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Facing the challenge and shaping the future for primary and secondary aged students with Foetal Alcohol Spectrum Disorders (FAS-eD Project)

LITERATURE REVIEW

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ABSTRACT

Foetal Alcohol Spectrum Disorders (FASD) is a broad spectrum of completely preventable intellectual and developmental deficits in individuals, resulting from maternal alcohol consumption during pregnancy. FASD can cause a range of physical and intellectual disabilities. Possible physical disabilities include facial differences and major organ damage, as well as hearing and vision impairments. Damage to the brain results in developmental disabilities, which can include general learning difficulties, language, social or motor skills impairment, memory impairment and attention deficits, poor consequential thinking, and poor planning ability. Children affected by FASD can also face misunderstanding about the often hidden cause of their very challenging learning behaviours.

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). FASD now accounts for the largest, non-genetic group of children presenting with learning difficulties/disabilities. The difficulties that children face in the classroom epitomise that much-used phrase 'complex needs' (Dittrich and Tutt, 2008; Carpenter 2009a). Their unusual style of learning and their extreme challenging behaviour is out of the experience of many teachers and, as there is significant shortfall in guidance for teachers on how to educate children with FASD in the UK, teachers find themselves 'pedagogically bereft' (Carpenter, 2009a).

Introduction

Prenatal alcohol exposure has multiple adverse outcomes, the most serious of which are mortality and Foetal Alcohol Spectrum Disorders (Bird and Christensen, 2009). Foetal Alcohol Spectrum Disorder (FASD) is 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, et al., 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.

A brief history of FASD

Although Jacqueline Rouquette wrote about prenatal alcohol exposure in 1957 (Lemoine 1997), 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) [see Appendix A], 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 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, whilst FAS is a clinical diagnosis (Hoyme, in Mukherjee et al., 2006), FASD is not (Astley & Clarren, 2000).

Prevalence

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 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, 2001) 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).

Among siblings of children diagnosed with FASD, the severity of the disorder tends to increase with each successive child born to alcohol-using mothers. Bird and Christensen (2009) found that FASDs

are recurrent in families, and the incidence of the disorder among children who have a sibling diagnosed with FASD ranges from 170 per 1000 (for older siblings) to 771 per 1000 (for younger siblings) (ibid). This evidence of long-term alcohol use among some mothers of children diagnosed with FASD also impacts upon FASD's overall prevalence.

FASD and the pattern of alcohol consumption

Although FASD is commonly associated with maternal chronic alcoholism and binge drinking, a recent significant study has been conducted by a combined American and Italian team in the Lazio region of Italy (May et al., 2006) to ascertain if mild, consistent consumption of alcohol would cause high levels of damage to unborn infants. Typically, in Italy, moderate alcohol consumption is integrated into everyday life as part of the social activity of sharing meals together, and Italian women are not known as binge drinkers, compared to some of their European counterparts. However, among the children of women studied in Lazio, 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 comparatively high. The authors state that 'overall, the rate of FASD in this Western European population may be 3.5%'. Although the methodological design of this study means that these findings may not be widely accepted, they raise the possibility that FASD might not only be associated with extreme patterns of maternal alcohol intake, but also with a more moderate, socially endorsed pattern of consumption. In Societies where the moderate social use of alcohol is increasingly the expected norm, this has serious implications for the growth in incidence of FASD.

<u>Diagnosing FAS</u>

The diagnosis of FAS is controversial, and underdiagnosis[1] is believed to be common. It is likely that there are many more children with FAS and FASD in our schools than records suggest. Health professionals may avoid making a diagnosis of FASD for a number of reasons. These include lack of knowledge about the effects on the unborn child of alcohol use during pregnancy, and failure to ask about alcohol use during pregnancy and to identify 'at-risk' pregnancies. Health professionals may also have inadequate knowledge of the diagnostic features and currently used diagnostic criteria and may lack confidence in the management of FASD, including uncertainty about referral

[1] FAS is often missed when a diagnosis of ADHD, ASD or ADD is given resulting in a partial diagnosis. This leads to 'underdiagnosis' of FAS.

processes, diagnostic services, and treatment. Reluctance to discuss the diagnosis with parents/carers and fear of stigmatising the child and family may also be deterrent (Elliott et al, 2006; Payne et al, 2005). Some professionals may be reluctant to deliver a socially unacceptable diagnosis which currently carries no associated benefits by way of specialised intervention or funding. Under diagnosis may be due also to the diagnostic overlap with a number of other conditions (e.g. Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD) etc.) and the rigorous demands of diagnosis (Autti-Ramo, 2002). The pattern of hyperactivity/inattention in children with a diagnosis of FASD may differ from that seen in children with familial ADHD, as may their response to stimulant medications (O'Malley et al, 2000).

