PRESENTATION

NIDAC - FASD: a birth mother’s perspective

Anne Russell - 50 minutes
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My name is Anne Russell and I am the founder of the Russell Family Fetal Alcohol Disorders Association or rffada. I work full-time for a registered training organisation called Training Connections Australia delivering FASD training around Australia. The rest of my time is spent volunteering for the rffada, providing parents and carers with information on the condition, presenting at conferences and maintaining the rffada website and facebook sites.
I became involved in FASD after discovering that my youngest son Seth’s behaviours were almost exactly the characteristics set down in the University of Washington’s Fetal Alcohol and Drug Unit. The bottom really dropped out of my world then. Its not something any mother wants to learn ----- that something she did caused her children to have brain injuries which would affect every aspect of their lives for the rest of his life. Thankfully after a very very difficult start to life, my oldest son is able to live a normal life. My youngest son was not so lucky.

I had always believed that my most important role in life would be that of a mother and I had vowed over and over again after I met my husband that any child of mine would not suffer the emotional trauma of living in a domestic violence situation with an abusive mother and a father who was completely browbeaten by his wife.

I knew that I could give my children the love they needed, I had no doubt about that and I knew what NOT to do when raising them, but I didn’t factor alcohol into the equation.

I found at the same time I read about the characteristics associated with FASD on the University’s website that alcohol is a teratogen – a substance that causes birth defects somewhat similar to thalidomide, Agent Orange or Mercury.
I also wondered why my doctor had told me to have a few drinks with my husband after an amniocentesis to reduce the chance of premature labour. Nine months before that a different doctor told me that getting drunk at a party before I knew I was pregnant would not cause harm.

I would dearly prefer to have known then to be careful of alcohol for so many reasons:
1. I would not have consumed more alcohol during the pregnancy after that first party
2. I may have had an idea as to what was wrong with Mick my first child when he didn’t thrive, didn’t suck well, didn’t achieve his milestones, and screamed all the time for, im sure, months, and the biggest one of all………….
3. if my doctor had said, the amount you consumed wont cause damage but don’t drink any more throughout your pregnancy because alcohol can cause birth defects and brain damage, my young son Seth would not now have full fetal alcohol syndrome.

Doctors have a huge responsibility to tell women of childbearing age how dangerous alcohol is to their unborn baby. As traumatic as it might be it must be said! This question shouldn’t be any harder than telling someone they have cancer or a heart condition surely yet I know of many many instances where it has not been said.

When Seth was 17 I couldn’t see him living longer than 2 years. His behaviour was so out of control and he was so depressed, suicidal and impulsive that I just couldn’t see beyond that time. He refused to take medication, refused to go to a doctor and the only time I managed to get him to a psychiatrist, the psychiatrist told him he had to start taking responsibility for his life. For the next five years he refused to go a doctor regardless as to what was wrong.
I thought we would have to section him.

If anyone had asked me whether I thought that women who have consumed a lot of alcohol before they find they are pregnant should terminate I would have said ‘yes’. Why, why would you put anyone through the hell that is FASD? At that time, all I wanted was for his pain to stop and the only way that could happen was -------------------------its not fair for medical practitioners to not talk about FASD------------please take the leap and tell pregnant women what alcohol can do to their baby and offer them support if they are alcoholic. But remember that research by Clarke in the US has shown that only 6% of women who have children with FASD are alcoholic – the remainder are social drinkers.
What does that mean ----social drinkers??? It means that if you tell them not to drink alcohol, they will take it on board and NOT drink while they are pregnant. But because there are no national media prevention or education programs, no specific services, no specific diagnostic teams, no diagnostic centres and no specialists, very very few women know that alcohol is a no no.

I am sure there are people in the audience are thinking (I have had this said to me many times)---=-- surely women these days know that alcohol is not to be consumed while pregnant----------I suggest to you that you go up to the clubs one night and see how many pregnant girls there are drinking. Whether it is because they don’t know that alcohol is dangerous, or they do know but don’t realise just how dangerous, or peer pressure has got the better of them, or they are alcoholic – it doesn’t matter ----it’s the baby who will suffer horribly.

