



THE NETWORK NEWS

FASD-CAN Incorporated

July 2015

A word from the Chair

This is a wonderful issue! So much is shared in the next few pages. My grateful thanks to Eleanor for sharing her insights through “Daniel’s Story”. I have long held the belief that the best way to educate about FASD is to tell our stories. It is good to see that many of our members are ‘spreading the word’ and getting involved with their communities and educating through their own stories. The ‘lived experience’ is undeniably powerful.

The committee has been very busy in recent months. We are still actively pursuing involvement with Ministry of Education around education programmes for teaching professionals and, although the wheels turn very slowly, we believe we are still working towards that end. Last month following several letters to Rt Hon Peter Dunne, FASD-CAN also began the consultation process with Ministry of Health in developing the FASD Action Plan. This plan was agreed to by the Government in response to recommendations set out in the Report of the Health Committee on “Inquiry into improving child

health outcomes and preventing child abuse with a focus from preconception until three years of age”. The response specifically states:

The Government is concerned about the impact of fetal alcohol spectrum disorder on the development of young people. It is developing a fetal alcohol spectrum disorder plan of action and will look to complete this work within 18 months of the Report being published.

Interestingly, time is up and it was not until we began writing to the Associate Minister of Health that the consultation process began. Read into that what you will but we intend to raise our voice in this area. It is very important to the future of our loved ones.

We have also lodged a complaint with the Human Rights Commission on behalf of all families and individuals living with FASD. This action speaks to the discrimination faced by those with FASD due to the lack of services available because FASD does not fit “disability criteria”.

In this issue:

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- Up-coming events

The Ministry of Health have declined to engage in a mediation with us and we are currently formulating a response and ‘next steps’. We will keep you posted.

Finally, please keep the 9th and 10th of September free for the FASDay ‘FASD Policy and Research Forum’ AND our very first FASD-CAN parent workshop.

Kia Kaha
Claire

Daniel's Story

By Eleanor Bensemann

I am Eleanor Bensemann – grandmother to at least two, possibly four, children affected by fetal alcohol. These are the children of my son, Darcy Alan Bensemann. Darcy had a mild intellectual disability, possibly caused by a traumatic birth. They are from two different relationships. Kirsty and Daniel's mother is Dianne and it is known she was a binge drinker while pregnant. She also has an intellectual disability and shared with me recently that she wondered if she too was affected by fetal alcohol as her mother was an alcoholic.

Kirsty, 21 years old now, and Daniel 18 have both been diagnosed with FASD. Jessica 13 and Shakura 11, whose mother is Hilda, have not. Nevertheless they do exhibit some of the symptoms.

However, this is Daniel's story. I know it intimately as my husband and I raised Daniel from the time he was one year old

Due to Darcy and Dianne's intellectual impairment and their drug and alcohol abuse, Daniel was removed from them at birth and became a ward of state, living with foster families. There was an attempt to return Daniel to his birth parents but this failed.

When he came to us in Grovetown, Marlborough he was a bright, cute little boy who met all his milestones. He was already walking and saying a few words, and there was nothing to indicate that his brain was affected. He was much loved by us and our extended family, and he and my husband Alan were especially close.

He attended pre-school as we both worked, and it became a home away from home for him, with caring staff who were very fond of him. There only real concern was that he was slow to be toilet trained and continued to have accidents even after he started school, at which time Alan

moved to part-time work and became Daniel's main caregiver.

At times his behaviour was worrying and he would have the occasional meltdown and sometimes use inappropriate language. However, this was not enough to cause alarm bells to ring. At first he did well at the small country school he attended, but as the work became more difficult he began to struggle.

Our son Darcy was killed in a vehicle accident in 2003 when Daniel was seven years old. Daniel's main contact with his father had been by telephone, although we arranged visits and tried to keep in touch. He didn't see his mother, who lived in the North Island, from the time he was five years old. We had lost touch with her after the relationship broke up.

Alan became unwell through 2004, having a hip replacement. He had lost a great deal of weight and had some worrying symptoms. Early in 2005 we were devastated when he was diagnosed with Motor Neurone Disease. During Alan's progressive illness he became unable to interact with Daniel as he had in the past. Daniel once attacked his grandfather with a stick as he sat in his wheelchair. He was ten years old when Alan died in October 2006.

