

SUBMISSION FROM THE NATIONAL AUTISTIC SOCIETY (RENFREWSHIRE BRANCH)

1. As parent/carers we welcome the Scottish Parliament's actions in identifying the needs of people and their families living with Autism in Scotland today. We hope this will bring our nation onto a level par with the rest of the UK, and will go further in recognising the needs of children and young people with autism and including them in any legislation.
2. We are aware of the need for a national strategy to be in place so there is an end to the postcode lottery that currently exists. One of our members recently became a step-mother to a young man aged 25 who has a diagnosis of an autistic spectrum disorder (ASD) and related challenging behaviour. In his home town of Aberdeen the young man and his family were well supported with respite and other services. After a bereavement, and having to move to a new area, the family were left with little support causing a great deal of stress. The issues are still ongoing. If this young man had moved into residential care the cost would have been substantial perhaps in the hundreds of thousands of pounds in the course of his life. Instead his family are trying to support him with little support and in a situation that has changed their lives.
3. This young man with a diagnosis of autism does not fit into the present system of adult care. These are geared up for physical disability and learning disability but there is not an autism team. Adults with autism have to fit into a learning disability team that is not geared up to meet their needs. Some adults with autism do have a learning disability however many do not but live with significant social and communication difficulties which affect all aspects of their life they have to fit in. People with physical disabilities rightly so have legislation that tries to curtail the affects of the barriers they face in their daily lives. We feel that legislation also has a crucial role to play in removing many of the barriers that people with autism face.
4. These barriers mean that individuals can often not take up a full role in society. Many people with autism are not in full time employment or education which will enhance their roles as citizens and active in society. We feel people with autism have many skills and much to offer and they should be given the support to do so.
5. Early intervention is crucial and ensures financial savings later in an individual's life. Some of our families have been supported by early intervention programmes such as Hanan and the Early Bird programme. These have been crucial in developing their child's communication skills and empowering them as parents. Special mention must be made of the early intervention programme offered by the Scottish Centre for Autism in Yorkhill hospital.

6. However some parents report difficulties in accessing such programmes and access to speech and language therapy and other therapies such as occupational therapy. Although there are long waiting lists for these, a diagnosis can support or in the case of the Early Bird programme is essential to getting support. Some families report a fairly quick route to diagnosis; however in many other cases waiting times are long. In my own case my youngest son was diagnosed within two years of a paediatrician raising concerns. He had access to a specialist unit, the Snowdrop wing in Springbank Nursery, which really aided his development. In the case of my eldest son he was not diagnosed until the age of nine, despite concerns being raised when he was three. He waited four years to be seen by his local diagnostic team before a referral to a neuropsychiatrist at Yorkhill Hospital. Such a delay meant that specialist support in school was not available to him and his behaviour was not understood in its proper context.
7. Education is crucial and the doorway to future opportunities. We welcome the commitment of the government in such initiatives as the best start for every child. In Renfrewshire, children are well supported in two excellent communication disorder units based at Saint Anthony's and St Paul's schools. Parents whose children attend speak highly of their child's experience of education. Parents of children who attend Clippen's, Mary Russell and Kersland schools also hold these establishments in high regard. Many children are also in mainstream settings with a range of support in place. These include an outreach team. However the outreach team is very busy. They have a substantial workload which they try to manage but many children do not receive a service which would benefit them and help them reach their full potential.
8. As parents we are aware that many of us describe ourselves as "professional parents" and have to advocate for the services our children need. One mother, who has had to act as an advocate for her son, was speaking to a teacher who described herself as an "expert" on autism but who said "I am a psychology graduate, I am a trained learning disability nurse, I have two children on the spectrum, but I am no expert." Parents have to learn how to negotiate and work with experts, learn new terminology, frequently explain how autism affects their child. Many parents are exhausted and hope that new legislation might mean some more support in navigating services.
9. We believe that support given to people with autism now will lead to long term financial savings. The prevention alone of people having to go into care may save millions of pounds. Greater understanding and awareness similar to the See Me campaign attempting to reduce the stigma of mental health difficulties may lessen the barriers people face in their day to day lives. Training of professionals in health, education, housing, social work and employment and training will be of benefit not only to people with autism but to wider society and Scotland would truly become a carer and fairer society.

10. We thank you for the opportunity to submit our evidence to your committee and hope the bill continues to move through the parliament. We hope the end result will be an Autism Bill for Scotland not a strategy which although applauded is not a guarantee of much needed legislation.

NAS Renfrewshire Branch Parent's support group
7 October 2010