

## **Submission on the provisions of the Autism Bill 2017**

### **Irish Society for Autism**

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The Irish Society for Autism is a national organisation formed in 1963. This year we celebrate 60 years of campaigning and providing services and supports to Autistic people and their families. We are the longest established organisation for Autistic people in Ireland.

We provide information and support services to thousands of people across the country including Autistic adults and children, parents and family members, educators, students, businesses, State Departments and health sectors workers. We provide resources such as our Autism Awareness cards and Autism Alert cards. We also provide comprehensive information on our website which is accessed by 1000's of individuals across the world. The numbers of people accessing our information is increasing.

We also offer training and information across numerous sectors, carry out research to enable us to understand how we can best serve the Autism community and advocate on behalf of Autistic people and their families. We regularly assist businesses who are working towards creating more Autism friendly workplaces and environments and help to increase their understanding of Autism.

The Irish Society for Autism is also a founding member of Autism Europe and a founding member of the World Autism Organisation. Pat Matthews was the first President of the World Autism Organisation, and we currently sit on the Executive Committee of the World Autism Organisation.

For his tireless work in the area of Autism in Ireland Dr Pat Matthews has previously been honoured with the People of the Year award and also an honorary doctorate from Trinity College.

#### **Context**

##### **Charter of Rights:**

On Thursday the 9th of May 1996, The European Charter of Rights for Persons with Autism was signed by 331 Members of the European Parliament and passed by the European Parliament. The Charter, co-authored by Dr Pat Matthews, Irish Society for Autism, aimed to have far reaching consequences on the quality of life for autistic people, children and adults, across Europe.

The Charter states that autistic people should have the same rights as enjoyed by all EU citizens, and that these rights should be enhanced and enforced by appropriate and relevant legislation in each member state.

The Charter recommends that diagnostic services, appropriate education, family support, housing, training and lifelong care should be adequately addressed and appropriate services provided at domestic level.

Twenty-seven years after the Charter was adopted, the protection of the rights of autistic people within EU Member States is far from being uniform or satisfactory.

## **United Nations:**

In 2008 the UN declared that April 2nd of each year will mark World Autism Awareness Day. In 2009, Pat Matthews our CEO, was invited to the United Nations in New York to speak on 'Autism and Human Rights: Understanding and Safeguarding the Rights of People with Autism in observance of World Autism Awareness Day'. He stressed at that time that what we needed was critical legislation which protects and promotes the rights of Autistic people.

The UN Convention on the Rights of Persons with Disabilities, UNCRPD, establishes the human rights and fundamental freedoms of persons with disabilities whose full enjoyment must be guaranteed without discrimination in order to remove all the barriers that prevent their participation as equal members of society. In the preamble, it states parties recognise 'the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support', such as autistic people who need lifelong residential services and support.

As a country that has ratified the UNCRPD we are obliged therefore to take action to fully protect the rights of persons with disabilities and in particular those who require intensive additional supports and services.

## **World Health Assembly:**

The World Health Assembly in the 2013 Resolution (WHA67.8) recommended to Member States '*to develop or update and implement relevant policies, legislation, and multisectoral plans, supported by sufficient human, financial and technical resources*'... to address the needs of autistic people.

## **Autism in Europe:**

On the 4<sup>th</sup> October 2023 the European Parliament adopted a non-binding resolution entitled "Harmonising rights of autistic people". The resolution of the European Parliament makes reference to "having regard to the Charter for Persons with Autism", which was co-authored by Dr Pat Matthews in his work with Autism Europe in 1996.

All of the above, The Charter of Rights, the UNCRPD, The World Health Assembly and the European Parliament Resolution, demand that each country provide specifically for Autistic people, and it is only through comprehensive and inclusive legislation specifically in relation to Autism that Ireland can achieve this.

The Irish Society for Autism has seen and been involved in many policy changes over the years. Many reports and strategies in relation to Autism have been written, none of which have had a substantial impact on the lives of Autistic people due to the lack of a legal framework to drive significant change.

## **Autism Legislation and the Autism Bill 2017**

Autism is very complex and encompasses the full range of abilities and disabilities. It is not confined nor defined by words and diagnosis.

Those who require very substantial support and residential services throughout their lives need to be comprehensively represented in all aspects of the bill and in all consultations.

Understanding the full spectrum of autism is crucial to the success of the Autism Bill and any strategy that follows. Service provision, across all sectors to Autistic people should not be discretionary, it should be as a right protected in law.

The current model of service provision is heavily weighted on the medical model which is not suitable. We need a bill that mandates a strategy that develops plans and responds to the needs of autistic people. Autistic people need to be accepted as equal citizens in their own right. Their citizenship needs to be valued and an Autism Bill will help achieve that.

The argument for autism specific legislation is not only the best practice model but is one that must be taken in order to fulfil our obligations as a nation.

Without legislation, plans can be pushed aside or lose pace if political will fails to drive them forward. Legislation ensures that the trajectory of an autism strategy stays on course.