Daniel was involved in the funeral and I tried to support him at this sad time as much as possible. However, in the months ahead, there were many incidents of extreme behaviour from Daniel including out-of-control rages, threatening language and physical assaults. Defiance and non-compliance became a daily occurrence.

Believing that the problems were caused by grief, I arranged for Daniel to have counselling with Rob Jenkins (Relationship Services) but this was of no use

to him. Rob said to me Daniel was the most non-compliant child he had met!

There were also problems at school where he was now in Year 5 and 6 and he was stood down on at least two occasions. He was under an RTLB for some of this time, and I believe she may have raised the possibility of FASD with me, but I was certainly not ready to listen to that!

In 2007 Daniel was referred to CAMHS due to his ongoing challenging behaviours. Maggie Dewar (Clinical Psychologist) did a psychometric test and found Daniel to have an Intellectual Disability. I had not suspected that at all, and broke down and cried when I was told the diagnosis. I knew what that had meant for our son Darcy.

In early 2008 I purchased a home in Picton where I was working as the Picton Librarian. Daniel began his intermediate years at Queen Charlotte College, and it was a sensible move to be living in Picton and cut down on all the travel. Daniel's behaviour was fine at school at first but there were enormous meltdowns when he got home. There was pressure to do homework which was beyond him.

As time went on I was sure intellectual disability did not explain Daniel's very worrying behaviour. Under the guidance of Philippa Loan of CAMHS in Blenheim fetal alcohol syndrome was eventually diagnosed on 8th September 2008-by Alisdair Hunter-Locum in Nelson at the time. However, knowing what it was didn't improve things, as I was not given any specialist advice on how to cope with Daniel, and in any case it would have been very difficult to help him on my own.

Eventually Daniel was placed on medication (Risperidone) which for a time had a miraculous affect and seemed to calm him right down. However, there were still outbursts often caused by frustration and Daniel continued to attack me. I called the police on several occasions, and had a system set up where they would take him to friends of mine to stay the night. He was always fine by the time he got there, but I was very upset and devastated by the events.

By then Daniel was under the Open Home Foundation who provided help and support to me, but they were used to dealing with abused children rather than

abused parents! Through IDEA various mentors were provided, who provided after-school care for Daniel. I also received some weekend respite care.

Eventually in early 2010 a Family Group Conference was held and Daniel was removed from my care and placed in a foster home. The foster parents were known to us as we attended the same church. I was initially distressed by this development as I had hoped I would be offered more support rather than having Daniel placed in another home. Eventually I came to appreciate the stress I had been living under, and enjoyed some time for myself.

The placement lasted six months, and then Daniel was in a variety of homes. He returned to my care in 2011 which I initiated as I felt he was in a very vulnerable situation being moved from place to place. Under Open Home and with guidance from Support Works, mentors were provided so that I was never in the house alone with Daniel while he was awake. These mentors were three members of the same family; a father-in-law, his son-in-law, and a nephew. (18). I expressed some concerns about this team in the early days, but it seemed there was no alternative. I later found out, much too late, that the youngest mentor had introduced Daniel to marijuana and alcohol. I should have picked up on that but I was very naive. Daniel was also smoking and had been for some time. He was still attending Queen Charlotte College, and had his own teacher aide at times. However he was often stood down and very nearly expelled on many occasions. He received very little education and has had none since. He is, however, quite capable of learning given the right support and conditions.

In November 2011 while I was in Auckland attending a Grandparents Raising Grandchildren Conference, Daniel attempted to hold up a dairy with a knife in a bid to steal cigarettes. After a short period of bail, he was remanded for assessment under the IDCCA Act to determine if it was fit to plea. He could not live with me as the police and the court decided it was no longer safe. The process was very long-winded, taking six months, and I have documented it elsewhere. He was eventually found unfit to plea and was placed under a Secure Order with Richmond Trust. This lasted two years in a variety of residential homes, and Daniel remained difficult for them to deal with.

