



**Achieving More Together / Cyflawni Mwy Gyda'n Gilydd**

ACHIEVING MORE TOGETHER / CYFLAWNI MWY GYDA'N GILYDD

# Foetal Alcohol Spectrum Disorders FASD

ACHIEVING MORE TOGETHER / CYFLAWN I MWY GYDA'N GILYDD

# THE NAS POST ADOPTION TRAINING AND DEVELOPMENT FRAMEWORK

- These materials have been developed for the National Adoption Service for adoptive families
- Their purpose is to provide a learning and development resource for adopters post placement
- These tools can be used by groups or by individuals.
- There is lots of information in the notes below each slide so it is important to read these too as they provide much more information, and some useful ideas for more reading.

# LEARNING OUTCOMES

By the end of this module participants will:

- Have a general understanding of FASD.
- Be able to judge with more confidence when it would be appropriate to seek an FASD assessment for your child.
- Considered what it might mean for your family and your parenting style if your child does have FASD.
- Know where to go for more information and advice.

# Foetal Alcohol Spectrum Disorder (FASD)

*“A range of detrimental effects to the foetus and baby’s development when alcohol is consumed during pregnancy. The detrimental effects of FASD, for the child and their family, are life-long.”*

(FASD Scotland website)

# WHAT IS FASD?

- Foetal Alcohol Spectrum Disorder (FASD) is an umbrella term covering a number of diagnoses.
- In its simplest terms it is a spectrum of behavioural, emotional, physical, and neurological issues that are caused by alcohol exposure during pregnancy and the effects last a lifetime.
- Foetal alcohol exposure is the leading preventable cause of learning disability in the UK.
- Approximately 6000-7000 babies are born each year in Britain with FASD – this equates to 1% of all children are likely to be affected.
- The number in Wales specifically is unknown, partly due to lack of widespread diagnostic criteria.
- There are various disorders under the umbrella – FAS, ARND, ARBD and PFAS



# WHAT IS FAS?

- Foetal Alcohol Syndrome
- Characterised by
  - Central Nervous System dysfunction
  - Facial dysmorphology
  - pre- and/or post- natal growth deficiency
  - Only diagnosed when there is confirmed maternal alcohol exposure

# WHAT IS ARND?

- Alcohol Related Neurodevelopmental Disorder
- Characterised by
  - Central Nervous System damage caused by pre-natal alcohol exposure
  - Learning difficulties
  - Poor social skills
  - Immature behaviour
  - Difficulty understanding cause and effect
  - Poor impulse control
  - Problems with memory, attention and judgement
  - Only diagnosed when there is confirmed maternal alcohol exposure



# WHAT IS ARBD?

- Alcohol Related Birth Defects
- Characterised by
  - Particular physical anomalies which may include major organs such as heart, skeletal, vision, hearing and fine/gross motor skills
  - Only diagnosed when there is confirmed maternal alcohol exposure

# WHAT IS PFAS?

- Partial Foetal Alcohol Syndrome
- Characterised by
  - Some of the physical signs of FAS but not the full range
  - Learning and Behavioural issues that would indicate damage to the Central Nervous System

# EVIDENCE BASED RECENT RECOMMENDATIONS

- Canadian guidelines update 2016
- FASD as the diagnosis
- “At-risk” category for those who don’t meet the diagnostic criteria
- Recognises difficulty with confirming prenatal alcohol exposure
- Revises neurological signs and definitions
- FASD **with** Sentinel Facial Features ( SFF)
- FASD **without** SFF

# WHAT CAN HAPPEN IN THE WOMB WHEN A MOTHER DRINKS ALCOHOL?

- The alcohol in the mother's blood passes through the placenta into the blood of the foetus.
- At this stage, the foetus' liver is not fully formed so is unable to filter out the toxins in the way that the mother's liver can.
- This alcohol in the foetus' blood can kill brain cells and damage the nervous system at any stage of the pregnancy.
- There is no definitive way of categorising how alcohol could affect an unborn baby. It would depend on the stage of pregnancy.
- Alcohol use by one mother may leave the baby totally unaffected.
- Similar alcohol use in another mother may leave the baby with FASD.

# WHAT VISIBLE SIGNS MIGHT MAKE ME THINK MY CHILD HAS AN FASD?

As with the autistic spectrum, there is a wide range of signs; many children may not show them all. Some children may have some of the signs but NOT actually have FASD.

