



# THE NETWORK NEWS

FASD-CAN Incorporated

April 2016

## A word from the Chair

As we head into winter it is a good time to reflect on the fruitfulness of our activities over summer. The biggest body of work we have undertaken in recent months is our consultation with the Ministry of Health and submission to the FASD Plan of Action. There is a lot riding on this plan and we are hopeful it will help our families and children into the future. I am certain that our collective parent voice has been heard in the formulation of this plan. We need to stop and really take stock of that because it was only

### Melinda Mae

Have you heard of tiny Melinda Mae,  
Who ate a monstrous whale?  
She thought she could,  
She said she would,  
So she started in right at the tail.

And everyone said "you're much too small"  
But that didn't bother Melinda at all,  
She took little bites, and she chewed very slow,  
Just like a good girl should...  
...and in eighty-nine years she ate that whale  
Because she said she would!

a few short years ago that FASD was barely spoken about in the halls of power and policy setters would have no clue where to go or who to talk to. Now they are talking to us! I know it seems like it will never be enough and I have heard the term "drop in the ocean" in reference to funding Government are committing to the FASD issue. However, we are further along than we were twelve months ago and for that I think we can all take a pat on the back. With strong parent/caregiver involvement we can continue progressing towards positive change. Sometimes this progress may feel slow and it reminds me of the saying that the only way to eat a whale is one bite at a time. This was derived from a poem by Shel Silverstein called Melinda Mae.

It seems to me that there is plenty of Melinda Mae in all of us – a grit and determination to achieve what we have set out to do with our children and with this organization. We do it because we think we CAN and because we've said we CAN. Hopefully it doesn't take us eighty-nine years!

## In this issue:

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- "A typical FASD day" – by Lisa Smith
- FASD and Money
- Government Update
- Interesting information and resources
- Up-coming events

Kia kaha  
Claire

# A typical FASD day

By Lisa Smith

8am: I hear Aaron awake which is far too early. Not a good omen. He comes jumping through and shouts "Fuck you, arsehole". Dad had not gone to work and reacted to Aaron's swearing. **Battle number 1** that I have to defuse. Not a good start at all as he is very wound up now. Dad leaves to go to work and I have to deal with the aftermath.

8.15am: Aaron refusing to take his medication. **Battle No 2** (normally I give him it the minute I hear noises in his room and he is still half asleep in bed – not today though). His light bulb is definitely glitching this morning and I know to expect a tough day. I can feel that something is bothering him. I know I need to bring in reinforcements. I put on my combat uniform (a posh outfit gives me the confidence to do well) as have a talk to do at the hospital FASD workshop this morning. I must remain cool, calm and collected and plan my next move with precision.



8.30am: In bathroom getting ready and I hear lots of banging, shouting and swearing. Our dog Bella is barking. He is terrorising my lovely cocker spaniel. Using the 'KISS' approach, I say to him; "Aaron, medicine". Still no sensible reply from Aaron. He whacks me hard on the bottom and then slams the door hard. Mmm that hasn't worked. Decided to message his friend to work his magic and get Aaron to take his meds.

8.45am: Yahoo! It has worked and he has taken his medication. Aaron comes barging into the bathroom again as I'm putting my 'war paint' on for the day. Feeling very on edge but try not to show it. He pushes me out of the way wanting to do his teeth and makes a mess of my hair in the process. Felt like reacting but would have triggered the next battle.

9.00am: I escape and hope that the doors will still be intact when I come home. Aaron in his room listening to Chuggington, a children's programme about trains. He still watches these programmes even at the age of 18. I put the dogs outside so they don't get attacked.

10am: In the education centre listening to the clinical psychologist finish her talk about strategies for managing FASD and thinking "I wish I had recorded the events from this morning and what it is like living with these individuals".

10.15am: A deep breath and then I am talking, giving the audience (about 100) a small window into my rollercoaster life with my son. Talked about our journey through the years especially the hurdles encountered with the education system. Told them about the warzone I was in this morning. Told them the real deal and didn't even need my slides. I could see that a few in the audience were quite moved and one was very tearful. Lots of good feedback afterwards.

11.00am: Went to work on the ward which was very busy. Caught up on some of my emails then headed home. A lovely day and wish I was able to go out and play golf. Ah well maybe another time.

12.00 noon: Back home and catching up on emails all related to FASD. Aaron a bit calmer and playing his X-box. Wish he would do something a bit more active. Feeling a bit sad that he doesn't have a lot of friends or a lot of activities he could be involved in.

1pm: Take dogs out for a walk. Enjoy the peace walking along by the river.

