

Pedagogically bereft! Improving learning outcomes for children with foetal alcohol spectrum disorders

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Foetal alcohol spectrum disorder (FASD) is the most common non-genetic cause of learning disability, affecting around 1% of live births in Europe, and costing an estimated \$2.9 million per individual across their lifespan. In adulthood, non-reversible brain damage is often compounded by secondary disabilities in adulthood, such as mental health problems and drug addiction. The challenge for today's educators is: 'How do we teach children with FASD?' Their unusual style of learning and their extreme challenging behaviour is out of the experience of many teachers. This article, written by Professor Barry Carpenter, OBE, National Director of the Specialist Schools & Academies Trust Complex Learning Difficulties and Disabilities Research Project, considers the status of FASD in the UK, and provides an overview of the author's recent research into effective educational strategies within the framework of *Every Child Matters*. Only government-led approaches can lead to improvements in the quality of teaching and learning for children with FASD and their future life chances.

Key words: foetal alcohol spectrum disorder, *Every Child Matters*, educational strategies.

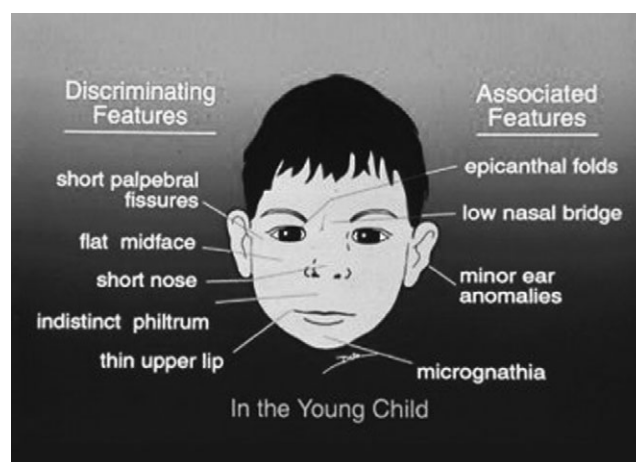
Introduction

Foetal alcohol spectrum disorder (FASD) is the most common preventable cause of learning disability/difficulty in the UK. This spectrum disorder includes children with 'full blown' foetal alcohol syndrome (FAS) who display distinctive craniofacial abnormalities, small head circumference and growth difficulties. The most obvious indicators are a small head, epicanthal folds around the eyes and an indistinct philtrum from the nose down to an often thin upper lip (Astley & Clarren, 2000) (see Figure 1). These children typically display intellectual impairment (Mukherjee, 2004). However, additional alcohol-related birth defects (ARBD) may include abnormalities in the heart, misplaced or absent genital organs, small stature or other physical difficulties.

Alcohol exposure can also cause a range of alcohol-related birth defects and neurodevelopmental disorders which, collectively with FAS, comprise FASD. On the FASD continuum, the group of children with some, but not all, of the

Figure 1: A combination of facial features which are particularly characteristic of children with FAS

Note: Streissguth & Little (1994).



characteristic FAS features are described as having partial FAS (pFAS). There are also those who are mildly affected and referred to as having foetal alcohol effects (FAE). Children with alcohol-related neurodevelopmental disorder (ARND) do not show the facial/physical characteristics associated with FAS, but difficulties in learning emerge as the child advances chronologically.

Prevalence

The issue of alcohol use during pregnancy is controversial. It is well accepted that heavy maternal alcohol consumption in early pregnancy – either chronic daily use or binge drinking – is required for the development of FAS, but, as described above, not all children exposed to alcohol *in utero* will be affected to the same degree, and some will not be affected at all. A number of factors, such as the pattern and timing of alcohol consumption, the stage of foetal development, and social behavioural factors such as poverty and smoking may exacerbate the impact of alcohol. The amount of alcohol necessary for foetal damage is unclear, and it remains debatable whether there is a threshold below which alcohol does not harm the foetus (O'Leary, Heuzenvoeder, Elliott & Bower, 2007). However, the clearest advice seems to be that pregnant women should not drink.

