Worcestershire's Early Years and Childcare Service

Foetal Alcohol Spectrum Disorder

Information sheets

Compiled by Jo Egerton,
Sunfield Research Institute

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Building Bridges With Understanding Project

These information sheets have been produced as part of a research project on Foetal Alcohol Spectrum Disorder (FASD) in the early years funded by Worcestershire County Council and jointly managed by Worcestershire County Council and Sunfield Research Institute, in consultation with the National Organisation for Fetal Alcohol Syndrome UK (NOFAS-UK). It aims to provide early years practitioners with the necessary knowledge and skills to support children who may have Foetal Alcohol Spectrum Disorder. Practitioners across Worcestershire have played a crucial role in developing and trialling these resources through a cycle of Action Research.

FASD is an umbrella term describing the range of birth defects which can occur in an individual whose mother drinks alcohol during pregnancy. Currently in the UK, information and resources for educating children affected are very limited.

The project's objective was to provide a toolkit of resources designed to improve practice and meet the needs of children presenting certain behaviours and learning difficulties. It was not within the remit of this project to equip practitioners diagnostically, but to leave in place a range of tools and suggested strategies to support Early Childhood Intervention.

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Information Sheet 1

Introduction to Foetal Alcohol Spectrum Disorder

Foetal Alcohol Spectrum Disorder is an umbrella term describing the range of birth defects that can occur in an individual whose mother drinks alcohol during pregnancy. Any amount of alcohol consumed during pregnancy crosses the placenta, and can result in birth defects, including physical, mental, behavioural and/or learning disabilities, with life long implications. Four criteria, including growth deficiency, facial features, central nervous system damage and prenatal alcohol exposure must all be met for a full diagnosis. However, many children not meeting the full diagnostic criteria may still be affected and experience difficulties under the Foetal Alcohol Spectrum Disorder umbrella term.

As the foetal brain develops throughout the whole pregnancy, children with Foetal Alcohol Spectrum Disorder often have permanent and irreversible brain injury as a direct consequence of alcohol consumed at any point in the pregnancy. This means that both the child's thought processes and behaviour may be very different to a child who was not exposed to alcohol before birth.

Foetal alcohol exposure is the leading known cause of intellectual disability in the Western world. According to international studies, it is estimated that one in every 100 children are born each year in the UK with Foetal Alcohol Spectrum Disorder. This number is greater than the combined numbers of children born in any year with Down's syndrome, cerebral palsy, cystic fibrosis and spina bifida. In a culture which sees binge drinking on the increase, the number of children with Foetal Alcohol Spectrum Disorder is set to escalate. This is a social problem with far-reaching individual and personal consequences, which is not limited to the UK alone.

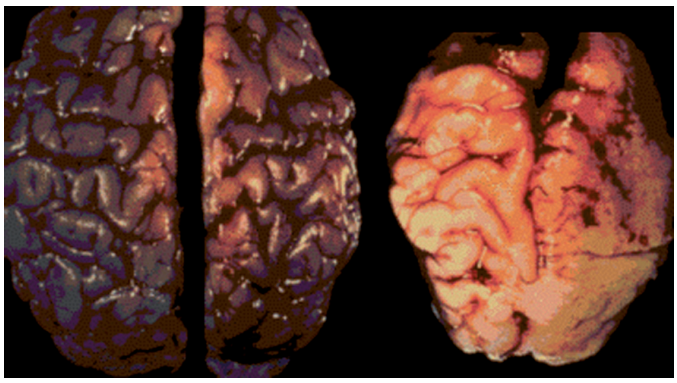
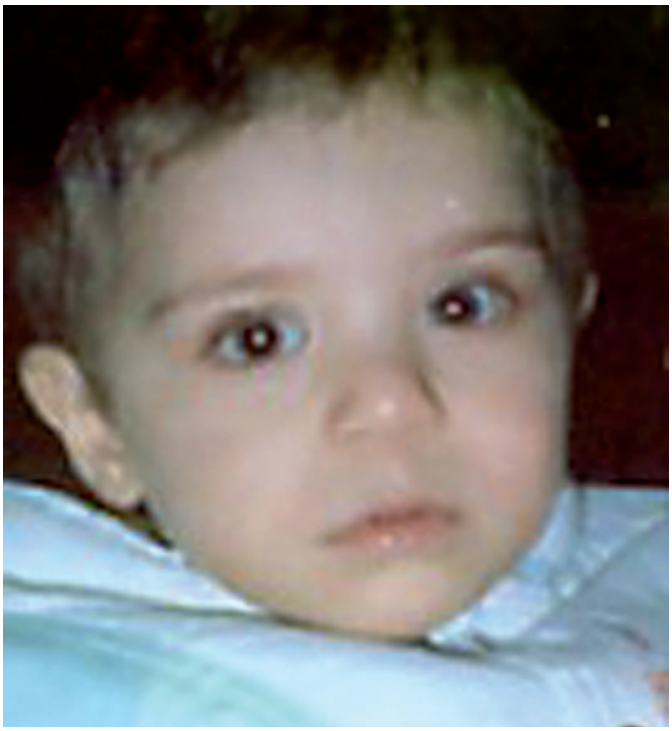


Photo: Sterling Clarren, MD

The life-long implications of Foetal Alcohol Spectrum Disorder are often compounded by secondary disabilities in adulthood such as mental health problems, drug addiction and involvement in criminal activity, with mental health problems escalating during adulthood – 23% of adults with Foetal Alcohol Spectrum Disorder have attempted suicide whilst as many as 43% have considered it. (These figures can be found on the internet at www.come-over.to/FAS/fasconf.htm)

The consequent implications of raising a child with Foetal Alcohol Spectrum Disorder are considerable. Families may need to provide a nurturing environment for many years because most people with Foetal Alcohol Spectrum Disorder will need life long support. For many parents, the length of care can seem overwhelming and is one of the greatest challenges.

