

**Reducing poverty by addressing equity with a  
focus on prenatal alcohol exposure and  
intergenerational trauma**

**Identify, address and remove systemic barriers**

**Outcomes from the Margaret May Blackwell  
Travel Study Fellowship**

**2018/2019**



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*The call to nurse is not only for the bedside care of the sick, but to help in seeking out the deep lying basic cause of illness and misery, that in the future there may be less sickness to nurse and do cure. (Wald, 1915, p. 65)*

# Acknowledgement

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I would like to take this opportunity to personally thank the Margaret May Blackwell Trust and both the New Zealand Nurses Organisation and the New Zealand Education and research Foundation for this amazing opportunity to develop my career and make a positive change in the world.

I would also like to acknowledge the support, patience and understanding from NZNO and NERF in the delay of completing this report when I experienced the personal tragedy of the loss of my son at the beginning of the Fellowship time, followed by the Covid19 pandemic and Level 4 lockdown near the end. It is strange times we live in.

I could not have done this without the support from my employer Bay of Plenty District Health Board and the management and colleagues at Community Health 4 Kids where I work. It was my colleagues who listen to my dreams and aspirations that told me about the Margaret May Blackwell scholarship and encouraged me to apply.

The services and people that took the time to spend with me.

Lastly but by no means least, I have to acknowledge the support and encouragement from my family during this period of intense highs and extreme lows. I could never have done this without my husband Gary holding the fort at home and looking after my small fluffy dog Tilly; and my adult children – Steven, Kaynon, Jaimee and Lyza. It is for them and the future generations that I continue to push myself far beyond what I ever thought I could achieve in an attempt to make the world a better place.

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# Introduction

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2018/2019 Topic: Supporting communities/whānau, hapū and iwi to limit the impact on children/tamariki of poverty, addiction, violence and relationship breakdown.

My passion has always been in prevention and 'getting it right from the start'. It is common knowledge that the First 1000 days of life (F1000d) from conception is absolutely critical in providing the foundation for the rest of life. The Topic for 2018/19 Margaret May Blackwell Travel Fellowship as mentioned above, caught my interest and whetted my appetite in how to improve the long term health outcomes for children and families who are living in poverty in Aotearoa. So I applied, and was successful in being awarded the Margaret May Blackwell Travel Study Fellowship with an application based on the lifelong effects that alcohol consumption during pregnancy may have. As well as the possibility of life long brain damage, the misuse of alcohol has wide reaching implications in poverty, addictions, violence and family breakdown, so the topic ticked all the boxes.

As I learned about Margaret May I found that we shared a similar interest of the connection between early childhood education/experiences and long term health outcomes. I met my husband Gary, when I was fourteen and he was fifteen. The seed of interest in long term health outcomes began with the birth of our first child when we were nineteen. By twenty five years of age our family was complete with four children. We both had difficult childhoods and wanted our children to have a different childhood experience than we did.

I learned about parenting and child development alongside my children through the Playcentre Education Programme. Gary was always willing to discuss what I had learned and together we formed our parenting style. After having various roles over the years within the Playcentre Association, I then was able to use my qualifications earned in Playcentre to gain employment as a Parent Educator for the Parents as First Teachers Programme where I stayed for 10 years.

Working with families in the community during my time as a Parent Educator I became curious about health so gained employment as a Community Karitane with Plunket; another similarity with Margaret May. The quality of the professional and personal development that these educational experiences provided combined with the privilege of working with families in their own homes and hearing their stories was life changing for me. It was then I started to wonder about the impact of health on development.

By that time, our children were young adults and mostly independent, so I went to back to school for three years and graduated as a Registered Nurse at the age of forty-five in 2010. It is the combination of these experiences that drives my work today.

I enjoyed the google search exploration of the world to find the appropriate services, programmes and conferences that would address the objectives noted in my application. I wanted to find out as much as I could about how other colonised countries were addressing this World Wide epidemic, with a view of what might work in New Zealand. These objectives included:

- Raising public awareness about alcohol and pregnancy
- Reducing the stigma
- Being in a position to support Iwi and DHB's locally, and nationally if applicable
- Developing and introducing Aotearoa/New Zealand friendly "Prevention Conversations"
- Developing and introducing a national Aotearoa/New Zealand friendly alcohol and pregnancy screening tool
- Developing /creating a database where the screening information is securely recorded and can be accessed as required by diagnosticians in the future.
- Learning how to change policy and work towards reducing the availability of cheap alcohol in supermarkets.
- De-normalising alcohol misuse in Aotearoa.
- Working alongside midwives in developing confidence in talking about alcohol and screening all pregnant women.

# Background

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New Zealand is known for its strong binge drinking culture where it is normal and even expected to “get messy”. This is especially concerning for New Zealand women of 15 to 24 age group where for the first time in 2001 women, of child bearing age, outnumbered men in being admitted to hospitals for alcohol poisoning – and this is steadily increasing (Savage & Coursey, 2007)

## Voices from the Past

Fetal Alcohol Spectrum Disorder (FASD) can be avoided. The possible detrimental effects of prenatal alcohol exposure have been known as early as 700BC when Aristotle noted that ‘Foolish, drunken, or hare-brained women most often bring forth children like unto themselves, morose and languid’. The bible in Judges 13.7 also references caution with alcohol and pregnancy where it is said ‘thou shalt conceive, now drink no wine or strong drink’.

Alcohol or Waipiro, which translates to “stinky water”, came to Aotearoa with colonisation. Prior to contact with Pakeha, Māori lived in one of the few parts of the world that had never developed alcoholic beverages. The Inuit people of Canada, the Trukese of Micronesia and a number of Native American Indian tribes share with Maori the attribution of being indigenous peoples who did not develop alcoholic drinks. It is reported that Maori were not initially interested in stinky water and happily traded for other items including blankets and tobacco (Hutt, 1999). My ancestors, who were tin miners in Cornwall UK, left Plymouth, South England on board the New Zealand Company ship Duke of Roxburgh and arrived in Wellington on the 7<sup>th</sup> of February 1840 – the day after Te Tiriti o Waitangi was written to begin its journey around Aotearoa. I am thinking there is a high possibility that alcohol/waipiro arrived with my ancestors.

However, by the 1870s things had changed. Several petitions were put to the government at the time calling for help to deal with the downstream effects of alcohol on the indigenous population. One particular petition set by Haimona Te Aoterangi and 167 Māori from Wanganui noted that ‘our children are not born healthy because the parents drink to excess and the child suffers’, eluding to the recognition that alcohol harms children (Te Aoterangi, 1874). I wonder what has happened with this knowledge. Is it not our responsibility and moral obligation to honour these voices from the past and action the cries for help?

## In recent times

In recent times the advancements in science and research developments confirm what we have suspected. This means that we no longer ignore the evidence, we can no longer bury our heads in the sand and wait for it all to blow over, as that is not going to happen. We have a moral responsibility to the people of Aotearoa to put our knowledge into practice. It is timely to think differently about the best use of the available health dollars.

Fetal alcohol spectrum disorder (FASD) is a preventable brain based injury that has lifelong health, education, justice and social implications. Conservative estimates place the cost of burden in Aotearoa/New Zealand at \$800 million per annum **Invalid source specified..** Because of the current stigma attached to mothers who use alcohol, it is difficult to obtain accurate data.

While not all alcohol exposed pregnancies will result in FASD, conservative (there's that word again) estimates are 1 in 100 for New Zealand. To provide a bit of perspective, in the December 2015 year there were 61,038 live births recorded in New Zealand **Invalid source specified..** Using these estimates indicates that 610 or more children are born every year with a preventable disability (Gibbs & Sherwood, 2017).

The evidence indicates that:

- at least one in two, half of New Zealand pregnancies are exposed to alcohol; one in ten are exposed at high-risk levels
- two in five pregnancies are unplanned, increasing the chance they will be exposed to alcohol
- pregnant women do not consistently receive timely maternity care or support for any alcohol and drug issues
- health professionals do not consistently provide information on the risks of alcohol use during pregnancy or routinely screen for alcohol issues
- most clinicians lack the capability to diagnose FASD
- families of people with FASD struggle to access appropriate support and report a lack of understanding from services, professionals and even other family members
- FASD affects about 50 percent of children and young people in Oranga Tamariki care **Invalid source specified..**
- Children who were exposed to alcohol in pregnancy are 19 times more likely to get in trouble with the law

## Current situation

The New Zealand Government has launched two action plans in an effort to address and combat the alcohol and drugs issues. Taking Action on Fetal Alcohol Spectrum Disorder: 2016 – 2019 Action Plan which includes 10 action areas (FASD Working Group, 2016); and the National Drug Policy 2015 to 2020 to minimise alcohol and other drug-related harm and promote and protect health and wellbeing (Ministry of Health, 2015). Both these action plans are currently being reviewed and will be updated in the near future.

Giving children the best start in life has been a priority for the New Zealand Government since 2009 **Invalid source specified..** All children should have the opportunity for the best start in life to increase the quality of the life term. FASD is a non-communicable brain based injury that is preventable. Currently there is conflicting information in the general public about how much alcohol is safe to drink and at what stages in the pregnancy, and this is causing confusion and mistrust. Research informs that families are likely to follow the message that best fits with their lifestyle. Increasing awareness of the possible effects of alcohol in pregnancy by providing consistent messages across multi-sectorial services and agencies is where it needs to start according to Stade, et al (2009). Big picture thinking is FASD can become a thing of the past. However the World Health Organisation (2013) has set a voluntary global target of at least a 10% relative reduction in the harmful use of alcohol within the national context seems a more realistic goal at this time.