Signs include:-

- Reduced intellectual ability
- Learning difficulties/disability
- ADHD
- Heart problems
- Behavioural and social difficulties that can be long-lasting and require therapeutic parenting in order to manage them
- Distinct facial features (e.g. flat nasal bridge, “railroad track” ears, upturned nose, smooth philtrum, thin upper lip)
- Other physical features

# WHAT INVISIBLE SIGNS MIGHT MAKE ME THINK MY CHILD HAS AN FASD?

Many children who have experienced trauma and neglect will display some of these signs. They will not all have FASD.

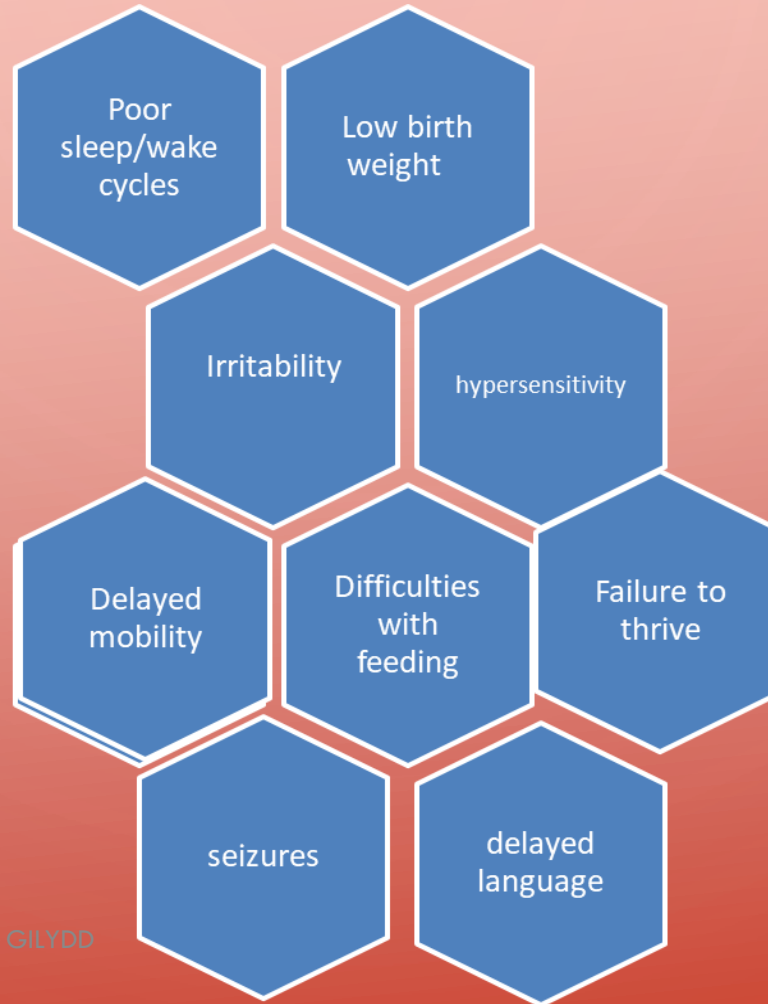
- Learning difficulties
- Acting on impulse
- Struggling with many aspects of school
- Difficulties understanding social situations
- Problems with higher level expressive language
- Significant difficulties with receptive language
- Struggle to understand abstract concepts including money, time and maths in general
- Problems with retaining information, paying attention or making measured judgements



