Giving the diagnosis to the young person with Asperger syndrome or high functioning autism: issues and strategies

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Editorial comment
There appears to be little written on this very important topic in the general literature on autistic spectrum disorders. This paper presents some of the issues involved and possible ways of explaining the diagnosis to the person concerned. The editors of GAP would like to hear from others who have views and experiences in this area to contribute to future issues.

Introduction
There is surprisingly little written on the issues surrounding giving the diagnosis to the individual with an asd in many of the standard texts on autism and Asperger syndrome (AS). Interestingly, what does exist, has been written by individuals with an asd themselves. There has been an increasing number of biographies in recent years by this group and professionals have been encouraged to try to view autism from the inside, through the perspective of those with autism, rather than speculating, from the outside, on why they might behave as they do – a position summed up by Theo Peeters (2000) who says:

‘they should be our future collaborators as they are the experts on their own autism’.

In this paper, the views of those with an asd have been drawn upon to consider the potential benefits and issues. Clearly, there can be no set or prescribed way of giving the diagnosis to a young person with an asd, as each person is different and so too is their family. Having said that, there are common issues that apply to most situations which it is important to take into account. In my view, the diagnosis should be given to the person with an asd in the majority of cases, for reasons that I will outline. There may be exceptions to this and parents and professionals have to judge whether giving the diagnosis is likely to cause more problems than it solves. What is clear, is that for all individuals with a diagnosis of Asperger syndrome or high functioning autism, there should be a debate between the family members and the professionals who know the individual well, as to whether the diagnosis should be given to the individual, and if so, how, when and by whom.

Late diagnosis
Many high functioning people with autism or Asperger syndrome are not diagnosed until the age of eleven years or beyond, some not being diagnosed until adulthood (Howlin and Moore, 1997). Some of these individuals have self-diagnosed from
accounts given in the media (Aston, 2000). There are also many adults with an asd who are never diagnosed at all or who are given a different diagnosis. Giving a diagnosis to those who are high functioning is particularly important as they are likely to live and work independently and will need to understand their problems in order to develop effective strategies and explain themselves to others. It seems likely that the earlier a person is given their diagnosis, the better the outcome. So effort is still required in raising the awareness of staff in mainstream schools, in particular, on the nature of Asperger syndrome and autism, giving clear advice on referral routes for assessment for children where this might be suspected.

**The potential benefits of giving the diagnosis to the individual**

From discussions with parents and the accounts of adults with an asd, there are several potential benefits in sharing the diagnosis with the person concerned. However, it should be said that their initial reaction to this information might lead to feelings of anger, denial and lack of self-worth discussed later in this paper, which will need sensitive and careful counselling over a number of weeks, and in some cases, over a longer period as they come to terms with the diagnosis and its implications. Having said that, the majority of biographies written by those with an asd point to the benefits of knowing they have autism or Asperger syndrome. Many individuals with an asd:

- are acutely aware of their own shortcomings and their self-esteem can be very low. Giving them their diagnosis may serve to enhance self-esteem.

- often find it hard to identify why they feel anxious or upset. Explaining why they experience difficulties in a situation can help in that process

- may know what they are anxious about, but be unable to generate a strategy. Having their diagnosis gives them access to the literature and professionals.

- can be very good at coming up with coping strategies themselves, if they know what their problems are

**Giving individuals with an asd the diagnosis is likely to**

- provide answers to the question often asked of them, or implied

  One able adult with Asperger syndrome told me, 'I was either teased or ignored, but I could not understand why.'

- make them aware that others have similar difficulties and enable them to explore support groups or contact groups, if they wish

- help to identify their strengths and skills and enable them to read about and meet successful people with an asd

- enable a discussion of appropriate choices of further education and a career
• change a negative self-image to a more positive image

Risks of not informing individuals of their diagnosis

Many of the points made in this section stem from the words of those with high functioning autism or Asperger syndrome. The person with an AS (and other people) may give negative explanations for their behaviour and problems.

