Specialist Schools and Academies Trust
THE SCHOOLS NETWORK™

COMPLEX LEARNING DIFFICULTIES AND DISABILITIES RESEARCH PROJECT (CLDD)

FOETAL ALCOHOL SPECTRUM DISORDERS

What is foetal alcohol spectrum disorder?

The term foetal alcohol spectrum disorder (FASD) is an umbrella term used to encompass the range of possible effects of prenatal exposure to alcohol (British Medical Association, 2007), including foetal alcohol syndrome (FAS), partial foetal alcohol syndrome (pFAS), foetal alcohol effects (FAE), alcohol related neurodevelopmental disorder (ARND) and alcohol related birth defects (ARBD). Any amount of alcohol consumed by a mother during pregnancy crosses the placenta, and can result in birth defects for her child, including physical, mental, behavioural and/or learning disabilities, with life long implications. Full FAS is associated with characteristic physical effects including facial dysmorphia, but, even where there are no observable effects, children are left with irreversible brain damage.

Foetal alcohol exposure is the leading known cause of intellectual disability in the Western world, and according to international studies, it is estimated that one in every 100 children is born with FASD (Autti-Ramo, 2002; British Medical Association, 2007; May and Gossage, 2001; Plant, 1985; Plant et al, 1999; Sampson et al, 1997). This is greater than the combined incidence of children born in any year with Down syndrome, cerebral palsy, cystic fibrosis and spina bifida. In a culture which sees binge drinking on the increase (Donaldson, 2009), the number of children with FASD is set to rise. Based upon the above estimate in the context of annual birth figures produced by the Office of National Statistics, there are likely to be 6–7,000 babies born with FASDs of varying severity in the UK each year.

Teachers and teaching support staff will undoubtedly meet students with FASD in their classrooms. They need to know how to respond to their learning needs effectively, enable them to maximise their potential, improve their life chances, and take their places alongside their mainstream peers as citizens (DfES, 2004; HM Government, 2004). To do this, teaching staff will need training and support to realise this in the context of the English National Curriculum and National Education Strategies (cf. http://nationalstrategies.standards.dcsf.gov.uk/) (Carpenter, 2009; 2011). In other countries (eg Canada, USA), research outcomes have led to improved educational support for students with FASD.

Four criteria, including growth deficiency, specific facial features, central nervous system damage and confirmed prenatal alcohol exposure must all be met for a full diagnosis of FAS. However, many students not meeting the full diagnostic criteria may still be affected and experience difficulties. For example:

- ARBD includes characteristics such as heart defects, sight/hearing problems, joint defects, etc
- ARND and FAE include attention deficits, behaviour disorders, obsessive/compulsive disorder.

The severity of presentation (eg facial dysmorphia) is not necessarily indicative of the severity of impairment (Stratton et al, 1996), and therefore it is also important that teachers are aware of the true effects of the hidden impairments associated with FASD, so they can recognise and accommodate students' learning needs. These students may score within normal limits on measures of IQ, and give the appearance of functioning at a level consistent with their chronological age. They appear physically mature, and are able to meet basic literacy demands and to use relatively sophisticated language. However, their academic abilities are below their IQ level, and their living skills, communication skills and adaptive behaviour levels are even more so (Streissguth et al, 1996). A lack of awareness of the difficulties of students' difficulties can lead to consistently unrealistic expectations. Without the

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appropriate supports and interventions, this can cause them to develop serious behavioural, cognitive, and psychological secondary disabilities.

Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (http://www.fascets.org/info.html) describe the learning issues for students with FASD as follows:

Primary characteristics of individuals with FASD

No one or two characteristics are necessarily diagnostically significant; many overlap with those of other diagnoses, eg ADD/ADHD, learning disabilities, and others

- memory problems
- difficulty storing and retrieving information
- inconsistent performance (on and off) days
- impulsivity, distractibility, disorganisation
- ability to repeat instructions, but inability to put them into action ('can talk the talk but can't walk the walk')
- difficulty with abstractions, such as maths, money management, time concepts
- cognitive processing deficits (may think more slowly)
- slow auditory pace (may only understand every third word of normally paced conversation)
- developmental lags (may act younger than chronological age)
- inability to predict outcomes or understand consequences

Primary characteristics of individuals with FASD

- highly verbal
- bright in some areas
- artistic, musical, mechanical
- athletic
- friendly, outgoing, affectionate
- determined, persistent
- willing
- helpful
- generous
- good with younger students

Secondary characteristics which individuals with FASD may develop due to chronic frustration

If their condition goes unrecognised, and they do not receive support, patterns of defensive behaviours commonly develop over time. These characteristics are believed to be preventable with appropriate supports.

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- fatigue, tantrums
- irritability, frustration, anger, aggression
- fear, anxiety, avoidance, withdrawal
- shut down, lying, running away
- trouble at home, school, and community
- legal trouble
- drug / alcohol abuse
- mental health problems (depression, self injury, suicidal tendencies)

The importance of providing appropriate support for students with FASD cannot be emphasised enough. The secondary behaviours described above may become disabling. Research describes the bleak outcomes for some young people with FASD: mental health problems (seen in 87% of children; O'Connor et al, 2002); disrupted school experience (60% over the age of 11 years; Riley, 2003); trouble with the law (60% of teenagers; Kelly, 2009); imprisonment (50%; Kelly, 2009); inappropriate sexual behaviour; problems with dependent living (80%; Riley, 2003) and employment (Streissguth and Kanter, 1997). They also are at increased risk of developing addictive behaviours such as alcohol abuse, thereby potentially continuing the cycle of FASD into the next generation (Baer et al, 2003). Streissguth and colleagues (1996) found that 3% of 6–11-year-olds, 12% of 12–20-year-olds, and 23% of adults from a cohort of 415 subjects diagnosed with FAS or Foetal Alcohol Effects had attempted suicide. (The adult figure is five times the US national average.)

Teaching and learning

The need for personalised, meaningful and high quality education is crucial if we are to divert this outcome. In developing personalised learning pathways for students with FASD, practitioners need to take account of their levels of impairment in terms of: sensory perceptual functioning; gross and fine motor skills; visual-motor integrative abilities; visual-spatial and visual-perceptual skills; attention and processing speed; expressive and receptive language; auditory and visual learning and memory; executive functioning; IQ and academic abilities.

It is important to build upon the positive personality characteristics, strengths and talents of students with FASD (Alberta Learning, 2004), and to manage their learning environment to allow them to flourish. This may include providing consistency, structure and repetition, sensory regulation, and a concrete, hands-on approach to learning. Students with FASD often have strong visual memories and good verbal fluency. They often have high energy levels, and a gregarious, fun loving, caring and affectionate nature. Many are skilled in visual arts and music, and different sports.

The adapted SCORES approach (Clarren, 2004; Lasser, 1999; see table below) summarises effective approaches for working with students with FASD. The summary emphasises the importance of structure. However, wherever possible, it is important that this structure is visual. A structured teaching approach, such as TEACCH (Mesibov et al, 2006), provides specific guidance about how this can be done. This may include:

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- creating clearly defined areas of the classroom which are used consistently for specific activities (eg a relaxation area, an area for independent work, etc)
- using screens or similar to reduce the visual distraction around the student's work area
- using visual timetables and visual systems (eg written, symbolled, pictorial, etc) to show the order of different tasks or the order of elements within a task; the level of complexity and communication should be tailored to the individual student
- organising work to be carried out in a systematic way using labelled shelves, trays, etc.

SCORES teaching and learning approaches (Clarren, 2004; Lasser, 1999)

S

Supervision

- Supervise students closely to keep them safe and prevent problems.