Teaching and supporting children with Foetal Alcohol Spectrum Disorder may require innovative approaches based on neurobehavioural strategies. This would allow for the development of teaching strategies which address the difficulties resulting from central nervous system damage. Already studies are reporting that the alarming increase in Attention Deficit Hyperactivity Disorder (ADHD) may be directly linked to Foetal Alcohol Spectrum Disorder.



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Based on the figures published in 2002, we know there are approximately 6,000 children with Foetal Alcohol Spectrum Disorder who have now reached school age. Given that the early years may represent the greatest opportunity in a child's life to prevent poor mental health outcomes, it is important that early years practitioners have the knowledge base and skills required to support these children at their point of learning need.

Information Sheet 2

How Foetal Alcohol Spectrum Disorder affects children

The term Foetal Alcohol Spectrum Disorder (FASD) is used to represent the range of effects that a child who has been prenatally exposed to alcohol may have. It is an umbrella term used to encompass the following:

- Foetal Alcohol Syndrome (FAS)
- Partial Foetal Alcohol Syndrome (PFAS)
- Foetal Alcohol Effects (FAE)
- Alcohol Related Neurodevelopmental Disorder (ARND)
- Alcohol Related Birth Defect (ARBD).

(Information Sheet 8 provides a description of the terms above.)

The foetal brain is vulnerable throughout the 40 weeks of pregnancy and many of the common physical deformities associated with FASD occur during the six weeks of early pregnancy when a woman often does not yet know that she is pregnant. The part of the foetus affected by alcohol consumption is dependent on the stage of pregnancy and the quantity of alcohol consumed.

The resulting primary disabilities (which occur as a direct result of alcohol on the foetus) include deficits that result from damage to the brain and those that result from damage to other parts of the developing foetus such as bones or organs. The changes in brain development are permanent; there is no cure for the damage caused.

How does FASD affect children's brains?

Whether a child has full Foetal Alcohol Syndrome, with a changed physical appearance, or whether they look the same as other children, their brain will be affected. This is caused by the brain not growing as it should and abnormal connections forming between different parts of the brain. This can cause challenges for the child in the following areas:

- Intellectual disability; lowered IQ
- Memory disorders
- Learning disorders
- Attention disorders
- Sensory disorders
- Speech and language disorders
- Mood disorders
- Behavioural disorders
- Autistic-like behaviours
- Sleep disorders.

Often the condition goes undiagnosed, or is misdiagnosed, for example as Autism or Attention Deficit Hyperactivity Disorder (ADHD), and this can lead to **secondary disabilities** which can include:

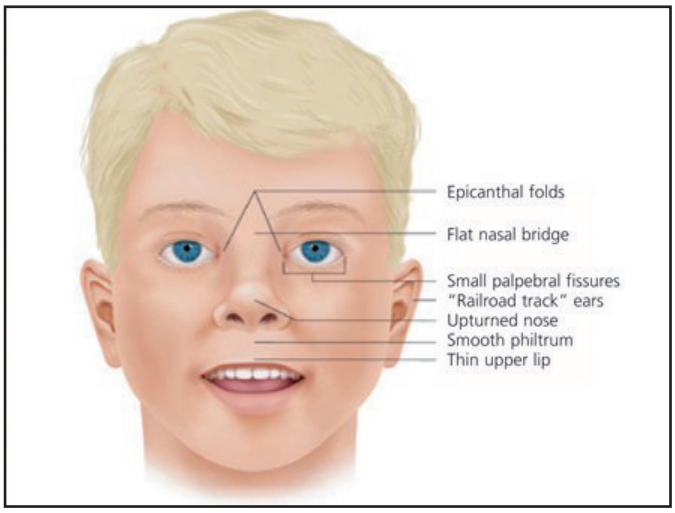
- Loneliness
- School expulsions
- Addictions
- Chronic unemployment
- Promiscuity
- Unplanned pregnancies
- Poverty
- Criminality
- Prison
- Homelessness
- Depression and suicide.

What does a child with full Foetal Alcohol Syndrome look like?

The way a child with full Foetal Alcohol Syndrome looks gives a clue to their disability.

- They may be small and weigh less than other children their age.
- Their head may be smaller than usual.
- They may have smaller eye openings which hide the corners of the eye.

- The middle part of their face may be flattened.
- They may have a small, upturned nose.
- They may have a flattened 'philtrum' (the two ridges running between nose and lips).
- They may have a thin upper lip.



Darryl Leja, www.nih.gov

Babies with FASD are often:

- Of low birthweight
- Over-sensitive to light, noise and touch
- Irritable
- Unable to suck effectively
- Slow to develop
- Vulnerable to ear infections
- Affected by poor sleep/wake cycles
- Too stiff or too floppy
- Resistant to accepting new situations.

As **toddlers and young children**, they are likely to have problems with:

- Poor muscle development and movement skills
- Coordination and balance
- Language
- Learning new skills that other children find easy
- Remembering
- Hyperactivity (they find it difficult to sit still)
- Lack of a sense of fear
- Understanding boundaries
- Their need for lots of physical contact
- Missing typical development milestones such as walking, toilet training, emotional development, etc.