Since his release all living situations have broken down, as Daniel refuses to live under household rules or pay board and absconds at the first opportunity. He went to live with his mother in Inglewood in October 2014, but unsurprisingly she could not cope with him and had him trespassed from her home after six weeks. Since then he has been virtually homeless living on the streets in both New Plymouth and latterly in Marlborough. Many of his possessions have been lost as he moves from one situation to another. He continues to cause problems with his behaviour, being addicted to alcohol and drinking to excess whenever possible. His benefit is spent on the day he gets it, and he has been arrested numerous times for disorderly and threatening behaviour, breaches of bail and resisting arrest.

At the time of writing Daniel is remanded in custody in Christchurch's Men's Prison, awaiting assessments under Section 38 1A and 1D of the Criminal Procedure (Mentally Impaired Persons) Act. (By the way, this is a dreadful name for the Act and another instance of how people are discriminated against!) I have asked that Valerie McGinn do these assessments, but I'm not sure if this will happen.

Daniel is fortunately in the Youth Unit and designated a Special Prisoner. I hired my own lawyer to make sure I was heard in court, but this is expensive and not sustainable. I think I may still be an Additional Guardian in which case the authorities are required to consult with me and keep me informed.

I can only be relieved that I now know where he is, and that he is being fed-in the meantime! The agencies trying to help him have so far been unable to find him anywhere to live, which is why he is in prison. If he had a bail address he wouldn't be.

So there we are-not too many positives in this story. All I can say is, do everything you can to keep your young FASD people out of the Justice System. It is imperative that this is recognised as a disability and not lumped in with "normal" Intellectual Disability. The needs are very different, and Daniel never fitted in well in those homes. He really can't live with other people, but finding a flat or a sleep-out for him has so far proved difficult. He will receive a number of support hours once he is set up, so it is a matter of patience. From past experience I can't see the assessments being done by the 23rd March when Daniel next appears in court, although the judge ordered them to be done by then.

I should say however there are many encouraging traits that Daniel himself has. He always loved sport, and managed to play in teams of hockey, rugby, cricket and soccer at different times. He loves the outdoors – tramping, hunting and fishing. He retains many facts and becomes very knowledgeable on subjects that interest him. He attended a Whenua Iti course while living in Nelson and did so well that staff didn't need to attend with him. He very proudly showed me trees he had helped plant when we visited Riwaka. He loves music and plays the guitar.

My other grandson asked his mother "How come Nana still helps Daniel when he's been so mean to her?" My daughter replied that a 14 year old boy couldn't possibly understand. The answer is because he's my grandson and I love him to bits. One thing we definitely learn through this journey is what unconditional love really means.

I just have to wait and pray for positive outcomes - that's all I can do.



Spreading the Word

Napier – Lisa Smith recently gave a talk at the local NZ Educational Institute meeting where the theme was on Autism and FASD. Lisa reported that there was a good turnout of over 60 teachers. However, at the end of the talk she could feel their frustrations rising to the surface during the discussions that followed. Many of those teachers who attended were struggling to meet the needs of FASD students due to lack of resources, support and funding. Lisa says, “It was interesting to hear of the difficulties faced by teaching professionals. However, parents who are fighting for their children’s needs to be met at school probably have the toughest job, especially when the school are not willing or able to make accommodations”. Lisa recommends that parents always take a strong advocate to school meetings because often, as parents, our emotions can interfere and affect the outcomes for our child. “Parents, make sure you do not give up the fight. Our kids have a right to an education to meet their individual needs”.

Nelson FASD Workshop – by Tracey Jongens

With the support of Alcohol Healthwatch, Christine Rogan, Dr Valerie McGinn and I presented a joint workshop for a multi-disciplinary audience in Nelson. The workshop was instigated by a Paediatrician based at the Nelson District Health Board and the RTLB service in Nelson. The workshop was attended by a variety of hospital and community based health professionals, the local RTLB Cluster, some early childhood workers, CYF social workers and a few other community people including at least one parent and one person from the Justice community. Approximately 70 – 80 people were in attendance.

Christine began the day with a brief introduction and then a viewing of “Babies and Booze” - a DVD developed by CYF and Alcohol Healthwatch. It has about a 20 minute screening time and includes the stories of a group of teen Mums, two Mum’s who, unwittingly, drank during their pregnancies and their experiences raising their children affected by FASD. It also has interviews with a couple of Social Workers who are Maori and looks at the effect of alcohol on the Maori community, as well as an adult who is living with a FASD diagnosis. It is a very powerful and poignant documentary which is beautifully presented, tells the NZ story and even though I have seen it a number of times it continues to produce an emotional response in me and leave a lasting impression.

