

SHAPING THE FUTURE AND FACING THE CHILDREN - FOETAL ALCOHOL SPECTRUM DISORDERS (FASD)

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Abstract

'FASD' operates as an umbrella term for a set of disorders caused by the consumption of alcohol by a mother whilst pregnant (Mukherjee, Hollins & Turk, 2006). Alcohol is a teratogenic compound (ie a substance which interferes with the normal development of the embryo or foetus) that 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.

Children affected can face difficulties in the areas of socially inappropriate behavior, inability to work out solutions spontaneously, inability to apply consequences from past actions, difficulty with abstract concepts, time and money, difficulty in storing, retrieving and processing information, the need for frequent cues and reminders to stay on task, remember equipment, etc, the need to talk to them self out loud to achieve verbal feedback, fine motor skills are affected more than gross motor skills, displaying apparent lack of remorse, erratic moods and 'roller coaster' emotions, inability to weigh pros and cons when evaluating situations and making decisions (Kellerman 2008).

A current educational research project funded by the Training and Development Agency for Schools aims to investigate the educational implications of FASD in the UK in order that the current and future educational workforce may be equipped to meet the needs of this group of learners. Working with a sample of 9 schools from the mainstream and special education sectors, the project will leave in place resources and guidelines for education to use when working with students affected

by FASD, in order to improve outcomes under Every Child Matters and ameliorate associated secondary disabilities.

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 (Carpenter, 2005). One such emerging disability is Foetal Alcohol Spectrum Disorders (FASD).

Foetal Alcohol Spectrum Disorders (FASD) is currently the most common, non-genetic cause of learning disability in the UK (Plant, 1985; Plant et al., 1999; Autti-Ramo, 2002; British Medical Association, 2007; May and Gossage, 2001; Sampson et al., 1997), 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 whilst pregnant (Mukherjee, Hollins & Turk, 2006). Alcohol is a teratogenic compound (ie a substance which interferes with the normal development of the embryo or foetus) that 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 4 categories of associated features:

- Pre- and postnatal 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 (FASD) has been developed in more recent years, operating as an umbrella term for a set of disorders caused by the consumption of alcohol by a mother whilst pregnant (Mukherjee, Hollins & Turk, 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, whilst FAS is a clinical diagnosis (Hoyme, in Mukherjee et al., 2006), FASD is not (Astley & 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 & Ferguson, 2006a) nor 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 & Ferguson (2006a, 2006b) point out that most children with FASD are not placed in special schools and 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 this group of 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 (British Medical Association, 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 3 to 4 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 Fetal 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 thousand in moderate risk populations, to rates of between 39.2 per thousand (May 2000) to 40+ per thousand 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 which are preventable (Warren and Blast 1988) and which 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; Autti-Ramo 2002). 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; McCarver et al., in O'Malley, 2005).

The facial anomalies which 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 palprebral 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).

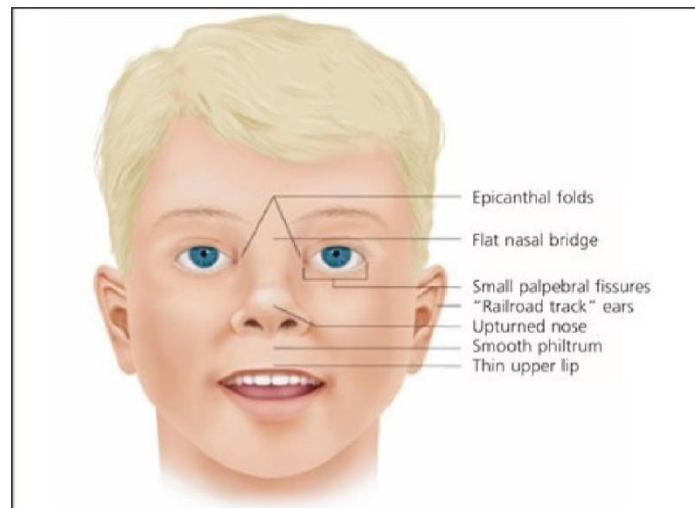


Figure 1: Facial Features of a Child with a Full FAS Diagnosis

Implications of FASD for child development

The developmental profile of the child with FASD 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 FASD 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) 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.

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 FASD is below that commonly associated with their IQ score, and their living skills, communication skills and adaptive behaviour¹ levels show an even greater deficit between actual and IQ-commensurate functioning. 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 section below.

The learning profile of children with FASD

Children with FASD do not fit general theories of learning development (see Table 2). Their short-term immediate verbal recall is often well developed, allowing them 'parrot back'; their implicit memory functioning or procedural or unconscious recall also typically functions within normal limits (Mattson & 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.

Table 2: 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)

Areas of impairment	Synthesis of observed impairments associated with FASD
Cognitive impairment	<ul style="list-style-type: none">• Impaired auditory learning• Impaired nonverbal intellectual ability• Impaired IQ

¹ 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. It can be defined by what an individual does each day, not by her or her ability (i.e. what he or she can do). Adaptive behaviours for infants and small children include sensor-motor skills, communication skills, self care skills and socialisation skills while those for childhood and early adolescence include the application of academic skills to daily life, the application of reasoning and judgement to environmental situations, and the development of group and interpersonal social skills (Sang, 1993). Atypical adaptive behaviour patterns can indicate the presence of developmental delay.

