

Foetal Alcohol Spectrum Disorder (FASD) Practice Guidance

Using this guidance

This guidance has been written by tri.x to support practitioners to understand FASD and some of the needs that people with FASD may have, and to think about some of the ways that they may need to adapt their practice to maximise the involvement of a person with FASD in care and support processes.

It should be used as supplementary guidance to available procedures, and all statutory requirements of the Care Act 2014 apply.

The information about FASD contained in this guidance is not comprehensive, and further information can be found on the National Organisation for Foetal Alcohol Syndrome-UK website <http://www.nofas-uk.org>

What is FASD?

Foetal Alcohol Spectrum Disorder (FASD) is the collective term used to describe 5 specific conditions that are caused directly by women drinking during pregnancy. Alcohol is a teratogen; a substance that is known to directly cause brain damage in a foetus leading to malformations and abnormal development.

The 5 FASD conditions

The 5 Foetal Alcohol Spectrum Disorder conditions are;

- 1) Foetal Alcohol Syndrome (FAS);
- 2) Alcohol Related Birth Defects (ARBD);
- 3) Alcohol Related Neurological Defects (ARND);
- 4) Foetal Alcohol Effects (FAE); and
- 5) Partial Foetal Alcohol Syndrome.

Foetal Alcohol Syndrome (FAS) is the only one of the FASD conditions that causes physical abnormalities, making it more readily recognised and easier to diagnose at an early stage.

Despite it being the most recognisable, FAS is *not* the most common of the FASD conditions and, because the functional difficulties present in other FASD conditions can be very similar to other disabilities, they are often misdiagnosed, for example as Attention Deficit Hyperactivity Disorder (ADHD) or Autism.

The stages of pregnancy

The nature of the difficulties present in a person with a FASD condition relate directly to the area of the brain that was damaged during pregnancy. This correlates with the stage (or stages) in pregnancy when the woman was drinking alcohol.

Week	Development of
0-4	Heart, spinal column, liver, kidney, intestines
4-8	Eyes, legs, hands, mouth and lips, eyelids, palate, toes and nose
8-10	Hearing, teeth, facial expressions, head movement, breathing
11-12	Fine motor skills, vocal cords, sucking

12-16	Taste buds, bone marrow, increase heart activity leading to rapid growth
0-40	Central nervous system

Difficulties caused

Difficulties can be physical, but more often than not are functional. They will be unique to each person, depending on the area of the brain that has been damaged, and how extensive the damage is.

Difficulties can;

- a) Be present in early childhood;
- b) Occur at different developmental stages;
- c) Not become apparent until adulthood (when the person is faced with unfamiliar situations e.g. work or managing money).

Those present in childhood can be taken through to adulthood when;

- a) There was no diagnosis in childhood;
- b) No treatment or strategies were provided in childhood;
- c) Treatment or strategies developed in childhood were not effective.

Physical difficulties include

- a) Movement and co-ordination difficulties
- b) Conditions associated with heart, kidney and lung damage
- c) Hearing or sight impairments

Functional difficulties include

- a) Difficulty understanding abstract concepts (money, time)
- b) Impaired social skills
- c) Problems with memory
- d) Problems maintaining concentration and focus
- e) Poor judgement and impulsive behaviours
- f) Difficulty managing and controlling emotion
- g) Inability to distinguish between appropriate and inappropriate behaviour
- h) Inability to learn consequences

Other difficulties include

- a) Low self esteem
- b) Anxiety and depression

Increased risk

Depending upon the functional difficulties they have a person with a FASD condition may be at increased risk of;

- a) Abuse;
- b) Self harm and suicide;
- c) Drug or alcohol misuse;
- d) Being a victim of crime;
- e) Taking part in criminal activity;
- f) Unplanned pregnancy and STD.

Possible Need for Care and Support

Some people with a FASD condition will have low level needs for support that they can manage informally, whereas others will have needs that are more complex.

The care and support that any person needs must *always* be based on an assessment of individual need and subsequent determination of eligibility. However, based upon the outcomes defined in the Care Act 2014 the following table suggests some of the care and support needs that may exist;

Outcome	Care and support
Manage and maintain nutrition	Preparing and cooking complex meals Shopping lists and budgeting Understanding healthy eating
Maintain personal hygiene	Strategies to build personal care into daily routine To make and keep appointments e.g. dentist Taking medication on time
Manage toilet needs	Rails to support independent transfer
Being appropriately clothed	Support with socks, zips, buttons, laces Understanding appropriate clothing choices Washing clothing
Be able to make use of the home safely	Mobility support Support to access to upstairs areas, or external areas

Maintain a habitable home environment	Strategies to build housework into daily routines Support to carry out more complex tasks
Develop/maintain family and other personal relationships	Making arrangements to see family or friends Using social media safely
Access/engage in work, training, education or volunteering	Finding employment or a learning opportunity Settling into a routine of work
Make use of community services	Identifying local community services Developing confidence to access services Learning to drive or use community transport safely
Carry out caring responsibilities for a child	Building a parenting routine Taking breaks from caring

Preventing, Delaying and Reducing Needs

Local Authority prevention services, such as Reablement, Occupational Therapy and Assistive Technology or Telecare can be extremely beneficial for a person who has a FASD condition and, as such, they should *always* be considered.

