Foetal alcohol spectrum disorders (FASD): raising awareness in early years settings

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In this article Carolyn Blackburn who is currently project officer for the Training and Development Agency for Schools and Teresa Whitehurst who is a research and development officer at Sunfield School in Worcestershire discuss how educationalists are being required to support an increasing number of children with new and emerging disabilities including Foetal Alcohol Spectrum Disorders (FASD) for which they may be ill equipped if knowledge and resources are not available. FASD is an umbrella term used to describe a range of intellectual and physical disabilities that may occur when alcohol is consumed by the mother during pregnancy. This may lead to learning difficulties in the areas of gross and fine motor control, social and emotional development, hyperactivity and attention disorders, understanding rules and cause and effect, receptive and expressive language, and problem solving and numeracy. Educating and caring for these children needs a unique approach that relies on reflective practice and adaptive teaching techniques. This article focuses on a collaborative project with Worcestershire Early Years entitled Building Bridges with Understanding. The project focused on raising awareness and increasing knowledge of FASD in early years practitioners to support children with a range of difficulties and provides access to a free downloadable resource pack.

Key words: alcohol, pregnancy, learning difficulties, early years, support.

Introduction

With an increasing number of children attending educational settings presenting unidentified and emerging special educational needs, the opportunity and necessity for staff to provide support to vulnerable children and their families is immense. It is essential, therefore, that education staff have the confidence to identify and meet such needs, and that they are supported in these endeavours with information and resources aimed at improving outcomes for such children, through directed early childhood intervention and adaptive teaching techniques.

Some of the children that educators encounter will present with a unique set of needs and behaviours that will leave many practitioners bewildered and challenged as to how best to support the child. Children affected by foetal alcohol spectrum disorders (FASD) present a new and growing early childhood intervention opportunity for the care and education system at a local, national and international level. Presently in the UK little is known about FASD and how to educate affected children. This is a matter of concern as early childhood is a time of vital importance in children’s development (DfES, 2004) when significant improvements in outcomes can be achieved with appropriate interventions to the extent 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.’

(Guralnick, 2004, p. 13)

FASD is a broad spectrum of completely preventable intellectual and developmental deficits in individuals, resulting from maternal alcohol consumption during pregnancy. Alcohol is a teratogenic compound (that is, a substance that 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).

Children with FASD will have physical and intellectual disabilities presented on a continuum, including damage to organs such as heart and lungs, and central nervous system damage causing learning difficulties in the areas of gross and fine motor skills, social and emotional development, hyperactivity and attention disorders, understanding rules and cause and effect, receptive and expressive language, sensory processing disorders and problem solving and numeracy. These children may not follow general theories of learning or be able to generalise rules and principles learnt from one situation to another. Educating and caring for these children, therefore, needs an informed approach that relies on reflective practice and adaptive teaching techniques.

History and prevalence of FASD

First officially recognised by Jones and Smith (1973, 1975), foetal alcohol syndrome (FAS) has received considerable worldwide attention in recent years. Prenatal alcohol exposure has now been recognised as a major public health issue in all industrialised nations, as well as in many developing countries where alcohol abuse by women of childbearing age is common. Indeed, foetal alcohol exposure is the leading known preventable cause of intellectual disabilities...

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 while pregnant (Mukherjee, Hollins & Turk, 2006). These disorders exist on a spectrum ranging from the full presentation of FAS to a set of conditions affecting the neuro-behavioural presentations of the condition without encompassing all of the features.

Where prenatal exposure to alcohol can be confirmed, two ‘labels’ exist under the umbrella term FASD (O’Malley, 2007): foetal alcohol syndrome (FAS) and alcohol related neurodevelopmental disorder (ARND). A diagnosis of ARND is made when maternal alcohol consumption can be confirmed alongside prominent neurocognitive deficits but in the absence of facial features or growth retardation. Two other labels are also commonly used: alcohol related birth defects (ARBD) and partial foetal alcohol syndrome (PFAS). A diagnosis of ARBD is made when maternal alcohol consumption can be confirmed alongside behaviour or structural abnormalities but where facial features may be absent, while PFAS requires evidence of maternal drinking combined with some facial features and neurocognitive deficits but other features may be absent (see Figure 1). It is important to note that these diagnoses are experienced on a continuum from mild to severe presentation of the disorder. However, while FAS is a clinical diagnosis, FASD is not (Astley & Clarren, 2000).

