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## **“One More For My Baby” Foetal Alcohol Syndrome and its Implications for Social Workers**

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**Published in *Child Care in Practice*, 2005, 11(3), 375-383**

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### **Background**

The knowledge that alcohol can cause problems with foetal development has been around since ancient times. In the Bible pregnant women were warned not to drink wine, or strong drink (Judges 13:7). Cultural taboos in ancient Carthage based on Greek and Roman mythology forbade a bridal couple to drink, in order to avoid producing sickly children and the ancient Greek philosopher Aristotle commented that “Foolish, drunken and hare-brained women most often bring forth children like unto themselves morose and languid.” Later on in history during the "gin epidemic" in England of 1720 to 1750, the Royal College of Physicians warned that parental drinking was a "cause of weak, feeble, and distempered children". A 19<sup>th</sup> century report to the legislature of Massachusetts (Howe et al., 1846) noted that the children of parents who habitually use alcohol “are very apt to be feeble in body and weak in mind.” In 1899 William Sullivan, a Liverpool prison physician, compared the mortality rate of children of alcoholic mothers and found that 44% of them had died before they reached their second

Please use the following citation: Cousins W (2005) “One more for my baby” Foetal alcohol syndrome and its implications for social workers, (Author postprint) in *Child Care in Practice*, 11(3), 375-383 [Accessed: (date) from [www.drugsandalcohol.ie](http://www.drugsandalcohol.ie)]

birthday whereas the mortality rate among children born to their non-alcoholic blood relatives was 24%.

Yet despite the historical evidence, it was not until modern times that the connection between maternal drinking and child development began to be studied in depth. The toxic effects of alcohol on child development were first described in France by a team led by Paul Lemoine (Lemoine *et al.*, 1968). As a paediatrician in post war France he noticed that children of chronically alcoholic women seemed to share certain common physical traits, unusual facial appearance, short stature, frequent malformations and psychomotor disturbance. These characteristics sometimes enabled the correct diagnosis of maternal alcoholism even when it had not been suspected before.

Shortly afterwards similar observations were made independently in Seattle and published in the Lancet (Jones & Smith 1973). Unusual patterns of physical anomalies were recognised in infants who were failing thrive. These consisted of microcephaly (small head), short palpebral fissures (small eye openings), epicanthal folds (extra skin folds close to the nose), and mid-facial hypoplasia (middle area of face appears flattened). There were many other abnormalities of the body including problems with eyes, joints, kidneys, genitals, cleft palate, and the heart. A child psychologist Ann Streissguth, was subsequently asked to examine these children and diagnosed varying degrees of learning disabilities (Streissguth *et al.*, 1997). A second Lancet article published later that same year for the first time provided the characteristic pattern of physical and mental characteristics with a name “Foetal Alcohol Syndrome” (FAS) (Jones *et al.*, 1973).

Laboratory experiments have more recently shown that exposure to alcohol at critical times during foetal brain development can induce excessive cell death during normal programmed death (a process known as apoptosis) or trigger apoptosis at inappropriate times. The result is smaller or abnormal brain structures with fewer connections between brain cells (US Institute of Health, 2005). This type of damage translates into the developmental delays and permanent cognitive and behavioural disabilities found in FAS/ E .

### Diagnosis

Making a diagnosis of FAS is complex, but broadly speaking is based on three factors: prenatal and postnatal growth retardation, central nervous system abnormalities and characteristic facial features (Smith 1979).

**Figure 1: FAS DIAGNOSIS**

<b>1. Prenatal and postnatal growth retardation</b>	Low birth weight and microcephaly (abnormally small head)
<b>2. Central nervous system abnormalities</b>	Intellectual impairment, developmental delays, behavioural problems and neurological abnormalities
<b>3. Facial features</b>	Small eyes, short eye openings, epicanthic folds, flat upturned nose, indistinct philtrum (groove in the middle of the upper lip), thin upper lip, crossed eyes, droopy eyelids and external ear malformation.

