# FASD – DISABILITY OR LEARNING DIFFICULTY?



## WHAT is this factsheet about?

FASD is a complex disorder with over 400 co-concurring conditions. There is often confusion and frustration surrounding FASD and whether it is a disability and/or learning difficulty.

A 'diagnosis' of disability and/or learning difficulty can sometimes determine what support, benefits and legal protections an individual is entitled to.

This factsheet explores:

- Whether/when FASD is a disability and/or learning difficulty;
- how individuals with disabilities or learning difficulties are protected;
- · how to access support;
- · how to enforce your legal rights.

## **KEY POINTS:**

- An individual with FASD may have a disability or a learning difficulty or both.
- You do not need a diagnosis of FASD to have a disability and/or a learning difficulty.
- An individual who meets the definition of disability under the Equality Act 2010 is legally protected against discrimination in the workplace, educational settings, the justice system, housing and in the provision of goods and services.
- Labels are sometimes unhelpful, but it can also feel empowering for some individuals to know if you or someone you care for has a disability and/or a learning difficulty.

## **UNDERSTAND** your rights

## FASD – disability and the Equality Act 2010

Many individuals with FASD will have a **disability** under the Equality Act 2010 (the 'Act') but it all depends how and to what degree FASD affects the individual. Everyone with FASD experiences the condition differently and will be defined as disabled under the Act if they meet the legal test below:

## Disability under the Equality Act 2010.

To be classed as 'disabled' under section 6 of the Equality Act 2010 you must have a physical or mental impairment that has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities.

Many individuals with FASD or suspected FASD will fit within this definition. Let's looks at each part of the definition and apply it to FASD:

**Impairment:** Individuals with FASD often experience physical and mental impairments such as problems with cognitive reasoning and adaptive functioning, sensory, mental health and physical conditions.

Adverse effect on <u>normal</u> day -to-day activities: The impairment may have an adverse effect on day-to day activities such as remembering to go to appointments, understanding money, learning at school.

**Long term:** - As there is no cure for FASD and it is a lifelong condition the <u>adverse effects</u> experienced by someone with FASD are very likely to be long-term.

**Substantial:** You must show that the *adverse effect* on day-to-day activities is *substantial* (this means the adverse effect must be more than minor or trivial).

For a more detailed explanation of the test see the flowchart at the back of this factsheet.

## A disabled person has legal protections:

People who have a disability under the Act are protected against discrimination:

### Education

 Publicly funded education providers have a duty not to discriminate against potential, current or former students. Private education and training providers also have a duty as service providers see FASD and SEND.

## **Employers**

 Employers have a duty not to discriminate against job applicants, workers or employees - see FASD and your employment rights.

### **Courts**

 Courts must make reasonable adjustments for people with disabilities to enable them to participate effectively in court proceedings.

## Public services and providers of goods and Services

 Public bodies must not discriminate against people in the provision of public services and must remove the barriers faced because of disability so the goods and services can be accessed and used in the same way, as far as possible, as someone who is not disabled.

## Housing

 A person who is letting out or managing accommodation must not discriminate against a person because of their disability.



## **UNDERSTAND** your rights

## **Reasonable Adjustments** under the Equality Act 2010

The Equality Act 2010 says changes or adjustments should be made to ensure a disabled person can access education, employment, housing, goods and services.

A <u>reasonable</u> adjustment may involve <u>changing the</u> <u>way things are done</u> such as a policy or a rule, <u>changing a physical feature</u> of a building or premises or <u>providing extra aids or services</u> to help the person access or do something. See Citizens Advice guidance here.

## Is FASD a learning disability?

As well as a disability under the Equality Act 2010, an individual with FASD may also have a **'learning disability'**.

'Learning disability' is a long-established term defined by the National Institute for Health and Care Excellence (NICE) and it is widely understood by UK health and social care professionals.

The widely accepted definition of 'learning disability' is taken from <u>NICE's</u> guideline on challenging behaviour and learning disabilities. It is defined by meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood. A learning disability occurs when the brain is still developing (before, during or soon after birth).

Intellectual disabilities (rather than learning disability) is the term widely used internationally.

A person's learning disability may be described as mild, moderate, severe or profound and is usually diagnosed by a doctor following psychological tests and clinical psychologist assessment.