I have watched my son write on all his furniture over and over again I WANT TO DIE. I have watched him try and play with other children who just ostracised him; I have held him in my arms when he was 19 sobbing that everything he has ever done has turned out wrong. At that time there were only two people who really knew how amazing this young boy was – everyone else thought he was an idiot because of his behaviour.

But what good is that when all he wanted was to belong to a group of his peers and everything about this condition turned them away. I thought I had had a hard life – I didn’t know anything.

Admittedly I didn’t have much of a childhood, I was in a family where domestic violence was a daily sometimes even hourly event where anger and double bind situations were common and where my mother’s emotions were the only ones allowed in the family. My father died when I was quite young leaving me with a mother who had serious mental health and personality issues. So I left to go overseas at 17 to get out of the house. My life from there as a précis of deleterious experiences was witnessing murders in Africa in a coupe de tat, trying to manage my own mental health problems when I had no idea that’s what they were and finding alcohol the only thing that made a difference, and then the positives-------meeting my husband; having my beautiful children and watching them grow up. Until alcohol took on a life of its own, I survived on a daily basis, looking after my children; not making the same mistakes as my mother; but still battling depression and anxiety – and drinking to keep them at bay. It wasn’t long before I realised I had to do something.

I was functional, still looked after the children, still cooked their dinner (I was a much better cook when I was drinking anyway); still mowed the lawn all the while thought I was living. But I did appreciate the little things the children did – they made me laugh.

When the children were young when and we were driving the often long distances between the bush towns in which we lived to the coast, I would ask them general knowledge questions, misguidedly thinking that improving their intelligence might help them do better at school.
Unfortunately I should have been doing what one of the parents on the rffada facebook group does with her FASD children and that is to pick an esoteric word for the day and discuss it on the way to school – words like ‘jealous’; ‘happy’; ‘God’ etc – all abstract concepts are difficult for people with FASD to conceptualise without a great deal of support so it is a good way of introducing them to these concepts. Of course at that stage I didn’t know my boys had FASD.
I asked questions of them, and Seth’s mate Tom, who even at 12 was an intellectual, answered them all quite quickly. Seth tried to answer but Tom always got there first. Half way through this process of questioning, an odour began circulating through the air conditioner. We all sprang to life, winding the windows down and sticking our noses out into the fresh air. After a few choked gasps to catch my breath, I squawked “Who **on earth** did that?’ --- Seth piped up “**I** did!” and then under his breath he mumbled “at least I got **that** one right!’

Just one more anecdote that I am sure the mothers of young teenage boys in the audience will particularly enjoy. After contact with the manager of a Youth Service for work, I was given a handful of condoms to take home to the boys. Although they were ostensibly for my oldest son Mick who at the time was around 17, I passed a couple on to Seth

aged 14 for him to place in his wallet not imagining my little boy would consider using them for at least another 10 years. This proactive, progressive act resulted in my little boy giggling like a pre-adolescent girl as he chased a number of strangely shaped balloons down the hallway and into the lounge room.
As a person who prides herself on re-using, re-cycling and renewing, I yelped, 'Seth, don't **waste** them' - realising seconds later what the implications of what 'not wasting' condoms really meant. Thankfully my words went over Seth's head.

These were the things that made my life a joy and even though at that time I was still drinking, it wasn't until later that my alcoholism reached the point where I was 'borderline functional'.

While Seth was a cutie when he was young, when he puberty everything changed drastically. Those cute idiosyncratic ways which had endeared him to almost everyone he met changed into seemingly deliberately destructive and damaging actions and words. He started drinking, using drugs, getting into trouble at school and with the police, having sex and staying out all night all in the space or around 6-9 months.