If all three of these characteristics are present then a diagnosis of Foetal Alcohol Syndrome can be made by a qualified medical practitioner. If some, but not all, characteristics are present then a diagnosis of Foetal Alcohol Effect (FAE) can be made. This diagnosis acknowledges that the effect of alcohol on the developing baby can occur along a continuum depending on the amount of alcohol consumed and the timing of exposure so that differing combinations of factors may interrelate and cause differing degrees of organic dysfunction in different individuals. The FAE end of the birth effects spectrum is less clear than that of full FAS and, as a result, is more difficult to diagnose even when it is suspected. Many children who have this condition may either not be diagnosed or be misdiagnosed as having a psychological condition such as conduct disorder. Others may be given a partial diagnosis of attention deficit hyperactivity disorder or attachment disorder (McCreight 1997). Some authorities prefer not to make a definite distinction between FAS and FAW, preferring instead to refer to Foetal Alcohol Spectrum Disorder (FASD).

### **Behavioural Effects**

The range of problems and concerns associated with FAS and FAE include poor habituation, sleep disturbances, poor sucking response, failure to thrive, delays in walking and talking, delayed toilet training, difficulty following instructions, temper tantrums and disobedience, distractibility and/or hyperactivity (Keating 2002)

McCreight (1991) outlined a number of additional behavioural characteristics that have been associated with FAS and FAE including poor impulse control, difficulty relating behaviour with consequences, poor short-term memory and poor personal boundaries. These difficulties

often lead to affected individuals having difficulty at school and becoming involved with the criminal justice system in later life.

### **Alcohol Consumption during Pregnancy**

There is no way of making absolute predictions about how much alcohol consumed at any particular point in a pregnancy will affect the developing baby. It is notoriously difficult to discover actual levels of maternal drinking because of unreliable self-reports and self-deception. (Brockington 1996) However, one study of alcoholic mothers found that one-half to one-third of the women who continued to drink heavily throughout their pregnancies had babies who fitted the FAS/E diagnosis including growth deficiencies (pre and post natal), problems with the functioning of the central nervous system and the characteristic pattern of facial features (Streissguth 1997).

It is still unclear as to why some children born to chronic alcoholic mothers display only partial symptoms or effects while others often display all the characteristics associated with full Foetal Alcohol Syndrome. A variety of factors may come into play in terms of risk for FAS/FAE including maternal weight, foetal weight, cell development at the time of alcohol exposure, age of mother, overall maternal health, exposure to other toxic substances and genetic susceptibility, including paternally derived factors (McCreight 1997).

### **Incidence**

The UK Department of Health does not collect specific information about the incidence of FAS. In England and Wales if FAS is recognised at the time of delivery, it may be recorded in

the clinical details on the HES (Hospital Episodes Statistics) record, however the number of cases recorded is small. In 2000–01, foetal alcohol syndrome was reported in 38 birth records on the Hospital Episode Statistics System (HES), representing 0.07 cases per 1,000 births (Hansard 2001). The World Health Organisation estimates an incidence of Foetal Alcohol Syndrome (FAS) at between 0.33 and 9.7 per 1000 live births in a range of countries.

## **Methodology**

A cohort of children, looked after by social services in Northern Ireland, and all under the age of five, were tracked for a two year period as part of a longitudinal study into the lives and care careers of young children in state care. In the first instance, this involved obtaining a download from SOS CARE (the social services computerised administrative system) containing details of all the children of the relevant age who were looked after on the project census date at the end of March 2000. This data provided key information including date of birth, gender and legal status.

Further information was then collected from the children's case files from the point of the child's entry to care up until the 31<sup>st</sup> March 2000 using a proforma designed to collect data on child and family characteristics and circumstances, family histories, and care planning. This exercise was then repeated two years later to collect information from April 2000 until the end of March 2002 or until the child left care.

