



‘WITH SHARED STRENGTH, GUIDANCE AND WISDOM, THOSE WITH FASD CAN GROW AND ACHIEVE’

A word from our Chair

This is the first newsletter since the departure of our founding chair, Claire Gyde, so I'd like to start by acknowledging the amazing effort Claire made to raise the profile of FASD in Aotearoa. Eight years ago, Claire had the foresight to see the need for an organization that would unite caregivers and advocate for improved awareness, services and greater support for families of individuals coping with FASD. Together with others who have played key roles in raising awareness and advocating for those with FASD in Aotearoa, and a group of enthusiastic parents, Claire founded FASD-CAN. Claire brought her drive, commitment, networking skills, compassion, public speaking skills and clear thinking to lead the organization through a period of increased recognition and support for individuals. Her contribution led FASD-CAN to where it is today, having secured some Government funding for two years that will enable the development of much needed support services. As the interim chair I appreciate I have big shoes to fill!

Building on the foundations that Claire and the FASD-CAN committee have laid, we have been busy over the past 3 months in positioning FASD-CAN to support those impacted by FASD using the core funding made available to us by the Ministry of Health (see separate article on our progress on this pilot project). We have held 2 strategy and planning meetings to consider our long-term goals. Our ultimate aim is to be a sustainable funded organisation modelled on similar organisations supporting families with neurodisabilities. We need consistent funding to further this aim and to eventually be able to employ staff to carry out the important work of supporting families. We are actively seeking funding to further this aim but acknowledge we have a long way to go to ensure that individuals and families impacted by FASD are adequately supported in Aotearoa.

Alongside the strategic work we are currently making improvements to our infrastructure, particularly our information technology and financial systems, to enable our organization to grow to become a fully functional and resourced national FASD support organization. We are also progressing policy development to ensure we address necessities such as child protection, privacy and cyber security.

We are heartened by discussions with staff from the Caregiver Experience and Learning Section of Oranga Tamariki over recent months, where they have indicated their interest in improving the FASD awareness of caregivers. We hope these discussions may, in due course, lead to training and resourcing in this area.

Tē tōia, tē haumatia

Nothing can be achieved without a plan, workforce and a way of doing things

Leigh Henderson
Chair

Integrating Te Tiriti o Waitangi

We appreciate our need to integrate Te Tiriti o Waitangi into our strategic and operational planning. To assist us with this we are thrilled to have co-opted Tania Henderson on to the committee. Tania has worked extensively in various health and community well-being service roles, supporting at risk, high needs Whānau and working with Māori organizations that are Whānau focused. Her focus over the past 8 years has been on FASD education and support for individuals with FASD. Has delivered education on FASD in multiple workshops and courses such as within the Tikanga Mātua Te Ao Maori Parenting Programme and workshops in schools for those working with FASD tamariki. Contributed to the Northern Region FASD Strategic Plan and as a panel member to the development of the NZ National FASD Training Tool (developed by Te Pou o te Whakaaro Nui) to ensure it included Tikanga practices. Subsequently ran the first of the Frontline Professional FASD Training Tool workshops. She has recently been a member of the panel which fed back to the Government on the 2016-2019 NZ FASD National Strategic Plan.

We believe her input will be invaluable in increasing our bicultural awareness and reaching out to Maori families, who are currently under-represented in our membership.

Ministry of Health – Funding Update

The end of 2020 ended on a high note for FASD-CAN with the announcement of funding from MOH to increase support for individuals and families with FASD in Aotearoa. We are mid-way in the 6-month implementation phase.

A major activity is to contract a Regional Navigator in one region. This person will be responsible for demonstrating the value of a dedicated person to provide localised support, to form relationships with professionals and service providers across sectors, advocate with and support caregivers at meetings and develop a regional resource of FASD-informed service providers. We are also planning a webinar series, investigating training workshops and the establishment of a caregiver support group via Zoom. A further component of the grant is to supply some direct grants to individuals and families to assist with their well-being.

To help us provide the right information and develop the best services we can for our whanau of families, we'll be sending out a survey in the very near future, with the goal of making sure we understand what we need to deliver to meet the needs of our all.

Watch this space and our website for those developments!

