



THE NETWORK NEWS

FASD-CAN Incorporated

September 2016

A word from the Chair

The AGM was held in Wellington on the 6th of August. At this meeting we welcomed two new members on to our committee, Eleanor Bensemman and Leigh Henderson. This signifies a small change for us as we have moved from having six committee members to seven. We value the additional experience. I also would like to thank out-going committee member Lisa Smith who has dedicated three years to the organization and has done a mountain of work behind the scenes.

Now in our fourth year, things are starting to come together as we continue to focus on our objective of uniting and strengthening families and educating about FASD across our communities.

The Parent/Caregiver workshop is testament to our commitment to bring families together. There is no substitute for connecting and meeting other caregivers on a similar path. The theme of the day was 'communication' but what has become increasingly evident to me is the importance of 'co-operation'. We have, as a

collective voice, helped to inform the FASD action plan. This is a huge shift and an endorsement of how our organization presents itself in a collaborative, honest and compassionate way. My heartfelt thanks goes out to everyone who attended Ministry of Health meetings and made submissions to the action plan. I maintain that the best way to teach about FASD is to share our experiences.

We have also been very fortunate to receive a \$15,000 donation from the Pora Whanau Trust. It feels somehow quite symbolic that Teina Pora, whose own case helped put FASD on the map in NZ, is our first benefactor.

I would also like to extend my thanks to Tracey Jongens and Christine Rogan who have both been instrumental in the development of the web based teacher guide. This is a fantastic resource and one which I hope encourages teachers to think and act differently when they have a child with FASD in their classroom. If we can make the school years a positive experience then I am sure the pathway to adulthood is made easier.

FASD-CAN has recently endorsed an open letter to John Key that seeks to increase the youth justice age to 17. This is an initiative from 'Just Speak' an organization formed to empower young people to speak out for change in the criminal justice system, informed by evidence and experience, towards a more just Aotearoa. For our FASD teens, sadly the justice system is a very tough place. We hope this goes some way towards helping those young offenders.

Kia Kaha
Claire

In this issue:

- • •
- Workshop Review: When Communication Matters
- Charities Approval
- FASD: Nelson
- A child's tale
- FASD Guide for Teachers
- Launch of the FASD Action Plan

Parent/Caregiver Workshop Review by Lisa Smith

When Communication Matters

On a very wet Wellington day 30 parents and caregivers came together for our second parent/caregiver workshop co-hosted by Alcohol Healthwatch with funding assistance from Health Promotion Agency.

The day began with a beautiful and impromptu mihi from two lovely young ladies who were there with whanau. A truly delightful surprise.

We were very fortunate that Catherine McCullough, a Senior Policy Analyst from the Ministry of Health came to talk about the details and the process of bringing together the FASD Action Plan. We learned some of the complexities of bringing all the information and other Ministries together on the same page to support the final document. Catherine also explained that some of the issues we raised had not gone into the plan as yet but it is a living document and will change over time. Focusing on what all the Ministries will sign up to was the key outcome and this is the first time that so many Ministerial Departments have come to an agreement on their roles in such a short time. Catherine has been the main driver for the FASD Action Plan and has consulted well with parents through FASD-CAN, emails, conversations and two focus group meetings.

Christine Rogan highlighted the New Guidelines on FASD Diagnosis and the old terms of Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome and ARND (Alcohol Related Neurodisability) is now being replaced by:

- FASD with Sentinel facial features
- FASD without Sentinel facial features
- At risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure (designation not a diagnosis).

Growth has been removed as a diagnostic factor as it is neither sensitive nor specific to indicate an FASD diagnosis. Discussion and concern was expressed re the threshold of Alcohol Exposure known to be associated with adverse neurodevelopmental effects. They have stated a threshold of 7 or more standard drinks (9.5 NZ standard drinks) or 2 or more binges of 4 or more standard drinks (5.4 NZ standard drinks). This is a very tentative statement and may change with new evidence.

To conclude it means that there is no more confusing terminology and that it is just FASD and there is no longer an assumption that FAS is more severe than FASD.

Tracey Jongens, an RTLB teacher and mum to a teenage son with FASD, summarized the structure and Funding arms of the Education System in New Zealand which was very helpful. She has been working with the Ministry of Education over the last year to inform an online teacher resource established through the Inclusive TKI website: inclusive.tki.org.nz.

Shona Davidson then discussed her journey with her son and FASD. Shona has a wealth of experience as her son is now in his 40's. She spoke of many situations where she has had to be her son's advocate and continues to do so now with the help of his wife. Shona and Philip's story offers hope to those with younger children as she went on to explain that her son held down a job, is married and has two beautiful children.