The damage caused and resulting physical and intellectual disability will vary from one individual to another, dependent upon dosage, timing and pattern of maternal alcohol consumption (Olson, Jirikowic, Kartin & Astley, 2007; O’Malley, 2007) as well as environmental and socio-economic factors relating to the mother, such as her general health and well-being, age, issues around poly substance use and abuse, hormonal cycle and the rate at which each individual processes alcohol. Generally the more a mother drinks, the greater the risk of foetal damage. In particular ‘binge’ drinking is associated with greater central nervous system damage (Olson et al., 2007). The characteristic facial features associated with FAS (see Figure 2) (palpebral fissesures, thin upper lip and an elongated philtrum) result from the consumption of alcohol by the mother during the first trimester of pregnancy.

![Figure 1: Differentiating the presentation of FASD](image)

Note: From Whitehurst (2010).
Damage to organs such as heart and lungs occurs at particular periods of pregnancy with the central nervous system being vulnerable to damage throughout the pregnancy.

The teratogenic effects of alcohol are currently not well understood and undoubtedly further research is required. Our current knowledge suggests there is an association between the consumption of alcohol by women who are pregnant and the risk of FAS or other conditions within the spectrum. The evidence to suggest that high-level consumption, either as a result of binge drinking or steady drinking, is generally accepted with animal model studies cited in support of this (Sulik, Johnston & Webb, 1981). There is also evidence to suggest that chronic low-level consumption, even within recommended Government guideline limits, is problematic (Hepper, Dornan & Little, 2005) with impact on the behaviour of the foetus observed during pregnancy.

There is a level of debate about the quantity and frequency of alcohol consumption that is required to produce disorders on this spectrum. Uncertainty may arise as a result of issues around accurate diagnosis, methodological problems such as recall bias of the amount of alcohol consumed, and analysis of alcohol consumption averaged to daily or weekly intake which is further compounded by uncertainty around what is regarded as a measure or unit of alcohol. In studies that report alcohol consumption levels there is little standardisation in the definitions of heavy, moderate and low drinking. Low-to-moderate drinking is considered to be less than one drink per day (equivalent to a maximum of 1.5 UK units or 12 g of alcohol daily). The Office for National Statistics (BMA, 2007) defines heavy drinking as eight or more units for men and six or more units for women on at least one day in the week. A further consideration to be explored are the protective factors inherent in either the mother, child or both, which may come into play to mitigate the impact of alcohol on the developing foetus, resulting in a scenario where not every child exposed to prenatally consumed alcohol is affected (Streissguth, 1997). However, despite this debate, there is a generally accepted consensus that FASDs are completely preventable through the elimination of drinking during pregnancy (BMA, 2007).

Investigators have measured incidence (the number of new individuals identified) using both passive and active methods of data collection. Passive methods involve the collection of data from existing birth records, while active methods involve screening using the diagnostic tools available. Worldwide incidence of FAS is estimated at 0.97 per 1,000 but it is important to note that these data are based almost exclusively on research conducted within the USA (BMA, 2007). It has been estimated that in western countries as many as nine per 1,000 live births involve children affected by FAS, PFAS or ARND (Autti-Rämö, 2002). It is important also to note that as more complete diagnoses and broader definitions of FASD become available, prevalence and incidence may increase. However, the extent to which a label of FASD impacts upon a parent’s willingness to seek a diagnosis may severely affect the extent to which this disorder can be identified and supporting services put in place.

Neurological deficits

Children affected by maternal alcohol consumption suffer from both primary and secondary disabilities in a range of domains, the effects of which are experienced throughout the lifespan. Although intellectual disability is not a feature of the diagnostic criteria of FAS, it is well reported that children prenatally exposed to alcohol have a compromised level of intellectual function. Studies by Streissguth, Barr and Sampson (1990) suggest that exposure to as little as one ounce of alcohol per day has been associated with decrements of six to seven points in IQ score.

These children have an inability to link cause and effect and often experience serious problems with Mathematics due to the effect of alcohol on the development of the parietal lobe (Goswami & Bryant, 2007). Affected children experience communication difficulties, presenting as speech delays or impediments (Abel, 1990), receptive and expressive difficulties (Shaywitz, Caparulo & Hodgson, 1981; Tenbrinck & Buchin, 1975) and problems with word comprehension. Verbal learning has been shown to be impaired, with affected children experiencing problems at the encoding level rather than retention and recollection (Mattson, Riley, Delis, Stern & Jones, 1996).

