RECOMMENDATIONS FOR IMPROVING PREVENTION OF FOETAL ALCOHOL SPECTRUM DISORDER IN TARANAKI

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BACKGROUND

Foetal alcohol spectrum disorder (FASD) is an umbrella term for the range of abnormalities resulting from prenatal alcohol exposure. It is common, and one of few disorders that is completely preventable if no alcohol is consumed during pregnancy.

At the severe end of the spectrum is the better known, foetal alcohol syndrome (FAS). This has characteristic physical features of growth retardation, facial features (small eye slits, thin upper lip, diminished groove between nose and upper lip), and central nervous system abnormalities of abnormal structure and function, such as intellectual impairment. (1).

Other conditions include partial FAS (pFAS), alcohol-related neuro-developmental disorder (ARND), and alcohol-related birth defects (ARBD)

The range and severity of effects differ between individuals, and the symptoms can manifest at different ages, which makes it difficult to diagnose.

It is unclear what the prevalence of FASD is due to the difficulty in diagnosis. As FAS is the most well-recognised due to the characteristic facial features and growth retardation, prevalence of this is more commonly reported. (2). There is no national data in New Zealand regarding the prevalence.

A 2015 review looked at prevalence rates in Australia, and while there was no nation-wide data, it found studies had identified higher rates among Indigenous Australians than non-Indigenous Australians. (3). The same review said that drinking behaviours were different between the two groups: A higher proportion of Indigenous women than non-Indigenous women abstain from drinking alcohol, but a higher proportion of Indigenous women drink at high risk levels. (3). The review summarised some of the results of FASD prevalence studies done in parts of Australia: (3)

- FAS – 0.02 per 1000 births (non-Indigenous), 2.76 per 1000 (Indigenous)
- FASD-related conditions – 15 per 1000 births (Indigenous), 2 per 1000 (Torres Strait Islander), non-Indigenous rate not reported

BMJ Best Practice reports prevalence estimates in the United States for FASD to be 10 per 1000 births, and FAS at 0.5-2 per 1000 births. (2).

A survey was conducted in 2009 at the Taranaki Base Hospital in New Plymouth looking at drinking behaviours during pregnancy. (4). The results showed: (4)

- 80% of women were drinking alcohol before pregnancy, 66% of which were binge drinking
- 28% continued consuming alcohol during pregnancy
- Most women stopped or reduced their alcohol consumption during pregnancy, but 7% did not
- 10% were drinking more than 2 units per typical day, and more than 7 units per week, and 4% drinking more than this
- 9% of the total cohort reported binge drinking during pregnancy

Data from the 'Growing up in New Zealand' (GUINZ) longitudinal study gathered in 2015 show similar results. It reported 71% consumed alcohol before they were aware they were pregnant, with 21% continuing during the first trimester, and 13% continuing after. (5). The authors in both studies concluded that many women do reduce their alcohol consumption because of pregnancy, but only after they became aware of it. (4, 5). It could be expected FASD prevalence in New Zealand could be higher than the United States estimates of 1% due to the high rates of hazardous drinking in the population. (4).

FASD is the leading cause of preventable intellectual and developmental problems. Because Taranaki women of childbearing age have reported high rates of alcohol consumption, including during pregnancy, it is important to look at what can be done to prevent FASD in this community.

Another medical student, Vanessa Somos, had previously worked with the Public Health Unit at the Taranaki District Health Board regarding FASD. She conducted a literature review and talked with several key informants and prepared a report. (6). Her research led her to define the problem in New Zealand and Taranaki, map out the causal pathway, identify stakeholders, analyse the current strategy, identify high risk populations, and analyse evidence for effective interventions. The report showed further research was necessary. This report will involve some of the key stakeholders identified by Somos, and aim to identify further interventions that could be put in place to prevent FASD.

METHODOLOGY

The primary aim of this study is to assess awareness of Foetal Alcohol Spectrum Disorder (FASD) in key stakeholders working with pregnant women, and to identify ways to improve health and eliminate disparities so we can work towards preventing FASD in Taranaki.

This study was conducted over nine weeks between November 2016 and January 2017 inclusive. Eleven survey questions were developed (Appendix 1) and interviews were held with seven key stakeholders working with pregnant women. The responses to each question were collated to look at key themes among respondents.

Respondents included:

- A paediatrician with more than 20 years of experience
- A general practitioner with 6 years of experience
- Two midwives with more than 20 years, and more than 30 years of experience, respectively
- A parent of a child diagnosed with FASD more than 5 years ago
- Two managers with an interest in Māori health working at the DHB, one with more than 5 years, and the other less than one year of experience in their current role

This report is not a comprehensive study, and was limited in time as the author was on a short placement in the Public Health Unit, with multiple projects. It was also conducted around the Christmas and New Year period and many potential stakeholders were busy and could not be interviewed. The author attempted to interview a broad range of stakeholders.

