Best practice in FASD training

Created as part of the Seashell and The National Organisation for FASD partnership, funded by the Department for Health and Social Care with input from experts and those with lived experience.

Funded by

Department
of Health &
Social Care

Seashell | NATIONAL ORGANISATION FOR FASD

A little bit about the

Best Practice in FASD Training Guide

This guide was produced by Seashell and The National Organisation for FASD as part of "Resources and Training to Support Children and Young People with FASD," funded by the Department of Health.

The project includes: development of this Best Practice in FASD Training Guide, an FASD: Preferred UK Language Guide, development of a 1-day "Introduction to FASD" training; a "Me and My FASD Toolkit" – including a website (www.FASD.me); and a 3-day training. The toolkit and 3-day training are focused on helping those with FASD understand and own the diagnosis.

Special thanks to our project advisors

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A little bit about
Seashell

Our charity is dedicated to providing a creative, happy and secure environment for children and young people with complex and severe learning disabilities which include little or no language abilities.

With the expertise of our specialist teachers, care staff, on-site therapy team, assistive technologists, swimming teachers and sports coaches, our students learn how to express themselves, engage with the world around them, become more independent and live safe, creative and fulfilling lives.

A little bit about
The National Organisation for FASD

The National Organisation for FASD (formerly NOFAS-UK) is dedicated to supporting people affected by Fetal Alcohol Spectrum Disorder (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy.

National FASD, founded in 2003, is a source for information on FASD to the general public, press and to medical and educational professionals. Our programmes are focused on promoting wellbeing for those with FASD and their families, providing materials for GPs, midwives, social workers, educators and creating cutting edge resources and experiences for people with FASD.

Checklist for

FASD training

FASD is a complex neurodevelopmental disorder. Due to the nature of its origin the courses need to be delivered by a trainer with FASD experience and appropriate training skills. It is essential that it provides a balanced coverage of related topics.

About the trainer

- Trainer has 3+ years' experience working in the field/living with people with FASD or presents in conjunction with someone who has
- Trainer regularly updates own knowledge and skills

The principles

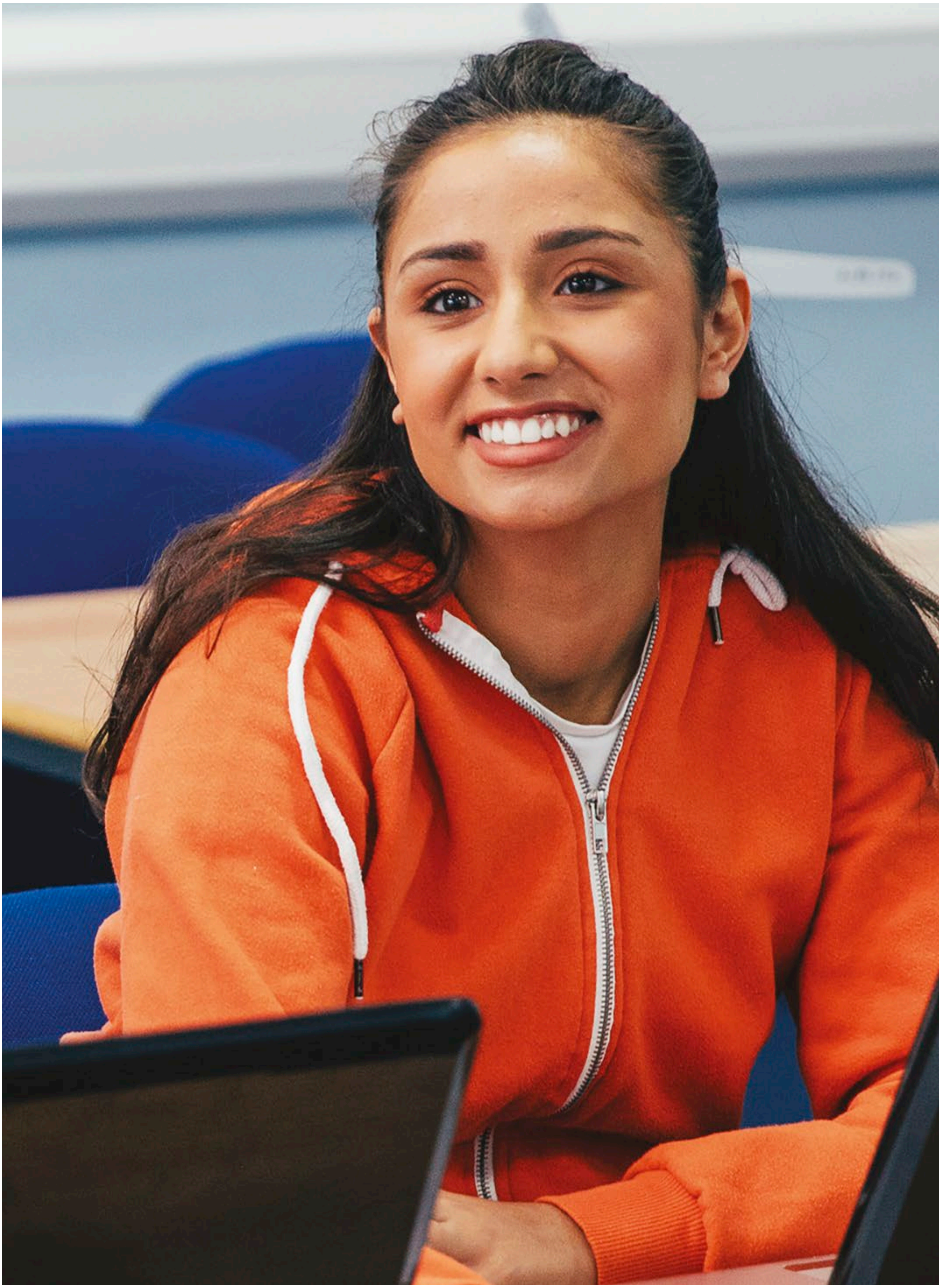
- Reflects current UK Governmental guidance and latest scientific understanding
- Adheres to 'no-blame, no shame' and non-judgemental ethos as described
- Follows the FASD: Preferred Language Guide by Seashell and The National organisation for FASD
- Organisation for FASD: Promotes dignity, ability and advocacy for and by people with FASD

