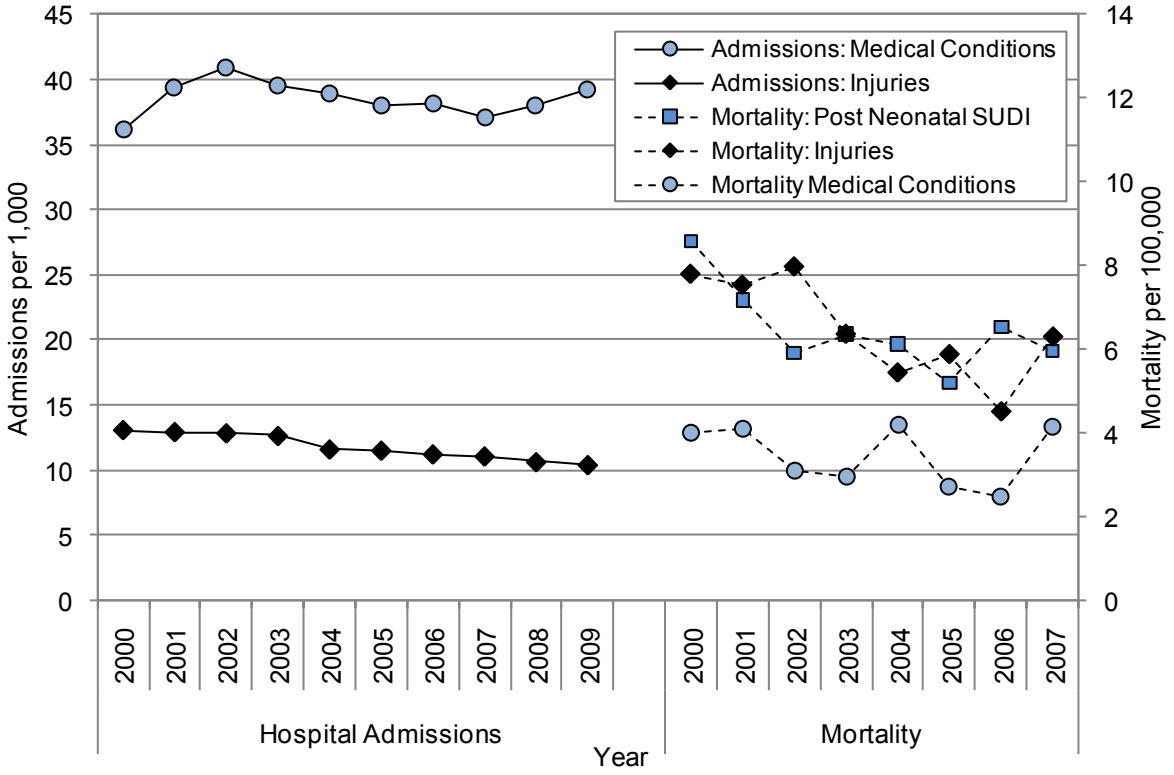
Source: Numerator: National Mortality Collection (Neonates removed); Denominator: Statistics NZ Estimated Resident Population. Note SUDI deaths are for infants aged 29-364 days only.

New Zealand Trends

Hospital Admissions: In New Zealand, medical admissions with a social gradient increased during the early 2000s, reached peak in 2002 and then declined, with an upswing in rates again being evident during 2007-2009. In contrast, injury admissions with a social gradient declined throughout 2000-2009 (**Figure 92**).

Mortality: In New Zealand, injury mortality with a social gradient declined during 2000-2006, with a small upswing in rates being evident in 2007. Mortality from medical conditions with a social gradient exhibited a fluctuating downward trend during 2000-2006, with an upswing in rates also being evident in 2007 (in both cases, it remains unclear whether this upswing reflects normal year to year variation, or the beginning of an upward trend, with 1-2 years more data being required to determine this). In contrast, post-neonatal SUDI declined during 2000-2002, and thereafter remained relatively static (**Figure 92**).

Figure 92. Hospital Admissions (2000-2009) and Mortality (2000-2007) from Conditions with a Social Gradient in New Zealand Children Aged 0-14 Years (excluding Neonates)



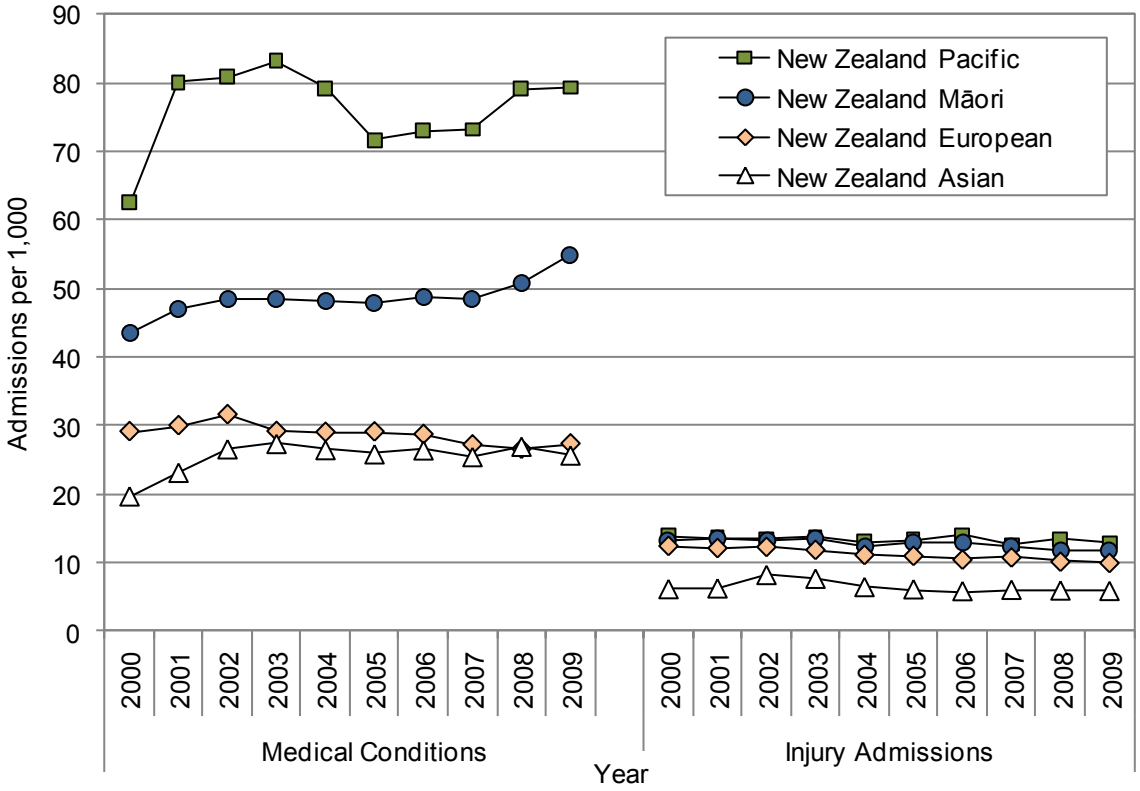
Source: Numerator Admissions: National Minimum Dataset (Neonates Removed); Numerator Mortality: National Mortality Collection (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population. Medical Conditions Admissions: Acute and Arranged Admissions Only; Injury Admissions: Emergency Department Cases Removed.

Trends by Ethnicity

Hospital Admissions: In New Zealand during 2000-2009, hospitalisations for medical conditions with a social gradient were consistently higher for Pacific > Māori > European and Asian children. For Pacific children, admissions increased during the early 2000s, reached a peak in 2003 and then declined, with an upswing in rates again being evident during 2007-2009. For Māori children, rates were static during the early-mid 2000s, but began to increase after 2007, while for Asian children rates during 2002-2009 remained relatively static. In contrast, for European children rates declined gradually during 2002-2009. Injury admissions with a social gradient were also higher for Pacific and Māori > European > Asian children, and while in absolute terms the magnitude of these differences appeared to be less marked than for medical conditions, for technical reasons, comparisons between these categories are not strictly possible (see Note 4 in Methods section) (**Figure 93**).

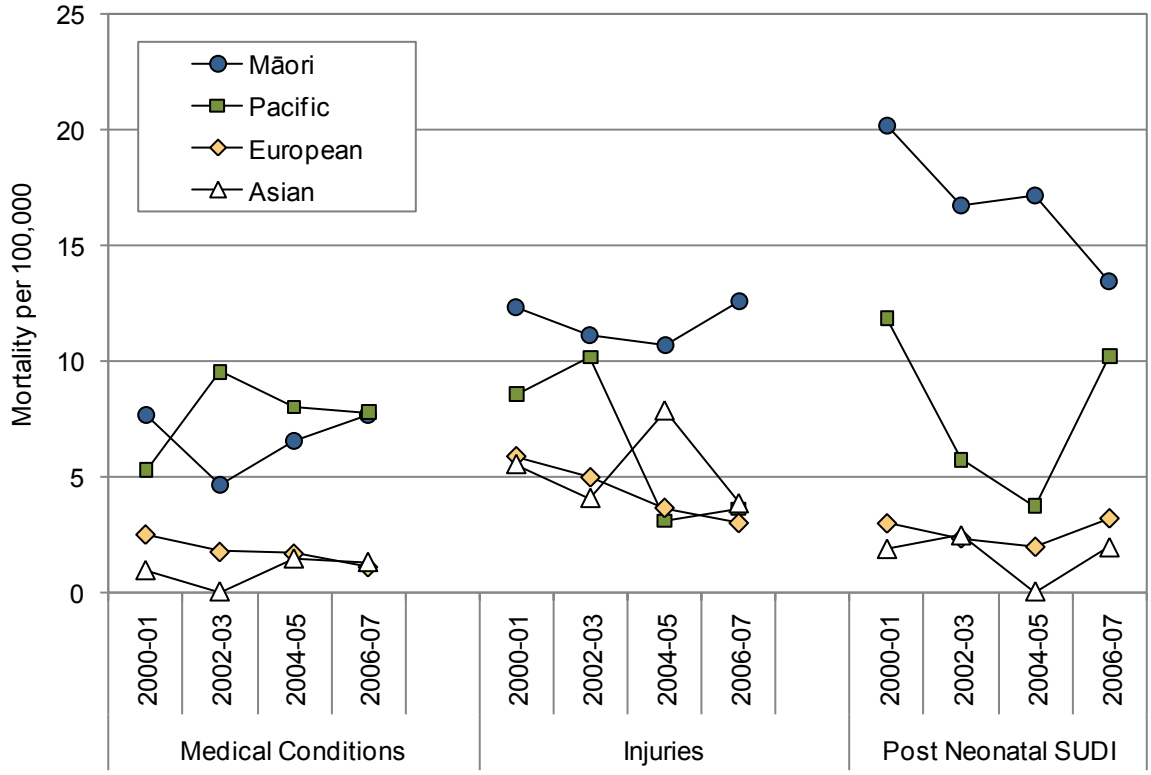
Mortality: In New Zealand during 2000-2007, SUDI mortality was consistently higher for Māori > Pacific > European and Asian infants, while mortality from medical conditions with a social gradient was generally higher for Māori and Pacific > European and Asian children. While mortality from injuries with a social gradient was also consistently higher for Māori than for European and Asian children, rates for Pacific children were more variable (**Figure 94**).

Figure 93. Hospital Admissions for Conditions with a Social Gradient in Children Aged 0-14 Years by Ethnicity, New Zealand 2000-2009



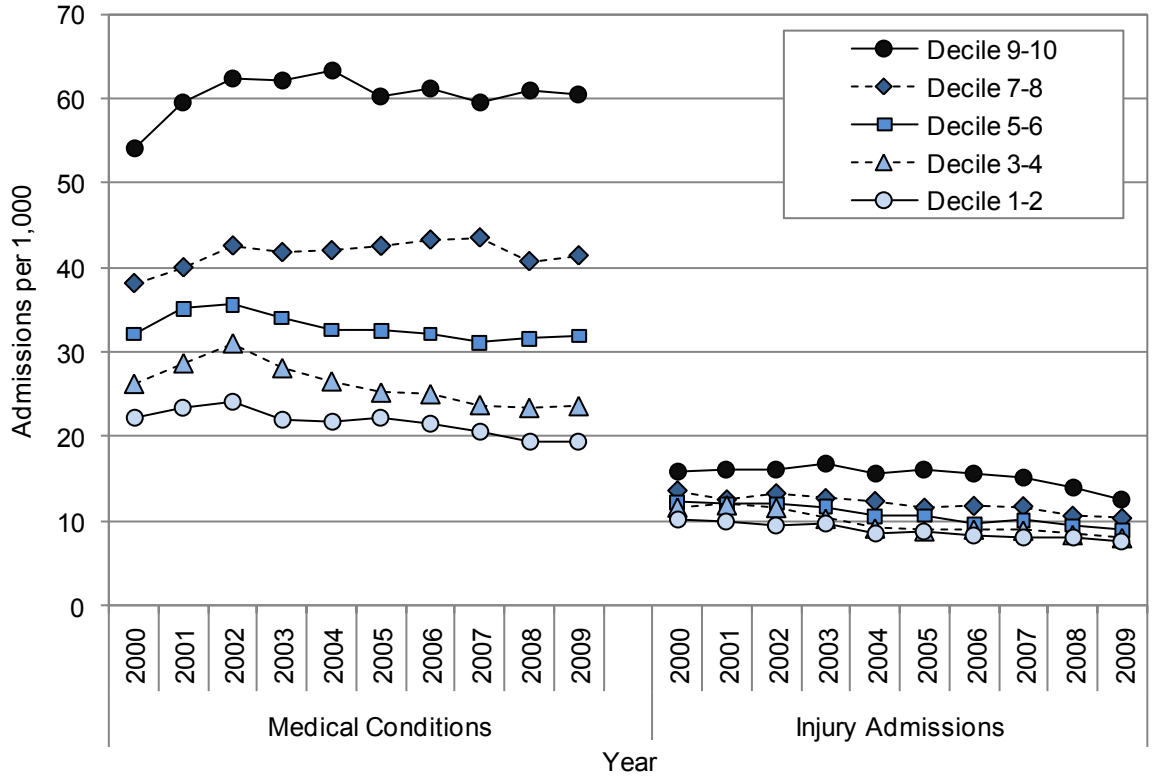
Source: Numerator: National Minimum Dataset (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population. Medical Conditions: Acute and Arranged Admissions only; Injury Admissions: Emergency Department Cases removed. Ethnicity is Level 1 Prioritised.

Figure 94. Mortality from Conditions with a Social Gradient in Children Aged 0-14 Years (excluding Neonates) by Ethnicity, New Zealand 2000-2007



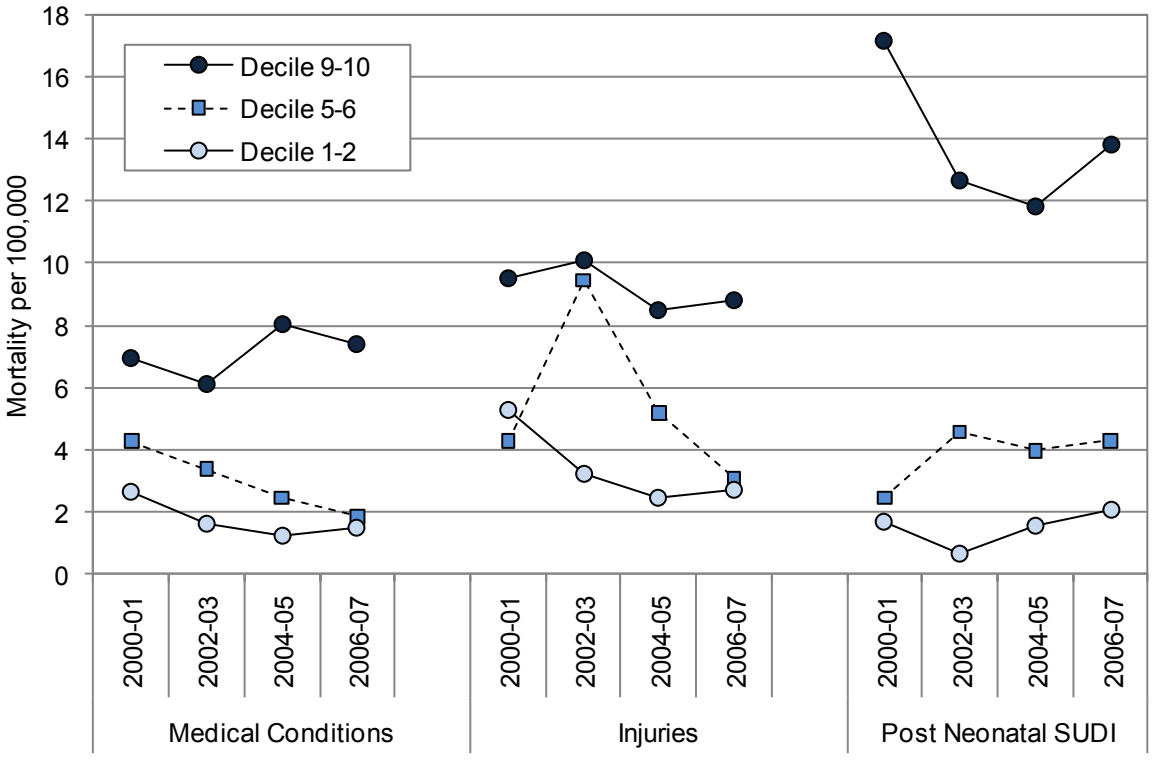
Source: Numerator: National Mortality Collection (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised. Note: SUDI deaths are for infants aged 29-364 days only.

Figure 95. Hospital Admissions for Conditions with a Social Gradient in Children Aged 0-14 Years by NZ Deprivation Index Decile, New Zealand 2000-2009



Source: Numerator: National Minimum Dataset (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population. Medical Conditions: Acute and Arranged Admissions only; Injury Admissions: Emergency Department Cases removed.

Figure 96. Mortality from Conditions with a Social Gradient in Children Aged 0-14 Years (excluding Neonates) by NZ Deprivation Index Decile, New Zealand 2000-2007



Source: Numerator: National Mortality Collection (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population. Note: SUDI deaths are for infants aged 29-364 days only.

Trends by NZ Deprivation Index Decile

Hospital Admissions: In New Zealand during 2000-2009, medical admissions with a social gradient were consistently higher for those living in Decile 9-10 > Decile 7-8 > Decile 5-6 > Decile 3-4 > Decile 1-2 areas. Injury admissions with a social gradient also demonstrated a consistent socioeconomic gradient over time, and while in absolute terms these differences were less marked than for medical conditions, for technical reasons comparisons between these admission categories are not strictly possible (see Note 4 in Methods section) (**Figure 95**).

Mortality: In New Zealand during 2000-2007, medical conditions and injuries with a social gradient, and post neonatal SUDI were all consistently higher for those in the most deprived (Decile 9-10) areas, than for those in the least deprived (Decile 1-2) areas, with the greatest absolute differences being seen for post neonatal SUDI (**Figure 96**).

