FASD-CAN’s ‘Life with FASD: Understand and Connect with Aroha’ workshop

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Input from our Facilitators and Participants

Our basic training course for parents, caregivers, grandparents and other whānau who have a young person with FASD in their care has been described as ‘life-changing’. Finding out how FASD affects the brain, and understanding why their child or teenager behaves the way they do is often a ‘light-bulb’ moment for caregivers, while gaining new ideas about parenting strategies which actually work is empowering for the whole whānau.

This free training is delivered either as a two-day, in-person course with morning and afternoon teas and lunches included – or online over seven interactive webinar sessions.

We asked two of our main facilitators about their experience of delivering the training.

Anna Gundesen

“We noticed that many of our attendees came in not knowing much about FASD; many felt it was somehow their fault that their tamariki had challenging behaviours. Their confidence around their own parenting was low. It’s easy to feel like this when you have extended family, friends, teachers telling you how to deal with your ‘naughty’ child – it can undermine your confidence enormously.

“But when our attendees learned about FASD as a brain-based disability and its primary characteristics like impaired memory, slow processing times and dysmaturity, we could see the lights coming on. These impact a child’s ability to meet expectations on every level, so knowing what’s going on in the brain allows caregivers and whānau to support their young person with new understanding and aroha.

“Building that kete of knowledge and tools is really empowering and when they can then pass that knowledge on to others in their family and to the professionals who come into contact with their child, it makes a huge difference. Parents and caregivers can stand up for their child – and for themselves – from a place of knowledge.

“Acceptance is another big thing that our students found in the training. A tamaiti with FASD doesn’t need to change or be ‘fixed’. It’s a disability, and as a facilitator it’s incredibly heartening to see the shift towards empathy as understanding and acceptance grows.

“The last thing we noticed was the ‘sideways learning’ that occurred organically – learning from other participants and sharing stories was a huge part of the wananga. They met their tribe and it was very empowering. We heard over and over again: ‘It feels so great to know we’re not alone and to talk to others who know what it’s like.’”

RuruHana Brownie (Ngāti Pūkenga, Ngā Puhi)

“From my years of working with whānau I know that many people think, ‘what have I done wrong?,’ when they’re faced with behavioural issues associated with FASD. If they don’t have the facts, there are so many unknowns, but once you know what you’re dealing with, you can begin to learn strategies that work.

“Contributing to the FASD-CAN training from a tangata whenua perspective was important to us. We knew that it had to have a te ao Māori education service delivery if it was going to be relevant.

“Normalising te reo within our training was not just superficial for us. It’s the language of my heart and I like to think that everyone gains from using a little bit of it in our workshops. It contributes a flavour of Aotearoa and it’s inclusive. It’s not particularly about honouring te Tiriti for me, it’s just about being a good human being and respecting tangata whenua. I’m not big on clinical training; I’ve got no degrees from university – but several in parenting!

“There’s so much harm, so much trauma and whakamaimai, pain out there. If we want to be part of the solution for FASD, we need to hear what the problems are and we’re ready for that. I’ve seen it all, and I’ve been challenged too – when people are hurting they are often angry and I understand that.

“A really big part of this training process for me is kaupapa whānau. Through whakawhanaungatanga, getting to know each other, and through tuhono, connection, we become whānau. And we’re here for our participants long-term – we have a support group up here in Whāngarei and we’re keen to welcome with aroha anyone who needs us.”

Participant feedback

We asked our participants what the most valuable part of the course was for them. Here are some of the responses.

“Being in a group of people who understand, and the facilitator having lived experience.”

“Access to structured information and resources. Positive, but realistic approach.”

“Realising that we as a family unit are not the only ones going through this and that there is light at the end of the tunnel!”

"The knowledge and the stories from others."

"Putting all the pieces together to help give me a much fuller understanding of the disability and also hearing from other group members in relation to their personal experiences and challenges."

"It's great knowing you are not alone, that others are on this journey too."

"Calm surroundings; passionate, knowledgeable trainers."

"Loved the Aotearoa direction."

"Easy flow, unhurried; exceptional marae; generosity and wellbeing; hauora, mauri ora."

"The lived experience of facilitators was a huge benefit."

"I've done other training in FASD but this is the first one devoted to me as a caregiver. I have found it really good. [It filled] my tank and [gave me a] personal sense of belonging through being with others who 'get it'. This has strengthened my compassion and encouragement for the way forward and reminded me of the gratitude I have for what I have gained from living on the edge."

If you would like to ask about having a 'Life with FASD' training in your area, please email us at admin@fasd-can.org.nz.

Above: Training in Te Tai Tokerau / Northland.

FASD-CAN
Fetal Alcohol Spectrum Disorder
Care Action Network