

**Submission to the House of Representatives (Federal)**  
**Standing Committee on Social Policy and**  
**Legal Affairs Inquiry into Foetal Alcohol Spectrum Disorders**  
**(FASD).**

Julie (not her real name) is in her 40's. She is considered an elder in her community. At different times she has worked in various roles but mostly as an Aboriginal Health Worker. She has many connections in the community. In fact, she has a lot of cultural knowledge that she wants to pass on to the next generation. For consecutive generations many in her immediate and extended family have been affected by alcohol abuse. This has impacted in varying degrees on her grandparents, her parents, herself and her siblings and her children and their children.

There is a child or two in each generation who has been identified to have the physical characteristics understood to be attributed to the influence of alcohol during pregnancy. There are many more adults and children who have not been identified with FASD within the family but have the behaviours consistent with being on the spectrum.

I got to know Julie at work. On a good day she appeared quite articulate, willing and friendly, trusting to the point of naivety, and keen to learn by doing things. Gradually I noticed the development of what I now understand to be secondary characteristics of FASD. On a bad or 'off' day she often displayed high levels of anxiety; she avoided situations that were too 'hard'; she would appear irritable and even have "tantrums". Her pain threshold would appear to be very low and she would often self medicate beyond safe levels. She would appear like a hypochondriac and if symptoms were suggested she would some time later declare that she indeed had these symptoms and would need to take time off. I realised that these declarations often coincided with tension within the team, or issues arising around her own work practice.

During a study day Julie confided with me about how she might keep the information in her brain once it had gone in there, particularly the numbers and the math! She felt very confident with the hands on skills but was not able to remember the number calculations. This was an often repeated anxiety that she would express quite matter-of-factly.

Julie's work history is like a bit of everything from a smorgasbord table. A three month stint here, 6 months there, 10 months somewhere else, few weeks here and so on. She would inevitably have a dispute with someone and move on.

**Prevention strategies:**

Product labelling about the impact of alcohol consumption in pregnancy will probably have little influence in a community where people are more focused on old habits for blotting out painful memories of abuse and domestic violence (particularly in relation to women and their pregnancies). For Julie, hope would be based on her great grandchildren being less impacted by alcohol than what has been her experience. Programs that provide intensive support before and during pregnancy for Aboriginal women, being supported by other Aboriginal women in partnership with midwives, doctors and other mainstream health service providers; will go a long way towards reducing alcohol consumption in pregnancy. Care that is provided within culturally safe relationships is a proven way forward.

**Intervention needs:**

If Julie and other FASD sufferers were 'identified', as distinct from 'labelled' appropriate modifications could be put in place (just as we now take for granted that modifications that are made for wheelchair bound people to have access to roadways, transport and buildings). This would provide hope and recognition for Julie and a way forward where she would be understood and provided with appropriate supports. Organic brain damage is mostly recognised through behavioural symptoms so training is required for health professionals, parents and families; schools and communities to ensure that the perception is more about what FASD people 'can't' do rather than 'won't' do. We have to put in place the appropriate modifications because FASD sufferers 'can't' do it themselves. This will require functional neurobehavioral assessments for FASD sufferers in different settings; on their good days and their bad days.

**Management issues:**

Julie lives in a regional area of South Australia. There are many Julie's Australia wide. It is understandable when regional and rural services already stretched with limited resources to implement FASD specific modifications will agree that there is "minimal post natal/ infant/childhood

investments in this very disabling area”.

There is a belief that a National push for recognition of FASD specific needs “won't happen and won't work in our part of the world. We need a strengthened child health team for all our kids”... with relationship based programs where history and culture is taken into account.

One third of the births at our local hospital are to Aboriginal families (about 100 each year). If we can implement supports for these families and FASD sufferers in our community we will make a big difference to the lives of the Julie's in our community and to their children, grandchildren and great grandchildren.

Biography:  
Anne Foale



I have been a midwife since the middle of the 1970's. My experience working in Aboriginal communities spans more than 30 years. In the 80's I regularly witnessed taxis from town arriving in the sand hills around the various camps supplying grog from the boot of the vehicle to people sitting around campfires. For the last 8 years I have been part of a developing Aboriginal Family Birthing Program, where Aboriginal women are the primary carers for Aboriginal pregnant women, working in partnership with midwives and doctors to support healthier birth outcomes for Aboriginal families. This program is now rolling out across all of South Australia.