Valerie, from her vast experience, then shared what FASD is and how it affects those on the FASD spectrum. Her presentation was insightful as always, and definitely showed the complexity of a FASD diagnosis. Valerie did talk about how a diagnosis is made and the clinical information around FASD, illustrating much of what she said with real life scenarios from her practice as well as sharing strategies to support a person living with FASD.

In the afternoon I presented on how the needs of those affected by FASD can be met in education and some of the strategies that those living with and/or teaching a person with FASD can use.

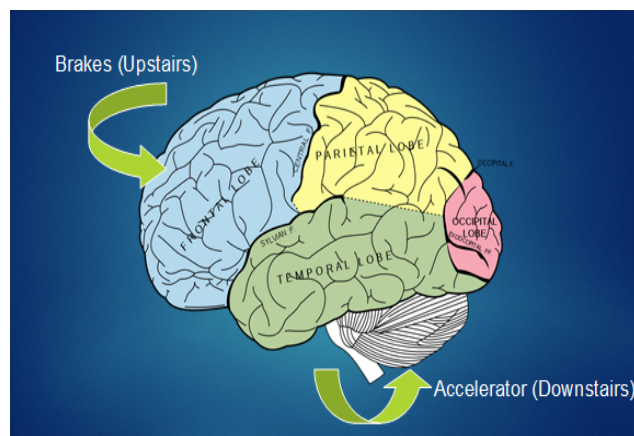
Feedback from the day certainly suggests that those who attended learnt lots, found the day rewarding and enjoyable. A delicious morning tea and lunch were provided and Nelson turned on a glorious day. There is quite an interest in FASD in the Nelson community with some exciting plans for developing more knowledge and expertise in the pipeline for 2016. A number of connections were made between people during the day, which is always a wonderful thing. The really nice thing about the day was how well each of our presentations dovetailed into one another's, although we had not discussed any of this prior to the day! Of course, having Christine at the helm - it was always going to flow!

A little piece of feedback:

"Your professional and engaging presentation was realistic, 'struck a chord' with all attendees and really highlighted both the issues and how support can be best framed up".

Interesting Information

This slide I thought was excellent in explaining the way the FASD brain behaves when met with stress. In the basal stem they will behave in a 'flight or fight' mode especially at times of stress. In a normal brain the information will be relayed to the brakes upstairs in the frontal lobe and the person will behave in a more controlled way. However in an FASD affected brain this will be hit or miss as to whether it gets up to the brakes. If the environment is not kept calm then the flight or fight will be escalated. – [Lisa Smith](#).



Common Ground

Did you know there is a free on-line tool to assist those who are supporting or caring for young people? It is called 'Common Ground'. It is awesome and it is important that all NZ families know it is there.

The **Mental Health Foundation**, **Skylight** and **Youthline** along with the **Ministry of Social Development** have partnered and worked together to launch the website. It provides resources to caregivers, whanau and friends who are concerned about the well-being and mental health of a young person they care for or know. It features not

only excellent information but topical videos, tips for raising teens in touch times, some useful links and support packs that can be sent free to you. It also offers a phone line and related facebook page. Check out the website; www.commonground.org.nz

Extended family and friends play a vital role in supporting young Kiwi's through challenging times in their lives. Sometimes it can be hard to see the signs of an emerging mental health issue until it gets to crisis point and, even if you do, it can be difficult to know what to do. Common Ground offers easy access to information that will help.

Youth Law Aotearoa

Is your child missing out at school?

At Youthlaw Aotearoa we offer FREE legal services to children and young people under 25 nationwide.

We have been operating for 28 years and have extensive experience in education law, including:

- Assisting young people with special education needs accessing education
- Attending disciplinary meetings at schools
- Providing advocacy for student issues
- Assisting clients with complaints to the Human Rights Commission
- Help in accessing special educational support
- ORRS applications

Youthlaw staff solicitors are unique specialist practitioners being some of the only lawyers practicing in the field of education law having the ability to assist with appeals of high needs special needs funding under Section 10 of the Education Act.