This has serious implications for these children in the classroom. While alternative diagnoses may make educators aware of some of their needs, other needs not associated with the alternative diagnosis may be overlooked. Unless professionals, including educators are sensitised by a correct diagnosis to all potential areas of need associated with FASD (e.g. secondary socio-emotional needs), a failure to take preventative action or notice early indicators for intervention may result, leaving the children potentially at greater risk of poor life outcomes due to a lack timely support (Stratton et al., 1996).

For a medically accepted diagnosis of FAS, in addition to key diagnostic features in the child, there also needs to be incontrovertible evidence of consumption of alcohol by the mother during pregnancy or maternal confirmation of this (ibid). Maternal verification is important due to the degree of overlap between FASD and other disorders; for example, Noonan syndrome, DiGeorge Syndrome (Don and Rourke, 1995). However, in many cases, maternal alcohol consumption during pregnancy cannot be verified. Children with FAS are often placed with adoptive or foster families before their condition is identified (May et al., 1983), and, in many cases, it is difficult for birth mothers to accept that their child's prenatal damage has been due to their own alcohol consumption whilst pregnant (Chandrasena et al., 2008; Hoyle 2006; Hayter 2007).

Anecdotally, within the medical profession there appears to be a paucity of knowledge and understanding of the disorder at both general practice and paediatric levels, although as Mukherjee et al. (2006) point out there have been no recent UK studies which investigate this. Earlier USA studies (e.g. Nanson et al., 1995), suggested that expertise in the field resided among a few

specialists. Sohler & Holmes (1999) found that even when children had been born displaying facial features, and were the issue of high risk pregnancies, routine paediatric screening failed to identify the disorder. Furthermore, despite the mothers in Sohler & Holmes' study being within a high risk group, 73% of the case notes contained no record of maternal alcohol consumption. A more recent survey of 1,600 paediatricians in the USA (Gahagan et al., 2006) suggests some improvement in the situation. However, they found that:

> *"...although 62% [of paediatricians surveyed] felt prepared to identify and 50% felt prepared to diagnose, only 34% felt prepared to manage and coordinate the treatment of children with fetal alcohol spectrum disorders".* (p. e657)

In 1996, the Institute of Medicine of the USA defined a new diagnostic paradigm. (An adaptation of this is shown in Appendix A.) Currently, the most effective diagnostic tool is the four-digit code (Astley, 2004), but alternative methods are being researched which can identify a child with FAS/FASD without having to rely upon maternal verification (Green et al., 2009).

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 dysmorphology, 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).