Clare Sainsbury, an able person with an ASD, (2000) writes:

‘getting the right label was one of the best things that has ever happened to me. By my teens I was seriously depressed after years of being different and not knowing why, and believing that since no-one gave a name to my problem, I must be imagining it, or not trying hard enough (after a decade of trying very hard and failing very hard to be like everyone else’ (p. 31)

‘When I didn’t have an official diagnostic label, my teachers unofficially labelled me as emotionally disturbed, rude and so on .... and my classmates.. labelled me as weirdo, freak and nerd. Frankly I prefer the official label.’ (p. 31)

Alison Hale, an able woman with an ASD, (1998) writes,

‘ I still believe one of my strongest defences against all my disabilities is the awareness of exactly where my problems lie.’ (p. 130).

Gunilla Gerland (1997), who was not diagnosed until she was an adult, said,

‘I tried asking questions to find out if there was anything the matter with me.....But questions that to me were deeply serious were answered in amused voices (by others), ‘Oh no there’s nothing wrong with you dear.’ (p.127)

She argues that other people lie to children with AS, using such phrases as:

Everybody feels like that sometime.
I’m sure they like you really.
You can do it if you just try. (p.125)

She acknowledges that these are intended to reassure and comfort, but believes they often have the opposite effect (ie if everyone feels like this – why am I the only one that can’t cope? Or, if everybody likes me, why do they not want to talk to me?) She argues that when others lie to avoid harsh truths,

‘ it is not in our interests – it is not surprising that many of us end up thinking we are crazy’ .... just to be able to explain to yourself why you can’t do some things is very helpful ‘(Gerland, 2000)

Because of their great difficulty in understanding the world, they are particularly dependent on receiving accurate information from the adults around them. Gunilla is very keen on sharing the diagnosis with the young person because,

‘If you can’t explain your problems to yourself, how can you explain your problems to others?’
She is now involved in running groups for young people with Asperger syndrome aged from 9 to 17 years where the focus is to explain the diagnosis to the young person. She has written a small booklet for those with Asperger syndrome and high functioning autism explaining some of the difficulties they might experience (Gerland, 2000).

It is not known how many parents have the diagnosis but choose not to share it with their child. By not doing so, in effect, all the consequences of late diagnosis as reported in the literature are then conferred on the child or young person. There are potential problems later in life if parents decide not to discuss and share the diagnosis with their son or daughter. One parent in her 70’s, had a son with Asperger syndrome in his 40’s, who had never been told of his diagnosis. He had lost his job and returned home to live with his mother on unemployment benefit, supplemented by his mother’s limited income. He then gained a place with a retraining agency. His mother felt that she should share his diagnosis with the training agency and with the benefits office so that he was trained for a job where he was likely to succeed and so that he could receive disability benefit. But first she felt she needed to discuss this with her son, which seemed a very daunting task.

**Potential difficulties in giving the diagnosis to the young person**

There are potential difficulties in giving the diagnosis to the young person. For some with Asperger syndrome and high functioning autism, it is a relief and a largely positive experience, but for others it might lead to depression or anger with energies being spent on challenging the diagnosis. Some might experience a mixture of emotions, both positive and negative. However, where the person’s initial response is anger, this does not necessarily indicate that it was wrong to introduce him or her to the diagnosis. The first discussion is but the start of an ongoing process of gradually explaining the underlying reasons for their behaviour, difficulties and strengths. The explanations and discussions can be frequently returned to when opportunities present themselves.

Tom Bailey, who was not diagnosed with AS until the age of 13, wrote an essay at school on the relief his diagnosis brought to himself and his mother (Bailey, 1999). The class had been asked to write an essay on a landmark in their lives and Tom chose to write about the impact of getting his diagnosis. He started it by writing,

‘neurotic mother, poor kid’ – this is what people would say to my Mum when she took me to see doctors.’