	<ul style="list-style-type: none"> • 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 / metacognition • 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: • Detecting and understanding nonverbal 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

The most common factors present in all children with FASD 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 1988), 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 FAS 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,² 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 FAS during the preschool years, and they may also have receptive and expressive difficulties (Shaywitz, Caparulo & Hodgson, 1981; Tenbrinck & Buchin, 1975). Their expressive difficulties include a limited and poorly articulated vocabulary, delayed use of sentences or more complex grammatical units (Abel, 1990; Becker et al., 1990; Streissguth & Giunta, 1988). Many children with FASD, 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 often is 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

² When a child or young person has receptive language difficulties they find it difficult to understand words, sentence structures or concepts when compared with their peers without difficulties. When a child or young person has expressive language difficulties, their speech and language production appears disordered or delayed when compared to other children their age.

(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, 1996b). They might also have difficulty balancing linguistic and socio-cognitive task demands in conversations (Hamilton 1981) and in narratives (e.g. Coggins et al. 1998, 2003, 2007, Thorne et al. 2007).

For children with FASD, difficulties in socio-emotional development are common and appear to continue into adulthood (Jacobson and Jacobson 2003). A particularly difficult aspect for parents to accept is that some children with FASD have problems forming attachments with their primary carers, though more research into this area is necessary (Mukherjee 2009, personal communication) as current research in this area does not differentiate between the varying ability levels of children with FASD. The vulnerability of these children is a constant worry to parents; for example, long after other children have learnt about not going with strangers, children with FASD will not understand the risks.

Compounding factors and secondary disabilities

Compounding factors may increase the psychological pressure of imposed non-conformity on the child with FAS/FASD and lead to their developing secondary disabilities. In individuals with FASD, 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 had heavy exposure to alcohol in the womb; O'Connor et al., 2002, 90% Streissguth and Kanter 1997), 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 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) 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:

Family relationships

It is worthy of note that children affected by prenatal 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 Fetal Alcohol Syndrome (FAS) are in foster or adoptive placement.

Lack of knowledge about the child's disability

Whilst information regarding the dangers of alcohol consumption is highlighted by the press and 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 fetus. Within the educational arena there has been almost no systematic research on the needs of students with FASD or on the most effective educational strategies (Ryan & Ferguson, 2006a; Kleinfeld and Westcott 1993; Streissguth et al 1991).

In a recent study which explored the support and education of children with FASD in the early years in Worcestershire, UK (Blackburn, 2009), 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 2009).

As most children with FASD 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 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 the child progresses through school. Therefore, repeated neuropsychological assessment may be needed at different times during the life of an individual with FASD 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 FASD 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 FASD report that conventional behavioural and learning approaches often fail to assist their children (Devries and Waller 2004; Malbin 2005). 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 2009, in press).

The aim of the UK Department for Children and Schools and Families, expressed in 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 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). 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 (cf. <http://nationalstrategies.standards.dcsf.gov.uk/>) (Carpenter, 2009; in preparation).

Children with FASD and the Curriculum

The profile of their learning difficulties (described in 'The learning profile of children with FASD' above) mean that children with FASD are difficult to accommodate within any key stage of the English National Curriculum. Support and education for children with FASD are best directed at the child's individual point of learning need. In developing personalised learning pathways for students with FASD, 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; IQ and academic abilities. It is important to build upon their positive personality characteristics, strengths and talents (Alberta Learning, 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 FASD. 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 to develop personalised learning pathways. 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 individual athletic skills in individual sports.

Each child affected by FASD will present a unique set of learning needs 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 (Carpenter 2009 in press).

The need for personalised, meaningful and high quality education is crucial if we are to divert this bleak outcome (Carpenter 2009). Personalised learning is seen as the educational perspective of personalisation with “a drive to tailor education to individual need, interest and aptitude so as to fulfil every young person’s potential” (DfES 2004). Personalising learning means meeting more of the educational needs of students more fully than ever before (SSAT 2009). It has been described as:

High expectations of every child, given practical form by high quality teaching based on a sound knowledge and understanding of each child's needs. It is not individualised learning where pupils sit alone. Nor is it pupils left to their own devices – which too often reinforces low aspirations. It means shaping teaching around the way different youngsters learn; it means taking the care to nurture the unique talents of every pupil. (David Miliband, 2004).

Current Research

A current educational research project funded by the Training and Development Agency for Schools aims to investigate the educational implications of FASD in the UK in order that the current and future workforce may be equipped to meet the needs of this group of learners. Working with a sample of 9 schools from the mainstream and special education sectors, the project will leave in place resources and guidelines for education staff to draw on when working with students affected by FASD in order to improve outcomes under Every Child Matters and ameliorate associated secondary disabilities. The project ends in October 2010.

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