

Parents Who Have Foetal Alcohol Spectrum Disorders (FASD)

A DISCUSSION PAPER

The National Organisation For Foetal Alcohol Syndrome-UK¹



Foetal Alcohol Spectrum Disorders (FASD) is an umbrella term for a range of effects caused by exposure to alcohol in utero, including irreversible brain damage. FASD is the most common, non-genetic cause of learning disability in the UK, and also causes executive functioning deficits and over 400 associated mental and physical conditions.

These issues are often compounded by secondary conditions if the underlying needs of the person with FASD are not met. With proper diagnosis, support, insight and understanding, people with FASD can lead successful lives that contribute to society in many ways. This paper focuses on issues related to parents who have FASD.

People with FASD have a brain-based disability. In the UK, the NHS states clearly, “If you have a disability and you’re a parent or about to become one, you’re entitled to the support you need to help you carry out your parenting role....Whatever your disability, you have the right to support from your local authority to help you in your role as a parent.”²

This discussion paper highlights some of the available research about parents with FASD and includes perspectives from adults with FASD who are parents. This paper quotes studies done in other countries. There is a need for more UK-based research. That said, these issues transcend borders.

Can someone with FASD successfully parent a child?

“It was expected that I would fail as any sort of parental figure”
R.J. Formanek, adult with FASD

Peter Choate wrote, “There is often a presumptive bias that individuals with disabilities, including FASD, are not capable of raising their children. Such a bias is unwarranted....The few studies that have been done, have shown that with appropriate intervention and supports, there is reason to believe that many FASD parents would be able to fulfill the requirements of the role (Denys, Rasmussen & Henneveld, 2011; Rasmussen Kully-Martnes, Denys, Badry, Henneveld, Wyper & Grant, 2010). This small literature base suggests that, as in the realm of disability research, there is reason to challenge the presumptive bias that FASD parents would, by definition, be unlikely up to the task.”³

As with other disabilities, there is a need to look at each case individually, without bias. As Choate summarised, “The assessment should focus on the core question - can this parent raise this child (Pezzot-

¹ This discussion paper was written by Sandra Butcher, Chief Executive, NOFAS-UK.org in June 2017. For more information www.nofas-uk.org, sandra.butcher@nofas-uk.org

² Help for disabled parents,” NHS Choices, available online 3 June 2017 at: <http://www.nhs.uk/Livewell/Disability/Pages/help-for-disabled-parents.aspx>

³ Peter Choate, “Parents With Fetal Alcohol Spectrum Disorders In The Child Protection Systems: Issues For Parenting Capacity Assessments,” The First Peoples’ Child and Family Review, Vol 8, No 1, 2013. Available online 3 June 2017 at <http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/202/30>

Pearce & Pearce, 2004)? In FASD cases, a second question might be added. Can this parent raise this child with supports? It does not need to be done alone.”⁴

Each person with FASD is affected differently. Dr. Barry Stanley summarized the question as follows:

FASD is truly a spectrum, consequently those with this condition vary in their abilities. A majority have normal or higher than normal intelligence. Many of those with FASD are capable of parenting, with various degrees of support. In custody cases it is important to see the FASD parent as an individual. Their history of the secondary disabilities of FASD should be examined-did they graduate from high school, have they had problems with the law, have they had drug or alcohol issues, have they maintained employment and finally what is their relationship history, especially with their children and other family members? It is important to establish to what extent the FASD individual is prepared to accept help when they need it, according to any disabilities they may have.