Older children with FASD may experience all of the difficulties above, but also have problems with:

- Distraction (they respond to everything happening around them)
- Impulsiveness (they do not think before they act)
- Paying attention, concentrating and understanding what they hear
- Accepting changes in routine
- Planning and problem solving
- Understanding why something happened (cause and effect)
- Learning from experience
- Responding to requests and questions
- Understanding their own feelings and the feelings of others
- Adapting to the normal stresses of day-to-day living
- Relating to other people (friends and strangers)
- Sensory overload (become confused by too much noise, movement, light, smells)
- Talking and listening (they may only understand one in three words)
- Thinking and doing things in the right order
- Understanding abstractions (e.g. maths, money, time)
- Inconsistent performance (i.e. 'on' and 'off' days)
- Age appropriate behaviour (i.e. they may act younger than their age)
- Lying to fit in and gain approval (e.g. saying they understand an instruction when they do not).

Other health difficulties

Alcohol also damages other body organs (e.g. eyes, ears, heart, limbs, kidneys and/or other organs) causing on-going health problems for the child. Their brain damage may also cause seizures and interrupted sleep patterns. It is important for children with FASD to have regular medical check-ups (see Information Sheet 7).

Diagnosing Foetal Alcohol Spectrum Disorder

Getting a diagnosis of FASD is one of the most important things people can do to help a child and their family. However, **do not try to diagnose it yourself**. FASD is difficult to diagnose because the symptoms the children show are also found in other conditions (e.g. Autism, ADHD). Often, because the child may be hyperactive, impulsive and engage in repetitive activities, they may be diagnosed with ADHD or other difficulties instead of FASD. It is important that they are diagnosed by a professional psychologist with special training or experience of FASD.

There is no cure for FASD; it is a lifelong disability. Adults with FASD have the same problems that they had when they were younger. Many need on-going support and help throughout their life. However, with the right support from a young age, given by informed and caring people, children can learn to work with and to accept their disability, and have more positive life outcomes.

Information Sheet 3

What can you do to support your families?

Parenting a child with Foetal Alcohol Spectrum Disorder (FASD) can be like trying to find your way around Glasgow with a road map of Edinburgh – love and care are not enough. Diagnosis is the most important first step to enable parents and professionals to support a child with FASD. Children who have a diagnosis have a better chance in life than those who do not.

How to work with families

The family of the child with FASD are the most important people in their child's life. Early intervention and a nurturing, structured home are crucial for the child to grow up happy and fulfilled. These children need a lot of attention from people close to them.

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Families, whether birth or adoptive, also need to be included and supported. Children with brain injuries are challenging to raise, and their parents need understanding – not criticism. It is important that professionals and parents are honest, straightforward and open with one another, and listen properly, valuing each other as members of a team.

Families and professionals can learn from one another. Families know their child better than anyone else. They can advise professionals on their child's personal strengths, special interests and safety issues. They know what works for them at home. Professionals can show families useful strategies to help children learn – for example:

- Modelling behaviours
- Setting up reward systems
- Encouraging appropriate behaviours
- Structuring activities.

These will help the child to build life skills, and avoid frustration and low self-esteem. If families and professionals work together and use the same strategies, the child will find it easier to learn.

How to provide practical and emotional support

Families need information about FASD, but make it available to all families in an early years group instead of targeting one family, which may embarrass them.

- Put up information posters
- Have information leaflets left out for any parent to pick up, or
- Include a leaflet on FASD in packs about your service.

If you suspect that there is a possibility that a child may have been affected by alcohol in the womb, do not approach the parents about this. However, when you work with the child, use approaches you know will work with children with FASD. You should also talk about the situation with your early years group leader and local authority representative.

Be non-judgemental. Learning that their child has FASD may make parents feel a sense of loss, anger, being overwhelmed or relief. If the child is still living with their birth family, the family may also feel shame and denial. Families raising a child or children with FASD face a lifetime of grief. 'The mothers of children with FASD, like other mothers, generally want to deliver happy, healthy babies. The damage their children suffered before birth was not inflicted with malice, intent, or even – in most cases – understanding, and may well be part of a larger tragedy that encompasses the child, the mother, and all those around them' (Yukon Education 2006).

You can support families by:

- Accepting their grief
- Listening to their concerns
- Being calm
- Helping them when possible
- Being there for them when needed
- Letting them go at their own pace
- Putting them in touch with another family who has a child with FASD (if the other family has agreed to this beforehand)
- Signposting to other agencies such as Homestart, Portage and the Parent Partnership Service.

Source: Gloria, Peter and Matthew Armistead (FASawareUK)

Information Sheet 4

Understanding the child with Foetal Alcohol Spectrum Disorder

Often children with Foetal Alcohol Spectrum Disorder (FASD) as toddlers seem bright and articulate. It is easy to think that nothing is wrong. The disability can be difficult to spot, especially in the early years, even for specialist doctors who know what to look for.

The child with FASD has no control over behaviours which parents and early years staff may find unacceptable or undesirable. These behaviours are caused by brain damage in the womb and need empathy and understanding, for example:

Why does the child not do what they are asked consistently?

- The child finds it difficult to understand how words relate to practical action. If there is a lot going on around them or they feel anxious, they find it even more difficult.
- When another person is speaking, the whole of their attention may be fixed on something unimportant (e.g. the way the person's hair moves) so they do not hear.
- They may not remember how to begin what they have been asked to do or what actions they need to do to finish it.
- They may not ask for help because they do not know they need it.

Why does the child ask the same questions, make the same mistakes every day and forget what they have learnt from one day to next?

- The child finds it difficult to hold words and ideas in their memory. They may not understand what those words mean in reality or what the answer means.
- They find it difficult to learn from experience.
- They do not understand or remember that their actions cause other things to happen.
- They find it difficult to think things through and make the right choices.
- What they do one day, they cannot necessarily do the next.