2.30pm: Arrive home and Aaron wound up again. **Battle no 3 begins.** Looking for a chrome muffler he had bought a long time ago. Couldn't find it and stating that Dad had chucked it out and he was going to "fucking bash him". Told me that his friend in Auckland is looking at buying a car down here and that they are going to look at it tomorrow. If it passes its WOF where can he keep it? Told him that it cannot be kept in our drive as there is no room. Thinking to myself that the temptation his too great and he may decide to drive it when we are out at work as has happened before. Suggested that we could ask our friends if it can be kept here.

3.00pm: Aaron still fixated on this muffler and hunting all over the place for it. Totally convinced that his Dad has chucked it out and lots of swearing coming. Saying that he will "fucking punch Dad so hard if he has thrown it out". I told him that I don't know and that it is probably in his room somewhere. Aaron now heading into the amber zone of heading for a meltdown. I decide to message my friend, Lee to come round and help. Thankfully Aaron knows he is starting to lose control and actually contacts Lee to ask if he can come to their place for the evening. Wow, a good decision by my son, knowing when he needs to ask for help to stop himself from lashing out at his Dad when he got home.

3.15pm: Lee comes and I breathe a sigh of relief. My reinforcements have arrived. Aaron goes off happily with her son.

3.45pm: Aaron messages saying sorry for his dreadful behaviour and that he has something to tell me when I come to pick him up later. Messaged him back and saying that "I love him and whatever it is I will listen and try to understand".

4.00pm – 8pm: Thankfully some relaxation time. Dad found his muffler in the Attic so that is one fixated thought solved. Now to deal with this vehicle that he is fixated on. Messaged friend in Auckland and suggested that if he is buying a car down here he come and pick it up soon or better still to buy one in Auckland thereby removing all temptation of my Son wanting to drive it. He doesn't even have his Learners but that has not stopped him before. **Averted battle no 4.**

7.00pm: Aaron phoned on landline annoyed as to why I wouldn't answer his texts. Told him that I am relaxing watching the TV and don't have my phone on me. Wants me to come and pick him up now. No point arguing. Told him I would be there shortly. Nigel not happy that I get very little peace. Again no point in arguing with him either. Feel like whatever I do I can't win. Thinking to myself; at least at work I am a good nurse but at home I often feel like a hopeless mother and wife. The emotional energy that goes into managing my son can be so tiring that I have no interest or time for anything/anybody else.

7.30 -8.30pm: Lovely chat with my friends Lee and Brian. Aaron joining in and having a laugh about things. Wish he was like that at home. The minute we leave he is cursing and swearing and sticking a finger up at someone who was looking out of their window because he was making a lot of noise. Thankfully it's dark so hopefully they won't have seen him. He perceives that people are looking at him all the time as if he has got three heads. I suppose it's all to do with his FASD. He is winding up again and peeping the car horn and being silly. He's 18 but at times like a toddler. Asked him what it was he wanted to tell me but said he had forgotton. Gut feeling is that there is something he doesn't want to tell me and I will find out soon enough. Need to prepare for something happening in the next few days. Will he disappear off with someone and doesn't want to tell me. Again he has done that in the past and this has been the way he's behaved. By not saying anything to me he is not 'lying'.

9pm: All is calm. Both father and son are in their bedrooms. Can finish watching my programme. However can't stop thinking about events of today. Decide to txt his support person as to what is happening. She messaged back to say that a friend from Palmerston is coming up tomorrow and that he is going to spend time with him. Said he doesn't want to us to know or meet him in case we talk about his FASD. **Prepared for battle no 5.**

9.30pm: Everything still nice and calm. What a day. However tomorrow has yet to come and wonder what the 'enemy' will throw my way. I read my book, drink my milo and cuddle my lovely wee cocker spaniel, Bella. I have a lot to be thankful for.

# Government Update

## **FASD Plan of Action**

150 submissions were received by the Ministry of Health for the “Taking Action on Foetal Alcohol Spectrum Disorder: Discussion Document”. Ministry of Health representatives consulted twice with parents and caregivers throughout the process in terms of developing the discussion document and then a discussion pre-submission deadline. Associate Health Minister Peter Dunne welcomed the strong level of interest shown by people in the proposed action plan. He stated; “this is a complex issue and I am delighted that we have had submissions from parents, caregivers, people affected by FASD, Health, Education, Social and justice sector, community organisations, Maori organisations, researchers, industry groups and members of the public”. The Cross-Government Action Plan is due to be launched in the middle of the year.