Table 81. Risk Factors for Hospital Admissions with a Social Gradient in Children Aged 0-14 Years, New Zealand 2005-2009

Medical Conditions							
Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	20.9	1.00		Decile 1-2	20.6	1.00	
Decile 2	20.2	0.97	0.94 - 1.00	Decile 3-4	24.2	1.18	1.15 - 1.20
Decile 3	23.3	1.11	1.08 - 1.15	Decile 5-6	31.9	1.55	1.52 - 1.58
Decile 4	25.0	1.19	1.16 - 1.23	Decile 7-8	42.3	2.05	2.02 - 2.09
Decile 5	29.9	1.43	1.39 - 1.47	Decile 9-10	60.4	2.94	2.89 - 2.98
Decile 6	33.5	1.60	1.56 - 1.64	Ethnicity			
Decile 7	38.3	1.83	1.78 - 1.88	Asian	26.1	0.94	0.92 - 0.96
Decile 8	45.7	2.18	2.13 - 2.24	European	27.8	1.00	
Decile 9	56.3	2.69	2.63 - 2.75	Māori	50.2	1.81	1.79 - 1.83
Decile 10	63.9	3.05	2.99 - 3.12	Pacific	75.3	2.71	2.68 - 2.75
Gender							
Female	34.4	1.00		Male	41.6	1.21	1.20 - 1.22
Injuries							
Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
NZ Deprivation Index Decile				NZ Deprivation Index Quintile			
Decile 1	8.4	1.00		Decile 1-2	8.1	1.00	
Decile 2	7.9	0.93	0.89 - 0.98	Decile 3-4	8.7	1.07	1.03 - 1.10
Decile 3	8.5	1.01	0.96 - 1.06	Decile 5-6	9.8	1.20	1.16 - 1.24
Decile 4	8.9	1.06	1.01 - 1.10	Decile 7-8	11.2	1.37	1.33 - 1.42
Decile 5	9.6	1.15	1.10 - 1.20	Decile 9-10	14.7	1.80	1.75 - 1.85
Decile 6	9.9	1.17	1.12 - 1.22	Ethnicity			
Decile 7	10.6	1.26	1.21 - 1.32	Asian	5.9	0.56	0.54 - 0.59
Decile 8	11.7	1.39	1.33 - 1.45	European	10.5	1.00	
Decile 9	14.8	1.75	1.69 - 1.83	Māori	12.4	1.18	1.15 - 1.20
Decile 10	14.6	1.73	1.67 - 1.80	Pacific	13.3	1.26	1.23 - 1.30
Gender							
Female	8.8	1.00		Male	13.0	1.48	1.45 - 1.50

Source: Numerator: National Minimum Dataset (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population. Medical Conditions: Acute and Arranged Admissions only; Injury Admissions: Emergency Department Cases removed. Rates are per 1,000, Rate Ratios are unadjusted; Ethnicity is Level 1 Prioritised.

Distribution by Ethnicity, Gender and NZDep Deprivation

Hospital Admissions: In New Zealand during 2005-2009, hospital admissions for medical conditions with a social gradient were *significantly* higher for Pacific > Māori > European > Asian children, males and those in average-more deprived (NZDep decile 3-10) areas. Similarly, injury admissions with a social gradient were *significantly* higher for Pacific > Māori > European > Asian children, males and those in average-more deprived (NZDep decile 4-10) areas. While the magnitude of the social differences appeared smaller for injury admissions, it must be remembered that that for technical reasons (See Note 4 in Methods Section) these categories are not strictly comparable (**Table 81**).

Mortality: In New Zealand during 2003-2007, mortality from medical conditions with a social gradient was *significantly* higher for Pacific and Māori > European and Asian children, and those in more deprived (Decile 7-10) areas. Similarly mortality from injuries with a social gradient was *significantly* higher for Māori > Asian, Pacific and European children, males and those in more deprived (Decile 7-10) areas (**Table 82**). Differences in SUDI mortality are considered in the Infant Mortality section.

Table 82. Risk Factors for Mortality with a Social Gradient in Children Aged 0-14 Years, New Zealand 2003-2007

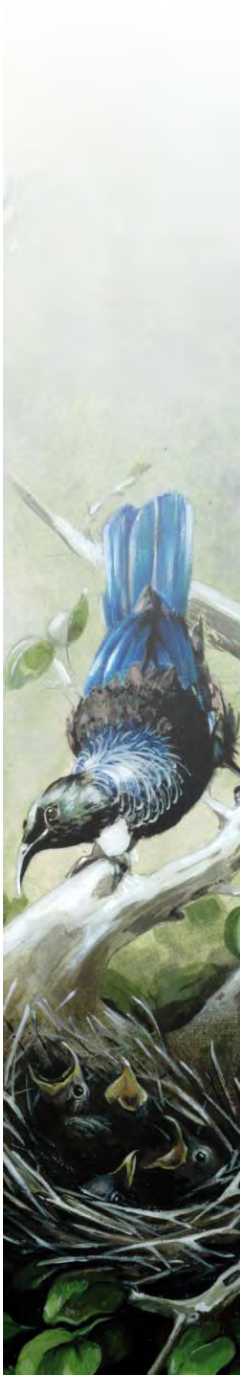
Medical Conditions							
Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
NZ Deprivation Index Decile				Prioritised Ethnicity			
Decile 1-2	1.34	1.00		Asian	1.11	0.83	0.29 - 2.33
Decile 3-4	0.97	0.73	0.29 - 1.81	European	1.34	1.00	
Decile 5-6	2.44	1.82	0.87 - 3.80	Māori	6.59	4.92	3.27 - 7.41
Decile 7-8	2.85	2.13	1.05 - 4.31	Pacific	8.80	6.57	4.11 - 10.50
Decile 9-10	7.58	5.66	3.01 - 10.62	Gender			
				Female	2.92	1.00	
				Male	3.66	1.25	0.90 - 1.74
Injuries							
Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
NZ Deprivation Index Decile				Prioritised Ethnicity			
Decile 1-2	2.80	1.00		Asian	4.98	1.44	0.86 - 2.38
Decile 3-4	4.63	1.65	0.98 - 2.77	European	3.47	1.00	
Decile 5-6	4.27	1.52	0.90 - 2.58	Māori	11.79	3.40	2.59 - 4.46
Decile 7-8	5.59	2.00	1.22 - 3.27	Pacific	4.16	1.20	0.71 - 2.02
Decile 9-10	9.29	3.31	2.10 - 5.22	Gender			
				Female	4.68	1.00	
				Male	6.65	1.42	1.11 - 1.83
SUDI: See Infant Mortality Section							

Source: Numerator: National Mortality Collection; Denominator Statistics NZ Estimated Resident Population; Rates are per 100,000; Rate Ratios are unadjusted; Ethnicity is Level 1 Prioritised.

Taranaki Distribution and Trends

Taranaki Distribution

In Taranaki during 2005-2009, hospital admissions for medical conditions (RR 0.75 95% CI 0.73-0.78) and injuries (RR 0.84 95% CI 0.79-0.89) with a social gradient were both *significantly* lower than the New Zealand average (**Table 83**).



Taranaki Trends

Hospital Admissions: In Taranaki, hospitalisations for medical conditions with a social gradient increased during the early 2000s, reached a peak in 2002 and then declined. Rates reached their lowest point in 2007, before rising again rapidly during 2008-2009. In contrast, injury admissions with a social gradient decreased gradually during 2000-2009 (**Figure 97**).

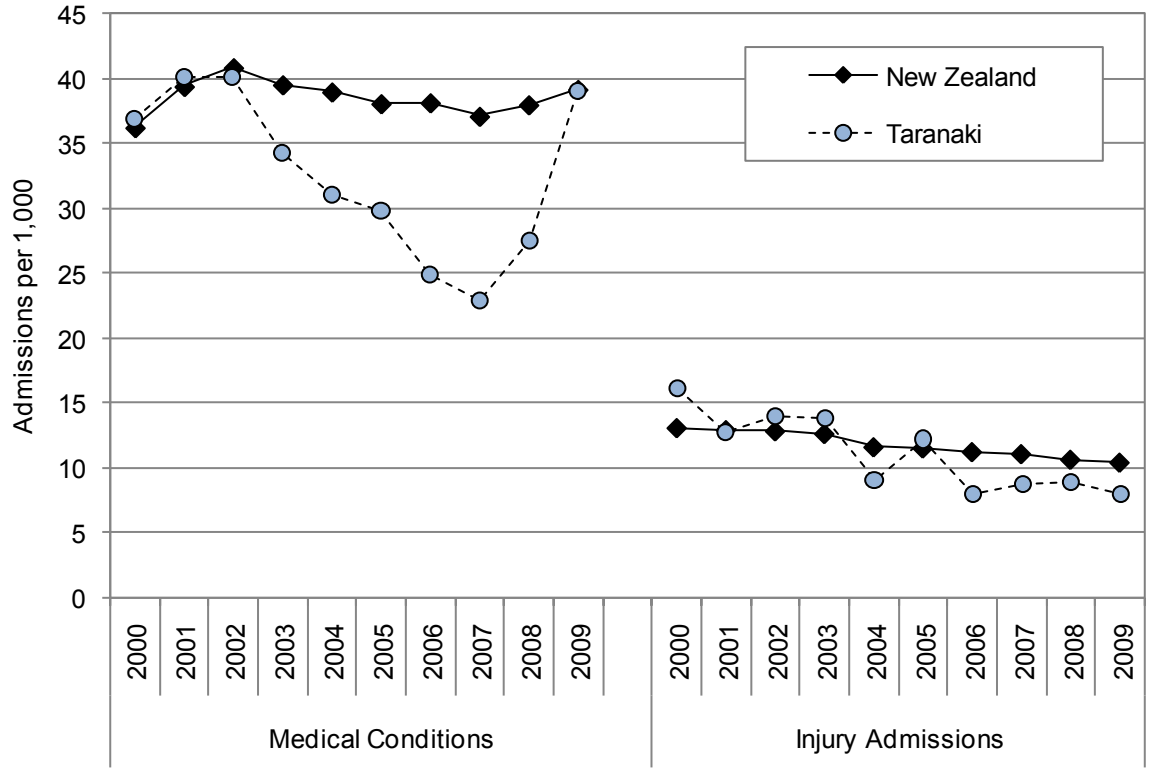
Mortality: In Taranaki during 2000-2007, while numbers were too small for trend analysis, 13 children died from injuries and 10 from medical conditions with a social gradient, while 15 (post neonatal) infants died as a result of SUDI.

Table 83. Hospital Admissions for Conditions with a Social Gradient in Children Aged 0-14 Years, Taranaki vs. New Zealand 2005-2009

DHB	Number: Total 2005-2009	Number: Annual Average	Rate per 1,000	Rate Ratio	95% CI
Medical Conditions					
Taranaki	3,267	653	28.7	0.75	0.73 - 0.78
New Zealand	169,600	33,920	38.1	1.00	
Injury Admissions					
Taranaki	1,045	209	9.2	0.84	0.79 - 0.89
New Zealand	48,816	9,763	11.0	1.00	

Source: Numerator National Minimum Dataset (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population; Medical Conditions: Acute and Arranged Only; Injury Admissions: Emergency Department Cases Removed.

Figure 97. Hospital Admissions for Conditions with a Social Gradient in Children Aged 0-14 Years, Taranaki vs. New Zealand 2000-2009



Source: Numerator-National Minimum Dataset (Neonates Removed); Denominator-Statistics NZ Estimated Resident Population; Medical Conditions: Acute and Arranged only; Injury Admissions: Emergency Department Cases removed.

Table 84. Hospital Admissions for Conditions with a Social Gradient in Children Aged 0-14 Years, Taranaki 2005-2009

Diagnosis	Taranaki			
	Number: Total 2005-2009	Number: Annual Average	Rate per 1,000	% of Total
Medical Conditions				
Asthma	545	109.0	4.79	16.68
Acute Bronchiolitis	479	95.8	4.21	14.66
Gastroenteritis	439	87.8	3.86	13.44
Acute Upper Respiratory Infections Excl Croup	326	65.2	2.87	9.98
Viral Infection of Unspecified Site	296	59.2	2.60	9.06
Bacterial/Non-Viral Pneumonia	296	59.2	2.60	9.06
Skin Infections	220	44.0	1.93	6.73
Epilepsy / Status Epilepticus	116	23.2	1.02	3.55
Urinary Tract Infection	109	21.8	0.96	3.34
Croup / Laryngitis / Tracheitis / Epiglottitis	107	21.4	0.94	3.28
Dermatitis and Eczema	97	19.4	0.85	2.97
Otitis Media	56	11.2	0.49	1.71
Febrile Convulsions	53	10.6	0.47	1.62
Inguinal Hernia	40	8.0	0.35	1.22
Osteomyelitis	21	4.2	0.18	0.64
Meningococcal Disease	16	3.2	0.14	0.49
Viral Pneumonia	14	2.8	0.12	0.43
Rheumatic Fever / Heart Disease	9	1.8	0.08	0.28
Viral / Other / NOS Meningitis	8	1.6	0.07	0.24
Bronchiectasis	8	1.6	0.07	0.24
Nutritional Deficiencies/Anaemias	6	1.2	0.05	0.18
Bacterial Meningitis	5	1.0	0.04	0.15
Vaccine Preventable Diseases	<5	s	s	s
Taranaki Total	3,267	653.4	28.73	100.00
Injury Admissions				
Falls	525	105.0	4.62	50.24
Mechanical Forces: Inanimate	236	47.2	2.08	22.58
Transport: Cyclist	69	13.8	0.61	6.60
Accidental Poisoning	66	13.2	0.58	6.32
Electricity / Fire / Burns	65	13.0	0.57	6.22
Transport: Vehicle Occupant	34	6.8	0.30	3.25
Mechanical Forces: Animate	25	5.0	0.22	2.39
Transport: Pedestrian	20	4.0	0.18	1.91
Drowning / Submersion	5	1.0	0.04	0.48
Taranaki Total	1,045	209.0	9.19	100.00

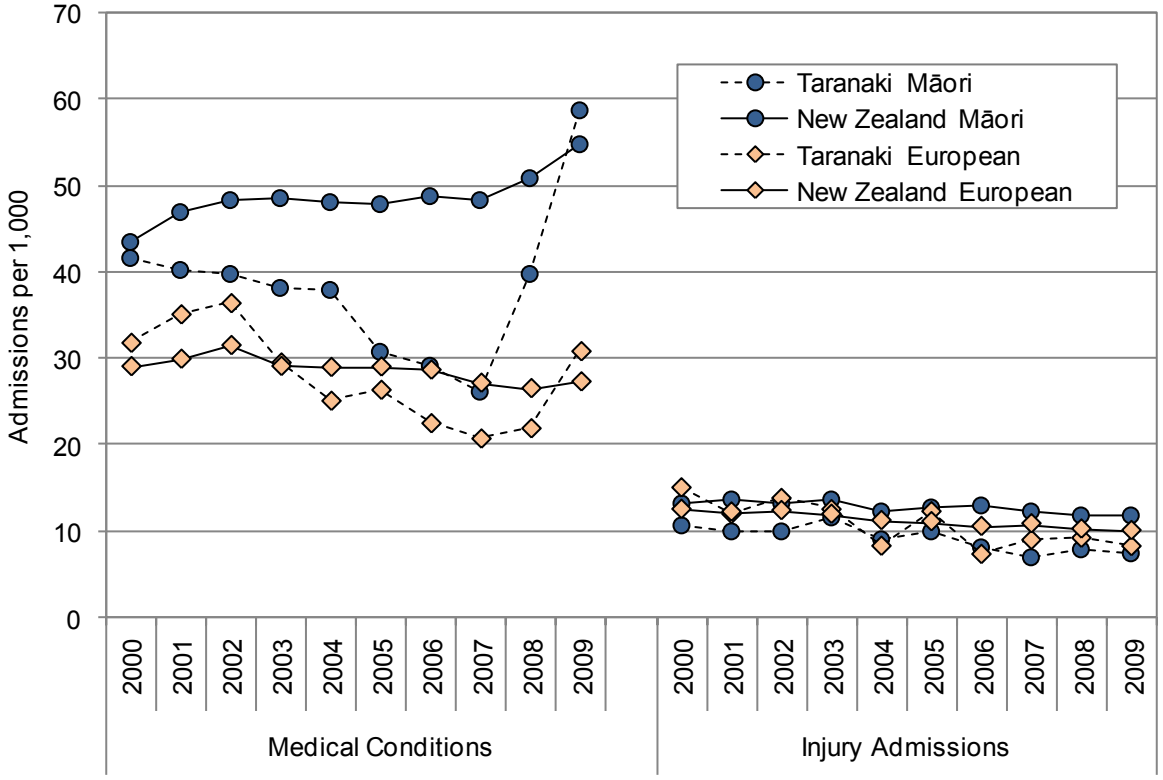
Source: Numerator-National Minimum Dataset (Neonates Removed); Denominator-Statistics NZ Estimated Resident Population; Medical Conditions Acute and Arranged Admissions only; Injuries Emergency Department Cases removed.

Taranaki Distribution by Cause

Hospital Admissions: In Taranaki during 2005-2009 asthma, bronchiolitis and gastroenteritis made the largest individual contributions to hospitalisations for medical conditions with a social gradient, with infectious and respiratory diseases collectively being responsible for the majority of admissions. During the same period falls, followed by inanimate mechanical forces, were the most frequent causes of injury admissions with a social gradient, although transport accidents as a group also made a significant contribution (**Table 84**).

Mortality: In Taranaki during 2003-2007, 6 children died from injuries with a social gradient, with drowning (n=3) making the greatest contribution. A further 4 children died from medical conditions with a social gradient, with viral pneumonia (n=3) making the single largest contribution. In addition, 11 infants died of (post neonatal) SUDI.

Figure 98. Hospital Admissions for Conditions with a Social Gradient in Children Aged 0-14 Years by Ethnicity, Taranaki vs. New Zealand 2000-2009



Source: Numerator National Minimum Dataset (Neonates Removed); Denominator: Statistics NZ Estimated Resident Population; Medical Conditions: Acute and Arranged Only; Injury Admissions: Emergency Department Cases Removed; Ethnicity is Level 1 Prioritised.

Taranaki Trends by Ethnicity

Hospital Admissions: In Taranaki, hospital admissions for medical conditions with a social gradient were higher for Māori than for European children. Rates for both ethnic groups declined during the mid 2000s, reached their lowest point in 2007 and then increased again, with the largest absolute increases being for Māori children. In contrast, injury admissions declined gradually for both ethnic groups (**Figure 98**). Small numbers precluded an analysis of mortality trends by ethnicity.

Summary

Medical admissions with a social gradient in children increased during the early 2000s, reached peak in 2002 and then declined, with an upswing in rates again being evident during 2007-2009. In contrast, injury admissions with a social gradient declined throughout 2000-2009. Medical admissions for Pacific children increased during the early 2000s, reached a peak in 2003 and then declined, with an upswing in rates again being evident during 2007-2009. For Māori children, rates were static during the early-mid 2000s, but increased after 2007, while for Asian children rates during 2002-2009 were static. Rates for European children declined gradually during 2002-2009.

During 2005-2009, infectious and respiratory diseases were responsible for the majority of hospitalisations for medical conditions with a social gradient, while falls, followed by inanimate mechanical forces were the leading causes of injury admissions. In contrast, during 2003-2007 SUDI made the single largest contribution to mortality with a social gradient. Vehicle occupant deaths were the second leading cause, followed by pedestrian injuries and drowning, while bacterial / non viral pneumonia was the leading cause of death from medical conditions.

In Taranaki, hospitalisations for medical conditions with a social gradient increased during the early 2000s, reached a peak in 2002 and then declined. Rates reached their lowest point in 2007, before rising again rapidly during 2008-2009. In contrast, injury admissions with a social gradient decreased gradually during 2000-2009. When broken down by ethnicity, hospital admissions for medical conditions with a social gradient were higher for Māori than for European children. Rates for both ethnic groups declined during the mid 2000s, reached their lowest point in 2007 and then increased again, with the largest absolute increases being for Māori children. In contrast, injury admissions declined gradually for both ethnic groups. In addition, during 2000-2007, 13 Taranaki children died from injuries and 10 from medical conditions with a social gradient, while 15 (post neonatal) infants died as a result of SUDI.

