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Shaping the future for children with foetal alcohol spectrum disorders

CAROLYN BLACKBURN, BARRY CARPENTER and JO EGERTON

This article describes work undertaken in connection with an ongoing research project funded by the Training and Development Agency for Schools. It illustrates the educational implications of foetal alcohol spectrum disorders (FASD) and its implications for the educational workforce in seeking to meet the needs of those children who are affected.

Key words: foetal alcohol syndrome, foetal alcohol spectrum disorders, special educational needs, workforce development.

Introduction

The education system at all levels supports an increasing number of children with new and emerging disabilities for whom educators may be ill equipped if knowledge and resources are not available. One such emerging disability is foetal alcohol spectrum disorders (FASD). FASD is currently the most common, non-genetic cause of learning disability in the UK (British Medical Association (BMA), 2007), affecting around 1% of live births in Europe (Autti-Ramo, 2002), and costing an estimated £2.9 million per individual across their lifespan (Peadon *et al.*, 2008).

FASD operates as an umbrella term for a set of disorders caused by the consumption of alcohol by a mother while pregnant (Mukherjee *et al.*, 2006). Alcohol is a teratogenic compound (i.e. a substance that interferes with the normal development of the embryo or foetus) which readily crosses the placenta. In the absence of a developed blood filtration system, the foetus is totally unprotected from alcohol circulating in the blood system (BMA, 2007), which can result in foetal damage.

The shared physical characteristics of infants born to mothers who drank alcohol during pregnancy were first recognised in 1968 by Lemoine *et al.* in France. The effects of heavy drinking in pregnancy on the foetus were independently described again in 1973 by three American paediatricians, Ulleland, Smith and Jones (Jones and Smith, 1973). They coined the term foetal alcohol syndrome (FAS), and identified four categories of associated features:

- pre- and post-natal growth deficiency – the babies were short in length, light in weight with a smaller than normal head circumference, and they did not ‘catch up’ with healthy children as they grew older;
- physical anomalies – the best known of these traits is the physical cluster of facial features common to these children;
- central nervous system dysfunction – this can be a significant problem for the child and includes learning difficulties, problems with concentration, and distractibility as well as difficulties with executive function;
- confirmed maternal alcohol consumption.

The term foetal alcohol spectrum disorders has been developed in more recent years (Mukherjee *et al.*, 2006). The strength of this term is that it gives the clear message that there is a range of disability rather than an all or nothing dichotomy. However, while FAS is a clinical diagnosis (Hoyme, in Mukherjee *et al.*, 2006), FASD is not (Astley and Clarren, 2000).

Within the educational arena there has been almost no systematic research on the needs of students with FASD or on the best educational strategies (Ryan and Ferguson, 2006), or any systematic training for teachers to educate young people on the consequences of maternal alcohol consumption. With FASD barely on the UK radar the situation is even more disconcerting. Ryan and Ferguson (2006) point out that most children with FASD are not placed in special schools. Therefore it is important for all teachers to have at their disposal a sound knowledge of the learning needs of this group of students and a range of interventions and strategies at their disposal in order to personalise learning for these students.

Prevalence of FASD

In the UK there are currently no reliable prevalence figures for FAS or FASD as they are not routinely collected or recorded by the British Paediatric Surveillance Unit (BMA, 2007). However, there is general consensus arising from separate research studies carried out in different countries that the figure for FAS is 1 in 1,000 with FASD being three to four times higher. The USA’s Centre for Disease Control (CDC) proposed a rate of 1 in 100 for FASD in 1995 using the National (USA) Birth Defects Monitoring Program

(O'Leary, 2002). Problems with studies conducted into the prevalence of FAS and FASD include inconsistent diagnostic methods, lack of agreement over which diagnoses within the foetal alcohol spectrum should be included and differing methodologies applied to studies.

The prevalence rates of FAS vary with the populations investigated. They range from 1 per 1,000 in relatively low-risk populations, through 4 per 1,000 in moderate-risk populations, to rates of between 39.2 per 1,000 (May 2000) to 40+ per 1,000 in certain very high-risk South African communities (Molteno, 2008). In France, the prevalence is estimated as 1 in 330, as it is in Germany; in Sweden, the estimates are 1 in 600, and in the USA, 1 in 1,000. O'Leary (2002) found the rate for Southern Australia to be 0.18 per 1,000. However, in research carried out among some disenfranchised indigenous communities, FAS is reported to occur in as many as 1 in 170 live births (Golden, 2005).