## **Ministry of Education**

Tracey Jongens, a member of FASD-CAN and an RTLB Teacher is working very closely with a focus group on developing the Teachers Resource on FASD. This should be available on their website by the end of this year. The website is: [www.inclusive.tki.org.nz](http://www.inclusive.tki.org.nz). There is already a useful resource for students with ADHD. Also discusses the principles of the Universal Design for Learning. Well worth having a look at.

**New Zealand Office for Disability Issues** – needs feedback on the Enabling Good Lives document. Share your experiences and help shape policy for disabled people. Over April and May information is being gathered from all sectors through public events and online surveys. Important that we stress the issues we have with FASD being recognised as a disability and the struggles that many of us have fighting for services. Submissions/dialogue are open re the new Disability strategy. There are a few options on how to contribute towards this discussion. Here is the link <http://jointheconversation.nz/>



## Spreading the Word

Four 'Moving Forward' one day Workshops were held throughout NZ in February. There was a lot of interest with full attendance at Rotorua. Canada is one of the leading countries in its progress of working with FASD. We were very fortunate to hear the latest information from Dr Jacqueline Pei and Tracey Mastrangelo from Alberta. Their presentation was extremely entertaining and stimulated a lot of discussion within the audience. Both Jacqueline and Tracey were gifted a Mania-Koru bone carving which Tracey Jongens presented following the Christchurch conference.

These talks were hosted by Fostering Kids, Alcohol Healthwatch and FASD-CAN.



Podcasts on the Moving Forward Conferences will be made available shortly. Look for the link on the FASD-CAN Parent and Carer Support Group facebook page.

Fostering Kids is available to support families who adopt, foster, home for life and group home caregivers. They can provide training, advocacy, information and support services. Their website is:

[www.fosteringkids.org.nz](http://www.fosteringkids.org.nz)

Claire Gyde, Dr Jacqueline Pei, Lisa Smith and Jackie Pritchard at Rotorua Workshop where about 150 people attended.

### Other events raising awareness....

Members of FASD-CAN continue on a weekly basis to raise awareness of FASD. Claire Gyde presented at a regional SYPHANZ conference on the 25<sup>th</sup> Feb in Palmerston North. It was attended by over 50 people from health, youth justice workers, teachers/special education, social workers and police. Many approached Claire after and stated that more training is necessary to be able to support FASD individuals better. This is something that has been addressed by FASD-CAN in its submission to the MOH.

Tracey Jongens in her role as an RTLB teacher is frequently asked to talk about FASD and the key principles around creating the right learning environment.

On 1<sup>st</sup> April Lisa Smith gave a presentation at the Hospital Play Specialist International Conference held at Starship Hospital in Auckland. It was well received by the sixty delegates who attended with good discussion afterwards on some of the children they had worked with whom they now realised were probably undiagnosed FASD.

# International News in brief

## Australian Prevalence rates higher than previously thought – 5-10%

Research has shown as many as 30 babies a day are born in Australia with alcohol spectrum disorders but the government has failed to listen to or act on this alarming statistic the Collaboration for Alcohol Related Developmental Disorders (CARDD) says.

The group has called on the federal government to meet with them to discuss the rise of Fetal Alcohol Spectrum Disorder (FASD) in the community.

CARDD coordinator Dr Jan Hammill said the meeting was essential to develop policies and services to prevent or deal with FASD and evaluate their effectiveness and their economic and other advantages.

“FASD is seen in increasing numbers of children in out-of-home care, early school dropout, young parenting, involvement with the juvenile justice system and then into incarceration as adults,” Dr Hammill said.

“Often FASD is found to be transgenerational reflected in family unemployment and larger families as women may not have the capacity to manage their fertility. People with FASD add greatly to statistics around domestic violence, educational failures, arson by juveniles, mental health problems and suicide. The costs to all human services are overwhelming and no doubt will be seen in significant registrations on the National Disability Insurance Scheme.”

Dr Hammill said research has established a prevalence rate of between 5-10% - a figure which has grown as more precise diagnostic tools become available. “Even based on a rate of 3.6%, 30 babies per day are being born with FASD in Australia,” she said. “In the past decade, among the total of 3 million births in Australia, at least 105,000 have been born with brain damage due to alcohol exposure before birth. This is more babies than with all other congenital abnormalities combined.”