Essential content

- Sensitive content warning at the beginning
- Prevalence
- What causes FASD? (Aetiology)
- Risks of alcohol in pregnancy
- Current FASD terminology
- Hope for the future
- How to get a diagnosis and why a diagnosis matters
- Latest Governmental and scientific advice (including: CMO guidance, SIGN Guideline, BMA Report, NICE Quality Standard)
- Practical strategies for supporting a person with FASD (tailored to audience need)
- Voices of the FASD community
- Highlights the role of professionals that may be involved with a person with FASD, providing them with strategies to help people with FASD succeed
- Signposts people toward additional information and support, including local support when possible
- FASD across the lifespan
- Co-existing conditions
- Impact on the family

Other considerations

- Discounted pricing for individuals with FASD and their families (if relevant)
- CPD or equivalent certification for attendees. Certificate of attendance as a minimum



Best practice in

FASD training

FASD is a complex neurodevelopmental disorder. Due to the nature of its origin the courses need to be delivered by or in conjunction with a trainer with FASD experience and appropriate training skills.

It is recommended that the training is delivered by or in conjunction with someone with 3+ years of experience working or living with people with FASD. This is because the condition is complex and the presentation may be (without diagnosis) considered to be conditions including autism, ADHD, attachment disorder, trauma and sensory processing disorder.

If there is a person with FASD co-presenting the course, the lead trainer needs to take into account, when planning the course, that the individual with FASD will need additional support or may not be able to present on the day.

> **The training should be non-judgemental and delivered to promote dignity, ableism and to advocate for people with FASD.**

Training should adhere to the National Organisation for FASD/Seashell FASD: Preferred UK Language Guide. This has been created with the input of the FASD community and professionals working within the field with the aim to promote dignity and end stigma.

FASD training should be delivered by somebody with experience of delivering training with sensitive content. It is advised to give a sensitive content warning at the beginning and signpost where people can get additional information and support.

This subject can be triggering for people attending in a professional capacity. They or a loved one may have consumed alcohol in pregnancy, sometimes due to inconsistent national advice They or loved ones may have been exposed to alcohol in utero.

Although first diagnosed in 1973, there is new research on FASD on a regular basis, therefore it is imperative that the training is conducted by a trainer who continually updates their own knowledge and skills and produces evidence-based information with an understanding of study design and international and regional differences. People with FASD and their families may need support from a variety of professionals and the training should identify these professionals and deliver an understanding of the role that these professionals may have with a person with FASD.

Whilst there is crossover in FASD presentation with conditions like autism and ADHD, experience in these conditions only does not equip somebody to deliver FASD training as there are significant differences.

It is important that the voice of the FASD community is heard within the training. Therefore, the training should be non-judgemental and delivered to promote dignity, ableism and to advocate for people with FASD. It is recommended that the training include people with FASD where possible, or videos including people with FASD and quotes from people with FASD.

Essential content for an

Introduction to FASD course

> It is important to recognise alcohol is a teratogen and this is the cause of the condition.