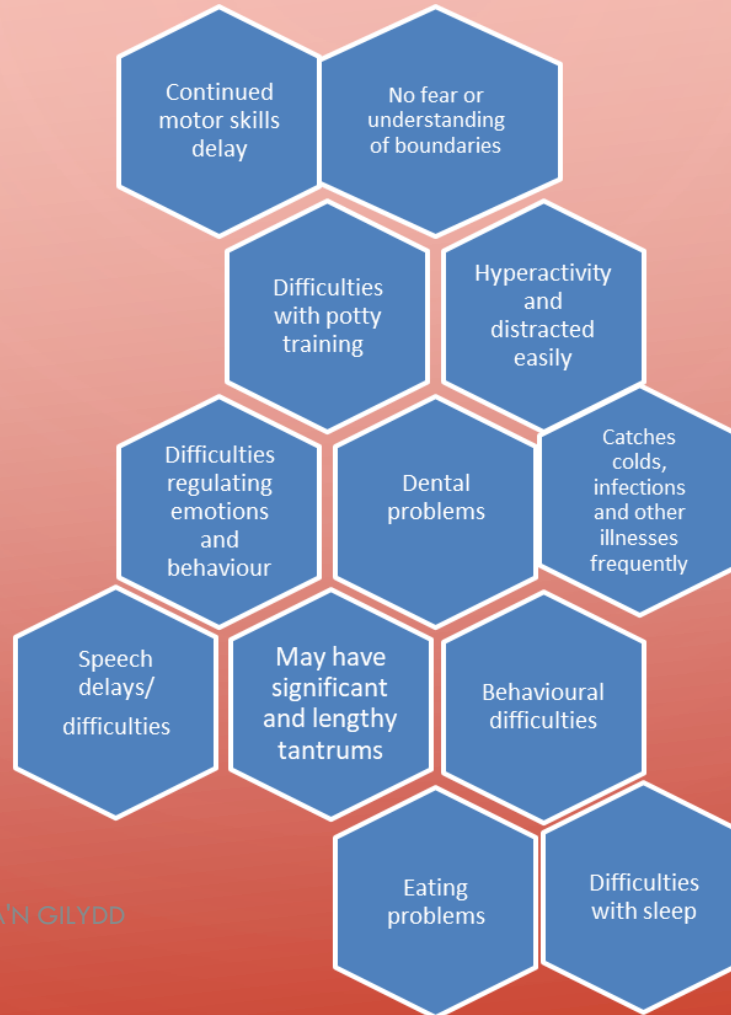
Some of the signs of FASD may not become obvious until a child starts secondary school, hits puberty or is expected to engage in more socially complex interactions.