In health we now have the science that informs us that childhood trauma, if left unaddressed, is carried forward into the next generations through DNA, epigenetics (Hopner & Webb, 2019) The statistics inform us that women who tend to continue to use alcohol during pregnancy are likely doing so in an attempt to ‘treat’ or ‘self-medicate’ their unaddressed, possibly unidentified, childhood trauma. Internationally these experiences or adversities include:

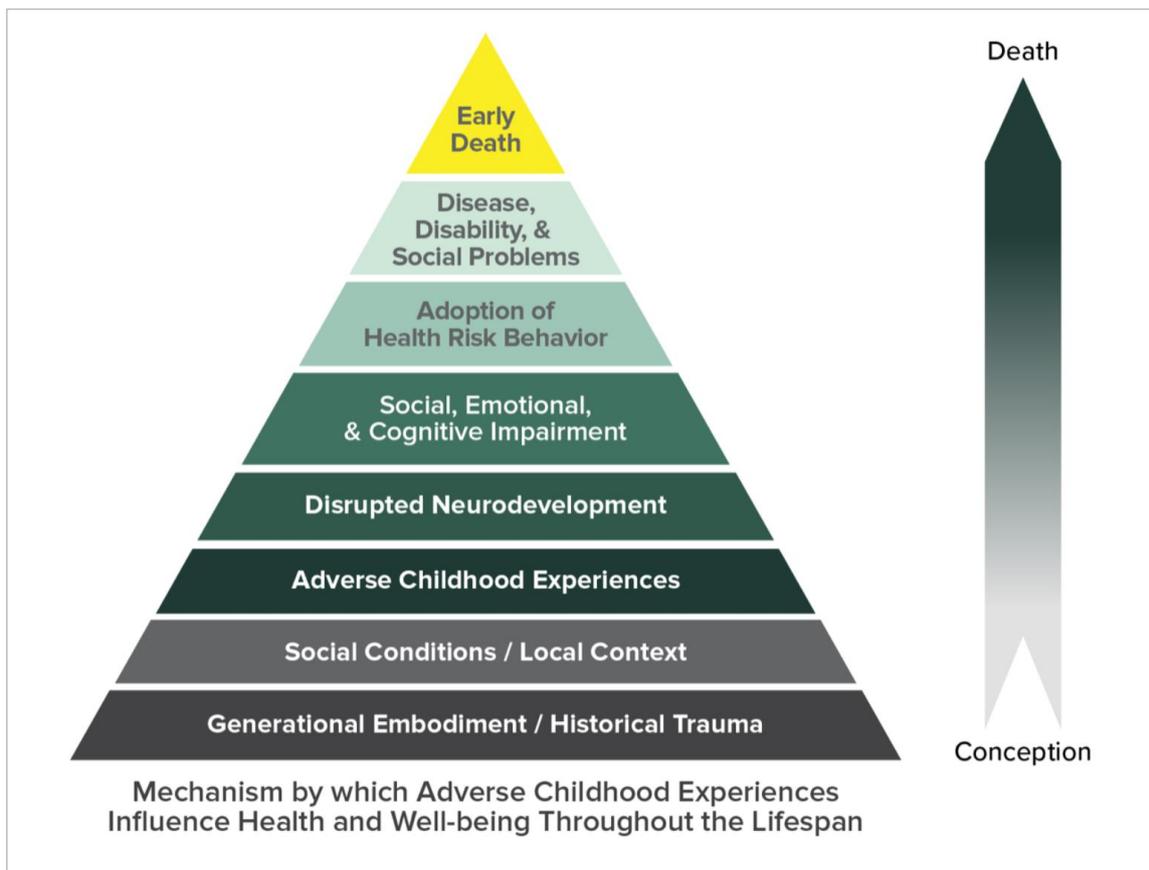
- exposure to family violence,
- sexual abuse,
- physical abuse,
- neglect,
- family harm,
- emotional abuse,
- parental separation,
- a parent in prison,
- a parent with a mental illness
- a parent battling with addictions

- and poverty.
- Nationally of course there is the trauma and impact of colonisation to throw into the mix.

Exposure to adversity in the early years impacts across the lifespan. Exposure to adversity damages the brain, the immune system, hormonal systems and changes DNA transcribe. It literally gets in the genes. People living with damaged brains cannot change without help and support. These traumas are known as Adverse Childhood Experiences –or ACEs (Centre for Disease Control and Prevention, 2020). Karen Thurston( 2016/2017) also raises the importance of addressing Adverse Childhood Experiences in her report to Margaret May Blackwell Fellowship. It is our responsibility to reduce the dose of adversity in our communities.

### The ACE Pyramid

The ACE Pyramid represents the conceptual framework for the ACE Study. The ACE Study has uncovered how ACEs are strongly related to development of risk factors for disease, and well-being throughout the life course.



# Margaret May Blackwell - What I hope to achieve

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I chose Australia and Canada as my countries of interest. This was based around upcoming FASD conferences being held, and the knowledge that both these countries are similar to that of Aotearoa with impacts of colonisation on the indigenous cultures.

To understand Fetal Alcohol Spectrum Disorder, we need to understand why women use alcohol in pregnancy. We need to understand trauma. Trauma is pervasive in society and its short and long term effects have been well documented. *Intergenerational trauma* is a psychological term that asserts that trauma can be transferred across generations. It is a term that is being increasingly used and heard across colonised countries. Intergenerational trauma, or transgenerational trauma, is what happens when untreated trauma-related stress experienced by survivors is unintentionally passed on to second and subsequent generations. Trauma can pertain to the ways that people recover from sexual abuse, from family violence, from imprisonment and from cultural disconnection. Much self-destructive behaviours can result from unresolved traumas. Studies have found that many 'wicked problems' in Indigenous communities, including alcohol and substance use, mental health problems, family violence or criminal behaviours, are symptomatic of the effects of this unresolved trauma reaching into the present day. Addictions, depression, anxiety, suicidal and homicidal thoughts are some of the wicked problems (Somos, 2016).

People need to have the opportunity to learn to identify trauma before they can begin to address it and heal from it. Unaddressed or unresolved trauma can unknowingly be passed on to others through behaviour. Children may experience difficulties with attachment, disconnection from extended families and culture, and high levels of stress from family and community members who are dealing with the impacts of trauma. This has been known to create developmental issues for children, who are particularly susceptible to distress at a young age. This creates a cycle of trauma, where the impact is passed from one generation to the next.

**In Aotearoa**, Intergenerational trauma predominantly affects the children, grandchildren and future generations of Tangata Whenua. A submission to the Government inquiry into mental health and addiction highlights the state of emergency for tangata whenua who are impacted by mental illness and addiction, within a context of poor service delivery and corresponding poor outcomes (National DHB GM Maori Strategic Reference Group, 2018). An emerging area of

interest is the impact of colonisation across the generations of the descendants of the New Zealand (Shipping) Company's colonisers.

**In Australia,** Intergenerational Trauma predominantly affects the children, grandchildren and future generations of the Stolen Generations. Stolen Generations members might also pass on the impacts of institutionalisation, finding it difficult to know how to nurture their children because they were denied the opportunity to be nurtured themselves (Weston & Thomas, 2018).

**In Canada,** Intergenerational Trauma predominantly affects First Nations People.

Intergenerational trauma is usually seen within one family in which the parents or grandparents were traumatized, and each generation of that family continues to experience trauma in some form. In these cases the source can usually be traced back to a devastating event, and the trauma is unique to that family.

Direct survivors of these experiences often transmit the trauma they experienced to later generations when they don't recognise or have the opportunity to address their issues. Over the course of time these behaviours, often destructive, become normalised within the family and their community, leading to the next generation suffering the same problems.

My primary learning objectives for attending the conferences and visiting with the chosen services and programmes listed below are aligned with the Taking Action on Fetal Alcohol Spectrum Disorder Action Plan (FASD Working Group, 2016) dual goal:

- that FASD is prevented
- and people with FASD and their family/whanau live the best possible lives .

## **Overall Goals:**

### **Prevention**

- That all New Zealanders can have every day informed conversations regarding FASD.
- That all New Zealanders can support parents to have alcohol free pregnancies.

### **Early Identification**

- That people with neurodevelopmental impairments are identified early and receive timely and effective assessments from FASD capable teams

### **Support**

- That people and their families, whanau and caregivers receive timely joined up support tailored to their needs, strengths, age and stage as identified with a gold standard FASD Assessment across the 10 domains.

### **Evidence**

- That community profiling is undertaken to gather the data to establish a baseline for the incidence of FASD.
- There is an improved New Zealand evidence base so we can make good decisions, effective investments and monitor outcomes and progress.

### **Overall Learning Outcomes:**

My intent is to use this action plan as a framework when visiting the different services and programmes. I planned to do this by:

- Learning and absorbing as much as I can on all aspects of Fetal Alcohol Spectrum Disorder prevention with an international perspective.
- Disseminating the findings as widely as possible within Bay of Plenty and throughout Aotearoa/New Zealand
- Working collaboratively across all disciplines with the view to establish appropriate clinics and services and programmes with a New Zealand flavour in consultation with Tangata Whenua

# AUSTRALIA

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## Perth

### Telethonkids Institute



Telethon kids vision is simple - HAPPY HEALTHY KIDS. Narelle Mullan, Program Manager for FASD Research Australia CRE, organised my 2 days with the institute, explained that in August 2018, Telethon Kids moved to their current facility at the Perth Children's Hospital (PCH) on the QEII Medical Centre campus – which is the largest centre of excellence in healthcare, research and education in the southern hemisphere.

TelethonKids Institute brings together community, researchers, practitioners, policy makers and funders, who share their mission to improve the health, development and lives of children and young people through excellence in research. I was attracted to TelethonKids statement about 'wanting knowledge applied so it makes a difference' as it fitted nicely with my vision of translating theory into practice.