Abuse in State Care Inquiry

Several of the FASD-CAN Committee members have recently attended The Royal Commission Abuse in Care Inquiry hui to understand more about their work. We know that many of you, who are part of the FASD-CAN community, are aware of abuse/s and neglect in relation to children, young people and adults impacted by FASD. They want to hear from both survivors and those caring for them.

Who is included?

Anyone who was abused in the care of State or faith-based organisations, including anyone who was in a children's home, fostered or adopted out, in a youth justice facility, in psychiatric care in any disability care or facility, at a health camp and at any school or early childhood centre. Survivors of abuse in police cells, court cells or police custody, or in transport between different care facilities as well as people who suffered abuse while in the care of a church or religious group of any religions or faith.

How will the inquiry work?

There are a variety of ways in which survivors will be able to share their experiences. Their aim is to ensure that all survivors from all communities they engage with feel safe and supported. They recognise Te Tiriti o Waitangi and are committed to working in partnership with Maori.

How do I make contact?

There are several ways of making contact including:

- Calling to register on 0800 222 727 (between 8:30am and 6pm)
- Emailing contact@abuseincare.org.nz or
- Writing to PO Box 10071, The Terrace, Wellington 6011
- Facebook [@abuseincareRCNZ](https://www.facebook.com/abuseincareRCNZ)
- Website www.abuseincare.org.nz

You can get involved independently or through FASD-CAN. If you'd like to work with FASD-CAN, please email lee.tempest@fasd-can.org.nz who can send you more information or help you with your submission. Submissions made can be kept anonymous.

Excellence in Foster Care Awards

The Excellence in Foster Care Awards are hosted by Caring Families Aotearoa and Oranga Tamariki to honour extraordinary foster caregivers. This year, Claire Gyde and her husband Paul are recipients of this award. Claire's and Paul's award recognizes their personal circumstance and also the contribution Claire has made to FASD in Aotearoa.

Oranga Tamariki (Youth Justice Demerit Points) Amendment Bill

The Oranga Tamariki (Youth Justice Demerit Points) Amendment Bill is currently being progressed. While the Bill is intended to introduce structured interventions to improve behaviours and increase accountability and transparency within the youth justice system, those advocating for youth with FASD within the justice system have raised significant concerns with their possible treatment if this Bill is progressed in its current form.

The Bill fails to understand and respond to the complex and layered challenges facing our rangatahi. Opponents of the Bill, including the Children's Commissioner, Judge Andrew Becroft, and Professor Anita Gibbs, have appeared before the first hearing to object to the Bill and, in Anita's submission, to highlight the lack of accommodation of the needs of youth with FASD within the justice system.

You can follow the progress of the Bill here: https://www.parliament.nz/en/pb/bills-and-laws/bills-proposed-laws/document/BILL_96165/oranga-tamariki-youth-justice-demerit-points-amendment

Commissioners report on FASD - Update

There has been some progress on the report to the Prime Minister, prepared by the Children's Commissioner and the Disability Commissioner with input from FASD-CAN. The Commissioners met with Jacinda Ardern, the Minister for Health and the Disability Minister in February and reported that the meeting went well, with an acknowledgement of the seriousness of the issue of FASD in New Zealand. They are now awaiting the Government's formal response.

Changes to KiwiSaver for individuals with FASD

In a surprising development, the government announced that certain population groups, including individuals with FASD, may be able to access their KiwiSaver contributions earlier than normal retirement due to a shorter life expectancy. While the reasoning they used to reach this position is not transparent, it does indicate there is some government recognition that individuals with FASD are different and disadvantaged. It is noteworthy that the evidence relating to the early average age of death is limited and relates to increased rates of suicide, violence, drug and alcohol addiction and accidental death.

You can find out more here <https://www.beehive.govt.nz/release/government-announces-list-life-shortening-conditions-guaranteeing-early-kiwisaver-access>

Research Project: Living with FASD in Aotearoa

Professor Anita Gibbs, University of Otago, has secured some funding to do a 2-year research project collecting data on living with FASD in Aotearoa.

Through her research, Anita will be looking to understand what interventions works well within our health, education, welfare, and justice systems to support positive outcomes and wellbeing for people living with FASD. It would be great for the FASD community to help her with this important work.

To be involved, contact Anita Gibbs:

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