When and how to help a young person with disclosing their autism diagnosis in school or college

Choosing to disclose their diagnosis is a huge decision for a young person. At best it can be the beginning of them claiming their diagnosis as a positive part of their identity, and can be the gateway to understanding and owning their future. At worst, it can lead to uncertainty and bullying, and much of how a young person sees themselves is affected by the views of those around them. The stakes are higher the older the child is, or when a diagnosis is very recent and they have not had time to process the information, which is much more common in girls who have been misdiagnosed or not had any diagnosis at all.

What they understand about autism and having positive role models is also very important. Given how difficult it is to get this right and how high the risks can be of making things worse for a young person, it is vital to start with the creation of a culture of acceptance of difference within which a disclosure can happen safely. If that isn't in place, think twice about disclosing at all. There is a world of difference between explaining autism in the context of a number of differences, and singling out a specific child as someone who has autism.

Wildlife presenter, Chris Packham, who presents BBC's Spring Watch programme and was diagnosed as an adult, has spoken in his book 'Fingers in the Sparkle Jar' about how he has struggled with relationships with his peers, experienced profound depression and wanted to commit suicide when he lost a pet with whom he had formed an incredibly strong bond. Would he, in that vulnerable state, have been able to cope with his peers having a name for the difference they could see in him, and taunting him as a result? I suspect not. It is easy for those of us working in autism and working with highly successful autistic people to see the positive aspects of autism, but it is important not to underestimate the fears that others may have.

The situation

You have a young person in your class who has a diagnosis of autism. Do you share that with the class and support them to build better relationships with peers, running the risk that it might go wrong and leave them more of a target than before? Minority groups can be the target of
bullying at school as elsewhere, so will you be making the situation worse? You might like to ask yourself the following questions:

1. **Is disclosure necessary, or is it better to work on an ethos of acceptance?**

How old is the child? Young children tend to be far more accepting of differences between themselves and others which is the best place to start in terms of educating them. At that age, they will not understand the detailed developmental differences, but they simply want an explanation for why one child is being treated differently to another. In these cases, it can be useful to look through the lens of 'what is fair' using stories.

As children get towards the end of primary school, the differences between a 'typically developing' child and an autistic child tends to become even more noticeable. At a time where most of the class is busy jostling for position, many young autistic people just opt out or get side-lined. This is a good time to reinforce messages of acceptance and value in difference. Transition to secondary school is an extremely difficult period for many autistic children who may have coped well in primary school, especially in the later years. Some of the best schools do a lot of work to build relationships between pupils at this stage with residential school trips, but unless this also fits in with a highly accepting school culture it can highlight even more differences in their lives outside school. Older teenagers on the other hand, can respond to group peer awareness programmes really well, becoming very supportive.

Autism awareness in isolation is likely to be less effective if it does not form part of the ethos of the school. Without an accepting culture being consciously created and reinforced, you run the risk of exacerbating an issue that already exists. As one very observant teenage autistic girl said, 'If you haven't covered a wider range of topics, you are basically just painting a target, and the pack will just attack you for not being part of the pack.'

2. **Does the young person know and accept their diagnosis?**

This is an area where the age of the young person and the peer group that we are talking about can be critically important. Whilst many young people who are diagnosed early grow up accepting their diagnosis as being just a part of them as much as their eye colour, people diagnosed in adolescence and late teenage years are already struggling with their identity which means that it could be a positive and reassuring explanation for their difference. Many autistic adults say that they wish they had known about their diagnosis earlier.

The NAS published a [guide for parents](#) on how to discuss diagnosis with their child. Some teenagers do not want to be different, resent having a life-long condition and may reject their diagnosis completely in which case the situation requires very careful handling indeed. Whatever collective decision you and the parents come to, it should always start from the young person and be in the context of ongoing involvement in supporting their wellbeing.

3. **Does the young person’s family want people at school to know?**

If not, you can do work with the class on the acceptance of difference in general terms, but you must not include any reference to a particular individual. A diagnosis is personal information.
and you must treat it as such. If the family are really keen then involve them by asking them to help you identify all the good things about the young person and what they love about them. Make sure that they are agree with the timing of the disclosure and are able to provide support to the young person. Don’t forget that there could also be a sibling who needs support as well, and any work you do with their brother or sister’s peers might also affect how they are seen in their peer group.

4. The young person wants to share their diagnosis, parents are happy to disclose, and you have an accepting culture in place, then what next?

There are a number of resources available to people who want to work on peer awareness within schools. What is appropriate for your group will depend on the age and profile of the young people you are working with.

For very young children you might like to look at:

Woodfer's World Produced by Ambitious about Autism, this resource for school staff includes a set of stories and an anti-bullying resource.

My Friend Sam by Liz Hannah Published by the NAS is a story told in large print with drawings which can be used for group work or story time.

For primary age children:

The 100% Awesomes from the Autism Education Trust is a lesson resource pack with a comic-based adventure with a lesson plan, DVD and resources designed for small group work in Years 5, 6 & 7.

For secondary age children:


The Autism Education Trust (AET) and the SEN context

The Autism Education Trust (AET) was set up in 2007 with funds from the Department for Children Schools and Families in order to improve good practice for children with autism in education. Since then it has worked tirelessly to provide help and support for people working in education so that they can provide a better start for some of the most vulnerable children in our education system. It is a partnership of over 30 organisations working across the autism sector including charities, local authorities, and people with autism, teaching schools, special and mainstream schools, commercial providers and universities.

In 2011, the AET was awarded a contract by the Department for Education (DfE) to develop a face to face training programme, national standards and competency frameworks for schools, and to select seven regional training hubs to deliver the programme across England. Following
the successful implementation of the schools programme, the DfE awarded the AET a contract in 2013 to extend the schools programme to meet the needs of the Early Years and Post 16 sectors, and the AET Early Years programme was born with the appointment of the first four training hubs and development of Early Years specific training, standards and competencies.

The Children and Families Act 2014 changed the landscape of support for children with SEN by going from birth to age 25. It also put the voice of the child and their family at the centre of planning for their future. It replaces the 'Statement of Educational Needs' with an 'Education Health and Care Plan' (EHCP) which puts an even greater emphasis on agencies supporting a child to work together.

To date the AET has run over 100,000 delegate sessions training education professionals since 2012.