RESULTS

Below are the collated results from the interviews held with the stakeholders.

1. What is your understanding of FASD?

All the respondents were aware of the effects of alcohol on an unborn child, however there was a range in the level of knowledge between them. The paediatrician, and the parent of a child with FASD, seemed to have the greatest knowledge, which was expected due to working closely with FASD or having experience living with FASD. Other respondents had a general idea of features. Most of the respondents seemed more familiar with foetal alcohol syndrome, which is at one end of the spectrum and involves physical dysmorphic features as well as brain functional changes.

Two of the respondents noted the importance of addressing the issues behind FASD, to work towards prevention.

Two of the respondents also talked about needing a whole system approach, including supporting individuals diagnosed with FASD, and their families to prevent further harm and secondary disabilities such as mental health issues.

One respondent identified that FASD was part of a bigger picture of alcohol-related harm.

One respondent gave a succinct definition: "FASD is a common, often unrecognised disorder, where there is significant neurocognitive dysfunction caused by antenatal alcohol exposure."

2. Who do you think is most at risk of having a child with FASD?

While each respondent gave some specific groups, a key theme coming from almost all of them (five out of seven) was that everyone is at risk - this could happen to anyone who drinks alcohol. "No one is immune." This is due to the heavy drinking culture in New Zealand, where binge drinking is common and a "way of life."

Some of the main groups of people mentioned were:

- Young women, who may engage in riskier behaviour and may not be planning for pregnancy
- People living in areas of high deprivation and low socioeconomic status, as there are often other stressors, and other issues such as smoking, drugs and violence
- Māori – there are a number of disparities and inequities seen between Māori and non-Māori in health, and those most at risk are those who are disconnected with their whānau or culture
- People who don't know the dangers of alcohol in pregnancy – if people are given inconsistent advice and not told of the risks
- People who don't know they are pregnant
- Alcoholics, which was thought to be more common than expected – about 2-3% of pregnant women continue to drink heavily throughout pregnancy

Also, mentioned by two respondents were people with mental health, and one respondent mentioned working women who like to have a glass of wine at night regularly to relax.

There are no prevalence numbers reported in NZ, but one respondent said they would expect prevalence to be at least the same, if not higher than USA numbers, because rates of maternal alcohol exposure is higher in NZ.

3. What advice would you give to a woman planning pregnancy regarding alcohol consumption?

All respondents agreed the message should be there is no safe amount of alcohol to drink when pregnant, as alcohol is a toxin to unborn babies. They would all advise women not to consume alcohol if they are planning to be, or are pregnant.

While some women may consume alcohol during pregnancy and have a healthy child, one respondent said, "it is like playing Russian Roulette," and you may not know your child has been affected until years later.

Two respondents said the stage of pregnancy may affect the outcome, but as with the amount of alcohol, there was no known safe time to drink during pregnancy.

The parent thought it was important to educate women about FASD, and how no one fully understands effects of FASD until they live with it. People often think it just involves their intelligence, but there are lots of other secondary disabilities that result. "No one knows about the holes in the walls (from emotional outbursts), drug addiction, suicidal thoughts and attempts, mental health problems, and so on." The child can look 'normal', and have a normal IQ, so it can be hard to spot the deficits until they are older, and it can be hard for others to understand there is a problem.

4. What advice would you give to a woman with a confirmed pregnancy? *(who may have been drinking alcohol until then)*

All the respondents stressed the most important message would be to stop drinking alcohol now, even if they had already been drinking. It is important to provide support and avoid scaring or worrying them. If the baby has been affected, there is nothing that can be done now, but it is important not to continue drinking as this could make things worse, and the baby may not be affected at all.

Two respondents said referral to alcohol and drug services should be considered, especially if addiction was suspected, and support should extend to the mother and any other children at home.

5. What do you think are the main reasons women consume alcohol during pregnancy?

All respondents talked about the cultural and social pressures of drinking, and how it is an accepted behaviour, and has become 'the norm', which makes it difficult not to drink.

Most respondents (five out of seven) also thought mental health, abuse, including sexual abuse, and addiction played a part, and being "stuck in the cycle of drugs, alcohol and violence, and don't know how to get out."

Four respondents said it was likely the situation they were in lead to drinking, with poverty, stress and hopelessness contributing, leading to alcohol being used to relax, or as an escape.

