Inquiry into Foetal Alcohol Spectrum Disorder.

Points of interest

- Need for recognition of FASD as a disability affecting many people
- Impact of FASD on foster care
- Lack of support for children and carers
- Failure of systems/agencies to understand FASD
- Misdiagnosis of FASD - Autism or FASD?
- Difficulties living with FASD
- The foster care system and FASD – the future?

As a long time foster carer and peer advocate I believe I have personally been involved with a number of children with FASD and their foster families who have struggled to get support for the child and the foster family because FASD was not known or acknowledged.
Many years ago some foster families recognised there was a group of children in care who seemed to display similar problems – behaviour issues, learning and relationship difficulties, understanding consequences, social issues etc.

It was not until one carer researched FASD and its related problems for children and families that the penny dropped. All the children in this recognised group had a mother with alcohol issues in her life, so the possibility of FASD was real. Whilst the foster families felt they had a possible answer, the authorities failed to acknowledge it.

Instead of understanding the child and catering for their needs these children were given little appropriate support. Now as adults they have dropped out of school, suffered relationship difficulties, homelessness, mental health issues, antisocial behaviour and unemployment. With recognition and appropriate intervention they may have achieved much more. Most cannot live independent lives as they need assistance with living skills, money and organisation. Many foster families are still struggling to support them as adults as most don’t fit into the current disability support criteria and there is no one else who really cares.

I have been closely involved with one family and have witnessed their tremendous struggle to understand their foster child and access the right services to assist her development, learning and behaviour. A beautiful and very articulate child she has spent a lifetime of frustration not fitting into the norm and not understood by her peers or any system she has become involved with through her difficulties. It has been a mammoth task for her foster carers who were often seen by authorities as the “cause of her problems” when in fact the girl had a huge unrecognised disability.

This family is not alone in their problems with systems that are supposed to assist.
Failure to recognise, diagnose and understand this disorder has huge ramifications for all society. Now an adult, this very vulnerable girl has been involved in early school drop out, vulnerable to inappropriate peer pressure, mental health system, homelessness, domestic violence, police protection, unemployment, and unplanned pregnancies. She now has a child herself whom she cannot care for.

Unfortunately this failure to recognise and understand the issues of FASD and the “anti” attitude of professionals and support services is still happening today. Recently another carer with a child who has all the facial features, behaviours and difficulties associated with FASD, asked for an assessment to plan for his future. Despite earlier recognition that this child may have FASD and the mother known to be an alcoholic, her foster child was diagnosed as suffering from Autism. Whilst at least the diagnosis of Autism will get this child some support, it is unfortunate that he may have been incorrectly labelled and the opportunity to really understand his needs has been lost. There is a great deal of International literature which would have been very useful for planning his future had FASD been diagnosed. The opportunity to recognise the prevalence of FASD has also been missed.

There is currently a huge increase in the number of children diagnosed with Autism. Could it be that some of these are misdiagnosed FASD sufferers? Failure to recognise this disorder and collect accurate statistics could jeopardise the future of many more children whose mothers unknowingly cause irreversible damage to their child and lifelong problems for everyone, because FASD is not accepted and widely known..

None of the children who I believe suffer from FASD have had an easy life and their problems are getting worse in adulthood. None have reached the potential we would hope for our children, despite very committed and caring foster homes.

I believe it has also affected the foster care system itself which is currently in crisis with the numbers of difficult children who need placement. Could some of these be affected by FASD? It is widely recognised overseas that many children with FASD enter the foster care system and multiple placements are common.

Could lack of recognition of these children, their needs and the needs of their carers be impacting on the foster care system itself and leaving vulnerable children without families to assist them. Caring for these children is hard work and carers are suffering burnout, particularly when they are not understood. Living in group homes and motel accommodation is not suitable for children with FASD who need constant parenting and stable environments.

I welcome this inquiry into Foetal Alcohol Spectrum Disorder. I believe recognition, intervention and management of this disorder is essential. Sufferers need understanding and appropriate services and children in the future need the opportunity to grow up to reach their full potential through education and prevention.

With our drinking culture and lack of understanding regarding alcohol and pregnancy, I believe FASD may be the answer to many issues in our society today. However, it is preventable and this inquiry has the power to make that happen.

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