This was followed by our guest speaker, David Henton, from Confident Communications, who gave an inspiring presentation on Effective Communication and ways to manage conflict. The most important part of being an effective communicator is becoming a better listener. Often when we are listening to others we are thinking about what we want to say and therefore do not truly focus on what the other person is saying. Through a practical interactive session, we learnt the importance of active listening and use of our nonverbal skills to fully engage in effective communication.

A quote that I will remember from David’s talk which I thought was very helpful for us FASD parent/carers is “It’s not Me versus You It’s Us versus the problem”. I used this technique in many difficult situations when my son had a meltdown and caused chaos at school. I used to always state at the start of the meeting that there is no blame to be laid anywhere and that I am just as upset about the issue as them. It allowed us to focus on the problem, not the child. I am sure David’s expertise and wisdom will help all of us advocate more effectively in the myriad of situations we encounter.

After lunch Claire Gyde gave a talk about dealing with Caregiver Stress which is something that we all live with constantly with our FASD children. It is hard sometimes to find time for ourselves and often many of us feel we are drowning with the perpetual stress that our kids put on us. However, where possible it is essential that we do take some time for ourselves so that we have the strength to carry on caring.

Following this, I lead an interactive session on “Safety Pins – Safety Plans” for our FASD individuals. We split into five groups and each were given a name: Superstars, Combat soldiers, The Saints, The Incredibles, The A- Team and The Warriors. The challenge was to fold five different cloth nappies and put them on a doll. Well there was lot of laughter as the teams struggled with the origami of nappies.

What has this to do with Safety plans?

Safety Pins – Nappies	Safety Plans
No one size fits all	Same
Trial and error will get the right fit for your child	Same
FAIL – First Attempt in Learning	We learn from failures
Nappies provide protection for the baby and protection for us.	Safety plans do the same
Team Approach – practical and will find the right one for the baby	Same – we need to involve a team around our FASD person who know the safety plan. Parents need to be working together and stick to the plan set.
Babies/toddlers need very close supervision to ensure safety. Also type of nappy will change as the baby becomes a toddler	Same for safety plan – however gets harder as they get older. Safety plans change over time
Pins can hurt if the jab you or the baby	Our kids are vulnerable. We may get hurt or the FASD child hurts themselves.
Nappies are bulky and restrict movement – again needs to change as the child grows	Same for safety plan.

I then discussed the safety plan and behaviour scale that I have used with my son since 13yrs of age. This was put together with the clinical psychologist and teacher who were part of the High and Complex Needs Plan.

The day was finished off with dinner out at a local Malaysian Restaurant which was a perfect end to a very productive day.

On behalf of FASD-CAN we would like to say many thanks to the Health Promotion Agency for supporting this Parent/Caregiver workshop. ``Very much looking forward to the next one``

Lisa Smith



Some of FASD-CAN members who attended our Wellington conference.

Charities Approval



The committee is delighted to advise that our application for charity status has been successful. Our official Registration Number is CC53623.

This will enable us to issue receipts for donations which will allow the donor to claim the 33% rebate on the donation (up to the value of one third of the donor's taxable income).

As a relatively new organization and charity with limited financial resources we are hopeful that our new status as a charity will encourage those with enthusiasm for supporting our causes to contribute some financial support.

This new charitable status brings with it some more administrative obligations which should be relatively straightforward but will however be carefully monitored by the committee.

