

SUBMISSION FROM TAMMY MCLELLAN

1. Only by legislation can people with autism access the services they need. If local services are not breaking the law by not providing the help then sadly it will not be provided. This is my conclusion with my experience throughout the life of my 17 year old son with autism and epilepsy. An autism bill is the only way forward.
2. The support we have received has been a constant fight through the beleaguered school/NHS system and, eventually, a diagnosis. Only tough parents can cope. I know of parents that cannot put themselves through the stress and so receive the minimum of support. The many meetings, constant phone-calls to get the best for your child/young person is time consuming and draining. And all this happens against the backdrop of still caring for the individual with autism/asperger's syndrome.
3. It is not right that a child is "written off" because it is so difficult to access the services. The Autism (Scotland) Bill is desperately needed to make it easier to obtain specific help from knowledgeable practitioners, for every parent and child. There really needs to be a statutory obligation that cannot be swept under the carpet – or altered on a local authority's whim.
4. An area of provision that I find totally lacking is for leaving school at 18. We are currently exploring this and there is no continuity of care. We are trying to figure out what is out there. It is us, the parents who have to do the investigation and the leg work.
5. I am simply advised "to go look"!! Then, apparently, even if I do find what is the most suitable for my son, that decision can be ruled out if a tribunal either doesn't agree with it, or will not fund it, but I am supposed to do all the work.
6. An autism bill is desperately needed to make sure that there is continuity of care throughout an autistic's life, for the autistic person and for their family. There are very aging adults out there caring for their autistic son/daughter with no provision for outside care should they get ill.
7. Finally, I would also like to point out that people with aspergers syndrome and autism can make a significantly positive input to society. They are intelligent, think "outside the box", focused and have commitment, all of which are good qualities for employment. However only 13% of autistics are employed, and so employers have to be taught how to respond to their social ineptitude and "weirdness" and be rewarded with a very loyal employee.
8. Surely it is cheaper for government to help get them employed rather than a lifetime of enforced unemployment and on benefits? Further, that is what many of them want. The National Autistic Society, I believe, produced a study to this effect. I believe that the major first priority for all

those who responded was “work”. This was even ahead of housing... They wish to be actively involved and have purpose and commitment in their lives, as do many of the rest of us. Should they be actively discriminated against in this way? A national strategy would/should address this issue.

9. An autism bill would also help parents to actually contribute to society more by being able to earn and require less benefit. My husband and I have had to take significant time off work to either care for Lewis or attend meetings and appointments to be our son’s advocate and get the best for him. Further, it might help some families stay together. I know of many families where the strain has taken its toll and the parents have divorced – with subsequent consequences for the autistic child and siblings and general cost to society.

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