

Belfast Health and Social Care Trust

In its response to the Autism Bill (NI) consultation the Belfast Trust welcomed a raised profile for people with autism and emphasised its commitment to seek improved opportunities for people with all disabilities. Within this context the Trust raised some concern that legislation focusing on one single disability could be perceived as disadvantaging those with other disabilities. The Trust remains concerned that a Bill focused purely on ASD will create a “hierarchy” of disability. It may also create confusion for people for whom ASD co-exists with another condition. Recent evidence would indicate that a significant proportion of people on the ASD spectrum have co-morbid disabilities. The Trust would not wish to see disputes arising over which disability took precedence and which are covered by legislation.

In relation to the specific Clauses of the Bill the Trust wishes to comment as follows:-

- **Amendment to the Disability Discrimination Act 1995 (c. 50)**

The Trust is committed to equality for all those with disabilities and therefore welcomes the proposed specific references to social (including communication) and also particular mention of social interaction and social relationships within this context. The Trust is of the view however, that legislation in N Ireland already has comprehensive provision particularly for children in need, which includes those with ASD. The Children Order 1995, The Disability Discrimination Act 1995 and the Children’s Services Planning Order 1998 already place significant responsibilities on Trusts for the assessment and provision of services for those in need. Much of the strategic development in N Ireland has been underpinned by the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. Both Conventions make it clear that provision of services should be made based on assessment of need. A Bill which uses a model of provision based on medical diagnosis is not in keeping with these well respected Conventions and makes a shift away from the accepted social model of disability.

- **Autism Strategy**

The Trust welcomes the emphasis placed on an interdepartmental approach to the preparation and implementation of this proposed Strategy as this reflects the essential requirement of a multi-disciplinary and interagency approach to meeting the needs of this group. The Trust has welcomed the existing ASD Strategy and is an active member of the Regional Network. The Trust takes the view that the leadership provided through that Network is already making excellent progress in the areas required. It is difficult to see what added value would be brought to this work by a legislative framework. It is noted that there is no specific reference in this section to consultation with the voluntary and community sectors which currently provide a range of valuable services to families and it may be appropriate to review this omission. The existing ASD Strategy puts families and voluntary sector partners right at the heart of the Network.

In relation to preparation and availability of data it should be noted that the requirements of the proposed Bill will have to be accompanied by more robust systems of data collection by all departments providing services particularly in instances of co-morbidity. Within this context it should also be noted that autism as a developmental condition can take differing timescales to diagnose and this may also impact on data collection. The Trust would be concerned that legislation could result in improvements in data collection for people with ASD at the expense of improved data collection and information systems for people with other disabilities such as Down's Syndrome or Cerebral Palsy.

- **Content of the Autism Strategy**

The Trust welcomes the specific reference to the “Health Care, Educational and Social Needs” of persons with autism and is acutely aware of the critical interface with schools and Education & Library Boards particularly in meeting the needs of children and young people. The Trust also welcomes the focus on meeting the needs of both persons with autism and also their families and carers. Within this context the Trust is mindful of the relative underinvestment in services for disabled persons and current budgetary constraints and considers it essential that appropriate cognizance is given to the resource issues accompanying additional statutory responsibilities and public awareness.

- **Interpretation**

The Trust notes the definition of “Autism” provided under Section 4 and in particular the inclusion of “any pervasive development disorder not otherwise specified”. In relation to carers the Trust considers that it may be helpful to provide some guidance in relation to the definition of “substantial” as it relates to the amount of care provided.

As outlined above Belfast Trust has significant concerns that such a Bill will result in ASD becoming a “more important” condition than other disabilities. Nevertheless

should the Bill be ratified, the Trust will play its full part in implementing any new recommendations.