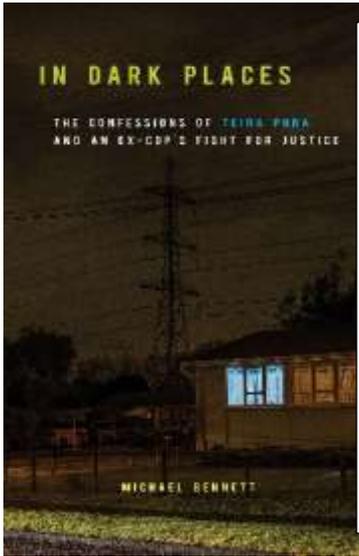
Australia's first accredited multidisciplinary FASD Diagnostic Centre is based on the Gold Coast at the Community Child Health Service and is keen to support expansion of FASD Diagnostic Centres across Queensland. Churchill Fellow, Medical and Clinical Director, senior lecturer at Griffith University and founder of the centre, Dr Doug Shelton, said “We have tried so hard to raise awareness of fetal alcohol spectrum disorders (FASD) by contributing to two government inquiries. One was in 2012 and another in 2015 yet nothing has changed in the prevention of FASD and at least 30 babies per day are being born with this preventable brain-based disability”.

As Dr Sharman Stone, Liberal member for Murray, said in an interview on ABC Radio National several years ago, "it is the power of the alcohol lobby". How do we tell the alcohol industry that the brains of babies are not negotiable for dollar donations to the coffers of politicians?

### **South Africa**

Although South Africa has the highest fetal alcohol syndrome rate in the world, government's efforts to address the problem have been inadequate. And the alcohol industry has evaded responsibility for tackling the root causes of the disease. In the Western and Northern Cape provinces, between 5% and 10% of children entering school have fetal alcohol syndrome. And there are areas in the Western Cape with clusters of higher fetal alcohol syndrome rates than those found in earlier studies.

# Interesting Information & Resources



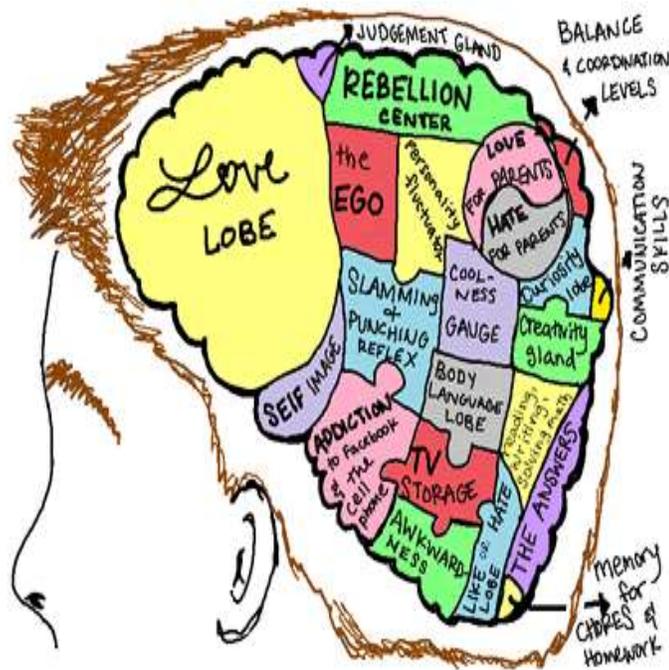
Tim McKinnel, an ex-cop turned private investigator, discovered the long forgotten case 18 years later, saw an injustice had been done and set out to win Teina's freedom.

Reaching from the mean streets of South Auckland to the highest court in the Commonwealth, this is the story not just of Tim's quest, but also of how an innocent man who was left rotting in a prison cell for two decades found the inner strength to rise above the dark places to which he had been condemned.

Dr Valerie McGinn diagnosed Pora with FASD in 2013, which was helpful for the team pushing his case, but also devastating.

"For the man whom they feel such affection and respect, FASD is another life sentence" writes Bennett. "But this sentence, no one can ever overturn"

**THE  
AVERAGE  
TEENAGE  
BRAIN**



If 'average' is as complicated as this picture denotes, the Teenage FASD brain is even more complex as they have to try and come to terms with their brain based disability which probably makes the rebellion centre far bigger than the love centre.

## FASD and MONEY

“Thanks mum, I’ll pay you back” he promises as we unload another lot of groceries from my car. What I have learned over the years is that my son’s path is always paved with good intent. In that moment, he truly believes that he will pay me back.

This week it seems the ‘obsession’ that has gobbled up his money is the new frozen yoghurt machine installed down at the local garage. The lovely lady from behind the counter gave me a huge smile as she explained that my son was her “best customer” this week. I smile back because this is preferable to the obsessions of the past which have included drugs.

