FASD: Not just a children's issue

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Good afternoon - Before I begin my presentation, I want to thank NADA for their support of the Russell family fetal alcohol disorders association and training connections australia and our FASD training program.

My name is Anne Russell. For over 12 years I've been involved in the world of fetal alcohol spectrum disorder.

Imagine having no common sense. You take your pills today but don't realize you must take them again tomorrow. You break into a house and the cops find you eating chips in front of the TV. Money is an abstract concept, so you give yours away to anyone who asks. When people say "I'll be there in a second" you think they really will. For many people with Fetal Alcohol Spectrum Disorder, that's what life is like.

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My first contact with the words fetal alcohol spectrum disorder was as the mother of a beautiful innocent young boy called Seth. Frightened and bewildered, I was looking for answers as to why Seth, who was almost always laughing and happy had turned into a morose, belligerent and self-destructive young man.

Over a period of only a few months he had become more and more hostile and the light in his eyes was gradually being replaced by the wide-eyed stare of a rabbit caught in headlights. He was making the change from a little boy to a young man and he seemed to be hell bent on trying to make sure he didn't see his next birthday. He was 13.

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Every morning for the seven years from that time until he was 20 years old I wondered whether each day would be his last; whether each hug was the last time I would hold him; or if the siren I heard in the middle of the night represented a harbinger of sorrow.

In contrast, one of the best sounds I have ever heard in my entire life was when Seth answered the phone with a 'ho ho ho' when he knew it was me. It meant that he was, if not happy, then at least not suicidal.

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This teenager who at that time, I could not see living past his 20th birthday is now 28 years old. Seth has a most wonderful wife and two absolutely beautiful children. He works part time which is all he can manage. He has been working for around 9 months now and really enjoying the job. My relentless optimism told me this was THE job he was going to be able to keep for years, but it was only two days ago that he rang to say that he didn't think he could manage working any longer.

He usually starts becoming stressed, fatigued and overwhelmed anywhere between 3 and 6 months in a job but this time he had been working for 9 months. Even though my optimism was displaced, 9 months is

definite progress. The two main issues which have plagued him all his adolescent and adult life in jobs and social interaction are:

1. that he has such verbal competence that no one believes he has a disability
2. you can see on this slide that even though he has the facial features of full FAS, he still doesn't look sufficiently different to alter the expectations of the people around him

When you combine even a few of the other characteristics of FASD you can see not only how difficult it is for the sufferers and their families to cope with this condition, but also for the services which may deal with them – and we've discussed this many times over the last two days.

So we can get some context, I will quickly go through FASD 101.

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FASD is an umbrella term not a diagnosis and it's caused when alcohol is consumed while pregnant. Alcohol is a teratogen which is a substance that causes birth defects. In fact people are starting to call alcohol 'the next thalidomide' and the identification and diagnosis of this condition 'a tsunami'.

Back to FASD 101 ------- If alcohol is consumed during the period of pregnancy called gastrulation, which is often cited as the 19th and 20th day of pregnancy then the facial features will not occur and there will not be a diagnosis of fetal alcohol syndrome. However if alcohol is consumed outside of that time the individual could have a significant brain injury but no facial features. This condition is called alcohol related neuro-developmental disorder and is by far the most common condition of the two but it is not diagnosed in Australia because we have no specific diagnostic teams, no specific services and no FASD medical specialists to which we can refer.

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Alcohol freely crosses the placenta and the blood alcohol concentration of the fetus can be the same or greater than that of the mother. Secondary disabilities follow when early intervention does not take place. They include mental health problems, SUD, inappropriate sexual behaviour, dropping out of school and poor academic showing, poor parenting, problems in employment, criminal justice involvement, and confinement in mental health institution or prison. Immature behaviour, not linking cause and consequence and not being able to generalise learning means that the individual's behaviour can be very challenging. I have seen over time with Seth that his behaviour is a method communicating that all is not well in his environment. If I could control his environment, incorporate structure and routine, provide a low stimulus environment and other interventions, his behaviour would improve.

SLIDE FACE

The facial features of the full syndrome which the minority of people with FASD will have includes a thin upper lip, flat philtrum, low set ears, short eye slits, flat midface and small head circumference. With Seth its only when you know about FAS and the facial anomalies that you can see them in him.

