

SUBMISSION FROM JANICE MYLAN

1. My name is Janice Mylan and I have a son, aged 22, diagnosed with Aspergers and other associated conditions. He fully supports this submission. I also have vast experience of working with many families and individuals with autistic spectrum disorders (ASD) and the like through various local and national voluntary support organisations.
2. The experiences with regards to all the key principles of the Bill over the years has been, to say the least, difficult and an uphill battle.
3. Diagnosis was (and from my ongoing support work experiences) still very difficult (and sometimes impossible) to get. For many of my son's early years we were accused of being over anxious parents who obviously did not understand how to discipline or bring up a child. We were pushed from pillar to post and even asked by our GP to become "detectives" as they did not quite know what to do or who we should go to. We have become great detectives however this is fundamentally wrong, exhausting and inappropriate. ASD is a medical condition requiring specialist knowledge and support which local authority services should have a duty to regard.
4. As my son was a "bright boy" and in early primary did not show "bad behaviour" but was regarded as "eccentric" the school also appeared to play down any difficulties that we were undoubtedly having and observing. As he got older and more distressed, anxious and depressed he then became a "behaviour problem". ASD is not so. It is a neurological condition but is seldom dealt with as such as at school or indeed when seeking medical help. It does not fit nicely into any compartment. A bit like how it is for people with ASD trying to fit their lives into a society that they do not understand and people do not understand them. Square peg round hole.
5. It was only thanks to other parents through support groups that we were finally able to find an excellent consultant and full diagnosis was given. We did have to go "out of area" in order to gain this and obviously local identification and diagnosis is essential if people are to get an accessible service.
6. There is also the question of "then what?" Any services we have accessed have been through our sheer determination.
7. Provision of diagnosis/assessment/planning/provision of services/training all has to be available locally and as uniform as possible. It is certainly a "postcode lottery" system that exists and many people and parents spend valuable time and energy just searching for well trained staff who have a sound understanding of ASD and the need of the individuals. Training of staff right across the services is patchy.

8. In schools, despite the existence of the Autism Toolbox now available there is little training on this so that this can be put into practice. Certainly we relied on the goodwill of education staff my son had, their respect of our knowledge as parents (we sought training ourselves and at our own cost) and provision of funding (if lucky).
9. Throughout his life there has been no clear pathway of provision of services. He, and we as parents, have had to repeat ourselves and look again and again at needs, assessments etc that it would be so easy just to give in. Many people do or certainly can only pull themselves back up on occasion and often only with the help of supportive and knowledgeable people around them. What about those that do not have access to or ability to do this?
10. With regards to college this was a mixed experience for my son. Colleges and further education establishments have to look at the transition services in particular as people with ASD find change and getting used to new environments/people etc difficult and sometimes impossible. Again, it was often down to us as parents to step in to ensure understanding at some level was in place and that provisions that should be happening were. The onus was very much on the student though and expectations too high from staff which was partly due to lack of resources but very much so to do with lack of training.
11. Training of staff (education, health, social work, police, job centres, employees and other organisations) is absolutely essential. How can people with ASD be truly taught, supported and become included members of society unless some level of understanding is there?
12. My son is now looking for employment. This has taken him and us as a family down another extremely difficult and rocky path. Criteria for help and support into employment in our area relies on adults having learning disabilities (IQ 70 or below) and ASD diagnosed. Aspergers is a neurological condition and most people do not have learning disabilities but do need help and support with employability skills but geared towards an understanding of their way of thinking. Nothing like this is available to my son and many others. Again, it depends on where you live and what information you are able to find yourself mostly and so far the provision of adult services seems depressingly little.
13. I hope that the Bill will eradicate the reliance on "those that shout the loudest and will offer a fair and level playing field for all and ensure that there are clearer pathways for people living with ASD.

Janice Mylan
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