

## **ANONYMOUS SUBMISSION**

### **Diagnostic/Identification Services**

1. HMIE have previously found that several education authorities are unable to quantify the numbers of pupils with an autistic spectrum disorder (ASD) or the number that have been diagnosed. Some local authorities have mentioned within the evidence to Parliament that they can meet the needs without the need for a diagnosis or for an autism bill to be passed. It is well known that many people with an undiagnosed ASD are grossly misunderstood throughout their school and adult life. They can suffer terribly and believe themselves to be failures or blame society for failing them. It comes as no surprise then that this situation, coupled with their well-known lack of empathy for others, can lead to our prisons containing many undiagnosed ASD people.
2. A diagnosis is a label and there are many who belong to the 'anti label' club. They do not accept that a label is a signpost to the correct remediation, and treatment process. It has been my experience and that of my pupils that those people without an ASD diagnosis or 'label' will be given many labels by the general populace – and few of them will be sympathetic.

### **Assessment/planning/provision of services**

3. Education is the one remaining treatment approach, which has a proven track record when dealing with the affects of autism. It plays a central role. In order to be successful the education required needs to be carried out by staff who have some idea of what they are dealing with or, who are enthusiastic about wanting to learn how to work with these children. Well meaning but often misguided individuals can unfortunately do more harm than good. Many high functioning autistic individuals and asperger syndrome pupils are deemed too bright for special schools so they are sent to their local secondary schools, which is in line with their academic abilities. However they do then require support with their social disabilities, as the attached evidence put forward by some of my pupils clearly shows. Education is a statutory right for children on the autistic spectrum but there is a major difference between education and, for want of a better word – schooling. The same can be said for inclusion and integration. Simply having an ASD pupil schooled means that they have had access to education, but whether or not they have understood it or can do something with it is open to question. Intelligence is the ability to access information, understand it and make use of it. Without the social foundation being laid, there is nothing for the academic to sit on. My take on inclusion (schooling) is that the pupil is included in the class to some degree, sits there with the other pupils, possibly with support and/or differentiated work. Some schools do wonderful work to make sure that their additional support needs (ASN) youngsters are totally included in everything by their peers. True integration (education) to me, means that the pupils are taught how to interact with their peers,

actively join in with the class, and are able to carry out the same mainstream work as their peers, albeit with a slightly reduced timetable.

4. I am not convinced that mainstream schools are the place for children with quite marked autism. I truly worry about the stress and sensory issues not to mention what benefit they could possibly gain. Indeed Baroness Warnock, the advocate for inclusion of children with special needs (1978) has since said that inclusion has been taken too far. In June 2005, she said, "It has gone too far. It was a sort of bright idea in the 1970's but it's become a kind of mantra.... it really isn't working". To me it should not just be about inclusion it should be a holistic approach – the whole child- academic and social.

## **Training**

5. The service we provide for some of the ASD pupils in our local education authority is a unit within a medium sized mainstream secondary school. It currently holds 11 pupils some diagnosed with high functioning autism (HFA), but mostly asperger's syndrome and of course mostly boys. (There are another four such units within the same education authority). We have two associate members at the moment. These are pupils who are as yet undiagnosed and have not officially been put forward for an official place with us. There are other undiagnosed pupils in the mainstream who seem to be 'coping' after a fashion but we keep a 'weather eye' on them. Many professionals feel that pupils with an ASD are outwardly 'coping' but often the reality is quite distressing. Our mainstream staff have all had some training in working with ASD pupils and are given an annual profile on each ASD pupil, in order to help them understand their behaviours and how to handle them.
6. The ASD pupils, when they are not in mainstream are taught a specialised ASD curriculum which is updated regularly. The aforementioned curriculum is taught through the cognitive route, just as maths and English are. Staff training is essential to ensure the successful delivery and outcomes of the programmes. It is impossible to be able to teach social skills, communication skills, feelings and emotions, life skills and problem solving without having an understanding of the condition the teachers are dealing with, otherwise harm can be done. A certain degree of skill is required in teaching these pupils, due to their different learning styles also, otherwise they end up being punished for something that is not deliberately their fault. Teachers need to be taught how to be aware of the following— language used in teaching, length of sentences/explanations, methodology, how to extract information, how to motivate, how to aid recall, how to teach study skills, and so much much more. It is well documented that the skills required for working with other ASN pupils are not generally useful in teaching pupils with HFA/asperger's syndrome – yet, paradoxically, the skills required, or methods used for teaching pupils with an ASD can be successfully used with ASN pupils. The same can be said for the environment.