It was in 1968 that the French team of Lemoine, Harrouseau, Borteyrun and Menuet established that women who drank

heavily while pregnant gave birth to underweight infants with distinct facial features, cognitive delays and challenging behaviour. The most widely reported studies, however, are those of Jones and Smith (1973) published in *The Lancet*, in which they first coined the term 'fetal alcohol syndrome'.

Prevalence rates of FAS range from one per 1,000 in relatively low-risk populations, through four per 1,000 in moderate-risk populations, to rates of 40+ per 1,000 in certain very high-risk South African communities (Molteno, 2008). In France, the prevalence is estimated at one in 330, as it is in Germany; in Sweden, the estimates are one in 600, and, in the US, one in 1,000. Alcohol has had an extremely destructive effect on indigenous populations such as Maoris, Aborigines and Native Americans, where FAS is reported in one in 170 live births (Golden, 2005). In most western countries, the current estimates of FASD prevalence are 1% of the child population (Sampson, Streissguth, Bookstein, Little, Clarren, Dehaene, Hanson & Graham, 1997).

A recent significant study has been that conducted by a combined US and Italian team in the Lazio region of Italy (May, Fiorentino, Gossage, Kalberg, Hoyme, Robinson, Coriale, Jones, del Campo, Tarani, Romeo, Kodituwakku, Deiana, Buckley & Ceccanti, 2006). Typically, in Italy, moderate alcohol consumption is integrated into everyday life as part of the social activity of sharing meals together. Italian women are not known as binge drinkers, compared to some of their European counterparts, and thus this study sought to ascertain if mild, consistent consumption would cause high levels of damage to unborn infants. The rates of full-blown FAS were 3.7–7.4 per 1,000 children, and for FASD, 20.3–40.5 per 1,000, which were high. The authors state that 'overall, the rate of FASD in this Western European population may be 3.5%'.

It is clear that FASD is multifactorial (Autti-Ramo, 2002). In various studies, the women interviewed were not only consuming large amounts of alcohol, but were also smoking and using drugs. Social circumstances were also a factor – women living in poverty were found to be more prone to binge drinking – and there were those women too whose genetic predisposition contributed to the impact of alcohol on the foetus (R. Gray, personal communication, November 2009).

Canadian research has shown that many children with FASD are initially misdiagnosed with autistic spectrum disorder (ASD), Asperger's syndrome (AS), attention deficit/hyperactivity disorder (AD/HD) and obsessive compulsive disorder (OCD) (O'Malley, 2007). FASD encompasses deficits in learning, attention, memory and judgement. Individuals with FASD are often misdiagnosed due to assessment outcomes focusing on their behaviours, rather than the alcohol-caused brain damage (Streissguth, Barr, Kogan & Bookstein, 1996).

Australian studies have reported this as a particularly neglected group of children who are over-represented in

certain population groups. For example, it is estimated that as many as 85% of children with FASD end up in the foster care system. As these children grow, they often experience poor mental health. They may become homeless and chronically unemployed, and many do not complete compulsory education. Again, it is reported that many young people with FASD will have early entry into the criminal justice system, and without intervention will become 'revolving door prisoners' (S. Meier, personal communication, 2008).

The challenge

Whatever the background, the challenge remains: how do we optimise learning for this pupil group? Even more so, we have to ask, how do we teach them? Despite the attention given to diagnosing FAS and describing the children's characteristics, there has been no systematic investigation of the educational needs of children with FASD or on best educational strategies for effective teaching and learning (Ryan & Ferguson, 2006). Often teachers, being unaware of this group of children, do not identify them or plan specifically to meet their learning needs.

Until recently, there was no direct guidance from any government agency in the UK to teachers on how to educate children with FASD. However, in October 2010, NOFAS-UK (www.nofas-uk.org) published a significant report offering guidance to teachers in all age phases (Blackburn, 2010). The three, major, parent-led organisations in the UK, NOFAS-UK, the FASD Trust (www.fasdtrust.co.uk) and FASAware (www.fasaware.co.uk), do provide some guidance, but it is in need of further development and direction in the current UK curriculum framework. In countries such as Canada and the US, there is extensive guidance and a well-developed system of provision for these children.