During my time at Telethonkids I was able discuss topics such as;

- Parents perceptive on getting a diagnosis
- Assessing alcohol exposure
- The face of FASD
- Neurodevelopmental assessments - what, why and how

**Making FASD History** – is a 3 year multi-site prevention programme. I met with Annalee Stearne who was one of the people involved in the initial development of this programme. Annalee explained that the focus of this program is sustainability and building capacity in local health services so that communities can continue to lead FASD prevention activities after the research is finished. The program was based on the successful Marulu strategy, a community led program of intervention in the Fitzroy Valley, Western Australia, which targeted community

health promotion activities and workforce education and training. Telethon Kids Institute was an important partner in the Marulu strategy and transferred learnings from this project to guide the development of the Making FASD History program.

Annalee went on to talk about plans for the future that include:

1. **Prevention** - key focus areas:

- development of preventative efforts targeting school-aged children
- use of biomarkers to screen for alcohol use in pregnancy

2. **Screening and Diagnosis** – key focus areas:

- understanding the impact of different levels of prenatal alcohol exposure on neurodevelopment, including epigenetic mechanisms
- upskilling the health workforce to improve screening and assessment practices
- upskilling the education sector to identify children at risk and refer for assessment
- upskilling the justice sector to identify people at risk and refer for assessment

3. **Management** – key focus areas:

- development of interventions to support youth in detention with FASD
- development of interventions to support parents and caregivers of a child with FASD
- establishing the annual cost to society of FASD in New Zealand
- The prevention approach that I am particularly keen to learn about is:
  - how to reduce the rates of drinking during pregnancy
  - increasing the number of pregnant women being advised by a health professional about the risks of alcohol in pregnancy
  - How to incorporate routine screening and brief interventions in primary maternity care
  - Awareness raising campaigns that are successful and cost efficient.
  - Development of teaching resources
- Upskilling frontline staff across all disciplines

### **FASD Clinical Workshop Programme:**

I was able to spend a day listening to speakers and participating in discussions pertaining to:

- Introduction to the Australian Guide to the diagnosis of FASD
- Parents perspective on getting and FASD diagnosis
- Assessing alcohol exposure
- The face of FASD
- Neurodevelopmental assessment – what, how and why

I have been able to utilise knowledge gained from this workshop in my work at Community Health 4 Kids.

### **2<sup>nd</sup> Australian FASD Conference 2018- Our Science, Our stories**



This is the 2nd Australasian Fetal Alcohol Spectrum Disorder Conference (FASD2018). These happen every 5 years.

The conference took place at the Pan Pacific Hotel in Perth, Western Australia and brought together people from academia, clinical practice, service provision and the community to share their knowledge, build networks and learn new skills.

FASD2018 was hosted by the *FASD Research Australia* Centre of Research Excellence and encompassed the very latest perspectives relating to prevention, diagnosis and management of FASD. The conference theme “FASD Our Science, Our Stories” reflects the strong partnerships that exist between researchers, practitioners and families in this field. One aim of the conference is to extend and deepen those partnerships.

This was my first time attending a conference such as this and I did not know what to expect.

The food was supplied and was amazing! I stayed in the budget option accommodation so I could make my sponsorship money go a bit further.

The program included a range of presentations - oral talks, posters, short and sharp, videos, panels and workshops. Concurrent streams comprised of a good mix of researchers, practitioners and families.

It was a privilege to be able to attend this conference and be surrounded by likeminded people with common goals of making the world a better place. The challenge I had was to make decisions about which workshops to attend as they were all fascinating and relevant.

Link to programme: <http://fasdconference.com/program/>

The overall goals of the FASD2018 conference that Participants could expect was to:

- advance their understanding of all aspects of FASD;
- improve knowledge about the Australian Guide to the Diagnosis of FASD;
- learn about different models of care through the life course;
- engage in meaningful exchange of ideas through focused workshops;
- Benefit from networking opportunities with peers and others with professional interest in FASD.

**The key take home messages for me were:**

1. Parent caregiver stories
2. Women want to know project
3. Genetics
4. Health promotion

## Parent caregiver stories:



### Claire Gyde

One of my favourite parts of the conference was listening to the stories of the parents and caregivers of children living with FASD. The common thread that came through for me was the incredible strength and resilience that they have in dealing with the challenges of everyday life, nicely balanced with unconditional love and strong sense of advocacy. There was also the honesty of the difficult and challenging days and times. I felt humbled and privileged to gain the personal insight into how it is for the child from their family's perspective.

Claire is the Chairperson of New Zealand's national FASD support group, FASD-CAN Incorporated. This organisation was established in 2013 by a small group of professionals and parents raising and working with children with Fetal Alcohol Spectrum Disorders. Claire has an adult son with FASD and frequently speaks publicly to deliver their personal story in the hope it helps others understand the 'lived experience'. Her mantra is that "if you speak to the hearts of people, then their heads will surely follow". Raising awareness of FASD is her passion and she does this so that FASD is recognised and accommodated by education, health, justice and the broader community.

## Women want to Know Project:



Women want to know – the Women want to know project was developed after Foundation for Alcohol Research and Education (FARE) found that pregnant women want clear advice from their health professional about the levels of alcohol consumption that are safe during pregnancy.

The 'Women Want to Know' project encourages health professionals to routinely discuss alcohol and pregnancy with women and to provide advice that is consistent with the [National Health and Medical Research Council's Australian Guidelines to Reduce Health Risks from Drinking Alcohol](#).

Results included:

- 97% think health professionals should ask about alcohol use in pregnancy
- This information and advice needs to come from a trusted health professional
- Health professionals want information about how to speak to women about alcohol and pregnancy.

The *Women Want to Know* project includes the following resources for health professionals:

### *Online e-Learning courses*

There are three FREE online e-Learning courses with Continuing Professional Development accreditation available for Health Professionals through the: [Royal Australian College of General Practitioners](#) (members only)

[Royal Australian and New Zealand College of Obstetricians and Gynaecologists](#) (free to members and non-members. Select the Pregnancy and Alcohol – WWTK course from the ‘Resources’ tab and log in. If you are not a member, please select ‘Log in as a guest’ and use the password FARE254)

[Australian College of Midwives](#) (free to members and non-members).

### *Resources*

Hard copies of the below leaflets and posters can be ordered from the [resources and publications](#) page.

### *Brochures*

A leaflet for health professionals on pregnancy and alcohol [HTML](#) | [PDF \(359 KB\)](#)

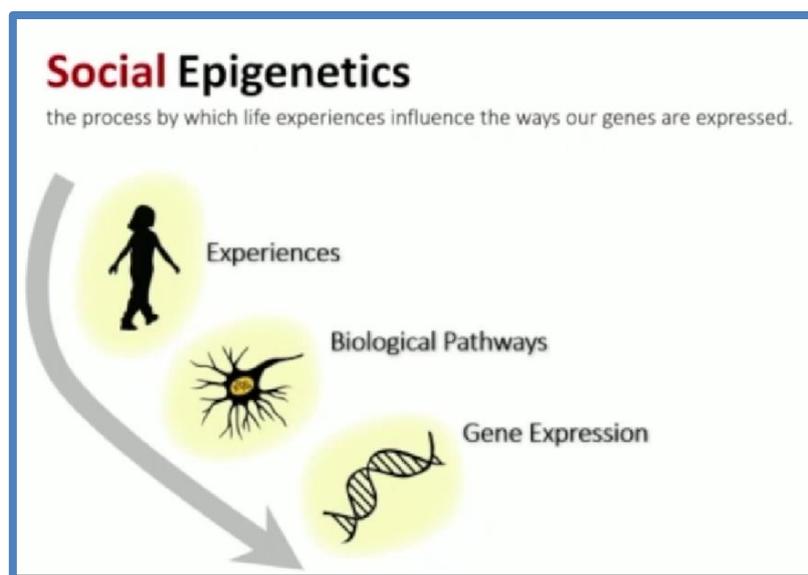
A leaflet on assessing alcohol consumption in pregnancy using AUDIT-C [HTML](#) | [PDF \(256 KB\)](#)

A leaflet for women on pregnancy and alcohol [HTML](#) | [\(PDF 309 KB\)](#)

A leaflet on the *Women Want to Know* project [HTML](#) | [\(PDF 331 KB\)](#).

Hard copies of the leaflets can be ordered from the [resources and publications](#) page.

## Genetics



Genetics – A DNA study of 84 twin/sibling pairs exposed to alcohol *in utero* indicates there's no safe limit of alcohol exposure for pregnant mothers. The study showed that two fetuses exposed to identical levels of alcohol can experience strikingly different levels of neurological damage.

Risk of damage does not depend solely on the pregnant woman's alcohol consumption; rather, fetal genetics plays a vital role, according to [findings](#) published in the journal *Advances in Paediatric Research*.

“The evidence is conclusive,” said lead author Susan Astley Hemingway, professor of paediatrics at the University Of Washington School Of Medicine.

From a public-health standpoint, she said, the biggest take-away is that a fetus' genetic makeup is a determinant to the risk of neurological damage from a mother's alcohol consumption. To protect all unborn babies, including those most genetically vulnerable, the only safe amount of alcohol is none at all, the report concludes.

## Health Promotion



Health promotion – what works? Who is the target group?

***Pre-Testie Bestie*** was the topic of high discussion following Tanya Radcliff (Health Promotion Agency) presentation. Pretestie Bestie is the second phase of the New Zealand Don't know? Don't drink campaign.

The target audience is young women aged 18 to 30-years-old who drink hazardously, are sexually active and not planning to get pregnant. Studies inform us that this audience drinks at hazardous levels and has a high level of unplanned pregnancy. This puts them at higher risk of drinking alcohol during the early stages of pregnancy which may result in children being born with fetal alcohol spectrum disorder (FASD).

After a period of trial and error regarding the best platform for this promotion, research found that the most successful way to reach young women was through their friends (*because they themselves would never have an unplanned pregnancy, but it could definitely happen to their best mate 😊*) and that the best platform was social media as opposed to television and newspapers. Tanya warned the participants prior to showing

the videos, that as we were not the targetted audience we may find the language inappropriate, however the targetted audience quickly 'liked' it and forwarded it on all their mates using multiple social networking platforms.