Four of the respondents thought poor advice could contribute, or women not understanding the implications of drinking while pregnant. This could be because it is assumed people know about the harms, and so it isn't talked about, or it could be lack of knowledge and support.

Younger women and those that don't know they are pregnant are also likely to consume alcohol, three respondents said.

"The same reasons people drink anyway," one respondent put it, which was echoed by several others.

a. Before they know they are pregnant?

Five respondents alluded to the drinking culture of our society being the problem, as it meant most people do drink alcohol. All people, especially young people, might find themselves pressured to drink to fit it, and alcohol increases risky behaviour.

One respondent mentioned the affordability of alcohol makes it that much more appealing, as it is easily accessible.

b. After they know they are pregnant?

All the respondents thought lack of knowledge of the dangers of alcohol in pregnancy could be the reason women may continue to drink alcohol once they know they are pregnant. This could be due to mixed messages, and not being told about the effects of alcohol on an unborn child, which could happen if they don't engage early with a lead maternity carer, or they could have poor health literacy, and may not be able to understand the implications of drinking alcohol during pregnancy.

Four respondents talked about addiction as a reason to continue drinking alcohol in pregnancy, especially if there is a lack of support networks.

Other reasons mentioned included people being risk takers, perhaps trying to hide their pregnancy, being psychologically unwell, and because they want to fit in.

6. What do you think are some things we could do to reduce FASD in Taranaki?

Almost all (six out of seven) of the respondents thought education and awareness campaigns were important. Some of the suggestions included:

- Target men as well as women, young and old, and Māori and non-Māori, so that everyone can support one another (four out of seven respondents)
- Need to get smarter on how the messages are promoted, and what mediums are used, and spread the message everywhere (six respondents)
    - For example, a smartphone app, posters on the toilet doors in clubs and pubs with QR codes to scan to get more information/support, signs on busses
    - Documentaries are good – can see the results of alcohol consumption during pregnancy
    - Social media campaigns

- The message needs to include what the risks are, and what FASD looks like in reality (four respondents)
    - FASD doesn't affect everyone in the same way, and no one knows how it is going to affect their child
    - "So they know they are creating a life sentence for their baby."

Three respondents talked about the need to improve health literacy, so that people can understand, and are equipped with the skills to look after their health. This would include understanding the messages about alcohol use in pregnancy, and knowing how to seek help if they require it.

Two respondents talked about prevention at all levels. This includes:

- Primary prevention - preventing women from drinking during pregnancy
- Secondary prevention - identifying women who continue to drink in pregnancy and offering support for them to stop
- Tertiary prevention - identifying people with FASD early so they can get the support they need

This involves educating the health, education and justice sectors as well. These two respondents said professionals in these areas often don't understand the implications of FASD, so they give poor advice, or don't know how to work with the affected individual and their family in these areas. Rates of FASD are higher in the criminal population, and knowledge about FASD is therefore important in this area.

The paediatrician said more resources are also needed for diagnosing FASD. This is important as it is a part of tertiary prevention, as early intervention and support can be provided, as well as helping to quantify how big the problem is, so awareness increases, and more resources can be put towards it. At the moment, there is no specific funding for FASD prevention or diagnosis.

The general practitioner thought compulsory alcohol use questioning from early teens onwards by all groups of health professionals would be useful. This could come up as an alert on the computer system during an admission or appointment that needed to be checked off. This would identify issues with alcohol use early on, and may prevent alcohol-related harm later in life. This could be difficult however, as a relationship would need to be built first so that patients would feel comfortable to reveal this information. They also noted there would need to be a process to follow if someone was identified as high risk.

Both midwives mentioned that they don't see women in the planning stage, only after they have become pregnant. One of the midwives said it could be good to have a free or inexpensive pre-conceptual clinic for women to get this advice out. They said women under 24 years old can seek help from family planning for free, but women are waiting longer to have children, so won't necessarily be able to access this help when they do start to plan pregnancy.

The importance of getting accessible support, available to all, around the region was also mentioned by one respondent. They said South Taranaki often gets missed, or forgotten.

"We need to be more willing to take risks and try new things (to improve health outcomes), and report well on outcomes," said one respondent.

a. Working with pregnant women?

There were mixed opinions regarding education of pregnant women. Most respondents (five out of seven) thought more education of pregnant women was required, and antenatal education programmes should be reviewed to ensure they clearly, and consistently, convey the message regarding alcohol consumption. Two respondents didn't think education would work, as people already know the message is to not drink while pregnant, yet some continue – perhaps they don't understand the full implications of the risk, and the effects of FASD.

