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Reflections on Opening Pandora's Box

Lorna Wing

Publishing my paper on Asperger's syndrome in 1981, and suggesting that it is part of the autistic spectrum, has had various consequences. These include the growth of interest in the syndrome among the general public as well as professionals. Controversy over definitions of subgroups and prevalence of autistic spectrum disorders has increased. Adult psychiatrists are becoming aware that high functioning autistic disorders can underlie psychiatric conditions. Naming the condition has helped many with the syndrome to greater understanding of their skills and disabilities. It has highlighted the special contribution people with Asperger syndrome have made to the world. There has been a growth of specialist services but many more are needed. Describing and naming the syndrome has had mainly positive effects.

KEY WORDS: Asperger's syndrome; history; diagnosis; prevalence.

INTRODUCTION

In 1981, I published a paper on a pattern of behaviour that had been described by the Austrian pediatrician, Hans Asperger (1944). Asperger's paper was in German and his work was little known in English-speaking countries until the 1980s. My paper (Wing, 1981) followed by Uta Frith's (1991) translation of Asperger's paper aroused considerable interest. The computer database of the National Autistic Society includes scientific work, publications concerning education and treatment, and personal and parental accounts. In 1981 it listed 2 publications mentioning Asperger's syndrome. This rose over time to reach 126 published in 2003. The grand total from 1981 to the time of writing (June, 2004) was over 900.

Accounts of people with behaviour fitting Asperger's descriptions can be found in the historical literature. Among these was Brother Juniper, stories of whose behaviour appeared in the legends, written in the 13th century, of the followers of St Francis of Assisi in 12th century Italy (see Frith, 2003). Asperger's syndrome seems to exert a fascination for the lay public, even those not personally involved. The evidence for this is the appearance of characters with Asperger's syndrome in movies such as ''Mercury Rising'', television plays, including episodes in popular series, and literary fiction. The recent novel (Haddon, 2003) titled ''The Curious Incident of the Dog in the Night Time'', in which the narrator is a teenager with the syndrome, has achieved remarkable general popularity in the UK, even to the extent of being the subject of a question in a radio quiz show. Such characters were depicted in fiction long before the syndrome was named. As Uta Frith (2003) pointed out, Sherlock Holmes was the perfect example. The enduring popularity of characters of this kind is further proof of the fascination that the syndrome exerts, which has probably been enhanced by giving it a name.

Searching past psychiatric literature, Sula Wolff (1995) found an account of six children, all boys, with behaviour very like that which Asperger described. This was published in 1926, in a German journal, by a Russian woman psychiatrist, G.E. Ssucharewa and translated into English by Wolff (1996). Wolff notes that this was probably the first paper on children with this pattern of behaviour. Ssucharewa used the term

National Autistic Society Centre for Social and Communication Disorders, Elliot House, 113 Masons Hill, Bromley, Kent, BR2 9HT, UK e-mail: lgwing@aol.com.

"schizoid personality disorder of childhood", a label also used by Wolff in her studies of such children over the course of more than 30 years. By the chances of history, Asperger's name rather than Ssucharewa's has become associated with the "syndrome". However, Asperger's paper stands out because of his obvious empathy with the children and his understanding of the basic rules for interacting with and helping them, which cannot be faulted.

All kinds of consequences, mostly unanticipated by me, have followed from my first publication, which I equated to opening Pandora's box (Wing, 2000). The following are personal, mainly unscientific, reflections.

Asperger's Syndrome and Autism

Asperger, despite listing numerous similarities, considered his syndrome to be different from Kanner's autism (Asperger, 1979). I once had the pleasure of meeting him when he visited the Institute of Psychiatry. We sat in the canteen discussing, over tea, the relationship of the syndrome to Kanner's autism. Professor Asperger listened with great courtesy to my arguments and we cordially agreed to differ.

From my epidemiological and clinical experience I have always considered Asperger's syndrome to be part of the autistic spectrum. It shares the impairments of social interaction, social communication and social imagination and the repetitive pattern of activities and interests that characterise the spectrum. Furthermore, some children who fit criteria for classic autism in their early years develop behaviour like Asperger described as they grow older. In an epidemiological study (Wing & Gould, 1979) we found a few children who fitted Kanner and Eisenberg's (1956) strict criteria for Kanner's "early infantile autism", another few who fitted Asperger's descriptions but many more who had varied mixtures of features from both.