So even though Seth is one of the few who have the full syndrome, he doesn't stand out as someone with a problem; he speaks well, he is a tall strong lad and he has a normal IQ – no wonder it's difficult for people to see beyond these things. That's where it is critical that workers not only identify the facial anomalies but also recognise the behaviour and history of people with alcohol related neuro-developmental disorder. Just to make it even more difficult, many people with FASD are misdiagnosed with personality disorders primarily borderline and anti-social PDs. They can also be misdiagnosed with ADHD, bipolar, PTSD, psychosis and many others – in fact FASD is often called 'the great masquerader' because it masquerades as other conditions.

Diagnosis is also critical as a preventative measure. If my first son Mick had been diagnosed with ARND when he was a toddler instead of 20 years later, Seth would not have a disability that amongst other things, means he cant work full time. He and his family will always be living in borderline poverty. He wouldn't be constantly struggling with alcohol and drug problems mental health, suicide ideation and others.

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The reason I established the rffada was to provide people with information about FASD, offer advocacy for parents and carers, give presentations and develop and deliver training as there wasn't any at that time – the rffada still has the only publicly available training in Australia. I could see the damage that was being done to Seth through my own ignorance, the unrealistic suggestions of medical professionals, clinicians and services not understanding that he really had a disability. They dismissed me because they believed I was a neurotic, overbearing mother. Even though that hurt, I could handle that – what really upset me was because they had dismissed me, they also dismissed Seth as having a disability.

With FASD, because of difficulty in comprehension and their desire to please, people with FASD will agree with your suggestions. It will also be difficult for any case worker to really understand or know where their client's real interests lie because they will change from day to day.

I had a client once who I am sure had FASD. I made an appointment for her at ATODS, gave her the time and date in a note and explained that she must attend or her allowance would be cut off (this was a requirement of Centrelink). My offer to take her to the appointment was declined with thanks because she said she had transportation. This was her last chance before Centrelink took action. I know that being an alcoholic can mean that appointments are missed but I wouldn't have missed that appointment because I would have wanted the money to continue drinking.

Anyway as you can imagine she missed that appointment. She knew the consequences and she knew that she only had to ring me and I would have picked her up from wherever she was and taken her to that appointment but she missed it anyway. What happened then was that ATODS refused to give her any more chances, she lost her allowance and her life was made even more difficult than it was if she did have FASD. This was around 18 years ago and I still haven't forgotten her because I didn't get why she didn't accept my help – now I know - this would have been exactly Seth's behaviour if it had been him.

At the same time I was case managing this client (I used to work in the Commonwealth Employment Service or CES) – for those of you who don't know what this was, it was sort of the employment arm of Centrelink – they were both government agencies ------- a colleague was case managing a client who had cervical cancer and was in the radiation phase of her treatment. She had told my colleague that she still had to attend five therapy sessions before she had completed her treatment and provided a list from the hospital of the times of her appointments. Needless to say that even though my colleague bent over backwards trying to get her to those appointments, reminding her, driving around trying to find her – she did not attend any of the remaining radiation treatments. That is a clear indication that something isn't right and her case manager now believes the same as me, that her client had undiagnosed FASD and didn't understand the importance of these appointments even though she had been told over and over.

So how can we identify a client with FASD so treatment can be modified? For a case worker I believe the best way is to take a history of the clients life and match it with FASD. Having an understanding that a client may have FASD will give you so many more strategies and interventions to use than if the behaviours were seen as isolated. Many people with FASD will have multiple diagnoses. In fact Kieran O'Malley a psychiatrist and FASD expert in Ireland says that the more diagnoses a person has the more likely they are to have FASD.

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Firstly I believe that all complex needs clients – unless they come from a professional or academic background - should be assumed to have FASD. Where the dual diagnosis model is now, the 'tripartite' comorbidity model will be in maybe another 10 years. It will be assumed that people who are diverted into drug and alcohol services will have a comorbidity problem consisting of mental health, drug and alcohol issues and FASD.

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Dan Dubovsky, a FASD Consultant in the United States, says that "While assessing the level of any comorbid conditions often requires one or the other to be at baseline, in most cases diagnosis can be reasonably established by history. This is also true of fetal alcohol spectrum disorder. A certain history is an indicator of possible prenatal exposure to alcohol."

At your initial assessment the following information will give you more understanding of the issues you may be dealing with. IQ, Medical history; Family history; Mental health; Developmental disabilities; Neuropsychological testing; Adaptive functioning testing.

