

Chapter 7

Why diagnosis matters

My son went without a diagnosis for 15 years. During that time, I felt completely alone, stigmatised and isolated. When he was finally diagnosed, I wept tears of pure joy.

(Birth mother)

His behaviour was appalling, and everyone assumed that I was a terrible mother. I rarely admitted to being his biological mother and just let them assume that he was adopted.

(Mother of 10-year-old boy)

THE PRESENT UNSATISFACTORY STATE OF DIAGNOSTIC SERVICES IN THE UK

Currently, there are major difficulties in getting a diagnosis of FASD in the UK. Diagnostic services are patchy across the country. There is only one specialist national clinic (in Redhill, Surrey). There are also a small, but increasing number of paediatricians with an interest in FASD, who are developing services in their local areas. In general, however, a “postcode lottery” still operates for diagnosis. There are no gold standard, multidisciplinary assessment teams, which are now regarded as routine in the USA and Canada.

There is, as yet, no clear pathway in the UK for the referral of individuals with suspected FASD to specialist clinics to allow a complete diagnostic evaluation. There are inadequate specialist services to support and follow up these referrals. There is inconsistency as to where individuals are referred. The services to which families are referred may not necessarily have the skills required to diagnose and manage FASD effectively. The development of clear referral pathways and provision of adequate specialist services for the comprehensive diagnosis and subsequent management of FASD needs to be addressed urgently (British Medical Association, 2016).

Professional knowledge and attitudes vary. The stigma associated with diagnosis still makes some professionals reluctant to pursue the issue, especially for a child still living with their birth mother. Given

this situation, is there any point in diagnosis and does it make any difference?

WHY DIAGNOSIS MATTERS

FASD is more common than most professionals appreciate, and well-intentioned practice can make a bad situation worse. Embarrassment and a reluctance to raise the issue of alcohol is counterproductive and not in either the child's, the mother's or society's best interests. Large numbers of children have been, and are being, born with this life-long untreatable condition. These children and their families suffer the consequences of both *missed diagnosis* and *mis-diagnosis*.

The missed diagnosis

For over 50 years, UK child care practice has been dominated by attachment theory and the impact of postnatal trauma, neglect and abuse. The concept of behaviour difficulties due to untreatable organic brain disease is new to most UK professionals. Unless trained in, and aware of, FASD, few professionals, including social workers, will consider pre-birth exposure to alcohol as an explanation for a child's behaviour. This lack of understanding has led to many parents and carers being unfairly blamed for their child's problems and then given the wrong strategies for managing them.

Prenatal alcohol damage can present unknowingly to a wide range of service providers. Individuals can present to the health services with physical issues, to psychiatry and psychology with behaviour problems, to education with learning problems, and in early adult life to the criminal justice system with offending behaviour. If the underlying cause of the problem is not considered at the point of referral, FASD will be missed.

These "missed diagnosed" children will instead be viewed as "poorly behaved", "non-compliant" or "conduct disordered" children. Their parents risk being criticised for being poor carers. However, the children and their families continue to experience problems that get worse as the child gets older. The family receives little support, and parents feel increasingly isolated and guilty. In severe cases, the situation may lead to family breakdown. The children then end up in care, are difficult to place, and suffer the additional trauma of multiple placements or residential behavioural units.

The mis-diagnosis

These are alcohol-exposed children who are given multiple, different and inaccurate diagnoses. They are diagnosed with ADHD, atypical autism, an attachment disorder or a conduct disorder. They risk being treated inappropriately with medication or having expensive “talking therapies” that are unlikely to work. The children are often taken from professional to professional, accumulating diagnoses as they grow older. Families and social workers are on a “diagnostic merry-go-round” in the vain hope that a new diagnosis will explain the child’s difficulties and provide a “cure” for their problems. Resources are wasted on numerous assessments, repeated visits, unnecessary appointments and inappropriate treatment. Families are progressively driven to despair.

Diagnosis affects prognosis

Without a diagnosis, appropriate intervention and family support, the outcomes for affected individuals can be very negative. For example, a long-term USA cohort study that followed up a group of affected individuals for over 30 years identified that, by the time they were adults, 90 per cent had mental health problems, 50 per cent were in prison, 30 per cent had their own drug and alcohol problems, with a further 50 per cent having problems with inappropriate sexualised behaviour. Girls were vulnerable to exploitation and rape with boys sometimes being perpetrators of harm (Streissguth and O’Malley, 2000).

Diagnosis improves the prognosis. Where good outcomes were seen, early intervention had usually been provided. Streissguth and O’Malley (2000) identified the following protective factors:

- Living in a stable and nurturing home environment for over 72 per cent of life. Stability between the ages of 8 and 12 appeared to be particularly critical.
- Being accurately diagnosed with FAS before the age of six.
- Receiving appropriate early education.
- Being eligible for special needs services.
- Never having experienced violence or abuse.

The prognosis was inversely related to the number of moves made by the child. The more placement moves a child had made, the worse the long-term outcome.

Failure to diagnose is not in either the mother’s or society’s best interests

It is often forgotten that there are also considerable risks for the birth mother in not making a diagnosis. An FASD diagnosis in her child

compels the birth mother to confront her alcohol dependence, and the birth of a damaged child is often the point at which she finally addresses her drinking. However, she cannot be offered help if her alcohol dependence is ignored by professionals. She will remain in denial and continue to drink.