*There are many parents who are not FASD who, for psychological reasons relating to their own childhood, are very poor parents. In comparison some FASD parents would provide more appropriate parenting. It is my opinion that a diagnosis of FASD should not be of its self a reason for removing a child from its mother.*⁵

A further complicating factor is that FASD is under-diagnosed, so there is also a need for those in various social services to be better educated on FASD more generally. “In cases where there is not a diagnosis, although it is suspected, a look at the functional capacity of the parent is more informative.”⁶

Parenting challenges experienced by those with FASD

FASD presents a range challenges with cognitive functioning and other issues that do add additional challenges for parenthood. Rutman and Van Bibber (2010) summarized them as follows:

- Memory and organization
- Perseveration
- Planning
- Generalizing from one situation to another
- Using consequences effectively
- Understanding the concept of time
- Registering and integrating sensory cues such as hunger, temperature, and pain
- Temper/patience and impulsivity
- Secondary issues related (in some, but not all cases) to alcohol and drug use/addiction, lack of positive role models and social supports, abusive domestic relationships, transience and homelessness, poverty and lack of resources, overcoming early abuse
- Being stigmatized because they had FASD – by social workers and society at large
- Others over-estimating their abilities or trivializing the degree or nature of their disability
- Unsupportive child welfare, including lack of access to parenting-related supports and resources (e.g. respite services or specific parenting programs) unless they were viewed as being at high risk of having their child apprehended or already had been investigated by the child welfare authorities
- Eligibility criteria for resources that are, in practice if not in actual policy, IQ-based

⁴ Choate.

⁵ Dr. Barry Stanley, Comment on Anna Azulai, “Supports for Women with FASD Who Are Parenting, November 29, 2012, Available online 3 June 2017 at <http://www.faschildwelfare.ca/blog/319>.

⁶ Choate, p. 84.

- Parenting resources and supports, including financial resources, differentially available to different “categories” of parents (i.e., foster, birth adoptive, and extended family, especially grandparents caring for grandchildren)⁷

Each person with FASD, each situation is different

“I had to do so much to show people I was a good mum.” Nyrene Cox, adult with FASD

When evaluating individual situations, Peter Choate (2013)⁸ highlighted core questions to be assessed:

- Can the parent read the child’s cues and to respond appropriately?
- Can the parent see the child at an appropriate developmental level?
- Can they provide a safe and nurturing environment?
- Can the parent help the child create meaningful relationships and experiences outside of the family?
- Can the parent support the child to acquire the skills needed to move through pre-adult developmental steps?
- Have various risks been assessed, including: poor impulse control that is connected to such things as crime, neglect of the child or other forms of maltreatment; addictions, mental health; problems with self-management including structures and routines that are beneficial to children; poor judgment, failing to respond to the needs of the child and not appreciating those needs, possibly bringing into the child’s life people who import risk into the family environment; does the child also have FASD and has this been taken into account?

Barry Stanley offers four key indicators of possible success:

1. *The parent needs to persevere on the needs of her child. This can be the focus around which, with help, she can extend her abilities and considerations.*
2. *The parent needs to accept that she has disabilities.*
3. *The parent needs to understand that she needs help, request it and accept it.*
4. *The parent and child require a positive environment.*⁹

Stanley reinforces the importance of a proper neuropsychological assessment of the cognitive and information processing abilities and disabilities of the parent.

Removing a child from a parent has risks for that child as well. According to Choate, “Research has shown that children who grow up in the child protection systems remain at high risk for poor outcomes (Courtney et al., 2011; Courtney et al., 2010; Doyle, 2008). This should act as a modifier in thinking that children may be better off away from family. That might be true in cases where the risks cannot be managed. But this clearly suggests that such a consideration should be an essential element to these assessments.”¹⁰

⁷ Ruttman and Van Bibber.

⁸ Choate, p 85.

⁹ Dr. Barry Stanley, Comment on Anna Azulai, “Supports for Women with FASD Who Are Parenting, November 29, 2012, Available online 3 June 2017 at <http://www.faschildwelfare.ca/blog/319>.

¹⁰ Choate, p. 87.