Even **one** of these things would have proved to be a huge stressor for the family but all of them almost at once just about undid me. I was newly sober so was still a little emotional and when he came home one night, vomiting, smelling of alcohol, clutching a drink and swearing black was blue that he had not been drinking; my heart just broke imaging all the pain that would be in his life as an alcoholic. I was certain this would be his lot and that it was my fault because he was genetically predisposed to addiction. I didn't want him to have to go through all that and it really broke my heart thinking that he might.

Alcoholism and a Christian-type value-system are not always mutually exclusive and I thank God that my values were never compromised while I was drinking. I looked after my family, mowed the lawn, cleaned the house, cooked and read stories to the boys; I just did everything I was supposed to as a mother, a wife and an employee, I just did most of them with a glass in my hand. My greatest joy in those days was to get up on a Sunday morning early, knowing that I didn't having to take the boys anywhere and have my first drink of the day. It's not hard to see how warped your thinking can get when you're an active alcoholic.

When Seth came home smelling of alcohol it was a huge surprise to me. It was ridiculous of him to think that we would believe him when confronted with such overpowering evidence to the contrary - but he did…………………This, I found out later, was a typical FASD behaviour. Because they so want to please and because they cant manage the link between cause and effect, combined with memory problems, confabulating or 'filling in the blanks' is very common amongst children and teenagers with FASD.

Unfortunately that evening was the start of Seth's drinking, drugging and self-harm period which lasted from that first night, until last year when he stopped using drugs. He still drinks but only moderately and certainly not alcoholically. During that period, he became an argumentative, angry, often dangerous, morose and dishonest young man.

He would tell me he was having sex with his girlfriend or he had gone out last night and met up with mates to have a few cones. He didn't seem to want to hide anything he did. He had turned into someone I didn't know …………but the strangest thing was that when I looked into his eyes, I saw such despair and anxiety – It was almost like he was trying to outrun his pain. He was in a lot of trouble psychologically. It seemed that everything he did was false --------almost as though he was acting out his life trying to behave normally by mimicking other people who he thought were 'normal. Even his smile was make-believe.

He was suspended from school for a week, he was diagnosed with ADHD by our paediatrician and put on dexamphetamine. From then on his normally strange sleep / wake cycle became even more bizarre.

He would often not be able to go to school because he was only able to get to sleep in the wee small hours. At that time I didn't realise the stimulant effect of this medication and was certainly not advised by the paediatrician (please remember this was over 14 years ago). This same doctor while reluctant to diagnose FAS four years later did say that while it was possible Seth had FAS, and that he should attend TAFE in order to increase his skills. Not an appropriate suggestion for someone with this condition who had his mental health damaged throughout his school and pre-school years and who, it was clear, did not respond to the traditional educational paradigm – but this was 14 years ago.

We had no support, no one to talk to, no one who knew about FASD, no specialists in FASD, no clinics, no support groups – we had no one other than each other to get through this. Those services we did try to access were not willing to look beyond what they decided was a neurotic mother 'stuffing up' her 'normal' child. I didn't care about what they were thinking about me – what I did care about was that because they dismissed me as a disturbed mother, they dismissed Seth's symptoms as fabrication because when they talked to him he sounded healthy both mentally and physically.

One of the many issues this condition bestows on its sufferers is outstanding verbal competence. They may be able to 'talk the talk' but they can't then '**walk** the talk'. So this results in misdirected expectations. People with FASD can speak well; hold a conversation (up to a point); as a child or young adolescent, discuss issues with people much older than they are or with their teachers, all the while appearing confident and competent, raising expectations and then…..not being able to fulfil them. Admittedly before I knew about FASD, I would have found it very difficult to believe that someone who could sound **so** competent could be **so** unable to follow through. However I was there and I told them I thought he had FASD, I told them I was in recovery and I was well-dressed, had a full time managerial job but still nothing.

So even though I told these services that Seth didn't have insight into his condition, if they asked him whether he thought he needed these services, and he said 'no' then that was how they rolled.

