Fetal Alcohol Spectrum Disorder (FASD): Supports and Resources

Receiving any medical or psychological diagnosis is a daunting prospect, and receiving a diagnosis of FASD may, understandably, be more unnerving than most. There are a number of reasons for this, but we also have suggestions and resources that may help navigate some of the challenges that a diagnosis of FASD can bring.

Learning about FASD

Research on specific interventions related to FASD has shown promising results in relation to improving disruptive behaviour, emotion regulation, self-esteem, anxiety and attention, as well as helping to improve academic skills, such as maths and literacy. However, a consistent finding in research is that parents, caregivers, educational professionals and other key stakeholders who are able to learn about FASD provide the greatest single support to those who receive this diagnosis. Having some knowledge of how FASD can affect individuals will allow you to provide effective support to them and, just as importantly as that, give them the understanding and empathy that they deserve. A summary guide, 'Understanding Fetal Alcohol Spectrum Disorder', and a specific guide for parents and carers, are available from NHS Ayrshire & Arran's website here.

A hidden condition

In addition to this, although there are physical features associated with fetal alcohol syndrome (also referred to as FASD with facial features), for most individuals affected by FASD it is very much a hidden condition. Because these individuals appear to be functioning at the same level as those around them, key stakeholders, such as teachers and employers, may not be aware of an individual’s diagnosis and the challenges that they can face. As such, they may not make adjustments necessary for them to succeed. Alert cards can be used to allow those with FASD to make those around them aware of their FASD in a subtle manner.
Secondly, FASD is a complex diagnosis. It can affect a broad range of areas in the lives of those with FASD, and this leads to many unique profiles of strengths and difficulties from individual to individual. An example of one such profile is shown on the right – you will notice that while this person’s physical age is 18, their social skills are at the level expected of someone much younger. Their expressive language is a strength - as they are functioning at the level of a 20-year-old - and yet their comprehension is similar to what would be expected of a 6-year-old. This can mean that an individual may appear, on the surface, to communicate really well, but, underneath, they are struggling to keep up. Another individual with FASD, however, may find that comprehension is relatively straightforward while expressing things in day-to-day communication is more of a challenge. This means that there is no ‘one-size-fits-all’ approach for these individuals or those who live, support and work with them on a daily basis.

With this in mind, a strengths profile can be a very useful tool for those affected by FASD. Put together with input from clinical psychology, paediatrics, speech and language therapy and occupational therapy, different versions of these profiles can be produced for the adults who care for or work with a child affected by FASD, as well as for the child themselves. These help tell the story of each individual, allowing adults to understand where they may need to provide additional supports, as well as to help the children themselves make sense of their own unique strengths and difficulties. Examples of these can be seen below.
Building support networks
As well as this, although there is limited research on the public’s awareness and understanding of FASD, it is fair to say that knowledge of FASD amongst the general population lags behind that of other neurodevelopmental conditions, such as autism or attention deficit hyperactivity disorder. A diagnosis of FASD can therefore feel isolating for the individuals involved. With this in mind, building networks with others who have had similar experiences can be a helpful thing to do. The FASD Hub from Adoption UK in Scotland, for example, has a dedicated community for parents and carers of children with FASD to connect with each other and share experiences and strategies that they have found helpful. More information on this can be found by visiting their website here.

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Other sources of information:

- NHS Ayrshire & Arran Fetal Alcohol Advisory & Support Team website
- Fetal Alcohol Advisory & Support Team Twitter
- FASD Network booklet for young adults with FASD
- Community Living booklet on supporting adults with FASD
- ACAMH podcast on FASD with Dr Jennifer Shields & Dr Sarah Brown
- FASD Hub Scotland