

SUBMISSION FROM TOURETTE SCOTLAND

1. In support of evidence for contributing towards the Autism (Scotland) Bill. Tourette syndrome (TS) is part of a suite of symptoms that are included in the autistic spectrum - a fact that is well documented. Many of Tourette Scotland's 800 plus members also have asperger's syndrome, dyspraxia, obsessive-compulsive disorder (OCD), Attention deficit hyperactivity disorder (ADHD) and come from families with other members who are aspergers in nature.
2. The limited services available to those with several co-morbidities, such as TS presents, have had inconstant and sporadic service provision. Even families that have autism present find that they don't get an accurate diagnosis for the autism elements of the condition. Management and support is down to the area and is a postcode lottery - all our members have had varying experiences. Sadly, the experience is, 95% of the time, a poor one. TS is often misdiagnosed; many experts do not include the autistic spectrum elements in the management of TS and even when this is clear, TS is not included in autistic services training.
3. There are no joined up services that include autism, let alone TS, and sufferers find themselves being passed between services, such as mental health (when the condition is neurological) and psychiatric services (because they are best able to prescribe drugs!)
4. No training or understanding exists in schools, employment services, training providers, criminal justice or public authorities. Diagnosis is often misleading, and sufferers are told that they have epilepsy, bipolar or do not have the autistic/sensory element explored.
5. There are few, if any, specialists in Scotland who can diagnose correctly (and the same goes for asperger's) let alone recommend a good management or support service. Tourette Scotland is a support organisation. We get referrals from professionals, yet we are voluntary and have no statutory funding! We have no guaranteed support from professionals and our members say when information from professionals is offered it is often out of date/inappropriate to the condition. The few 'good eggs' in our field are struggling to attain more help from within their own services.
6. We have spent a lot of time as an organisation trying to overcome myths about the autistic spectrum and overcome the desperate isolation of people on the spectrum. The asperger's and TS peoples' families want better opportunities and to be treated as those with a learning difference, not a learning difficulty. No special classes, no exclusions, no being put aside as people who can't be viable. There are some funny ideas about what a disability is! Neurological differences are not a reason for exclusion from school, working or social life.

7. The strategy should: recommend joined up services, more information, more research, and most of all, more resources!

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