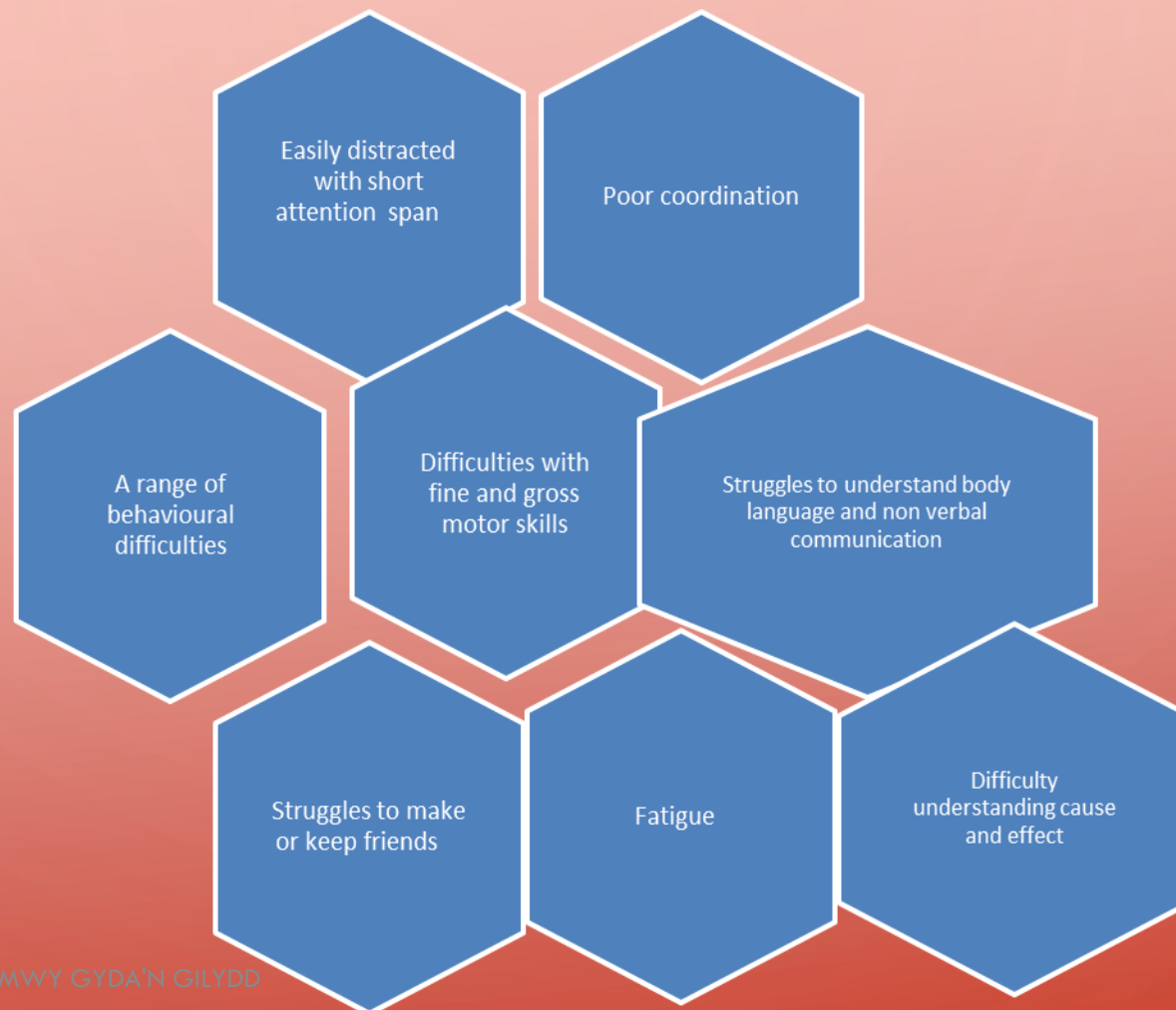
# SIGNS AND SYMPTOMS 0-2 YEAR OLDS



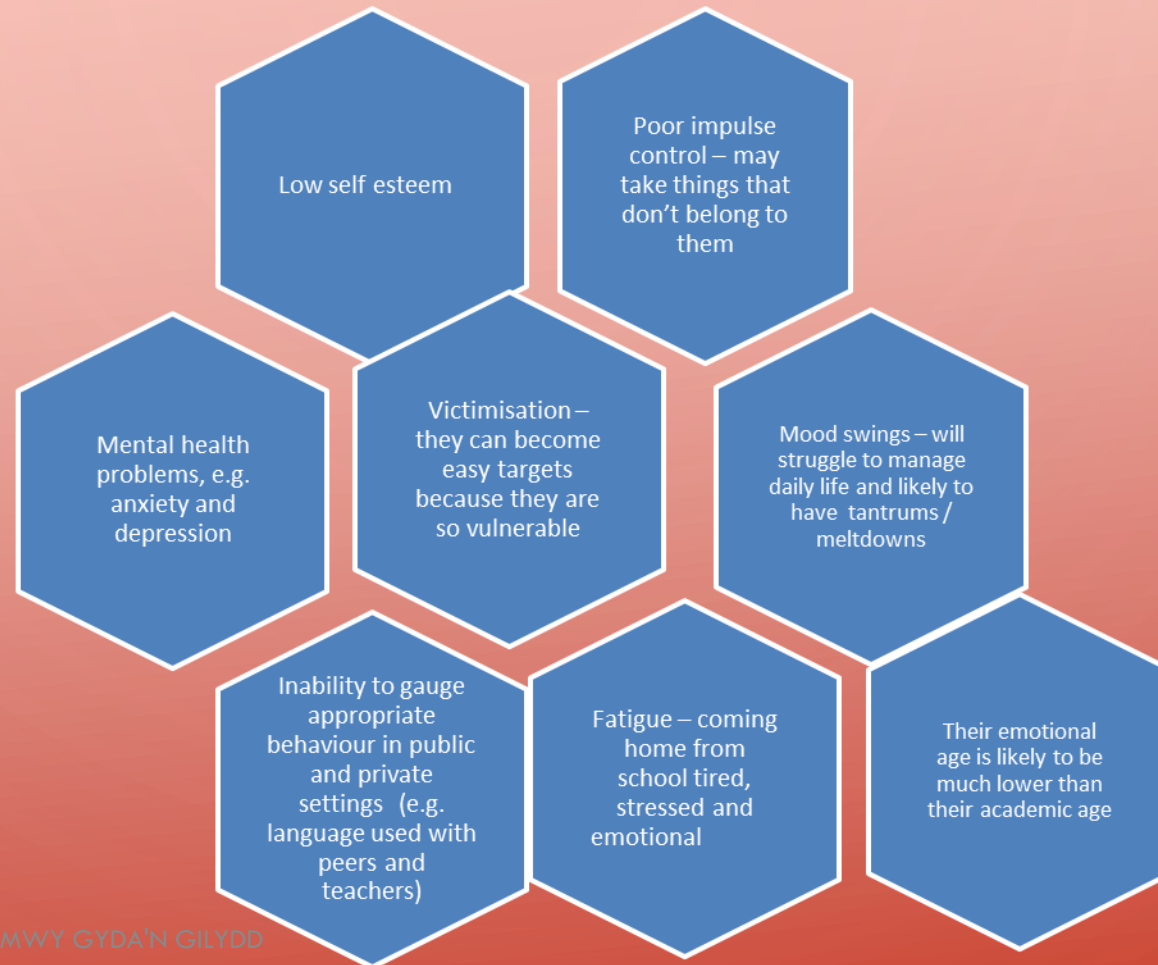
# SIGNS AND SYMPTOMS TODDLERS



# SIGNS AND SYMPTOMS SCHOOL AGE CHILDREN



# SIGNS AND SYMPTOMS TEENAGERS



# WHY IS IT SO DIFFICULT TO DIAGNOSE FASD?

- There is no physical “test”
- Various diagnostic criteria and guidelines
- Few practitioners feel able to diagnose/ lack of FASD clinics
- It can be difficult to get a definitive history of birth mother’s alcohol use during pregnancy
- Practitioners may be reluctant to label a child with this stigmatising disability
- Concerns regarding lack of services if a diagnosis is given
- Facial features become less easy to identify in adolescents and adults
- Difficulties may become more apparent in adolescents and adults

# WHY GET A DIAGNOSIS?

- To get advice on behaviour management and other interventions to improve children's wellbeing
- In order to help families plan for the future
- To prevent indirect consequence of the disorders, known as secondary disabilities – e.g. deteriorating issues with behaviour, social exclusion and some mental illnesses

# THE FUTURE?

- Despite 40 years of research gaps persist
- Evidence continues to emerge to improve understanding and knowledge base of FASD
- Diagnostic biomarkers?
- Analysing correlation between SFF and patterns of neurological deficits