Strategies that work

“Having FASD allowed me to parent differently as I instinctively knew I didn’t want to raise a child who felt less than, unworthy and invisible like I did as a child.” Savanna Pietrantonio, Adult with FASD

While not minimising the challenges facing a parent with FASD and while recognizing that given the nature of the spectrum parenthood may not prove possible for all with FASD, there are nevertheless some known strategies and supports that can help. These were summarised by Rutman & Van Bibber as follows:

- Strategies to self-regulate, calm, and control their impulses and temper
- Taking ‘time outs’ to collect themselves
- Using memory aids such as calendars, schedules, organizers, post-it notes
- Using self-talk and other strategies to make transitions within the day’s activities
- Having consistency in the day’s schedule and activities
- Applying guidance techniques consistently
- Setting boundaries and focusing on their children’s positive behaviours
- Parenting education and support programs for adults living with FASD grounded in a deep understanding of FASD as a neuro-behavioural disability.
- Programs that offer outreach-oriented support and advocacy and that use learning approaches that are hands-on and experiential
- Recognizing the degree of diversity that exists among people with FASD¹¹

Grant, Ernst, Streissguth, and Porter (1997) highlighted supports that can be useful for parents with FASD. For example, families may need help with referrals, linking with appropriate service providers and possible mediation with Child Protective Services or foster families (as needed). They may need help with paperwork, transportation to appointments, accessing financial support due to their disability. They may need counselling on family planning and long-term birth control measures. They may need assistance in accessing treatment if they are abusing alcohol or other substances. They may need help creating a stable/safe/protective home environment, including access to housing. They may need role modeling and assistance regarding paying bills, food shopping, hygiene. Service providers may need to be better educated regarding FASD.¹²

The pressures should not be on parents with FASD to cope alone, nor should they be penalised for asking for help or highlighting areas of need. Peter Choate said, “The FASD parent who has the insight to recognize that they cannot do it alone, and needs supports, should be viewed as possessing a self-insightful strength. They may well be more willing to create a scaffold of support around them. The viability and utility of this is an important consideration that should be central to the assessment.”¹³

There are many studies that show that a ‘neurobehavioural’ approach to supporting those with FASD can help significantly (these strategies are widely available, see for example, Diane Malbin, *Trying Differently Not Harder*, 2002).

¹¹ Deborah Rutman & Marilyn Van Bibber, “Parenting with Fetal Alcohol Spectrum Disorder,” *Int J Ment Health Addiction* (2010) 8:351–361 DOI 10.1007/s11469-009-9264-7. Available online 3 June 2017 at <http://fasd.alberta.ca/documents/Parenting-with-FASD.pdf>

¹² T. Grant, C. Ernst, A. Streissguth, A. Porter, “An Advocacy Program for Mothers with FAS/FAE” (1997) in A. Streissguth, J. Kanter (eds) “The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities,” Seattle, University of Washington Press. Available 3 June 2017 online at: <http://depts.washington.edu/pcapuw/FASmoms.pdf>

¹³ Choate

Look at the whole picture

“Coming from a childhood of neglect and trauma, it has made me be a better parent.”

Lee Harvey-Heath, adult with FASD

While there is limited information specific to supporting parents with FASD, there is a known literature that can be drawn upon to help people with intellectual disabilities (ID). The key points are summarized by Stephen Greenspan¹⁴ as follows:

Look at the person, and not the label...There is a tendency to assume that parents with FASD (or ID) cannot function as parents and are so globally impaired that there is no point even trying to work with them. This, in fact, is a mistaken assumption.

Gear parenting interventions to areas of specific need based on adequate assessment methods....It is especially important not to base decisions on psychological tests that address general abilities or traits and which have nothing to do with parenting. It is important for assessments to be repeated over a period of time, in order to see if and how parents are benefiting from interventions and supports.

Professionals should seek to use a ‘wraparound’ model, to provide a mix of formal and informal supports as needed. As a rule, parents with FASD do better when such supports are in place. Evaluators should observe the parents in such supportive settings and should seek input from people who know the parent well rather than just relying on their own brief observations in artificial and anxiety-producing settings such as an agency office.