For the birth mother whose child is removed, the risk is that she will misuse more alcohol to cope with her emotional pain and distress. Her dependence on alcohol will get worse. Any children still left at home with her will suffer from increasing levels of neglect. The birth mother may also become pregnant again and the damage to her developing foetus increases as she gets older and her drinking escalates. Her next child will be even more severely affected than the one just removed. The risk of FASD in a pregnancy after the birth of an affected child is 77 per cent (771 per 1,000) compared to the general population risk of one per cent. Social and health costs will multiply and the downward spiral will continue.

No diagnosis now means no services in the future

Finally, without a willingness to make more diagnoses, backed up by a proper prevalence study in the UK population, there will continue to be confusion around numbers of affected individuals in our society and it will be impossible to persuade health and social service commissioners of the need for additional services. They will continue to wrongly assume that FASD is a rare disorder that they do not need to resource.

WHY DIAGNOSIS REALLY MATTERS FOR LOOKED AFTER CHILDREN

Recent research suggests that the number of affected children jumps alarmingly when the likelihood of children in care being affected is considered in more depth. Only two UK studies have been undertaken (Selwyn and Wijedasa, 2011; Gregory *et al*, 2015). Selwyn and Wijedasa analysed the case files of 120 black and minority ethnic children from three local authorities who had received an adoption recommendation. In approximately one-third of the cases, parental drug or alcohol misuse led to the children becoming looked after. Dr Geraldine Gregory's local audit in Peterborough found that 34 per cent of children referred to her for looked after health assessments and 75 per cent of children referred for adoption medicals had a history of prenatal alcohol exposure. In most cases, the information on prenatal alcohol and/or drug exposure came to light only during her medical assessment. In only a very few cases was the information provided as part of the social care request for assessment.

If FASD is not considered as a possibility, and because the neurological impact of alcohol does not usually present until the child is aged at least five years or even older, social workers will be unknowingly placing children for permanence with unprepared or even elderly carers. Placements will break down because of the challenges the child presents, the incorrect advice given to carers about managing the child and the absence of effective support. This issue is becoming even more urgent as the number of special guardianship orders and kinship placements steadily increases. Children are now being placed more frequently with carers who are likely to be older and less active and who may be unable to manage the child long term.

Due to inadequate information about their exposure to alcohol, children will continue to be placed with adopters, long-term foster or kinship carers who have no prior knowledge of possible long-term problems and who have had no training in the management of the alcohol-affected child. These families face years of unresolved anxiety, guilt and unanswered questions. For all parents and carers, there is a major emotional impact in being given a diagnosis many years after placement. For some, it will be a relief to know at last "what is wrong". Others will be angry that they were kept in the dark and given inadequate explanations that did not address their concerns. All families must come to terms with the fact that they have a child who is likely to have continuing long-term special needs and who will have an impact on the whole family.

Alcohol-dependent mothers frequently have several children in quick succession. Over time, her dependence on alcohol gets worse and the amount of alcohol she drinks in pregnancy increases. Her children become progressively more damaged, with the youngest being the most severely affected. To keep siblings together, the same adoptive family might be asked to take a number of these children, either all together or over a period of several years. FASD charities report that some adopters are caring for three, four or five siblings, all of whom have been exposed to alcohol before birth. Each child may have few problems initially, but their needs become more complex and challenging as they get older. There is a limit to how many children and how many problems a family can manage. Every family has its breaking point, as this case history shows.

CASE STUDY

A professional couple had three attractive, healthy sisters placed with them for adoption. The children had relatively few problems initially. The oldest child developed behaviour problems in secondary school and for many years refused to attend. She is now 16 and out of education.

The middle child developed problems in primary school and is currently in a small specialised behaviour unit. The youngest child was unable to go to nursery because of her aggressive outbursts and the education authority is looking for a primary school that will take her. The parents felt angry and isolated and that they were being held responsible for the way their children behaved.

It was only when the youngest child was diagnosed with FAS that the family's problems began to make sense. They eventually found out that the children's birth mother had consumed substantial amounts of vodka during pregnancy, in addition to her known cocaine habit. All three children were damaged by this prenatal alcohol. Typically, the oldest child was the least damaged, the youngest the most severely affected. This well-known pattern reflects their birth mother's increased drinking as she got older and became more alcohol dependent. Brain damage meant that all the children simply could not cope with the demands of school. The adoptive parents are now in their late 50s. It seems likely that none of their children will ever be independent. The adoptive mother has had to give up her job and with it her pension. She has been driven to the point of breakdown on several occasions. Despite the provisions of the Children Act 1989 for "children in need", the family has been assessed as ineligible for respite care or an adoption allowance. They are very fearful of the future but remain totally committed to the children.

Sadly, most affected individuals get their main support from FASD charitable organisations, or local family support groups run by parents with an affected child, or the American and Canadian websites. Unless there is a radical shift in professional knowledge and practice, diagnosis and support will continue to be undertaken not by multi-disciplinary professional teams but by desperate carers helped only by "Dr Google".

KEY LEARNING POINT

- Given the high numbers of affected children in the care system and the implications for permanent placement, it is vital that social workers become familiar with FASD and always question, at the earliest possible opportunity, whether pre-birth alcohol consumption might play a part in the child's difficulties.