

Southern Education and Library Board and Western Education and Library Board

This represents a response on behalf of both the Southern Education and Library Board (SELB) and the Western Education and Library Board (WELB). Both Boards welcome the opportunity to comment on the Autism Bill as follows:-

Co-ordinated Strategy:

The need for a co-ordinated Autism Strategy between Health and Education Departments is widely accepted. At this stage, considerable progress has been made in respect of inter-departmental co-operation and work to develop a co-ordinated Autism Strategy. The planning in relation to this work has already begun by both Health and Education. Further benefits are envisaged in the future for children and young people who have Autism, in the absence of an Autism Bill, through the implementation of a co-ordinated Autism Strategy.

The view of SELB and WELB is that an Autism Bill is unnecessary and unhelpful. There is concern that the Bill may also be potentially discriminatory for the children and young people concerned. In this regard, it is important to consider the potential pitfalls which may occur as a consequence of the creation of Autism specific legislation.

There are also real concerns that the children and young people who have other conditions may also require specific legislation; the equality issues which could arise in this area require judicious consideration of Special Educational Needs in general as well as in relation to Autism in particular.

Autism - Diagnostic Continuum:

Autism is a medical diagnosis and as such it is not directly related to Special Educational Need. However, many children on the Autistic Spectrum may have a Special Educational Need. This may arise from a particularly severe presentation of Autism or may arise from other conditions which co-occur with it.

Autism is a spectrum disorder and is more commonly referred to as Autistic Spectrum Disorder (ASD). There is wide diversity in presentation between individuals who share the diagnostic label and also within the same individual over time and context. Many children with a diagnosis of ASD do not have identified Special Educational Needs. Indeed, the continuum of need in relation to Autism should also be reflected in the continuum of services and provision which may be required to support children and young people.

There is a danger that the proposed Autism Bill will create an impression that children or young people by virtue of a diagnosis label are disabled. This would likely reinforce a perception that there is something inherently 'wrong' with the child or young person or that they are incompetent. This could lead not only to a loss of opportunity for each individual but to discriminatory behavior, prejudice and negative intervention responses in schools or in the workplace. Indeed, there is growing

acceptance of the use of the term Autism Spectrum Conditions to avoid such a perception.

Donna Williams (1994a) author of *Nobody Nowhere* (1992) and *Somebody Somewhere* (1994b) writes:

"When people without autism assume that people with autism are merely 'slow' or 'broken' versions of themselves, they may not only insult, but additionally confuse and frustrate the person with autism with behavior that naturally stems from these arrogant and ignorant assumptions." (p. 197)

The label 'disability' is not neutral. It has the potential to have significant social, emotional, educational and employment consequences for individuals with Autism.

Existing Education Legislation:

The educational legislation governing the assessment and identification of Special Educational Need does not promote a 'medical model' approach as this would be considered inconsistent with the philosophy of individualisation of assessment, identification and intervention. The educational approach is framed within a contextual model. Special difficulties and needs are assessed in the context of the environment and circumstances of the child or young person.

One of the functions of existing ASD services is to support parents and schools in making appropriate adjustments to the environment to accommodate the different processing styles of children and young people with ASD. In this respect, the child or young person is not perceived as 'the problem'. The focus shifts to that of the environment and the extent to which it accommodates the identified needs of each individual. Many factors outside of a diagnosis of Autism determine the likelihood of a disability.

Impact on Children and Young People:

It is the experience of the ASD Services in SELB and WELB that many children and young people with a diagnosis of ASD do not perceive themselves as having a disability. They consider that there are positive strengths to their condition. Indeed, they are encouraged in this regard by their parents, school and the ASD Service. The idea that they may now be required to refer to their 'disability' rather than a 'condition' would likely cause considerable anxiety and distress in their struggle against the associations which such a label could bring. It could also block the essential focus of the ASD Services which has been to promote inclusion through adjustments and accommodations. Simply, the label of 'disability' does not reflect the real life experiences of many children and young people with Autism.

The needs of children and young people with ASD require a graduated response not a categorical one. These children and young people do not require special legislative treatment.

Conclusion:

As statutory and voluntary bodies work to support the continuing development of children and young people with Autism there is increased confidence and competence that this can be delivered within existing supports and provisions without Autism specific legislation.