

## **SUBMISSION FROM LEONARD CHESHIRE DISABILITY**

### **About Leonard Cheshire Disability**

1. Leonard Cheshire Disability supports over 21,000 disabled people in the UK and works in 52 countries. We campaign for change and provide innovative services that give disabled people the opportunity to live life their way.
2. Our work includes policy development, national and local campaigning, supporting local campaigns action groups of disabled people, influencing politicians and policy makers across the UK, producing influential research reports and engagement work.
3. We campaign with disabled people to break down the physical, social and attitudinal barriers that prevent genuine equality.

### **Executive summary**

4. We fully support the proposal for an Autism (Scotland) Bill and believe that a strategy underpinned by legislation is the best way to for the Scottish Government to fulfil its obligations under the Disability Discrimination Act, the Equality Act 2010 and the UN Convention on the Rights of People with Disabilities.
5. We believe that a strategy should address two specific issues, namely:
  - The diagnosis of autistic spectrum disorder (ASD);
  - Measures to ensure that service providers understand what this means, and what they can do about it.

### **Our response**

6. Few adults on the autism spectrum receiving adequate support and care and most local authorities have no idea how many people with autism live in their area. The best estimates are that one in 100 adults has a condition somewhere on the autistic spectrum. According to figures from the National Autistic Society (NAS) and a recent Adult Psychiatric Morbidity Survey, it is thought that there are between 40,000 and 50,000 people with autism in Scotland. Leonard Cheshire Disability hopes the introduction of an autism strategy will help ascertain how many autistic people there are in Scotland - if we do not know the true scale of the problem we cannot find a real solution to it.
7. For too long adults with autism have been invisible, marginalised, and left to cope in a system they cannot negotiate without assistance. Often people with autism are delayed in being diagnosed. A recent report by the NAS stated that 56% of those surveyed said they found it hard to get their

condition recognised. This means that some people with autism fall through the cracks of the current system. The overwhelming majority (95%) of people who responded to NAS study also said that more appropriate services were needed for people with ASD and 48% rated their overall experience of services as poor or very poor.

8. Additionally, it is a source of concern that, when people with autism do receive a diagnosis, little is available to them in the way of diagnostic support. There needs to be an end to the battle between adult mental health and learning disability over who supports people with autism. Without post-diagnostic support, a person is not treated like an individual and there is the risk of mental health problems, stress, anxiety and depression. Therefore it is vital that legislation is implemented to ensure that every stakeholder knows that there is a duty on Parliament to hold them to account.
9. The introduction of a national autism strategy on a voluntary basis risks leaving the implementation of a strategy vulnerable to political whim and a willingness to engage, and would allow the continuation of the current post-code lottery for support. Research by the NAS has already found that over a quarter of people with autism have had to go outside their local authority area in order to get the right support.
10. The proposed Autism (Scotland) Bill would bring Scotland into line with developments in the rest of the United Kingdom. The Autism Act received Royal Assent in November 2009 and the need for regulation to support the delivery of the autistic spectrum disorder strategy is under consideration in Wales. Scotland should not get left behind in providing appropriate accessible support for people with autism.

Leonard Cheshire Disability  
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