One option could be targeting midwives, as they are a crucial group involved in maternity care. It is important to check they are all spreading the same message, that there is no known safe amount of alcohol during pregnancy (four respondents). One respondent said would also be useful to introduce a more comprehensive alcohol screening tool for midwives to assess alcohol use, rather than a simple yes or no question. However, the midwives said they already have a lot of information to give, and questions to ask of pregnant women in the first visits, so it would increase their workload and risked overloading women with too much information at once. More consultation is probably needed to assess this.

Four of the respondents mentioned the benefits of having multiple health agencies involved who work in conjunction with each other. It is important to keep contact with the woman's general practitioner as well as with the midwife, and if issues are identified they should be referred to the appropriate agencies for more support. These agencies could include maternal social workers, Tui Ora, and Alcohol and Drug services. All organisations should be educated about where to get help and how to intervene if they are working with a pregnant woman who discloses alcohol use.

One respondent talked about the Hapu Ora wananga. This is a kaupapa Māori pregnancy education workshop run over two days, with education focused on the mother, whānau and wider support, for example, Work and Income, housing, Well Child, and general practice providers. It covers topics such as safe sleeping, and breast feeding, and could deliver messages regarding alcohol and pregnancy too.

b. Working with family/whānau?

Four respondents noted it is important for the interventions and treatment to be holistic, and consider the wider situation, including whānau and social determinants.

A key theme that came up was that pregnant women need a good support network to have a healthy pregnancy (four respondents). Whānau are particularly important to include in this, and so men, and other whānau, need to also be educated so that they can provide support, and understand why it is important to avoid alcohol. As with smoking cessation, it is important to offer assistance in reducing or stopping alcohol consumption for other family members too, so they can support the pregnant woman, and target the children too so they are well informed to make the right choices themselves.

As the parent and paediatrician pointed out, it is also important to consider families living with FASD to ensure they get the support they need. They require education after the diagnosis as well, to understand how best to help their child, and how to cope themselves, and direction about where to find out more information. They may also need other support services such as counselling, as they could suffer from grief after the diagnosis, and respite care could also be an

option. It's important not to judge or lay blame, as this won't help, what will help is providing the support needed.

Four respondents said alcohol is such an accepted drug in our culture, and the binging consumption patterns make it more dangerous. "Alcohol seems to be more about getting drunk than having fun." Alcohol related harm affects more than just pregnant women, so abuse and misuse of alcohol in the whole population needs to be addressed.

c. Working with sale and supply of alcohol?

All respondents gave examples relating to changing alcohol policy, to reduce the availability. Suggestions included:

- Raising the price
- Having earlier closing times at on-licence premises
- Having more restrictions on where a liquor outlet can open, and how many can be in an area.

Other suggestions included having stricter rules on advertising, and removing alcohol advertising from sport.

One respondent stressed the importance that all members of communities and local iwi should be consulted as part of the process in developing local policies. To ensure this happens, communities and iwi need to first be empowered to understand the process and how to respond, so they can make submissions to the council to influence policies and decisions. These measures will be useful in the reduction of all alcohol-related harm.

One problem brought up by a respondent is that the current legislation doesn't stop people consuming alcohol until they are judged to be intoxicated, when it becomes illegal to serve them.

Two respondents discussed the labels on bottles which recommend not drinking if pregnant. One thought they were good, and talked about having signs anywhere alcohol is sold reinforcing those messages, while the other respondent wondered if anybody even reads them. "It's like smoking and cigarette packets – people just ignore it."

One respondent wondered if there could be laws about drinking and pregnancy, and if drinking during pregnancy would be considered child abuse or neglect, if they are informed about the risks, and do so anyway. "Could people be fined or arrested? Is it not neglect if they are informed and still take the risk? But is it too late then?"

"The smoking culture has changed – how do you do the same with alcohol? It's really hard." One respondent may have the answer, "The government needs to take a tougher stance."

d. Working with high risk groups?

Four respondents thought education was important, as the high-risk groups include people who are less educated. It would be good to start the education in young people, who often engage in riskier behaviour, so they grow up knowing the messages regarding sexual health, pregnancy, and alcohol, and are equipped to make responsible choices.

Three of the respondents said education and support needs to be available to all pregnant women, especially young women, and encouraging young women to continue education, such as at the YMCA, WITT or Stratford Teen Mums Centre, is important.

Five respondents talked about increasing engagement of high risk women with services. Those that are high risk often don't engage with services, so other options need to be considered. For example, Tui Ora has a programme for pregnant women, that doesn't follow a traditional teaching structure, and instead there are activities such as sitting together and weaving, where the women can learn by talking rather than the classroom setting. It's important that other methods of teaching are considered to help to spread the messages in a way that people feel comfortable to engage in.