Characteristic features of FAS

Although a safe level of alcohol consumption during pregnancy has not been established (Gray and Henderson, 2006; BMA, 2007), it is clear that alcohol consumed in pregnancy can result in primary and secondary disabilities that are preventable (Warren and Blast, 1988) and that persist into adulthood (Hawks, 1993). The stage of pregnancy at which the foetus is exposed to alcohol is an important factor in considering potential harm (O'Malley, 2007). The effects are largely the result of timing and dosage of alcohol, but contributory factors also include the presence of other drugs including tobacco, maternal health, diet, age and physiology (e.g. more efficient liver metabolism, other genetic factors, etc.; McCarver, 2001).

The facial anomalies that are a distinctive hallmark of FAS (see Figure 1) are formed only when there is maternal

alcohol consumption at a particular stage of the pregnancy. The three core features are: short palpebral fissures, thin upper lip and philtrum elongation. Other characteristic features include: a flattened midface; epicanthal folds; a short upturned nose; receding forehead and chin; asymmetrical ears. However, this facial dysmorphism, which typically makes the syndrome noticeable in the post-birth period and infancy, can dissipate with age, thus reducing the likelihood of diagnosis as the child grows older (Greenbaum *et al.*, 2002).

Implications of FASD for child development

The developmental profile of the child with foetal alcohol spectrum disorders is variable, and the severity of presentation is not necessarily indicative of the severity of impairment (Stratton *et al.*, 1996). Some children will not present any observable characteristics of FASD; their symptoms will be purely behavioural. It is important that teachers are aware of the true effects of the hidden impairments, so they can recognise and accommodate children's learning needs.

Children with foetal alcohol spectrum disorders may score within normal limits on measures of IQ, appear physically mature and give the appearance of functioning at a level consistent with their chronological age. Their expressive language may be in advance of their actual age, and their reading skills may be chronologically appropriate. However, as Benton Gibbard *et al.* (2003, p. 72) write:

many areas of cognitive functioning are only peripherally assessed through an IQ measure, such as attention and concentration. In addition, IQ testing does not assess other domains, such as higher order executive functions.

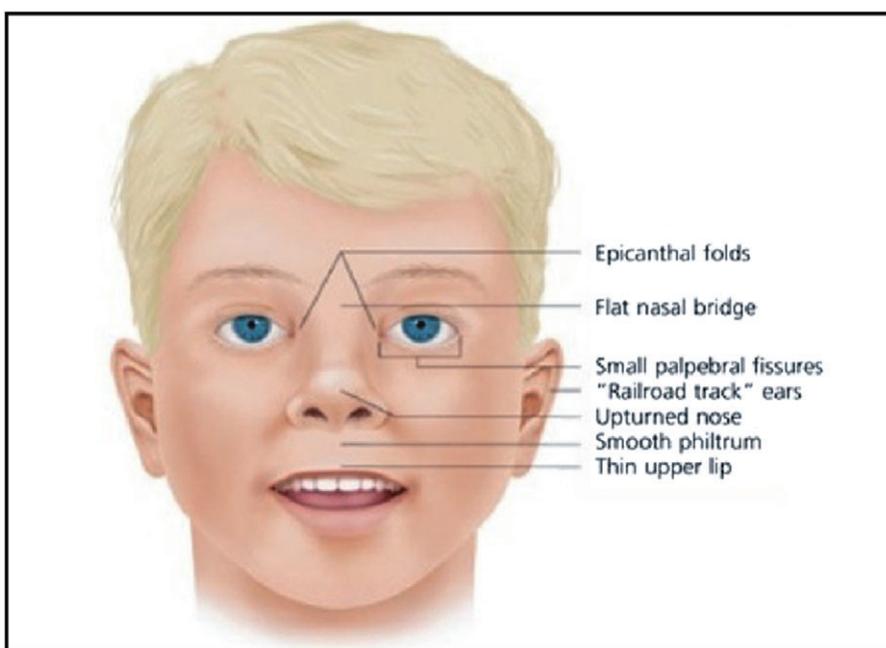


Figure 1. Facial features of a child with a full FAS diagnosis

Table 1. Synthesis of observed impairments associated with FASD compiled from a summary of neuropsychological research by Benton Gibbard *et al.* (2003) and Kodituwakku *et al.* (2006)