The campaign aims to reduce the number of babies born with fetal alcohol spectrum disorder (FASD), which is estimated to affect up to 3,000 babies born each year in New Zealand.

In New Zealand, two out of every five babies born each year are a result of an unplanned pregnancy (24,000 births). Approximately half of women drink alcohol in early pregnancy before they know they are pregnant, inadvertently exposing their developing baby to risk.

The campaign aims to reduce alcohol consumption during early pregnancy by encouraging women to stop drinking if there is any chance they could be pregnant.

As a side note – when I was at the 8<sup>th</sup> International FASD Conference in Canada a few months later, people from all over the FASD world had heard of the New Zealand Pretestie Bestie videos.

## Alice Springs

### Central Australian Aboriginal Congress Aboriginal Corporation



Remembering that Prevention is my Passion, I met with Indigenous Health Promotions Officer Donna Lemon who is the FASD Prevention coordinator, a role that I was interested in learning about how it could be adapted in the Bay of Plenty. Donna explained that the role is only a few months old and is still developing; however the intent being that this position will engage and support stakeholders to develop and implement strategies to prevent FASD and improve the support available for children with FASD and their families.

When talking with Donna about the recent International FASD Awareness Day, Donna commented how they had to adapt “Red shoes Rock” awareness campaign in Central Australia as red is a colour involved with ‘sacred man’s business’. Instead of red shoes, they used the branches from a local tree for people to be able to hang hats on. The hats are representative of the sacredness of the head and recognition of the importance of protecting the brain from damage that alcohol consumption may cause during pregnancy.

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Womens Council in Alice Springs hosted an FASD Awareness day breakfast for the community. There were also Awareness Raising workshops available throughout the day. Donna shared her health promotion resources that she had used during these sessions, including a lifelike baby doll with the FASD sentinel facial features, alongside a baby doll that had not been prenatally exposed to alcohol. Donna said that the initial reaction to the doll with the FASD features by the general public was ‘shock’ and ‘horror’, however did promote worthwhile discussions.



Me and Donna Lemon with the FASD Awareness promotion dolls

Jenna Pauli who is the Health Promotion Manager at CAAC spoke of “Our Clients” and how the foundation is based on words from Gandhi:

Our clients are the most important visitors on our premises.

They are not dependant on us.

We are dependent on them.

They are not an interruption to our work.

They are the purpose of it.

They are not an outsider to our business.

They are part of it.

We are not doing them a favour by serving them.

They are doing us a favour by giving us the opportunity to do it.

An important mantra for us to consider in Aotearoa?

In Alice Springs, project activities are focused on:

- Prevention mapping: Via an Environmental Scan of the Alice Springs area to understand how health services and programs are provided, and how they contribute to and support FASD prevention.

- Workforce capacity building and training: By workforce AUDIT-C screening and brief intervention training, delivered to Congress clinics and their staff.
- Alcohol use in pregnancy screening embedded into antenatal processes in Alice Springs: Through the development of referral pathways for at-risk groups attending Congress clinics.
- Community education activities and raising awareness with a focus on FASD prevention: Through the delivery of culturally appropriate education sessions in schools and the wider community.
- Health promotion messaging: Via development and implementing of a FASD and prenatal alcohol exposure prevention health campaign.

Jenna also spoke of the priorities for the congress. The following pictogram sums it up:



Central Australian  
Aboriginal Congress  
ABORIGINAL COMMUNITY CONTROLLED HEALTH SERVICES

# OUR PRIORITIES

(what we will do for 2019 to 2023 to achieve our vision)

## 1 Aboriginal health in Aboriginal hands

As an Aboriginal community controlled health service committed to the principles of self-determination, we seek to engage and empower the Aboriginal peoples of Central Australia in everything we do. Responding to the needs and wishes of the community, we will speak out on their behalf on issues that affect their health, and ensure that we respect their diverse cultures and ways of being across the organisation.

### 1.1 Community control

We will ensure that effective structures and processes of Aboriginal community control continue to be the foundation for all our work.

### 1.2 A voice for our people

We will continue to be a strong advocate for the rights and needs of Aboriginal peoples, based on our strong local, regional and national reputation.

### 1.3 Community engagement

We will actively engage the Aboriginal community in their own health care and in the work of Congress.

### 1.4 Cultural responsiveness

We will ensure a welcoming, culturally responsive environment for our clients and staff, and deliver our services with integrity and respect for Aboriginal culture and experience.

## 2 Delivering quality health services

We will deliver evidence-informed comprehensive primary health care services, seeking to get the right balance between preventing ill health and providing effective treatment for those who are sick. We will make our services highly accessible to Aboriginal people and families, and ensure that all our services work together to address their needs across the life course.

### 2.1 Treatment for those who are sick

We will provide high quality, acute and continuing care for our clients who suffer illness or injury, including management of chronic disease.

### 2.2 Illness prevention and health promotion

Using both individual and population level approaches, including community development, we will work with an empowered Aboriginal community to prevent ill health and promote good health.

### 2.3 Action on the causes of ill health

We will seek to address the social, cultural, economic and political determinants of health, including environmental health and housing, through the delivery of services, the development of healthy public policy, by working in partnership with other organisations, and by speaking out on the needs of the communities we serve.

## 3 Supporting remote communities

At the request of remote Aboriginal communities across Central Australia, and in consultation with them, we will deliver health services beyond the boundaries of Alice Springs. In doing so, we will ensure high standards of service quality, cultural responsiveness, and governance, paying particular attention to the resources required to deliver quality services.

### 3.1 Delivering health services to remote communities

We will deliver primary health care services to remote communities while desired by those places, taking into account wherever possible their particular needs and priorities.

### 3.2 Giving remote communities a strong local voice

We will ensure that the remote communities we serve, have a strong voice in service delivery and health advocacy, and will respect their local cultural authority.

## 4 Supporting our staff

We will recruit, retain, support and develop our staff to ensure high quality, culturally responsive services for our clients and a safe and respectful workplace. As an Aboriginal community controlled service we will pay particular attention to recruiting and supporting Aboriginal staff.

### 4.1 Aboriginal staff

We will continue our focus on employing and supporting Aboriginal people, seeking to increase the number and proportion of Aboriginal staff at all levels and in all roles.

### 4.2 A skilled, professional workforce

We will support the recruitment, retention and development of a skilled, culturally responsive and professional workforce, ensuring that they have the skills and confidence to deliver and shape effective services through the provision of orientation, induction and ongoing education and training.

### 4.3 Empowered staff in a respectful workplace

We will encourage our staff to share their skills and experience, support them with high quality human resources services, and ensure the provision of safe and respectful work environments.

## 5 Working together

Our strength is our capacity to work together for the health of our people. We will ensure that Congress continues to be well-managed with internal systems, frameworks and infrastructure that ensure the effectiveness and stability of our services. We will encourage good communication within and outside the organisation, critical reflection and responsible innovation.

### 5.1 Governance and leadership

Under the leadership of our Board, we will ensure that Congress has exemplary governance and management policies and processes within an effective organisational structure.

### 5.2 A learning organisation

Responding to the needs of the communities we serve, we will conduct and use research and evidence to inform the development of all our services, programs, health policy positions and submissions, and support a quality improvement culture for all our activities.

### 5.3 Finances

We will seek stable and diversified funding and other income to ensure our services are sustainable, and provide high levels of accountability and transparency to the community and our funders.

### 5.4 Infrastructure

We will support our clients and staff by providing safe and appropriate infrastructure and technology, with a particular focus on enabling our teams to work together.

### 5.5 Partnerships

We recognise that we cannot achieve our vision by ourselves, and commit to working with Aboriginal organisations, governments, research institutes, universities and other organisations with similar values to build healthier lives for the communities we serve.



### OUR VALUES (how we act)

Cultural integrity  
Equity and Social Justice  
Respect and empathy  
Recognition  
Resourcefulness  
Responsibility  
Relationships

## Midwifery Group Practice – Central Australia

The Midwifery Group Practice is located on the edges of Alice Springs Hospital. We had arranged to spend the day at a nearby Aboriginal Reservation, however there was ‘Sorry Business’ happening with the passing of a prominent chief.

I used this time to talk with midwives about the work being done with the Making FASD History programme and their experiences with it. We also discussed the different support services available to pregnant women.

Common themes that came through in these discussions include:

- ‘Grog’ (alcohol) is a significant problem and the number one killer of aboriginal people in Alice Springs. The Northern Territory is the only jurisdiction in Australia where armed police are permanently stationed outside bottle shops to prevent ‘problem drinkers’ accessing alcohol, and to stop people bringing liquor into town camps.
- There is a Banned Drinkers Register (BDR). This register requires all people purchasing liquor at bottle shops to have their photo identification scanned, and people listed on the register — those who have committed alcohol-related offences or have nominated themselves to be listed because they have a drinking problem — will be refused service.
- ‘Gunja’ (cannabis), is also widely used amongst urban aboriginal people. Aboriginal people who are connected to country are trying to spread the word that ‘Gunja isn’t our culture, it harms our spirit’
- There is a ‘Hey Dad, The First 12 Months’ Early Parenting Support service

Yarning about parenthood and your bub -

[https://assets.jeanhailes.org.au/Booklets/Yarning\\_about\\_parenthood\\_and\\_your\\_bub.pdf](https://assets.jeanhailes.org.au/Booklets/Yarning_about_parenthood_and_your_bub.pdf) is a popular resource for the local midwives.

# Gold Coast

## FASD Hub – Gold Coast Health



I had the privilege of spending a week with Doug Shelton, Haydin Hill and their skilled team at the FASD Hub in the Gold Coast.