INFANT MORTALITY

Introduction

Infant mortality is often used as a barometer of the social wellbeing of a country [201]. New Zealand's infant mortality rates are middling by international standards, being lower than those of the USA and some Eastern European countries, but higher than those of Central and Northern Europe [202]. Despite this, mortality during the first year of life in New Zealand remains much higher than at any other point during childhood or adolescence. In the year to March 2008, a total of 330 New Zealand infants died prior to their first birthday [203].

Despite these relatively high numbers, New Zealand's infant mortality rates have declined during the past 40 years, with rates falling from 18.2 per 1,000 in 1968, to 5.3 per 1,000 in March 2008 [203]. While infant mortality rates are generally higher for Pacific > Māori > European / Other babies, males, and those in the most deprived areas [204], total infant mortality rates are of limited utility in guiding population health interventions, as the causes of mortality differ markedly with the age of the infant. During the neonatal period (birth-28 days) extreme prematurity, congenital anomalies and intrauterine / birth asphyxia are the leading causes of mortality, while in the post neonatal period (29-364 days) SIDS and congenital anomalies make the greatest contribution [175]. Thus any interventions aimed at reducing New Zealand's infant mortality rates must, in the first instance, be based on an understanding of their component causes.

The following section uses information from the National Mortality Collection to review neonatal, post neonatal and total infant mortality since 1990.

Data Source and Methods

Definition

1. Total Infant Mortality: Death of a live born infant prior to 365 days of life
2. Neonatal Mortality: Death of a live born infant in the first 28 days of life
3. Post-Neonatal Mortality: Death of a live born infant after 28 days but prior to 365 days of life
4. Sudden Unexpected Death in Infancy (SUDI): Death of a live born infant <365 days of life, where the cause of death is attributed to SIDS, Accidental Suffocation / Strangulation in Bed or Ill-Defined/Unspecified Causes

Data Sources

Numerator: National Mortality Collection: All deaths in the first year of life, using the definitions for total, neonatal and post neonatal mortality outlined above. Cause of death was derived from the main underlying cause of death (clinical code) as follows: Extreme Prematurity (ICD-10 P072), Congenital Anomalies (ICD-10 Q00-Q99), Perinatal Conditions (ICD-10 P00-P96); SIDS (ICD-10 R95); SUDI (ICD-10 R95, W75, R99).
Denominator: Birth Registration Dataset: All live births 20+ weeks gestation.

Notes on Interpretation

Note 1: See **Appendix 5** for an overview of the dataset used.
Note 2: 95% confidence intervals have been provided for the rate ratios in this section and where appropriate, the terms significant or not significant have been used to communicate the significance of the observed associations. Tests of statistical significance have not been applied to other data in this section, and thus (unless the terms *significant* or *non-significant* are specifically used) the associations described do not imply statistical significance or non-significance (see **Appendix 1** for further discussion of this issue).

Indicator Category Ideal B

New Zealand Distribution and Trends

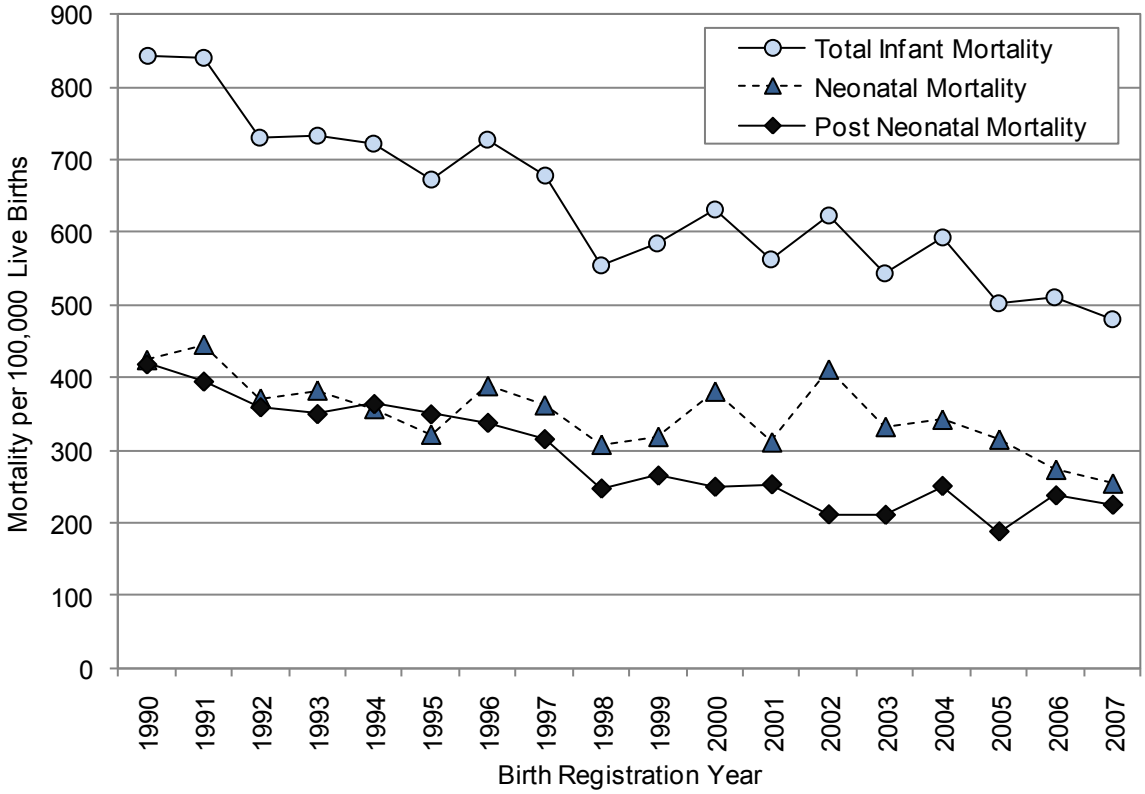
New Zealand Trends

In New Zealand during 1990-2007, neonatal and post neonatal mortality both declined, with neonatal mortality exceeding post neonatal mortality during the 2000s (**Figure 99**).

New Zealand Trends by Ethnicity

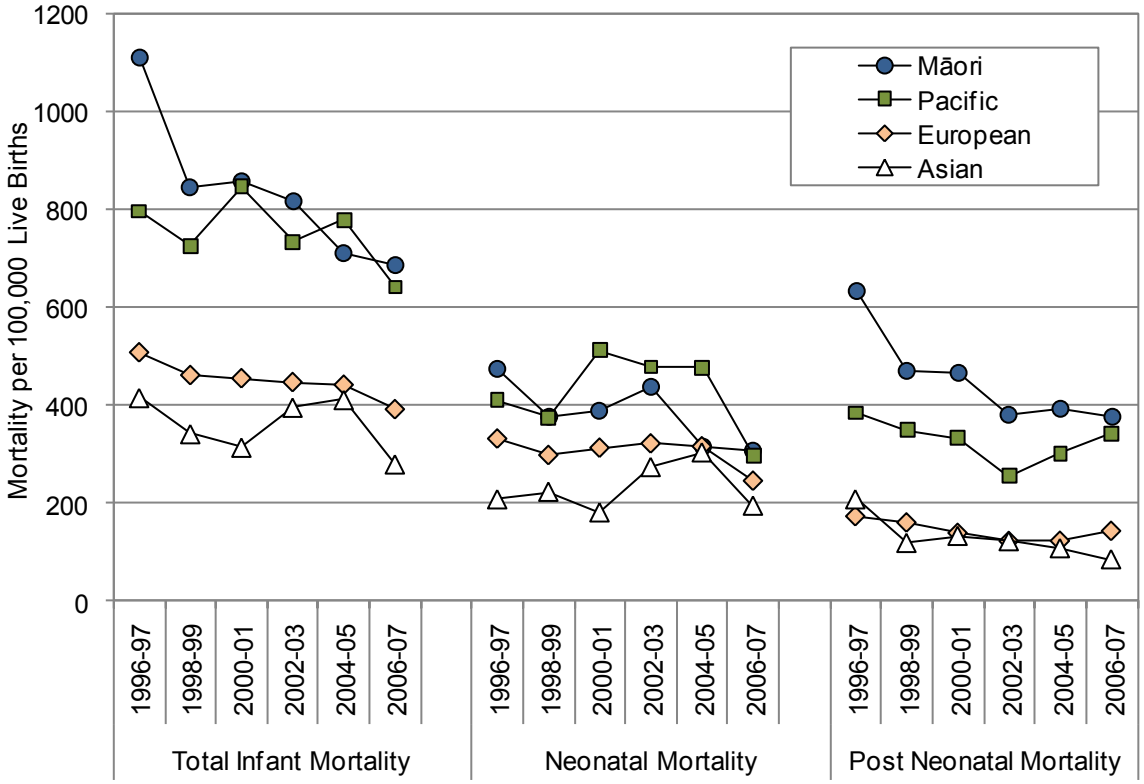
In New Zealand during the late 1990s, neonatal mortality was generally higher for Pacific and Māori > European > Asian infants, although ethnic differences were less consistent during the 2000s. In contrast, post neonatal mortality was higher for Māori > Pacific > European and Asian infants throughout 1996-2007 (**Figure 100**).

Figure 99. Total Infant, Neonatal and Post Neonatal Mortality, New Zealand 1990-2007

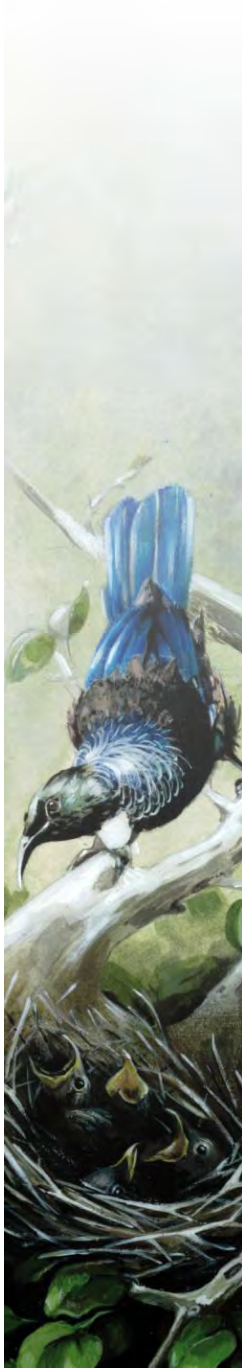


Source: Numerator: National Mortality Collection; Denominator: Birth Registration Dataset

Figure 100. Total Infant, Neonatal and Post Neonatal Mortality by Ethnicity, New Zealand 1996-2007



Source: Numerator: National Mortality Collection; Denominator: Birth Registration Dataset. Ethnicity is Level 1 Prioritised



Distribution by Cause

In New Zealand during 2003-2007, extreme prematurity and congenital anomalies were the leading causes of neonatal mortality, although intrauterine / birth asphyxia also made a significant contribution. In contrast, SUDI was the leading cause of post-neonatal mortality, followed by congenital anomalies (**Table 85**).

Table 85. Neonatal and Post Neonatal Mortality by Cause, New Zealand 2003–2007

Cause of Death	Number: Total 2003-2007	Number: Annual Average	Rate per 100,000	Percent of Deaths
Neonatal Mortality				
Extreme Prematurity	215	43.0	71.8	23.8
Congenital Anomalies: CVS	56	11.2	18.7	6.2
Congenital Anomalies: CNS	31	6.2	10.4	3.4
Congenital Anomalies: Other	135	27.0	45.1	14.9
Intrauterine / Birth Asphyxia	47	9.4	15.7	5.2
Other Perinatal Conditions	342	68.4	114.2	37.8
SUDI: Suffocation / Strangulation in Bed	20	4.0	6.7	2.2
SUDI: SIDS or Unspecified	18	3.6	6.0	2.0
Injury / Poisoning	9	1.8	3.0	1.0
Other Causes	32	6.4	10.7	3.5
Total Neonatal Mortality	905	181.0	302.3	100.0
Post Neonatal Mortality				
SUDI: SIDS	189	37.8	63.1	28.4
SUDI: Suffocation / Strangulation in Bed	68	13.6	22.7	10.2
SUDI: Unspecified	10	2.0	3.3	1.5
Congenital Anomalies: CVS	52	10.4	17.4	7.8
Congenital Anomalies: CNS	10	2.0	3.3	1.5
Congenital Anomalies: Other	63	12.6	21.0	9.5
Other Perinatal Conditions	56	11.2	18.7	8.4
Injury / Poisoning	30	6.0	10.0	4.5
Other Causes	187	37.4	62.5	28.1
Total Post Neonatal Mortality	665	133.0	222.1	100.0
New Zealand Total	1,570	314.0	524.3	100.0

Source: Numerator: National Mortality Collection; Denominator: Birth Registration Dataset

Distribution by Ethnicity, Gender and NZDep Deprivation

In New Zealand during 2003-2007, neonatal mortality was *significantly* higher for Pacific > Māori, European and Asian infants, males and those in more deprived areas, while post neonatal mortality was *significantly* higher for Māori and Pacific > European and Asian infants, males and those in more deprived areas. SUDI was *significantly* higher for Māori > Pacific > European > Asian infants, and those in average to more deprived areas (**Table 86**).

Table 86. Risk Factors for Neonatal and Post Neonatal Mortality, and Sudden Unexpected Death in Infancy (SUDI), New Zealand 2003–2007

Neonatal Mortality							
Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
NZ Deprivation Index Decile				Ethnicity			
Decile 1-2	225.9	1.00		Asian	255.9	0.90	0.70 - 1.16
Decile 3-4	227.3	1.01	0.77 - 1.31	European	283.8	1.00	
Decile 5-6	270.1	1.20	0.93 - 1.53	Māori	319.2	1.12	0.97 - 1.31
Decile 7-8	329.1	1.46	1.15 - 1.84	Pacific	404.5	1.42	1.17 - 1.73
Decile 9-10	396.2	1.75	1.41 - 2.19	Gender			
				Female	277.0	1.00	
				Male	326.2	1.18	1.03 - 1.34
Post Neonatal Mortality							
Variable	Rate	RR	95% CI	Variable	Rate	RR	95% CI
NZ Deprivation Index Decile				Ethnicity			
Decile 1-2	107.6	1.00		Asian	106.6	0.80	0.54 - 1.17
Decile 3-4	130.5	1.21	0.84 - 1.75	European	133.8	1.00	
Decile 5-6	166.8	1.55	1.10 - 2.19	Māori	388.5	2.90	2.44 - 3.46
Decile 7-8	219.4	2.04	1.48 - 2.81	Pacific	295.6	2.21	1.73 - 2.82
Decile 9-10	386.1	3.59	2.66 - 4.84	Gender			
				Female	190.6	1.00	
				Male	252.0	1.32	1.13 - 1.54
Sudden Unexpected Death in Infancy (SUDI)							
Variable	Rate	RR	95% CI	Variable	Rate	RR	
NZ Deprivation Index Decile				Ethnicity			
Decile 1-2	32.3	1.00		Asian	14.2	0.29	0.11 - 0.80
Decile 3-4	69.2	2.14	1.17 - 3.93	European	48.9	1.00	
Decile 5-6	68.9	2.14	1.17 - 3.88	Māori	227.8	4.66	3.56 - 6.10
Decile 7-8	88.4	2.74	1.55 - 4.83	Pacific	96.4	1.97	1.30 - 3.01
Decile 9-10	200.0	6.20	3.65 - 10.52	Gender			
				Female	93.3	1.00	
				Male	110.0	1.18	0.94 - 1.48

Source: Numerator: National Mortality Collection; Denominator: Birth Registration Dataset; Rates are per 100,000, Rate Ratios are Unadjusted, Ethnicity is Level 1 Prioritised. SUDI is neonatal AND post neonatal.

Taranaki Distribution and Trends

Taranaki Distribution

In Taranaki during 2003-2007, both neonatal mortality (RR 0.96 95% CI 0.62-1.47) and post neonatal mortality (RR 1.30 95% CI 0.84 - 2.01) were not *significantly* different from the New Zealand average (**Table 87**).

Taranaki Distribution by Cause

In Taranaki during 2003-2007, congenital anomalies were the most frequent causes of neonatal mortality, while SUDI was the most frequent cause of post neonatal mortality (**Table 88**).

Taranaki Trends

In Taranaki during 1990-2007 large year to year variations made trends in total, neonatal and post neonatal mortality difficult to interpret precisely, although all three outcomes did exhibit a general downward trend (**Figure 101**).

Table 87. Neonatal and Post Neonatal Mortality, Taranaki vs. New Zealand 2003-2007

DHB	Total No. Deaths 2003-2007	No. Deaths Annual Average	Rate per 100,000	Rate Ratio	95% CI
Neonatal Mortality					
Taranaki	21	4.2	289.4	0.96	0.62 - 1.47
New Zealand	905	181.0	302.3	1.00	
Post Neonatal Mortality					
Taranaki	21	4.2	289.4	1.30	0.84 - 2.01
New Zealand	665	133.0	222.1	1.00	

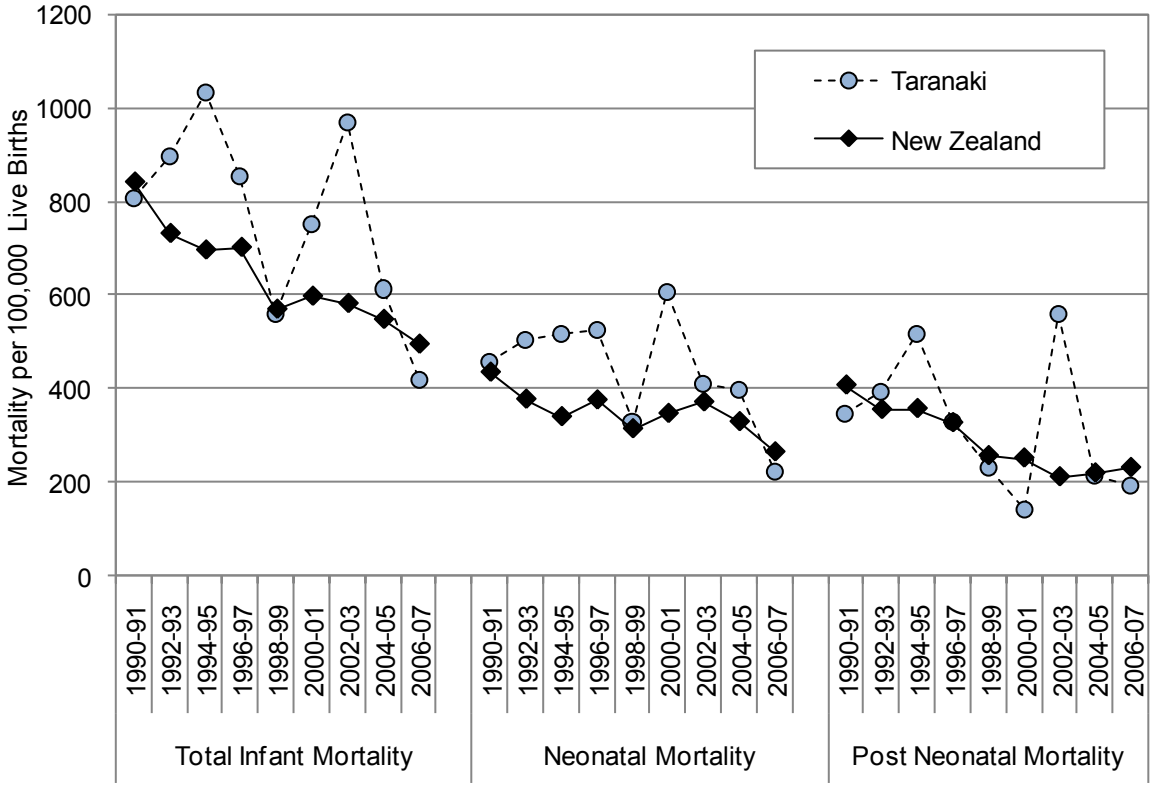
Source: Numerator: National Mortality Collection; Denominator: Birth Registration Dataset

Table 88. Neonatal and Post Neonatal Mortality by Cause, Taranaki 2003–2007

Cause of Death	Number: Total 2003-2007	Number: Annual Average	Rate per 100,000	Percent of Deaths
Taranaki				
Neonatal Mortality				
Congenital Anomalies	5	1.0	68.9	23.8
Other Perinatal Conditions	16	3.2	220.5	76.2
Total Neonatal Mortality	21	4.2	289.4	100.0
Post Neonatal Mortality				
SUDI: All Causes	11	2.2	151.6	52.4
Congenital Anomalies	5	1.0	68.9	23.8
Other Causes	5	1.0	68.9	23.8
Total Post Neonatal Mortality	21	4.2	289.4	100.0
Taranaki Total	42	8.4	578.8	100.0

Source: Numerator: National Mortality Collection; Denominator: Birth Registration Dataset

Figure 101. Total Infant, Neonatal and Post Neonatal Mortality, Taranaki vs. New Zealand 1990-2007



Source: Numerator National Mortality Collection; Denominator Birth Registration Dataset

Summary

In New Zealand during 1990-2007, neonatal and post neonatal mortality both declined, with neonatal mortality exceeding post neonatal mortality during the 2000s. When broken down by ethnicity, neonatal mortality was higher for Pacific and Māori > European > Asian infants during the late 1990s, although ethnic differences were less consistent during the 2000s. In contrast, post neonatal mortality was higher for Māori > Pacific > European and Asian infants throughout 1996-2007.