Sensitive content warning

The issues involved are delicate and if delivered without caution can cause further stigmatisation and potential harm to the parent/child relationship and identity of the child. It is important that any trainer be aware this content may affect people in the room personally as well as professionally.

Prevalence

Current FASD estimates in England are conservative and it is likely to be more prevalent than autism or ADHD. It is important to include prevalence figures, both national and international. It is useful to have a discussion about cultural differences and implications. FASD is not a rare condition, however it is being regularly missed by professionals.

Risks of alcohol in pregnancy

The session should include the 2016 guidance from the UK Chief Medical Officers. There is no safe amount of alcohol to drink in pregnancy and no safe time within a pregnancy. The guidance has changed over the years and has been the cause of confusion over both advice to pregnant women and also levels necessary to warrant an FASD assessment for diagnosis. There must be no ambiguity in the ‘no alcohol, no risk’ message.

Latest governmental and scientific advice

Trainings should be based on 2016 Chief Medical Officers’ guidance on alcohol in pregnancy; SIGN 156 on “Children and young people exposed prenatally to alcohol” (2019); BMA report on Alcohol in Pregnancy (2016); and the NICE Quality Standard on FASD (forthcoming). These processes all involved extensive research and involvement from the nation’s leading scientific and medical experts, who reviewed relevant international scientific literature.

What causes FASD? (Aetiology)

FASD is caused by prenatal alcohol exposure. It is important to recognise alcohol is a teratogen and this is the cause of the condition.

Current FASD terminology

The guidance from SIGN 156 (2019) is that Foetal Alcohol Spectrum Disorder is to be diagnosed as FASD with sentinel facial features and FASD without sentinel facial features. Whilst this is the current guidance, it is important to explain the old diagnostic terms – FAS, ARND, ARBD, PFAS, ND-PAE as some participants may have clients/family members who have these diagnoses.

FASD across the lifespan

For almost 50 years there has been a focus on specific facial features being associated with FASD. Sentinel facial features are present in a minority of people with FASD and need to be explained as such. It is vital to explain that FASD will present differently in every individual.

Some will have a learning disability as part of their diagnosis, most will not. Whilst there will be physical effects in some people with FASD, the primary effect is neurological.

The course should look at how this can affect behaviour and learning. The course should explain how people with FASD can present with significant variance and should give examples of presentation at different ages and stages across a person’s lifespan. This should include areas of difficulty such as within education settings as well as at home and the benefit of accessing an EHCP. Many people with FASD will have sensory processing disorder which can help to explain certain patterns of behaviour and options for support.

Co-existing conditions

There are 428 co-occurring conditions in people with FASD (Popova, et al., 2016). The training session needs to consider that participants may have clients/ family members who have received other diagnoses that may relate to their FASD that had not previously been considered. There may also be participants attending who have a client or family member who has a diagnosis of autism or ADHD. Discussions often then occur about misdiagnosis or aetiology.

How and why to get a diagnosis

Information should be given within the training on the importance of diagnosis and different ways to access diagnosis within England and the differences in service provision based on the age of the person. Difficulties with diagnosis and solutions to aid the process should be included.

Impact on family

Where FASD has not been considered or diagnosed or where the family has received poor information or support, life can be stressful for a person with FASD and their families. Families can be supported by giving them FASD resources or links and strategies to try. It is important to recognise that families may still face challenges, which need to be acknowledged as well as the many positives of caring for a child with FASD. There may be various professionals involved with a person with FASD and their role should be explained within a course. Training should highlight the fact that extreme behaviours are a result of the neurodevelopmental condition and not due to parenting.

> **Training should highlight the fact that extreme behaviours are a result of the neurodevelopmental condition and not due to parenting.**

Practical strategies tailored to audience need

The content of the strategies will depend on the audience on the day. However, FASD must be presented as a brain-based, full body condition. Practical strength-based strategies need to be given that are appropriate for different age groups and in different settings such as home, school and on trips. The strategies can be to support memory, sensory processing difficulties, especially auditory processing and many more. Case studies can be a useful way for many people to apply strategies and aid learning. It is critical that people understand that due to the nature of FASD, FASD-informed strategies will differ from those for other neurodevelopmental conditions and will vary from person to person since FASD affects each person differently. Also, that strategies may have fluctuating success.

Hope for the future

Trainings can be overwhelming for people with FASD and/or those working with or caring for someone with FASD. It is essential to give examples where people with FASD are succeeding and of their many talents and skills. Some of these successes are the result of creative and tenacious individuals with FASD and compassionate families and professionals who have been able to offer FASD-informed strategies or scaffolds.