Throughout this process of data collection the guiding principle was that researchers would record information *as stated by the social workers* and keep any re-interpretation of this to an absolute minimum.

A total of 388 case files (95% of the relevant population) were included in 2000 and 348 (86%) in 2002.

## **Results**

At the first case file data collection point (covering the period up until the end of March 2000) 58.7% of the 388 children's mothers had been described in the case files as having problems with alcohol misuse. When 348 of the same case files were accessed two years later the records showed that 12 of the children had received a medical diagnosis of FAS, more than 3% of this population. This is equivalent to an incidence rate of 32.6 per thousand births. In all but one case the child's mother had a history of drinking problems previously listed in the child's case file. It would thus appear that young children being looked after by Social Services are substantially more at risk from this condition than the general UK population. None of the children received a diagnosis of Foetal Alcohol Effect.

## **The FAS Children**

Eight of twelve FAS-diagnosed children were boys and four were girls. Half of the children had records of emotional or behavioural problems recorded in their case file between 2000 and 2002.

Information on the source of the first referral to social services was available for ten of the children. Four were first referred by hospitals, two by health visitors, two by their mothers, one by a GP and one anonymously. Six first became looked after because of neglect, four because

of predicted parent inadequacy, one through power of the courts and one due to suspected abuse. Six of the children first became looked after before the age of one year, four became looked after at one year of age and one became looked after aged two.

All of the twelve children with FAS described in this study had lived in substitute care. Three had one out-of-home placement, five had two, three had three placements and one had four. By the second census point in 2002 no child was living with his or her birth parents. Five were in non-relative foster care, five were adopted and two were living in kinship care.

### **Family Background**

In nine cases information was available about the age of the FAS diagnosed child's mother at the time of the child's birth. One was aged 19, one was aged 24, one 27 and the remaining six were aged between 33 and 40. When the child first came to the attention of social services three of the mothers were living alone, five were living with the child's father and three with another partner. Two years later, four of the mothers were now living alone, two with the child's father, two with other partners, one was living with relatives or friends, one was deceased and the whereabouts of two were unknown. In these respects, the mothers of the FAS-affected children were broadly similar to the other mothers in the study.

An unexpected finding was that eleven of the FAS mothers were described in case files as being from the Catholic community with only one described as Protestant. The other mothers in the study were almost equally distributed between the Catholic and Protestant communities. As the numbers involved are small, it may be that this finding was a chance occurrence, however it may be that differing cultural beliefs and practises within the Catholic and



Protestant communities in Northern Ireland have an influence on women's alcohol consumption.

Alcohol problems were not solely confined to the mothers and five of the children's fathers were also recorded as having alcohol problems. In addition to the family history of alcohol abuse seven of the children came from families with a history of mental health problems; six came from families with a history of domestic violence. Four came from families in which there had been a history of sexual abuse, four had a history of offending behaviour within the family and three had family histories which involved drug abuse.

## **Discussion**

FAS is clearly an issue for social workers working in family and child care. As it is a complex diagnosis, it may go unrecognised at birth and its prevalence could be significantly underestimated. This underestimation may be even more likely with the more subtle symptoms of FAE and it is possibly significant that while there was a high prevalence of full-blown FAS within this particular group of children, there were no recorded cases of FAE. Social workers may be currently involved with FAS/FAE children who have not been diagnosed. This particular study followed a group of under-fives, however FAS and FAE are life-long conditions and older children and teenagers can also be affected. The behavioural difficulties which are often a feature of foetal alcohol spectrum disorders become more of an issue with older children and result in these young people coming to the attention of social services because of involvement with the criminal justice system rather than through the referrals from health professionals which made up 7 of the 12 referrals in the group of younger children in this study. Social care professionals should consider the potential for Foetal Alcohol Spectrum

disorders in adolescents and involvement with the criminal justice system should not mask the possibility of this underlying medical cause for problem behaviour.