Behaviourally these children present with attentional problems, poor impulse control, working memory problems and poor adaptive functioning (O’Malley, 2007) and are often diagnosed with attention deficit/hyperactivity disorder (AD/HD) (Coles, Platzman, Raskind-Hood, Brown, Falek & Smith, 1997). Qualitative differences in attention were noted by Coles et al. (1997) in a comparison between children with and without FAS. Children in the former group displayed evidence of difficulty in focusing and sustaining attention, while children in the latter group were able to maintain and focus attention but displayed difficulties in the subsequent shifting of their attention. Children with FASD experience problems in the domain of social interactions. While they may be eager to make friends, they simply do not understand
the nuances required to formulate friendships. Similarities in the difficulties experienced by children with FASD have been compared to those of children with autistic spectrum disorders.

Very often the profile that emerges as a result of the impact upon neurological development is one of a developmentally fragmented child. While some areas of development are preserved and will be consistent with chronological age, other areas are impacted upon to the extent that a child may appear proficient in some tasks but inconsistent in others.

**Professional knowledge of FASD**

With the majority of research having been conducted in the USA, knowledge of FASD in the UK is limited both at public and professional levels. While information regarding the dangers of drinking is a point of political and media concern, its potential to harm the unborn child is rarely mentioned. 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. Ryan and 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 modify and adapt their instructional techniques. Within the medical profession there is little evidence of knowledge or understanding of the disorder either at a General Practitioner level or even paediatric level (Nanson, Bolaria, Snyder, Morse & Weiner, 1995). Even when children are born displaying facial features and were a result of high-risk pregnancies, routine paediatric screening failed to identify the disorder (Sohler & Holmes, 1999). Furthermore, despite the mothers in the latter study being within a high-risk group, 73% of the case notes contained no record of maternal alcohol consumption. Expectant mothers are rarely advised at point of contact with the midwife of the potential dangers of continuing drinking during pregnancy. Kesmodel and Kesmodel (2002) found that 65% of pregnant women received little or no information from their midwife, with a majority of 74% believing it was acceptable to continue drinking.

**Implications for education**

It would appear that the role of the educational system with regard to FASD is twofold. Firstly, educationalists have the potential to influence the likelihood of children being born with FASD by providing sound education on the consequences of drinking during pregnancy. Young people cannot be expected to take action and responsibility for drinking during pregnancy if they remain unaware of the dangers of alcohol to their unborn child. Secondly, educationalists must be prepared for the challenge of FASD in the classroom. Many children are currently slipping through the net and have no diagnosis, yet remain seated in classrooms unable to engage in the learning environment as a consequence of lifelong damage to their neurological systems caused through alcohol. Is the UK educational system ready for these challenges?

These challenges very clearly demonstrate the need for neuroscience and education to set aside their inherent difficulties and differences, and work together to produce pedagogies underpinned by sound evidence and a wider understanding of the implications and impact of the neurological limitations of certain groups of learners. This venture can surely only succeed if our educationalists are equipped with the foundations of knowledge necessary to understand the challenges that lie before them. The need to empower teachers to design pedagogies because they are in the best position to judge how to engage young people (Johnson & Hallgarten, 2002) must be synthesised with an understanding of the contribution that neuroscience can make to educational research (Goswami, 2004). Sunfield Research Institute, based in central England, was founded in 2005 with an emphasis on family-centred and child-focused perspectives on research practice. Sunfield believes that research is the lifeblood of good practice and that working together as a trans-disciplinary team is key to ensuring this path is walked together (Carpenter & Egerton, 2007).

**Sunfield/Worcestershire County Council Early Years Project**

Sunfield Research Institute worked in collaboration with Worcestershire County Council in the UK to raise awareness of FASD among early childhood practitioners and consider a range of strategies to address behaviour difficulties associated with this condition.

The main objective of the project was to provide a toolkit of resources designed to improve practice and meet the needs of children presenting certain behaviours and learning difficulties. The project was not designed to equip practitioners diagnostically, but to raise their awareness of FASD and provide a range of tools and suggested strategies to support early childhood intervention.

In an initial questionnaire sent to practitioners across Worcestershire, 78% of early years managers indicated that they knew little or nothing about FASD, but 40% of early years settings were supporting children with a range of needs, including speech and language difficulties, poor short-term memory, hyperactivity and inattention, impulsivity and general learning difficulties, all of which are behaviours presented by children with FASD. Insightfully, one practitioner acknowledged that:

‘because there’s so little understanding and so little 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, p. 21)

Practitioners across Worcestershire demonstrated enthusiasm for the project to improve their own knowledge and skills, reflecting their commitment to improving outcomes for vulnerable children in their care.
Sunfield drew on the knowledge and experience of practitioners across Worcestershire, who played a crucial role in developing and trialling the resources, through a cycle of action research. Action research was considered a particularly appropriate methodology given its focus on changing an issue within the working environment to improve knowledge and practice. It is a collaborative strategy often involving the participants of the research (such as early years practitioners) in planning and carrying out the research with the researcher, and ‘it is thus democratic and inclusive’ (Roberts-Holmes, 2005).