Structure

- Teach students that every day has a consistent structure to it.
- Make sure routines are explicit, firmly in place and followed.
- Ensure each class and every learning activity is planned and structured.
- Use task analysis to ensure that all steps required to complete an assignment are given and understood.
- Make sure directions are simple, and given orally and in visual form.

Simplicity

- Keep everything simple – rules, routines, directions, language, explanations and expectations.

Support

- Provide unconditional emotional support to the student.
- Ensure support for students' families and teachers as necessary to deal with emotional issues such as grief, loss and frustration.

Success

- Identify students' strengths and help them recognise and use their own strengths.
- Look for positive events, set up situations to ensure accomplishments and celebrate success.

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C	**Communication** • This takes place regularly between the home and school. • Everyone involved with these students knows what others are doing to help and communicates when there are changes in plans. • Teach students how to communicate feelings and needs. **Consistency** • Routines, rules and expectations need to be consistent. • Give steps to complete a task in the same way every time.
O	**Organisation** • Teach organisation skills in the classroom. • The classroom is organised—a place for everything and everything in its place. • Learning activities and daily routines are organised.
R	**Rules** • They are simple and easy to follow. • Use concrete and positive language —'Walk' rather than negative 'Don't run' or abstract 'Be careful'. • All staff use the same words for each rule. • Check whether students know and understand what the rules mean. • If a student does not follow a rule, an adult corrects the behaviour immediately, without scolding, and encourages the student to try the behaviour again, this time following the rule.
E	**Expectations** • Expectations need to be realistic, attainable and easily understood. • Take into consideration special and individual needs of students for life and social skills as well as academics. • Clearly specify what is to be expected and accomplished for any given task or activity.
S	**Self-worth** • Students feel accepted, valued and safe. • Give positive encouragement each day. • Build on students' strengths to help them cope with the frustration of things they cannot do.

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Current research indicates that three main areas offer the main challenge to teachers (Yukon Education, 2006; Kleinfeld and Wescott, 1993):

Numeracy and mathematics

Researchers in neuroscience have reported that in many children with FASD, the parietal lobe is severely affected (Goswami, 2004; Kopera-Frye et al, 1996). This area of the brain deals with numeracy and mathematical computation. The teaching challenge here is more than a straightforward differentiation of the mathematics curriculum.

Executive function and behaviours for learning

The lack of structure and self discipline means that students with FASD are often erratic and unfocused. They lack the basic organisational skills that are fundamental to effective learning. Their disorientation in the classroom environment leads them to disengage quickly from the learning flow. Cumulatively, this means that they do not make satisfactory learning gains or adequate progress in learning management.

PSHE (emotional wellbeing)

The literature in this area has widely reported the vulnerability of young people with FASD to mental health problems. Their lack of social skills, and difficulties informing sustainable friendships, makes them susceptible to feelings of negativity and poor self-esteem. US studies have reported high levels of suicide amongst young adults with FASD (Streissguth et al, 1996). We believe that targeted educational

The cognitive and behavioural profile of students with FASD changes over time, so the learning needs of primary and secondary students are subtly different. Learning, behavioural/emotional and social difficulties typically become more evident as they progress through school. Therefore, repeated neuropsychological assessment may be needed at different times during the life of an individual with FASD to capture their evolving strengths and weaknesses accurately, and to plan appropriate interventions.

Transition between primary and secondary schools needs to be carefully managed, as this is an area in which support strategies and services can often become disrupted, and communication can break down between practitioners (Ward et al, 2003). For teenagers, issues around emotions, friendships and sexual behaviour, independence and achievement compound their primary impairments (Connor and Huggins, 2005).

Whatever the background, the challenge remains, ‘How do we optimise learning for this student group?’. There is as yet no direct guidance from any government agency in the UK to teachers on how to educate students with FASD. However, currently the Training and Development Agency for Schools (TDA) are supporting the FAS-eD research project which is looking into effective teaching and learning approaches for children with FASD (reporting October 2010). There is also information available on working with children with FASD in the early years from Worcestershire County Council/Sunfield School (Blackburn, 2009).

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