

SUBMISSION FROM JENNIFER WALTON

1. I am writing in support of the Autism (Scotland) Bill proposed by Hugh O'Donnell. Our son was diagnosed with an autism spectrum disorder (ASD) in 2009, and since then we have had a constant struggle to access appropriate services for him, including education and healthcare. I have come to know many people with children on the autism spectrum, ALL of whom have encountered difficulty getting necessary support for their children.
2. We are members of the National Autistic Society, and we know there is an Autism Act in England, and national strategies for autism in Wales and Northern Ireland. Regrettably, people in Scotland with ASDs do not have the same provision. It is easy to disregard people who may not be able to speak for themselves, and who are in some sense outcast from society. However, a decent society should not continue to do so, especially when our neighbours do not. Scotland can be proud of many things, but not its record of care for people with ASDs.
3. I believe a Bill is necessary to ensure an autism strategy is enacted. It is my experience that there is a significant gap between what central government and local authorities say they do for people with ASDs and what they actually do. Our son has been on the special needs register since diagnosis, yet we have not been consulted on our views for what an autism strategy should include. Without the introduction of this Bill, we would not even know about the government's long-awaited draft strategy.
4. I support the Bill because it specifies a time frame within which an appropriate strategy for autism is to be produced, and for guidance to be issued to local authorities. I agree that local authorities require guidance from Scottish Ministers to oblige them to focus on autism, as it is clearly overlooked in some areas. Where no duty to have regard to guidance exists, it is too easy for health and local authorities to disregard existing advice on autism best practice. Therefore, I support the Bill's principle of having regard to guidance.
5. The Scottish Government's submission at paragraph 7 refers to "Scotland's equivalent of a national strategy". Unfortunately, it has not delivered essential services to people with ASDs across Scotland. In the short time since my son was diagnosed, I have met people who have had to move regions in Scotland in order to get support for their children, eg from the Borders to Edinburgh, and from Edinburgh to Glasgow. Given the socially isolating nature of having a disabled child, I can only assume that there are many more people with ASDs in Scotland who do not have access to essential services, whom I have not met, and more still about whom the authorities do not even know. Too much leeway is given to local authorities to avoid their duty to provide services to people with ASDs, which has

resulted in totally inadequate provision, or no provision at all in some areas, and forced people to move.

6. Regarding concerns raised in the Scottish Government's submission at paragraph 14 over the "risk of establishing a hierarchy with resultant pressure from other lobby groups", I would like to point out that there is already a hierarchy in society with disabled people at the bottom. However, people with physical disabilities are generally viewed and treated with more sympathy than those with autism, which is an anti-social disability. It is all the more necessary for people with ASDs to be supported by an autism specific law, and not remain as the poor relation, sometimes invisible and often overlooked by local authorities.
7. We were advised (by a social worker, in an early years setting) to contact the social work department following our son's diagnosis. However, the social work department did not help us, would not even waitlist our son, and closed his case without informing us. Clearly, a person with autism was not their priority even though, according to the Scottish Government's submission, autism is supposed to be covered by social work legislation. In practice, autism is not effectively covered by existing legislation.
8. Despite being a relatively common condition (around 1 in 100 people), in my experience, autism is not well known or understood by health visitors, nursery nurses, or teachers. The Scottish Government's submission refers in paragraph 16 to the Autism Toolkit as being a "significant education resource" with a copy provided to every school. I visited ten schools in Edinburgh while researching education provision for my child, and none of the teachers I met actually use this resource and many (including head teachers) did not even know of its existence. It seems clear from this experience that people take little notice of issues relating to autism as a disability unless compelled to do so, and this is another reason why legislation specific to autism is necessary.
9. In summary, my view is that a national strategy is a vital first step towards effective legislation to meet the needs of people with ASDs throughout Scotland. Good intentions or words on paper are of little use to people living with autism every day. Action is required, and this will only happen if authorities are legally required to act. The consequences of not providing support can mean sufferers of ASDs become even more disabled than would otherwise be the case. The impact on society is damaging and costly as a result of ineffective and/or insufficient support.
10. I call upon the Committee and the Scottish Government to support the Autism (Scotland) Bill. Thank you for considering my views.

Jennifer Walton
7 October 2010