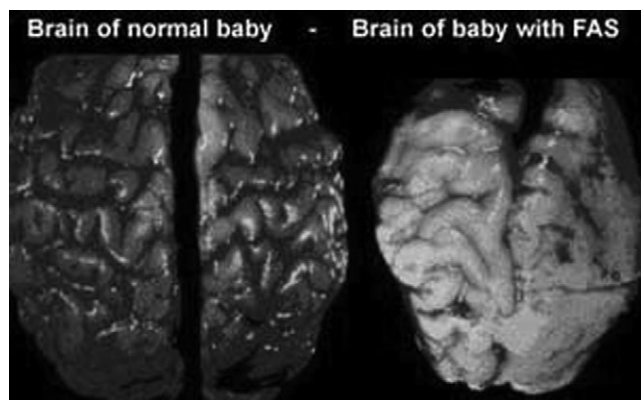
There is a great educational vulnerability around these children, which means that the current style and structure of many classrooms is not conducive to engaging them as effective learners. Many of their behavioural traits militate against sustained learning with cumulative gains. As one mother, Julia Brown, the founder of the FASD Trust, stated:

'It's like living with someone who is drunk. They are clumsy, suffer memory loss, and display socially inappropriate behaviour. They think they are invincible: that they are Superman and can fly!'

If a formal identification of a child with FASD has not taken place in the early years, then it is often at school that specific concerns are raised for the first time. Brain damage is the most serious aspect of FASD (see Figure 2). This damage is permanent. It can be accommodated, but not reversed. FASD affects cognition, behaviour and social skills. It is a pervasive developmental disorder with lifelong implications for schooling and beyond. Whereas the facial features of the child with FAS make it easier to detect, for those elsewhere on the spectrum, if they do not have these facial features, then it is usually the intensity of the school learning situation which highlights their particular needs.

Figure 2: Comparison of brain of normal baby with brain of baby with FAS

Note: The photograph on the right shows an example of extreme alcohol damage to the brain of a baby with FAS. As with this baby, those who have this degree of damage are unlikely to survive into infancy. Photo: Sterling Clarren, MD.



Many UK school settings will not be aware that they have children with FASD in their pupil population – they may be present, but with the alternative diagnoses described above. Classroom accommodation, adaptation and amelioration are required to engage children with FASD as effective learners.

The developmental profile of children with FASD is variable. Their expressive language may be in advance of their actual age, and their reading skills may be chronologically appropriate. However, in areas such as social skills and emotional maturity, they may be performing at half of their developmental age. Mathematical and numerical concepts are particularly challenging for this group of children in that, for some, the parietal lobe, which controls numeracy and computational activity in the brain, may have significantly reduced functioning (Kopera-Frye, Dehaene & Streissguth, 1996). This means that children with FASD are difficult to accommodate within any Key Stage of the English National Curriculum.

Sadly, the root cause of the children's problems relates to the alcohol damage suffered during pregnancy. This is a particular issue in the UK. As Riley (2007) has stated:

'Binge drinking, which is so common in the UK, is particularly harmful to the developing baby. Damage to the brain is the most devastating, and can occur at any point during pregnancy.'

Identifying learning needs

In 2008, the author carried out a preliminary piece of qualitative research, seeking to explore some existing educational practice concerning FASD in the West Midlands – what teachers had identified as the key learning issues for these children in their classrooms, and what their effective teaching strategies were. The purposive sample comprised 20

teachers in primary, secondary and special schools, all of whom were currently working with a child with a diagnosis of FASD or had worked with such a child within the previous two years. Information was gathered through semi-structured interviews with teachers and, where possible, the students themselves, and through direct, periodic, non-participant observations of teachers and children in classroom environments.

In the semi-structured interviews, teachers were asked to identify the challenges to the classroom learning environment presented by the children. The following is a list of the top 10 challenges reported by these teachers:

1. hyperactivity;
2. short attention span;
3. erratic mood swings;
4. poor memory;
5. lack of social skills;
6. auditory/vocal processing;
7. visual sequencing;
8. sensory integration difficulties (particularly lack of co-ordination);
9. poor retention of task instruction;
10. numeracy/mathematical difficulties.