When broken down by cause, extreme prematurity and congenital anomalies were the leading causes of neonatal mortality in New Zealand during 2003-2007. In contrast, SUDI was the leading cause of post-neonatal mortality, followed by congenital anomalies. During this period, neonatal mortality was *significantly* higher for Pacific > Māori, European and Asian infants, males and those in more deprived areas, while post neonatal mortality was *significantly* higher for Māori and Pacific > European and Asian infants, males and those in more deprived areas. SUDI was *significantly* higher for Māori > Pacific > European > Asian infants, and those in average to more deprived areas.

In Taranaki during 2003-2007, both neonatal mortality (RR 0.96 95% CI 0.62-1.47) and post neonatal mortality (RR 1.30 95% CI 0.84 - 2.01) were not *significantly* different from the New Zealand average. During this period, congenital anomalies were the most frequent causes of neonatal mortality, while SUDI was the most frequent cause of post neonatal mortality.

INJURIES ARISING FROM THE ASSAULT, NEGLECT OR MALTREATMENT OF CHILDREN

Introduction

Longitudinal studies suggest that 4-10% of New Zealand children experience physical abuse and 11-20% experience sexual abuse during childhood and that the long term consequences for these children are significant [205]. During the 1990s, New Zealand ranked 3rd highest amongst rich nations for its child maltreatment death rates [206], with 49 children <15 years dying as a result of maltreatment between 1996 and 2000. This situation does not appear to have improved over time, with mortality rates almost doubling during the late 1980s and changing very little since then [207]. Mortality represents the tip of the iceberg however, with the number of notifications to Child Youth and Family (CYF) for possible abuse or neglect increasing each year. In 2008, a total of 104,181 notifications were recorded by CYF and of these, 48,957 were deemed to require further action (see last year's report). This is of concern, as in addition to the physical effects, research has shown that survivors of childhood abuse often suffer long term psychological sequelae including depression, post-traumatic stress disorder, substance abuse, suicide / suicide attempts and high risk sexual behaviour [208].

The following section explores hospital admissions and mortality from injuries arising from the assault, neglect or maltreatment of children aged 0-14 years using information from the National Minimum Dataset and the National Mortality Collection.

Data Source and Methods

Definition

1. *Hospitalisations for Injuries Arising From the Assault / Neglect / Maltreatment of Children Aged 0-14 Years*
2. *Deaths from Injuries Arising from the Assault / Neglect / Maltreatment of Children Aged 0-14 Years*

Data Source

1. Hospital Admissions

Numerator: National Minimum Dataset: Hospital admissions of children (0-14 years) with a primary diagnosis of injury (ICD-10-AM S00-T79) and an external cause code of intentional injury (ICD-10-AM X85-Y09) in any of the first 10 External Cause codes. As outlined in Appendix 4, in order to ensure comparability over time, all cases with an Emergency Department Specialty Code (M05-M08) on discharge were excluded.

2. Mortality

Numerator: National Mortality Collection: Deaths in children (0-14 years) with a clinical code (cause of death) of Intentional Injury (ICD-10-AM X85-Y09).

Denominator: NZ Statistics NZ Estimated Resident Population

Interpretation

The limitations of the National Minimum Dataset are discussed at length in **Appendix 4**. The reader is urged to review this Appendix before interpreting any trends based on hospital admission data.

Indicator Category Admissions Proxy C; Mortality Ideal B

New Zealand and Taranaki Distribution and Trends

Taranaki vs. New Zealand Distribution and Trends

In Taranaki during 2005-2009, hospital admissions for injuries arising from the assault, neglect or maltreatment of children were similar to the New Zealand average (RR 1.02 95% CI 0.67-1.55) (**Table 89**), with large year to year variations being evident during 2000-2009 (**Figure 102**).

Taranaki and New Zealand Mortality

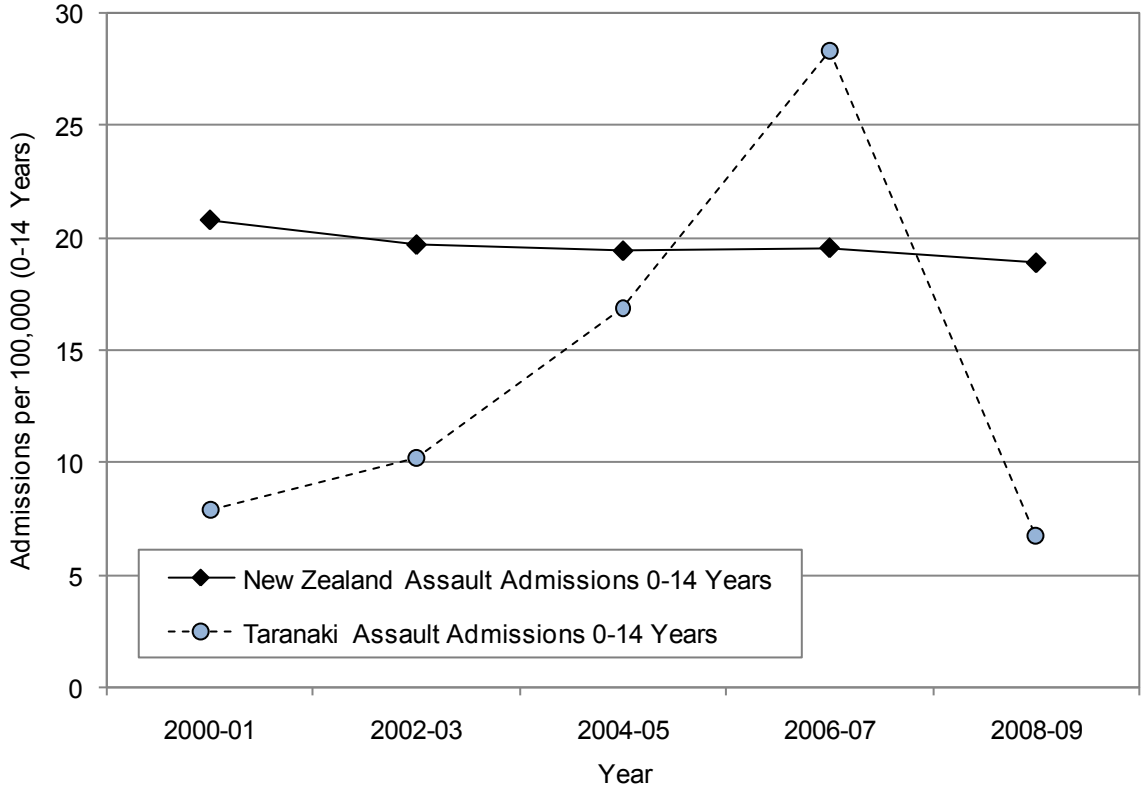
In New Zealand during 2000-2007 mortality from injuries arising from the assault, neglect or maltreatment of children remained relatively static, with deaths averaging 8 per year during this period (**Figure 103**). Similarly in Taranaki during 2000-2007, a total of 3 children died as the result of assault, neglect or maltreatment.

Table 89. Hospital Admissions due to Injuries Arising from the Assault, Neglect or Maltreatment of Children 0-14 Years, Taranaki vs. New Zealand 2005-2009

DHB	Total No. Admissions 2005-2009	No. Admissions Annual Average	Rate per 100,000	Rate Ratio	95% CI
Injuries Arising from the Assault, Neglect or Maltreatment of Children					
Taranaki	22	4.4	19.3	1.02	0.67 - 1.55
New Zealand	846	169.2	19.0	1.00	

Source: Numerator: National Minimum Dataset; Denominator: Statistics NZ Estimated Resident Population

Figure 102. Hospital Admissions due to Injuries Arising from the Assault, Neglect or Maltreatment of Children 0-14 Years, Taranaki vs. New Zealand 2000-2009



Source: Numerator: National Minimum Dataset; Denominator: Statistics NZ Estimated Resident Population

New Zealand Distribution by Age and Gender

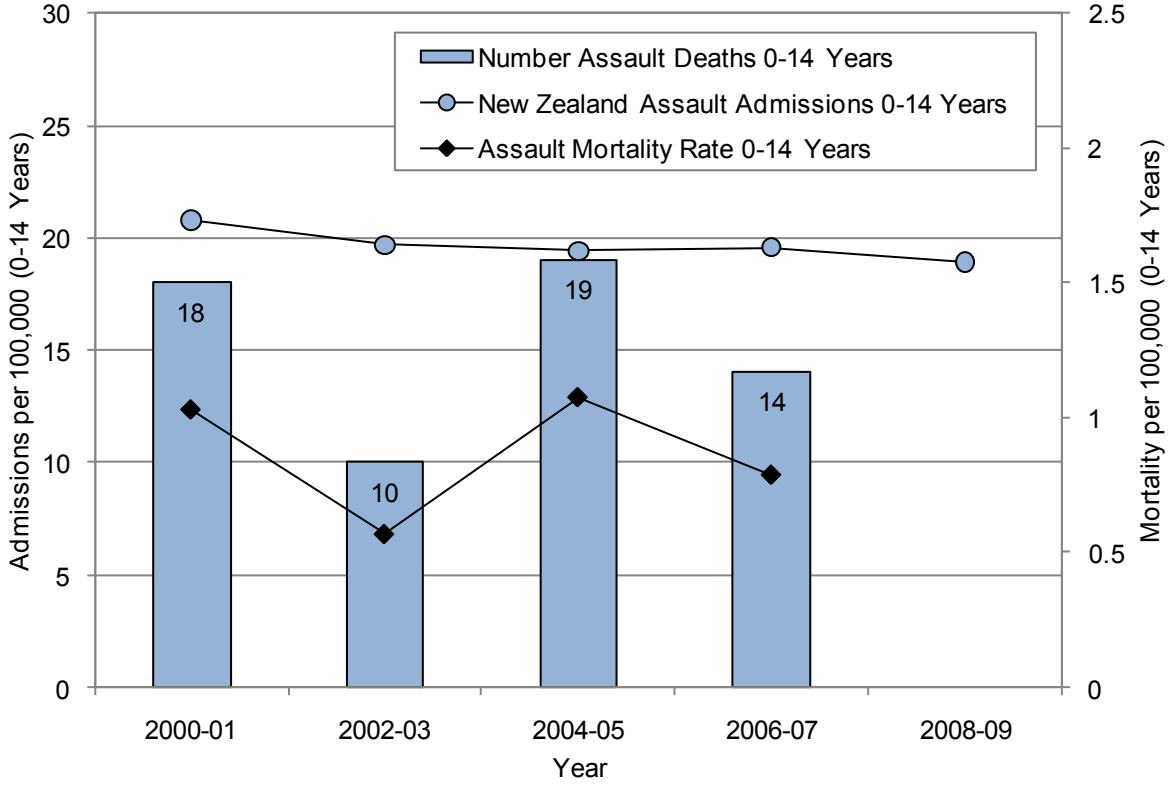
In New Zealand during 2005-2009, hospital admissions for injuries arising from the assault, neglect or maltreatment of children exhibited a J-shaped distribution with age, with rates being higher for infants <1 year and those > 11 years of age. In contrast, mortality was highest for infants < 1 year. While the gender balance for admissions was relatively even during infancy and early childhood, admissions for males became more predominant as adolescence approached (**Figure 104**).

New Zealand Distribution by Gender, Ethnicity and NZ Deprivation Index Decile

In New Zealand during 2005-2009, hospital admissions for injuries arising from the assault, neglect or maltreatment of children were significantly higher for males, Māori > Pacific > European and Asian children, and those living in the more deprived areas (**Table 90**).

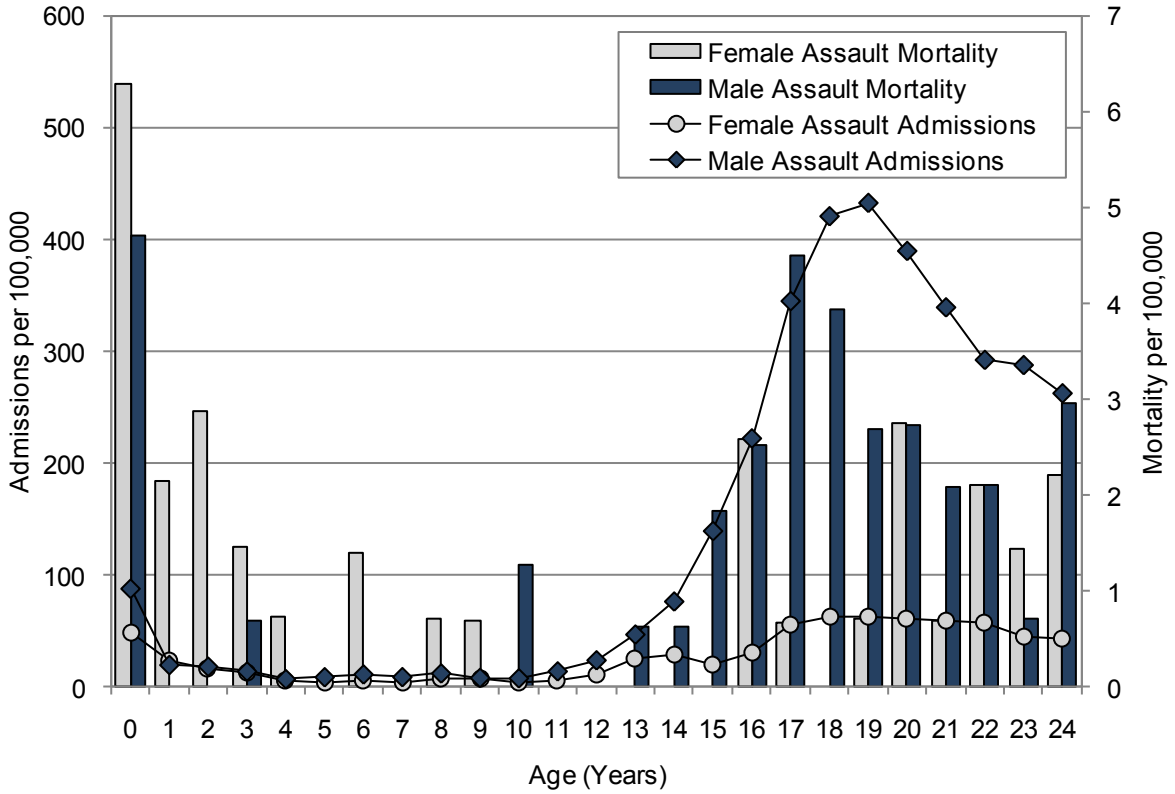
In New Zealand during 2000-2009, hospital admissions for injuries arising from the assault, neglect or maltreatment of children were consistently higher for Māori and Pacific > European > Asian children, with rates also being higher for Māori than for Pacific children during the last 4 years (**Figure 105**).

Figure 103. Hospital Admissions (2000-2009) and Deaths (2000-2007) due to Injuries Arising from the Assault, Neglect or Maltreatment of New Zealand Children 0-14 Years



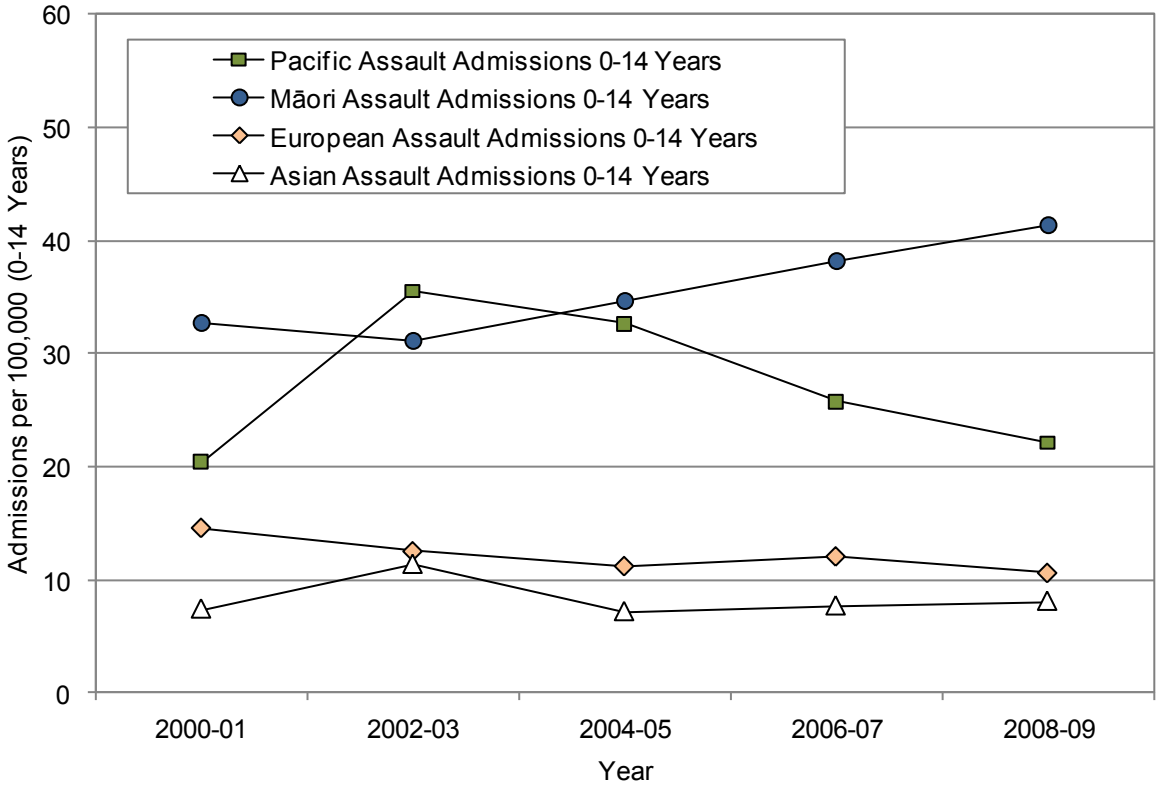
Source: Numerator Admissions: National Minimum Dataset, Numerator Mortality: National Mortality Collection; Denominator: Statistics NZ Estimated Resident Population.