The Gold Coast Clinic is a very new FASD specialist clinic that opened March 2018. The clinic provides formal FASD assessment for Children 7-10 years of age. The clinic is also currently offering FASD assessment for younger children aged 3 -7 years in conjunction with research project through Griffith University.

For children that fall within the Gold Coast Hospital Health Service and meet criteria for Child Developmental Services, assessment is offered from birth – 10 years of age (with children up to 16 years / or still attending school) seen at Developmental Clinic at Gold Coast University Hospital.

Referrals are accepted from General Practitioners, Paediatricians, Other medical specialists, Psychologists, Allied health professionals, Families, Child protection services, Education Departments, Justice Departments

### **Learning Goals:**

- to examine the practice-based evidence, projects and programmes that this interagency clinic has implemented to understand the potential connections to the Griffith University research project.
- To observe FASD assessments across the age range taking place
- To understand the follow up work that goes on
- To observe family feedback sessions
- To understand how the clinic was initiated

Because the clinic is newly established I am anticipating that it will be founded on the most up-to-date evidenced base.

Specialists at the clinic include:

- Clinical Director / Consultant Paediatrician
- Consultant Paediatrician
- Senior Clinical Psychologist x2
- Advanced Clinical Neuropsychologist
- Senior Clinical Neuropsychologist
- Clinical Neuropsychologist Registrar
- Senior Speech Language Pathologist x2
- Senior Physiotherapist x2
- Senior Occupational Therapist
- Senior Social Worker
- Senior Psychologist
- **Nurse Navigator**
- Administration Officer

### **Multi-disciplinary approach**

I was able to spend a timeslot with each of the disciplines and observe their part in the diagnostic process. It was fascinating to observe the different facets coming together. I was in awe of the respect that the clinicians had for each other and the work they do. The team strongly believes that an FASD diagnosis cannot be done in isolation by 1 or even 2 clinicians and needs to be a team approach.

Australia has chosen to adapt the Gold Standard Canadian FASD Diagnostic Criteria to meet the needs of their populations (Bower & Elliot, 2020). A diagnosis of FASD requires evidence of prenatal alcohol exposure and severe impairment in three or more domains of the central nervous system structure or function.

A diagnosis of FASD can be divided into one of two sub-categories:

- i. FASD with three sentinel facial features

ii. FASD with less than three sentinel facial features

There are clinical tools available to assess the facial features. Studies have found that approximately 4% of people with FASD have the facial features, indicating that 96% have a hidden disability as they look like everyone else.

**The 10 Neurodevelopmental domains that are assessed are as follows**

1. Brain Structure/neurology
2. Motor skills
3. Cognition
4. Language
5. Academic achievement
6. Memory
7. Attention
8. Executive function, including impulse control and hyperactivity
9. Affect Regulation
10. Adaptive Behaviour, Social Skills, or Social Communication

10 domains to cover –as per Australian FASD Diagnosis (Bower & Elliot, 2020) each domain has examples of a standardised test or assessment tool attached to it (pp. 21-32)

When all 10 domains have been completed, the team comes together to discuss and debate their findings.

**To obtain a diagnosis of FASD.....**

What I like best about this process is that the child has a very thorough assessment and at the end will come out with an Individual Profile of strengths and areas of deficit regardless of the outcome. Caregivers and educators can then utilise this profile to support the unique needs of the child and the appropriate services can be engaged right from the start.

The other thing I like about this process is that it can also confirm or deny any existing diagnosis, or even identify an undiagnosed health condition.

Doug Shelton stressed several times that “it is not about ‘hunting for a diagnosis’ as such, but to understand how best to meet the child’s needs”. FASD specific assessments also uncover likely management strategies for schools and parents even if the child does not meet criteria for FASD – therefore a great beginning point anyway.

Spending time with Haydin Till, Neuro psychologist, assisted me to identify 4 Key Goals:

- Reducing stigma and stereotypes
- Policy Development
- Early screening consistency
- Alert system

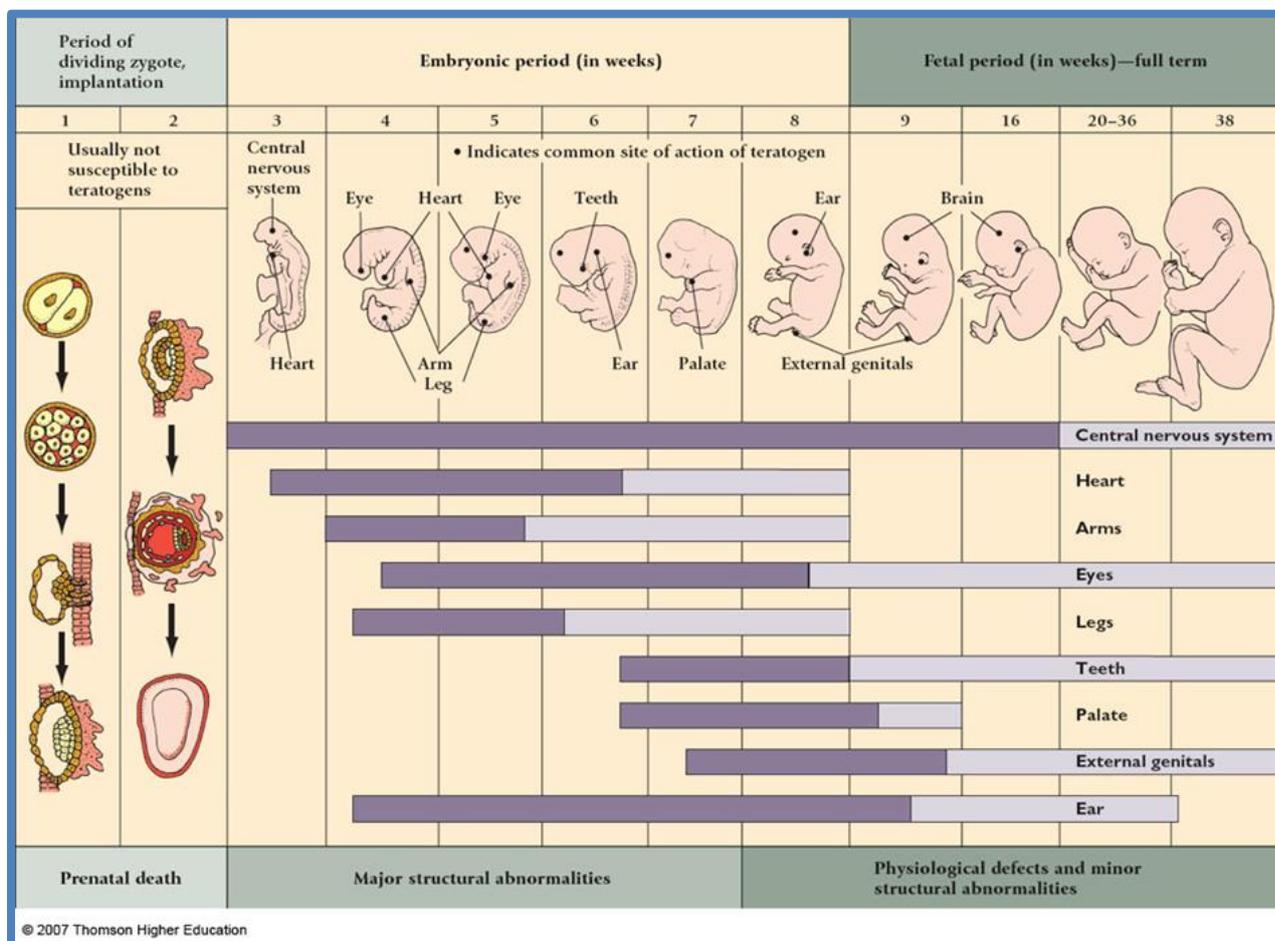
**Reducing stigma and stereotypes:** the first step in getting somewhere is deciding you are not going to stay where you are. To date we have not had any significant conversations about stigma and stereotyping. There are many reasons for that. But we can no longer afford to avoid the difficulties inherent in such painful discussions. When you deny or ignore, you delay that which, when accepted and faced, can be conquered. As we did when we first began screening women for Family Violence, we must face the unease, the fear, the isolation, the exclusion and the marginalisation, that our reluctance to tackle this issues has helped to deepen.

**Policy Development:** Currently FASD is not a funded disability in New Zealand as the threshold is based on an Intellectual Quota (IQ) of 70 or less. Most people with FASD score in the low 70s. Currently in Australia the National Disability Insurance Scheme (NDIS) only recognises FASD with Three Sentinel Facial Features as a disability – remember this encompasses only 4% of people affected by alcohol in utero.

**Early screening consistency:** FASD Hub strongly recommends that universal alcohol screening is routinely carried out using a recognised brief intervention tool. All women of child bearing age to be screened for alcohol use. It is time to move from the “wait and see to identify and act.” This is supported by findings in the What Women Want to Know project.

**Alert system:** Early identified at risk. Investigate an alert to be placed when a mother discloses alcohol use in pregnancy. This can be used for more accurate future reference/diagnosis and will provide a more robust and accurate history, rather than waiting until behaviours are emerging and relying on the parent to recall alcohol use in pregnancy.

## Critical Periods of Fetal Development



# Canada

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## Vancouver

### The Asante Centre



The Asante Centre advocate that they are growing, learning, and pushing boundaries to make the world a better place for people with developmental diversities.

The centre has an Assessment & Diagnosis component. Assessment and diagnosis helps prevent behavioural labels. It develops a more appropriate (and accurate) understanding of the individual, their strengths and needs. The Centre works with a variety of referral streams including FASD.

I had arranged to meet with Alison Pooley; however the times didn't match up so we ended up speaking on the phone. Alison spoke passionately about the importance of advocating for strengths based approach that changes the dominant narrative that FASD is an Indigenous issue. Asante Centre believes that neurodevelopmental conditions affect everyone. It was their commitment to honoring indigenous approaches to healing and wellness that caught my attention. Alison said that it is the centres view that they have much to learn from the indigenous world view as it pertains to wellness for developmental stressors and diverse abilities. These will be discussed further in the recommendations section of this report.