Why is the child's play often repetitive and without meaning?

- Without help, the child does not understand how to turn real situations into play (e.g. a trip with dad to the garage turned into play using toy cars in a toy garage).
- They do not understand why other people do what they do.
- They cannot predict what their actions will cause to happen.
- They do not understand how to do something by putting different actions together.
- Repeating the same activities or actions is calming for them.

Why does the child have difficulty in learning to take turns and share?

- The child finds it difficult to understand time or sequencing – that after your turn it will be mine again.

Why does the child have difficulty in shifting from one activity to another?

- They may be anxious because they cannot remember how to finish the old activity or how to start the new one.

Why is the child hyperactive?

- The child has a physiological need to move while learning.
- Poor sensory processing means that the child may be clumsy, distractable, aggressive and possibly withdrawn, displaying poor behavioural regulation. This may be mistaken for hyperactivity.
- They do not recognise which thing is most important to attend to so their interest keeps jumping from one thing to another.

Why is the child constantly injuring or bruising themself?

- This is caused by the child's difficulties with movement skills and judging space coupled with poor sensory processing.

Why does the child chat frequently about nothing and not listen to others?

- The child is sociable and likes to talk, but they find it difficult to remember things to talk about.
- They do not understand how to take turns (i.e. they find it difficult to predict that after your turn it will be mine again) or how to apply what others say to their own situation.

Why does the child constantly disrupt other children?

- The child finds it difficult to cope with all the stimulation around them.
- They do not understand the meaning of activities they are taking part in.
- They do not understand the effect their behaviour has on others.

Why does the child not show remorse when they hurt or disrupt other people?

- The child does not understand or predict the effect of their behaviour on others.
- They find it difficult to learn from experience and apply learning to new situations.
- They find it difficult to remember what happened.

Why is the child emotionally unpredictable, and why do they have outbursts?

- The child finds it difficult to delay their responses to allow time to solve problems.
- They are easily frustrated because they cannot see the way forward.
- They cannot 'tune out' what is going on around them and constantly respond to it.
- They often misinterpret other children's and adults' words and actions, leading to anxiety and frustration.

Why does the child have difficulty with relating to others and touching others inappropriately? Why are they too trusting of unknown people?

- The child does not understand how to begin to communicate with others.
- They want to join in, but do not understand how to do this.
- They find it difficult to understand the 'bigger picture' in what other children are doing and saying.
- They find it hard to pick out social cues from others.
- They get needed feedback from touching other people, but find it painful when others touch them, and therefore can react emotionally.
- They do not understand personal space and boundaries – where they end and other people begin – or remember previous learning about how to relate to other people.
- They do not understand how people they know and people they do not know are different.

Information Sheet 5

What strategies can I use to help the child learn?

Each child with Foetal Alcohol Spectrum Disorder (FASD) has their own special talents, needs, problems and abilities. With the right help, they can learn. However, without early intervention, three-year-old children with FASD can be a year behind other three-year-olds. If they do get the right help early enough, they may be able to keep up in the early years, and their future chances are better. Please see Focus on Strategies for further information about strategies for specific learning areas.

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Five things to remember before you start...

1. **Check the child's health** – These children need the best possible chance to learn. First, check that there are no additional treatable health problems (e.g. sight or hearing difficulties, Attention Deficit Hyperactivity Disorder, etc.) which may make it difficult for them. If necessary, ask the family to check this with their doctor.
2. **Work with families** – The child with FASD needs the same approach at home and in the playgroup to reinforce learning. Families and professionals can help each other by sharing what they know.
3. **Be patient** – These children find it difficult to learn and remember. They often have to be taught things that other children pick up automatically. They might do something several times, and then be unable to do it the next time. When you give them an instruction, they might immediately do something else. This is because they may have got distracted and forgotten your instruction. Calmly remind them again. Children with FASD need to be taught things many times, and to be constantly reminded of what to do.
4. **Focus on the positives** – Give lots of praise to children for what they can do. These children want to please, but because learning is difficult for them they may easily become discouraged and frustrated, which can lead to anger and aggression. Praise children for trying as well as for success.
5. **Make sure the child's attention is on you before speaking to them** –

- Come down to their level, say their name, and maybe touch their shoulder.
- Ask them to look at you. When you have their full attention, speak using a short, simple sentence to tell them what you would like them to do.
- Give only one instruction at a time to the child on their own. They may not understand an instruction given to a group of children.
- Songs or music and rhythm cues are good ways of getting the attention of a child with FASD. Try setting words that describe daily routines to favourite song tunes. Children often find them fun and easier to learn.
- Turn negative words, like 'Don't', into positive words, like 'Let's do this instead.' Children with FASD face daily criticsm for doing things wrong.

How can I help the child to learn?

Children with FASD will always find remembering, ordering and organisation difficult. They need to start practising early.

- **Make the environment calming, with everything tidy, organised and ordered**

Children with FASD can become over-excited, anxious, distracted or confused if there is too much clutter, noise, light or too many bright colours on the walls because they find it difficult to ignore anything around them.

- **Create a visual timetable**

Help the child to know what will come next by using objects or laminated photos of places or objects associated with different activities placed on a visual timetable. Let the child take the first photo to the activity to remind them where they are going. Start with what is happening first and next (two photos), adding another photo as each one is removed. Once the child understands this, gradually increase the number of photos on the timetable. Make sure the child can see the timetable easily.

- **Set realistic goals**

Put together a lndividual Education Plan (IEP) with realistic expectations and goals. These children are often creative, artistic and musical, with a good sense of humour. They can be caring, with a love of animals, and a desire to please. Build on their strengths and successes to overcome weakness and problems. It is important to teach the child how to work around the things they find difficult.