Four of the respondents talked about the importance of a multidisciplinary team approach, where multiple services are involved as well as alcohol and drug services, because alcohol isn't usually the only issue. There also needs to be more connection between these services. Two respondents said good research about the factors involved, and being able to tailor and target interventions so that they are relevant to the target population is necessary.

One respondent said community organisations working with high risk populations, such as Tu Tama Wahine and Tui Ora, need more education about FASD, so they can spread the messages to the people they work with. This might also lead to FASD being detected earlier, if people are more aware about it.

7. How can we eliminate health disparities and reduce inequity in high risk populations?

"It's about identifying who and where those groups are and developing strategies around that."

Three respondents talked about the need for disadvantaged groups to be consulted and involved in the process of putting interventions in place. They are the consumers of these services and they've had experience with them, and know what does and doesn't work. Communities need to be enabled to develop solutions that work for them.

Māori who are disconnected to their culture and/or whānau are one group that was identified as high risk by five respondents. The Whānau Ora Outcomes Framework was recommended by one respondent as a tool which empowers whānau, using a holistic approach. (7). This framework could be adopted across agencies, and help to build strong, resilient whānau. Some suggestions of how to improve health outcomes in Māori included encouraging participation in culture and iwi groups, with activities such as kapahaka, as this can provide a sense of belonging, and support, and help for them to get out of the cycle. It is important to continue reporting indicators of performance, and health, by ethnicity, as then we can see where the gaps are, and what needs to be targeted.

More investment in Māori health providers is required, says two respondents. As identified, Māori can be a higher risk group and can often face inequity, especially Māori that are disconnected. Work needs to be done to build Māori capability and capacity in the health sector. Māori often respond better when engaging with other Māori. One respondent who works in the Māori health field, said data from the end of 2015 showed only 1.5 percent of total health resources in New Zealand are dedicated to Māori health. The Taranaki DHB is one of the top three in the country with Māori health funding, with 2.5 percent dedicated to Māori health. If

you consider the percentage of the population that are Māori, and the fact that they generally have worse health outcomes, this number is lacking. The health gap between Māori and non-Māori in Taranaki was reported by this respondent to be about 2.5 times.

The same respondent also talked about the 'Whyora?' programme at TDHB. They said it was great, and was supporting Māori into the health industry, especially as Māori patients often respond better when engaging with Māori. They suggested it would be good if there was a bonding scheme attached to the programme, so they have a job available once they complete the programme. It was important to assist Māori into careers in health, said the respondent, because while the Māori workforce in the health sector has increased from 6.5 to 8.7 percent, it is still low.

The same respondent talked about the high outpatient appointment DNA (did not attend) rates in some Māori, and how they may need different support to reduce this. They said Māori health care providers need to be resourced to follow up with them, and check if they will have any trouble attending appointments, which could include reasons such as not being able to get there. They talked about a Kaiawhina pilot in Taranaki, as part of a Whānau Ora approach, which supported people to go to appointments, and in interactions with the police, social workers, drug and alcohol services, and budget services. This involved women working in their own communities to do this, as they shared a connection, and it wouldn't be as effective with Kaiawhina from a different area or iwi. Another respondent also said, "The role of nannies and aunties is important – we underestimate the role whānau can play."

One respondent thought it was important to consider the whole situation; usually alcohol abuse isn't the only problem. Other contributing factors need to be considered, for example living in an area of high deprivation and low socioeconomic status, struggling with being able to afford food, and perhaps being in a violent situation can all contribute, and cause stressful situations. The reasons behind the alcohol use need to be addressed alongside education and support for alcohol abuse, so a coordinated, collaborative approach can be used.

One respondent said technology is making it easier to chase up people, and provide a variety of resources, so it is harder for people to not engage.

Three respondents talked about the need to prioritise resources, so they target the disadvantaged. One thought it is too heavily influenced by politics, which makes it very risk averse. Commitment to making a change is avoided unless it is a safe choice. "They need to make bold, sometimes unpopular decisions." Another problem is that different government departments and organisations have different area boundaries. The Taranaki DHB is part of Midlands PHO (includes Lakes, Tairawhiti, Taranaki and Waikato DHBS) and has a different boundary to the Ministry of Social Development (includes Taranaki, King Country and Whanganui), which is also different to the Ministry of Education boundary (includes Taranaki, Whanganui and Manawatu). This makes it a challenge to come up with inter-agency plans.

One respondent said Victim blaming isn't useful, as it needs to be remembered that women drinking during pregnancy are "victims of their circumstances." Like with smoking, it is known to be bad, but without the support to stop they can't change their behaviour. It is important health providers create a non-judgemental environment so women feel comfortable to be honest, and admit if they have a problem so that help and support can be provided.

