

'Binge drinking' among mothers raises number of children with fetal alcohol spectrum disorder

Effective education of, and support for, infants with intellectual disabilities can ease their transition to adolescence and adulthood, says Charlie Callanan

THE RISING number of children diagnosed with fetal alcohol spectrum disorder (FASD) has been likened by one expert to a 'tidal wave'.

Barry Carpenter, an international consultant in complex learning difficulties, asserts that high levels of binge drinking among young women in the UK are directly linked to an increase in the number of babies born with developmental problems.

According to the British Medical Association (BMA) (2007), FASD is 'the leading known cause of non-genetic intellectual disability in the Western world'. Meanwhile, the Royal College of Nursing's (2011) position statement on the role of learning disability nurses lists the greater incidence of FASD as a major factor in the rise in the number of children and adults with learning disabilities.

'FASD is an issue of which nurses in practice are becoming more aware,' says Michael Brown, chair of the RCN learning disability nursing forum committee and nurse consultant in learning disability.

'Health services are recognising the clinical features, and the care and support needs, of children and adults with FASD. Learning disability nurses must become much more aware of the diagnosis, treatment and intervention issues, and the needs of this group as they start to grow older.'

Fetal alcohol spectrum disorder is an umbrella term for a range of birth defects caused by alcohol consumption by mothers during their pregnancies.

The defects may have physical features, including heart problems, or intellectual and psychological manifestations, such as reduced intellectual ability and behavioural problems.

Brain damage caused by the effects of alcohol on the fetus during pregnancy is permanent so professionals tend to focus



The number of children affected by disorders linked with pre-natal exposure to alcohol appears to be rising

on the management of children and adults with FASD. Such management involves a multidisciplinary approach involving, for example, nurses, paediatricians, psychiatrists, psychologists, speech and language therapists, education experts and social services.

Professor Carpenter says that the rising number of children with FASD has severe social consequences. For example, in the most affected countries, disproportionately high numbers of people with the disorder are unemployed or in the criminal justice system, and many have developed mental health problems. He adds that research

from the US shows that about 32 per cent of people with FASD who are aged over 30 commit suicide.

Physical effects of FASD can include a smaller head circumference, specific facial characteristics, heart problems, kidney damage, and sight and hearing problems.

Social problems, including contact with criminal justice services, may arise because of immature behaviour, poor impulse control, confused social skills, poor judgement and difficulties in learning from consequences.

Developmental disorders

Other characteristics of prenatal exposure to alcohol include attention and memory deficits, hyperactivity, and difficulties understanding and enacting abstract concepts, such as telling the time and dealing with money. These characteristics are known collectively as fetal alcohol syndrome (FAS).

Although physical features are apparent in many children with FAS, identification of associated disorders can be problematic. Such disorders include:

- Alcohol-related birth defects. These can include physical or intellectual anomalies, such as cardiac, skeletal, visual, aural, and fine or gross motor problems.
- Alcohol-related neurodevelopmental disorder. Caused by damage to the central nervous system (CNS), this can present as learning difficulties, poor impulse control and social skills, and problems with memory, attention and judgement.
- Fetal alcohol syndrome, indicated by characteristic facial features, CNS dysfunction and growth deficiency.
- Partial fetal alcohol syndrome, in which FAS characteristics are partial or incomplete.

Professor Carpenter says: 'It is probably not until children with FASD are in school that you can tell through their learning and behaviour responses that they have difficulties.'

'There is a problem with misdiagnosis because we have not known enough about the disability.'

Professor Carpenter says that it is common for FASD to be misdiagnosed in children initially as attention deficit hyperactivity disorder or autism.

The problem of mis- or partial diagnosis is illustrated by the case study below. The name of the boy in the study has been changed to ensure his anonymity.

Dr Brown says that when children come to the attention of health services, professionals are unlikely to consider that their health problems may be a result of maternal alcohol use. 'Unless you are alert to the possibility, and can ask the relevant questions as part of assessments and diagnoses, it will be missed.

'Learning disability nurses need to become more aware of the anticipated increase in prevalence, to integrate the necessary approaches into their

assessments, and to offer the right kind of treatments,' says Dr Brown.

Worldwide prevalence rates suggest that at least one in 100 children are affected by fetal alcohol problems.

A study of hospital admissions in the north west and north east of England (Morleo *et al* 2011) suggests that the condition is under-reported in England.

Effective prevention

The report shows that despite a significant increase in the number of women admitted to hospital with alcohol-related diagnoses, there was no equivalent increase in the reporting of FASD.

The authors conclude: 'If FASD is to be identified, treated and prevented effectively, improvements in intelligence systems, practitioner awareness and screening are essential.'

Dr Brown and Professor Carpenter say that learning disability nurses need further education and training to recognise and address the needs of children and adults with FASD.

'Unless learning disability nurses are aware of the developmental profile of

this group then their interventions are not going to be focused correctly,' says Dr Carpenter. 'They need training to meet the specific needs of people with FASD.'

The BMA (2007) recommends that nurses make formal diagnoses of FASD so that early-intervention and treatment programmes can be initiated, and thereby reduce the risk of additional mental health, educational and social problems commonly found in people affected by the disorder.

Professor Carpenter says: 'We have to believe that early interventions from nurses and midwives, better teaching by the education profession, and more support for the families of young people with FASD from learning disability nurses can improve the life chances and opportunities of such young people, especially as they move into adulthood.'

Charlie Callanan is a freelance journalist

Case study

Stephen, whose mother was dependent on alcohol and drugs, was born prematurely. At the age of seven months he was fostered, and was subsequently adopted.

His foster parents were unaware of the nature or extent of Stephen's health problems, but soon realised that he was not meeting his developmental milestones.

Stephen had physical health problems that are often found in children with attention deficit hyperactivity disorder (ADHD) and was initially diagnosed with autism and ADHD.

However, his parents thought his problems were related to maternal alcohol abuse. His mother says: 'There is a huge difference between fetal alcohol syndrome and more commonly diagnosed problems. We thought we owed it to him to find out what was wrong with him, so we worked

night and day to get his educational statement of special needs.'

Eventually, Stephen was diagnosed with fetal alcohol syndrome (FAS) as well as autism and ADHD.

Stephen's behaviour was problematic when he was at nursery but less so when he attended school. His mother says: 'Stephen wants to fit in at school. He is good at hiding his FAS and copying what his peers do, although this sometimes gets him into lots of trouble. It is hard for him because he does not understand what he has done wrong.'

Stephen is now aged 16. His mother worries about his future but remains positive. 'He is a fighter,' she says. 'The doctors said he would not speak or feed properly, and would never go to mainstream school and learn, yet he is doing all those things. He is a clever boy in his own way.'

Find out more

The British Association for Early Childhood Education has published a guideline on child development. Called Development Matters in the Early Years Foundation Stage, the guideline is available at tinyurl.com/bqhphsf

The Department of Education's Developmental Matters in the Early Years Foundation Stage framework can be downloaded from tinyurl.com/cy4wqyy

Surrey and Borders Partnership NHS Foundation Trust presents an online fetal alcohol spectrum disorder clinic at tinyurl.com/br29oso

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