- **Keep things simple**

Keep activities short and simple so the child does not lose concentration. Change the activities frequently to keep their interest. Break down more difficult activities into very small steps and teach the child each step before moving on to the next one.

- **Ask the child to do one activity at a time**

Everything else needs to be tidied away so they are not distracted. All their attention should be on what they are trying to do.

- **Make the beginning, middle and end of activities obvious**

This will teach the child how to do things in the right order. Also ask them to help you set up and put away activities to support this.

- **Make activities exciting**

Make use of the child's high level of natural curiosity. When you bring something new into the early years setting, increase the interest by hiding it and helping them to guess what it could be. Bring unusual things or gadgets to talk about.

- **Help them to succeed**

Over the course of the day, include a high number of activities which the child can succeed in (around three-quarters of all the activities they do) so they can get a lot of positive feedback. They may need to have an adult working alongside them. Most children need classroom support and management which may need to be on-going throughout their life.

- **Name things around them**

Children with FASD find it difficult to name things and people. Name things being used in an activity and ask the child to repeat the names after you. Talking out loud helps the child to learn and to be aware of what they are doing. Label objects around them and help them to read the words or symbols.

- **Help them to organise**

Encourage the children to match and put things in order in real life situations. For example, returning a blue box to join the same colour boxes kept on one shelf; putting blocks into the box with the right picture on the front.

- **Teach the child how to play**

Often children with FASD struggle with play and how to behave with other children. Show the child how to play purposefully with toys and help them to expand their

play. For example, using a toy garage explore different pretend situations. Show them cause and effect by using simple, pop-up toys, and make obvious the connections between what they do and what happens. Help them to practise sequencing (e.g. putting clothes on a doll in the right order).

- **Teach them how to ask for help**

This is an important skill. Often the child may not realise what they need help with. They may not know how to ask for help. Practising this skill early will help them in the future, and save them from becoming frustrated and angry.

- **Practise skills that support learning**

Children with FASD may have difficulties with fine motor skills, like using a pencil or scissors, and gross motor skills, like kicking or catching a ball. Help them practise these skills regularly in ways that are fun and achievable – starting with tearing instead of cutting, or swimming or dancing instead of ball games.

- **Help them with timing**

Children with FASD find it difficult to understand time. Near the end of an activity, provide them with a visual count down (e.g. an egg timer), and regularly call their attention to it to help them see how much time is left.

- **Allow frequent healthy snacks**

It is important that children who are hyperactive keep up their blood sugar levels, otherwise they may become tired, irritable and distractible. Frequent healthy snacks will help them to learn and participate positively.

- **Allow frequent exercise breaks**

Give the child frequent opportunities to run about and release energy (e.g. running, jumping, bouncing) between work tasks.

Information Sheet 6

How can I encourage positive behaviour?

Life can be confusing and difficult for children with Foetal Alcohol Spectrum Disorder (FASD). They struggle to understand people, situations and what they are supposed to do. When things become overwhelming, they may lose control. Please see Focus on Strategies for further information about strategies for specific learning areas.

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There are three ways that you can help the child to behave positively:

1. Teach them how to behave with other children through role playing different situations supported by an adult. Keep practising to help them remember
2. Help to raise the child's self-esteem by knowing what they do well, telling them so, supporting them to do it and giving lots of praise and concrete rewards
3. Know how to recognise difficult situations, how to prevent them happening and what to do if they do happen. Help the child to do the same. Through role-play, practise over and over again with them what to do.

How do I help with social skills?

Children with FASD find it difficult to understand boundaries and personal space. For example, they do not understand that a toy that is lying around may be owned by someone else, or the right way to touch people. Children need to be taught boundaries through play, simple games and repetition.

- Children with FASD do not automatically know how to be someone's friend. They cannot be taught the right behaviour by asking them to copy their peers. Help them to role play different behaviours supported by an adult.
- Talk to the child about what is happening socially and teach them positively what action to take. For example, in a library, point out another noisy child and whisper to your child, 'Mum likes you to be quiet in the library. Let's see how quiet you can be.'
- Children often touch others more if they themselves need sensory feedback. Vibrating toys, rubbing arms and legs with a towel, hand or foot massages with creams and lying under a weighted blanket all give needed sensory feedback. Sometimes children with Foetal Alcohol Spectrum Disorder have the opposite reaction to tactile experiences. They may have a low tolerance for certain fabric or foods.
- Pointing to and naming their own body parts can increase a child's awareness of where they are physically in space.
- Movement based programmes (e.g. Sherborne Developmental Movement) can also provide children with predictable sensory feedback.
- Do not be upset if a child rejects or shies away from physical contact. Although children with FASD touch others, they are often hypersensitive to being touched themselves. Warn the child before you touch them.
- Because of their learning disabilities, children with FASD do not understand how to behave with strangers, or how to avoid dangerous social situations. They need constant supervision and role play practice to develop safe behaviours around strangers.

Building a child's self-esteem

Children with FASD find it difficult to get things right. It is important to build their self-esteem as much as possible. They will need to feel good about themselves to help them cope with the difficult times. Help them to see their own strengths and know their limits.

Positive self-image – Encourage the child to think positively about themselves. Model what to say in real life situations. When they find something difficult, teach the child to say, 'I can do this. I'll give it another try,' instead of 'I can't do this. I'm stupid.'

Positive attention – Reward and praise positive behaviors, and when possible ignore negative ones, so the child receives adult attention in response to good behaviour. Do not use sanctions – they do not work for a child who has problems with memory and controlling their responses. Give them ways of getting attention for doing positive things – perhaps encourage them to show a special object or something they have done.