## BC Children's Hospital



I meet with Tessa Diaczun and Kathleen Duddy from BC Children's hospital at the conference.

Tessa and Kathleen explained that the RICHER Initiative is the first program of its kind in British Columbia that seeks to address health equity disparities. The model recognises the importance of trusted relationships and seeks to increase capacity and resilience for the families served. Working from a child/family centered philosophy the family's particular needs and circumstance are taken into consideration when providing healthcare services, which are linked to specialised healthcare and their community-based support networks.

From what I could tell from the discussions, the assessment process sounded very similar to that I experienced at the FASD Hub in the Gold Coast, except they covered the 0 to 19 age range. Multi-disciplinary assessments carried out by skilled clinicians with a strong interest in child development and neurodiversity.

What was different from the Gold Coast Hub was that this assessment clinic also offers programmes which include education sessions for families and community service providers. Tessa and Kathleen shared some of the resources and programmes that they use including:

- Transition Timeline
- Building Strengths, Creating hope
- Family Toolbox

I have looked through these resources and would like to take them to local iwi services for their review.

## 8<sup>th</sup> International Conference on Fetal Alcohol Spectrum Disorder

### **8th International Conference on Fetal Alcohol Spectrum Disorder**

*Research, Results and Relevance*

*Integrating Research, Policy and Promising Practice Around the World*

**March 6-9, 2019**

Wow, what an experience. People from all over the world whose main interest is FASD – I was in my element. I think my kiwi accent must have been fascinating as people kept asking me things



This advanced level conference/meeting continues to bring together global experts from multiple disciplines to share international research. From the pure science, to prevention, diagnosis and intervention across the lifespan, the conference will address the implications of this research and promote scientific/community collaboration. It provides an opportunity to enhance understanding of the relationships between knowledge and research and critical actions related to FASD. First held in 1987, the conference brings together people passionate about this work in a stimulating environment where they can learn and forge new partnerships.

#### **The conference promised participants will be challenged to:**

- Consider the implication and potential application of emerging evidence-based, and cutting edge research
- Expand and challenge their knowledge and understanding of hard science
- Explore different models of advanced practice from and across disciplines
- Engage in knowledge exchange and focused dialogue through formal sessions, networking and onsite meetings
- Develop connections and partnerships among global researchers, networks, governments, communities, service providers and families.

Like the Australian conference I found it difficult to choose how to spend my time as the options were all so fascinating – so I decided to make it a bit easier by choosing to follow the theme of prevention, as this is where I hope to focus my future work in this area.

One of the highlights for me was making use of break times to network with speakers who I wanted to learn more from, and identifying people who asked interesting questions and probing them for more. These are the valuable moments that have lasting impressions.

I now have a very comprehensive 500 page syllabus full of the most up to date research and promising practices from around the world as a resource. I have been already been able to direct colleagues and clinicians to evidenced based information upon request.

## Cornwall

### Cornwall Community Hospital



Debbie Champ put together a weeklong programme for me while in Ottawa and Cornwall. Debbie is a Mental Health Nurse Practitioner in the Withdrawal Management Services at Cornwall Community Hospital, as well as the Residential Program and lead in the NeoNatal Abstinent Syndrome Program. I was interested in how Canada manages pregnant women who have addictions.

I was privileged to be able to follow Debbie and observe her in her everyday work. The people and families that we spent time with were very accepting of having a kiwi along.

Debbie shared the different programmes and services that she utilises including:

- **Substance Abuse Community Treatment Programme:** This is a weekly or biweekly (as determined by the client) individual session that is offered, in their home or the clinic, to clients who are concerned with their drug or alcohol use. Services include assessment, therapy, referral, follow-up and relapse.
- **Supportive Housing Program:** This service is for individuals who have had multiple treatment episodes and have had difficulty to maintaining safe housing. It has been found that intensive case management is needed to aid the client is securing safe and secure housing. Services include frequent therapy sessions, ongoing life skills training and rent supplement support. These strategies have been links to increases success in maintaining a healthy lifestyle.

- **Specialized Opioid Treatment Programme:** Debbie spoke of the high opioid addiction challenges that Ontario is facing. A lot of her work is supporting pregnant people with opioid addictions. The programme focuses on the needs of individuals and their families. Services include assessment, therapy, case management, and referral and relapse prevention. The programme is based on client centred care which takes a harm reduction approach. Working collaboratively with community agencies is a strong focus.
- **St. Denis Centre:** Debbie and I spent a day mixing and mingling with the men at this centre. St. Denis is a 16 bed supportive addiction treatment facility for men aged 18 and over. The average stay is four to six months. The service offers 24 hour counseling, intensive case management, and referral. Programmes that are held daily on the premises include: life skills, recreation, recovery enhancement and relapse prevention. It was interesting talking with the men who were dads about how their addictions impact on their families. The men and their families have access to groups that include:
  - i. **psycho-educational** sessions (up to 4 hours) that are designed to increase awareness, understanding, and support to those involved with loved ones who are experiencing substance abuse and/or problem gambling.
  - ii. **Next step** – which is a four session education group that discusses topics including coping with urges, relapse prevention, assertiveness, emotions, communication and more.
  - iii. **Concurrent Disorder Group** - is a 6 month programme that provides psychoeducation and group therapy to help manage concurrent disorders as well as prevent the development of substance abuse issues and mental health.



Myself and Debbie Champ outside her home in Manotick

## Eastern Ontario Health Unit



Aleta Poulin is the Lead Public Health Nurse for the Healthy Babies, Healthy Children (HBHC) programme and works out of the Eastern Ontario Health Unit. I had the privilege of spending 3 days following Aleta and her work. I was also able to spend time with PHNs who have different roles.

### **Homevisits:**

Homevisits were familiar to me and very similar to my role as a Preschool Public Health Nurse. Being the end of winter, it was very cold with snow piled high everywhere. I prepared as I do for Homevisits in Tauranga and dressed warmly expecting the cold damp housing that we have in New Zealand. However, I was wrong.

### **Housing:**

The houses were extremely well heated and insulated. Aleta explained that because it gets so cold in Canada in the winter, that the government has made it illegal for heating to be turned off if people cannot pay their power bills, as they would literally freeze to death otherwise. The building codes and regulations are superior to that in New Zealand.

The need for Social housing is increasing.

*Comparison Note: I did not observe any signs of homelessness while in Cornwall as opposed to many homeless people living in tents outside shops in Vancouver.*

### **Language:**

Aleta explained that most people in Ontario are bi-lingual – English and French speaking. This came about because the French were the first Europeans to settle in Canada. I found it interesting that while Aleta and her colleagues easily went between English and French, did not use any First Peoples language other than place names and people's names, unlike in Aotearoa it is common to hear people incorporating Te Reo greetings, body parts and actions in everyday conversations.

**Sport:**

Ice Hockey sticks and putts were in the toy boxes of most family homes that I visited – compared to most New Zealand Homes having rugby balls.

**Programmes:**

Aleta shared parenting and bonding programmes and resources that the team uses as a preventative approach. Research informs that early attachment in the womb increases an improved life course outcome. Parents may be more inclined to not use drugs and alcohol in pregnancy when they become unattached to their unborn baby. Anne Hodren (2015), Margaret May Blackwell recipient has beautifully articulated similar findings to my own; please refer to Anne Hodren's (2015) report (pp. 50-54).

***Healthy Babies, Healthy Children Program***

This is the most widely used targeted home visiting programme in Ontario.

Ideally all clients are to be screened at birth using a 40 question risk assessment tool and if 2 to 5 risks are identified then the parent is offered a follow-up phone call. The phone call then offers Homevisits.

Aleta was very interested in our universal Well Child Tamariki Ora Programme being accepted by 95% of families, as she described the most difficult issue is the 'stigma' that is currently attached to the programme.

***Ncast Parent Interaction Feeding and Teaching Scales***

Aleta explained that the NCAST Parent-Child Interaction (PCI) Feeding and Teaching Scales are valid and reliable measures that allow professionals to assess both the child and parent strengths and vulnerabilities. The scales, which can be used clinically and for research, contain a well-developed set of observable behaviours that typically occur within the context of a feeding situation in the birth to 12month age range, as well as teaching encounters in the birth to 3 years age range.

The scores on both the feeding and Teaching Scales show a significant correlation with the child's subsequent measure of cognitive abilities. In Aotearoa the Well Child/Tamariki Ora programme utilises NCAST.

***Partners in Parenting Education (PIPE)***

PIPE is a research informed programme, based on the theoretical work of many researchers. PIPE is recognised and used around the world including Christchurch, Aotearoa. Aleta recommends PIPE because it provides the health professional who is delivering the programme with a fun, interactive and

practical learning process to follow that engages and educated the family. When combined with the Healthy Babies, Healthy Children programme PIPE assists families to learn experientially about emotional development, family structure, routine, consistency and predictability of their child.

#### ***Keys to Interactive Parenting Scale – KIPS***

I asked Aleta about how they measure for success or change and she was excited to tell me about KIPS. KIPS is an evaluation tool that measures parent-child interaction over time. It is thought with coaching and support many families will demonstrate improvement across all areas of the tool.

KIPS measures 12 key facets of parenting that are used in partnership with families to promote parent child relationships, promote learning and support parting confidence. The use of validated Evaluation Tools is a significant area of improvement in CH4K and is something I will be raising with our management team.

## **Ottawa**

### **Mother Connections Programme:**

I met with Francine Fitzsimmons who is the Manager of the Addiction Services which includes the Mother Connections Programme. This programme is a targeted homebased intensive case management programme for women who consume alcohol and/or drugs and who are pregnant and/or parenting children between 0 and 6 years of age. The services that are delivered by Registered Nurses include therapy, education, assessment, and referral and relapse prevention work.