Given that many children with FAS/FAE come from families with multiple difficulties the need for early identification is essential. Without this identification children have little chance of having their special needs being catered for. In fact those needs may even contribute to a situation where children may suffer abuse, or neglect at the hands of parents whose parenting skills are impaired due to alcohol misuse. In a U.S. study, Burd and Wilson (2004) found that the mortality rate (from all causes) in people diagnosed with FAS was over 5% and in addition to this, the mortality rate in siblings of diagnosed cases of FAS was increased 530% compared to siblings of matched controls. These are striking statistics and a diagnosis of FAS may thus be considered a marker for risk in siblings of an affected child.

Extra supports on a long-term basis are crucial for alcohol-affected infants in dysfunctional families. A chaotic home environment is problematic for any child but can be devastating for children with special needs due to FAS ( McCreight 1997). Streissguth et al (1997) studied 415 individuals between 6 and 51 years of age diagnosed with FAS or FAE and found that living in a stable and nurturing home, being diagnosed as before the age of 6 years and never having experienced personal violence were associated with more positive outcomes.

None of the FAS-affected children in the current study were living with their birth parents at the second data collection point at the end of March 2002. All were being cared for by adoptive or foster parents. It may be that specialised family support packages are needed for birth families to enable them to provide the home environment needed by FAS affected children in order for them to achieve their developmental potential. In practice however,

service delivery to FAS-affected families is often problematic as multiple agencies including social services, mental health, schools and special education, the juvenile and criminal justice systems as well as the health professionals and sheltered housing may be involved (Evans 1997).

Keating (2002) argues that once a child has been diagnosed as having FAS a Case Manager should be responsible for drawing a long term care plan for each individual child taking into account their particular needs and co-ordinating services with the various agencies. This plan would cover areas such as:

- (1) Family support or the provision of alternative carers
- (2) Medical need
- (3) Educational needs
- (4) Support during the transition to adulthood.

If children with FAS cannot be placed permanently with their biological parents then social workers become responsible for arranging alternative care arrangements. Prospective foster or adoptive parents should reach their decision to become involved with a child on the basis of honest and informed consideration. It is unfair to expect families to take on the challenges and responsibilities of caring for a child affected by FAS without a clear idea of what this may involve. The children also need every opportunity to develop their potential and to overcome their difficult start in life. As with any child, permanent placement is desirable and the risk of multiple placements should be avoided. Edelstein (1995) recommends specialist pre-adoption counselling to guide adoptive applicants toward a successful evaluation of the risks and possibilities involved in adopting a child who has been exposed pre-natally to alcohol.

FAS and FAE present many difficulties for parents, health and social care professionals. They are, however preventable conditions. In spite of this, public awareness of FAS and FAE remains low within the UK and Ireland. In the USA, all alcoholic beverages are legally required to have a label warning of potential birth defects if women drink during pregnancy; in contrast, European countries have tended to take a more moderate view recommending light, infrequent drinking.

Patterns of alcohol use in the UK and Ireland are changing and research has shown that, in recent years, regular alcohol consumption has increased among the female population, particularly among younger women and teenage girls (Alcohol Concern 2004). It might therefore be assumed that the number of children potentially affected by their mothers' alcohol consumption during pregnancy may also be increasing. Kvigne et al (2003) argue that to prevent FAS and other alcohol-related effects, it is essential to counsel women of child-bearing age prior to conception and to insure ready access to effective family planning measures for women who are unable to abstain from alcohol during pregnancy. As most of the mothers in this study were over the age of 30 at the time of their FAS affected child's birth, social workers should not assume that alcohol education and counseling is only relevant to younger women.

By understanding the potential consequences of FAS and FAE social workers may be able to help lower incidence rates in at risk populations as well as helping providing necessary supports for affected children and their carers. An ounce of prevention may be worth more than a pound of "cure".

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