Figure 104. Hospital Admissions (2005-2009) and Deaths (2003-2007) due to Injuries Arising from the Assault, Neglect or Maltreatment of New Zealand Children and Young People by Age and Gender



Source: Numerator Admissions: National Minimum Dataset, Numerator Mortality: National Mortality Collection; Denominator: Statistics NZ Estimated Resident Population

Figure 105. Hospital Admissions due to Injuries Arising from the Assault, Neglect or Maltreatment of Children 0-14 Years by Ethnicity, New Zealand 2000-2009



Source: Numerator: National Minimum Dataset; Denominator: Statistics NZ Estimated Resident Population. Ethnicity is Level 1 Prioritised.

Nature of the Injury Sustained

During 2005-2009, the type of intentional injury leading to hospital admission varied with the age of the child, with those in the 0-4 year age bracket tending to be assigned an ICD-10 Y07 "Maltreatment" code (including mental cruelty, physical abuse, sexual abuse or torture), while older children (particularly males aged 13-14 years) were more likely to be assigned to ICD-10 Y04 "Assault by Bodily Force" (including unarmed brawl or fight). While it is tempting to speculate that this reflects a transition towards assaults occurring in non-family contexts as children approach adolescence, the ICD-10 5th digit (describing the relationship of the victim to the perpetrator) was most frequently 9 (unspecified person), making such hypotheses difficult to substantiate. As a result of this likely transition however, the tables below consider only pre-school (0-4 years) and primary school (5-12 years) age children, with information on older children (13+ years) being considered in the youth assault section in last year's report.

During 2005-2009, the most common types of injury sustained as the result of the assault, neglect or maltreatment of children aged 0-4 years were subdural haemorrhages and superficial scalp injuries, followed by fractures of the skull and face and fractures of the femur. For children aged 5-12 years, head and upper limb injuries predominated, with superficial scalp injuries and fractures of the skull and facial bones being amongst the most common injuries (**Table 91**).

Table 90. Distribution of Hospital Admissions due to Injuries Arising from the Assault, Neglect or Maltreatment of Children 0-14 Years by Ethnicity, NZ Deprivation Index Decile and Gender, New Zealand 2005-2009

Variable	Number: Total 2005-2009	Rate per 100,000	Rate Ratio	95% CI
NZ Deprivation Index Decile				
Decile 1	23	5.3	1.00	
Decile 2	35	8.4	1.57	0.93 - 2.65
Decile 3	33	8.3	1.56	0.92 - 2.66
Decile 4	44	10.1	1.90	1.15 - 3.15
Decile 5	57	15.1	2.83	1.74 - 4.60
Decile 6	73	16.6	3.10	1.94 - 4.96
Decile 7	77	18.3	3.44	2.16 - 5.48
Decile 8	122	25.1	4.70	3.01 - 7.34
Decile 9	164	34.2	6.42	4.15 - 9.94
Decile 10	199	35.1	6.59	4.28 - 10.15
NZ Deprivation Index Quintile				
Decile 1-2	58	6.8	1.00	
Decile 3-4	77	9.3	1.36	0.97 - 1.91
Decile 5-6	130	15.9	2.33	1.71 - 3.17
Decile 7-8	199	22.0	3.22	2.40 - 4.31
Decile 9-10	363	34.7	5.09	3.86 - 6.71
Gender				
Female	291	13.4	1.00	
Male	555	24.3	1.82	1.58 - 2.10
Prioritised Ethnicity				
Asian	32	7.9	0.72	0.50 - 1.03
European	277	11.1	1.00	
Māori	408	37.9	3.43	2.94 - 3.99
Pacific	109	25.9	2.34	1.88 - 2.92

Source: Numerator: National Minimum Dataset; Denominator: Statistics NZ Estimated Resident Population. Rate is per 100,000 per year; Ethnicity is Level 1 Prioritised; Rate Ratios are unadjusted

Table 91. Nature of Injury Arising from Assault, Neglect or Maltreatment in Hospitalised Children 0-12 Years by Age Group, New Zealand 2005-2009

Nature of Injury	Total Number 2005-2009	% of Injuries to Age Group
Children 0-4 Years		
Traumatic Subdural Haemorrhage (S065)	105	29.0
Superficial Scalp Injury (S000)	55	15.2
Fracture Skull or Facial Bones (S02)	18	5.0
Other Head Injuries (Remainder S00-S09)	44	12.2
Injuries to Abdomen, Spine and Pelvis (S30-S39)	18	5.0
Injuries to Thorax (Including Rib Fractures) (S20-S29)	15	4.1
Injuries to Upper Limb (S40-S69)	24	6.6
Fracture of Femur (S72)	15	4.1
Other Injuries to Lower Limb (S70-S99)	16	4.4
Maltreatment Unspecified (T749)	38	10.5
Other Injuries	14	3.9
Total	362	100.0
Children 5-12 Years		
Superficial Scalp Injury (S000)	26	13.1
Fracture Skull or Facial Bones (S02)	18	9.1
Concussion (S060)	14	7.1
Other Head Injuries (Remainder S00-S09)	41	20.7
Injuries to Abdomen, Spine and Pelvis (S30-S39)	16	8.1
Injuries to Thorax (Including Rib Fractures) (S20-S29)	13	6.6
Injuries to Upper Limb (S40-S69)	36	18.2
Injuries to Lower Limb (S70-S99)	11	5.6
Maltreatment Unspecified (T749)	10	5.1
Other Injuries	13	6.6
Total	198	100.0

Source: National Minimum Dataset

Summary

In New Zealand during 2005-2009, hospital admissions for injuries sustained as the result of the assault, neglect or maltreatment of children exhibited a J-shaped distribution with age, with rates being highest for infants < 1 year, and those > 11 years of age. In contrast, mortality was highest for infants < 1 year. While the gender balance for admissions was relatively even during infancy and early childhood, hospital admissions for males became more predominant as adolescence approached. In addition, admissions were also significantly higher for males, Māori > Pacific > European and Asian children, and those in the most deprived areas.

In Taranaki during 2005-2009, hospital admissions for injuries arising from the assault, neglect or maltreatment of children were similar to the New Zealand average (RR 1.02 95% CI 0.67-1.55), with large year to year variations being evident during 2000-2009. During 2000-2007, 3 Taranaki children died as the result of assault, neglect or maltreatment.

APPENDICES AND REFERENCES

APPENDIX 1: STATISTICAL SIGNIFICANCE TESTING AND ITS USE IN THIS REPORT

Understanding Statistical Significance Testing

Inferential statistics are used when a researcher wishes to use a sample to draw conclusions about the population as a whole (e.g. weighing a class of 10 year old boys, in order to estimate the average weight of all 10 year old boys in New Zealand). Any measurements based on a sample however, even if drawn at random, will always differ from that of the population as a whole, simply because of chance. Similarly, when a researcher wishes to determine whether the risk of a particular condition (e.g. lung cancer) is truly different between two groups (smokers and non-smokers), they must also consider the possibility that the differences observed arose from chance variations in the populations sampled.

Over time, statisticians have developed a range of measures to quantify the uncertainty associated with random sampling error (i.e. to quantify the level of confidence we can have that the average weight of boys in our sample reflects the true weight of all 10 year old boys, or that the rates of lung cancer in smokers are really different to those in non-smokers). Of these measures, two of the most frequently used are:

P values: The p value from a statistical test tells us the probability that we would have seen a difference at least as large as the one observed, if there were no real differences between the groups studied (e.g. if statistical testing of the difference in lung cancer rates between smokers and non-smokers resulted in a p value of 0.01, this tells us that the probability of such a difference occurring if the two groups were identical is 0.01 or 1%. Traditionally, results are considered to be statistically significant (i.e. unlikely to be due to chance) if the probability is <0.05 (i.e. less than 5%) [209].

Confidence Intervals: A 95% Confidence Interval suggests that if you were to repeat the sampling process 100 times, 95 times out of 100 the confidence interval would include the true value. In general terms, if the 95% confidence intervals of two samples overlap, there is no significant difference between them (i.e. the p value would be ≥0.05), whereas if they do not overlap, they can be assumed to be statistically different at the 95% confidence level (i.e. the p value would be <0.05) [209].

The Use of Statistical Significance Testing in this Report

In the preparation of this report a large range of data sources were used. For the purposes of statistical significance testing however, these data sources can be considered as belonging of one of two groups: Population Surveys and Routine Administrative Datasets. The relevance of statistical testing to each of these data sources is described separately below:

Population Surveys: A number of indicators in this report utilise data derived from national surveys (e.g.2006/07 New Zealand Health Survey), where information from a sample has been used to make inferences about the population as a whole. In this context statistical significance testing is appropriate, and where such information is available in published reports, it has been incorporated into the text accompanying each graph or table (i.e. the words significant, or not significant in italics are used to imply that a test of statistical significance has been applied to the data and that the significance of the associations are as indicated). In a small number of cases however information on statistical significance was not available in published reports, and in such cases any associations described do not imply statistical significance.

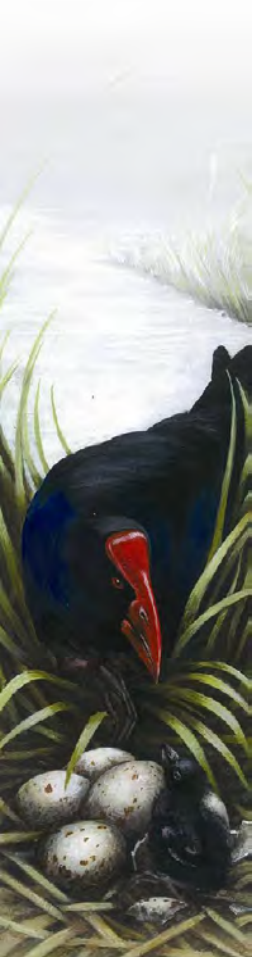
Numbers and Rates Derived from Routine Administrative Data: A large number of the indicators in this report are based on data derived from New Zealand's administrative datasets (e.g. National Minimum Dataset, National Mortality Collection), which capture

information on all of the events occurring in a particular category. Such datasets can thus be viewed as providing information on the entire population, rather than a sample and as a consequence, 95% confidence intervals are not required to quantify the precision of the estimate (e.g. the number of leukaemia deaths in 2003-2007, although small, is not an estimate but rather reflects the total number of deaths during this period). As a consequence, 95% confidence intervals have not been provided for any of the descriptive data (numbers, proportions, rates) presented in this report, on the basis that the numbers presented are derived from the total population under study.

Rate Ratios Derived from Routine Administrative Data: In considering whether statistical significance testing is ever required when using total population data Rothman [210] notes that if one wishes only to consider descriptive information (e.g. rates) relating to the population in question (e.g. New Zealand), then statistical significance testing is probably not required (as per the argument above). If however, one wishes to use total population data to explore biological phenomena more generally, then the same population can also be considered to be a sample of a larger super-population, for which statistical significance testing may be required (e.g. the fact that SIDS in New Zealand is 10 times higher in the most deprived NZDep areas might be used to make inferences about the impact of the socioeconomic environment on SIDS mortality more generally (i.e. outside of New Zealand, or the 5 year period concerned)). Similarly, in the local context the strength of observed associations is likely to vary with the time period under study (e.g. in updating 5-year asthma admission data from 2004-2008 to 2005-2009, rate ratios for Pacific children are likely to change due to random fluctuations in annual rates, even though the data utilised includes all admissions recorded for that particular 5-year period). Thus in this report, whenever measures of association (i.e. rate ratios) are presented, 95% confidence intervals have been provided on the assumption that the reader may wish to use such measures to infer wider relationships between the variables under study [210].

The Signalling of Statistical Significance in this Report

In order to assist the reader to identify whether tests of statistical significance have been applied in a particular section, the significance of the associations presented has been signalled in the text with the words *significant*, or *not significant* in italics. Where the words *significant* or *non-significant* do not appear in the text, then the associations described do not imply statistical significance or non-significance.



APPENDIX 2: SEARCH METHODS FOR POLICY DOCUMENTS AND EVIDENCE BASED REVIEWS

One of the features of this reporting series is the inclusion of sections which briefly review local policy documents (e.g. Ministry of Health Strategies / Toolkits) and international evidence based reviews relevant to the prevention / management of child and youth health issues. The approaches taken in these sections borrow heavily from the principles of the Evidence Based Medicine (EBM) movement, which has emerged in recent years as a means of providing busy clinicians with up to date overviews of the evidence in particular areas [211]. Such overviews generally rely on reviewers collating all of the available evidence (e.g. published and unpublished trials and observational studies), evaluating this in a rigorous manner, and then publishing the resulting synthesis in a format which allows clinicians to quickly evaluate the effectiveness of the intervention(s) reviewed. While the evidence base for population level interventions is much less developed than for individual patient therapies (as such interventions often have longer follow up times, more diffuse outcomes, and less readily identifiable "control" groups [212]), there is nevertheless a reasonable body of evidence emerging as to the effectiveness of population level interventions in particular areas.

The brief overviews presented in this report, thus aim to provide busy DHB staff with a logical starting point for considering the types of intervention available to address particular child and youth health issues. In preparing these overviews however, the methodology used was not exhaustive, but rather involved searching a restricted number of EBM journals and databases (e.g. the Cochrane Library) for systematic reviews of population level interventions in child and youth health (see Text Box below).

Methodology Used in Preparing Policy / Evidence Based Review Tables

New Zealand (Health) Policy Documents

Each review table aims to provide an overview of Ministry of Health (or where appropriate, other Government Agency) policy documents and strategies relevant to the area. The Ministry of Health's website (http://www.MOH.govt.nz) was searched for key documents. All identified documents were then scanned and the most relevant summarised, with the focus being on those which provided strategic guidance to DHBs on the prevention / population level management of the issues in question.

Evidence Based and Other Reviews

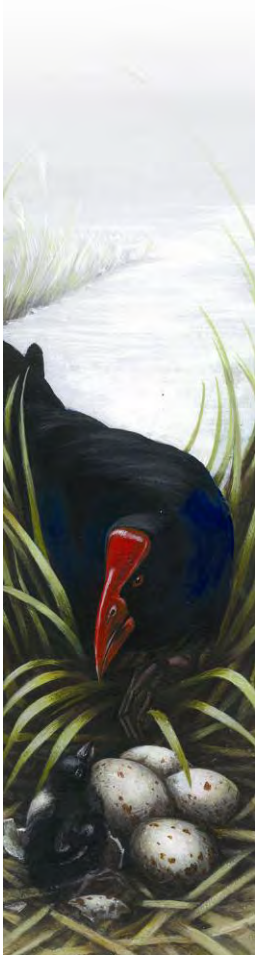
The five databases listed below were searched for reviews which considered the effectiveness of population level interventions to prevent / manage each of the issues in question. While this list is not exhaustive, the databases were selected on the basis of the calibre of the institutions publishing the reviews. In addition, the search strategy concentrated on publications which attempted to synthesise all of the available evidence, thereby providing as broad as possible coverage of the relevant literature. In general, only literature from 2000 onwards was searched, although earlier publications were included if there was a paucity of more recent information. While individual trials and protocols were not specifically sought, if there was no other relevant information available, an attempt was made to locate individual research reports or recommendations. While not being exhaustive, it is nevertheless hoped that these brief overviews will provide a useful starting point for DHBs wishing to explore strategies to address particular child and youth health issues.

Evidence Based Medicine Reviews-Full Text: This allows three databases to be searched simultaneously:
1) The ACP Journal Club comprising two journals; ACP Journal Club and Evidence-Based Medicine
2) The Cochrane Database of Systematic Reviews, and
3) The Database of Reviews of Effects (DARE) produced by National Health Services' Centre for Reviews and Dissemination at the University of York, UK.

The Health Care Needs Assessment Series: This was funded by the U.K. Department of Health/National Institute of Clinical Excellence and was compiled and managed in the Department of Public Health and Epidemiology at the University of Birmingham between 1991 and 2000. (http://www.hcna.bham.ac.uk/)

Centre for Reviews and Dissemination (CRD): This is a Department of the University of York and is part of the National Centre for Health Research (NCHR) (http://www.york.ac.uk/inst/crd/). While CRD produces the database of Review Effects (DARE), captured in the Evidence Based Medicine Review Database, searching the CRD site identifies other reviews not captured by DARE. This database is available through most local library services.

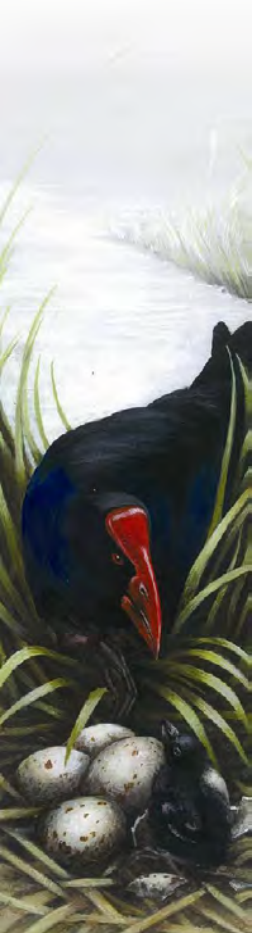
National Institute for Health and Clinical Excellence (NICE): This is an independent organisation based in the United Kingdom which provides national guidance on promotion of the promotion of good health, and on the prevention and treatment of ill health. (http://www.nice.org.uk)



Guide to Community Preventive Services: Systematic Reviews and Evidence Based Recommendations: This guide was developed by the non-federal Task Force on Community Preventive Services whose members are appointed by the Director of the Centre for Disease Control and Prevention (CDC) (http://www.thecommunityguide.org/about/). The Guide summarises what is known about the effectiveness, economic efficiency, and feasibility of interventions to promote community health and prevent disease.

While undertaking this task, it quickly became apparent that the quality of evidence varied considerably depending on the issue reviewed (e.g. while a considerable literature exists on the effective management of cystic fibrosis, there was a paucity of evidence based solutions for the prevention of congenital anomalies (with the exception of folic acid and neural tube defects)). In addition, in some cases the research provided reasonably strong guidance as what did not work, but little advice as to effective interventions which would.

Thus in many cases, the brief overview tables serve to highlight the current paucity of evidence on population level interventions to address child and youth health need (although the absence of systematic / other reviews, does not rule out the existence of individual studies in particular areas). In this context, while the search strategy utilised did not primarily aim to identify individual studies, or reviews of individual patient therapies, in cases where such studies were identified, and where no other systematic reviews were available, they were included under the heading of *Other Relevant Publications*. In such cases however, the reader needs to be reminded that these studies were identified in a non-systematic manner and that their findings should thus not be given the same weight as systematic reviews (e.g. Cochrane reviews) where all the available evidence has been evaluated using a rigorous methodology.



APPENDIX 3: DATA QUALITY GRADING SYSTEM FOR INDICATORS IN THIS REPORT

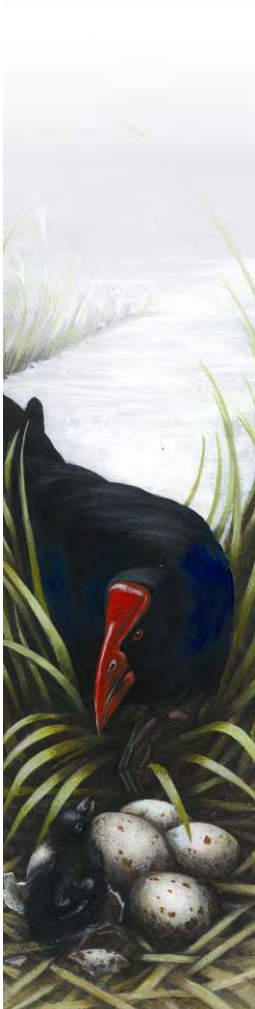
One of the central aims of the initial Child and Youth Health Indicator project undertaken by the Paediatric Society was to develop an overall map of all of the issues which needed to be taken into account when planning child and youth health services and strategies at a population level. Yet very early on in the course of consultation it became apparent that adequate data sources were available for only a fraction of the issues that those working in the health sector considered important to child and youth health. In order to ensure that issues for which adequate data was available did not take undue precedence over those for which reliable data was lacking, it was decided that a set of indicator selection criteria would be developed, which awarded a high priority to issues of public health importance. Where an issue was deemed to have met these criteria but where routine data sources were lacking, "non-traditional" data sources would then be considered, in order to ensure that the issue did not fall below the public health radar.