There is some evidence that a step-by-step mentoring or coaching approach, geared to a very specific ‘teachable moment,’ can be more effective when working with parents with cognitive impairments, including parents with FASD, than is a group classroom approach where material is presented didactically, and where it is likely that the parents will not remember or assimilate the messages.

Exercise empathy and flexibility. Because parents with FASD (as well as parents with ID) are poor perspective-takers, tend to be somewhat emotionally reactive, and have difficulty remembering commitments or appointments, they do not understand the consequences of expressing anger at an evaluator or failing to appear sufficiently diligent in following directions. Some degree of flexibility, therefore, is called for when working with such parents, and protective workers and court personnel should be willing to go an extra mile.

If an assessment is being done, it is critical that parents with FASD are observed in action and in the context of their lives. As Choate wrote, this “allows for a competency-based perspective that considers both the risk and protective factors.”¹⁵

FASD parents arrive in child protection courts with what can often seem to be challenging histories and many obstacles to successful parenting. It is easy to overwhelm them. This can lead to giving up or a sense that it will never be possible to raise their own children. ...To overwhelm an FASD parent is to set them up for failure.... Recommendations should take into consideration the motivation of the parent to succeed through learning and supports. In writing recommendations, a key question becomes what is possible within a reasonable period of time. What steps can be taken that will make a difference in parenting? Recommendations that focus on that, are practical, and can be implemented with resources available, will be the most useful.

An assessor, who takes into consideration solutions that may reflect not only the FASD but also the willingness of the extended family and the community to support the parent to meet the needs of the

¹⁴ Stephen Greenspan, “Parents Who Have FASD in Dependency Courts,” Judges Pages Newsletter, Winter 2014. Available 3 June 2017 online at: http://www.casaforchildren.org/site/c.mtJSJ7MPisE/b.8968417/k.9EAE/JP5_Greenspan.htm

¹⁵ Choate, p. 85.

child, offers better hope for a child. Being raised inside the family system seems to offer a child better hope than being raised within the child protection system (Fuchs et al., 2010)...

When using an ecological and strengths based approach with FASD parents, a view of what is possible using the strengths of the parent and those who would support the parent. There can be a circle of positive attachment figures for a child that includes the FASD parent and other primary figures. This will spread the load and still provide a secure base for the child [emphasis added].¹⁶

Parents with FASD deserve to be heard on this issue

Key stakeholders are too often left out of the discussion. There are many parents with FASD who are successful in raising loved and loving children. There is no 'one-size-fits-all' approach. Below are perspectives from some parents with FASD.

R.J. Formanek¹⁷

My biggest initial challenge to being a parent at the age of 17 was presumption. People would presume that I would be thoughtless, perhaps violent around or towards my son. That I would "forget" to change or feed him... I don't really know. What I do know is that it was expected that I would fail as any sort of parental figure. I was scared... I won't lie. But I did know about ME... that I would not hurt or harm or cause something to happen to my own child... I KNEW that.

Presumptions are hard, and this added a pressure to everything I did with my son for a while... but eventually this too was lost. We soon found my son could recognize in me what so many could not see for themselves... he saw ME. Not someone with "issues" he saw me... his father... the man who would protect him, no matter what. He saw that in me, and that gave me the confidence to be the person I was meant to be. Hypervigilance ... generally is not a great ally, but as a parent? My son always knew where safety was, he still does to this day, because he knew that dad loved him and would be there to chase the monsters away.

We both learned many things together, and formed a bond that seems to transcend parenting... we are like brothers as much as parent and son...I would not want to change my relationships with my children in any way... it may not be typical, but it is so very REAL...

People "expected" me to be "violent".... I was not a bully, did not pick fights... I reacted. But the presumption was... that I would hurt my own child. That killed me. You see... I WAS the beaten child... I know the broken bones, the blood... the scream so loud and foreign you yourself cannot for one second think that sound came out of your body. That WAS me. There was no question.... and it hurt to see people think I would ever do that. I never did. Not ONCE did I strike out at my child, physically OR VERBALLY in anger...

