



AutismInitiativesNorthernIreland

real partnerships, unique solutions, positive outcomes.

Evidence to Health Committee on Autism Bill

Autism Initiatives Northern Ireland is the largest voluntary sector provider of direct services to people with autism in Northern Ireland. The organisation employs over 200 staff and works directly with over 200 families. It is part of a UK based organisation which has its headquarters in Liverpool and has a sister organisation in the Republic of Ireland called ASD Initiatives.

Autism Initiatives Services in Northern Ireland

Supported Housing

We operate a number of schemes usually in partnership with a housing association with funding for care and support from NIHE Supporting People and/or the Health and Social Care Trust. There are 10 services providing places for 47 people and employing 123 staff located in Lisburn, Belfast, Bangor, Armagh, Newcastle and Dunmurry.

Residential

Autism Initiatives run 3 small residential facilities staffed by 48 people and providing services for a total of 24 service users, many of whom have complex physical disabilities and are frail and vulnerable. These services are based in Belfast and Newcastle including Mary Murray House, which won a People's Vote through the Big Lottery Fund to install a sensory garden.

Day Care

Autism Initiatives provides day care opportunities in its own right (and in partnership with a social enterprise business called Autism Work Ventures).

- Beechill, Belfast offers a very specialist day care experience for 3 people with complex disabilities and autism.
- Bryansford Road, Newcastle, Co.Down provides a structured day activity programme for 40 people.
- Hospital Road, Armagh offers a day care programme for 3 service users.
- Chocolate Memories, Moneyreagh is a social enterprise business making and distributing chocolate -9 service users are involved.

- Garden Centre, Newcastle -8 service users are involved with this project
- Virtual Art Gallery -3 service users who are also artists are deriving some income from selling their art work online.

There are 11 staff employed in day services. Services are offered to 68 service users (some of whom already attend some of our other services).

Community Service

We offer a wide range of community services. Outreach in Belfast for adults and children provide social opportunities for people with autism and respite for their carers. A new community house in Carryduff will be a base for these activities. We also have a 'One Stop Shop' in L'Derry and run a number of Floating Support Schemes to help service users remain in their own homes or prepare for independent living. Over 100 service users take part in activities organized through these services with about 25 staff providing support. A counselling service is offered to staff, service users and their families by volunteer counsellors who have been trained through the University of Ulster and accredited by the British Association.

In total Autism Initiatives NI provides services to well over 200 people with autism and their families. We employ about 250 people and have specialized in supporting challenging individuals who have been resettled from long-stay hospital or are perceived to be challenging, most times this is due to a lack of understanding and ability by other agencies to facilitate the person's Autism. We continue to seek new and innovative ways of providing practical support services to people with autism who are in need.

The Autism Bill

Autism Initiatives Northern Ireland have been strong supporters of the Autism Bill during the long period of its development. We believe the large numbers of people with autism and the relatively sudden increase in the identification of children and adults with the condition are strong arguments for a legislative and strategic approach. As a direct service organisation, in regular contact with families that we can help and many that we cannot, we would prefer to see the bulk of resources directed to people with autism and their families. We believe the removal of the proposal to have an advocate for people with autism is a sensible economy.

1. Amendment to the Disability Discrimination Act

The Disability Discrimination Act made it unlawful to discriminate against a disabled person. The definition of disability is important, the Act says: 'a person has a disability for the purposes of this Act if he has a physical or mental

impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.’

This definition is further clarified in schedule 1 of the Act with the listing of a number of characteristics that help define what a disability is. There is evidence from employment tribunals that discrimination cases have often focused on whether a claimant was a disabled person or not.

The proposed amendment to insert the words ‘social (including communication)’ into the definition in Section 1 of the Act seem sensible to us. Similarly the proposed addition of ‘taking part in normal social interaction; or forming social relationships’ also seem to be helpful clarifications.

Autism is a spectrum condition and the range of the condition is very wide. Many people with Autism already demonstrate that they have difficulties with carrying out normal day to day activities. These amendments make this more explicit and will also clarify that other people with Autism have a condition that can be disabling. Not all people who have Autism are necessarily disabled according to the definition of the DDA because their Autism may not prevent them from carrying out normal day to day activities. There are, however, people with Autism where the effect of their condition is hidden and they can have enormous difficulties with daily living but do not appear to be disabled.

2. Autism Strategy

We support the proposed Autism Bill as it sets out the need for an Autism Strategy across the full range of Government departments and activities. Health and Social Care will be the service providers of last resort for people with Autism unless other departments and agencies are involved fully in an Autism strategy.

Autism Initiatives Northern Ireland are enthusiastic participants in the implementation of the Regional ASD Strategy set out by the Minister for Health, Social Services and Public Safety. We would like to pay tribute to the work of Dr Stephen Bergin and Lord Maginnis for the work they have done to date and look forward to working with them further in the future. The Regional Strategy allows for the involvement of other departments and agencies and this has included Education professionals, the Department of Employment and Learning, DSD and others. A more formal requirement for involvement and co-operation would be valuable –especially at a time of acute financial concern. The temptation will surely be for departments to restrict their activities to their statutory responsibilities rather than to co-operate across departmental boundaries.

If this full co-operation does not happen the risk remains that people with Autism may find that they do not get the support they need. These could be people who might thrive in ordinary community life. But as a result of not getting the right

support they may find themselves lacking support and therefore develop mental health problems or get in trouble with the law and need more extensive intervention in the future. There is a specific need for the Department of Health, Social Services and Public Safety and the Department of Education to explore how they can work more closely together and perhaps join up their services more completely.

2. (3) The collation of data on the prevalence of Autism is essential to enable the proper planning of services to take place. As noted earlier Autism is a spectrum condition. The identification of numbers of people with the condition is not enough. The production of statistics should also include some means of identifying future need. For example it may be surmised that a child with Autism who is being educated in a grammar school may have less need for supported living services in the future than a child educated in a special school. This is an inexact science of course. It does seem clear to us that while much attention is often focused on children with Autism the fact remains that kids with Autism grow up!

3. Content of the Autism Strategy

We agree with all the elements of this section of the Bill. The recognition that people with Autism have needs throughout their lives is particularly important. In paragraph 4 and paragraph 5 there are proposals for an awareness campaign for the public and awareness training for civil servants. As we said earlier we would prefer to see resources directed to services for people with Autism. As a result we would prefer to see awareness raising and training carried out as part of general disability awareness campaigns. Equality Schemes, Audit of Inequalities and public campaigns by the Equality Commission may meet the same objectives set out in these clauses without diverting resources from the Department of Health, Social Services and Public Safety.