7. The specially designed ASD environment of the unit imparts calmness to the pupils. We have been running for 13 years now and have had many successes, including James Cusack who features so heavily in the National Autism Society (NAS) *We Exist* publication. The pupils are in mainstream schooling for between 65 – 95% of their time. We have proof from previous attempts, that 100% mainstreaming is simply far too stressful because these pupils are not just dealing with their workload they are dealing with all the social stressors also. Two of our extremely bright pupils tried in the past and one nearly had a complete nervous breakdown. The pupils are supported by a personal support assistant (PSA) initially and the ultimate aim is to be 'solo' within the first few years. Our pupils go onto further education or employment. Many are in long-term relationships, and one has just got married.
8. Apart from teacher training, which is paramount, at the very least for those teachers running units for pupils with an ASD, PSAs should also be trained as they can do so much harm without meaning to due to a lack of understanding/training. They need to know how to identify a pupil who is overwhelmed with instructions, stressed, experiencing sensory difficulties – otherwise these pupils will once again receive unwelcome and inaccurate labels. In the past it has misguidedly been thought that if ASD pupils are with their mainstream peers, then they will learn to copy them. This can be true for some, as it is documented in the literature, but at a cost and without them understanding the meanings behind some of the behaviours. However in reality it is like saying to a blind child "here is a book, now read it". The higher functioning the pupil, the more able they are to learn the hidden curriculum of social skills.
9. Some people ask why ASD's should be singled out for a special bill as opposed to other disabilities/special needs. I would argue that ASD is the most 'hidden disability' or 'invisible impairment' and the most misunderstood as there are no or few outward physical signs. Their behaviour is therefore labelled as malicious, aggressive, violent, stubborn or even "conduct disorder" or attention deficit hyperactivity disorder (ADHD). In fact they could just want to express their feelings about something. They are often seen as able but non compliant. Due to the fact that they speak their minds relentlessly, this is misinterpreted as insolence/rudeness. They are unable to explain why they are saying or behaving in certain ways and are therefore disciplined. They need to be taught these skills. There are many other labels – too many to mention and these pupils remember them vividly from the past. You will read the labels given to one of my pupils in his evidence letter attached.

### **Adults with ASD**

10. In adulthood, the inability of many undiagnosed people to mix with others in employment or socially, means that they attract new labels such as weirdo, loner, geek, antisocial, selfish, arrogant etc. Often they have not done well in school, due to lack of understanding and no support. They

may have left as soon as possible to avoid further torture (Read *Martian in the Playground* by Claire Simsbury). Many will not receive the qualifications they were capable of if they had received the correct support. Some may end up doing mundane unskilled jobs. Then depression often sets in as depression is very common with the populace. Small wonder that alcohol/drugs and crime often then manifest themselves. For others a lifetime of anti-depressants follows because of their unfulfilled lives. Well-meaning employment careers specialists may place them in jobs where social skills are required and this compounds their failure as they cannot cope.

11. This group of clients have very specific support needs and anyone working with them must be aware. Those professionals supporting the ASD people post-school setting may not have any awareness and treat them as ASN which is totally inappropriate for the higher functioning person. Our careers advisor is extremely knowledgeable and is continually arguing for post-school ASD specific resources and trained staff. After all, our educational investment in these pupils is in jeopardy, if the post school set up is wrong.
12. Finally, diagnosed people with an ASD are entitled to apply for Disability Living Allowance. The Government is encouraging people on benefits to seek employment. For many people severely affected by their ASD, at the lower end of the spectrum, this would not be totally realistic. For higher functioning people it should be a right to find suitable employment
13. Ideally, due to the fact that this is such a specialist field, it makes sense for there to be a trained and experienced individual with each education authority, who has overall responsibility for ensuring the needs of those on the spectrum are met. This would avoid costly mistakes, tribunals etc.
14. The world would be a poorer place without some of the brilliant minds, of those considered to have asperger's syndrome (past and present). Certainly, due to their unique way of thinking, they continue to make marvellous contributions to medicine, science, engineering etc,
15. I fully support the Bill as it would make a difference to so many more lives, people with an ASD and their families. If implemented successfully, it would enable many people with an ASD to access the help and support they need.

A teacher  
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