<i>Areas of impairment</i>	<i>Synthesis of observed impairments associated with FASD</i>
Cognitive impairment	<ul style="list-style-type: none"> • Impaired auditory learning • Impaired non-verbal intellectual ability • Impaired IQ • Memory function impairment – including visual, short-term, working memory, explicit memory functioning, conscious memory recall • Impaired strategic manipulation of information to improve recall • Impaired initial encoding of information • Visual–motor integration and visual–perceptual deficits, including reading disorders, impaired visual–spatial perception • Slow information processing • Impairment of higher-level receptive and expressive language • Impaired comprehension • Impaired arithmetical reasoning and mathematical skills (e.g. money management and telling time) • Cognitive inflexibility • Poor executive function ('dysexecutive syndrome'): • Impaired concept formation • Poor abstract reasoning/meta-cognition • Impaired ability to plan
Behavioural/ emotional difficulties	<ul style="list-style-type: none"> • Difficulty in focusing attention and maintaining attention in the presence of distractors • Poor impulse control/response inhibition • Disorganisation • Impaired persistence • Perseverative behaviour • Attention deficit hyperactivity disorder (usually earlier-onset, inattention subtype; often unresponsive to medication) • Developmental, psychiatric and medical conditions, attachment disorder, post-traumatic stress disorder • Anxiety disorders
Social difficulties	<ul style="list-style-type: none"> • Emotional immaturity (e.g. age-inappropriate emotional interactions and responses) • Lack of effective reciprocal social behaviour (leading to alienation from others) • Difficulty in understanding the social consequences of behaviour • Lack of social perception including difficulties with: <ul style="list-style-type: none"> • Detecting and understanding non-verbal communication/subtle social cues • Understanding another's perspective • Self-reflection and • insight into own actions
Other difficulties	<ul style="list-style-type: none"> • Gross and fine motor function difficulties • Sensory processing difficulties

These deficits will have a profound effect on the ability of a person with FASD to function . . . without appropriate supports and interventions.

Thus, the academic ability of individuals with foetal alcohol spectrum disorders is below that commonly associated with their IQ score, and their living skills, communication skills and adaptive behaviour levels show an even greater deficit between actual and IQ-commensurate functioning. Adaptive behaviour or functioning is an age-related, cultural construct of social competence (e.g. daily living, social, motor and communication skills) across different settings and situations – the family, the peer group, the working group, etc.). In areas such as social skills and emotional maturity, they may be performing at a developmental level associated with half their chronological age (Streissguth *et al.*, 1996). The reasons for this are described in the next section.

The learning profile of children with foetal alcohol spectrum disorders

Children with foetal alcohol spectrum disorders do not fit general theories of learning development (see Table 1). Their short-term immediate verbal recall is often well devel-

oped, allowing them to 'parrot back'; their implicit memory functioning or procedural or unconscious recall also typically functions within normal limits (Mattson and Riley, 1999). This can lead to a false impression of 'good memory'. However, other significant neurocognitive impairments impede their ability to function independently, and they often do not make age-appropriate gains in intellectual function due to impaired learning, memory, attention, concentration, higher-order executive functions, etc.

The most common factors present in all children with foetal alcohol spectrum disorders are 'cognitive confusion' (Shaywitz *et al.*, 1981), learning and memory impairment as well as an inability to understand the consequences of their actions. However, studies show that there is no consistent pattern of learning difficulties in FAS, even in severe cases (Abel and Sokol, 1987), and each child will have a unique set of learning difficulties depending on which area(s) of the brain were damaged and/or reduced in size *in utero*.

Not all children with foetal alcohol syndrome have significant learning difficulties (Streissguth *et al.*, 1991). Those children with a higher IQ score will remain delayed in some areas of learning, but may advance in others as they reach

adulthood. However, their irreversible brain damage may also have caused difficulties in the areas of social and emotional development, hyperactivity and attention, understanding rules and cause and effect, receptive and expressive language, generalisation of learning, sensory processing and problem solving and numeracy. Although hyperactivity may improve over age, inattention and impulsivity generally do not.