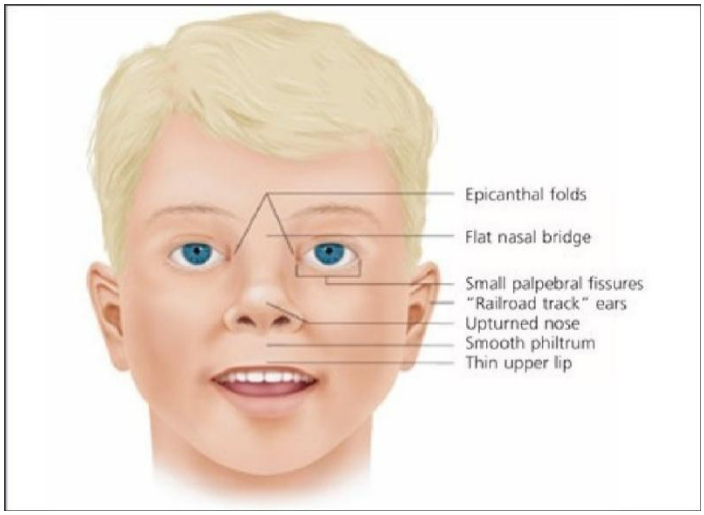

Figure 1: Facial Features of a Child with a Full FAS Diagnosis

A plethora of alternative terms has been suggested by researchers (eg Astley and Clarren, 2000; Barr and Streissguth, 2001; Moore et al., 2002) to describe the range of effects of maternal alcohol consumption (Tindle, 2002) – a result of attempts to find appropriate terms to describe children who showed some features of the spectrum, but did not meet the four criteria laid down by Jones and Smith. In addition to foetal alcohol syndrome (FAS), these include partial FAS (pFAS), alcohol related birth defects (ARBD), and alcohol related neurodevelopmental disorder (ARND) [see Appendix A].

Foetal development and alcohol

Figure 2 (below) shows how the foetus develops throughout pregnancy. The most important time for organ development in the foetus is during the first 12 weeks (Abel, 1988). Later in pregnancy the foetus is growing rapidly and exposure to alcohol results in damage of a different nature, including growth retardation and lack of appropriate development. The darker areas in Figure 2 below represent times when alcohol damage to the foetus is at its greatest, whilst lighter areas represent times when potential harm exists but the risk is slightly reduced.

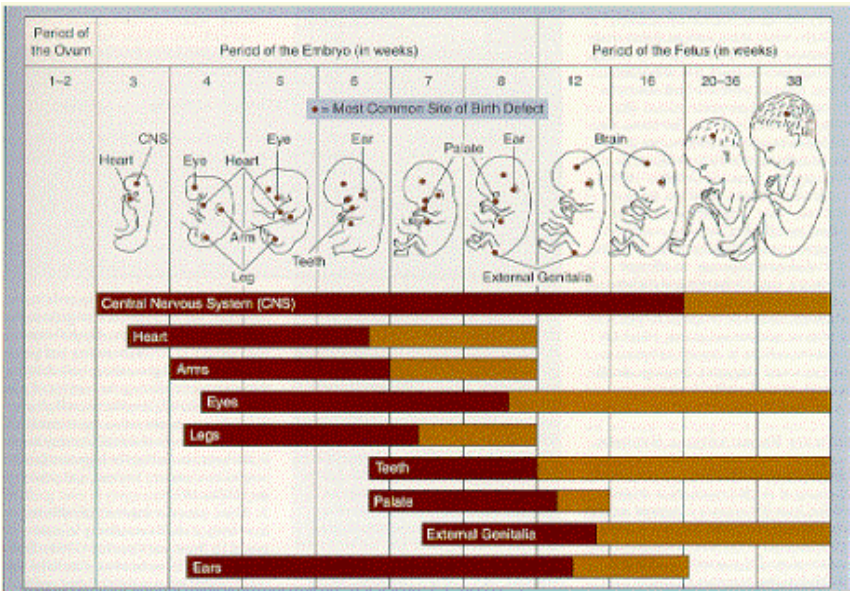

Figure 2: Development of the embryo (Coles, in Mukherjee et al., 2006)

The foetal brain is vulnerable throughout the pregnancy. Table 1 below gives an overview of the cognitive effects of damage to different regions of the brain.

Table 1: An overview of the cognitive effects of damage to different regions of the brain commonly compromised by FASD (Blackburn 2009 fromKellerman, 2008, Blaschke et al., 2009, Mukherjee, 2009)

Areas of brain commonly compromised by FASD	Area of Learning Affected
Frontal Lobe	• Executive function • Co-ordination • Processing and labelling/memory • Focussing and Shifting attention • Planning • Understanding consequences • Maintaining and Shifting attention
Corpus Callosum	• Speed of processing • Connecting two sides of the brain
Hippocampus	• Ability to consolidate new memories • General Learning and emotional regulation
Amygdyla	• Ability to regulate reactions with the environment such as whether to attack or escape • Decision Making

Parietal Lobe	• Spatial awareness • Mathematical ability • Dyspraxia
Basal Ganglia	• Initiation and modulation of motor activity • Motor timing behaviours, specifically difficulty in producing accurate and consistent motor responses when intercepting a moving target or moving through a spatial target in a specified amount of time. • Cognitive functioning
Cerebellum	• Postural control, gait, balance, and the coordination of bilateral movements • Behaviour and memory
Globus Pallidus , Acumberns, Thalamus, Cortex circuit	• Decision Making

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..." (p.72)*

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 behaviour[2] 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	• Impaired auditory learning • Impaired nonverbal 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

[2] 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.