Asking for help – One of the most important things is to teach the child how and when to ask for help without getting angry or upset. Again, this needs to be taught through lots of practice in role-play and reminders in real life situations.

Help them to realise that every day is a new day – If the day has been difficult for the child, end it by sharing a positive outlook with them:

- Reassure them that everyone has difficult days
- Remind them how the problem was solved, and that they can put it behind them
- Remind them that together you can avoid it happening again.

What to do when the child loses control

Avoiding the situation

- Plan in advance what you will do when an outburst happens and practice with the child what do to. Give them strategies they can use and explore the different things they could do (e.g. go to a calm place) through role-play.
- Keep an eye on situations which might be difficult, and plan how to redirect children to another pleasurable activity before the situation gets out of control.
- Be aware when the child is becoming over-excited, anxious, confused, etc. Reduce the confusion in the environment (e.g. reduce noise, light, clutter, etc.). Redirect the child sensitively to another activity – perhaps outdoor exercise with a member of staff or some time in the relaxation space with a favourite activity or person.

What to do if an outburst happens

- If the child has an outburst, do not take it personally.
- Follow your plan of action for when a child loses control.
- Make the area safe by moving other children and dangerous objects away.
- Calmly help the child to regain control using the different ways that you have practised together.
- When the child is calm and able to listen without getting upset, talk with them about why the situation happened (in a positive, constructive way, not a critical way).
- Talk about what the child can do next time in a similar situation.
- Practise with the child what to do many times.

How to prevent outbursts

- **Understand the triggers for the child's behaviour** and how to avoid them or minimise them. The child may have lost control because:
  - They did not understand the situation
  - Too much was expected of them
  - They became overwhelmed by everything going on around them (noise, touch, smells, light, etc.).

- **Teach the child what to do to avoid having an outburst**, and practise this over and over again.

- **Teach the child about their emotions**. Give them a word for the emotion or feeling they are experiencing (e.g. if they have fallen down – 'It hurts'; if their toy is taken – 'You're angry'). This helps them to begin to identify their emotions, and to find ways of talking about them.

- **Keep the child's space calm, tidy and organised**, so they do not become confused or overwhelmed by noise, disorder, demands, etc.

- **Make a relaxation space** where they can go to calm down with a low-energy, favourite activity (e.g. calming music, low lighting, sensory toys). Teach calming techniques such as relaxation exercises and rhythmic breathing. These experiences should always be pleasant, so the child can return to an earlier activity feeling calmer and positive about themselves.

- **Introduce routines**. Routines that do not change from day to day will reduce stress for the child, and make it easier for them to learn and to know what to expect next.

- **Teach the child how to ask for help**. Often these children do not know when they need help, or that other people can help them. Help them to spot when the task is too hard to do on their own. Give them a strategy for asking for help.

- **Make sure the child knows what is happening next**. When you tell them what will happen, support your words with a picture or object. If their next activity is 'Snack', gain eye contact, say 'Snack time', and give them a cup as a visual cue. (Although they can hear and maybe repeat back the words you say, they may not be able to give them 'real world' meaning.) When you back up what you say with an object or picture, they learn to associate the key word with something concrete.

- **Give the child advance warning** that you want them to leave one activity for another. Introduce an egg timer or hour glass to count down the time to the next activity, and at intervals physically show the child that the sand in the timer is disappearing.

- **If the child has a difficulty** with something non-routine or a transition, stop and pay attention to them. Calm them by talking in a quiet, level voice; assure them everything is OK, and gently encourage them to change activities.

Information Sheet 7

Health and mental health issues for children with Foetal Alcohol Spectrum Disorder

Children with Foetal Alcohol Spectrum Disorder (FASD) will require help to get the medical and support services that they need. There are many different health issues associated with FASD. It is important that children have regular checkups and that their health is looked after.

www.nofas-uk.org

The child with FASD will need a full health evaluation. The following specialists may take part:

- Geneticist
- Developmental paediatrician
- Psychologist
- Physiotherapist
- Occupational therapist
- Speech and language therapist
- Audiologist
- Dietician
- Social worker.

Together they will build up a picture of the child's abilities, difficulties and needs. They will then be able to give advice to carers, teachers and therapists on how to help the child learn and develop. They will put families in touch with services and people who can help them.

Children with FASD have some degree of central nervous system damage. This may cause them to:

- Be hyperactive
- Shudder uncontrollably
- Be irritable
- Have panic attacks
- Overreact to noise, light, touch, movement
- Have poor sleep/wake patterns
- Have a weak sucking reflex
- Fail to thrive.

Children have a central nervous system which is organised so that they can block out things around them that do not matter (e.g. noise, light, touch, movement, etc.). The child with FASD who has a damaged central nervous system cannot do this. They have to react to everything around them whether it is important or not. Because of this, the infant or young child can easily become overwhelmed. They startle, shudder, cry or become agitated. They may try to get away from it by looking away, scrunching up their eyes tightly and frowning. If the stimulation continues, they become increasingly agitated. It is important to keep this child's environment calm and low key so they can cope.

Children with FASD often have sensory processing disorders resulting in their being either over or under responsive to their environment. Sensory processing and integration involves the brain's ability to process and organise information from the sensory systems efficiently (i.e. vision, hearing, smell, taste, touch, vestibular sensation – movement – and proprioception – muscle and body position in space). A child with sensory dysfunction may:

- Be constantly on the move
- Enjoy crashing and jumping

- Display a strong desire to spin, swing or roll
- Seek out vibration
- Seek out or avoid strong flavours or smells
- Avoid or fear movement
- Have extreme preferences about clothing, food, textures or tastes.