A person with a 'learning disability' will also have a disability under the Equality Act 2010.

In the June 2007, guide for healthcare professionals, the BMA stated that FAS, although not a common condition, is nevertheless regarded as the leading known cause of nongenetic intellectual disability in the Western world.

Despite this, Individuals with FASD often struggle to get a diagnosis of 'learning disability' because good expressive language can mask difficulties, IQ may be 70 or over and FASD is often misdiagnosed, underdiagnosed and misunderstood.

However, a person with FASD may still have a disability under the Equality Act 2010 even if they do not meet the NICE criteria for learning disability.

### Children with Disabilities Team

The Children with Disabilities Team supports children and young people who have a permanent and substantial physical and/or learning disability.

These teams work with children and their families with the highest level of need due to their disability. The LA will have its own eligibility criteria which you will find in the LA's Local Offer.

## Is FASD a learning difficulty?

Learning difficulty is a **general term to describe any difficulty in learning.** It is different from a learning **disability** because a learning difficulty does not affect general intellect.

Many individuals with FASD will have a learning difficulty if, for example, they struggle with processing speed, receptive language, abstract concepts and any other skills needed to learn.

Dyslexia, dyspraxia, dyscalculia, dysgraphia and attention deficit hyperactivity disorder (ADHD) are specific learning difficulties (SpLDs) and sit under the umbrella term of 'learning difficulty'. SpLDs can also affect an individual with FASD and make it even more difficult to learn.

A person might have a mild learning difficulty or a severe learning difficulty. An individual can have a learning disability or a learning difficulty or both.

# What protection and support can I get if I have a learning disability or a learning difficulty?

The support available is set out at the back of this Factsheet.

Advocates can help you to access information and services. Every LA commissions advocacy services. The NHS website has useful links for obtaining an advocate **here**.



## **MYTHBUSTERS**

"My aunt comes to social services appointments, but they won't discuss things with her because I am 24 and seen as having capacity but I still need help"

If you have a disability under the Equality Act 2010 your LA will be under an obligation to consider reasonable adjustments which may include permitting your aunt to attend with you. You may be able to find an independent advocate to help you.

## I have been told I cannot get an FASD diagnosis now I am an adult

You do not need a diagnosis to have a disability under the Equality Act 2010 and nor do you need one to have a learning disability or a learning difficulty. You need to meet the tests set out for each in the factsheet. A diagnosis of FASD (or any other diagnosis) is not required to access support for SEN or a social care plan from your LA. These are based on your needs and not a medical diagnosis.

## HOW can I enforce my rights?

- Use any available internal complaints procedure before making an external complaint. Ask the organisation (school, workplace, court etc) in question for details of this.
- You can make a claim to an Employment Tribunal if your employer discriminates against you - see FASD and your employment rights.
- You can also complain to an independent Ombudsman in relation to housing, local government and social care and as a consumer. Find details on the Ombudsman Association website here.
- If you do not agree with a decision about your entitlement to benefits you can appeal and it will be decided by the Social Security and Child Support Tribunal. More information is available on the Government website <a href="here">here</a>.
- If you disagree with how your LA has enacted their obligations you can go through your LA's complaint's procedure and write to your local MP.

# My school/my employer/the court refuse to carry out reasonable adjustments – what can I do?

Write down what you are struggling with and why. Then write down a list of adjustments you think will help. Give this to your school/employer/court/landlord and if you believe you have a disability under the Equality Act 2010 then write this down too and remind them of their legal duty to make reasonable adjustments. Keep a copy and if they refuse to make the adjustments take further action - see below.

## I need to have a physical condition to be classified as disabled

No, under the Equality Act 2010 an impairment can be mental or physical and a learning difficulty or learning disability does not need to be physical either.

# I am told my child is not disabled enough to qualify for the Children with Disabilities Team

All LAs will have their own eligibility criteria and unless your child has profound needs it can be difficult to qualify especially as it often excludes emotional, behavioural and mental health difficulties.

## **KEY RESOURCES:**

## **GUIDANCE AND HELPFUL ORGANISATIONS:**

- Mencap has helpful information on how to determine whether someone has a disability or a learning difficulty.
- <u>Scope</u> provides practical and emotional support for disabled people.
- <u>Citizens Advice</u> has a wide range of resources and guidance on disability and discrimination.
- <u>NICE</u> definitions of learning disability and learning difficulty.
- <u>Equality and Human Rights Commission (EHRC)</u> is the UK's independent equality and human rights regulator and has helpful information about disability discrimination.
- Find a solicitor, the law society's register of solicitors can be found here.
- <u>See Factsheets</u> see FASD and SEND, FASD and EHCPs for further information about disability in education.