Ross Porter

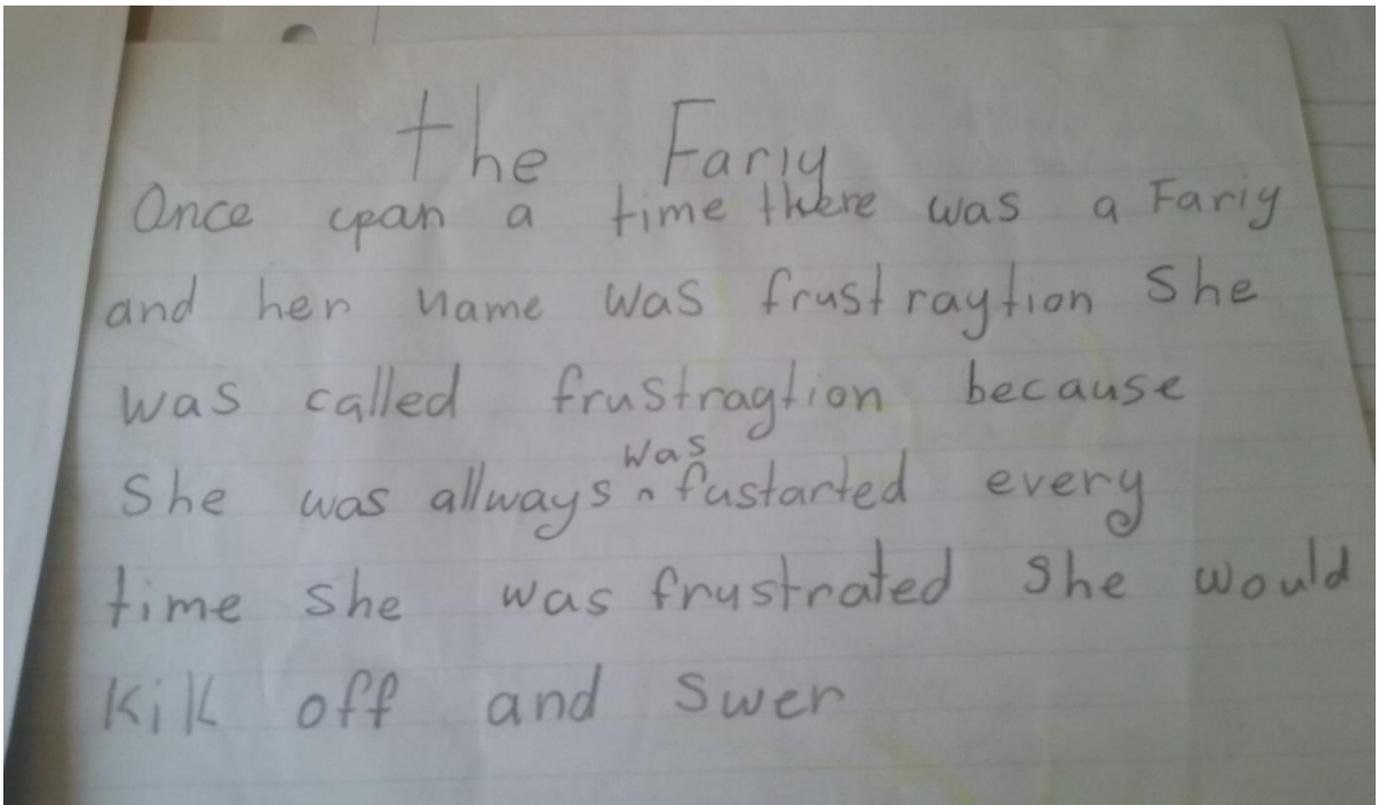
Progress has been made in Nelson over the last year in the area of FASD.

Last year saw the formation of a FASD Steering Group being set up and led by Helke Florkowski (Pediatrician, Nelson & Marlborough District Health Board). This has snow-balled from starting off with 4 or 5 members to now around 22 members. These members come from a variety of backgrounds including Child Development, Child & adolescent Mental Health, Youth Justice, Drug & Alcohol, Education, Maternity, private practice, behavioural services, CYFs, ASD services, primary health, NASC, and parents/caregivers. The team also consists of 4 working parties; prevention, diagnosis, support and finance. This has led to an increase in public and professional awareness around FASD. Public and professional talks have been given around prevention and support. The formation of two parent/care-giver support groups, one in Blenheim and one in Nelson which are active. There are plans to form a third in Motueka. There has been a professional shift from trying to categorise who is responsible for the different facets of FASD to a collaborative approach of multidisciplinary action. Professionals have not only volunteered their time to the steering group, but also their time to diagnosis and testing for those that fall out with the criteria for services. It would seem that at grassroots level there is a steady pressure building to push FASD further up the agenda of many professions. With the recent political interest there is a hope to link both the actions in Nelson with Ministry of Health by keeping Catherine McCullough updated on news from the steering group. Although not much has changed for most of the individuals with FASD and their families, there seems to be a definite shift in the right direction, and in my opinion a very significant one.

Cat Ward

A child's tale by Katie Tempest Humphries

Sometimes our children can offer us a rich insight into their world. One of the ways Katie communicates her feelings and emotions is through her writings. This short story was written when she was 10 years old and expresses the high levels of frustration that are a constant companion in her life. As her mum and dad, her stories often compound our own grief as we realize how hard it often is for her to get through each day in a neurotypical world.



Ministry of Education – FASD Guide for Teachers

On August 16, 2016 the Ministry of Education (MOE) launched their new FASD Guide for Teachers. This is an online resource and is part of the Te Kete Ipurangi (TKI) resource for teachers.