It was very obvious that retention and overlearning were not key features of the learning pattern of the child with FASD. As one teacher said, *'It's very much "here today, gone tomorrow"!'.*

Regardless of the difficulties identified, how we optimise the learning of these children remains the challenge. The observations of children with FASD in class, alongside an extensive international literature survey which reported teaching children with FASD, led to the identification of 10 major teaching responses to the 10 learning needs profiled above. These were:

1. a calm learning environment, free from clutter;
2. focused tasks presented in small steps;
3. personal space for the student with plenty of support and praise;
4. visual structuring;
5. scripting/role play;
6. short, key information-carrying word instructions;
7. visual clarity and graphic simplicity;
8. frequent, short exercise programmes during the day;
9. a breakdown of tasks with visual and tactile clues, and time given for the child to complete the task;
10. multisensory learning – giving messages through a variety of sensory pathways.

As one student with FASD said:

'When a teacher uses visual clues, I can understand the topic. I learn better when things are presented in a visual way. My brain does not always cope with the words the teacher says. I would say to teachers, "Please show me, don't tell me . . . "'

Managing the child with FASD in the classroom environment

Observations indicated that the structure of the classroom was absolutely key to how children with FASD functioned in their learning environment. Where teachers had carefully considered physical structure, deployment of staffing, visually based resources, groupings of children and their teaching styles, then the levels of engagement for these children were considerably higher than in classrooms where this did not happen. Discussions with teachers showed that when considering these five points, in relation to physical structure, they had thought through the lighting of the classroom, creating distraction-free environments, and any sensitivity to colour that the child may show. For example, when deploying staff they knew that Mathematics was a particularly challenging curriculum area for the child and therefore ensured that a teaching assistant was available to support the child with FASD during these sessions. As manual dexterity is not a strength of children with FASD, pencil holders were provided. In order to strengthen visual learning, visual clutter on tables was kept to an absolute minimum.

Peer groupings were inevitably the major problem area. The child with FASD is often irrational, yet longs for friendships. Ten teachers reported that they had tried 'buddy systems', but, in several instances, this had led to the buddy actually being physically or verbally abused by the child with FASD. Most teachers adopted a rotational system, where the child with FASD joined different groups for different curriculum areas. This was easier to achieve in the secondary school context than in the primary school context.

An overriding message in relation to teaching staff is that the child with FASD is a visually dominant learner – not in the same pronounced way as the child with ASD, but their visual processing was certainly more efficient than their auditory/vocal processing. These teacher interventions to mediate the learning environment mirror the advice offered by Kleinfeld and Westcott (1993) for managing the child with FASD in the classroom. They suggest:

- seating the child at the front of the classroom, always in the same seat;
- minimising distractions;
- providing a calm space;
- ensuring visually clear display;
- using tape on the floor to define spatial boundaries;
- keeping the classroom door closed;
- closing blinds partially (if bright light);
- avoiding bells.

In a recent study, Blackburn, Carpenter and Egerton (2010, p. 143) state: 'Support and education for children with foetal alcohol spectrum disorders are best directed at the child's individual point of learning need'. From their study, they identified that the main strategies for working with children and young people with FASD were:

- clear, concrete, simple language backed up with visual clues;
- consistency with language, rewards and routines;

- being prepared to repeat instructions and rules;
- implementing and sticking to a routine;
- providing structure and constant supervision;
- employing adaptive teaching techniques which focus upon the child's interests, strengths and developmental stage.

Due to lack of specific guidance, several teachers had invented their own starting points for educating the child with FASD, and often borrowed from the world of ASD. There were many examples of teachers using social stories (Gray & White, 2002). This technique was extended by the researcher into 'scripting' whereby children were given opportunities to role play forthcoming situations that they would encounter and rehearse the actions and language that they may have to use in those situations. For example, a 10-year-old with FASD was about to use the local shop to help his mother. A script was devised for him whereby he could practise the exchange of money for a selection of goods and the language to be used in making the purchases. This ensured that when he went to the shop independently for the first time, his chance of success was much higher than if he had not been prepared.

