

CARERS Northern Ireland

the voice of carers

Introduction

We are pleased to have an opportunity to assist the Committee in considering the potential for the proposed Autism Bill to improve the lives of people with autism and their carers.

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. There are 185,000 carers in Northern Ireland and every year another 69,000 people begin caring, many of whom do not know how to cope with their new and demanding role. This includes parents and others struggling to come to terms with the impact that autism has on a family, and on individuals living with autism.

Carers Northern Ireland is here to improve carers' lives.

- We fight for equality for carers. We want carers to have the same right as everyone else to an ordinary life – a fair level of income, adequate support to protect their health and wellbeing and access to the world of work, leisure and education
- We want carers to be recognised and actively involved as key partners in the design, delivery and provision of health and social care services.

Carers often contact Carers Northern Ireland's information and advice service when they have reached crisis point and do not know where to turn to for help. We help carers through the maze and give them:

- Advice on their rights so they can make important decisions about their lives
- Information about the practical help available to make caring easier
- Support by putting them in touch with other carers who understand the ups and downs of caring and can help ease their isolation and signpost to other local help

Carers give so much to society yet studies (including the Health & Social Wellbeing Survey and the NI Life and Times Survey) show that they are prone to poor health, stress, social isolation and poverty because of their caring role.

For most families, support from the wider family network is not forthcoming, so they are highly reliant for backup, information and support on the statutory services provided by Health & Social Care Trusts.

The Autism Bill

In responding to the proposals, we are conscious that opinion is divided amongst carers who are aware of the Bill, with some being strongly in favour of the legislation, and some who feel strongly that it is not worth the cost and effort involved.

Proposals relating to Autism Strategy

Our sense is that most carers are not particularly concerned about the detail of this or any other legislation – what they care about are the support and services they can access day to day.

Carers Northern Ireland is strongly in favour of concerted attempts to improve support for autism and to ensure consistent access to services and support across Northern Ireland. We therefore support an effective, properly implemented Autism Strategy.

We are not convinced, however, that legislation is required to put a strategy into place. There have already been a number of strategies developed within Health and Social Care to drive service improvements in Northern Ireland, including a Carers' Strategy. The content of these strategies is broadly similar to the contents proposed in the Bill and have been developed without the need for legislation.

Our experience is that the success of these rests on a number of factors: clarity of vision, buy-in at a senior enough level within the service, clear and achievable recommendations, effective monitoring arrangements and adequate resourcing. None of these factors require legislation.

Moreover, the Autism Spectrum Disorder Strategic Plan and the Regional ASD Network established in 2009 appears to offer an existing mechanism for achieving many of the objectives laid out in the Bill. It has already achieved considerable success in driving down waiting lists for diagnostic services. It may well be more effective to build on the work of this Strategic Action Plan and this Regional Network rather than to develop a new strategy which will no doubt cover much of the same ground. This may, in fact, delay implementation of much-needed positive changes on the ground.

Proposal to amend Disability Discrimination Act

Although it is undoubtedly true that carers are more concerned with the practical help they get than with the legislative basis on which it is provided, there is equally undoubtedly a real benefit to having clear and unambiguous rights in law.

Whereas we cannot see that a duty to develop a Strategy offers this benefit, there may well be benefit in amending the disability legislation to make absolutely clear the rights of people with autism to rely on the protections of the DDA.

The one concern that we would have is that, in refining the existing definition in the DDA, an attempt to improve access to legal rights and protections might inadvertently have the opposite effect. We could not hazard a legal opinion ourselves, but we would urge the committee to take legal advice from experts in the field of Equality that any amendment of the DDA will not have the consequence of excluding people with autism, particularly those with co-morbidity, from coming under the new definition.