SUBMISSION FROM M TAYLOR

Difficulties I experience

- It was a relief to get a diagnosis for asperger's syndrome, albeit late in life at the age of 41. The constant daily difficulties, especially socially, became harder when I went to high school, then depression set in, along with anxiety and isolation, which continues in my adult life. I am now 45 and for most of my life since the age of 16 I have been on antidepressants.
- 2. I am naturally a quiet person, so find communicating, especially verbal (and written) extremely difficult. It took me hours to write this statement and I had to ask a friend to type it for me. In the few part-time jobs that I've had which always make my depression and anxiety worse verbal communication has been a huge drawback, even although I'd expend huge amounts of mental energy trying to "fit in" socially and be what other people expected me to be (eg to talk a lot). I was always conscientious in my work, but was not appreciated and at times bullied. My confidence, of the little that I had, was constantly being shattered. I felt as if I wasn't worthwhile on a daily basis and have been unable to sustain employment as a consequence of this.

Help that I need but don't get

- 1. Access to a professionally qualified counsellor or psychologist who has a detailed understanding of autism spectrum disorders (ASD) particularly asperger's to help with emotional issues, positive thinking, how to accept and live with the condition, how to move forward in life.
- 2. I also need practical help with things like forms and how to understand and deal with bills. I have difficulty understanding and applying for welfare benefits. I have difficulties with other life skills, including making decisions, making telephone calls and a whole host of other things that are compromised by the difficulties caused by asperger's syndrome.
- 3. Any careers advice that I've had has been very poor, even before I was diagnosed. Good careers advice for ASD people should recognise their strong points as well as reflecting a detailed understanding of their difficulties and take all of these elements should be taken into account in making appropriate career recommendations. This would save people such as myself a lot of wasted time and money pursuing unsuitable courses of study and equally unsuitable careers and all of the disappointment, stress, frustration and mental ill-health caused by these.
- 4. I also feel that there are not enough employers willing to take on people who have ASD and especially not enough willing to persevere in supporting the difficulties that people have in order to reap the benefits of their talents. I am a graduate, but have never been able to capitalise on my years of study by forging a professional career and I imagine that this is very common among people with asperger's syndrome.

Employers need to be made more aware of how ASD affects people and how to manage the condition in the workplace, as this would not only increase the employment prospects of people already diagnosed, but would also benefit undiagnosed staff among the workforce and the employers trying to deal with their difficulties without knowing the root cause.

Why the passage of the Autism (Scotland) Bill into law matters to me

- 5. There is, in my experience, very little cohesive or sustained help or support available for ASD sufferers, particularly the ongoing support that is necessary to reduce anxiety and maintain structure and motivation. I think that if more people were diagnosed when they are young preferably at primary school their prospects for a more fulfilled and productive life would be much greater, but only if their rights to appropriate additional support in education were to be put in place and consistently maintained throughout primary and secondary school.
- 6. Counselling, help with life skills, support and good careers advice would help individuals to decide which course/apprenticeship/job would suit them best and save time and money engaging in the quest to find suitable employment and sustaining a lot of emotional upset and souldestroying hardship along the way, repeating the same mistakes over and over again and never realising why it keeps going wrong.
- 7. This requires support to find work after completing courses, as well as support between courses or jobs, especially when these have ended badly, as is so often the case. There seems to be a lot of front-end support to get people into training or jobs, but not enough to keep them there or deal with the aftermath of things going wrong. This needs to change.
- 8. When difficulties arise at work with workmates and employers, it all becomes too much for the person with an ASD to cope with or find solutions to on their own, especially when there is bullying. People with ASD can be intimidated by formal complaints mechanisms that are heavily dependent on a system of recording and account giving that disadvantage employees who have the style of thinking and perceiving associated with ASD. The least stressful solution for many people with ASD is simply to leave their employment, despite the other difficulties and sources of stress that this creates for them.
- 9. I think that it would be helpful to have a representative body to advocate in a manner similar to a union, but specifically for people with disabilities - including but not just for people with ASD - and tasked specifically with taking on matters relating to all disability rights and interests to provide support, equality and a voice for all people who are vulnerable in society.
- 10. Mental health issues need to be addressed, particularly the current situation whereby adults and children who have asperger's syndrome too often find their problems dismissed as being a normal part of their

condition rather than something that requires proper psychological or psychiatric support which results in them being treated as low priority for services as a consequence. Appropriate treatment is essential to health and wellbeing – both for the individual and for their partners and families. The earlier in life this is provided the better the long term outcome might potentially be in adulthood.

11. I am supporting the Autism (Scotland) Bill because I believe that life long, across-the-board support for people with ASD will only become possible when service providers are bound by statutory duties to make adequate and appropriate provision for people such as myself. Discretionary measures do not work and allow public authorities to categorise our needs as low priority, resulting in us being sidelined, ignored and left to struggle on until crisis point is reached. There needs to be more anticipatory care and support available, rather than reactive crisis management. This is something which is especially helpful for people with a condition like ASD, where planning, structure and routine are so important, and which, in the long term, will save health and social work services money and resources and avoid many of the mental health problems suffered by people on the autism spectrum and the burden that these can create for their families, even in adulthood.

M Taylor 8 October 2010