Primary data for this project were gathered through an initial questionnaire, followed by individual interviews and an evaluation of a resource pack/toolkit.

The general themes arising from the questionnaires and interviews were:

- enthusiasm among Worcestershire early years practitioners for this research project, driven by dedication and commitment to improving outcomes for vulnerable children in their care;
- a lack of knowledge about FASD by early years practitioners and other professionals (such as health and social work professionals) with whom they liaise in order to support children;
- mixed messages from the media and official bodies about safe alcohol limits for pregnant women;
- uncertainty about how a child with FASD might access an early years curriculum such as the Early Years Foundation Stage (EYFS) in a typical early years setting;
- high and increasing numbers of children entering early years settings with a range of needs including speech and language delays and impairments, behavioural problems, unusual levels of immaturity, children with needs in the area of hyperactivity, complying with boundaries and poor social skills;
- a need for very visual and concrete strategies to support an increasing number of children with emerging needs in settings;
- a need for further information, training and specific strategies for supporting children with FASD and clarification for women about safe and appropriate alcohol intake while pregnant.

Other practitioners were aware that FASD was linked to maternal alcohol consumption, but were confused about how much alcohol consumption was necessary to damage a developing foetus and which members of society are affected, making statements such as:

‘It’s mums that drink heavily during pregnancy, so that when their children are born, they have a lot of learning problems.’

(Blackburn, 2009, p. 18)

‘It’s when parents are drinking quite a lot during pregnancy and obviously the child is then affected by that. When the child comes out of the womb they would have been exposed to alcohol the same as the parent and would have alcohol poisoning.’

(Blackburn, 2009, p. 18)

Practitioners commented on the conflicting advice provided by the media as well as official bodies about alcohol consumption during pregnancy, which naturally impacts on the information and advice they pass on to others, including parents using their service.

**Increasing numbers of children with additional needs in settings**

Representatives of all 33 settings who participated in an interview reported having an increasing number of children with difficulties and delays in the area of speech and language, both receptive and expressive, and representatives of all settings felt that much of the undesirable behaviour they are faced with is related directly to poor understanding and children’s inability to express themselves adequately.

Many of the settings felt that delayed speech was impacted by an inability to listen or focus on an activity, reporting that some children found it difficult to hold a simple two-way conversation at age three or four. Social and emotional skills were felt by most practitioners to be one of the most important areas for children to master before they enter compulsory education. Many settings (76%) reported high numbers of children displaying poor social skills, including turn-taking, sharing, and co-operative and associative play, even among those children in the 40- to 60-month developmental phase.

**Looking forward: best practice in early education**

Early years settings are supporting an increasing number of children who need additional support to enable them to achieve and meet the outcomes contained in the Every Child Matters agenda and the Early Years Foundation Stage.

Best practice in supporting children who have been identified as having FASD in their early years would seem to rest on the basic principles of consistency, simplicity, structure, repetition, routine, constant supervision and valuing the child for their achievements and strengths. The DfES (2005) advocates that early years practitioners employ knowledge, reflective practice and an empathetic outlook to support children in their care, informing us that ‘Effective practice in
the early years requires committed, enthusiastic and reflective practitioners with a breadth and depth of knowledge, skills and understanding and that ‘effective practitioners use their own learning to improve their work with young children and their families in ways which are sensitive, positive and non-judgemental’ (DFES, 2005).

The Centre for Excellence and Outcomes in Children and Young (C4EO), through extensive research into how to ‘narrow the gap in outcomes for young children through effective practices in the early years’, has drawn a similar conclusion, stating that ‘effective pre-schools are characterised by a focus on individual children’s needs, both in terms of learning and social development’ (C4EO, 2009).

Reading the information sheets contained in the Resource Pack which resulted from this project and observing the basic rules outlined in the ‘Focus on Strategies’ will ensure practitioners provide a learning environment which will engage children with FASD and enhance their potential for achievement through directed early childhood intervention and improve families’ experience of their child’s early years education.