Many children with FASD may appear clumsy and impulsive, craving high-intensity movement. Yet when they do engage in movement activities, their hand-eye co-ordination is often not well developed, and they display an inappropriate use of physical force. In her excellent guidance for working with young children with FASD in the early years, 'Building bridges with understanding', Blackburn (2009) advises the use of 'fidget items' (for example, a stress ball, koosh ball, bean bag, spiral shoelace or spiral keyring) to focus the child's need to move constantly and also to improve their concentration. Certainly many teachers found that providing children with the opportunity for regular short bursts of activity was an effective way of addressing the inappropriate movements and physical hyperactivity the child with FASD may otherwise display. Many children with FASD benefit from the intervention of an occupational therapist who can devise a sensory-integration programme. Within the curriculum, it is more than what teachers commonly understand to be PE! Focused, taught movements can support brain development (Carpenter, 2007).

Managing the child with FASD in the classroom environment

The erratic learning pattern of the child with FASD meant that many teachers found it difficult to plan learning activities for the child. Based on a differentiated model of curriculum planning (Carpenter, Ashdown & Bovair, 2001), a planning model was evolved which included a core, extension and support activity. The purpose of this was for the teacher to be able to pitch the learning for the day depending upon the child's mood and attitude to learning. If the child was particularly distracted or emotionally volatile, then the support activity could be implemented, but if they were calm and engaged, then the extension activity could be used. This approach prevented the children from becoming completely disengaged from learning, and ensured they were less disruptive in the classroom environment (O'Brien & Guiney, 2001).

The description of the core activity always articulated the central skills that would be acquired, and the support activity involved a dimension of the core learning task that promoted self-image and the reinforcing of success through achievement. The activity was designed to be simpler and to link to earlier learning. The extension activity was a parallel activity reinforcing the same core skills but in a different form, and enabled the child to explore aspects of the core activity, but often in short bursts due to their limited concentration span.

Many of the children observed in this study particularly enjoyed activities that focused on themselves. A particularly good example developed by one teacher was a personal learning plan which was used very effectively to remind the child of their own goals and the successes that they had achieved. This plan was listed as:

- me and my future – their dreams and aspirations;
- my support – what physical resources were available in the classroom to assist the child;
- my progress – there was a performance chart logging the child's progress;
- my subjects – this described some of the key learning activities the child could enjoy in each subject
- my goals – these were goals set by the child themselves as steps to improve and raise their attainment
- my best work – evidence of their success showcased in their work folder.

The plan was designed using digital photographs, visual symbols and bold text. Often when the child was very withdrawn or lacking in self-esteem, it would be used to remind them how successful they had been at times, and help them look to what their future achievements may be.

Understanding the learner with FASD

Children with FASD are very erratic and unpredictable learners, and it is necessary to reframe our traditional expectations. Strategies adopted must take into consideration neurological differences. Due to their sensory processing difficulties, we need to consider how children with FASD make sense of, and use of, information from the sensory world (Jirikowic, 2007). Children with FASD often over-react, even to simple things like a fly landing near them. They may startle if someone approaches them from behind. They may be driven to seek or avoid certain sensations.

There is also significant emotional dysregulation in children with FASD, and they are prone to significant mood swings. Their capacity for self-regulation is impaired; they find it difficult to self-calm, and seem not to respond well to parental calming techniques such as hugging. Classrooms have to be carefully designed to accommodate their learning and behavioural needs. Some primary teachers in this study had developed 'safe areas' in their classrooms, providing a personal space for the child with FASD, containing cushions and favourite toys/activities known to have a calming effect.

Every Child Matters

It would be easy to create a whole pedagogy around the child with FASD, but in the context of inclusive education, it is better to seek to blend their learning styles into inclusive classroom settings. In this study, the learning needs of the child with FASD, and the teaching response to that need, were set within the context of the five outcomes of *Every Child Matters*. For example:

- be healthy – a programme of focused exercise to moderate the child's hyperkinetic traits, aimed at self-motivation and self-regulation;
- stay safe – social stories to address the child's lack of environmental awareness or to explore and explain various social situations, potential dangers, and how to keep personally safe;
- enjoy and achieve – visual presentation of tasks and over-learning routines to support learning continuity and retention;
- make a positive contribution – an adapted environment, to include the use of specific, visually supported instructions, social stories and a personal space for the child to withdraw to, which reduces instances of personal frustration leading to loss of self-control and subsequent embarrassment;
- achieve economic well-being – give the child concrete experiences of time, number, space, money, etc., which may overcome their mathematical challenge.