FASD-CAN has been involved since the very beginning of this development, which we are really pleased about. In 2014, members of the FASD-CAN committee met with the MOE in Wellington as we had become aware that the MOE were looking to develop a resource supporting FASD. It was important to us that the experience of NZ families living with FASD was represented in any national document.

Following this, the draft Literature Review was sent to FASD-CAN to review, prior to being published. FASD-CAN was able to suggest some very important changes to the information included and the author revised the original accordingly.

Quite by chance, I was at a professional development in 2015 and the presenter mentioned she was about to begin work on the FASD Guide. This was really awesome timing, as I was able to make myself known to her and as a result, Christine Rogan and I were able to suggest contacts, websites and information to share with the writing team.

I stayed in contact with this team and in March, I was contacted to engage further around the Guide. This contact coincided with the visit of Dr Jacqueline Pei and Tracy Mastrangelo to NZ. I was able to get the writer of the guide to travel to Christchurch and attend an education focus day with RTLB and Dr Pei and Tracy and to meet them. This was a really important aspect in the development of the guide.

At the end of May, Christine Rogan and I peer reviewed the guide. This culminated on August 16th with the release of the guide. To view the guide go to: <http://inclusive.tki.org.nz/guides/fasd/>

Since its release I have sent the link to a few internationally renowned educators with an interest in FASD - Dr Jacqueline Pei and Tracy Mastrangelo in Canada and Dr Carolyn Blackburn, UK. All have responded very favorably about the resource.

The guide is available to the public. Please feel free to share this!

The guide will continue to be further developed. The writers would really like to see some NZ videos of:

Teacher's meeting the needs of those with FASD in their classroom programmes

Students with FASD who are able to articulate what living with FASD means and how can schools help them best.

If you know anyone who would like to help with this, please feel free to email me on:

traceyj@rtlb34.school.nz

Tracey Jongens

The FASD Action Plan

The really big news of the year so far is the launch of the FASD Action Plan which occurred on the 16th of August. We were fortunate to have a good representation of FASD-CAN members attend Parliament – a significant event for us all.

ASSOCIATE MINISTER OF HEALTH, PETER DUNNE, WITH JAKOB GYDE (PHOTOGRAPHER OF COVER IMAGE)



The plan itself is not a cure-all but it is a good start. It clearly has a strong prevention focus and the underlying intent of the document is sound. The goal of the plan is broad: “FASD is prevented and people with FASD and their family/whanau live the best possible lives”. Of course, in a society where there is alcohol, there will always be FASD. There will always, therefore, be a need to provide joined up services, support and diagnosis. The ten action points in the plan are:

1. Increase collaboration and coordination to better support activities aimed at shifting NZ’s drinking culture and targeting harmful alcohol consumption.
2. Develop and disseminate clear, unambiguous and consistent messages to increase the whole community’s awareness of the risks of drinking during pregnancy, including FASD.
3. Support primary care to provide high-quality, responsive and equitable maternity care, including screening and brief intervention for alcohol.
4. Increase access to equitable and culturally competent sexual and reproductive health care
5. Increase access to support and specialist services for women with alcohol and drug issues
6. Enhance the ability of frontline professionals to recognize and respond effectively and compassionately to people with FASD and other neurodevelopmental impairments
7. Improve the capability of clinicians to diagnose FASD
8. Improve cross-sector collaboration and capacity to provide effective assessments for people showing signs of significant neurodevelopmental impairment
9. Develop a coordinated, consistent, accessible and appropriately resourced pathway for supporting affected people and their families, whanau and caregivers.
10. Conduct research into the incidence of FASD and other neurodevelopmental impairments in a NZ cohort.

You can read the full plan online:

<http://www.health.govt.nz/publication/taking-action-fetal-alcohol-spectrum-disorder-2016-2019-action-plan>

Minister Dunne's launch speech can be viewed online:

<https://www.beehive.govt.nz/speech/launch-taking-action-fetal-alcohol-spectrum-disorder-2016-2019-parliament-buildings-wellingto>



The photo on the cover of the plan was taken in Taranaki bush. It signifies 'Strength & Growth'. This powerful imagery speaks to the essence of the plan; that the multi-sectorial, strategic and coordinated approach to FASD will help strengthen families and enable those living with FASD to grow and achieve. It also signifies the strength-based view and approach we must take if we are to cherish and celebrate our children's successes.

**PHOTO THAT ADORNS COVER OF THE FASD PLAN
BY JAKOB GYDE**