Francine explained that the programme has not been utilised as much as they had anticipated, as once again the issue of stigma was raised.

## **Toronto**

I had arranged to visit with Toronto Sick Childrens Hospital, however due to the horrific incident at the Christchurch Mosques I returned home a week earlier than planned. The impact of this tragedy and being so far away from home hit me harder than I anticipated.



Au Revoir Canada

# Aotearoa New Zealand

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Having experienced an international perspective on FASD I was now interested in finding out how Aotearoa fits into the bigger picture. What is going on in other parts of New Zealand, and how might this apply in the Bay of Plenty.

## Hawkes Bay

### [Hawkes Bay District Health Board Developmental Assessment Programme FASD Assessment Path](#)

While I have not yet had the opportunity to physically spend time in Hawkes Bay, I did mix and mingle with Andi Crawford Clinical Psychologist and Sarah Goldsworthy from the Hawkes Bay FASD Team while in Canada at the International Conference. Andi worked closely with Doug Shelton and his dedicated FASD team as discussed in Gold Coast section of this report. Hawkes Bay have created a Developmental Assessment Programme (DAP) FASD Assessment Pathway (Health and Safety Developments, 2015) which includes Strong Support for replicating the approach in other areas (p. 41) and Lessons learned and considerations for replication of the approach (p. 43). Since returning from my travel fellowship I am excited to report that I have been working alongside our BOPDHB Community Paediatrician David Jones here in Bay of Plenty investigating the possibility of replicating this service in our area. There is a meeting scheduled with our funders and planners on 19<sup>th</sup> of October to progress FASD prevention and support services in our area.

## Taranaki

### [Wicked Problem Toolkit](#)

FASD has been described as a wicked problem. A wicked problem, as discussed earlier in this report, is one for which the solution is very difficult or seemingly impossible to achieve due to their multifactorial nature – in the case of FASD is unravelling why some women continue to use alcohol beyond confirmation of pregnancy, knowing that it may harm their unborn baby for life.

Tackling wicked problems is an evolving art that requires thinking that is capable of grasping the big picture. The combination of Adverse Childhood Experiences, unaddressed childhood trauma, intergenerational trauma and the impact of colonisation is a cocktail of wicked

problems. Taranaki District Health Board has created a 'Wicked Problem Toolkit' (Somos, 2016, p. 17). The method for addressing wicked problems is:

1. Analyse
2. Engage
3. Plan
4. Deliver
5. Learn and improve
6. With the goal being to improve population health and eliminate disparities.

The combination of the Hawkes Bays Developmental Assessment Pathway and the Wicked Problems Toolkit from Taranaki will be very useful in moving FASD prevention and services forward in the Bay of Plenty.

# Recommendations

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Research shapes innovation and innovation creates something new and better. Education is the way forward in changing attitudes and views. The Margaret May Blackwell Trust has provided the opportunity for health professionals like me and the previous recipients to build a shared knowledge base and provide a solid evidenced based foundation in which to translate research into practice. This is reflected in the quality of the previous recipient's reports and recommendations.

FASD is the commonest preventable cause of neurodevelopmental disorders in children and young people. Public Health is defined as "the art and science of preventing disease, prolonging life and promoting health through the organized efforts of society." The most fundamental approach to reducing inequalities in health is to tackle their root cause; that is, address the wicked problems of social, cultural, economic and historical inequalities themselves.

Based on my new found knowledge, the following are my recommendations to begin to address FASD as a significant public health issue.

## 1. FASD Informed communities

FASD cannot be addressed in isolation by health professionals only. **Everyone** needs to know and understand how together we can increase the numbers of alcohol free pregnancies in the Bay of Plenty and Aotearoa and therefore decrease the numbers of babies being born with permanent brain injury

By utilising the first two priorities of the Taking Action on Fetal Alcohol Spectrum Disorder: 2016 – 2019 Action Plan, Prevention and Early Identification, we can begin to raise the profile of this world wide pandemic by:

### *Reducing Stigma:*

Reducing stigma by raising public awareness about alcohol and pregnancy.

Stigma is discrimination against an identifiable group of people, place or nation. With Fetal Alcohol Spectrum Disorder the identifiable group is pregnant women who consume alcohol. Stigma is associated with lack of knowledge about why women continue to use alcohol after confirmation of pregnancy and need to blame someone or something. FASD informed communities have a role to play in reducing stigma.

As indicated in the low uptake of the Mother Connections programme, reducing stigma needs to be prioritised prior to developing and implementing programmes and services.

### ***Using Shared language:***

The language we use has a powerful impact on the way people with FASD are perceived and are treated. I used to contribute to the stigma by saying things like “FASD is 100% preventable.” I now understand that saying this oversimplifies a complex issue and adds to the stigma and stereotyping. Thankfully Telethonkids (2019) has published a language guide to promote dignity for those impacted by FASD.

I recommend that Aotearoa looks to adapt and adopt shared language.

### ***Developing and introducing Aotearoa/New Zealand friendly “Prevention Conversations”***

Prevention Conversations are a shared responsibility. Reducing Stigma and developing a shared language can lead to honest Prevention Conversations within families and communities. Like all effective and memorable conversations the prevention conversation is ‘organic’; a two way conversation that is carried forward.

## **2. FASD Informed practice**

FASD or better still, Neurodevelopmental Informed Practice will change the way we think about challenging clients and families. Being informed will enhance the way we develop and deliver programmes which in turn will improve outcomes for families’ while reducing the prevalence of alcohol exposed pregnancies. FASD informed practice includes reflective practice, strength based approach, individualised approach with an FASD lens.

Recommendations include but are not restricted to:

### ***Introduction to FASD for all new DHB employee’s in the orientation programme***

An education session can be developed that provides an introduction to FASD. The session should include reducing stigma, shared language and prevention conversations as discussed above.

The same education session could be offered to other community, Government and NGO’s services that work with children and families.

### ***Increase Knowledge on Adverse Childhood Experience – ACE’s and explore the potential for assessment and care planning.***

ACE’s is an evidenced based tool that can begin to address Intergenerational trauma.

Women often use alcohol to cope with past trauma. All practitioners working with children and families should have the opportunity to gain an understanding of the long term impacts of ACE’s and the links to neuroscience.

Anne Hodren (2015) reports that: The study findings are relevant for preventative work with caregivers who have experienced ACEs in their own childhood exploring the

impact of these on their care-giving and also supporting their parenting capacity. The study findings are also useful in exploring the relevance to working with whanau who have children who have been impacted by ACEs. This could include support using knowledge of the ACEs impact on neurodevelopment and attachment relationships for both the caregiver and the child and minimizing these impacts. It is worth considering if screening more widely for ACEs in the New Zealand context may improve service provision for whanau in particular vulnerable whanau (p. 100).

### *Universal alcohol screening*

Reducing Stigma and developing a shared language can lead to Prevention Conversations with clients. The Women Want to Know Project findings – discussed in the Australian section of this report, supports a New Zealand friendly screening and brief intervention tool to be developed and implemented. The project also found that frontline workers want guidance and support in initialising these conversations confidently.

Alcohol screening needs to be planned and purposeful to get an honest answer. A prevention conversation can assist in:

- Identifying and promising collaborative practice.
- Help recognise opportunities to apply trauma informed approaches
- Bring attention to opportunities and challenges within the current context.

## **3. FASD Service Development**

FASD is the commonest preventable cause of neurodevelopmental disorders in children and young people. It affects at least 1% of the population and is associated with a range of significant adverse physical, emotional, behavioural and developmental outcomes. People with FASD have much higher rates of school failure and involvement with the youth and criminal justice systems. There is a clear need for a range of services to prevent, assess, intervene and support children and their families. Oranga Tamariki has considerable interest in this area as many of their clients have unrecognised FASD. At present, there are no local FASD services. Nationally there is very limited service availability mostly in Auckland, Hawkes Bay, Northland and Taranaki. Individual clinicians try to support children on a case by case basis, but there are considerable systems issues that prevent this from occurring.

### ***Pathway development***

Review options for pathway development so that children can be formally assessed. This is likely to require support across services including Paediatrics, CAMHS, Child Development, Education and Oranga Tamariki.

One option could be to investigate the replication of Hawkes Bay District Health Board Developmental Assessment Pathway.

Following on from this, the next step could be to look to establish a working group extending across agencies including Maori Health, Disability, Public Health, Education, Midwifery and DHB services to develop a coordinated approach to education, prevention, assessment and intervention.

### ***Recognising FASD as a disability***

FASD is often described as a hidden or invisible disability. Three reasons impacting on this are:

1. That the disorders of FASD are more difficult to diagnose than full Fetal Alcohol Syndrome and may be associated with other conditions such as attachment disorder, Attention Deficit Hyperactivity Disorder, Autistic Spectrum Disorder or Conduct Disorder.
2. Because of the stigma attached, clinicians can be more reluctant to diagnose FASD on its own and the associated conditions listed above are more socially acceptable for families and communities.
3. FASD is not currently recognised as a disability that is eligible for financial support in Aotearoa (unless the child is also diagnosed with an intellectual disability).

I recommend that work is done to increase the knowledge of Disability Support services to include FASD in funding packages. This will require the examination of current policies to bring them inline to be inclusive.

### ***Child development services to include FASD Diagnosis***

The small amount of FASD diagnosis assessment that is being completed in Aotearoa is being cobbled together by clinicians who have passion, vision and drive to improve the lives of people living with FASD and their families. FASD diagnostic teams are currently absorbing comprehensive assessments within their existing funding allocations.