So when Seth became suicidal we had no one. The one time I rang the ambulance because I was afraid he would follow through on his threat to kill himself, the police came and looked through his room, found his utensils and charged him. Then he went to the hospital where the psychologist found that he was just a normal young man who was just under a lot of pressure.
No help for us again!

I am telling you this, venting my frustration and my anger at the services which were not there for us because **things have not changed in all this time**. There are so many parents and carers many of whom are connected to the rffada parents and carers group on FaceBook, looking for help with behaviour, medication, schools, diagnosis and there are still no supports……..

So as Seth got older, he stayed out at night more often and for longer. Not only that but he also met up with increasingly disturbed 'friends'. His 'friends' became those people he met up with in the middle of the night in the park. He couldn't see the difference between a person who was genuinely interested in him and his life and a person he had just met in the street who had asked him for a smoke.

I stayed up night after night trying to find out where he was, walking the streets, driving around the suburbs, ringing his friends. If anyone ever tells me that parents should keep their children at home, I will let them know that in my experience, unless you handcuff the child to the bed or lock the doors and windows with bolts, and then remain awake night after night outside their door then no parent is consistently able to keep his or her child at home when they want to go out particularly if they have FASD. Because people with FASD are unable to see cause and effect, the consequences of going out without permission, in the middle of a school night to do nothing but roam around, eludes them.

Parents have to sleep. When the parents are asleep, the child just walks out. With a child with FASD, they don't even try to hide it – if they want to go out they just walk out the front door. Tell me how you are going to keep a child in the house? Grab him and physically make him stay at home? Wrestle him, tie him down? It just isn't possible without compromising his rights as a human being.

A person with FASD typically has a problematic sleep/wake cycle and sleeps very poorly wakes up in the wee hours and decides to do something: cooking, or get stuff out of the fridge or the cupboard to make a sandwich. As a teenager that's not so bad but when it happens as a child, how do you protect them from lighting the gas or turning on the electricity and cooking their cake directly onto the element; or turning on the gas and forgetting to light it – and then remembering 30 minutes later!!

In those days we didn't have motion sensors but at least now we do and at least have the opportunity to try and stop the child or teenager from leaving by talking with him or her. There is still nothing else which will keep him at home if he wants to leave.

I remained half awake all night every night for 10 years from when Seth was between 8 and 18 except for 3 weeks when he was 14 and moved out of home. When he was 18, I knew that while he was officially an adult he was probably operating at about a 6 year old level. By then we had obtained a diagnosis from Dr Sterling Clarren at the University of Washington and even though we had known for years, we now had a proper official diagnosis so everything would be okay right? NO! Disability Queensland didn't accept that diagnosis because it was from the United States – so I asked Dr Elizabeth Elliott from the Telethon Institute to write a letter about his diagnosis – that's got to be okay you think??? NO! they wouldn't accept that because it was from a paediatrician and Seth was at that time over the age – 16 I think.

When I was at my lowest, Seth met Hayley.
I don't know about Seth, but I loved Hayley from the moment she came into our lives and our home and it was the start of Seth becoming more stable and more manageable although anti-psychotic medication meant that he was much easier to be around and I suspect that if he hadn't been on medication, their relationship would not have lasted. The fact that it has is a credit to them both that it has.

Hayley is an angel – a girl with a difficult background who grew up on Thursday Island, Melbourne and Mackay, her skin tinged with the caramel of a Torres Strait Islander with so many relatives I still can't remember them all even after seven years together - five years of marriage and three years before that. She has borne us two delightful grandchildren and dealt with many of Seth's difficulties with grace.

I wish I could express to you how difficult it is to know that I have hurt the two most precious, beautiful, heartbreakingly loved people in my world. That each time I see them, text them or talk with them on the phone my first thought is always how can they ever still love me knowing what I did to them ………and yet they do.
I am always thinking about them, dreaming about them, watching them dream their dreams.