One respondent talked about the link between the wide income gap in New Zealand and inequity. “To fix health inequity, first you need to address economic inequality.” To target the entire population, the approach needs to be at the government level, with policy and legislation.

8. What are some strength and resilience factors you have observed in women in high risk populations that we could build on, to eliminate health disparities?

All respondents mentioned the need for good support networks. Having a stable relationship and partner support helps, and conversely, if a relationship breaks up, this can have a negative impact and lead to a higher risk of drinking. Having at least one friend or family member offering support is important. For Māori, having a cohesive whānau, and being connected to their iwi and culture can be protective, so participation in activities such as kapahaka should be encouraged.

One respondent said if people have good internal resources to be able to champion for themselves, and be self-motivated to look after and manage their health, they’ll be more resilient. Other factors include the insight to identify the problems family alcoholism have caused, so they are aware and want to change. This insight could be built upon by giving the appropriate support.

Having children can be protective in itself, and most women do change their health behaviours when they find out they are pregnant. One respondent mentioned that if the pregnancy is particularly very precious to them because it may be their only chance at having a child, for example if they are an older mother, or have had fertility issues, then they are more likely to be aware of the health risks and needs.

One respondent said offering incentives to remain alcohol free in pregnancy could also work, and has been seen to work in smoking cessation. Incentives could be childcare essentials such as nappies, or a bed, which they get if they attend all the appointments, agree to be tested for alcohol, and engage in the service.

Having good role models is also important. One respondent talked about how sharing positive stories of people who have gotten out of the cycle, and given up alcohol even when it was hard, help too.

One respondent talked about the importance of education and health literacy. “Most women would change just by knowing it’s bad (to drink alcohol in pregnancy). They have an innate resilience.” We need to ensure the right messages get out, and that everyone understands the implications.

Another respondent said if people can support themselves by being employed, and being able to provide food and essentials for their family, then this can also make people more resilient.

The parent talked about moving forward after an FASD diagnosis. It takes time to come to terms with the diagnosis, and lots of families struggle because of the spiky pattern to it – children can behave quite well and do well academically some days, and not on other days. “Most parents want to make their child better, or ‘normal’. It’s not until you accept that won’t happen that you can parent properly.” Families need good support networks and it helps to be able to talk to people that understand what they are going through. It also helps to be reminded of the good things their child can do, rather than just the stuff they can’t.

9. Do you have any additional comments?

"I wish I knew how to make it better."

"There is no silver bullet or magic cure to prevent or fix it."

"Drugs and alcohol is one of the biggest issues we grapple with, if not the biggest, and we need more resources to deal with this."

The parent said individuals and families need a lot more support than they're getting now. This is partly because FASD is not fully understood across all sectors, and "until it is, there will be injustice." The brain damage in FASD cannot be fixed, but the environment can be altered to help those affected cope, and this area is currently lacking.

Another respondent identified the anti-drink driving campaigns had worked well.

One respondent said we need to find better ways to work with young people in the justice system, as prison can be a negative environment and get them involved with a 'bad crowd'.

The paediatrician talked about the diagnostic process. They said it was in collaboration with the Ministry of Education psychologists which was useful because then the Ministry of Education is already involved from the diagnosis. This means they are already offering support through the school, which is very important in FASD. The problem is that there is only a limited number of children that go through the complete multi-disciplinary team (MDT) assessment in Taranaki, only about six to 12 per year. This is because the process is very time intensive for health professionals, requiring up to 20 hours for a psychologist per child, and there are no child psychologists in the paediatric department at the TDHB. Developmental paediatricians can diagnose children at being at high risk of FASD from a medical assessment, but without the full MDT assessment, can't be formally diagnosed. To get to the MDT assessment stage, the child will have been identified by a Ministry of Education team as having a "severe behaviour problem." The child also must be at least seven years old, so they can complete the psychometrics part. Physical findings, like those seen in Foetal Alcohol Syndrome are much less common.

They talked about the profile of behaviour and learning disorders that fit an FASD diagnosis:

- Often diagnosed with ADHD, but not responding to treatment
- Not learning from previous mistakes
- Overall, IQ is lower, but can be in normal range
- Level of function is below the IQ level, meaning they have trouble with their adaptive behaviour and executive function, which doesn't match up to their measured 'intelligence level', and so is often misunderstood

The paediatrician talked about the current support. They said Child and Adolescent Mental Health Services (CAMHS) can be involved, but the major support is through the school. The parent expressed that the school hadn't always been very supportive, due to their limited knowledge of FASD.