Such an approach however, meant that many of the indicators included in the Indicator Framework may not have met the stricter data quality criteria utilised by other Government agencies. In order to highlight the impacts that such data quality issues may have had on the interpretability of the data, it was felt necessary to grade each indicator on the degree to which it captured the issue it was designed to measure, as well as the quality of its data source. Thus each indicator in the framework was assigned to one of three categories: Ideal, Proxy or Bookmark, and an assessment made as to whether its data sources were Excellent (A), Adequate (B), or whether Further Work (C) was required in order to improve the interpretability of the indicator (**Table 92**). These categories are outlined below:

Ideal Indicators: An indicator was considered ideal if it offered the potential to measure the total extent of a particular issue e.g. because the birth registration dataset captures >99% of births in New Zealand and information on gestational age is >98% complete, the preterm birth indicator derived from this dataset was considered ideal, in that it allowed conclusions to be drawn about trends in the incidence of preterm birth over time.

Proxy Indicators: In many cases, while it was not possible to measure the full extent of an issue, it was possible to assess the number of children and young people attending publicly funded services for its management e.g. while hospital admission data is unable to provide any commentary on the total number of injuries occurring in the community (as many injuries are treated in primary care, or at home), such data is nevertheless useful for assessing the workload such injuries create for secondary and tertiary services. One of the chief limitations of proxy indicators, however, is the variable extent to which they capture the total burden of morbidity (e.g. while nearly all non-fatal cases of meningococcal disease are likely to be captured by hospital admission data, the same datasets are likely to record only a fraction of gastroenteritis cases occurring in the community). While it is generally assumed that if admission thresholds remain constant (i.e. that children with a given level of severity for a condition will be managed in the same way), then such indicators can be used to track trends in the underlying burden of morbidity, in reality such thresholds are very seldom static and vary in ways which are both predictable (e.g. the introduction of pulse oximetry altering admission thresholds for infants with bronchiolitis over time) and unpredictable (e.g. differences in the ways in which DHBs upload their emergency department cases to the National Minimum Dataset). Thus while being of considerable utility in planning for future health service demand, such indicators are less useful for tracking temporal trends in the total burden of morbidity occurring in the community.

Bookmark Indicators: In many cases, consultation suggested that there was a need for indicators in areas where no data sources existed e.g. indicators to assess the prevalence of disability amongst New Zealand children by diagnostic category (e.g. autism, cerebral palsy) and by degree of functional impairment (e.g. visual acuity, degree of hearing loss).



While more traditional approaches to indicator development might have suggested that such issues should be excluded from the monitoring framework until such time as high quality data sources could be developed, such approaches may also have inadvertently resulted in the needs of children and young people with these conditions slipping below the public health radar, and as a consequence being awarded a lesser priority in resource allocation decisions. Thus it was decided that a number of “Bookmark Indicators” should be created, which served to highlight particular issues until such time as more appropriate data sources could be developed. Where possible, such indicators would use currently available data sources to capture particular facets of the wider issue e.g. over time sections on Mental Health have included indicators such as – Children Calling Telephone Based Counselling Services, Inpatient Hospital Admissions for Mental Health Issues and Hospital Admissions and Mortality from Self Inflicted Injuries. While it is acknowledged that collectively these indicators fail to capture the full scope of child and youth mental health issues (the majority of which are managed on an outpatient basis and are thus not adequately represented by inpatient hospital admissions), it is nevertheless hoped that these indicators will serve as a “Bookmark” for child and youth mental health issues, until such time as better indicators can be developed.

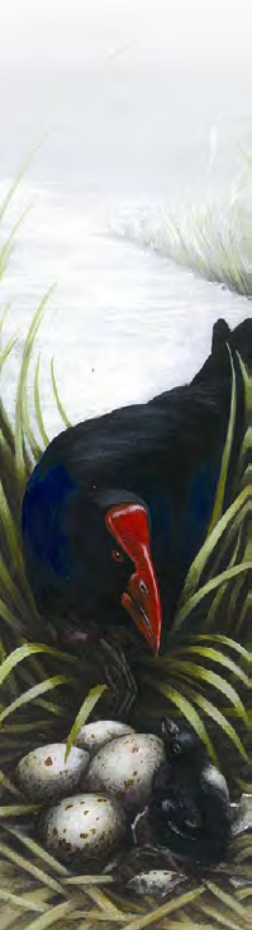


Table 92. Indicator Categories Based on the Type of the Indicator and the Quality of its Data Source

Indicator Type	Data Quality		
	Excellent (A)	Adequate (B)	Further Work Required (C)
Ideal	Measures total extent of an issue and data quality permits appropriate interpretation of trends and population level differences (No NZ indicators currently in this category)	Measures total extent of an issue and data quality permits adequate interpretation of information once the limitations of the datasets have been outlined e.g. Interpretation of trends in highest attainment at school leaving requires an understanding of changes associated with the roll out of the NCEA which began in 2002. While such changes make interpretation of trends difficult, improvements in data quality per se are unlikely to improve this situation	Measures total extent of an issue but data quality limits appropriate interpretation e.g. While theoretically the MOH's two oral health indicators provide near complete coverage of children at 5 and 12 years of age, in reality information is only collected on those who have completed treatment, potentially discounting the poor oral health status of children still undergoing treatment for dental caries at these points in time
Proxy	Measures attendances at publicly funded services for management of an issue and data quality permits appropriate interpretation of trends and population level differences (No NZ indicators currently in this category)	Measures attendances at publicly funded services for management of an issue and data quality permits adequate interpretation once the limitations of the datasets have been outlined e.g. Hospital admission data, when combined with mortality data, provides a reasonable overview of the incidence of invasive meningococcal disease. While a number of data quality issues apply to all indicators derived from these datasets (e.g. accuracy of coding), such limitations are unlikely to significantly hinder the interpretation of the data in this context	Measures attendances at publicly funded services for management of an issue but data quality currently limits appropriate interpretation e.g. Because of the inconsistent manner in which some DHBs have uploaded their emergency department cases to the hospital admission dataset over time, it is difficult to interpret trends in hospital admissions for minor injuries with any certainty. Thus while cross sectional analyses provide an overview of the types if injuries presenting to secondary and tertiary services, interpretation of trend data is significantly impeded by the quality of the datasets
Bookmark	Measures one facet of a wider issue, or provides a brief overview of the literature in an area where no data sources currently exist. Data quality for isolated facets permits appropriate interpretation. (No NZ indicators currently in this category)	Measures one facet of a wider issue, or provides a brief overview of the literature in an area where no data sources currently exist. Data quality for isolated facets permits adequate interpretation once the limitations of the datasets have been outlined e.g. The 2006/07 New Zealand Health Survey provides a reasonable snapshot of overweight and obesity amongst New Zealand children at a single point in time. For this isolated snapshot, data quality permits adequate interpretation of the issues covered by this survey	Measures one facet of a wider issue, or provides a brief overview of the literature in an area where no data sources currently exist. Data quality for isolated facets limits appropriate interpretation e.g. In the absence of routine data on the extent of alcohol related harm amongst New Zealand young people, an analysis of hospital admissions with mention of alcohol in any of the first 15 diagnostic codes provides a snapshot of the types of issues presenting to secondary care services. Significant data quality issues however preclude this data being used to make any inferences about trends in alcohol related harm

APPENDIX 4: THE NATIONAL MINIMUM DATASET

Mode of Data Collection

The National Minimum Dataset (NMDS) is New Zealand's national hospital discharge data collection and is maintained by the Ministry of Health. The information contained in the dataset has been submitted by public hospitals in a pre-agreed electronic format since 1993. Private hospital discharges for publicly funded events (e.g. births, geriatric care) have been submitted since 1997. The original NMDS was implemented in 1993, with public hospital information back loaded to 1988 [213]. Information contained in the NMDS includes principal and additional diagnoses, procedures, external causes of injury, length of stay and sub-specialty code and demographic information such as age, ethnicity and usual area of residence.

Dataset Quality and Changes in Coding Over Time

There are a number of key issues which must be taken into account when interpreting information from the NMDS. Many of these issues arise as a result of regional differences in the way in which data is coded and uploaded to the NMDS. These include

1. Inconsistencies in the way in which different providers upload day cases to the NMDS, and how this has changed over time.
2. The changeover from the ICD-9 to ICD-10 coding system, and irregularities in the way in which diagnoses and procedures are allocated ICD codes.
3. Changes in the way in which ethnicity information has been collected over time and across regions (**Appendix 6**).

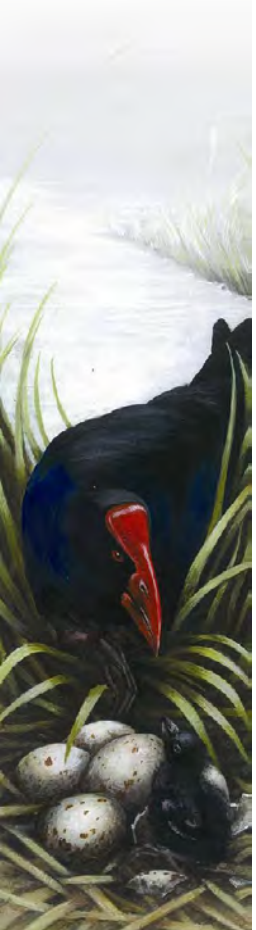
The following sections discuss the first two if these issues, while the third is discussed in Appendix 6, which reviews the way in which ethnicity information is collected and coded within the health sector.

1. Inconsistencies in the Uploading of Day-Cases to the NMDS

One of the key issues with time series analysis using hospital discharge data is the variability with which different providers upload day cases to the NMDS. Day cases are defined as cases that are admitted and discharged on the same day, with the "three hour rule" (treatment time >3 hours) traditionally being utilised to define an admission event. In contrast patients who spend at least one (mid)night in hospital are classified as inpatients irrespective of their length of stay [214].

In the past, there have been significant regional variations in the way in which different providers have uploaded their day cases to the NMDS, leading to problems with both time series analysis and regional comparisons. These inconsistencies have included

1. During the mid 1990's, a number of providers began to include A&E events as day cases if the total time in the Emergency Department (including waiting time) exceeded 3 hours, rather than uploading only those whose actual treatment time exceeded 3 hours [214]. NZHIS provided feedback which rectified this anomaly and since January 1995 the correct procedure has been used (these additional cases were coded using medical and surgical sub-specialty codes and are thus difficult to filter out using traditional Emergency sub-specialty filters).
2. Over time, a number of providers have become more efficient at recording the time of first treatment within the Emergency Department (rather than time of attendance) and thus during the late 1990s and early 2000s have become more efficient in identifying emergency department cases which meet the 3-hour treatment rule and are thus eligible to be uploaded to the NMDS. This has resulted in a large number of additional cases being uploaded to the NMDS, particularly in the upper North Island.



3. In addition, some providers admit cases to their short stay observation units while other providers do not, leading to regional variations in the appearance of day cases in the NMDS [215].

Previous Attempts to Address Inconsistent Uploading at the Analytical Stage

When producing their annual Hospital Throughput reports, the Ministry of Health has adopted the following filter to ensure regional and time series comparability with respect to day patient admissions [215]. In its analyses it excludes all cases where:

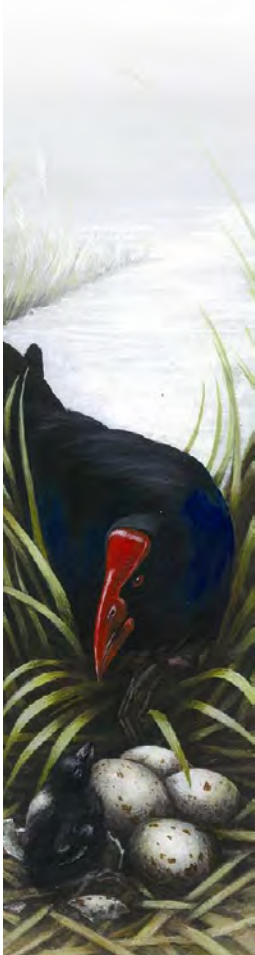
1. the admission and discharge date are the same (length of stay = 0)
2. and the patient was discharged alive
3. and the health specialty code on discharge is that of Emergency Medicine (M05, M06, M07, and M08).

While this coding filter succeeds in ensuring a degree of comparability between regions and across time (although it fails to correct the anomalies occurring during the mid 1990s when A&E cases were uploaded using medical sub-specialty codes), the exclusion of emergency day cases from time series analysis has a number of limitations including:

1. Exclusion of only those with a length of stay of 0 days means that those emergency cases who begin their treatment late at night and are discharged in the early hours of the following morning (up ¼ of emergency cases have a length of stay of 1 day in some DHBs) are included as genuine hospital admissions, whereas those who begin their treatment early in the morning and are discharged late in the afternoon or the evening of the same day are excluded.
2. With a move towards the development of specialist paediatric emergency departments in larger urban centres (e.g. Auckland), there remains the possibility that some larger DHBs are now seeing and treating a number of acute medical patients within the emergency setting, while in regional centres similar patients continue to be assessed on the paediatric medical ward / assessment unit and thus receive a paediatric medical specialty code. The exclusion of all emergency presentations from time series and sub-regional analysis may thus differentially exclude a large portion of the workload occurring in large urban centres where access to specialist advice and treatment is available within the Emergency Department setting.

The potential impact of inconsistent uploading of day cases to the NMDS is likely to be greatest for those conditions most commonly treated in the emergency department setting. Analysis of 2001-2003 hospital admission data suggests that >1/3 of NMDS emergency department discharges for those 0-24 years were due to injury, with another 1/3 were due to ambulatory sensitive conditions (e.g. asthma, gastroenteritis, respiratory infections). In contrast, only 2% of those presenting with bacterial meningitis and 4% of those with septic arthritis were discharged with an emergency sub-specialty code.

Further sub-analysis of these two admission categories however demonstrated that inclusion / exclusion of emergency department admissions had quite different effects depending on the category of admission under study (injury vs. ambulatory sensitive admissions) and whether the region had access to a specialist Paediatric Emergency Department. In this analysis the Wider Auckland Region, (comprising 1/3 of the NZ population and whose residents have access to specialist Paediatric Emergency Departments) was compared to the rest of NZ. For ambulatory sensitive admissions, exclusion of emergency department cases resulted in Auckland's admission rates being consistently lower than in the rest of New Zealand. It was only when emergency cases were included in this analysis that Auckland's admission rates began to approximate those of the rest of NZ. In contrast for injuries, inclusion of emergency department cases resulted in hospital admissions in the Auckland Region consistently exceeding the rest of New Zealand. It was only when emergency cases were excluded from the analysis that Auckland's injury admission rates began to approximate those of the rest of NZ. (These findings occurred despite Auckland having a similar proportion of children living in the most deprived NZDep small areas as the rest of NZ).



Loosely interpreted, the findings of this analysis suggest that the workload of large specialist paediatric emergency departments must not be discounted when examining trends in ambulatory sensitive or other medical admissions, as it is only when emergency cases are included in the analysis that the admission rates of the Wider Auckland Region (with its access to Specialist Paediatric Emergency care) begin to approximate the rest of NZ. In contrast, it is possible that specialist paediatric emergency departments have much less of an influence on admission thresholds for injury, with these being handled in a similar manner by different emergency departments across the country. Thus for injury data, the greater tendency for some emergency departments to upload their cases to the NMDS must be taken into account in any analysis.

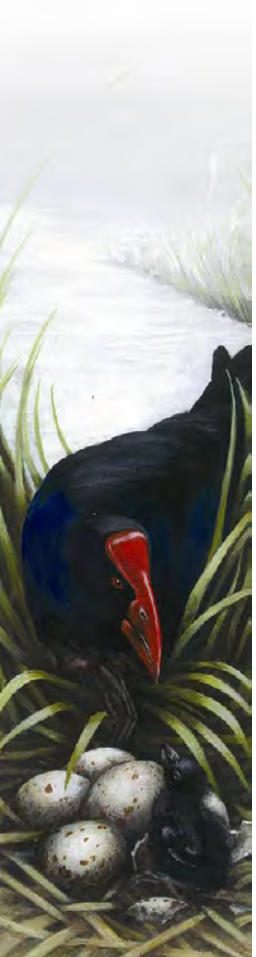
Implications for Interpreting Time Series Analyses in these Reports

Throughout this report, analysis of time series and other information has been undertaken using unfiltered hospital admission data, with the exception of the injury and poisoning sections. Here emergency department discharges have been filtered out of the dataset, in an attempt to address some of the inconsistencies discussed above. Despite such an approach, there remains the potential for the inconsistent uploading of day cases to significantly influence the time series analyses presented in this report. In particular, such practices may lead to an over estimate of the number of medical admissions commonly treated in the emergency department setting (e.g. asthma, skin infections, respiratory tract infections), while at the same time the filtering out of injury/poisoning emergency cases may lead to undercounting for a number of more minor types of injury. Nevertheless, the filtering process utilised in this report are thought to provide the best balance when considering hospital admissions amongst those 0-24 years. Despite this, the reader must bear in mind that a potential for significant residual bias remains, when interpreting the time series analyses presented in this report.

2. Data Quality and Coding Changes over Time (ICD-9 and ICD-10)

Change Over from ICD-9 to ICD-10 Coding

From 1988 until June 1999, clinical information in the NMDS was coded using versions of the ICD-9 classification system (ICD-9 CM until June 1995, then ICD-9-CM-A until June 1999). From July 1999 onwards, the ICD-10-AM classification system has been used, although for time series analysis, back and forward mapping between the two classification systems is possible fusing pre-defined algorithms [213].



The introduction of ICD-10-AM represents the most significant change in the International Classification of Diseases (ICD) in over 50 years and uses an alphanumeric coding system for diseases in which the first character of the code is always a letter followed by several numbers. This has allowed for the expansion of the number of codes to provide for recently recognised conditions and to provide greater specificity about common diseases (there are about 8,000 categories in ICD-10-AM as compared to 5,000 in ICD-9). While for most conditions there is a reasonable 1:1 correspondence between ICD-9 and ICD-10 codes, for some this may lead to some irregularities in time series analysis [216]. Where possible such irregularities will be highlighted in the text, although care should still be taken when interpreting time series analysis across the 1999-2000 period as some conditions may not be directly comparable between the two coding systems.

Accuracy of ICD Coding

In recent years the Ministry of Health has undertaken a number of reviews of the quality of ICD coding in the NMDS. In the latest audit 2708 events were audited over 10 sites during a 3 month period during 2001/2002. Overall the audit found that 22% of events required a change in coding, although this also included changes at the fourth and fifth character level. The average ICD code change was 16%, with changes to the principal diagnosis being 11%, to additional diagnoses being 23% and to procedure coding being 11%. There were 1625 external causes of injury codes, of which 15% were re-coded differently [217]. These findings were similar to an audit undertaken a year previously.