Establishing precise criteria for any syndrome defined solely on aspects of behaviour is difficult or impossible. The borderlines of the autistic spectrum merge, at the lower end of the scale of ability, with profound mental retardation. At the upper end of this scale, they merge into mildly eccentric variations of typical development. Within the spectrum, the subgroups that have been suggested merge into each other (Wing, 2005). Asperger, perhaps wisely, did not lay down specific criteria for his syndrome. The problems met in the various attempts by others to define Asperger's syndrome are illustrated in studies by Leekam, Libby, Wing, Gould, and Gillberg (2000) and Manjiviona and Prior (1999). The criteria in the American Psychiatric Association's (1994) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) and the World Health Organisation's (1993) research criteria for mental and behavioural disorders, based on the International Classification of Diseases (ICD-10) are the least like Asperger's own descriptions. They emphasise age appropriate development up to age 3 years of language, self help skills and curiosity, which is, in most cases, very difficult to ascertain. An attempt to apply these criteria precisely to 200 children and adults seen by my colleagues and me resulted in the diagnosis being made in only three cases, whereas applying criteria like Asperger's own descriptions (Ehlers & Gillberg, 1993) gave the diagnosis in nearly half of the group (Leekam et al., 2000). It is not surprising that there are wide discrepancies in the reporting of the prevalence of Asperger's syndrome (Fombonne, 2001; Wing & Potter, 2002).

A great deal of effort has been expended on investigating whether or not Asperger's syndrome can be separated from high functioning autism on criteria other than those related to level of ability. Eric Schopler (1996) expressed his strong disapproval of the fact that, by referring to it as "Asperger's syndrome" I had identified it as a separate condition from autism, although I have always considered it to be part of the autistic spectrum. Schopler was correct in stating that my paper had started controversy where none should exist. From the National Autistic Society's database, I found abstracts of 64 studies comparing Asperger's syndrome and autism. They varied widely in the psychological, behavioural or neurological variables that were considered. The authors of 15 concluded that these conditions were different, but on statistical rather than absolute criteria, 29 found no important differences and 20 were unable to reach any definite conclusion. The great majority of the abstracts mentioning both Asperger's syndrome and autism grouped them together, overtly or tacitly. Howlin (2003), in a follow-up into adult life, found no differences between high functioning adults with or without early language delays. Diagnostic issues have been discussed by Volkmar and Klin (2000).

Effects on Estimates of Prevalence of Autistic Spectrum Disorders

Kanner and Eisenberg (1956) laid down strict criteria for Kanner's "early infantile autism". However, since then, the criteria for autism have

steadily widened. In the DSM-IV/ICD-10 editions of the international classification systems, Asperger's syndrome appeared for the first time It was included under the heading of "pervasive developmental disorder" together with other autistic spectrum disorders. Over the years since the 1960s, epidemiological studies have tended to show a marked increase in perceived prevalence rates of both autism and other autistic spectrum disorders. Studies using DSM-IV/ICD-10 criteria have given the highest rates of all (Wing & Potter, 2002). Careful study of the trends suggests that major reasons for the perceived rise are increased awareness of autistic spectrum disorders and broadening of the criteria. It is possible that increasing interest in Asperger's syndrome has been one of the influences that has led to this broadening for "typical" autism as well as for the whole autistic spectrum. This is particularly likely in the light of the muddle over definitions of the syndrome mentioned above.

Asperger's Syndrome and Adult Psychiatry

Awareness of the existence of Asperger's syndrome is, by slow degrees, impinging upon adult psychiatry. The realisation is dawning that, before the condition had a name, some people with Asperger's syndrome who were referred to psychiatric clinics were misdiagnosed as having any one (or more) of a variety of psychiatric disorders. (Fitzgerald & Corvin, 2001; Nylander & Gillberg, 2001). For example, there are marked similarities between the DSM-IV/ICD-10 criteria for schizoid and schizotypal personality disorders and Asperger's descriptions (Wolff, 1995, 1996). In other cases, the person concerned did have a psychiatric condition but the underlying Asperger's syndrome was not recognised (Tantam, 1988). The situation is gradually improving but many mistakes are still made, with adverse effects upon treatment.

One special problem is that of the disorders of posture and movement resembling catatonia that occur in perhaps 10% of adolescents and adults with autistic spectrum disorders, including Asperger's syndrome (Wing & Shah, 2000). Hare and Malone (2004) have suggested that it should be classified specifically as "autistic catatonia". This can be a serious problem diminishing quality of life even in some people with high levels of ability but only a few researchers have given it any attention.

Knowledge of Asperger's syndrome is having an effect on forensic psychiatry (Wing, 1997). There are various reasons why a person with the syndrome may break the law. These include misunderstanding of social rules and being led astray by companions who take advantage of the person's social naivety. Although forensic psychiatrists are beginning to understand the problems, in the UK the law as it stands finds it hard to deal with someone who has a high level of intelligence but who seems indifferent to the fact that their behaviour has been inappropriate and illegal. Laws relating to psychiatric conditions should be framed to take into account developmental disorders such as Asperger's syndrome.