Reablement

A short term Reablement service can support a person to;

- a) Learn daily living skills, or find alternative ways of doing things;
- b) Practice using equipment or technology; or
- c) Implement a strategy or approach recommended by another professional (e.g. a Psychologist).

If a person’s potential for reablement is likely to exceed 6 weeks consideration to an extension of the service should be considered, as opposed to the provision of longer term support *unless* that support is able to continue working in an enabling way.

Occupational Therapy

If the person has physical difficulties Local Authority Occupational Therapy services can assess the home environment, and identify potential hazards or challenges for them. This could be loose carpets, steps or access issues. Minor works or adaptations can then be

arranged to reduce the risk and enable to person to use their home safely. Equipment can also be provided to support the person to carry out tasks of daily living as independently and safely as possible, for example grab rails to assist bathing or raised seating in the kitchen so the person can prepare food.

Assistive Technology or Telecare

Gadgets can help a person to;

- a) Remember when to do things (i.e. develop a routine);
- b) Communicate with others;
- c) Take medication independently;
- d) Carry out tasks such as making a cup of tea; and
- e) Stay safe in their home.

Maximising Involvement in Care and Support Processes

The precise ways to maximise each person’s involvement in care and support processes will be determined by their unique difficulties. Practitioners should avoid making assumptions or generalisations about this and always take steps to find out the best way to maximise their involvement *before* proceeding.

The following table sets out some of the steps that practitioners should consider taking in most circumstances;

Difficulty	Step
The person may have low self esteem and lack confidence in their own abilities	Use positive language and recognise strengths
The person may feel socially uneasy or find it difficult to start a conversation	<p>Spend time talking to the person about things that are of interest to them, so as to build rapport and ‘break the ice’</p> <p>Consider using an alternative method of assessment; self assessment or communication via email can work well for a person with FASD, as it allows for them to provide information at a time that works best for them and avoids the need for face to face social interaction</p>

<p>Some people will find it hard to remember appointments</p>	<p>Write down the details of any appointments</p> <p>Contact the person on the day of any meeting to confirm the details and see if they have any questions</p>
<p>The person may find it hard to self advocate or communicate generally</p>	<p>Take time to find out the person's preferred communication style</p> <p>Establish support needs and facilitate the support of an advocate, friend or carer</p> <p>(this support may not only be needed during the meeting, but also beforehand to help the person prepare, or afterwards to help them talk through the meeting and next steps)</p>
<p>The person may find it difficult to maintain concentration and focus</p>	<p>Avoid arranging lengthy meetings</p> <p>Minimise distractions from the environment (e.g. noise, other people or activities)</p>
<p>The person may become overwhelmed, emotional or disengaged</p>	<p>Break information into manageable chunks</p> <p>Don't ask too many questions; try to keep to questions that are pertinent to the situation in hand</p> <p>Offer regular opportunities to take a break</p> <p>Do not invite anyone that the person does not want to be there</p>
<p>The person may find it difficult to digest information or make a decision</p>	<p>Provide information at an early stage and in an accessible way</p> <p>Allow time for the person to process the information</p> <p>Provide support e.g. an advocate to help them make sense of information and make a decision</p>

Specialist Information and Advice

If the FASD diagnosis occurred in childhood the person and their family may already have received lots of information and advice. However, if diagnosis is recent or if adulthood has led to changes in the nature of the person's difficulties steps should be taken to ensure that they have access to the information and advice they need, or that would be of benefit to them.

The National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK) can be contacted for advice on the national helpline 0208 458 5951 or by email at help@NOFAS-UK.org.

Supporting Carers

The impact of caring for a person with a FASD condition should not be underestimated and every carer is likely to need support at some point over the course of their caring role.

The risk to the wellbeing of carers is increased when;

- a) They have limited informal networks of support;
- b) Strategies or approaches to support the person to manage their difficulties are not in place, or are not effective; or
- c) The person is misusing drugs, alcohol or taking part in criminal activity.

All carers should be offered a carers assessment in line with the statutory requirements of the Care Act.

Carers may benefit from accessing a specialist carers support network, especially if the carer is the person's birth mother (and therefore the one who consumed the alcohol). The FASD UK Alliance has information about local support networks and an active Facebook support group. For further information see their website <https://fasd-uk.net/>