Language delays are often observed in children with *full* foetal alcohol syndrome during the pre-school years, and they may also have receptive and expressive difficulties (Shaywitz *et al.*, 1981). Their expressive difficulties include a limited and poorly articulated vocabulary and delayed use of sentences or more complex grammatical units (Becker *et al.*, 1990). Many children with foetal alcohol spectrum disorders, however, have mixed expressive-receptive language disabilities, and once language has been sufficiently developed, their basic language skills can be a strength (Benton Gibbard *et al.*, 2003). But an excessive quantity of speech, particularly questions, may mask their impaired expressive language skills. Although apparently articulate, their verbal communication typically lacks complex meaningful content, and their actual comprehension of complex material is often significantly compromised (Benton Gibbard *et al.*, 2003). Their comments may be off target or unrelated to the topic of conversation. Their receptive language skills are also compromised. They may not understand what to do after oral instructions from their teacher although they appear to be paying attention (British Columbia Special Programs Branch, 1996). Even short-term memory for quite simple sentences is delayed (Becker *et al.*, 1990).

Verbal learning has been shown to be impaired with affected children experiencing problems at the encoding level (the initial stages of memory formation) rather than retention and recollection (Mattson *et al.*, 1996). They might also have difficulty balancing linguistic and socio-cognitive task demands in conversations (Hamilton, 1981) and in narratives (e.g. Thorne *et al.*, 2007).

For children with foetal alcohol spectrum disorders, difficulties in socio-emotional development are common and appear to continue into adulthood (Jacobson and Jacobson *et al.*, 1993). A particularly difficult aspect for parents to accept is that some children with foetal alcohol spectrum disorders have problems forming attachments with their primary carers, though more research into this area is necessary as current research does not differentiate between the varying ability levels of children with foetal alcohol spectrum disorders. The vulnerability of these children is a constant worry to parents; for example, long after other children have learned about not going with strangers, children with foetal alcohol spectrum disorders will not understand the risks.

Compounding factors and secondary disabilities

Compounding factors may increase the psychological pressure of imposed nonconformity on the child with foetal alcohol spectrum disorders and lead to their developing secondary disabilities. In individuals with foetal alcohol spectrum disorders, these secondary disabilities may include mental health problems (seen in 87% of a University of California sample of 23 children (5–13 years) who had experienced heavy exposure to alcohol in the womb; O'Connor *et al.*, 2002), disrupted school experience (60% over the age of 11 years; Riley, 2003); trouble with the law (60% of 415 teenagers with FAS/FAE; Streissguth and Kanter, 1997), confinement (50%; Streissguth and Kanter, 1997), inappropriate sexual behaviour, problems with dependent living (80%; Riley, 2003) and employment (Streissguth and Kanter, 1997). They are also 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) also 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 (in the USA, the adult figure is five times the national average).

Compounding factors may include the following categories.

Family relationships

It is worthy of note that children affected by pre-natal alcohol exposure often come to the attention of protective service agencies – they frequently enter foster care and may be placed for adoption (May *et al.*, 2006). Astley *et al.* (2002), in a study of children in foster care in Washington, USA, found that among the sample of children who were fostered, the prevalence of FAS was 10 to 15 times greater than in the general population. Streissguth *et al.* (1985) identified that 73–80% of children with full-blown foetal alcohol syndrome are in foster or adoptive placement.

Lack of knowledge about the child's disability

While information regarding the dangers of alcohol consumption is highlighted by the press and is the subject of numerous social studies, few articles to date have followed through the likely consequences of alcohol-fuelled sexual liaison to consider the effects of the mother's continuing high level of alcohol consumption on the resulting foetus. Within the educational arena there has been almost no systematic research on the needs of students with foetal alcohol spectrum disorders or on the most effective educational strategies (Ryan and Ferguson, 2006).

In a recent study that explored the support and education of children with foetal alcohol spectrum disorders in the early

years in Worcestershire, UK (Blackburn, 2009a), it was found that 78% of 161 Early Years staff who responded to a survey sent out to Worcester County Council Early Years and Childcare Service had a low-level knowledge of FASD and felt that this lack of knowledge would impact negatively on their ability to meet the needs of a child affected. As one practitioner pointed out:

‘Because there’s so little understanding and awareness about FASD at the moment, it would be difficult for staff to plan for these children, because they haven’t had the training to support them’ (Blackburn, 2009b, p. 21).