	• 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	• 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	• 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	• 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,[3] 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 et al, 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 (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, 1993). A particularly difficult aspect for parents to accept is that some children with FASD have problems forming attachments with their primary

[3] 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.

carers, though more research into this area is necessary (Mukherjee 2009) 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, leading to a deprivation of "... some of the requisites for normal psychological development" (Verrier, 1993). Verrier argues that, for all children who are separated from a biological mother, the natural evolutionary attachment process which begins in utero and is a "continuum of physiological,

psychological and spiritual events" is interrupted. The experience of separation, even if at birth, causes a sense of abandonment and loss which is "indelibly imprinted upon the conscious minds of children" causing a 'primal wound'. This primal wound in all children who have been separated from their birth parents, she believes, is responsible for some of the disruptive behaviour, previously attributed by educators of these children with FAS to their disability, as they struggle to come to terms with the trauma of their unexplained sense of loss.

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 foetus.

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."*

This is a matter of concern. Commenting in general on the importance of early intervention for children with disabilities, Guralnick (2004) writes that there is:

> " *...unequivocal evidence that the declines in intellectual development that occur in the absence of systematic early intervention, can be substantially*

reduced by interventions implemented and evaluated during the first 5 years of life. " (p.13).

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

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). What is clear is that there is 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 2009a, in press). The aim of this present research project is to develop strategies, guidance and resources to enable educators to support children with FASD to reach their potential as learners through personalised learning pathways relevant to their learning profile.

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, 2009a, in preparation).

In other countries (e.g. Canada, USA), research outcomes have led to improved educational support, and it is hoped that educational support in England for children with FASD will be enhanced by this current project.

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 (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.

Rathburn, writing in Kleinfeld and Westcott (1993), recommends that we "build solutions with them [individuals with FAS/FAE] where they are, instead of where we wish they would be". Merrell (1991) writes:

> *"The alcohol affected child is like a garden. Some seeds need to be planted year after year, like the carrots and radishes. The seeds the birds carry away have to be replaced almost immediately. But there are bulbs that grow in the garden and every year they come up almost without tending. It can be too easy to see what failed to come up this year and step on the crocuses close to the ground. The important thing is to be thankful that there is a garden. It is not a wasteland." (p313).*

However, a starting point is needed in order to avoid duplication of research and study, and ensure that this project builds on prior learning in order to contextualise paradigms and pedagogies for UK educationalists. Research indicates that four focus areas offer the main challenge to teachers (Yukon Education, 2006; Kleinfeld and Wescott, 1993). These are:

- Behaviour for learning

- Executive function
- PSHE
- Numeracy and mathematics.

Behaviours for learning

Behaviourally children with FASD present with attentional problems, poor impulse control, working memory problems and poor adaptive functioning (Greenbaum et al., 2002; Clarke and Benton Gibbard, 2003; O'Malley, 2007), and are often misdiagnosed with Attention Deficit Hyperactivity Disorder (ADHD) (Coles et al, 1997; O'Malley, 2007). Qualitative differences in attention were noted by Coles et al (1997) in a comparison of 149 Afro-American children (average age 7.63 years) with and without FAS. Children in the former group displayed evidence of difficulty in focusing and sustaining attention whilst children in the latter group were able to maintain and focus attention, but displayed difficulties in the subsequent shifting of their attention.