The paediatrician also talked about treatment. Many end up with medical treatment, for example Ritalin, which can be effective, especially with impulsivity, but it doesn't fix the whole problem.

The paediatrician also mentioned that the Hawkes Bay DHB has its own 'Action Plan for FASD' which was developed before the national plan, and could be helpful to talk to the paediatricians there in the process of developing a local plan for Taranaki DHB.

DISCUSSION

High risk groups were identified as:

- Everyone – because of heavy cultural and social pressures of drinking in New Zealand
- Young women – possible risky behaviour
- People living in low socioeconomic/high deprivation area – other stressors contributing
- Māori disconnected from whānau/culture
- Those unaware of dangers of alcohol use in pregnancy, perhaps due to inconsistent advice
- Those unaware of pregnancy
- Alcoholics
- Those with mental health conditions, or a history of abuse

All respondents agreed there was no safe amount of alcohol that could be consumed during pregnancy, and no safe time. This should be the advice given out consistently by health professionals. A study could be done that involves all health professionals working with pregnant women in the region, that investigates the advice given by them, to identify if the message is consistent. A review of antenatal education programmes could also be useful to confirm the message is clear and consistent.

It appeared that respondents were unsure if maternal alcohol consumption required a referral to alcohol and drug services or not. There needs to be guidelines set in place regarding what to do if a pregnant woman or her whānau or friend discloses prenatal alcohol consumption, or it is suspected.

The author was recommended to read Chapter 16, Alcohol Policies: A Consumer's Guide, in "Alcohol: No Ordinary Commodity" (8). This includes a table rating policy-relevant strategies and interventions by effectiveness, breadth of research support, and cross national testing. It shows that the most effective interventions in reducing alcohol-related harm at a population level include:

- Alcohol taxation
- Banning sales
- Changing the minimum legal purchase age
- Restricting hours and days of sales
- Restricting density of outlets
- Enhancing enforcement of on premise laws and legal requirements

All respondents spoke about restrictions on the sale and supply of alcohol, and suggested the same interventions given above. It seems that ultimately, these are interventions that will have the biggest, and most widespread effects. It is important that all these factors are considered, and perhaps changes can be made when the local alcohol policies are next renewed.

Another suggestion was further restriction on advertising, which has been shown to be effective in young people's drinking, but not for the overall population, and can be hard to regulate, with mediums such as the internet. (8).

Education and awareness campaigns were suggested by almost all (six out of seven) respondents as ways to reduce FASD. They should target the whole population and the use of a

variety of mediums could help with this, such as smartphone apps, social media, posters, and documentaries.

In “Alcohol: No Ordinary Commodity”, education was shown to have no long-term effects on drinking, but it could be useful in the short term. (8). This could mean educating women and whānau when planning a pregnancy, or in the early stages could be more useful, than educating adolescents in the school setting. However, the latter could still be important as it may make young people more aware of the consequences of risky behaviour they may engage in. Having a pre-conceptual clinic with a midwife that is free to all could be useful to get advice regarding alcohol consumption to the woman before she becomes pregnant, and ensure the information is accessible.

Often those at high risk have low engagement with services, and the question becomes how do you get those women and whānau involved. Five respondents talked about this, and one gave an example of a programme run by Tui Ora for pregnant women. They said it doesn’t follow a traditional teaching structure and instead there are activities such as sitting together and weaving, when women can feel comfortable to talk with one another and learn in this way, and from others’ experiences, rather than in a classroom, which isn’t effective for everyone.

One key point brought up by three respondents, was that high-risk groups of women need to be consulted and involved in the process of putting interventions in place. Only then can we begin to fully understand the factors involved, and being consumers of these services, they will know what does and doesn’t work. Communities need to be enabled to develop solutions that work for them. An example of where this has worked, is in the predominantly aboriginal community of Fitzroy Crossing, in Western Australia (9-12). The women in the community made a stand to ban alcohol to protect their culture and children after noticing high rates of brain damage in their children. (9). They invited paediatricians and researchers to quantify the prevalence, and identify what could be done, and The Lililwan study is an ongoing project related to this. (9-13). Having the community support and input has been a huge part of this project. “Because local women are involved in every stage of the research - they are trained as researchers and act as community navigators persuading people to participate - the participation rate is 95 per cent, nearly unheard of for such a study.” (8).

When thinking particularly about Māori, it was identified they can be at higher risk due to inequity in all aspects of health, and if they are disconnected to their whānau or culture. The Whānau Ora Outcomes Framework was recommended as it aims to empower whānau and improve resilience. (7). As in the above example at Fitzroy Crossing, it can be seen that empowered communities can make a huge difference to health outcomes. If community and iwi members can be empowered, they can support the rest of the community, in ways like the Kaiawhina programme. More investment in Māori health providers is required to increase their input in the health sector, and with more resources, more support can be offered.