The problem with constantly ‘living in the moment’ means that he is unable to plan ahead. To work out that he will have to buy groceries so that he can cook himself an evening meal **every** night, not just tonight. To understand that letting everyone smoke his cigarettes, means that he runs out and has no money set aside for more. His fall-back position is me. He phones to tell me he is starving or hasn’t had a cigarette all day and is ‘going crazy’. Each week he also swears that he is giving up smoking. Again, good intentions. Today I replied that it would be a good idea for him to give up because he can’t afford it. His comeback was, ‘neither can you eh mum?’ We both laughed and I thanked him for at least acknowledging he was costing me a fortune!

To be fair, some weeks he does give me money which I accept, but generally he forgets how much he has borrowed and what it was for because that moment has passed. What he *urgently* needed last Thursday isn’t even a distant memory. It doesn’t register at all today.

Last week he phoned while watching Shortland Street on TV. He explained to me that everyone on the programme was drinking fancy coffees and he desperately wanted one. He asked for \$5 so he could go down to the local service station and get a coffee to go. Although the conversation progressed along the lines of ‘make yourself a drink with the coffee you have in the cupboard’, that clearly was not going to cut it. I suggested that he wait 10 minutes and then reconsider if a special coffee was something he really needed. My thinking was the TV programme would have moved on and hopefully he would move on with

it. However, 10 minutes later, the badgering began again. I think that only a parent of a child with FASD really knows how difficult that constant nagging is. If you are like me, you know it is fruitless to fight it, but fight it we do. At its worst, this will trigger abuse and aggression, at best it will end in slammed doors. I have decided long ago to very carefully pick my battles, so that evening he got his special coffee. From the outside looking in, it would appear this action is enabling his behaviour. However, I accept that his brain was unable to shift from the coffee focus, so I feel reconciled with my decision.

Money management is impacted by a number of things around executive function. My son was spending a lot of money on take away food, even though he had plenty of food in his cupboards, fridge and freezer. One morning I phoned him and asked him what he had planned for his meal that evening, knowing very well that he would have nothing planned! I suggested that he should take some chicken out of the freezer to thaw which he thought was the most ridiculous thing he had ever heard. “Why would I be thinking about dinner when it’s only 11am? I will think about that at 5pm!” Of course, we all know that come 5pm with no plan, he would be down the fish and chip shop wasting his money on food with almost no nutritional value!

I share these stories to question if money and the concept of value of money is too abstract for those living with FASD to grasp or, is it more about the lack of executive function? When I take my son grocery shopping he is a reasonably astute buyer. He weighs up the cost benefit equation quite quickly. For example, he might really like Milo cereal but sees that it costs \$5.99 a box. A bag of Rice Bubbles is \$2.99 for a slightly larger quantity. Like all of us, he makes the decision to settle on his second choice of cereal based on the cost of it. The concept of value for money is clearly not too abstract for him.

Budgeting on the other hand is the formulation of a plan into the future. It involves understanding what your expected income is and then spreading that income across fixed commitments. It leads on then to making decisions about how to spend the discretionary surplus. If you are really clever, it also involves planning for a ‘rainy day’ so that you have

something in the coffers for unexpected events such as the car breaking down. For those with FASD, the inability to predict the future coupled with an impulsivity that is second to none, blows any planning to pieces!

So, what we must do is try and establish some form of plan. For example, we have done the following:

- We have addressed the 'fixed commitments' by establishing an automatic payment which covers rent and power. We know that he will always have warm shelter which, although most take for granted, is a huge relief to us as his parents.
- Taking him to the grocery store on pay day so that he fills his cupboards each week with food he can cook.
- Rationing his cigarettes and handing out in daily amounts.

Although very simple strategies when written down, don't be fooled into thinking it is easy. As our kids grow into adults, they yearn for independence and, from my experience, they fight these helpful interventions every step of the way.

The final thing, and this has been a lesson for me, is to recognise and accept that my son's brain function prevents him from handling money well. I give where and when I think I should after weighing up his ability to do differently or learn from the consequence of being reckless with his money. One thing I never stop doing however, is having the budget conversations with him. I hope that one day it might sink in and all his good intentions will be put to action.





## FASD-CAN PARENT/CAREGIVER WORKSHOP

We are going to hold a second parent/caregiver workshop day.

The theme of this day is about **Communication**. How to communicate effectively in meetings. How to communicate effectively for the benefit of those with FASD. How to develop a safety plan and seek support.

Details are yet to be ironed out but pencil in the 6<sup>th</sup> of August.

Travel subsidies will be made available to families. Kindly sponsored by the Health Promotion Agency.