Kathi Hughes, Team Leader for The Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD) funded by the British Columbia Ministry of Education, argues that what is needed in society is a shift in paradigm which redefines the meaning of 'behaviours' (Hughes, 2006). In order for society to understand individuals affected by FASD, we must understand FASD as a primary physical disability. Behaviours presented by students in the classroom are a result of changes in the structure and function of the brain. FASD she argues is "an invisible handicapping condition with behavioural symptoms"

An appropriate learning environment should facilitate children's engagement and promote appropriate behaviour for learning. Research carried out in Canada and USA (Yukon Education Department 2006; Streissguth and Kanter, 1997; Rathburn, in Kleinfeld and Wescott, 1993) recommends that the most effective teaching and learning approaches for children with FASD requires the following factors to be in place:

- The use of clear, concrete, simple language backed up with visual clues
- Consistency of expectations, boundaries, routines, language and rewards
- Repetition of instructions and rules
- Implementation of and adherence to a routine

- Provision of structure and constant supervision
- Employment of adaptive teaching techniques that focus on the child's strengths, interests and developmental stage
- Constant, consistent and immediate praise.

In addition, Tanner-Halverson in Streissguth and Kanter (1993) advocates that classrooms have well-defined areas using shapes and colours, visual cues for reminders of routines and memory maps as pictorial descriptions of lessons.

Executive function

Rasmussen (2005) in her work on neurobehavioural functioning of children with FASD describes a pattern of "cognitive and neuropsychological deficits which children with FASD display in the areas of executive functioning, mathematics, and memory". Individuals with FASD often have symptoms or present behaviours that are a direct result of damage to the prefrontal cortex (Kellerman 2008). This area of the brain controls executive function and the effects on an individual from damage to this area of the brain can include:

- Socially inappropriate behavior, as if inebriated
- Inability to work out solutions spontaneously
- Inability to control sexual impulses, especially in social situations
- 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)

In order to understand these behaviours, Diane Malbin recommends that educators

> "*..shift perspective from thinking the child "won't to "can't."* (Malbin 2002)

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

However, students with FASD have talents and strengths which teachers can identify and maximise in order to overcome these difficulties and engage them in the curriculum (Malbin1999). Individuals with FASD may show positive personality characteristics, including persistence and commitment in low-stress situations. Malbin notes that these individuals often enjoy repetitive work and succeed in structured situations. Learning strengths frequently seen in individuals with FASD include strong visual memories, good verbal fluency and a positive use of visual language techniques. They can often learn effectively when tasks involve a hands-on approach. Their high energy level allows them to be involved in many activities. If they have a rich fantasy life, it enhances storytelling. Other strengths include creativity in visual arts and music, and athletic skills in individual sports.

> *"The pattern for each person with FASD is unique, but teachers can become aware of individual strengths and needs, and can tailor programs and supports to build strengths and create hope for students with FASD*." (Clarren, 2004)

PSHE (socio-emotional well-being)

Children with FASD experience problems in the domain of social interactions. Whilst they may be eager to make friends, they simply do not understand the nuances required to formulate friendships.

It has been argued that impaired social communication among children with FASD results from disruptions in linguistic behaviours, underlying social cognitive behaviour difficulties, and impaired

higher order executive functions such as memory, attention, and planning (Coggins et al., 2003). Children with an FASD often may not provide listeners with adequate information. Indeed, caregivers report that they do not typically accommodate the perspectives of others during communication and interaction (Timler et al., 2005). They frequently do not use their language to describe adequately what others may think or know about a situation, show poor cause-and-effect reasoning, and seem unaware of the consequences of their actions (Streissguth et al., 1996).

Descriptions of children's failure to account for another's intentions or feelings have led to the speculation that children with FASD, like those with ASD, may have a deficit in "theory of mind".[4] Diverse explanations have been proposed to account for the fundamental changes in children's thinking that enable them to infer another's beliefs and desires (see Astington, Harris, & Olson, 1988; Hale & Tager-Flusberg, 2003; and Lohmann & Tomasello, 2003). Baron-Cohen and Howlin, 1993) have suggested that theory of mind deficits have far-reaching and devastating effects during everyday social interactions, including limiting one's ability to be sensitive to and anticipate another's intentions and desires as well as to interpret the motivation behind those intentions and desires.

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 forming 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 (O'Malley et al 2008; Streissguth et al., 1996).

Children with FASD need to be taught specifically and sensitively to ensure success in peer relationships. Targeted educational interventions around strengthening emotional resilience could potentially have a sustained and positive impact on the mental health of these young people. A recent study looking at social cognition and emotion-processing abilities in children with FASD recommends that these children:

[4] Theory of mind represents the ability to infer the mental state of others, that is, to interpret and predict another's knowledge, intentions, beliefs, emotions, and desires, especially when this knowledge may differ from the child's own knowledge (Baron-Cohen, 1989).

