



The National Autistic Society NI
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National Autistic Society NI response to A Private Members Bill to Amend the Autism NI Act 2011

About National Autistic Society NI

The National Autistic Society is the UK's leading charity for autistic people. Since 1962, we have been transforming lives, changing attitudes and helping to create a society that works for autistic adults and children. We transform lives by providing support, guidance and practical autistic adults and children in Northern Ireland, as well family members and carers.

Since our creation, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work. We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, Health and Social Care Trusts, the Education Authority and government to help them provide more autism-friendly spaces, deliver better services and improve laws.

We are here for the 700,000 autistic people, and for their three million family members and carers in England, Wales, Scotland and Northern Ireland, as demonstrated by the following:

- (a) 5 million people visited our website last year.
- (b) We have been providing families in Northern Ireland with advice on education rights and entitlements since 2006.
- (c) We have 116 volunteer-led local branches across the UK, supporting around 20,000 people. 75% of the UK population live within 20 miles of a National Autistic Society branch. Northern Ireland has 11 NAS branches.
- (d) In 2019 we opened a bespoke Autism Centre in Carryduff providing an autism-specific day centre for adults with complex needs via tailor-made programmes with access to on-site behaviour support, speech and language therapy and occupational therapy.
- (e) The Autism Centre in Carryduff is also used to provide support and activities for autistic adults, children and their families via youth clubs, summer schemes and training opportunities.

- (f) We run the UK's largest online community for autistic people and their families.

About Autism

Autism is a lifelong disability which affects how people communicate and interact with the world. There is no known 'cure', and it is not an illness or disease. Autism is a spectrum condition. This means autistic people have varying and complex needs, ranging from 24-hour care to the simple need for clearer communication and a little longer to do tasks at work and school. Additionally, around a third of autistic people have learning disabilities.

Autistic people have difficulties with communication and social interaction. These can include not being able to speak, delays in processing information or difficulty holding conversations and making friends. Autistic people can also experience intense anxiety and extreme unease around unexpected change.

Many autistic people have sensory issues with noise, smells and bright lights, which can be very painful and distressing. This can be a particular issue for autistic children at school.

Autism is sometimes described as a 'hidden' disability, because it may not be obvious that an autistic child or adult has a disability until their needs are not met to an extent that they become overwhelmed. As a result, their behaviour may be perceived as 'challenging' if they are unable to follow instructions or fit in with existing rules and structures. These challenges can make the world feel very scary and hard to understand. They can also send an autistic person into physical and/or emotional 'meltdowns' or 'shutdowns'.

Children and adults on the autism spectrum can be helped and supported in a variety of ways to manage their condition and fulfil their potential. Each person must be supported as an individual, with interventions adapted to their specific needs.

Like all people, autistic people have their individual strengths but life can become a huge struggle if the right support or understanding is not provided. It is very important that autistic people get help from an early age and learn strategies to cope with the world. We believe that attitudes in society towards autistic people also need to change.

The National Autistic Society NI welcomes the opportunity to comment on the Private Members Bill

Additional components of autism strategy

2 Section 4A

The National Autistic Society NI feels that the Private Members Bill has missed an opportunity with regards to training. According to the report ¹“Prevalence of Autism (Including Asperger Syndrome) in school age children in Northern Ireland Annual Report 2021” the prevalence of autism in school children was 4.5%. Given this figure it is likely that most educational professionals will encounter a child with autism in their career. Autism training is therefore essential to ensure that autistic pupils meet their full potential. These children will become adults and throughout the course of their lives will also use health and social care services. The National Autistic Society NI believes that the Private members bill should have contained a mechanism to make:

- Autism training for Education professionals and Health and Social Care staff mandatory

There are duties in the statutory guidance of the Autism Act in England whereby there will be mandatory training for health and social care staff.

Section 2 4B

The National Autistic Society NI would question why this is limited to “early” intervention which implies only young children, but autistic people are diagnosed at all different ages including in adulthood and need services and support this should be reworded. The National Autistic Society recommends the following rewording:

- The Autism Strategy must set out how the Department is to make provision for an autism intervention and support service

Presently in Northern Ireland there are extremely long waiting lists for children and adults to have an autism assessment, the Bill could address this by inserting a clause such as:

- The Autism Strategy must set out how the Department is going to address the length of time persons with autism are waiting for an autism assessment.

Section 2 4D

The National Autistic Society welcomes the specific inclusion of adults in the legislation as previous strategies have failed to adequately address their needs. The National Autistic Society would suggest the following amendments:

- that point e “supported living” should be changed to housing as there are different housing options that autistic people may want to avail of not just supported living

¹ <https://www.health-ni.gov.uk/sites/default/files/publications/health/asd-children-ni-2021.pdf>

- that mental health needs should be added to the list given the high rate of co-existing mental health problems experienced by autistic people
- that physical health should be added to the list
- that independent living skills should be added to the list

Methodology of the autism strategy

(3) The National Autistic Society NI would welcome clarity as to the meaning of this section "The autism strategy must take a multidisciplinary approach" we are not clear as to what this means within this context.

(4) The National Autistic Society NI would reword this section in the following way:

- The Autism Strategy must set out how it will ensure consistency of practice across HSC Trusts

(6) The National Autistic Society NI would suggest that it is not just "bodies with an interest in promoting the rights of persons with autism" that should be involved in developing measurable targets, for genuine Co-production to take place it must also involve autistic people and their families and carers. The Department of Health has set up an autism forum which is comprised of the voluntary sector, parents/carers and autistic people to co-produce the next autism strategy. This forum is co-chaired by two autistic people. The National Autistic Society would suggest that clarity should be sought around how this forum is consulted in setting those measurable targets? We would also suggest that there is a role for the Autism reviewer in setting these targets.

Annual Autism Funding Reports

The National Autistic Society NI is unclear as to how this could be accomplished as funding for people with autism can come from a number of different sources for example if there is a co-existing condition such as mental health or Learning disability then it may come from these streams. The National Autistic Society NI believes that the Autism Strategy should come with its own budget as is the case in England which has a 73 million budget for this financial year. What has to be measured is not just how money is being spent but the impact of that funding on the lives of autistic people and their families and carers.

Autism Reviewer

3C states that the Department must appoint a person as the autism reviewer The National Autistic Society NI suggests that this Autism Reviewer should be independent of the Northern Ireland government departments to ensure credibility and avoid a conflict of interest.

(2) This states that the Reviewer must issue a report annually on the exercise of their functions
We would suggest that the report should be on the progress of the implementation of the strategy

Functions of the autism reviewer

As outlined earlier the Department of health has instigated an autism forum co-chaired by two autistic advocates and comprised of autistic people parents/carers and the voluntary sector the National Autistic Society NI would suggest the following be added to the Functions of the reviewer

- To work with the autism forum and lay the annual report before the forum
- to make recommendations to the Northern Ireland Assembly

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