

Inquiry into Foetal Alcohol Spectrum Disorder

Tuesday, May 15, 2012

I am a health professional who has worked in NT Aboriginal communities for the past 20 years and prior to this the NSW North Coast Koori population for 4 more years. I am also a co - foster carer, who has seen more than their fair share of children affected by FASD enter and leave our home.

I am not going to provide statistics or data on this subject, as I have read other submissions (Prue Walker, Dr Wendy Hoy, Anyinyingi Health etc) and this has been covered admirably by those who can do it far better than I can.

I would like to take a more personal account of what I have seen and had to deal with over my years of working in the NT with the over abundance of the effects of alcohol on women and children in regard to FASD issues only.

I am writing this because it is close to my heart and I now know that it is starting to get a focus on Government agendas which is not before time.

This is a major problem for Aboriginal children and will have lasting effects for many generations to come. It is an area which is grossly under recognised, undertreated and underserved.

FASD is such a difficult topic in every regard It is even difficult to see, let alone diagnose or treat as it has such a broad spectrum of signs and symptoms, from absolutely none at all, to very obvious gross disability. The FASD issues are one of those very difficult topics that get caught up between Government services and as such, fall through the gaps.

Most staff whether it be health or education are not familiar enough with it, that they just don't see it or recognise it well enough.

Department of Health staff in remote communities are very focused on acute care and see kids who have a physical problem or an acute onset of illness and treat the cause of that problem. It maybe that the child won't eat or appears neglected or failing to thrive and it is sometimes easier to look for a simple cause like an infection etc and treat the acute illness or issue, so that the staff can get them out the door and back home instead of being tied down to a long involved consult which they never have time for.

Alternatively if no obvious cause is found, than they jump straight to blaming parents or some other factors, so that they can put them through to another service like Department of Children and Families (DCF) for further management.

By the time these same kids get to school (if they go at all!) the Department of Education staff won't know all the factors influencing the child's life, in the past and just see that the child doesn't process work or is slow to learn and seems distracted or disruptive etc and will probably put it down to bad parenting, coke cola for breakfast, no decent food in the diet, poor hygiene, socialisation issues or just being a typical remote Aboriginal kid etc. etc.

Even if teachers are dedicated and keen to find out more, they cannot as it would mean investigating the mother's medical records and breaching confidentiality (which won't happen).

The history taking during pregnancy is another major issue, with no appropriate screening tool and very few dedicated Midwives working in remote regions of central Australia to give preconception, antenatal, pregnancy or postnatal education to young women or mothers. Adequate history is so dependent on whether it is accurate as well. This often depends on who asked the questions, if at all, whether it was documented accurately, which in many cases it will not be. Sadly we practitioners often get the answer we want from Aboriginal mob and not what is the truth. They do this because they want to please us and they know what they should be telling us.

It is a rare skill to find staff who can interview an Aboriginal person without leading questions.

As a foster carer, I have been witness to too many of these kids and they are just the obvious ones. There are many more with normal looks and not one single sign of FASD with mild to major mental processing problems, who are frustrated and entombed in a body or mind that just won't work for them, with little chance of getting any services directed their way because of lack of diagnosis which could lead to enabling assistance. There is no expertise in diagnosing these children and they only see a paediatrician if they are sick, so the vast percentage go thru life undiagnosed, untreated and abandoned by the systems.

Prevention strategies

Aboriginal health is unique in that we try to continually send non-indigenous staff out to educate, screen and inflict our ideas on what they should and shouldn't do, thereby setting up a program that will not work.

I have found that we non - Aboriginal staff who work in Aboriginal services, talk long and hard about ownership and involvement, but do very little about actually trying to make sure our programs are as worthwhile and holistically inclusive as we would like.

All programs and services directed to, for and at Aboriginal people, must have Non-Aboriginal staff mentored for the entire duration of the program by local Aboriginal colleagues.

Why should traditional people of central Australia, listen to what we, east coast academics, bureaucrats and health professionals have to say? As good as our intentions or knowledge base is, it doesn't belong in their world, unless we are walking and talking alongside one of their own people and putting it forward in a way they understand and can relate to.

I have always stated that *"the more I work with and get to know Aboriginal people, the less I actually know"*.

I have been privileged in my workplace to have been introduced to my working life, by having 2 excellent mentors who travelled with me for the first 2 years of my work in Central Australian Aboriginal communities and this has set me up to be a trusted and respected educator of women and girls in Remote regions.

My point is that whatever program is set up it needs to be a multipronged approach to tackle any stage of the FASD issues ie - prevention, education or solution it will need to include

- Specific, adequate funding for specialized staff and resources to address all aspects of need , over a decent period of time (more than 5 years) to make it a believable, trustworthy effort and sustainable to ensure it will.
 - o Raise awareness,
 - o Provide Education and Prevention
 - o Allow Early detection and proper Diagnosis
 - o Institute effective Treatment/intervention programs
- Raise the focus of FASD and have Management at high levels of Health and Education take notice, to enable support of staff to attend training on the subject.
- Address the staffing issues in regard to
 - o Lack of Remote Midwives to provide prenatal education and preventative programs, as well as screening in the antenatal period, with a focus on recruitment and retention of these eligible Midwives
 - o Skilled Specialists Clinicians/ Paediatricians to diagnose appropriately & enable early detection and assistance in care/intervention
 - o Skilled teacher workforce who are trained in the nuances of the spectrum and can assist kids in their classes
 - o Local Aboriginal and non - Aboriginal colleagues working together, so that as the Non- Aboriginal staff move on, the knowledge and skills will stay in the Community to make it a more sustainable approach across all sectors.
 - o Consulting local people re solutions with enough financial support to make local appropriate resources which have been tried and tested locally.

Thank you for giving me the opportunity to add my comments.

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