It's complicated. he's 38 now, moved back in with me at 20 and we are the best roommates EVER!). Yeah.... proud dad.

Lee Harvey-Heath¹⁸

Being a parent with FASD is at times very challenging, even more so when people tell you you are incapable, but I love my children just as much as the next person, and they love me just the same. In

¹⁶ Choate, p. 87.

¹⁷ R.J. Formanek, co-founder and co-administrator, FASD: Flying With Broken Wings Facebook support group (<https://www.facebook.com/groups/FASDaFlyingwithbrokenWings/>) with more than 3,600 members including a large proportion of those with FASD. Private correspondence, 3 June 2017, used with permission. R.J. received his diagnosis at the age of 47, the first adult in Ontario to be diagnosed.

¹⁸ Lee Harvey-Heath is father to four children, aged 10, 6, 3, and 1. He was diagnosed as an adult, after a challenging young adulthood. He has founded FASD Devon and Cornwall (<https://www.facebook.com/FASDDAC/>), speaks about FASD in front of a wide range of audiences, mentors young people with FASD, and works locally, nationally and via social media to raise awareness of FASD.

some ways I feel coming from a childhood of neglect and trauma, it has made me be a better parent because I am more determined to make sure my children are as happy and healthy as they can possibly be. I choose not to listen to those who say I can't be a father, because the smile my children give me when they see me tells me I can.

Nyrene Cox¹⁹

I was brought up with both my parents who were alcoholic and still are.

When I first became a parent at 18 I was then unaware of my FASD, I remember being told by my mother "you've made your bed now lie in it". So I had to do so much to show people I was a good mum and my children were well taken care of and loved. I can say yes, it's been hard and yes there have been times when teachers at parents evening have made me feel stupid in some way or another. But I've done it. All three of my children do have dyslexia, so as a parent who also has this I made sure they all got the right help in school and made sure their voices are heard. My youngest son also has ADHD and ASD.

Savanna Pietrantonio²⁰

Raising a child and having the disability FASD has been the hardest, most challenging life journey back to myself that I've ever experienced. While FASD absolutely creates challenges and puts up barriers for me, it has also helped me understand my child and be able to respond to his needs through a heart and soul bond that enables me to have a strong and clearer personal, intuitive understanding of how to communicate with, support and give unconditional love to build relationship with my child.

As FASD advocates, the advice we tell parents is take everything you've learned about parenting and throw it away. Traditional parenting doesn't work. I found that having FASD allowed me to parent differently as I instinctively knew I didn't want to raise a child who felt less than, unworthy and invisible like I did as a child. I knew I valued relationship over discipline and individuality over being forced to conform and that my child would never feel the trauma of emotional neglect, alienation or misunderstanding or impatience from me.

I also knew that I had to make his brain better than mine. I knew that someday my child would outgrow my developmental age and that he would need to become better equipped and prepared with tools and resilience to handle life and all its challenges, than I had been.

My north star for parenting has always been to align my thoughts with love and that is the touchstone that has kept our bond resilient through hardship and crisis and brings us together when FASD threatens to tear us apart. My beautiful, kind and gentle son has FASD and is 24. He's a Mechanical Engineer living and working in Toronto, Ontario.

Resources

Living with FASD - As a Person, As a Parent, Video by YourAlberta, 2013. Available online 21 June 2017 at: <https://www.youtube.com/watch?v=Qnt49T5VZ90>

¹⁹ Nyrene Cox is an adult with suspected FASD, mum to three - a 25-year-old son, 21-year old daughter, and a son who is 16. She is married and works at a major retail store.

²⁰ Savanna Pietrantonio is mum to a 25 year old son. She is one of the administrators of the Flying With Broken Wings Facebook Support group (<https://www.facebook.com/groups/FASDaFlyingwithbrokenWings/>) and she founded and runs with her partner a local FASD support group in Hamilton, Ontario (<http://www.hamiltonfasdsupport.ca>).