The future for people with FASD

FASD costs the US \$36 billion dollars per year, and the total lifetime cost of an individual with FAS to society is estimated at \$2.9 million (Peadon et al., 2008). The long-term costs of FASD impact on health care, residential services, disability services, housing, social services, adult vocational services, sexual health counselling and support services. Young people living with undetected and undiagnosed FASD will often enter the criminal justice system and without intervention will become long-term prisoners. The lifelong implications of FASD are often compounded by secondary disabilities in adulthood such as mental health problems and drug addiction. Mental health problems may escalate during adulthood – 23% of adults with FASD have attempted suicide, while as many as 43% have considered it (Huggins, Grant, O'Malley & Streissguth, 2008).

In particular, friendships are problematic for people with FASD, and, in adulthood, they find themselves socially isolated and excluded from many community-based programmes due to their inability to sustain friendships, initiate socially appropriate peer interaction or to cement and secure friendship bonds (Streissguth & Kanter, 1997). (This is a pattern also reported by Taylor and Houghton (2008) in a recent edition of the *British Journal of Special Education* for children with AD/HD, again underscoring the interface between these two disabling conditions.)

Conclusion

There is clearly a significant shortfall in guidance for teachers on how to educate children with FASD in the UK. Yet

FASD now accounts for the largest, non-genetic group of children presenting with learning difficulties/disabilities. Their difficulties epitomise that much-used phrase, 'complex needs'. Their unusual style of learning and their extreme challenging behaviour is out of the experience of many teachers, and therefore they find themselves, as the title of this article says, 'pedagogically bereft'.

Through teacher interview, classroom observation and literature search, the research study described above attempted to offer some structure to the process of teaching and learning, and to provide some evidence-based suggestions for how children with FASD may meet that major twenty-first-century challenge, engagement. There is much yet to be done, and the only way that there will be significant improvements in the quality of teaching and learning for these children is through a government-led initiative to address the needs of this sorely neglected pupil group. The needs of these children have to be set into the wider context of society's debate about alcohol, for without such a debate the numbers of children with FASD will grow year on year.

The Children's Plan: One Year On (Define Research & Insight, 2008) launched the Youth Alcohol Plan, which is committed to a hard-hitting campaign to make young people think about the consequences of drinking too much alcohol. As a society, we find discussions around alcohol consumption difficult. The DCSF's study (DCSF, 2008) on the use of alcohol among children and young people has acknowledged that the causal myth of the 'age of the first drink' is a huge obstacle to overcome.

From all professional sectors that are aware of this problem, we are hearing pleas to recognise the scale of the problem. In the *British Journal of Psychiatry*, Gupta and Warner (2008) have recently stated that 'an unrecognised, alcohol-related dementia time bomb is facing young drinkers'. Gilmore (2009), reporting for the Royal Society of Physicians, has stated that:

'The younger they drink, the more likely they are to have alcohol-related problems later in life. It is now common to see young men and women in their early 20s with end-stage alcohol liver damage.'

One social commentator, Sigman (2008), has pointed out that 'When it comes to our logic regarding introducing children to alcohol, we seem to be thinking under the influence of the devil's buttermilk.'

These societal debates are necessary if we are to prevent a rapid escalation beyond the current high levels of FASD in the UK. FASDs can be especially hard for families because they are 'invisible' disorders that show up primarily as behaviour and learning problems (Olson & Astley, 2007). We only have to listen to the profound words of Elizabeth Russell, a mother of two sons with FASD, to realise how people wish that they had been given appropriate warnings upon which they could have based effective personal choices – not only for themselves, but also for their offspring:

'If my son, Mick's, paediatrician had enquired about my alcohol intake when he diagnosed Mick at six months of age as "possibly retarded", Seth (my other son) would not now have Fetal Alcohol Syndrome. We would have two relatively healthy children in whose future was woven the thread of peace and contentment, not fear and apprehension, and I would never again have to look at my son's terrified eyes hiding behind a make-believe smile.'

(www.rffada.org)

However, today, they are not the major concern of the classroom teacher. For them, it is the challenge of the child with FASD who faces them: how are the learning needs of this child to be met; is there responsiveness in the curriculum; do we have the capacity to evolve teaching strategies that will touch that child with FASD at his or her point of learning need?

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