Taranaki have capacity to complete about 6 FASD assessments per year. This is nowhere near enough to meet the demand. In New Zealand the rate of FASD has been

purported to be approximately 1% or 1 per 100 live births, though this has not been confirmed. This is due to limited prevalence studies being conducted, combined with the stigma attached to prenatal alcohol exposure.

Hawkes Bay have done the hard work and created a Developmental Assessment Pathway that includes guidelines for replication of services in other areas. My recommendation, supported by my experience at the FASD Hub in the Gold Coast, is that DHBs across Aotearoa investigate the possibility of replicating this multi-disciplinary model.

### *Child development services focus on infant caregiver relationship*

Take another look at child development service structure. Anne Hodren (2015) found that services for vulnerable whanau need to have a focus on the infant caregiver relationship that is informed by robust neuroscience, development and attachment theory. Anne reports that time together with clients' needs to be used to assess the relationship, focus on what the caregiver and support worker notice about the baby and the relationship and explore strategies and support for the parent and child. For vulnerable whanau this would include having a focus on exploring parent's history of adverse childhood experiences and the impact on their parenting. This includes programmes that are one to one, for groups and any written or visual resources.

### *FASD Prevalence Studies*

While research is currently being conducted to capture the patterns of maternal alcohol consumption in New Zealand with the cohort of children involved in the GUINZ, this is not representative of the local prevalence. Tauranga has a reputation for young women 'who like to party'. The barrier of stigma, as discussed throughout this document, needs to be addressed prior to completing a local prevalence study. A prevalence study needs to be conducted to understand the level of need within our communities so funding can be allocated accordingly.

### *Shared database for resources*

While there are a number of small projects being rolled out in primary care services, maraes and local health agencies, there is a lack of connection and data sharing among these projects.

A centralised information database that is available to all New Zealand health care practitioners who have questions about FASD, prevention and evidenced based interventions is required. A shared resource database will contribute towards consistency of messages across Aotearoa which in turn will increase public confidence.

### *Shared database for clinicians*

A secure database to be developed for the results of a universal alcohol screening of all women of child bearing age. The database can be accessed as required by diagnosticians in the future.

### *Vulnerable unborn programme*

Aotearoa has a Vulnerable Unborn Register. This register provides a directory to parents that have been identified to require extra support and assistance to parent their child to the best of their ability. I would like to see every pregnant woman and her partner who is referred to the Vulnerable Unborn register to be offered an evidenced based infant mental health programme. Refer to Hodren (2015) for a comprehensive assessment of these services.

## **4. Examining policies**

Policies need to support FASD Informed Practice.

My recommendations are as follows:

- That the appropriate people with the right skills are contracted to examine health policies to ensure that they support FASD informed practice and make recommendations.
- De-normalising alcohol misuse in Aotearoa.
- Work with local council to examine and change policies that work towards reducing the accessibility and availability of cheap alcohol in supermarkets.

## **5. The role of Nursing in FASD**

Traditionally nursing has been seen to be at the bedside of the sick. I find it interesting that over 100 years ago in 1915, Wald stated: The call to nurse is not only for the bedside care of the sick, but to help in seeking out the deep lying basic cause of illness and misery, that in the future there may be less sickness to nurse and to cure (p. 65). Our understanding of the deep lying basic cause of illness and misery has grown exponentially since 1915. This is aided by the research and scientific advancements that have occurred over the last few decades. The advancements include neuroscience, brain development, epigenetics, brain imaging, understanding the impacts of Adverse Childhood Experiences, trauma informed care, intergenerational trauma and the impacts of colonisation. I believe improving life course outcomes by focusing on the first 1000 days of life is a nursing responsibility that begins to address the deep laying basic cause of illness – also known as the wicked problems.

Nurses who have specialised experience in child development could be supported to have a significant role in the assessment process of Neurodevelopmental disorders including FASD.

Developmental Nurses could be educated to support paediatricians in completing some of the domains of the assessment process. This would reduce waitlist time for individuals and families, and free up paediatricians time to complete the diagnosis process.

***Prevention:***

Families and whanau understand the risks of drinking during pregnancy and are supported to have healthy, alcohol free pregnancies. Women with AOD issues consistently receive proactive, practical and non-judgemental support to improve their health and wellbeing and effectively reduce their risk of having a child with FASD.

***Protective factors reduce risk factors. Nurses can:***

- Raise awareness in the community
- Raise awareness across all government services and agencies
- Undertake screening and brief interventions
- Ensure that FASD messages are consistent across all agencies
- Build evidence-based knowledge through professional development opportunities
- Collect and record data required to set baselines
- Develop services
- Evaluate initiatives
- Address the stigma
- Prescribing – contraception – as discussed in Thurston (2016/2017)
- F1000d/FASD informed workforce – nurse advocates/champions in each area
- Lobbying to have alcohol only available from alcohol suppliers (get it out of supermarkets and dairies)
- Provide advice to minister
- Change the NZ drinking culture
- Healthy relationships – work in colleges/high schools

***Early Identification:***

People with neurodevelopmental impairments are identified early and receive timely and effective assessments from FASD capable teams. Nurses can:

- Undertake screening and brief interventions
- Complete behaviour observations in preschool, school and home environments

- Multi Disciplinary Assessment Team –
  - Nurse navigator
  - Specialist Developmental Nurses could be trained or registered to use standardised tests, freeing up paediatricians time for other things
- Policy development to consider neurodevelopment concerns.

**Support:**

People and their families, whanau and caregivers receive timely, joined up support tailored to their needs, strengths, age and stage. Nurses can support in:

- Developing (or using existing) homebased parenting programmes
- Developing support services tailored to local need.
- Support FASD to be recognised as a disability so the right services can be put in place.
- Be a voice for the Assessment for parents of FASD children

**Evidence:**

An improved evidence base allows us to make good decisions and effective investments, and monitor outcomes and progress. Nurses can

- Undertake Prevalence studies within their communities to determine the incidence of FASD.
- Complete database information as required
- Participate in evaluation processes of strategies that are put in place.

## 6. Consideration for Margaret May Blackwell Fellowship

Due to the current world situation with Covid19 and significantly reduced ability to travel internationally, can I ask the board to consider using the available funds to combine the findings and recommendations from past recipients into a report to Government?

I believe a combination of these reports will provide a clear blueprint on how to begin to address the wicked problems.

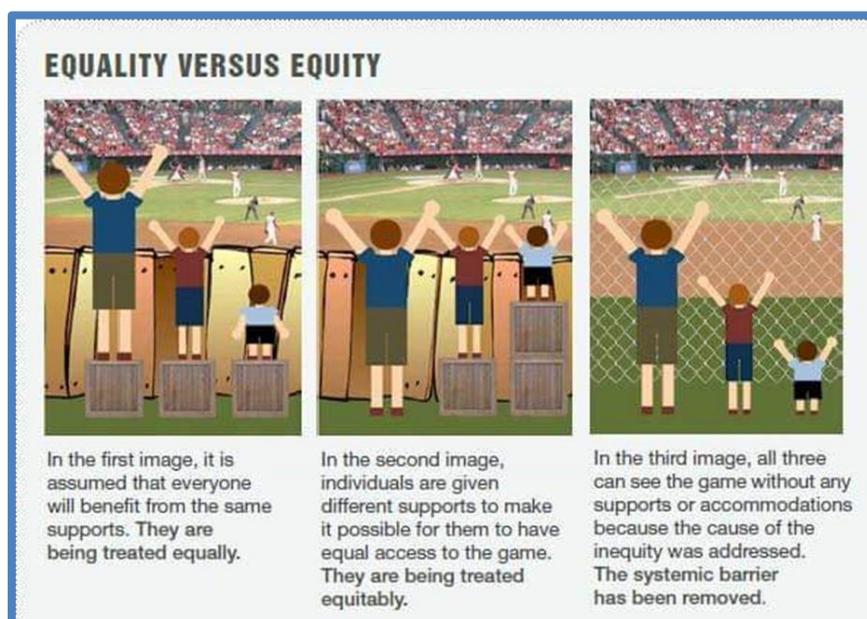
*Disclaimer: I have not mentioned FASD and Justice in this report as it is focused on birth to 5 years olds as per Margaret May Blackwell criteria. However, I want to acknowledge that research in Canada and the USA shows that children with FASD are 19 times more likely to end up in prison than those who are not affected.*

# Conclusion

Since returning from my overseas experience I have been able to promote change within Community Health 4 Kids by integrating knowledge into practice. I was part of a steering group that redeveloped our services Public Health Nurse assessment process. We now have an Admission to Discharge planner that has the potential to begin to address the wicked problems. This is in its infant state currently and will be reviewed early next year by the team.

In the Bay of Plenty DHB Paediatricians, Toi te Ora Public Health, Maternal Infant Child and Adolescent Mental Health, and Funding and Planning have recently expressed interest in the timeliness of beginning to address FASD in our district. A meeting is scheduled later this month (October 2020)

Reducing poverty by addressing equity, with a focus on prenatal alcohol exposure and intergenerational trauma, is one pathway to begin to supporting communities/whānau, hapū and iwi to limit the impact on children/tamariki of poverty, addiction, violence and relationship breakdown. Margaret May Blackwell Travel Fellowship provided the opportunity to begin to address the wicked problems associated with Fetal Alcohol Spectrum Disorder.



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## Budget

	Australia	Canada	Europe	Totals
Flights	250.00 849.00 262.00	3439.00 1140.00	*462.00	6402.00
Accommodation	2587.00 450.00	401.00		3438.00
Food	1540.00 22 day @ \$70 per day	1820.00 26 days @ \$70 per day		3360.00
Travel				
Gifts	44.00	27.70 22.00		93.70
Conference			750.00	750.00
Insurance	250.00			250.00
Miscellaneous	86.91			86.91
Sub Totals	6318.91	6849.70	1212.00	
Total				<b>14380.61</b>

- \*\$6172.00 spent - \$5709.54 refunded through insurance, leaving a deficit of \$462.46