As most children with foetal alcohol spectrum disorders are not placed in special schools, it is crucial that education staff are aware of the learning needs of this group of students coupled with a range of interventions and strategies to employ in their efforts to achieve the best outcomes for children affected.

Transition between primary and secondary school

The cognitive and behavioural profile of children with foetal alcohol spectrum disorders 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 the child progresses through school. Therefore, repeated neuropsychological assessment may be needed at different times during the life of an individual with foetal alcohol spectrum disorders to capture accurately their evolving strengths and weaknesses, 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). A lack of awareness of these children’s difficulties can lead to consistently unrealistic expectations. Without the appropriate supports and interventions, this can cause the child to develop serious behavioural, cognitive and psychological secondary disabilities.

The challenge for education staff

There has been a significant shortfall in guidance for teachers on how to educate children with foetal alcohol spectrum disorders in the UK, whereas in countries such as Canada there is extensive guidance and a well-developed system of provision for these children. Carers of children with foetal alcohol spectrum disorders report that conventional behavioural and learning approaches often fail to assist their children (Devries and Waller, 2004). These children’s difficulties epitomise that much-used phrase, ‘complex needs’.

Their atypical style of learning and their extreme challenging behaviour is out of the experience of many teachers, and therefore they find themselves ‘pedagogically bereft’ (Carpenter, forthcoming).

The aim of the UK Department for Children and Schools and Families, expressed in their 21st-Century Schools White Paper (DCSF, 2009), is that every child in the UK will have an education that prepares them for the challenges of the 21st century by ensuring that:

‘every child enjoys their childhood, does well at school and turns 18 with the knowledge, skills and qualifications that will give them the best chance of success in adult life . . . to secure the future success of our country and society’ (DCSF, 2009).

Teachers and teaching support staff will undoubtedly meet children with foetal alcohol spectrum disorders in their classrooms. They need to know how to respond to their learning needs effectively and enable them to maximise their potential, improve their life chances and take their places alongside their mainstream peers as citizens. In order to achieve this, educators will need to be well informed and equipped, reflective, patient, creative and empathetic. They will need training and support to realise this in the context of the English National Curriculum and National Education Strategies (see DCSF, 1997–2010).

Children with foetal alcohol spectrum disorders and the Curriculum

The profile of their learning difficulties (described in ‘The learning profile of children with foetal alcohol spectrum disorders’ above) makes children with foetal alcohol spectrum disorders difficult to accommodate within any key stage of the English National Curriculum. Support and education for children with foetal alcohol spectrum disorders are best directed at the child’s individual point of learning need. In developing personalised learning pathways for students with foetal alcohol spectrum disorders, practitioners have to take account of students’ 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; and IQ and academic abilities. It is important to build upon their positive personality characteristics, strengths and talents (Clarren, 2004), and to manage the learning environment to allow these to flourish. This will include providing consistency, structure and repetition, sensory regulation and a concrete, hands-on approach to learning.

Shaping the future: effective pedagogies

The challenge remains: how do we optimise learning for this pupil group? We have a responsibility to ensure that teachers

are prepared. As mentioned above, currently there is no direct guidance from any government agency in the UK to teachers on how to educate children with foetal alcohol spectrum disorders. The three major parent-led organisations in the UK, NOFAS-UK, the FASD Trust and FASAware, do provide some guidance, but it is in need of further development and routing within the current curriculum framework in the UK.

The educational response needs to take account of these learners' strengths as well as their difficulties in order to develop personalised learning pathways. Students with foetal alcohol spectrum disorders 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 athletic skills in individual sports.

Each child affected by FASD will present a unique set of learning needs that is dependent on the nature and extent of damage caused to the brain for that individual. However, for all children affected there is a 'multiple educational jeopardy' – 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. The need for personalised, meaningful and high-quality education is crucial if we are to avoid this bleak outcome (Carpenter, 2009).

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Correspondence

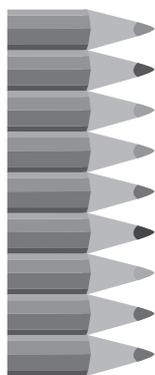
Carolyn Blackburn
33 Sandles Road
Droitwich Spa
Worcestershire
WR9 8RA
Email: carolynb@fasdeducation.org.uk

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- Secondary Resource/Book to support Teaching and Learning (Non ICT)
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