At an individual level, brief intervention with at-risk drinkers, medical and social detoxification, and talk therapies were shown to be effective and well-studied interventions. (8). However, this can only be achieved if an individual is found to be at risk. By implementing compulsory alcohol use questioning in any admission to hospital or appointment with a health professional, it would allow at-risk drinkers to be identified early. This would mean interventions could take place before there is any harm caused by alcohol, such as FASD.

One respondent thought it would be useful to introduce more comprehensive alcohol use questionnaire for midwives to assess alcohol use. However, the midwives said there is already a lot of information to give and questions to ask of pregnant women, so it would increase their workload and risk overloading the women, so more consultation with midwives could be done to assess whether this would be a viable intervention, and if it would be effective.

Working with the wider whānau can be useful as they can provide support to pregnant women to avoid alcohol if they themselves understand the risks. Whānau should be encouraged to attend appointments along with the pregnant woman, where suitable, so that they can also understand the health risks to the unborn baby to motivate them to support the woman. If possible, they could also be counselled on their own alcohol use, but this is likely to create a lot of work, and there isn't necessarily the time or resources to do so.

Unfortunately, there are limited resources for the diagnosis of FASD, so that in Taranaki, there are only between six to 12 complete multidisciplinary assessments per year. Increased resources are required to be able to diagnose more cases of FASD, as early diagnosis is key to preventing negative outcomes, such as trouble with education and the law, and mental health comorbidities. Also, as the paediatrician reasoned, by being able to diagnose more cases, it will give a better indication of how big the problem is in Taranaki.

Ultimately the results from the study line up well with the FASD Action Plan released by the Ministry of Health in 2016. It would be useful to look at other local action plans when determining the next step forward with developing interventions. The paediatrician mentioned the Hawkes Bay DHB had developed one of their own, and this would be useful to look at.

RECOMMENDATIONS

Below are some possible interventions that could improve prevention of FASD.

1. Investigate the advice given out by all health professionals (especially general practitioners and midwives) regarding alcohol consumption during pregnancy to check consistent advice is being given
2. Educate health professionals about FASD and how it causes problems with adaptive behaviour and executive function, and not necessarily low intelligence (IQ)
3. Establish guidelines for health professionals to follow if prenatal alcohol consumption is suspected or disclosed, including when to refer, and who to refer to
4. Consider changes to policy and legislation surrounding alcohol sales and supply
5. Educate women planning or in the early stages of pregnancy about FASD and the effects it can have
    a. Consult midwives regarding a free to all, pre-conceptual midwife clinic for education
    b. Review antenatal education content
6. Involve members from high risk groups in the development and implementation of prevention strategies in their communities
    a. Empower communities and iwi to be involved
7. Implement compulsory alcohol use questioning in any admission or appointment with a health professional
    a. Consult midwives regarding the use of a comprehensive alcohol use questionnaire
8. Determine if more resources can be used to increase the diagnosis of FASD early, to provide support and minimise negative outcomes, such as poor education, mental health comorbidities, and criminal behaviour
9. Consider other locally developed action plans when deciding on the next step forward for intervention

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APPENDIX 1

FOETAL ALCOHOL SPECTRUM DISORDER INTERVIEW

The purpose of this project is to:

Assess awareness of Foetal Alcohol Spectrum Disorder (FASD) in key stakeholders working with pregnant women, and to identify ways to improve health and eliminate disparities so we can work towards preventing FASD in Taranaki.

All the information you give will remain strictly confidential and only used for this project. Data will be summarised as themes and no participating organisations or individuals will be identified.

1. What is your role/position?
2. How long have you been in that role/position?
3. What is your understanding of FASD?
4. Who do you think is most at risk of having a child with FASD?
5. What advice would you give to a woman planning pregnancy regarding alcohol consumption?
6. What advice would you give to a woman with a confirmed pregnancy? *(who may have been drinking alcohol until then)*
7. What do you think are the main reasons women consume alcohol during pregnancy?
    a. Before they know they are pregnant?
    b. After they know they are pregnant?
8. What do you think are some things we could do to reduce FASD in Taranaki?
    a. Working with pregnant women?
    b. Working with family/whānau?
    c. Working with sale and supply of alcohol?
    d. Working with high risk groups?
9. How can we eliminate health disparities and reduce inequity in high risk populations?
10. What are some strength and resilience factors you have observed in women in high risk populations that we could build on, to eliminate health disparities?
11. Do you have any additional comments?

Thank you for your time

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