- Improved screening, diagnosis and management



# FASD HAS SOME POSITIVES TOO!

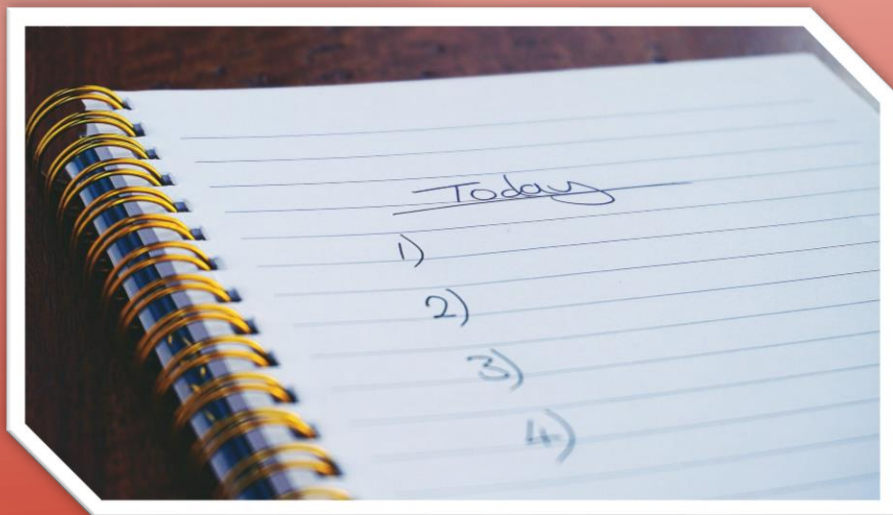
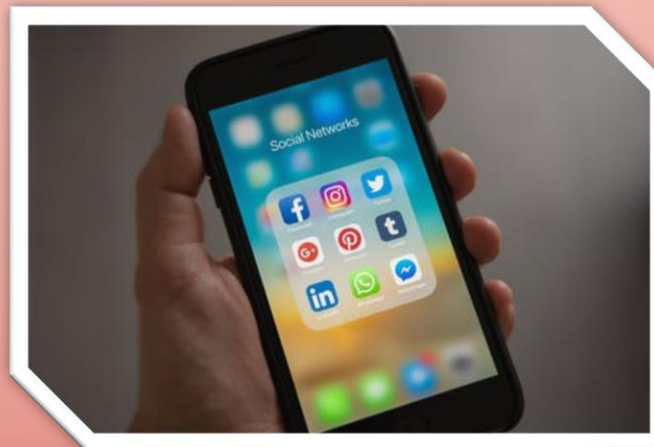
There are many positive aspects to the personalities and characteristics of a person with FASD including:-

- Likes cuddles, cheerful and tactile
- Friendly, outgoing, gregarious and tactile
- Happy in an environment that accepts them and provides ongoing support
- Loving, caring, kind, concerned, sensitive, loyal, faithful
- Affectionate, compassionate, sensitive
- Determined, committed, persistent
- Spontaneous, curious, involved
- Energetic, hard-working, athletic
- Fair and co-operative
- Likes to be asked to help
- Highly verbal
- Kind with younger children and animals
- Able to problem solve with appropriate support
- Concrete thinking
- Strong visual memory
- Ability to learn by doing (kinaesthetic learner)
- Artistic
- Musical
- Mechanical skills
- Interested in construction and gardening
- Good sense of humour
- Enjoys telling stories

# DOING THINGS DIFFERENTLY

- As parents, you may need to pay more attention to ensuring routines are in place and children are helped to prepare for their daily activities.
- Think about your child's emotional/social age rather than their chronological age may help.
- You may need to continue helping older children, teenagers and adults with these daily living tasks.