In addition to physical characteristics and brain abnormalities (see Information Sheet 2), the child with FASD may have other health problems. These can include:

- Cleft palate (opening in the roof of the mouth)
- Teeth abnormalities
- Eye problems (e.g. nearsightedness, farsightedness, astigmatism, 'lazy' eye, crossed eyes)
- Hearing difficulties and ear infections
- Spine curvature
- Heart defects
- Kidney and genital abnormalities
- Unusual chest shape
- Unusual fingers and toes
- Muscles that are too floppy or too stiff
- Difficulties with making large and small movements
- Seizures.

Some of these difficulties, such as problems with hearing, sight and posture, can affect children's ability to learn. Therefore these need to be looked at as soon as possible so the children are not left behind.

Children with FASD may be put in danger by other difficulties:

- A very high pain threshold – they could have a serious injury or infection without knowing it
- Difficulties in telling whether they are hungry or full up – they could forget to eat or eat too much
- Difficulties in knowing whether they are hot or cold – they may wear clothes which are not suited to the weather
- Difficulties with their balance and judging distance – this may make them clumsy, and in certain situations could be dangerous.

Professionals and families need to be aware of and share information about these issues so they know what signs to look for and what to do about it.

Mental health issues

At all times in their life, up to 90% of people with FASD are likely to have mental health problems, including when they are children. They need loving support to gain a healthy and positive self-image, and to accept their unique differences.

Information Sheet 8

Glossary

Audiologist is a medical hearing specialist. Frequent ear infections can be common with FASD.

Cardiologist is a medical heart specialist. Some children with FASD have heart and other organ defects, which may require corrective surgery.

Central Nervous System is the brain and the spinal cord. These control the activities of the body.

Dietician is a trained health professional who works with people to develop a balanced and nutritious diet which will support and maintain their health.

Ear, Nose and Throat (ENT) Consultant is a doctor who specialises in the diagnosis and treatment of ear, nose and throat conditions.

Educational Audiologist is a qualified teacher of the deaf who has an additional qualification in audiology, including hearing assessment.

Educational Psychologist is a qualified teacher who has additional training as a psychologist and will help children who find it difficult to learn, understand or communicate with others.

Foetal Alcohol Syndrome (FAS) describes a condition within Foetal Alcohol Spectrum Disorder (see below), which includes specific physical features caused by damage to the brain from alcohol drunk by a mother-to-be during the first three months of pregnancy (although alcohol damage can occur throughout the whole nine months of pregnancy). Most children with an alcohol damage-related diagnosis in the UK are diagnosed with Foetal Alcohol Syndrome as opposed to Foetal Alcohol Spectrum Disorder. This is because their facial characteristics make their diagnosis easier. Many of the children without these features go undiagnosed. See Information Sheet 2 for a description of the features.

Foetal Alcohol Spectrum Disorder (FASD) is an umbrella term which describes a range of birth defects that can occur in an individual whose mother drinks alcohol during pregnancy. Other diagnoses covered by the term 'Foetal Alcohol Spectrum Disorder' include:

- Alcohol Related Birth Defects (ARBD) – includes characteristics such as heart defects, sight/hearing problems, joint defects, etc.
- Alcohol Related Neuro-developmental Disorders (ARND) – includes disorders such as attention deficits, behaviour disorders, obsessive/compulsive disorder
- Foetal Alcohol Effects (FAE) – the symptoms are not usually visible (e.g. behaviour disorders, attention deficits, etc.)
- Foetal Alcohol Syndrome (FAS) – see above
- Partial Foetal Alcohol Syndrome (pFAS).

General Practitioner (GP) is a family doctor who works in the community and is often the first point of contact for families.

Genito-Urinary Medicine – children may have problems with bladder control and structure, and genital deformities. Referrals may also be given to **Incontinence Nurse Advisors**.

Health Visitor is a health professional who visits family homes in the early years to check on children's health and development and provide advice to families about the care of very young children, normal child development, sleep patterns, feeding, behaviour and safety.

Key Worker/Lead Professional acts as the co-ordinator of services for a particular child to ensure that the help offered is what parents find most useful and is organised in the way that best suits their child's needs.

Neurologist is a doctor who specialises in the brain and nervous system.

Occupational Therapist is a trained and registered health professional who uses mental or physical activity to help people to recover from a disease or injury. They help children improve their developmental function by therapeutic techniques and advise on the use of specialist equipment and environmental adaptations.

Ophthalmologist is a doctor based in a hospital who specialises in the diagnosis and treatment of eye defects and diseases.

Orthoptist specialises in the correction of vision by non-surgical means.

Paediatrician is a doctor who specialises in working with babies and children.

Physiotherapist is a trained and registered health professional who treats disease, injury or deformity by physical methods, including manipulation, massage, infrared heat treatment and exercise, but not by drugs. Children affected by FASD may need help with under developed muscle tone, hip and shoulder joint problems, gross motor skills and balance.

Portage Home Visitor is someone who works in the home with pre-school children who have additional needs and is trained to deliver a home-based, educational support service.

Psychologist is a trained and registered health professional who treats the human mind with a view to encouraging a healthy mindset and affecting behaviour.

Special Educational Needs Co-ordinator (SENCo) is a teacher who has particular responsibility for ensuring that all children with SEN are receiving the provision that they need. Some Early Years Area SENCos work across a number of different early years settings.

Speech and Language Therapist is a trained and registered health professional who works with people to improve their speech and language. Many children affected by FASD present with advanced expressive language, but poor receptive skills. They may also need help with turn taking, waiting in queues, holding a conversation and listening skills.