## **KEY LEGISLATION:**

- Equality Act 2010, section 6, disability.
- <u>Equality Act 2010 Guidance</u> on matters to be taken into account in determining questions relating to the definition of disability.

# **FASD** and DISABILITY UNDER THE EQUALITY ACT 2010



#### WHAT DOES THAT MEAN?

#### FASD SPECIFIC EXAMPLES

Does the individual have a physical or mental impairment?

- > You have an impairment if your physical or mental abilities are reduced in some way
- > There is no specific 'list' of impairments
- > It does not matter how that impairment has been caused
- No need to be a clinically diagnosed condition
- > Your impairment doesn't have to stop you doing anything as long as it makes it harder
- > It might cause you pain, make tasks take a long time or mean you can't do an activity more than once

- > short term or working memory issues mental impairment
- vision or hearing problems physical impairment
- > adaptive functioning difficulties mental impairment.
- > executive functioning difficulties mental impairment
- > Attention, concentration or hyperactivity mental impairment

Does that impairment have an adverse effect on their ability to carry out normal day-to-day activities?

- Activities are things people do on a regular or daily basis
- A normal day to day activity is something like getting dressed, going to the toilet, watching TV, reading a paper or preparing meals
- For example, if you struggle with day-to-day activity like shopping because of sensory overload (which is a mental impairment) then that impairment would have an adverse effect on day-to-day activities.
- ✓ reading a book
- remembering and getting to appointments
- ✓ sitting still in a classroom.
- $\checkmark$  going to a soft play
- ✓ preparing a meal
- dressing in clothing suitable for the weather
- ✓ washing clothes
- dealing with money in a supermarket
- ✓ cleaning the house
- ✓ waiting in a queue

Is the effect of your impairment substantial?

- The effect must be more than just 'minor' or 'trivial'.
- The effect on your normal day-to-day activities might be substantial if you have more than one impairment.
- The focus should be on what an individual cannot do or can do only with difficulty and not on what they can do easily.
- ➤ A difference in brain structure may mean you struggle to manage your finances the effect of the impairment on your brain may be substantial if you struggle to pay your bills on time without help.
- > Hyperactivity this impairment is likely to have a 'substantial' adverse effect if you struggle to sit down in a classroom for a period of time to learn.
- Memory may impact your ability to make appointments and remember to attend them the adverse effect of this impairment may be substantial on your every day life if you need help to remember to attend appointments.

Is that <u>effect long</u> term?

The effect has lasted (or is likely to last) more than 12 months – or it is likely to recur

As there is no cure for FASD and it lasts a lifetime the **effects** are often likely to be long-term.

# FASD and LEARNING **DIFFICULTIES**



#### **How does FASD fit** What does it mean? into this definition? Those with FASD will often Learning difficulty is a general term to describe any difficulty have a learning difficulty When in learning such as reading, because they can struggle FASD is a writing, spelling, mathematics. with processing speed, receptive language, abstract learning concepts and many other difficulty skills needed to learn. A person may have: 1. a learning difficulty of a An individual with FASD general nature and/or may also have Specific Learning Difficulties which 2. A specific learning difficulty may cause them further/multiple difficulties (SpLD) like dyslexia, dyspraxia, dyscalculia, with learning. dysgraphia and attention deficit hyperactivity disorder Even if they do not fit into (ADHD). the NICE definition of learning disability, (for Learning difficulties may be example, if their IQ is 70 or over) they may still have a

learning difficulty.