While the potential for such coding errors must be taken into consideration when interpreting the findings of this report, it may be that the 16% error rate is an overestimate,

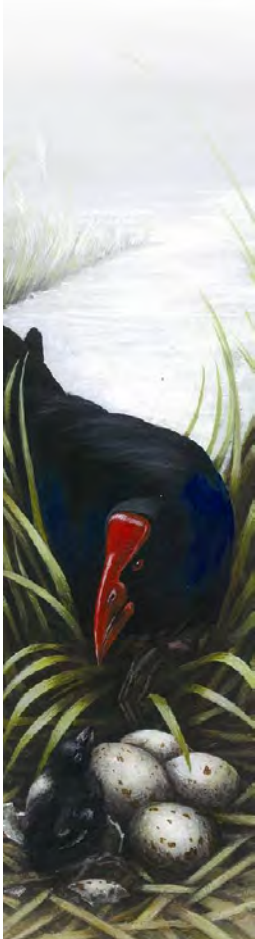
as in the majority of the analyses undertaken in this report, only the principal diagnosis (with an error rate of 11%) is used to describe the reason for admission. In addition, for most admissions the diagnostic category (e.g. lower respiratory tract infections) is assigned using information at the 3 digit level (with the 16% error rate also including issues with coding at the 4th or 5th digit level).

3. Ethnicity Information in the NMDS

The reader is referred to **Appendix 6** for a discussion of this issue.

Conclusion

In general the inconsistencies outlined above tend to make time series and (regional) comparative analyses based on the NMDS less reliable than those based on Mortality or Birth Registration data (where legislation dictates inclusion criteria and the type of information collected). While hospital discharge data still remains a valuable and reasonably reliable proxy for measuring the health outcomes of children and young people in this country, the reader is cautioned to take into consideration the biases discussed above, when interpreting the findings outlined in this report.



APPENDIX 5: NATIONAL MORTALITY COLLECTION

Mode of Data Collection

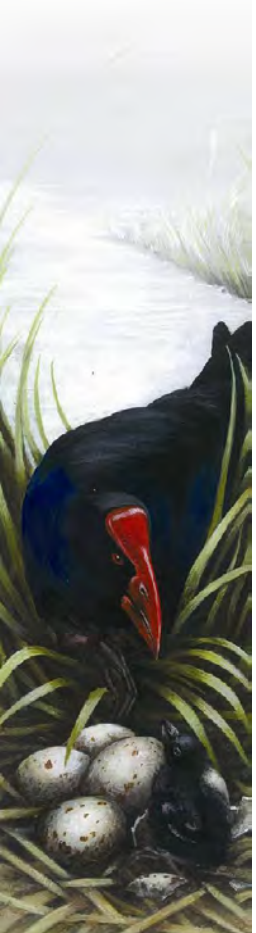
The National Mortality Collection is a dataset managed by the Ministry of Health, which contains information on the underlying cause(s) of death, as well as basic demographic data, for all deaths registered in New Zealand since 1988. Foetal and infant data is a subset of the Mortality Collection, with cases in this subset having additional information on factors such as birth weight and gestational age [218].

Each month Births, Deaths and Marriages send the Ministry of Health electronic death registration information, Medical Certificates of Cause of Death, and Coroner's reports. Additional information on the cause of death is obtained from the National Minimum Dataset (NMDS), private hospital discharge returns, the NZ Cancer Registry (NZCR), the Department of Courts, the Police, the Land Transport Authority, Water Safety NZ, Media Search and from writing letters to certifying doctors, coroners and medical records officers in public hospitals. Using information from these data sources, an underlying cause of death (ICD-10-AM) is assigned by MoH staff using the World Health Organisation's rules and guidelines for mortality coding [218].

Data Quality Issues Relating to the National Mortality Collection

Unlike the NMDS, where information on the principal diagnosis is coded at the hospital level and then forwarded electronically to the MoH, in the National Mortality Collection each of the approximately 28,000 deaths occurring in New Zealand each year is coded manually by MoH staff. For most deaths the Medical Certificate of Cause of Death provides the information required, although coders also have access to the information contained in the NMDS, NZ Cancer Registry, LSTA, Police, Water Safety NZ and ESR [219]. As a consequence, while coding is still reliant on the accuracy of the death certificate and other supporting information, there remains the capacity for a uniform approach to the coding which is not possible for hospital admission data.

While there are few published accounts of the quality of coding information contained in the National Mortality Collection, the dataset lacks some of the inconsistencies associated with the NMDS, as the process of death registration is mandated by law and there are few ambiguities as to the inclusion of cases over time. As a consequence, time series analyses derived from this dataset are likely to be more reliable than that provided by the NMDS. One issue that may affect the quality of information derived from this dataset however is the collection of ethnicity data, which is discussed in more detail in Appendix 6 of this report.



APPENDIX 6: MEASUREMENT OF ETHNICITY

The majority of rates calculated in this report rely on the division of numerators (e.g. hospital admissions, mortality data) by Statistics New Zealand Estimated Resident Population denominators. Calculation of accurate ethnic specific rates relies on the assumption that information on ethnicity is collected in a similar manner in both the numerator and the denominator, and that a single child will be identified similarly in each dataset. In New Zealand this has not always been the case, and in addition the manner of collecting information on ethnicity has varied significantly over time. Since 1996 however, there has been a move to ensure that ethnicity information is collected in a similar manner across all administrative datasets in New Zealand (Census, Hospital Admission, Mortality, Births). The following section briefly reviews how information on ethnicity has been collected in national data collections since the early 1980s and the implications of this for the information contained in this report.

1981 Census and Health Sector Definitions

Earlier definitions of ethnicity in official statistics relied on the concept of fractions of descent, with the 1981 census asking people to decide whether they were fully of one ethnic origin (e.g. Full Pacific, Full Māori) or if of more than one origin, what fraction of that ethnic group they identified with (e.g. 7/8 Pacific + 1/8 Māori). When prioritisation was required, those with >50% of Pacific or Māori blood were deemed to meet the ethnic group criteria of the time [220]. A similar approach was used to recording ethnicity in health sector statistics, with birth and death registration forms asking the degree of Pacific or Māori blood of the parents of a newborn baby / the deceased individual. For hospital admissions, ancestry based definitions were also used during the early 1980s, with admission officers often assuming ethnicity, or leaving the question blank [221].

1986 Census and Health Sector Definitions

Following a review expressing concern at the relevance of basing ethnicity on fractions of descent, a recommendation was made to move towards self-identified cultural affiliation. Thus the 1986 Census asked the question “What is your ethnic origin?” and people were asked to tick the box(s) that applied to them. Birth and death registration forms however, continued to use the “fractions of blood” question until 1995, making comparable numerator and denominator data difficult to obtain [220]. For hospital admissions, the move from an ancestry based to a self-identified definition of ethnicity began in the mid-80s, although non-standard forms were used and typically allowed a single ethnicity only [221].

1991 Census and Health Sector Definitions

A review suggested that the 1986 ethnicity question was unclear as to whether it was measuring ancestry or cultural affiliation, so the 1991 Census asked two questions:

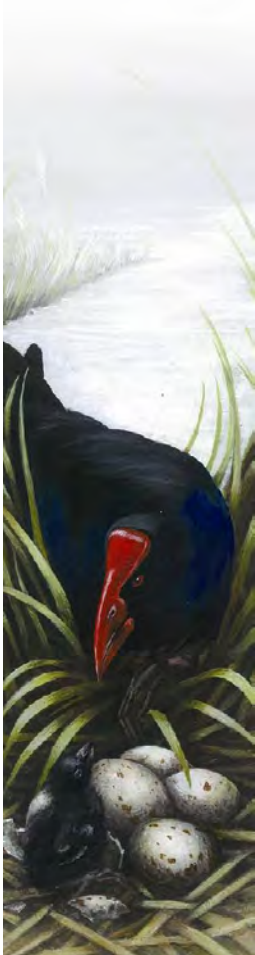
1. Which ethnic group do you belong to? (tick the box or boxes which apply to you)
2. Have you any NZ Māori ancestry? (if yes, what iwi do you belong to?)

As indicated above however, birth and death registrations continued with ancestry based definitions of ethnicity during this period, while a number of hospitals were beginning to use self-identified definitions in a non standard manner [221].

1996 Census and Health Sector Definitions

While the concepts and definitions remained the same as for the 1991 census, the ethnicity question in the 1996 Census differed in that:

- The NZ Māori category was moved to the top of the ethnic categories
- The 1996 question made it more explicit that people could tick more than 1 box.
- There was a new “Other European” category with 6 sub groups



As a result of these changes, there was a large increase in the number of multiple responses, as well as an increase in the Māori ethnic group in the 1996 Census [220]. Within the health sector however, there were much larger changes in the way in which ethnicity information was collected. From late 1995, birth and death registration forms incorporated a new ethnicity question identical to that in the 1996 Census, allowing for an expansion of the number of ethnic groups counted (previously only Māori and Pacific) and resulting in a large increase in the proportion of Pacific and Māori births and deaths. From July 1996 onwards, all hospitals were also required to inquire about ethnicity in a standardised way, with a question that was compatible with the 1996 Census and that allowed multiple ethnic affiliations [221]. A random audit of hospital admission forms conducted by Statistics NZ in 1999 however, indicated that the standard ethnicity question had not yet been implemented by many hospitals. In addition, an assessment of hospital admissions by ethnicity over time showed no large increases in the proportions of Māori and Pacific admissions after the 1996 "change over", as had occurred for birth and death statistics, potentially suggesting that the change to a standard form allowing for multiple ethnic affiliations in fact did not occur. Similarities in the number of people reporting a "sole" ethnic group pre and post 1996 also suggest that the way in which information on multiple ethnic affiliations was collected did not change either. Thus while the quality of information available since 1996 has been much better than that previously, there remains some concern that hospitals continue to undercount multiple ethnic identifications and as a result, may continue to undercount Pacific and Māori peoples [221].

2001 Census and Health Sector Definitions

The 2001 Census reverted back to the wording used in the 1991 Census after a review showed that this question provided a better measure of ethnicity based on the current statistical standard [220]. The health sector also continued to use self-identified definitions of ethnicity during this period, with the *Ethnicity Data Protocols for the Health and Disability Sector* providing guidelines which ensured that the information collected across the sector was consistent with the wording of the 2001 Census (i.e. *Which ethnic groups do you belong to (Mark the space or spaces that apply to you)?*)

2006 Census Questions

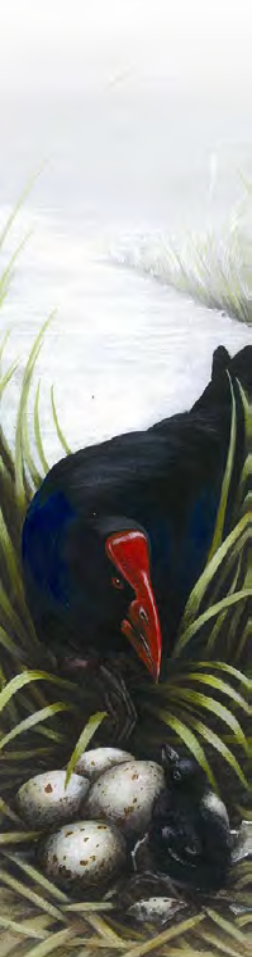
The 2006 Census used identical wording to the 2001 Census. Within the "Other" ethnic group however, a new category was created which allowed for the responses of those identifying as a "New Zealander". In previous years this sub-category had been assigned to the European ethnic group. At the 2006 Census, a total of 429,429 individuals (10.6% of the NZ population) identified themselves as a New Zealander, a large increase from previous years and a trend, which if continued, poses a serious threat to the availability of valid population denominators for use with health sector data. As yet the consequences of this change have not been fully addressed by the health sector and in this report, where prioritised ethnicity has been used, 2006 Census data has combined the New Zealander category with the European category, as per the protocol in previous censuses.

The Current Recording of Ethnicity in New Zealand's National Datasets

In New Zealand at present, only 3 ethnic groups per person are currently stored electronically in the National Minimum Dataset and the National Mortality Collection, with Statistics New Zealand's prioritisation algorithms being used if more than 3 ethnic groups are identified [213]. These datasets also use Statistics New Zealand's Hierarchical Ethnicity Classification, which has 4 levels, each providing greater detail:

- Level 1 (least detailed level) e.g. code 1 is European
- Level 2 e.g. code 12 is Other European
- Level 3 e.g. code 121 is British and Irish
- Level 4 (most detailed level) e.g. code 12111 is Celtic

For those reporting multiple ethnic affiliations, information may also be prioritised according to Statistics New Zealand's protocols, with Māori ethnicity taking precedence over Pacific > Asian > Other > European ethnic groups [222]. This ensures that each individual is counted only once and that the sum of the ethnic group sub-populations

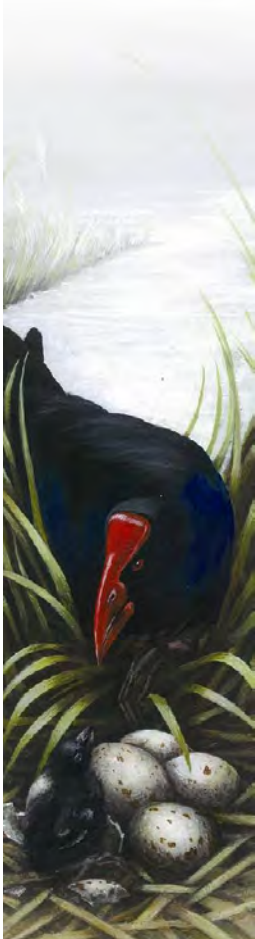


equals the total NZ population [221]. The implications of prioritisation for Pacific groups however are that the outcomes of those identifying as both Māori and Pacific are only recorded under the Māori ethnic group.

Ethnicity Classifications Utilised in this Report and Implications for Interpretation of Results.

Because of inconsistencies in the manner in which ethnicity information was collected prior to 1996, all ethnic specific analysis presented in this report are for the 1996 year onwards. The information thus reflects self-identified concepts of ethnicity, with Statistics NZ's Level 1 Ethnicity Classification being used, which recognise 5 ethnic groups: European (including New Zealander), Māori, Pacific, Asian (including Indian) and Other (including Middle Eastern, Latin American and African). In order to ensure that each health event is only counted once, prioritised ethnic group has been used throughout.

Caution however must be taken when interpreting the ethnic specific information contained in these reports, as while the quality of information available since 1996 has been much better than previously, there remains some concern as to the way in which ethnicity information is collected within the health sector. Recent analysis of post 1996 data has suggested that hospitals continue to undercount multiple ethnic identifications and as a result, recent admission rates may continue to undercount Māori and Pacific peoples [221]. Similarly a linked analysis of the ethnicity information provided on census forms and death certificates suggests that during the 1996-1999 period, death certificate data tended to undercount Māori by about 7% [223]. Thus the ethnic specific rates presented in this report must be interpreted with these cautions in mind.



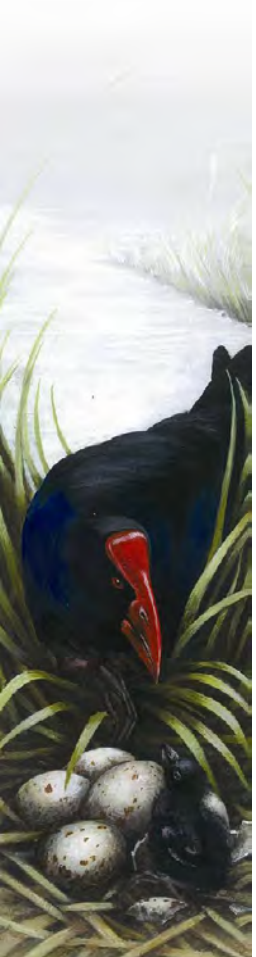
APPENDIX 7: NZ DEPRIVATION INDEX

The NZ Deprivation Index (NZDep) is a small area index of deprivation, which has been used as a proxy for socioeconomic status in this report. The main concept underpinning small area indices of deprivation is that the socioeconomic environment in which a person lives can confer risks / benefits which may be independent of their own social position within a community [224]. They are thus aggregate measures, providing information about the wider socioeconomic environment in which a person lives, rather than about their individual socioeconomic status.

The NZDep was first created using information from the 1991 census, but has since been updated following each census. The NZDep2006 combines 9 variables from the 2006 census which reflect 8 dimensions of deprivation (**Table 93**). Each variable represents a standardised proportion of people living in an area who lack a defined material or social resource (e.g. access to a car, income below a particular threshold), with all 9 variables being combined to give a score representing the average degree of deprivation experienced by people in that area. While the NZDep provides deprivation scores at meshblock level (Statistics NZ areas containing approx 90 people), for the purposes of mapping to national datasets, these are aggregated to Census Area Unit level (≈1,000-2,000 people). Individual area scores are then ranked and placed on an ordinal scale from 1 to 10, with decile 1 reflecting the least deprived 10% of small areas and decile 10 reflecting the most deprived 10% of small areas [225].

Table 93. Variables used in the NZDep2006 Index of Deprivation [226]

No	Factor	Variable in Order of Decreasing Weight in the Index
1	Income	People aged 18-64 receiving means tested benefit
2	Employment	People aged 18-64 unemployed
3	Income	People living in households with income below an income threshold
4	Communication	People with no access to a telephone
5	Transport	People with no access to a car
6	Support	People aged <65 living in a single parent family
7	Qualifications	People aged 18-64 without any qualifications
8	Owned Home	People not living in own home
9	Living Space	People living in households below a bedroom occupancy threshold



The advantage of NZDep is its ability to assign measures of socioeconomic status to the elderly, the unemployed and to children (where income and occupational measures often don't apply), as well as to provide proxy measures of socioeconomic status for large datasets when other demographic information is lacking. Small area indices have limitations however, as not all individuals in a particular area are accurately represented by their area's aggregate score. While this may be less of a problem for very affluent or very deprived neighbourhoods, in average areas, aggregate measures may be much less predictive of individual socioeconomic status [224]. Despite these limitations, the NZDep has been shown to be predictive of mortality and morbidity from a number of diseases in New Zealand.

Note: As New Zealand's national datasets have traditionally continued to use the previous Census' domicile codes for 1-2 years after any new Census, all of the numerators (e.g. numbers of hospital admissions, deaths) and denominators in this report have been mapped to NZDep2001.