Finally, after yet another incident of raging at home with his mother, he said,

‘I need somebody to help me with myself’

and he was subsequently assessed and diagnosed as having Asperger syndrome. On the other hand, David Hawke, on being given the diagnosis said,

‘I didn’t want anything to do with it. It scared me. I didn’t like going to the psychologists and stopped going and they didn’t bother me again (in Sainsbury, 2000).’
However, the potential difficulties arising from giving the diagnosis should not necessarily be a reason to withhold that information. The person’s initial response might not be their eventual reaction and their comments and feelings on being given the diagnosis can serve as future areas to work on and discuss. Similarly, the differences between those with an Asd need to be taken into account and an acknowledgement that the agenda for discussions around the diagnosis are as much influenced by the person with the asd as by the ideas that their parents or professionals might have. As Gerland (2000) says,

.....’you are not best helped if the people around you.......act as experts telling you that they know exactly what your condition is. What you need is guidance from them to come to your own truth, and to develop your personal approach to your condition.’

There are those who do not want to foreground the autism or Asperger syndrome and wish to see this as but a part of the person. In fact, speaking with adults who now earn a living talking about having autism, the occupational hazard is that most people they meet want to talk to them about autism. In addition, some feel they are constantly being observed for signs to confirm or disprove their diagnosis. They are constantly having to decide whether or not to tell new people they meet they have an asd. Advising them on who to give their diagnosis to is a useful topic to discuss.

**Issues to consider once the decision has been made to explain the diagnosis to a person with an asd**

Generally speaking, it is the parents who should decide on when the diagnosis is shared with their son or daughter. Where a professional involved with the young person feels that such a discussion would be helpful, s/he should consult with the parents and together discuss how and when and by whom the diagnosis will be explained to the individual (see Figure 1)

**Figure 1:** Questions that may be useful to consider before embarking on a discussion of the diagnosis with the young person with an asd

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<tr>
<td>1</td>
<td>Is the individual ready for this discussion?</td>
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<td>2</td>
<td>What leads you to make this judgement?</td>
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<td>3</td>
<td>Do his brothers and sisters know of his/her diagnosis, and if not, should they be told first?</td>
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<td>4</td>
<td>Are important others (eg the school staff; employers) aware of the diagnosis?</td>
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<td>5</td>
<td>Are his/her peers aware of the diagnosis?</td>
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<td>6</td>
<td>Who will initiate the discussion of his/her diagnosis?</td>
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<td>7</td>
<td>Who will you tell about this and his/her response to the information?</td>
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<td>8</td>
<td>What do you think the benefits might be to him/her and to others?</td>
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<td>9</td>
<td>What are the potential negative consequences of sharing the diagnosis?</td>
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<td>10</td>
<td>How will you illustrate what AS or asd means?</td>
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**When to explain the diagnosis to the young person with an asd**

There can be no set time in terms of chronological age that is best, given the differences between individuals with an asd. However, Wilkner Svanfeldt et al. (2000), a Swedish team of psychologists who have worked with children on explaining their diagnosis, say that in their experience, it is often around the age of 9
years, when a child starts to ask questions about his/her diagnosis, but for some it might be younger or older than this. An opportunity might present itself and this might prompt a discussion, if this seems appropriate (eg a TV programme on autism prompts the child to say – ‘that’s just like me’ or he says – ‘why does no-one want to play with me’? Or ‘Is there a ‘Friends R Us store?’ or ‘why do I keep losing my job?’).

**How and by whom should the diagnosis be given to the young person**

This is clearly something that is best discussed with the parents. However, there are instances where this has not been done, where professionals have taken the decision to discuss the diagnosis without telling the parents. Or there have been instances where the parents have been given the diagnosis of an asd in the presence of their son or daughter. One family said that the response of their 12 year old son on hearing the news was to become very angry and depressed and he demanded that they sought a second opinion. So they came away from the consultation having to deal with all their own feelings surrounding the diagnosis and a very angry son.

