

## **SUBMISSION FROM JUSTIN WILLIAMS**

1. This letter is written in response to a call for evidence to the Education, Lifelong Learning and Culture Committee with respect to the Autism (Scotland) Bill.
2. I write as a health professional and academic researcher who works extensively with children with autism and researches into the condition. I am also a parent of a boy who was diagnosed with asperger's syndrome when he was six years old. I therefore have extensive knowledge and experience of autism from several different viewpoints.
3. In all these roles I am strongly supportive of the Autism (Scotland) Bill. As a parent I witnessed my son receiving inadequate and even detrimental educational provision. He was only helped by obtaining resources outside of the local authority. Day-in and day-out, I meet families in my professional work in the same position who have to make do with what the local authority provides. It pains me greatly to see these children suffering in the face of such woefully inadequate provision, when I know how much can be achieved when the right resources and skills are available. So yes, I very much support any measures that could improve access to improved resources for people with autism.
4. Furthermore, I appreciate that autism places particular demands on service providers. Autism is an unusual form of chronic health problem in that it affects all ages from infancy to old age, all classes, races and localities. It places demands on a huge range of services. This means that everyone is responsible, but either no one takes responsibility, or they take responsibility for the wrong bits. For example, funding for autism services is largely held by social services and education. However, the expertise to manage mental health problems exists in health services. Consequently, it is not unusual for situations to arise where mental health professionals are excluded, whilst funds are delivered to unnecessary or ineffective private services. So, I agree that we need a strategic, nationally organised programme to coordinate services to better meet children's needs. We need a strategy to define roles and determine responsibilities. And, we need a strategy based on sound academic reasoning and good science where that is possible.
5. However there is one aspect of the Bill that gives me cause for concern. At earlier stages of this Bill some consideration was given to the notion of some sort of statutory case register. I see that the Bill now just states, at section 2(5) that "guidance issued under this section must in particular include guidance about— ... (b) the identification of persons with such conditions".

6. I think it is important to recognise the risks of trying to identify cases. Firstly, a demand for the identification of cases carries the risk of resulting in some sort of statutory case register. Whilst the original intentions may be very positive, it is easy to see that being registered with autism could become a negative. It could be stigmatising and cause problems for individuals who don't want to be considered as having autism. Currently, we sometimes see people who want to have their diagnosis "removed". Nevertheless, they may still have some needs that require some resource to be met.
7. Secondly, the decision to be on or off the register could end up getting priority over meeting a person's needs. And such a decision could be very tricky. Autism has a highly variable clinical picture. Furthermore, because autism is a developmental disorder, the clinical picture changes significantly over time, and needs for services change markedly over a period of development and aging. Determining whether someone has or has not got autism can require highly expert assessment, the resources for which will always be scarce. Furthermore, this is not always necessary in order for needs to be met and the relevance of the judgement often changes over time. One can easily envisage a shift whereby parents are no longer battling in the legal system for needs to be met, but instead are battling to have the diagnosis recognized by an 'expert' who is deemed suitably authoritative by the government agencies. This would not be a good use of resources.
8. I see this as a key potential problem for an autism strategy bill. If it relies on case identification in an attempt to determine resource allocation, it will be in danger of becoming a red-tape nightmare. If instead, the emphasis is placed on identifying the *needs* of individuals, rather than the individuals themselves, then in my view the Bill would be more effective.
9. I would be delighted to have the opportunity to discuss any of these issues further, and so please feel free to contact me should you wish to do so. In the meantime, may I wish the Committee every success with this Bill.

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and Royal Aberdeen Children's Hospital.  
7 October 2010