For those people in the audience who have children with FASD or family or friends with FASD I want you to know that there is hope.
As ive said to you, Seth faced more challenges in a day than most people face in a year and he was very rarely "rewarded" by people outside of his family for trying because his trying was like most other people's blunders.
Each step I took back then was trying to make Seth's life a little easier but the only thing we had at that time was each other – unfortunately as I said, that is still the case 12 years on.

Being responsible for his condition, I felt that it came with an enormous obligation I have not, and could never evade – that of doing everything in my power to make his life as normal and as satisfying as possible. I also felt that the responsibility incorporated doing as much as I could to spread the word about the devastating effects of drinking alcohol during pregnancy.

I believe, and I know Seth would agree, that for him to suffer the effects of this condition without raising awareness would be almost to admit that everything he has had to endure and will have to endure in the future would be for nothing.

Now Seth is 28, he is in recovery and has a job and I couldn't imagine life without him. He is a good dad and a happy and compliant husband. I say 'compliant' because he often has to be reminded of what to do or when to do it but he does it mostly without question. I am happy for them.

I have done everything I could to help them and they seem to be doing very well. Mick has a fiancé; a full time well paid job, a house and two dogs. Seth will always have to struggle more and unfortunately the boys are not as close as I would like them to be. I think that happened while Seth was going through his teenage years – it must have been hard for Mick who was not as affected as Seth.

Thank you for giving me the opportunity to express my perspective as a birth mum. I would never have expected when I was a teenager myself that I would have been in this position. But there is hope and this is the one thing I want you to take away from my presentation today. While it is a very very difficult condition and it may take time before you see any positive changes, **and** it may take a toll on your health, your finances and your marriage, it can get better—but we do need medical and allied health providers, counsellors and youth services to seek out training on this condition so they can better understand their clients with FASD whether they are diagnosed or not.

Because you will be working with someone who has been prenatally affected by alcohol there is no question – the odds are favourable. According to statistics from the united states and Canada there will be around 220,000 people with FASD in Australia and they will most likely be masquerading as people with ADD, ADHD, Austism, Aspergers, ODD, PDD, mental health problems, personality disorders ----- unfortunately anything but fASD ---- unless they are Indigenous. While FASD is not just an Indigenous issue it seems as though people are more comfortable diagnosing this condition amongst Indigenous people.

One last thing! You may not be aware but there is currently a federal government Inquiry on FASD. Unfortunately because there has been no promotion many people do not know therefore the number of submissions to the government are comparatively few – particularly in the Northern Territory. If you are from the NT and are likely to be working with people with FASD and have not lodged your submission with the government please do so – otherwise it is likely the Inqiry will find that fasd is not the issue we thought it was.

Thank you

is that of mother to two adult children with diagnoses under fetal alcohol spectrum and grandmother to two unaffected boys, the children of Seth, my son with full FAS. While my grandchildren have not been directly exposed to alcohol in utero, I recently read that Kobor and Weinberg found that alcohol exposure prior to conception appears to be able to induce epigenetic changes in the parental genetic material that can be passed on to the offspring and affect offspring outcome. So it doesn't end when the alcohol exposure ends. To even think that I could have harmed my beautiful little grandchildren as well is just not something I can even think about.
The role of mother has been my most joyful and my most heartbreaking. Motherhood is a wonderful experience as im sure many of you are aware. It can also be stressful and demanding and exhausting and nerve-racking and that's just when you have children who DON'T have FASD. But when you are the birth mother of a child or children with Fetal Alcohol Syndrome and Alcohol Related Neuro-developmental Disorder, all of those feelings and experiences seem to be exaggerated.

The joy is based on the little things that happen on a day to day basis. The things that you can often miss if you aren't careful ……………. or you can accidentally dismiss them, knowing they are special but not having the time or the energy to devote to examining and feeling them.