It is to be hoped that awareness of Asperger's syndrome and its relevance to adult psychiatry will lead to the inclusion of teaching of child development in the training of psychiatrists working with adults. Routine recording of detailed developmental histories could well deepen understanding of many psychiatric conditions, not just autistic spectrum disorders. In particular, systematic collection of information on childhood development might help to clarify the relationship between Asperger's syndrome and schizoid, schizotypal, obsessive- compulsive and possibly other personality disorders diagnosed in adult life.

Special Qualities of People with Asperger's Syndrome

In his original paper, Asperger pointed out that traits of his syndrome were necessary for high achievement in the arts and sciences. He also remarked that his syndrome was the "extreme end of the normal male personality"—a splendid opening for a lively discussion. Simon Baron-Cohen (1998, 2003), among others, has pursued these themes in his writings and these ideas have generated considerable popular interest.

Some books and papers have been published discussing people from the past who might have had Asperger's syndrome. These include the philosopher Ludwig Wittgenstein (Wolff, 1995) the prison reformer, John Howard (Lucas, 2001) the mathematician, Ramanujan (Fitzgerald, 2004). My own favourite candidate is Isaac Newton. Some people disapprove of such discussions and publications. My view is that they are interesting and thought provoking and in no way derogatory to the individuals concerned.

It is possible that high functioning people with Asperger's syndrome have always been responsible for innovative ideas that have moved the world on, since they are not bound by conventional socially accepted wisdom. Temple Grandin is a woman with high functioning autism who is a world expert on livestock handling equipment She has suggested that, in prehistoric times, the sociable people sat around

discussing their feelings while high functioning people in the autistic spectrum got on with inventing the wheel. A number of people with high functioning autistic spectrum disorders have published accounts of their lives, including Temple Grandin (Grandin & Scariano, 1986) Gunilla Gerland (2003) and Clare Sainsbury (2000). These authors have used their own experiences to help others with the same problems.

Implications for People with Asperger's Syndrome

One practical consequence of the publicity given to Asperger's syndrome is that some people, who have not been given a diagnosis, have thought about the relevance to their own personalities and problems. In recent years my colleagues and I have met adolescents and adults of all ages who have asked to see us to discuss the possibility that they have Asperger's syndrome. They want to know if this could be the explanation of the difficulties they have had in coping with the social world. Some men have consulted us together with their wives, who want to understand their husbands better (Slater-Walker & Slater-Walker, 2002). For almost all, the discussions have proved helpful and positive. We find this one of the most rewarding aspects of our clinical work.

We have also met a few people who intensely resent the suggestion that they have Asperger's syndrome. In contrast the great majority have found the diagnosis to be helpful and comforting. At last they have an explanation of why they have always felt different from other people. The diagnosis helps them to realise that they are not alone even if they are in a minority. Most parents also have found that the diagnosis gives them better understanding of their children.

The publicity concerning the special skills of people with Asperger's syndrome and the historical characters who were high achievers and who might have had the syndrome have given many people with this condition more confidence in themselves. Some, undaunted by pressure for political correctness, cheerfully refer to themselves as ''Aspies''. They emphasise that their way of thinking and behaving is different from the majority of humans but equally valid and in some ways superior. In support of this view they cite their accurate memory for facts, their uncompromising honesty, their clear, concrete thinking and their total lack of hypocrisy. They contrast this with the more devious, socially driven behaviour of the majority, whom they refer to as ''neurotypicals''.

The first voluntary associations set up to help people with autistic spectrum disorders and their families were started in the UK and USA in the 1960s. The initiators were mainly parents of younger children with typical autism. They were soon joined by professionals in the field. This pattern seems to have been followed by associations in many other countries throughout the world. Now that the diagnostic criteria are much broader and many adults have been diagnosed as having autistic spectrum disorders, those who are more able want to be actively involved in the voluntary associations.

In the UK, people with Asperger's syndrome have formed their own groups, often with the help of the internet. Some of these groups are within the National Autistic Society, some are independent. Some have joined the National Autistic Society as ordinary members and a number have been elected to the governing bodies on the same basis as parent or professional members. Some want to change the constitution so that a specified number of people with autistic spectrum disorders are on the governing bodies specifically to represent those in the spectrum. Some would like to see the governing bodies composed entirely of people in the spectrum. Similar ideas are being or will be presented to associations in other countries. How the arguments will be resolved remains to be seen.

Another contentious issue is the move by some people to divide the National Autistic Society in the UK into two separate associations, one for Asperger's syndrome and one for autism. Those who take this view tend to feel that the Society as it is constituted at present does more for one group than for the other. Both groups feel this equally strongly. However, it appears that the majority of members consider that the Society should continue to represent the whole autistic spectrum.

Development of Services

Although people with Asperger's syndrome have undoubted special abilities, it cannot be denied that they find many aspects of life difficult, especially the world of social interaction with its subtle, unspoken, ever changing rules. Many, perhaps most, need special help during childhood and in adult life. Recognition of the existence of Asperger's syndrome has led to the beginning of development of specialised services.