## What support is available?

- A diagnosis of a specific learning difficulties (SpLDs) such as in dyslexia, dyspraxia, dyscalculia, dysgraphia and attention deficit hyperactivity disorder (ADHD) are made using assessments. Every school must have a designated teacher for special educational needs (SENCo) who you can contact. Or contact your GP if you suspect you or a child has an SpLD.
- If a child has general difficulties with learning due to receptive language, processing speed etc then this should be recognised by the school but there is often no medical 'diagnosis' for an individual with a general learning difficulty – it is a general umbrella term for those who have a difficulty with learning. Nevertheless, this should be recognised and support given. If you have any concerns contact the SENCo.
- School SEN register: if you child has a learning difficulty they should be added to the SEN register and identified as requiring SEN Support. This is a dynamic list that children can be added to or removed from at any time, depending on how appropriate it is to their needs. The SEN Register must be managed following guidance from the SEND Code of Practice but it is not a guarantee of specific provision for a child.
- Educational, Health and Care Plan (EHCP): A child or young person aged up to 25 with a learning difficulty (s20(2)(a)) or a disability (s20(2)(b)) which calls for special educational provision to be made is legally entitled to an EHC assessment under s36(8) of the Children and Families Act 2014 (also see FASD and EHCPs and FASD and SEND)
- Financial Support: You do not need a formal diagnosis to receive the following financial support if you meet the entitlement criteria:
- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- > Attendance Allowance (AA)
- Other benefits you may be entitled to include:
- Housing Benefit
- Income Support
- Jobseekers Allowance
- **Pension Credit**
- **Universal Credit**

Citizens Advice may be able to help you to understand what you are entitled to and how to access them..

Access to Work can help you get or stay in work if you have a disability or health condition.

mild, moderate or severe.

A person may have one or a combination of learning difficulties.

A learning difficulty is different from a learning disability because a learning difficulty does not affect general intellect (IQ).

# FASD and LEARNING DISABILITY



## What does it mean?

# How does FASD fit into this definition?

## What support is available?

When FASD is a learning disability

'Learning disability' is defined by the NICE's guideline on challenging behaviour and learning disabilities. It is defined by meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood. A learning disability occurs when the brain is still developing (before, during or soon after birth).

Intellectual disabilities (rather than learning disability) is the term widely used internationally.

A person's learning disability may be described as mild, moderate, severe or profound and is usually diagnosed by a doctor following psychological tests and clinical psychologist assessment.

Someone with a learning disability has reduced intellectual ability and has difficulties with everyday activities such as household tasks, socialising or managing money. These difficulties will affect someone for their whole life.

FASD is regarded as the most common, non-genetic cause of learning disability in the UK and many individuals with FASD will have a learning disability under NICE.

However, just because an individual has FASD does not mean then automatically have a learning disability. Individuals with FASD may have cognitive abilities ranging from severe intellectual disability to above average intellectual ability. It depends on how and to what extent FASD affects the particular individual as to whether they meet the NICE definition.

Unfortunately, individuals with FASD are generally less likely to be be recognised as having a learning disability because FASD is widely misdiagnosed and misunderstood.

Individuals with FASD often struggle to fit within the NICE definition of learning disability because they may have an IQ of 70 or above or/and their difficulties with adaptive or social functioning is not properly identified – this may be one reason FASD is often described as a 'hidden disability'.

- If you suspect that you or someone you care for has FASD you may wonder if you or they have a learning disability. You may wish to discuss your concerns with your GP who will be able to refer you for assessment for a learning disability the tests usually involve an intelligence (or IQ) test and a standardised achievement (reading, writing, arithmetic) test. You do not need a diagnosis of FASD to have a learning disability.
- Mencap has a helpful link setting out how to get a diagnosis for a learning disability. They point out that professionals can be confused by some characteristics of learning disability, and even experts can struggle to make an accurate diagnosis.
- Educational, Health and Care Plan
  (EHCP): A child or young person aged up
  to 25 with a learning difficulty (s20(2)(a))
  or a disability (s20(2)(b)) which calls for
  special educational provision to be made
  is legally entitled to an EHC assessment
  under s36(8) of the Children and Families
  Act 2014 (also see FASD and EHCPs and
  FASD and SEND)
- Free annual health check: Anyone aged 14 or over who is on their doctor's learning disability register is eligible. See the NHS website here. You can ask to go on this register if you think you have a learning disability.
- A Lasting Power of Attorney (LPA)
   The Mental Capacity Act 2005 aims to empower people to make their own decisions, if needed with support. A lasting power of attorney is one way to get support with decision making. Easy read guides and more information is available <a href="https://example.com/her-example.com
- Financial Support and Other Benefits: see previous page 'Learning difficulty' for further benefits and support as they apply to those with a learning disability too.