I have found so much joy and beauty in my life just watching my sons and now grandsons play at the beach or play with the lego that has been passed down for two generations. They have given me my life and when my children were young they kept me going – kept me alive and always grateful.

As they grew older, I kept a record of many of these little things they did over the years. I put them into a book and when I had time, I typed them up into a book of their life to be given to them when they were 18. The books were filled with sayings, experiences and, at the end, their little anecdotes.

I will read out to you a document I wrote only a short time after I found out about the reason for the boys' problems. It is now located on a website over in the United States and I only just came upon it again.
In my own self-interest, I would have preferred not to know that my addiction had physically harmed my children. But regardless of how I felt, my boys deserved a diagnosis. It was the first step to obtaining the particular help that was vital for my youngest son who at that time was almost 17 years old. He was struggling with licit and illicit substance abuse, depression, anxiety, suicide attempts and ideation, employment problems and interpersonal crises.

My husband and I found his behaviours frustrating and bewildering given that even with my alcoholism, we were a loving, caring family. We did not know where to turn or how to integrate his more challenging behaviours into the kind and loving person we knew he was.

It was not until I was researching ADHD with which he was diagnosed at aged 13, that I discovered three words that completely stunned me - Foetal Alcohol Syndrome.
I went to a doctor who advised that I didn't really need to have a diagnosis, I went to another who, although in agreement with the diagnosis, provided me with options which did not match my son's abilities. I went to a third doctor who asked my why I was doing this to myself. I was willing to do anything to help my boys but didn't know where to start and couldn't find anyone to give me advice.

After weeks of recrimination and denial, I decided to face this problem head on. I spoke to my husband and together we told our boys.

My 17-year-old is now in appropriate full time employment and has a Rehabilitation Consultant from CRS Australia who understands his condition and is prepared to read the material available in order to undertake the most appropriate tests and assessments for him.

In hindsight, while the diagnosis was the most difficult thing I have had to face in my life, it was the start of a new life for my son. Even though he still has to confront the same problems he had before the diagnosis, he now has a reason for some of the things he finds so difficult in his life.

He says of that time, "I really didn't understand what it meant for me. I am the same person but have more of an idea why I do the things I do. My parents understand me better now."

I can recognise that dealing with a complex and emotive issue such as telling a mother that she has harmed her child can be very tough for a doctor. However I believe this is preferable to allowing a child to go through life with no explanation for his often self-defeating idiosyncrasies; with no access to the assistance and understanding he needs; no reason for his suicidal fantasies, and with parents who misunderstand his resistance as defiance, and his lack of remorse as cruelty.

As with many regrettable diagnoses, the benefits must be measured in the long-term rather that the short-term. Most mothers will cope for the sake of their children and a diagnosis can mean a great difference to an affected child. My children were not diagnosed until they were 20 and 17. For my youngest son, while trying to cope with his feelings and behaviours through his teenage years, self-medicated with marijuana and alcohol and became self-destructive. I believe that this predisposition will now be with him for the rest of his life.

If he had been diagnosed as a young boy, we may have been able to prevent some of these potentially life threatening secondary disabilities.

A diagnosis can provide the catalyst to appropriate care. No amount of assistance would benefit individuals with FASD unless moderated by knowledge of this condition. The behaviours and characteristics exhibited by people with the Foetal Alcohol Spectrum Disorders are quite specific and rarely comprehended by people who do not have an understanding of FASD.

My eldest son who is now 21 says of the time that we told him of his condition, "I didn't understand at first. I felt bad but mainly for my mother because she blamed herself and she didn't know. It has made me more aware that I need to concentrate harder on what I am doing. If I saw a pregnant woman drinking I would tell her that what she is doing could be dangerous to her child."

Unless professionals of varied disciplines understand the reasons for the behavioural idiosyncrasies of a child, teenager or adult with FASD, we are going to let our community and society down. No matter how many difficulties a diagnosis may cause, there can be nothing but benefit for the child providing they receive the ongoing assistance and care they need to be the best they can be.