

Diagnoses made too late

Disclosing a neurodevelopmental disorder to parents is always difficult, in spite of current training in this task¹. Regardless of how well trained we are, we will always find the task difficult and often worry we have got it 'wrong'. However, I have found myself almost thanked when telling parents that their child still has a problem. Often these parents have sought a second or third opinion after being told their child was healthy. One parent wept as I showed her the abnormal scan, saying, 'I knew there was something wrong'. Another couple, as I outlined their child's language and behavioural problems, said, 'That's exactly what we think he's got wrong with him'. These comments identify the failure of the appropriate professionals to see children with neurodevelopmental disorders as soon as their parents become concerned and to make a correct diagnosis. The article in this issue by Howlin and Asgharian² on the diagnosis of autism and Asperger syndrome supports this clinical impression. Their data are from the UK but discussions with colleagues in other parts of Europe and North America suggest difficulties with diagnoses are not unique to the UK. While many clinicians, having seen an inappropriate label of autism applied to a child with learning disorders who has some withdrawal and is rather shy, would caution about diagnosing these conditions too early, the data suggest this is not a common finding. Parents are usually aware of their child's problems by 18 months in autism and by 30 months in Asperger. Many first sought a diagnostic consultation at the child's average age of just over 2 years for the autism group and 3½ years for the Asperger group. However, it is worrying that at the initial consultation at least a quarter of the parents of children with autism and more with Asperger were told that there was no problem. Even at the third consultation many parents were still given this opinion. Howlin and Asgharian report a confirmed diagnosis by 5½ years in autism and 11 years in Asperger. This delay in diagnosis has consequences for the child and the family.

And yet the possibilities of early diagnosis of autism have recently improved. In the forthcoming third edition of Gillberg and Coleman's *The Biology of the Autistic Syndromes*³, one noticeable change is the length of the chapter on diagnosis in infancy. Although the papers by Dahlgren and Gillberg⁴, and Baron-Cohen et al.⁵ had been published at the time of Gillberg and Coleman's second edition, their work was only preliminary. Their approaches can now be more firmly recommended. The age at diagnosis should therefore be dropping. It is hoped that if Howlin and Asgharian repeat their study in 5 years' time there should be some evidence of this.

The age at which children are diagnosed with autism suggests that many are identified by school age and hopefully a programme is developed with education

authorities to meet their needs. But the situation with Asperger differs; the children are identified as having problems later in their school career. The teachers of these children are often bewildered by their behaviour, which may be seen as deliberate, possibly resulting in the teacher feeling hostile towards the child.

It seems to me that health services are responsible for identifying these children in a preschool period and giving appropriate advice to our educational colleagues, many of whom are unfamiliar with the word 'Asperger'. Gillberg and Coleman are cautious in their discussion of the results of intervention in Asperger syndrome, saying that diagnosis and information is our main contribution. They write, 'Some might consider this a nihilistic approach but it is not. To the contrary, it means accepting somebody with a unique personality and a rather unusual set of behavioural traits without feeling the need to change him/her to achieve "normality" at any cost.'⁶ Certainly this would confirm my own clinical feelings. The children with Asperger whom I have visited in school who have been diagnosed early seem accepted in the community, whereas those diagnosed later are at odds with it. Furthermore, their parents have had many years of distress, feeling they have a child who has a problem that no-one will acknowledge.

Paediatricians, neurologists, and child psychiatrists and psychologists need to work regularly with these disorders to prevent a delay in diagnosis. Those who refer need to know who is familiar with the types of problems these children present. As with so many other disabilities, early identification of the children and prompt diagnosis is essential.

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References

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