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So if we can identify a client who is likely to have FASD from their history – what is that history?
The following is a list by no means exhaustive, of the possible problems associated with FASD in adolescents and adults:

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- Low academic achievement
- Increased truancy, school refusal and dropout may result
- Trouble understanding maths - problems managing time and money result
- Seems to understand instructions but unable to carry them out
- Memory and understanding problems persist - result in children being seen as lazy, stubborn, and unwilling to learn

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- Increased problems with abstract thinking and the ability to link cause and effect - high risk for problems with law
- Impulsive, lack of inhibition and easily influenced - early sexual activity and substance abuse are common

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- Difficulty showing remorse or taking responsibility for actions
- Difficulty identifying and labeling feelings
- Difficulty holding down jobs
- Unable to live independently
- Problems parenting children
- Problems managing money
- Poor social skills and difficulties with relationships

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- Unpredictable behaviours
- Depression and other mental health problems
- Withdrawn and isolated
- Not learning from mistakes
- Involvement with the law
- Alcohol and other substance misuse

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And how would you manage a person with FASD or a person with suspected FASD? Firstly learn as much as you can about the condition. Then find out how the client was referred. It is **unlikely** that the person with FASD will self-refer to drug and alcohol or mental health services unless in an absolute crisis.

The majority of referrals will be via:

- Court ordered diversion (Courts: drug/mental health/district)
- Family/friend referral or intervention

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There are five steps that you could adopt when your client has come via one of these referral pathways. The steps are:

- Identify legitimate client interests
- Identify non-negotiable aspects of intervention
- Identify negotiable aspects of intervention
- Negotiate the case plan
- Agree on criteria for progress

It will be difficult for the client with FASD to participate with any depth in the discussion of these steps. Because of difficulty in comprehension and their desire to please, they will agree with your suggestions. It will be difficult for any case worker to really find out the interests of a person with FASD because they will change from day to day. It will be equally difficult to gain informed consent because of the inability to link cause and consequence.

[1]Questions which require planning, organisation and introspection will not yield answers which have any great depth, they will be answers related to something seen or heard on the day or will be interests or beliefs which were part of the opinions and attitudes of their family of origin.

[2]Most case management models encourage workers to empower clients to take responsibility for decisions and choices they need to make for themselves and empathically confront clients with the negative consequences of poor decisions.

People with FASD are typically unable to take this responsibility or understand the consequences of their actions. Tough love and natural justice do not work and should not be used as consequences. I took Seth to a psychiatrist for help when he was suicidal. The psychiatrist told me he knew about FAS after I told him that Seth had been diagnosed overseas with this condition. When we told him the problems that Seth was experiencing he said that he would not work with him until Seth started taking responsibility for his actions ie that Seth stopped smoking marijuana. It was a terrible 45 minutes and the consequences were that it took a long long time before Seth went back to any medical professional – years actually.

Eighty-six per cent of the individuals with FASD have an IQ in the "normal" range and do not qualify for services for developmental disabilities. They nevertheless have impaired mental functioning caused by brain damage that is permanent and incurable.

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[1] Barber J. Beyond casework. London: MacMillan 1991
[2] Dan Dubovsky – FASD Specialist Building FASD State Systems Meeting May 5-6, 2004

[3]There are several primary hurdles to the successful treatment of FASD clients. Most importantly recognition and diagnosis do not occur with sufficient frequency. That's because to my knowledge there is only one registered training organisation delivering publicly available training in the whole of Australia – Training Connections Australia delivering the rffada's training.

Precipitate discharge and inadequate post treatment supports along with the belief that the client is able to follow through after discharge do not help the client with FASD.

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There are other factors which can reduce or negate the success of mainstream programs. The inability of a person with FASD to understand abstract concepts makes 12 step programs problematic.

The belief that if the client says he understands or agrees, then he does causes

- The belief that the client will work on his program independently
- The misunderstanding that the client will or must take responsibility for his choices
- The assumption that the client is making informed decisions about his life

FASD is a difficult condition for everyone concerned: from the parent to the service provider – if we want to make sure that we don't do further damage, then we need to be certain we can identify people with FASD. FASD-friendly programs will not hurt someone without the condition and they will make a huge difference to people who do have FASD. I would have given anything for my children not to have been further damaged by their interaction with the people around them – teachers, we parents, their friends, medical professionals and services.

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Thank you for the opportunity to present on this subject which as you can imagine is very close to my heart. NADA is a progressive organisation and I am grateful for their support of FASD as an issue in Australia particularly to the drug and alcohol community.

The cliché – if you can help just one person then it has been worthwhile stands very true with FASD Research has now commenced on identifying whether there the DNA is altered in people with FASD and whether these changes are being passed down to children and grandchildren and so on.

Thanks

[3] FASD Grows up - Mary Berube, MSW, RSW