You can contact us via 0800 UTHLAW or at www.youthlaw.co.nz or info@youthlaw.conz



At times we cannot help but compare and wish for a different life than the one we have with our child. This quote helps put it into perspective. All our children are unique and are doing the very best they can.

Keep up the good work but make sure you find time to rest up and have some 'FASD FREE TIME'.



There are a couple of face-to-face FASD Caregiver Support Groups which have begun. FASD-CAN fully endorses this and encourages all members to meet and connect where they can.

The Hibiscus Coast Support Group in Auckland meets the 3rd Tues of Every Month. The recent meeting in June saw representatives attending from a fostering agency, Key Assets who are seeing a growing number of clients presenting with behaviours congruent to FASD. Full information on this support group can be found in the March Newsletter or phone Lee Tempest on 021 176 82220.

Rainbow Umbrella Charitable Trust Social Club, Napier is holding an informal social club once a month at Tamatea Intermediate school for children and families with physical and intellectual disabilities. The first one was held on the 24th June and 12 families attended, three of whom had children with FASD. It was lovely to see the kids enjoying the activities and having fun with each other. Again it is about connecting, sharing and supporting each other and I hope that we will continue to grow and possibly hold the club more frequently as the facilities are free. More information can be found on our facebook page: Rainbow Umbrella Charitable Trust.

Nelson Groups – there are a number of initiatives underway in Nelson at the moment. A group of professionals have got together and formed the **Nelson FASD Steering group**. The aim of the group is to raise awareness and improve the services for FASD in Nelson. In June, the first discussion group for FASD was held. Despite it being one of this winter's coldest nights, 20 people turned out, a mixture of professionals and care-givers. From this, a group of care-givers have formed a support group, we aim to have our first meeting in August. For more information, or to come along please contact Cat Ward on 021 2542477. A second discussion group is being held on Wednesday 29th July at Motueka Family Service Centre. Again please contact Cat for more information.

FASD-CAN facebook page [search FASD Network NZ on facebook]. As always, this is a good place to visit, find support, share, learn and vent.

Caring for the Caregiver

This was a subject of discussion on our facebook page recently. Some soul searching questions were posed – what does support look like? - what do we expect our family and friends to do for us? From the discussion came this letter:

Dear support person

I am going to ask you for some help and share some insight into my world. This world is not entirely unique to me just because my child has FASD. Much of how I feel, I am certain, has been felt by many caregivers raising a loved one with special needs.

Firstly, I am thankful that you are part of my extended circle of care. It means more to me than you will probably ever know, and please forgive me if I have not shown this gratitude. You see, there are times when I feel so overwhelmed by the problems that my child presents me with, that, as silly as it sounds, I need to focus on just breathing - in and out, in and out.... I often find I do not have the time for pleasantries. No excuse, but a reason.

You say 'I wish there was something I could do', well, there are a number of things you can do:

- Educate yourself about FASD. I don't expect you to know everything about my child, but you will be in a better position to understand and support us if you know about the disability we are living with. It will take time to learn as FASD is very complex. I will help you put the text book descriptions in context of my child. FASD is also very individual.
- Come with me to meetings to provide moral support but also to contribute. After all, once you know about FASD and have the privilege of knowing someone close to you living with it (ie; me and my child), then that places you in the 'expert' category, just like me.
- Sometimes, just let me vent. I may not always make sense but I need a 'release valve'. Please let me feel comfortable to release my emotions around you. It could be that on any given day I could feel exhausted, trapped, sad, angry, guilt ridden, self-pitying and simply 'over it'. I do not always open these flood gates in search of advice. Sometimes I just want to say some stuff out loud, acknowledge it for what it is, have a cry and move on. If you are there to offer an ear and a hug, that would be great.
- Understand that there are times when I can't do lunch, or coffee or meet up for that drink. It is not that I don't want to but I might be too worn out from the events of the past day/week/month and I just don't have the energy. It could be that I can't leave the house because my child is in a bad space and not coping. Just accept that sometimes my answer to your invite will be "no" but please, please don't stop asking me. I need the outside world but we need to acknowledge that the timing might not always work out.
- Please do not stand in judgement of my parenting style. I am working with a child with brain damage and much of what we take for granted in normal cognitive and behavioural approaches, does not work with a brain affected by FASD.
- If I am isolating myself by going on and on about FASD, then please gently remind me from time to time that I am my own person and there are other things in the big wide world for me to think about and enjoy.
- Understand my grief. It does not end.
- Make me laugh ☺. I need humour and nothing heals the soul like a good belly laugh.
- Give me a break occasionally by offering to take my child out or even an overnight stay once in a while.
- Understand that normal mile stones may not be part of my child's life but he/she will progress in their own way, at their own speed. Help me celebrate those moments, no matter how small.
- Be my crisis contact person. I might need you at very short notice.
- Finally, and maybe most importantly, love my child. In a world that is constantly telling him/her that they don't quite measure up, be a safe harbour for us both. Understand unconditionally.