> *"...receive assistance in social and emotional processing domains, specifically targeting interventions to deal with their unique deficits."* (Greenbaum et al, 2009)

Such an intervention would need to address the building of specific cognitive skills and the practice of appropriate actions, in concrete ways, to improve children's Theory of Mind so that they may more easily predict the reactions of others. A Social Communication Intervention undertaken by Timler et al (2005) used social scripts and role play to improve Theory of Mind and False Belief[5] skills in children with FASD. Susan Ryan (2006) taught the concept of personal space and boundaries using carpet squares for children to sit on during circle time. Social Stories (Gray 2002) can help students to practice new and forgotten skills, prepare children for new situations and environments and explore emotional and safety issues (Ryan 2006; Rathburn in Kleinfeld and Westcott 1993; Carpenter 2009a; Blackburn 2009).

The needs of these children and their families may best be met with a Team Around the Child (TAC) approach, which "places the emphasis firmly on the needs of the child, rather than on organisations or service providers" (Limbrick 2005). The TAC is designed to meet the child and their family's needs holistically and enhance their potential for achieving individual success. Susan Ryan (2006) advocates the development of partnerships and collaboration between families, schools and community agencies and the implementation of 'wrap-around services', including counselling and coaching on social and behavioural skills for students; planned after school activities; family support and counselling on issues related to behaviour for parents and respite care for families.

Numeracy and mathematics

Children with FASD often experience serious problems with maths due to the effect of alcohol on the development of the brain's parietal lobe (Goswami & Bryant, 2007; Keper-Freye et al 1996; Riikonen et al., 1999). Poor myelinisation, particularly in areas impacting the cross-hemispheric transfer of information (Ma et al., 2005; Riley et a.,l 1995; Wozniak et al., 2006), has also been suggested as a possible cause of the functional deficits in mathematical abilities and achievement

[5] To gain false belief skills a child must predict that a person's behaviour is dependent on what that person thinks or knows even when that belief is false.

that are reported consistently among alcohol affected individuals from infancy (Jacobson 2002) to adulthood (Kopera-Frye et al., 1996).

It is thought that general difficulties with mathematical skills relate to visuo-spatial skills and working memory deficits (Ashcraft, 1995). Both of these areas have been found to be compromised in children who are alcohol affected (Kodituwakku et al., 1995; Rasmussen 2005; Aronson and Hagberg, 1998; Aronson et al., 1985; Carmichael-Olson et al., 1998; Coles et al., 2002; Kaemingk and Paquette, 1999; Mattson and Roebuck, 2002; Mattson et al., 2006; Mose et al., 1992; Platzman et al 2000; Spohr et al 1993; Steinhausen et al., 1982; Ueckerer and Nadel, 1996 in Kable et al., 2007). The teaching challenge here is more than differentiation of the mathematics curriculum; rather it is how can the child with FASD engage with mathematics?

Literature suggests that generally maths is best taught in concrete visual terms as part of general life skills (e.g. cooking, shopping, etc.) (Rathburn in Kleinfeld and Westcott, 1993; Yukon Education, 2006; Region 6, Fetal Alcohol Spectrum Disorder Child and Youth Sub-Committee; Carpenter, 2009a; Blackburn, 2009). For example, money concepts can be demonstrated using real coins in role play situations such as restaurants and shops; and time can be taught using paper chains or paper clip chains with each link representing a period of time. .

Kable et al (2007) have achieved some success with an active learning approach to teaching maths, adapted from the 'plan-do-review' methodology developed by the High-Scope Perry Preschool Project. There were several key components of the teaching program designed to compensate for the neurodevelopment difficulties commonly seen in alcohol-affected children. A slower pace of instruction using interactive experiences was used so that information of size, quantity, time, sequences of events, and mathematical operations could be fully processed and integrated. This pace was important to compensate for slower speed of processing (due to disruptions to myelin development) which have been linked to prenatal alcohol exposure. The study also included tangible objects and used tools (such as vertical number lines to facilitate learning that adding results in numbers going up and subtracting results in numbers going down) to compensate for deficits in visual/spatial processing. The project also involved parents in their child's educational journey and targeted maths intervention groups.