**The position of other family members in relation to the diagnosis**

Parents also need to make the decision as to whether to tell other members of their family, both immediate and extended, and, if so, when and how. If other family members are not given an explanation of the young person’s diagnosis, then they may misunderstand their brother or sister or grandchild and their parents’ response to him/her, and may become alienated from the individual and angry. Some parents have chosen not to share the diagnosis with their child or other family members. They have been concerned that the child or others might then use the diagnosis as an excuse for their behaviour (eg ‘I/he can’t help it, I’ve/he’s got autism.’). Most siblings however, know there is something different about their brother or sister and ask questions such as, ‘Will he ever talk? Will he go to my school?’ These questions often start to arise when they meet other children of the same age as their brother or sister with an asd.

Brothers and sisters may be teased by other children for having an odd brother or sister and so it is helpful to develop a script with them to respond. It is possible for parents to introduce the term autism to a child as young as three or four years of age and they may use the term, initially, without understanding. Their understanding will gradually develop and the booklets produced by Julie Davies (1993) can be useful to illustrate some of the behaviours found in autism. There is also a useful chapter on this topic written by Harris (1994) in her book on siblings of children with autism. Siegel (1996) encourages parents to suggest to siblings that the label Asperger syndrome is an empty box into which they can put all the observations about how their brother or sister is different.

**Sharing the diagnosis at school with the child’s classmates or the young person’s peers**

Decisions need to be taken again as to whether there are benefits to sharing the diagnosis with the children in the class, the students at college and the wider study or work environment. This requires skilful handling and advice and consent from the parents. The diagnosis might not be mentioned per se, but a discussion on the person’s differences might be helpful. If not planned carefully, there may be unfortunate consequences. One 10 year old boy at a small, private school made the decision to tell
his classmates that he had Asperger syndrome in the hope that it might reduce the teasing. Unfortunately, this disclosure had the reverse effect and other pupils then called him names based on the term Asperger. The boy and his parents were devastated.

**Who should give the diagnosis to the individual?**

Parents will have spent many years giving explanations to their son or daughter in response to their questions and behaviours without mentioning the diagnosis. They may then reach a stage where they want to name and discuss the diagnosis in more detail. They may choose to do this alone or may want to involve other professionals who have a good relationship with their child. Where their son or daughter has become distressed about their problems, parents may want to seek advice and input from psychologists or other professionals who can arrange individual or group sessions. Some professionals run groups for those with an asd where diagnosis might be discussed and there are some who run groups for siblings (Evans, 1999). It may be helpful for some to have individual sessions with a psychologist or other professional. Hare (1997) suggests that cognitive behavioural therapy might be useful with older children with Asperger syndrome. In this approach, the emphasis is on the way an individual’s behaviour is influenced both by their immediate situation and their interpretation of it, rather than focusing on more global and historical factors.

**Strategies to use in giving the diagnosis to the individual**

**Group discussions on diagnosis for individuals with an asd**

A group of psychologists in Sweden reported on their experience of running groups for children with Asperger syndrome to discuss their diagnosis (Svanfeldt et al., 2000). They ran two groups, one for 9 to 13 years olds and the second for those aged 14 to 17 years. Details of the group sessions are given in Figure 2. They believe it is important to discuss diagnosis with the child, as, in their experience, children know they are different and may develop fantasies about why, and about their prognosis. They may overhear many conversations and pick up and worry about certain terms and words such as brain dysfunction, brain damage and neurological deficit.