Voices of the FASD community

It is vital that voices of the FASD community are present in any training session. As the adage goes, ‘Nothing about us, without us’. This could be achieved by having a person with FASD or a family member attending the training to talk about their experience, through the use of films or video clips that include people with FASD or by using case studies or quotes from people with FASD. Local FASD UK Alliance groups are a great place to start and should be involved in trainings in their local areas when possible.

Professionals

All courses should highlight the role of the different professionals that may be involved with a person with FASD and their families. This can help people with FASD and their families to navigate the route to understanding, diagnosis and support. Providing people with FASD and their families strategies for home, school and other social settings can help to support people with FASD to succeed.

Signposting

FASD is a complex condition and people with FASD and their families may need varying levels of support. The support available differs per area. It is crucial to signpost people toward additional information and support, including local support where possible. **The FASD UK Alliance has a list of groups: www.fasd-uk.net.**

Fact and fiction
Myths surrounding FASD

Fiction

It is not a physical disability

Fact

FASD is a range of conditions caused by prenatal alcohol exposure, some of which are physical.

Fiction

You grow out of FASD

Fact

FASD is a lifelong disability; there is no cure but people with FASD can be supported to manage their lives successfully.

Fiction

FASD is the birth mother's fault

Fact

Alcohol is the cause, not the birth mother. Research shows reasons for alcohol use in pregnancy include lack of knowledge, poor advice, stress, alcohol dependency and pressure from a partner.

Fiction

Nothing works for people with FASD

Fact

With the right support people living with FASD can achieve great things.

Fiction

Only 'alcoholics' have children with FASD

Fact

There is no known safe amount of alcohol to drink in pregnancy. There are people living with FASD from all groups within society.

Fiction

It's just bad behaviour - they need to try harder

Fact

Behaviour is affected by cognitive processing, emotion regulation and impulse control which are common difficulties for someone living with FASD.

> **“There are people living with FASD from all groups within society.**

Fiction

It’s ok to drink in the last trimester

Fact

There is no known safe time to drink alcohol during pregnancy. The brain and central nervous system are still developing.

Fiction

The placenta protects the foetus

Fact

Alcohol passes through the placenta to the baby. The baby is unable to process the alcohol because their liver is not yet functioning.

Fiction

Poverty causes FASD

Fact

There are people living with FASD from all groups within society.

Fiction

You can tell if someone has FASD because of the way they look

Fact

Less than 10% of people living with FASD will have different facial features.

Fiction

Negative behaviour is caused by poor parenting

Fact

FASD is a brain-based disability and what may be considered as unwanted behaviour should be re-framed as a communication of a difficulty or a need for further support.

Fiction

There’s no point in diagnosing if there’s no cure

Fact

Diagnosis is the key to understanding appropriate strategies and accessing support. It also helps to understand prevalence and in turn improve service provision.

Fiction

Everyone with FASD presents the same

Fact

People with FASD will all have their own individual presentation.

Fiction

FASD has taken away their future

Fact

Given the appropriate support, people with FASD can achieve great things and have full and happy lives.

Fiction

They're just over-protective parents making excuses

Fact

Many people with FASD need support from someone they trust, such as a parent or carer, to help them understand their environment and decode information.

Fiction

It's ok to have 1 or 2 drinks in pregnancy

Fact

The Chief Medical Officers have said since 2016 that there is no safe amount of alcohol to drink in pregnancy. Some research shows that one drink of alcohol can affect foetal behaviour in the womb.

Fiction

It hasn't been proven that a little alcohol can cause FASD

Fact

The Chief Medical Officers have said there is no safe amount of alcohol to drink in pregnancy since 2016. The fact is, there is no proven safe amount of alcohol in pregnancy.

Fiction

FASD means you have a low IQ

Fact

Whilst some people living with FASD have a low IQ many will have IQ within the normal range. However, it is typical to have difficulty with executive functioning skills as well as other brain functions.

> **The Chief Medical Officers have said there is no safe amount of alcohol to drink in pregnancy.**

Fiction

ARND and PFAS aren’t as bad as “full FAS”

Fact

All of these conditions are FASD and FASD is the new diagnostic term. There is no “full FAS”. The main feature across the spectrum is that prenatal alcohol exposure has affected the brain development and function.

Fiction

Cognitive Behavioural Therapy or counselling will fix the difficulties

Fact

Traditional therapies may not be suitable for some behaviours due to brain changes caused by prenatal alcohol exposure. They can, in some cases, make things worse. Any therapies should be FASD-informed.

Fiction

Consequences will work to modify behaviour

Fact

People living with FASD struggle to link cause and effect due to damage to specific areas of the brain. What may be seen as bad behaviour is not intentional. Traditional punishments are unlikely to work for people with FASD.

The National Organisation for FASD

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