The present research

This project seeks to investigate the educational implications of FASD in the UK and develop practical resources to enable educators, and those who train them, to support pupils affected by FASD in the context of UK educational policy. The project will focus on the key areas highlighted above – Behaviour for Learning; PHSE (Emotional Well Being); Executive Functioning; and Numeracy and Mathematics. The aims and expected outcomes of the project include:

- Increased awareness of FASD and the learning needs of children affected
- Development of information and strategies to enable educators to support children with FASD to reach their potential as learners
- Development of CPD guidance and resources to support educators to construct personalised learning pathways for students with FASD that are relevant and pertinent to their learning profile
- Promotion of families as co-educators of children with FASD
- Dissemination of key outcomes to key audiences concerned with the education, care and development of children and young people with FASD.

It is intended that the outcomes of this research will enable educators, including Initial Teacher Training students and Teaching Assistants, to extend their knowledge, skills and understanding in the area of FASD and feel confident in supporting the young people affected.

As a result of the development of FASD primary and secondary learning frameworks, the project team will be able to make guidance and resources available to educators which will support them in developing personalised learning pathways for their students with FASD. In order to create frameworks with which educators will be comfortable and familiar, strategies and pedagogies will be borrowed and adapted from other overlapping areas of Special Educational Needs such as Autistic Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Sensory Integration Disorders (SID) and Attachment Disorders.

For the young people, it is anticipated that they will, with guided support, come to perceive themselves as competent learners, and it is hoped that increased self-esteem and social

competency will ameliorate the possible secondary disability outcomes through individual achievement in each of the five areas of Every Child Matters (DfES, 2004; DCSF, 2007).

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, 2009a in press).

The need for personalised, meaningful and high quality education is crucial if we are to divert this bleak outcome (Carpenter, 2009b). 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)

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APPENDIX A

Educational or Diagnostic Term	Factors Required for Confirmation/Diagnosis
Fetal Alcohol Syndrome (FAS) with confirmed maternal alcohol exposure (requires all features A – D)	A. Confirmed maternal alcohol exposure B. Evidence of a characteristic pattern of minor facial anomalies, including Q2 of the following: 1. Short palpebral fissures (e10th percentile) 2. Thin vermillion border of the upper lip (score 4 or 5 with the lip/philtrum guide) 3. Smooth philtrum (score 4 or 5 with the lip/philtrum guide) C. Evidence of prenatal and/or postnatal growth retardation 1. Height or weight e10th percentile, corrected for racial norms, if possible D. Evidence of deficient brain growth or abnormal morphogenesis, including Q1 of the following: 1. Structural brain abnormalities 2. Head circumference e10th percentile
II. FAS Without Confirmed Maternal Alcohol Exposure	IB, IC and ID, as above
III. Partial FAS With Confirmed Maternal Alcohol Exposure (requires all feature A.s, AYC)	Confirmed maternal alcohol exposure B. 1 B as above C. One of the following other characteristics 1. 1 C as above 2. Evidence of deficient brain growth or abnormal morphogenesis, including Q1 of the following 1 D as above 3. Evidence of a complex pattern of behavioral or cognitive abnormalities inconsistent with developmental level that cannot be explained by genetic predisposition, family background, or environment alone a. This pattern includes marked impairment in the performance of complex tasks (complex problem solving, planning, judgment, abstraction, metacognition, and arithmetic tasks); higher-level receptive and expressive language deficits; and disordered behavior (difficulties in personal manner, emotional lability, motor dysfunction, poor academic performance, and deficient social interaction)
IV. Partial FAS Without Confirmed Maternal Alcohol Exposure	IIIB and IIIC, as above
V. ARND (requires both A and B)	A. Confirmed maternal alcohol exposure B. At least one of the following: 1. Evidence of deficient brain growth or abnormal morphogenesis, including Q1 of the following: a. Structural brain abnormalities b. Head circumference e10th percentile 2. III 3 as above

TABLE 1: Modified 1996 Institute of Medicine Criteria for Diagnosis of FASD by Hoyme et al