# USING VISUAL REMINDERS



# HELPING WITH ORGANISATIONAL SKILLS





# WHY MAY A CHILD DISPLAY CHALLENGING BEHAVIOUR?

- Sensory overload (e.g. large crowds, loud noises, changes to routine around mealtimes)
- Getting frustrated with themselves or with others (helping a child to recognise what it **feels like** when they are starting to become angry or feeling overwhelmed can help)
- Unable to effectively communicate what's going on in their head (they may have limited expressive language but more commonly it is their receptive language which is immature). They may struggle to read body language – it can be helpful to do specific work with them on recognising social cues, facial expressions and other non-verbal communication
- Need for stimulation – the majority of children with FASD also have ADHD. They struggle to sit still and stay focussed without fidgeting; providing them with something to fidget with in the classroom, for example, can be really helpful.

# IDEAS TO HELP



# MORE IDEAS TO HELP

- Ask a child to repeat instructions back to you **in their own words** to check they've understood; repeating back rote style does not necessarily equate with understanding.
- Give one instruction at a time, in a concrete format; e.g. "Tell me what you are thinking about while you look at that photo of yourself" rather than "Penny for your thoughts".
- You can help children understand physical boundaries/personal space by using coloured tape to mark out a child's space at the dining table or desk in school
- Some children have a genuine difficulty in understanding ownership and often get into trouble for taking things that aren't theirs. These children need regular reminders that they need to ask before taking something, and that somethings can be borrowed but others need to be paid for





# WHAT IF YOU HAVE A CHILD WHO STRUGGLES WITH FOOD?

- The most important thing is to consult a medical professional if you are at all worried about feeding issues, including weight loss or if the child isn't growing.
- The child may have problems with their sucking reflex.
- They may take a long time to eat and then regurgitate their food.
- It's really important to stick to strict routines around food/ mealtimes.
- Make sure you use the same bottles, teats, bibs, plates, spoons, etc.
- If a baby is easily distracted while feeding, consider going to do it in a quiet, darker room.
- Avoid having the TV or music playing while a child is eating.
- Consider whether children with sensory issues will find certain foods difficult to eat due to texture, flavour, etc.

# IT'S A NIGHTMARE GETTING MY CHILD DRESSED. WHAT CAN I DO?

- If they have problem with fine motor skills they might need help with buttons, zips, laces.
- They may not be a good judge about whether to wear warm clothes in winter and less layers in summer!
- Consider whether cuffs, waistbands, collars, lace up shoes etc. can feel overly restrictive.
- Some children may even find clothes that are too bright over stimulating.

# KEEPING A CHILD WITH FASD SAFE

- A child with FASD is likely to need closer supervision because socially and emotionally they can be at half their chronological age. We need to meet their safety and care needs based on their social/emotional age.
- A hyposensitive child may not feel pain as expected; they may touch the fire and not pull away quickly because they don't feel the heat in the way others would. They may not feel the need to add cold water to a hot bath as they struggle to judge the water temperature.
- It's important to look for other signs of pain that a child may not be able to tell us about, e.g. swelling, bruising.

# A FINAL REMINDER!

You may have done this course because you suspect your child has FASD.

FASD can **ONLY** be formally diagnosed if there is clear evidence of maternal alcohol use during pregnancy **AND** after genetic testing has been done to rule out other conditions.

Although a formal diagnosis **MAY** help, you are still parenting the same child.  
The most important things to do are –

- Reflect on what your child **CAN** do, rather than what they can't
- Consider **WHY** they may struggle in comparison to their peers
- Parent them in a way that will help you develop a secure relationship with them
- Provide many opportunities for play and joyful moments
- Seek professional advice from GP, Health Visitor, School Nurse, CAMHS, social services, etc. if you have concerns

- This course is part of a series developed by the National Adoption Service to support adopters after approval.
- These can be accessed at the National Adoption Service website.
- Please talk to your adoption support team for further information