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The Lost Generation

Very late diagnosis of Asperger Syndrome

In medicine, early diagnosis is considered better than late diagnosis. After all, the earlier a condition is detected, the sooner intervention can begin, and the better the outcome could be. In the Autism Research Centre (ARC) at Cambridge University, we have been putting effort into improving early diagnosis of autism spectrum conditions (ASC). We pioneered research in this area by developing a screening instrument called the Checklist for Autism in Toddlers (CHAT) which is used at 18 months of age, and are working on a major revision of this, called the Q-CHAT, in order to try to improve its power to detect as many cases of ASC in the toddler period. We also developed a screening instrument for Asperger Syndrome (AS) in primary school age children, called the Childhood Asperger Screening Test (CAST), used between 4 and 11 years of age.

So why an article focusing on very late diagnosis, if the most important age to screen and diagnose is infancy and childhood? The answer is simple: AS is one of the major subgroups on the autistic spectrum and yet, until Dr Lorna Wing published her article about AS in 1981 (in the journal Psychological Medicine), the English-speaking medical profession had barely heard of it. Indeed, the first book in English on AS was only published in 1991 (Asperger Syndrome, edited by Professor Uta Frith, Cambridge University Press). That was just 15 years ago. So, AS is a relatively recently recognized condition. (This is despite the fact that Dr Hans Asperger, the paediatrician in Vienna who first documented what is nowadays known as AS, wrote his article on this in 1944. Probably because his account was in German, it was overlooked by the wider world for the next 40 years). Interestingly, it took until 1994 for the international classification systems that define how a diagnosis is made to recognize the existence of AS. In the last 15 years, thanks in no small part to a veritable publishing explosion on the subject of AS (much of this literature coming out of the small but influential publisher Jessica Kingsley Ltd), most teachers, clinicians, social workers, and parents have now heard of AS, and thankfully many children with AS are being identified and diagnosed by middle childhood.

But what of the generation who were born before 1980, who may have had AS but for whom there was no diagnosis available? No specialist clinical teams, not even the concept of AS. How did they fare? The answer is that they were overlooked, and struggled through their school years. And the reason we run a clinic for the very late diagnosis of AS is because these are the lost generation: those who today would receive their diagnosis by 6 or 8 years old, if they were a 21st century child. They come to our clinic in young adulthood or even middle age, and they tell us a now-familiar story.

All through their school years they had trouble making friends or fitting in. Many were bullied by the other children, both physically and verbally. Many felt, in Claire Sainsbury's chilling words, like "an alien in the playground". (This is the title of her excellent book). The lucky ones managed to stay in school long enough to get their SATs, and some got to university. But not without feeling their teens were an uphill struggle. By young adulthood many had suffered clinical depression and even felt suicidal. All because their underlying condition of AS had gone unrecognized and therefore unsupported. Some of them had enjoyed the closeness of an intimate relationship only for this to break down. Some had found employment only for them to run into problems in the work place through not understanding what the employer and other staff might expect of them, or through getting into conflict, or being passed over for promotion because of their lack of team skills.

The unlucky ones succumbed to the low self-esteem that comes from a childhood of being bullied or feeling excluded – never being invited to other children's homes or birthday parties, for example – and dropped out of school. In some cases, they were asked to leave because the school couldn't cope with their odd and disruptive behaviour in class. In other cases, the children themselves gradually truanted, because the lessons seemed pointless. (Why wouldn't the teacher let them pursue their interests in military history, or in the molecular structure of proteins , or in ancient Chinese maps, or in prime numbers, to the exclusion of all other subjects? Why were they forced to study subjects like English or broad subjects like Geography, when all they wanted to do was pursue a narrow topic in depth?). Sadly, these unlucky ones left school by 15 years old, with no qualifications on paper, and many have been unemployed for long periods if not continuously, ever since.

The Cambridge Lifespan Asperger Syndrome Service (CLASS)

And then – somehow – they heard that AS exists. Maybe through a newspaper article, or a website, or in a poster on the wall in the GP/Health Centre waiting room. And for many of them, they describe that moment of feeling: "This is me". Coming to the CLASS clinic for many is a process of confirmation of their own self-diagnosis. Whatever their age, they are asked to come with a parent or someone who knew them as a child, so that a diagnosis can be made not only using information from the patient themselves, but also from an independent observer. This is because AS is a developmental condition, and requires that there were signs of social difficulties – alongside narrow interests or what are sometimes pejoratively called 'obsessions' – from early childhood. In most cases, the diagnostic interview (which takes about 3 hours) easily picks out the red thread that runs through the patient's life, where all the characteristic features are evident.

Because so much research and clinical practice has focused on early diagnosis, there were precious few clinical tools available for the diagnosis of adults with suspected AS. CLASS has therefore had to develop new methods for the very late diagnosis of AS in adulthood. These methods include screening instruments such as the Autism Spectrum Quotient (AQ) and the Empathy Quotient (EQ); and a semi-structured interview schedule for the diagnosis itself, called the Adult Asperger Assessment (AAA). (All of these methods have been published and are available for free via our website at www.autismresearchcentre.com).

The CLASS clinic is diagnostic only. Patients come from all over the UK, so the most we can offer is to confirm or rule out the diagnosis. We then write a report and send it to the patient's GP, with a set of recommendations for what local services should be providing for this particular person. The recommendations also frequently include encouraging the person to contact the NAS to find out about local support groups, the sheltered employment agency (Prospects), the befriending service, and sheltered accommodation if needed. For most people, even receiving the diagnosis comes as an immense relief and is itself a form of intervention, since now they have a way of making sense of a lifetime of feeling different.

Some join chat rooms for AS on the internet, and meet other people like themselves. Some justifiably take pride in their new identity as someone with AS, since AS is not just a medical condition (causing social difficulties) but is also a personality style in which the individual shows superior attention to detail, the capacity to go deeply into narrow subjects, a talent at recalling systematic and patterned information (dates and other numerical information), and which can result in remarkable artistic, scientific or technical skill.

But the reality also is that GPs do not always follow up the recommendations of the CLASS clinic, and the person with AS may be left with little or no support. Local services often find it hard to decide whose responsibility AS is: social services, education, health, mental health, learning difficulties? Whilst each agency passes the buck onto the other, the person with AS may be left floundering, their needs still as unmet as they were in their school days. We are still a long way away from what should be an expectation by families and by those with AS: that after someone receives a diagnosis of AS – at any age – the system picks up that person and puts together an appropriate package of support for them.

Is this due to lack of funding? In part this must be one of the factors. We know this because the CLASS clinic itself has had to rely from its inception on charitable grants, all from a Sainsbury Family trust, the Three Guineas Trust. Set up by Claire Sainsbury, daughter of the Minister for Science Lord David Sainsbury, this charity has a specific mission to help advance practical services for people with AS. Claire herself has AS and received her diagnosis late. So it took very little to persuade her that this kind of clinic was much needed. Thanks to her charity, CLASS has been able to offer diagnostic assessments free of charge to patients for 8 years, resulting in 300 patients across the UK receiving a diagnosis. Thankfully, the Three Guineas Trust has filled the gap financially for another 2 years. We are very grateful for this charitable generosity and hope that by 2011, the National Health Service will be in a healthier state to fulfil what should be a right for adults with AS.

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