This will have implications for children with FASD throughout their lives, as:

’a child’s experience in the early years has a major impact on their future life chances. A secure, safe and happy childhood is important in its own right, and it provides the foundation for children to make the most of their abilities and talents as they grow up.’

(DFES, 2008, p. 6)

It is important for educators to be realistic about their expectations of children with FASD. The main strategies to support children with FASD are:

- Use clear, concrete, simple language backed up with visual clues.
- Be consistent with language, rewards and routines.
- Be prepared to repeat instructions and rules.
- Implement and adhere to a routine.
- Provide structure and constant supervision.
- Employ adaptive teaching techniques that focus on the child’s strengths, interests and developmental stage.

There is no shortage of literature highlighting the advantages and disadvantages of the use of labels in special education (see Dittrich & Tutt, 2008; Laughlan & Boyle, 2007) and concern regarding over-reliance on labels, leading to social exclusion and stigmatisation. This may be especially true where the cause of a disability can be attributed to maternal alcohol consumption. Receiving a diagnosis of this disorder, however, may also function as a protective factor, reducing the development of secondary disabilities such as disrupted school experiences and mental health problems (Mukherjee et al., 2006; Streissguth, 1997).

Students with FASD may also find their difficulties, correctly or incorrectly, identified as other conditions such as AD/HD, autism, learning disabilities or emotional disturbance (Streissguth & Kanter, 1997), which may not be satisfactory for some parents. Susan Fleisher, adoptive mother of a child with FASD and founder of the National Organisation for Foetal Alcohol Syndrome (UK) comments:

‘My daughter is lucky because, by chance, I learned about FAS. When parents, schools, doctors and social services know what they are dealing with we can begin to improve lives for children like my daughter and everyone affected.’

(BMA, 2007, p. 10)

Ascribing labels or attaching emphasis to a diagnosis aligned with pedagogy may not sit comfortably with all educational professionals who may question its significance. However, it is apparent that early childhood intervention services can no longer focus solely upon children with traditionally recognised disabilities, but must also offer support to families of children with special educational needs in emerging categories (Carpenter, 2005). Educationalists must meet the challenge that children with FASD will present in their settings and are ideally placed to offer support and advice to families. However, if they are unaware of these emerging categories, and the behaviours and needs of the children represented, the danger is that children and families will have unmet needs. In addition educationalists will not only face daily confusion and bewilderment with regard to the children they are striving to support, but may feel an overwhelming sense of disappointment as they attempt to educate children without understanding the true nature of their needs. This reflects the contention by the Department for Children, Schools and Families (DCSF, 2007) which argues that a skilled and appropriately trained workforce with a focus on narrowing the gap across all outcome areas is needed to support vulnerable children.

The British Medical Association reinforces the need for knowledge, stating that ‘a lack of knowledge about FASD will limit opportunities for diagnosis, prevention and early intervention’ (BMA, 2007). Resources to achieve this aim are currently unavailable as ‘knowledge and expertise regarding FASD amongst health and education practitioners in the UK is limited’ (Carpenter, 2005). At present, information is not available for parents or educators about FASD in the Early Support Programme materials, designed by the Government to achieve better co-ordinated, family focused services for young disabled children and their families or in the new Inclusion Development Programme (IDP) which is a new project of confidence-raising training for teachers, support staff and early years practitioners. This project aims to improve the skills of teachers by advising them on how to develop teaching strategies for children with special educational needs and by providing guidance on dealing with common classroom challenges.

Schools and other educational establishments need to enable staff to be responsive in their approach to their care and
pedagogical approaches. These need to be innovative, dynamic and, at times, ground-breaking to meet the learning needs of the children and young people they will encounter (Carpenter, 2007). Indeed, if we in our varying professions do not continue to change to meet the needs of the children and young people we serve, then our schools and the pedagogy they employ will soon become obsolete. The value of this project in raising awareness among early years practitioners in Worcestershire about FASD and the research process can be seen in the usefulness of and enthusiasm for the resulting resource pack, which can be seen as a tool written by practitioners for practitioners.

Conclusion

Through practitioner-based research projects and reflective practice, educationalists can prepare themselves and the settings they represent for new and emerging profiles of disability; disabilities which are the result of increased technology (the ability to support premature babies earlier brings its own set of vulnerable children to the care and education system) and changes in lifestyle (increased binge drinking, and drug and alcohol use among young people). Informed and skilled practitioners will be well placed to meet such children and their families at their point of need and can themselves be advocates for the synergy which exists between theory and practice and the emerging need for evidence-informed professionals to be at the forefront of educational practice.

Note


References

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