

Committee on Children, Equality, Disability, Integration and Youth

Opening Statement

Cathaoirleach, Committee members, I am pleased to be able to address today's session on the Autism Spectrum Disorder Bill 2017 ("the Bill").

At the outset I wish to acknowledge the cross-party work of this Committee and its clear efforts in seeking to drive progress for people with disabilities, including autistic people.

This is a shared goal and it is reflected in a range of Programme for Government commitments relating to disability and to action on autism.

It is under these under commitments that the Department, post transfer of disability functions from the Department of Health, will over the coming period bring forward measures such as the Disability Services Action Plan, the Progressing Disability Services or PDS Roadmap, and the Autism Innovation Strategy. We will also be continuing ongoing targeted consultations on the next National Disability Strategy, progressing soon to full public consultation.

To address the Autism Strategy in particular, we currently intend to deliver a draft strategy by the end of this year, depending on the exact timing of consultations. The Autism Innovation Strategy will focus on bolstering provision within the mainstream offering in terms of services and initiatives for autistic people, without creating overly rigid or separate structures at a time when our understanding of autism continues to evolve, and without establishing sets of rights not enjoyed by other persons with disabilities.

Our approach is to ensure that we advance a coherent, responsive, and effective framework, across not only the Autism Innovation Strategy but across the full programme that I have referenced, that addresses the bespoke needs of autistic people and those of other disabled persons, on a responsive, equal, and evidence informed basis.

Autism is a complex issue in relation to which our understanding, at a policy and clinical level, is maturing. The apparent increase in incidence rates of autism, along with the need to vindicate the rights of autistic people as with other persons with disabilities, merits the appropriate policy response. It is for this reason that government is advancing a

national strategy on autism. Yet there is much about the nature of this rising rate that is not properly understood, in the national and international context, and we must ensure that our responses can evolve with our understanding, are operationally practicable, and are advanced on the basis and principle of equal provision.

It is with this approach in mind that any consideration of the proposed Autism Spectrum Disorder Bill should take place.

At its core the Bill is a laudable document that seeks to improve access to services, foster greater understanding of autism, and advance the social inclusion of autistic people. The Department shares these goals, but does not consider legislation to be the most appropriate means of advancing those goals. In that regard we note certain issues of concern in relation to the Bill.

These include policy concerns such as alignment with existing and planned national policy and with the UNCRPD, concerns regarding equality of provision that may also extend to legal risk, potentially significant adverse operational consequences, and concerns around enshrining certain terms in legislation

when our understanding of autism continues to develop. There are also technical and drafting issues which arise.

This is reflected in the government position on this Bill to date. Government has not opposed the Bill, and is in fact committed to much of the action called for. The question of Government support for the legislation under discussion today is of course a policy matter for Government to decide. In further considering this, there will be a number of important factors to take into account.

A key consideration is whether the best means of advancing the goals of the Bill is to allow policy and action frameworks such as the Autism Innovation Strategy to be developed and progressed, in order to drive reforms and improvements by way of bolstering more inclusive and more effective mainstream progress that includes and takes account of the bespoke needs of autistic people.

In 1996, the landmark report of the Commission on the Status of People with Disabilities was published, in a process that firmly and fully embraced the ethos of “nothing about us without us”. The Commission established a fundamental

principle for disability equality in Ireland, mirrored in other instruments such as the CRPD. We must not fall into the trap of conceiving of disability equality only in terms of differences between disabled and non-disabled people. We must also think of it in terms of equality in and between people with disabilities, so that we do not create hierarchies or discriminate between disabled persons on the basis of impairment or medicalised categorisation.

This is not to say that we cannot recognise and respond to bespoke needs – we can. But it is to say that we cannot grant unto one cohort of disabled persons rights and entitlements that are not enjoyed by all disabled persons. To do so is not only undesirable but potentially risks legal challenge.

Advancing action on autism via primary legislation carries a risk of unintended consequences. For example, the definitions in the Bill are based in the language of medical diagnoses, which will evolve in line with our understanding and with clinical practice. Medical categorisation itself does not align with the language and ethos of the UNCRPD. Failing to include a particular condition in a list of definitions could lock out from supports someone the Bill may in fact be intended to assist. In

our view, complex and evolving issues are better addressed through more responsive frameworks, such as national strategies with robust monitoring and accountability mechanisms, with the ability to pivot in real time to changing needs and issues. This has held true for a wide framework of strategies that have delivered tangible progress across a range of equality grounds.

Turning to the provisions regarding health services, the Department is concerned that the Bill could serve to undermine efforts now underway to drive the very improvements the Bill seeks to bring about.

The creation of separate or parallel channels for services and assessments for autistic people gives rise to significant operational concern. The Bill would appear to seek to duplicate the assessment of need process, which is already inclusive of autistic people, with an unclear basis for seeking to do so. This risks operational uncertainty and duplication of labour, whilst also being open to potential legal challenge on equality grounds. A more sustainable and feasible approach in the long terms is to ensure that our mainstream services meet

the needs of all disabled persons, including autistic people. That is the programme of work being advanced, referenced earlier.

A balance must therefore be struck in ensuring that improvements to the mainstream delivery of health and social care services take sufficient account of the needs of autistic people and that services are accessible to these cohorts.

The optimal pathway for this is not the creation of parallel or additional entitlements. Rather it is to advance the important reform efforts currently underway across the health system which are intended to benefit all people with disabilities, including autistic people, and to change and review our delivery of those mainstream services to ensure they are inclusive of autistic people.

That shift in the mainstream is the business of the Autism Innovation Strategy, which will focus on clear foundational actions to identify gaps and bespoke needs in relation to autism that are not accounted for in existing mainstream measures, and to bolster and enhance mainstream provisions

in relation to autism, including in relation to services, data, attitudes, and public understanding.

In conclusion, whilst it is recognised that the goal of the Bill is a well-intentioned desire to drive improvements, significant issues arise for consideration.

I look forward to further discussion, thank you.