Information Sheet 9

List of organisations

This set of ten information sheets was compiled with reference to the resources produced by the organisations below. These organisations are listed for information, but this should not be taken as endorsement.

Organisation websites in the UK

National Organisation for Fetal Alcohol Syndrome UK (NOFAS-UK)
157 Beaufort Park,
London, NW11 6DA
Tel: 0208 458 5951
Email: Nofas-uk@midlantic.co.uk
Website: www.nofas-UK.org

FAS Aware UK
Website: www.fasaware.co.uk

FASD Trust
Website: www.fasdtrust.co.uk

Organisation websites based abroad

Better Endings New Beginnings
Website: www.betterendings.org

Edmonton Fetal Alcohol Network
Website: www.region6fasd.ca/home.php

FAS Alaska
c/o Debra Evensen,
PO Box 1092, Homer,
Alaska 99603, USA
Tel: 001-907-235-8900
Email: debevensen@alaska.net
Website: www.fasalaska.com

FASD Connections
Website: www.fasdconnections.ca/index.htm

Fetal Alcohol Syndrome Community Resource Center (FAS-CRC)
4710 E. 29th Street #7, Tuscon,
Arizona 85711, USA
Website: www.come-over.to/FASCRC/

Fetal Alcohol Syndrome Family Resource Institute (FAS-FRI)
PO Box 2525,
Lynnwood, WA 98036, USA
Tel: 001 253 531 2878
Website: www.fetalalcoholsyndrome.org

Minnesota Organization on Fetal Alcohol Syndrome
1885 University Avenue, Suite 395, St. Paul,
Minnesota 55104, USA
Tel: 001-651-917-2370
Fax: 001-651-917-2405
Website: www.mofas.org

National Organisation on Fetal Alcohol Syndrome (NOFAS-USA)
900 17th Street, NW, Suite 910,
Washington, DC 20006, USA
Tel: 001 800 66 NOFAS
Website: www.nofas.org

SAMHSA Fetal Alcohol Spectrum Disorder Center for Excellence
1700 Research Boulevard, Suite 400,
Rockville, MD 20850, USA
Tel: 001-866-786-7327
Website: fasdcenter.samhsa.gov

The ARC of the United States
1010 Wayne Avenue, Suite 650,
Silver Spring, MD 20910, USA
Tel: 001 301 565 3842
Website: www.thearc.org

University of Washington Fetal Alcohol and Drug Unit
180 Nickerson St., Suite 309,
Seattle, WA 98109, USA
Tel: 001-206-543-7155
Fax: 001-206-685-2903
Website: depts.washington.edu/fadu

Other useful addresses

Contact a Family
Contact a Family helps families who care for children with any disability or special need. They are a main source of information about rare disorders and are able to put families in touch with one another.
Website: www.cafamily.org.uk
Freephone Helpline: 0808 808 3555

Home-Start
Voluntary organisation supporting families through approved home-visiting volunteers.
Website: www.home-start.org.uk

National Parent Partnership Network
Parent partnership services are statutory services that offer information, advice and support for parents of children and young people with special educational needs (SEN).
Website: www.parentpartnership.org.uk

National Portage Association
A home-visiting educational service for pre-school children with additional support or special needs.
Website: www.portage.org.uk

The Sherborne Association (UK)
Sherborne Developmental Movement
Website: www.sunfield.org.uk and www.sherbornemovement.org

Information Sheet 10

Further reading about Foetal Alcohol Spectrum Disorder

This set of ten information sheets was compiled with reference to the resources listed below. These resources are listed for information only, and this should not be taken as endorsement.

British Columbia Ministry for Children and Families (1998) **Working Together for the Prevention of Fetal Alcohol Syndrome** (Community Action Guide). Victoria, Canada: British Columbia Ministry for Children and Families. [Online at: www.mcf.gov.bc.ca/fasd/pdf/guide.pdf; accessed: 17.1.08]

British Medical Association (2007) **Fetal Alcohol Spectrum Disorders: A guide for Healthcare professionals**. London: British Medical Association.

Centre for Disabilities, University of South Dakota (2002) **Fetal Alcohol Syndrome Handbook**. Sioux Falls, SD: University of South Dakota. [Online at: www.usd.edu/cd/publications/fashandbook.pdf; accessed: 18.1.08]

Dorris, M. (1989) **The Broken Cord: A family's ongoing struggle with Fetal Alcohol Syndrome**. New York, NY: Harper and Row.

Kleinfeld, J. and Wescott, S. (eds) (1993) **Fantastic Antone Succeeds: Experiences in educating children with Fetal Alcohol Syndrome**. Fairbanks, AK: University of Alaska Press.

Kleinfeld, J., Morse, B., Westcott, S. (eds) (2000) **Fantastic Antone Grows Up**. Fairbanks, AK: University of Alaska Press.

Stratton, K., Howe, C. and Battaglia, F. (eds) (1996) **Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment**. Washington, DC: National Academy Press. [Online at: www.nap.edu/openbook.php?record_id=4991&page=R1; accessed: 17.1.08]

Streissguth, A. and Kanter, J. (eds) (1997) **The Challenge of Fetal Alcohol Syndrome: Overcoming secondary disabilities**. Washington, DC: University of Washington Press.

Streissguth, A. (1997) **Fetal Alcohol Syndrome: A guide for families and communities**. Baltimore, MD: Paul H. Brookes.

Wake Forest University Health Services (2004) **Fetal Alcohol Syndrome: A parents' guide to caring for a child diagnosed with FAS**. Winston-Salem, NC: Wake Forest University. [Online at: www.otispregnancy.org/pdf/FAS_booklet.pdf; accessed: 18.1.08]