**Figure 2:** Details of the group sessions to discuss the diagnosis of Asperger syndrome

| 1 | Location: Autism Center, Stockholm, Sweden |
| 2 | Leaders: 2 psychologists                   |
| 3 | Number of children: 13 to 15, all of whom knew they had Asperger syndrome |
| 4 | Placement: all from mainstream school      |
| 5 | Number of sessions: 5 sessions over 5 weeks, plus homework |
| 6 | Length of sessions: 90 minutes, with a 5 minute break and 10 minutes for snack at the end |
| 7 | Focus: to encourage the children to ask questions about their diagnosis |
| 8 | Materials: Flip chart and white board to record comments. Flip chart records kept for reference in future sessions. Mailbox for them to post questions. |
| 9 | Escape route: orange card system – to enable them to leave the room for a short break |

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Prior to the first session, the two leaders met with all the parents, so they could tell them important things about their children. The leaders met the parents again after the course to give an opportunity to hear the children’s reactions to the course in both settings. In the first session, they talked about the terms they had heard and the diagnostic criteria and considered which of these applied to themselves. In the second session they discussed some of the problems they had with meaning, playing games and changing rules. In the third session, they discussed the structure of the brain and how some networks seemed blocked or not properly connected which meant they had to develop other strategies. In session four, they discussed positive and negative experiences about school and met an older person with an asd who provided a good role model. In the final session, they talked a lot about their strengths and things they were good at as they wanted the last session to be very positive. They then formulated a response which the children could give when people asked them what Asperger syndrome was and they were given age appropriate literature and web site addresses. A booklet was created at the end of the course containing all that they had discussed.

**Conclusions on running the groups**

It was a very positive experience and members would have liked the groups to continue. The younger group in particular was very interested and curious and active and eager to understand and had very many questions. The older group (14 to 17yrs) were interested, but it took longer for their questions to emerge, although they were good questions when they did. A lot of the teenagers did not want to come to a group and denied having Asperger syndrome. So the leaders concluded that it was important to do this early. The children had so many bad fantasies about what was wrong with them. It was felt important to highlight their strengths and to give a realistic view of their problems. Time, place and punctuality were very important, and these should not be changed.

**Other strategies**

*Literature written by those with Asperger syndrome and those with high functioning autism*

Several books have been written and published by adults with Asperger syndrome which give extremely useful insights into their lives and what they have found helpful (eg Gerland, 2000, Grandin, 1992; Sainsbury, 2000, Williams, 1996). Extracts from these could be used in discussions about the diagnosis. There are also websites set up and run by people with autism and Asperger syndrome which can serve a similar purpose. Appendix 1 gives details of publications which could be used and some useful websites.

*Letters to the individuals with Asperger syndrome*

Elizabeth Newson, a consultant psychologist who assesses and diagnoses children with an asd has written letters to some of the children with Asperger syndrome she
has diagnosed (Newson, 2000). These are customised to fit the child’s particular profile, needs and interests. They explain the diagnosis and suggest strategies for dealing with some of their individual difficulties.

**Passports to individuals with an asd**

For those individuals who are not able to ‘tell’ others what they need and for those who lose the ability to communicate clearly when they are stressed, it can be helpful to write with them a passport or manual which gives information on the things they most enjoy and situations which are likely to cause great distress. Jane Jones (2000) has written about the use of these in the special school within which she works. These are particularly useful to staff who are new to the children and/or new to autistic spectrum disorders in helping them to understand the child’s perspective.

**Concluding comments**

The parents of the person with an asd will need to come to their own conclusions about whether to give the diagnosis to their son or daughter and if so, when and how. The accounts of those who have written about the experience of having autism and Asperger syndrome seem to indicate very strongly that knowing they have an asd has been vital. Of course, they do not represent the whole population of those with an asd and there may be instances where giving the diagnosis is not advisable. What also seems clear is that there is a need for more to be written about the subject to guide both parents and professionals in this very important and skilled area of work.

**References**


Wilkner Svanfeldt, P, Hogfeldt, S and Gerland, G (2000) They tell me I have Asperger Syndrome, what is that? A way of giving information about Asperger Syndrome to young people diagnosed as Asperger Syndrome, paper presented at the Autism Europe Conference, Glasgow, May 2000


**Appendix 1**: Useful publications and websites


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