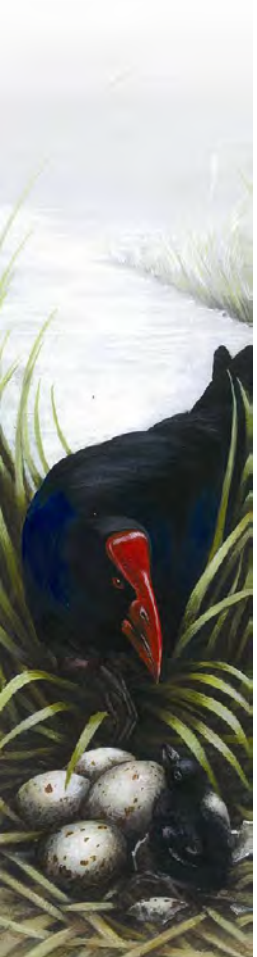
APPENDIX 8: CONGENITAL ANOMALY CODES

Table 94. ICD-10-AM Congenital Anomaly Coding Used in this Report (Table 1 of 2)

Q00-Q07 Malformations of Nervous System	
Q00	Anencephaly
Q01	Encephalocele
Q02	Microcephaly
Q03	Congenital Hydrocephalus
Q04	Other Brain Malformations
Q05	Spina Bifida
Q06	Other Spinal Cord Malformations
Q07	Other CNS Malformations
Q10-Q18 Malformations of Eye, Ear, Face and Neck	
Q10-Q15	Eyelid / Lacrimal / Eye / Orbit Malformations
Q16	Ear Malformations Impairing Hearing
Q170	Accessory Auricle
Q171-Q175,Q178-Q179	Other Ear Malformations
Q18	Other Face / Neck Malformations
Q20-28 Malformations of Circulatory System	
Q20	Malformations Cardiac Chambers / Connections
Q210	Ventricular Septal Defect
Q211	Atrial Septal Defect
Q212	Atrioventricular Septal Defect
Q213	Tetralogy of Fallot
Q214, Q218-Q219	Other Cardiac Septal Malformations
Q22	Pulmonary / Tricuspid Valve Malformations
Q23	Aortic / Mitral Valve Malformations
Q24	Other Heart Malformations
Q250	Patent Ductus Arteriosus
Q251-Q259	Malformations Great Arteries Excluding PDA
Q26	Malformations Great Veins
Q27	Other Peripheral Vascular Malformations
Q28	Other Circulatory Malformations
Q30-34 Malformations of Respiratory System	
Q30	Nose Malformations
Q31	Larynx Malformations
Q32	Trachea / Bronchus Malformations
Q33	Lung Malformations
Q34	Other Respiratory Malformations
Q35-37 Cleft Lip and Cleft Palate	
Q35	Cleft Palate
Q36	Cleft Lip
Q37	Cleft Palate and Lip

Table 95. ICD-10-AM Congenital Anomaly Coding Used in this Report (Table 2 of 2)

Q38-45 Other Congenital Malformations of Digestive System	
Q381	Ankyloglossia Tongue Tie
Q380,Q382-Q388	Tongue / Mouth / Pharynx Malformations
Q39-Q40	Oesophagus / Upper Alimentary Malformations
Q41-Q43	Intestinal Malformations
Q44-Q45	Other Digestive Malformations
Q50-56 Malformations of Genital Organs	
Q50-Q52	Female Genital Malformations
Q53	Undescended Testicle
Q54	Hypospadius
Q55	Other Male Genital Malformations
Q56	Indeterminate Sex / Pseudohermaphrodism
Q60-64 Malformations of Urinary System	
Q60	Renal Agenesis / Reduction Defects
Q61	Cystic Kidney Disease
Q62	Renal Pelvis Obstruction / Ureter Malformations
Q63-Q64	Other Kidney / Urinary Malformations
Q65-79 Malformations of MusculoSkeletal System	
Q650-Q652	Congenital Dislocation Hip
Q653-Q655	Congenital Subluxation Hip
Q656,Q658-Q659	Other Deformities Hip
Q66	Foot Deformities
Q67-Q68, Q79	Other Musculoskeletal Malformations
Q69	Polydactyly
Q70	Syndactyly
Q71-Q74	Reduction Defects / Other Limb Malformations
Q75-Q76	Skull / Facial Bones / Spine / Thorax Malformations
Q77-Q78	Osteochondrodysplasia
Q80-89 Other Congenital Malformations	
Q80	Ichthyosis
Q81	Epidermolysis Bullosa
Q825	Non-Neoplastic Naevus
Q820-Q824, Q828-Q829	Other Skin Malformations
Q83	Breast Malformations
Q84	Other Integument Malformations
Q85-Q87, Q89	Other Malformations
Q90-99 Chromosomal Abnormalities	
Q90	Down Syndrome
Q91	Edwards and Patau Syndromes
Q92	Other Autosomal Trisomies
Q93,Q95	Monosomies and Autosomal Deletions / Other Rearrangements
Q96	Turners Syndrome
Q97	Other Sex Chromosome Anomalies Female Phenotype
Q98	Sex Chromosome Anomalies Male Phenotype
Q99	Other Chromosome Anomalies



APPENDIX 9: METHODS USED TO DEVELOP THE CHILDREN'S SOCIAL HEALTH MONITOR

Introduction

In response to deteriorating economic conditions in New Zealand and Australia in the late 2000s, a Working Group of health professionals from a range of organisations[3] with an interest in child health was formed in early 2009. Over the course of the year, this Working Group discussed the conceptualisation of an indicator set to monitor the impact of the recession on child wellbeing, the types of indicators which might be included, and the criteria by which individual indicators should be selected. As a result of these discussions, it was proposed that a Children's Social Health Monitor be developed, which comprised the following:

1. *A Basket of Indicators to Monitor Prevailing Economic Conditions:* Ideally, indicators would capture different facets of economic wellbeing (e.g. in a recession several quarters of negative growth (*GDP*) may precede upswings in *Unemployment Rates*, which in turn will influence the number of *Children Reliant on Benefit Recipients*.
2. *A Basket of Indicators to Monitor Children's Wellbeing:* Ideally indicators would respond relatively quickly (e.g. months - small number of years) to family's adaptations to deteriorating economic conditions (e.g. hospitalisations for poverty related conditions) and would provide an overview of family wellbeing from a variety of different perspectives.

Indicator Selection Criteria

In selecting these indicators, it was decided that only routinely collected data sources which were of good quality, and which provided complete population coverage would be used, in order to ensure the indicator set was methodologically robust and could be consistently monitored over time. In order to achieve this aim, the Working Group developed a set of selection criteria, against which candidate indicators were scored. These selection criteria included:

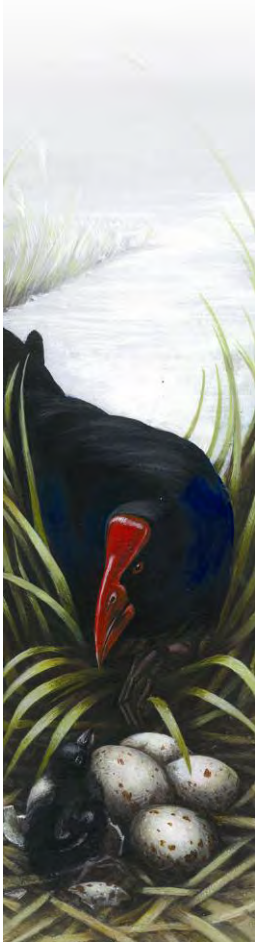
Conceptual Criteria

Criteria for Indicators to Monitor Prevailing Macroeconomic Conditions

1. Internationally recognised and reported measure of economic performance / wellbeing
2. Should impact on at least one facet of children's wellbeing (i.e. the pathway(s) via which it impacts on children's wellbeing should be relatively well understood, or an association between the indicator and wellbeing documented in the literature).
3. Likely to change in response to a recession (i.e. months-small number of years)

Criteria for Indicators to Monitor Children's Health and Wellbeing

1. The condition is likely to be influenced by family's physical adaptations to worsening economic conditions (e.g. saving on heating to pay for food, moving in with family to save on rent).
2. The condition is likely to be influenced by family's psychological adaptations to worsening economic conditions (e.g. increased family conflict in response to financial stress).



[3] The Paediatric Society of New Zealand, the Population Child Health Special Interest Group of the Royal Australasian College of Physicians, the New Zealand Child and Youth Epidemiology Service, TAHA (the Well Pacific Mother and Infant Service), the Māori SIDS Programme, the Kia Mataara Well Child Consortium, the New Zealand Council of Christian Social Services, and academics from the Universities of Auckland and Otago

3. The condition exhibits a socioeconomic gradient (e.g. rates are higher in more deprived areas)
4. The condition is likely to respond to changing economic conditions in the short to medium term (e.g. months to 1-2 years)

Data Quality Criteria

Data Quality Criteria (for either of the above indicator categories)

1. Needs to be routinely collected
2. Available at the national level i.e. complete coverage of target population
3. Updated at least annually (although quarterly preferable)
4. Availability of consistent time series data going back several years (i.e. standard and stable method of data collection)
5. Distribution can be broken down by e.g. ethnicity, socioeconomic status, region

Selection of the Baseline Indicator Set

In mid-2009 a long list of candidate indicators (selected by means of a scan of the available literature, email consultation with child health networks, and the suggestions of Working Group members) were then scored against each of these criteria by Working Group members and other health professionals (n=20). Those scoring the indicators were also asked to select a Top 5 Economic and Top 5 Health and Wellbeing Indicators for inclusion in the Children's Social Health Monitor. The resulting Top 5 Economic and Wellbeing indicators (as determined both by criteria scoring and priority ranking) were:

Economic Indicators:

Gross Domestic Product

Income Inequality

Child Poverty

Unemployment Rates

The Number of Children Reliant on Benefit Recipients

Child Health and Wellbeing Indicators:

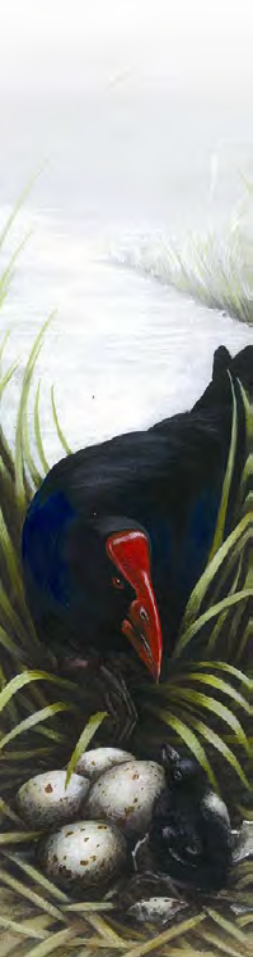
Hospital Admissions with a Social Gradient

Mortality with a Social Gradient

Infant Mortality

Hospital Admissions and Mortality from Non-Accidental Injury

Ambulatory Sensitive Hospital Admissions



Methodology for Developing the Hospital Admissions and Mortality with a Social Gradient Indicator

While all of the Top 5 Economic Indicators, and a number of the Child Health and Wellbeing indicators already had established methodologies, the hospital admissions and mortality with a social gradient indicator had to be developed specifically for the Children's Social Health Monitor. The methodology used to develop this indicator is outlined below:

Hospital Admissions

In considering which conditions should be included in the analysis of hospital admissions with a social gradient, the 40 most frequent causes of hospital admission in children aged 0-14 years (excluding neonates) were reviewed, and those exhibiting a social gradient (a rate ratio of ≥1.8 for NZDep Decile 9-10 vs. Decile 1-2; or for Māori, Pacific or Asian vs. European children) were selected. A small number of conditions with rate ratios in the 1.5-1.8 range were also included, if they demonstrated a consistent social gradient (i.e. rates increased in a stepwise manner with increasing NZDep deprivation) and the association

was biologically plausible (the plausibility of the association was debated by Working Group members).

Inclusion and Exclusion Criteria

Neonatal hospital admissions (<29 days) were excluded on the basis that these admissions are more likely to reflect issues arising prior to / at the time of birth (e.g. preterm infants may register multiple admissions as they transition from intensive care (NICU) → special care nurseries (SCBU) → the postnatal ward), and respiratory infections / other medical conditions arising in these contexts are likely to differ in their aetiology from those arising in the community.

For medical conditions, only acute and arranged hospital admissions were included, as Waiting List admissions are likely to reflect service capacity, rather than the burden of health need (e.g. the inclusion of Waiting List admissions would result in a large number of children with otitis media and chronic tonsillitis (who were being admitted for grommets and tonsillectomies) being included, and the demographic profile of these children may be very different from children attending hospital acutely for the same conditions).

For injury admissions, filtering by admission type was not possible, as a number of DHBs admitted injury cases under (now discontinued) ACC admission codes, making it difficult to distinguish between acute and waiting list admissions in this context. As with other NZCYES reports, all injury cases with an Emergency Department Specialty Code (M05-M08) on discharge were excluded as a result of inconsistent uploading of Emergency Department cases across DHBs (see **Appendix 4** for further detail). This differential filtering however means that it is not possible to accurately compare the magnitude of the social gradients between the medical condition and injury categories, as they were derived using different methodologies (and social differences in Emergency Department vs. primary care attendances for minor medical conditions may have accounted for some of the social gradients seen). No such differential filtering occurred for mortality data however (see below), and thus the magnitude of the social differences seen in this context is more readily comparable.

Mortality

In the case of mortality, because in many instances, the number of deaths from a particular condition was insufficient to calculate reliable rate ratios by NZDep and ethnicity, the rate ratios derived from the analysis of hospital admission data were used to denote category membership. The most frequent causes of mortality in those 0-14 years (excluding neonates) were reviewed however, in order to ensure that no additional conditions making a large contribution to mortality had been missed by the analysis of hospital admission data. This identified two further conditions (which by analysis of mortality of data met rate ratio criteria); deaths from drowning and Sudden Unexpected Death in Infancy, which were then included in the coding algorithms (for both hospital admissions and mortality data). A number of deaths were also identified which were attributed to issues arising in the perinatal period (e.g. extreme prematurity, congenital anomalies). However, in order to preserve consistency with previous exclusion criteria (i.e. the exclusion of conditions arising in the perinatal period) these perinatal deaths were not included in coding algorithms.

In Conclusion

While it is hoped that over time this indicator set will be expanded and further refined, it is intended that the NZ Child and Youth Epidemiology Service will monitor this core minimum indicator set on an annual basis, until the economic position of New Zealand children improves appreciably.

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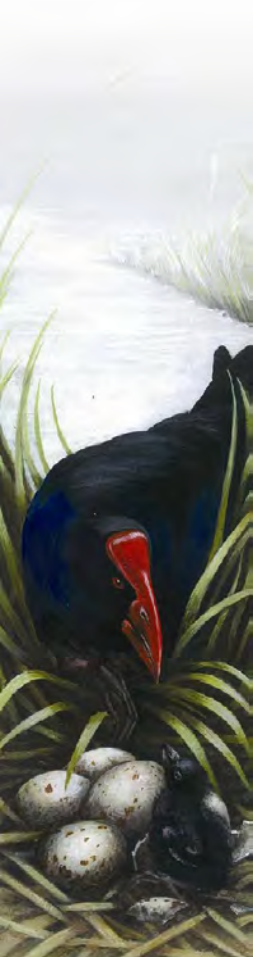

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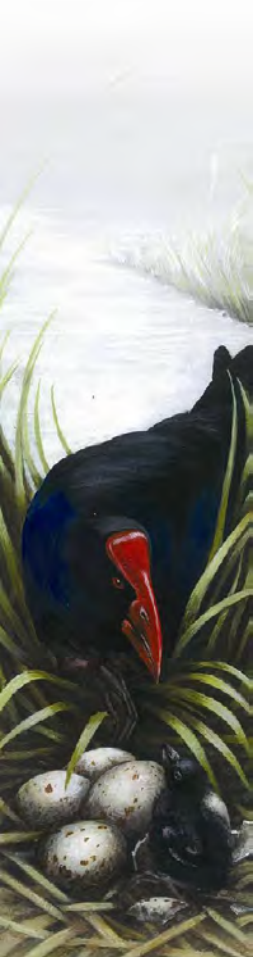

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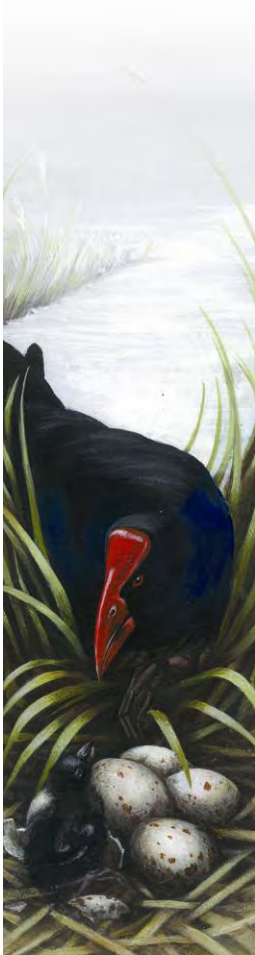

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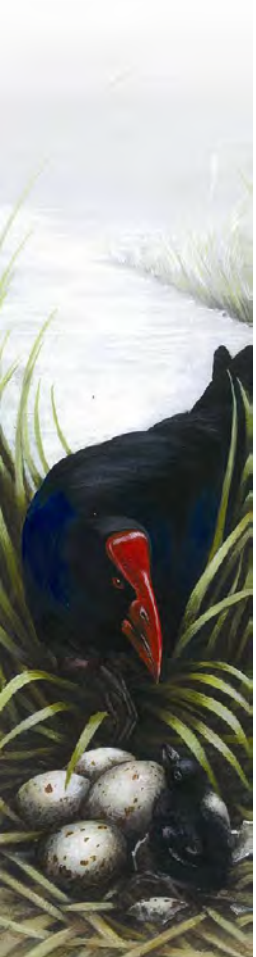

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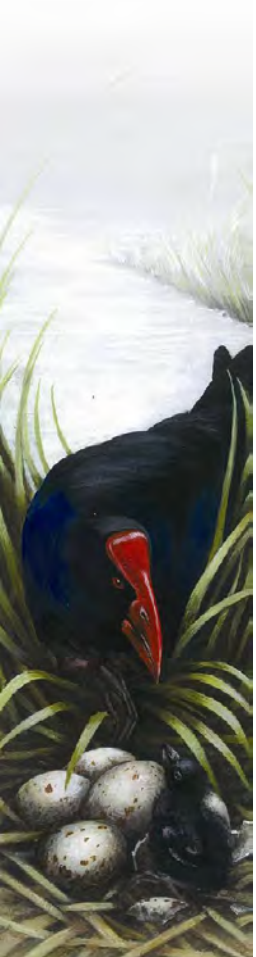

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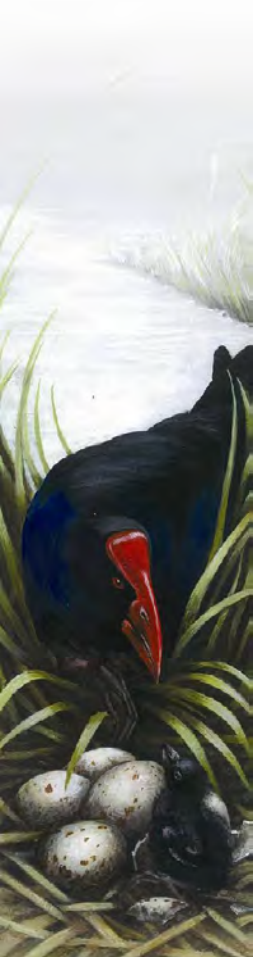

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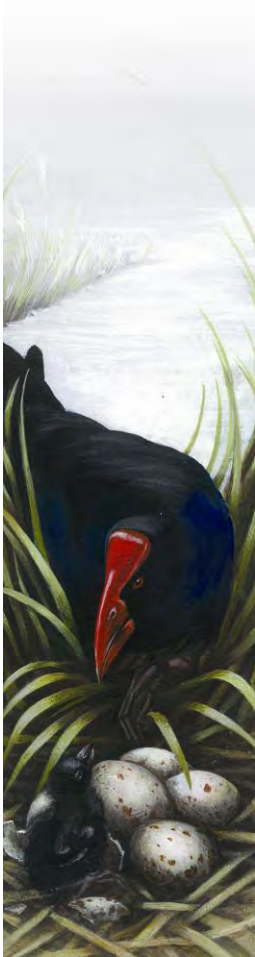
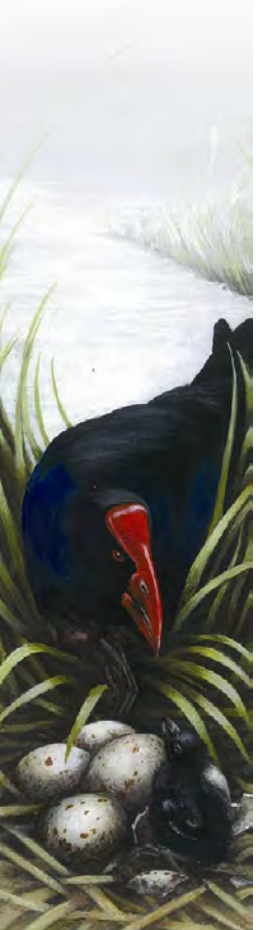
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