With my love and respect,

Judge takes a look at FASD in Aotearoa

Christine Rogan, Health Promotion Advisor for Alcohol Healthwatch reflects on Judge Crawford visit to Aotearoa.

It was a very great pleasure to accompany Judge Catherine Crawford, as she travelled around Auckland and Northland gathering and sharing knowledge on the topic of FASD and Youth Justice. A Children's Magistrate in Western Australia Catherine (she said to only refer to her as 'Judge' in her Court) was visiting New Zealand as part of a Churchill Fellowship investigation into how young people with FASD are accommodated in various criminal jurisdictions.

More than 300 people from across multiple sectors came to hear Catherine and others speak on the topic during a tightly packed programme of meetings and talks over 5 days. The intent was to hear from those working to improve the identification and outcomes for children and young people with FASD at increased *risk* of offending and reoffending, as well as to share what had been gleaned thus far. I

emphasise the word 'risk' because heading down a justice pathway is not a foregone conclusion for those born with FASD, it is just that we are shining a light on that issue at present because so much can and should be done there. It is well recognised by Catherine and those she engaged with that this 'risk' is predominantly the result of a poor fit between the child's permanent deficits and the lack of well informed, appropriately structure in their social environment – be it within health, education, social services, justice or home.

Naturally Catherine's investigation focused on ways to accommodate young people with FASD already in trouble with the law to reduce recidivism, but it extended to understanding what keeps them out of trouble in the first place. It was so refreshing to hear of positive results once the right stuff was in place. Examples shared put pay to the notion that FASD is impossible to treat. It is challenging, so we have to work smarter!

It is hoped Catherine's report is available for dissemination in time for FASDAY this coming September. In the meantime, thanks to the University of Auckland Law School, Catherine's **lecture is now on YouTube**, ['How youth affected by FASD are treated in criminal jurisdictions'](#) and/or to listen to an [audio of her lecture](#) views the issues through the Human Rights lens.



Save the Date!

Attitude TV

Attitude TV has recently interviewed two young men living with FASD and their families with the aim of presenting a documentary highlighting the struggles they face. It is very brave of them to open up their worlds in this way and we look forward to a respectful representation of their journeys. This is scheduled to be aired on Sunday the 19th of July.

FASDay (9 Sept)

To mark **World FASD Awareness Day** this year, the University of Auckland Centre for Addiction Research has once again teamed up with Alcohol Healthwatch to host a 'FASD Policy and Research Forum' at the University's Tamaki Campus. This will follow up the 2014 '[FASD Call To Action](#)'.

The event provides an opportunity to explore progress and inform future strategic action. Guest speakers will include Health Economist Dr Brian Easton who will share some recent research he has carried out on the likely cost of FASD to the New Zealand economy and the value of prevention, plus Clinical Psychologist and PhD Candidate Andi Crawford updating us on expansion to FASD services and community action in the Hawkes Bay. Registration details will be available shortly.

Parent Workshop (10 Sept)

September 10 has been set aside just for caregivers and family members affected by FASD (confirmed or suspected). This educational workshop in Auckland will provide the opportunity to share and learn from each other and those familiar with FASD intervention. This workshop is co-sponsored by FASD-CAN, Alcohol Healthwatch and the FASD Centre Aotearoa.

For FASD-CAN members, there will be no cost to attend and we will be seeking to raise scholarship money so out-of-region travel costs present less of a barrier. Caregivers can register their interest by contacting christine@ahw.org.nz or the FASD-CAN Secretary tracey.jongens@fasd-can.org.nz