These include diagnosis; treatment for associated conditions such as epilepsy, Tourette's syndrome,

psychiatric conditions; education at pre-school, school age and post school levels; counselling; employment and accommodation for adults. Methods have been developed to help more able people *learn* social skills in the absence or impairment of instinctive understanding. Publications giving practical advice are now available and increasing in number (for example, Abrams & Henriques, 2004: Gillberg, 2002; Gray & White, 2002; Klin & Volkmar, 2000). There have been positive advances in provision of services in many countries, but there is still a long way to go. In the UK there is still a dearth of information and knowledge among professionals, such as health visitors, social workers and GPs (family doctors), who are not specialists but who will meet children and adults with autistic spectrum disorders, often before they have been diagnosed, in the course of their work.

In the field of education in the UK, there is a current, sometimes acrimonious, debate about whether people with autistic spectrum disorders should attend mainstream or specialist schools. So-called "integrated education" in mainstream schools is favoured by some for ideological (and financial) reasons. They consider that this provides equality of treatment. Children with Asperger's syndrome, because of their level of ability, are particularly likely to be placed in mainstream schools. Those opposing this trend point to the children's need for special techniques of teaching. They also point to the fact that mainstream school exposes the children to teasing and bullying by their peers, which can have disastrous effects on a vulnerable child's development. A survey by the National Autistic Society (Barnard, Prior, & Potter. 2000) found that 21% of children with autistic spectrum disorders attending mainstream schools were excluded at least once for varying periods of time compared with 1.2% of the total school population. For the more able children with autistic spectrum disorders, the figure was 29%.

This raises questions concerning what happened to children with Asperger's syndrome before the syndrome was identified. Some must have been placed in special schools. Others must have attended mainstream schools. Doubtless they suffered teasing and bullying then as now, but the greater degree of organisation and discipline common in schools in the past probably made it easier for children with Asperger syndrome to cope in the classroom, if not the playground.

Finding and keeping paid employment is a particular problem for many people with Asperger's syndrome. Supported employment schemes have been set up in some areas of the UK and the USA. They have demonstrated that, with expert support, more able people with autistic spectrum disorders can make excellent employees in the kind of work that utilises their special skills (Mawhood & Howlin, 1999).

CONCLUSIONS

The consequences of identifying and naming Asperger's syndrome as an entity have been both positive and negative. On the positive side can be cited the help many people with the syndrome and their families derive from understanding the nature of their problems and appreciating their special skills. The development of all kinds of specialised services for more able people in the autistic spectrum has also been of benefit to those receiving them. The interest and sympathy aroused in the public by real and fictional stories of people with Asperger's syndrome have had a mainly positive effect. Giving a different label from autism has allowed some more able people to accept the diagnosis.

On the negative side are the arguments about the relationship to autism and the moves to split the British National Autistic Society into two separate groups. However, knowledge of Asperger's descriptions of the pattern of behaviour given his name has widened the boundaries of the autistic spectrum far beyond Kanner and Eisenberg's (1956) criteria for autism. Apart from the benefits to the people with autistic spectrum disorders themselves, this broader view has stimulated interest in the ways in which social interaction, social communication and social imagination can be manifested in typical as well as atypical development. It is to be hoped that research in these fields will have implications for typical development and brain function as well for the study of autistic spectrum disorders.

My personal view is that a multi-dimensional is much more appropriate than a categorical approach. Human development can deviate in many different ways. There appear to be few if any restrictions on the possible combinations of specific deviations from typicality. Autistic spectrum disorders are held together solely by the absence or impairment of the social instinct, together with the problems of social communication and social imagination. These can be associated with any other developmental disorders. It could be argued that the choice of the social

impairments as the core for identifying and naming a group is purely arbitrary. Why not specify and name a group who all have, for example, reading, motor or sensory difficulties, regardless of the cause or any other problems? The reason is that the social difficulties have such a profound impact on the lives of the people concerned.

However, given that it is helpful to recognise a group with these social difficulties, it makes more sense to study specific aspects of dysfunction rather than diagnostic subgroups that can be defined only on arbitrary criteria. Research into, for example, different carefully defined manifestations of social impairment, or unusual responses to specific sensory stimuli, or patterns of motor difficulties, together with the neurological correlates, might well be more enlightening than work on subgroups for whom the ill defined criteria make comparisons between studies difficult. In clinical work, examining the profile of skills and disabilities of individuals is a better basis for designing a helpful programme for the person concerned than assigning them to a diagnostic subgroup.

The story of autism and Asperger's syndrome attests to the truth of three wise sayings. There is nothing new under the sun. Nothing exists until it has a name. Nature never draws a line without smudging it.

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