If codes of practice, plans or strategies are to be successful and hold weight they need to be embedded in legislation.

The example of Northern Ireland supports this statement. Autism legislation was introduced in 2011 and updated in 2022 with the Autism Amendment Act. This legislation provides practical guidance on methodology for the autism strategy, specifics in relation to funding, the appointment of an independent reviewer and the provision of data collection.

Autism legislation would:

- bring entitlements of autistic people in line with the population.
- bind government departments and state bodies in co-operating, developing, and implementing a strategy for autistic people and their families.
- ensure that the focus is across the life span of the autistic person.
- stop autistic people falling between the gaps of services that deal with intellectual disability and mental health issues.

And more importantly would:

- signify acceptance of autism in the broadest context.

In relation to the Autism Bill 2017, we are very aware that some of the terminology used is not generally acceptable and we have previously communicated our thoughts on amending the words used in the bill and understand and welcome that the wording will be reviewed and amended.

### **Training:**

Section 6 refers to training on Autism. Awareness and acceptance are dependent on each other. Acceptance comes through education and understanding. A comprehensive education campaign for all should be integral to the bill and strategy. Training needs to be multi-perspective, from and to autistic people, parents and family members, caregivers and professionals.

## **Data Gathering:**

While Section 7 of the Autism Bill 2017 provides for data gathering, we suggest that greater emphasis be placed on the needs of autistic people throughout their life.

For example, the Taskforce on Autism in 2001. The Irish Society for Autism were heavily involved in this strategy and a lot of people invested their time and energy into it. In particular, the recommendation that the Taskforce made in relation to the urgent establishment of an autism database and prevalence records to facilitate proper planning. There are still no reliable statistics on the prevalence of Autism in Ireland.

Even our closest neighbour, Northern Ireland gathers significant data in terms of referrals and diagnoses, on a quarterly basis, for both school going aged children (aged 5 to 17) and adults. Northern Ireland introduced their Autism Act legislation in 2011.

Without knowledge we cannot plan effectively for the services and supports that are required. How many assessments does the HSE need to plan for every year? For children and for adults?

The provision of data is key to the success of the Autism Bill 2017 and the development of a strategy. For too long we have relied on estimates and studies without real evidence.

The ESRI found in a review in 2020 that in the NIDD database autistic people were underrepresented. They were hopeful that the NASS (National Ability Supports Systems) database would focus on improving the data on services for individuals so that it would be more comprehensive. The NASS Autism Supplementary Bulletin 2022 states

*"It is important to note that the data returned for children by the newly established Children's Disability Network Teams (CDNTs) are less complete than the data provided by service providers for adults accessing HSE disability-funded services.....the data are largely incomplete for most of these children.."*

Current statistics are dependent on service providers providing the information required which is not a legal requirement and therefore at the discretion of the provider. At a minimum all professionals and providers, public and private, involved in the area of Autism should be legally bound to provide the data required in order to achieve comprehensive statistics. If there is no legal requirement the exercise will be futile. The strategy will have no valid foundation.

## **Ageing:**

We also believe it is important to highlight the ageing profile of our population. According to TILDA (The Irish Longitudinal Study on Ageing) the number of people aged 65 and over is projected to double between 2011 and 2031.

TILDA highlights that despite the evidence indicating the *"importance of ageing, there is a lack of social, economic and health information on older persons in Ireland. This information is essential to enable forward planning and to ensure a "healthy and happy" life span in later life"* (TILDA, 2023).

Policy making and service provision will therefore be constrained without further understanding of the aging autistic adult and their needs.

### **Families:**

Throughout the bill the family of the Autistic person is referred to on 3 occasions. The importance of family cannot be underestimated especially for those with significant needs. As it stands the bill does not sufficiently reflect this. The Irish Society for Autism recommends that the importance of the family is emphasised and is more integral to the bill.

### **DPO (Disabled Persons Organisation):**

The best practice approach to autism strategies are those designed in close partnership with all autism organisations, especially those who advocate for those who cannot represent themselves.

The UNCRPD makes specific reference to the role of civil society organisations and in doing so lays the way for non-DPO input and support in furthering the rights of people with disabilities.

Article 33 (33) of UNCRPD states “Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process” (UNCRPD, 2008)<sup>i</sup>. While there is clearly a defined role to be played by DPOs in the formation of any plans and strategies that impact on their lives, there is a clear provision in Article 33 for input from non-DPO organisations.

Those who cannot represent themselves must have their rights and needs represented and respected. Their needs can only be represented by listening to family members and organisations that have lived experience of those with significant needs.

### **Conclusion:**

The Irish Society for Autisms believes that Autism legislation together with a comprehensive autism strategy is essential if people with autism, their families and carers, are to be provided with the necessary supports and structures throughout every stage of life. Age specific structured service provision is an essential component. Furthermore, autistic people and their families require access to:

- timely diagnosis
- appropriate early support services and services across their life span
- education
- employment
- housing
- a range of health and other services including access to appropriate residential services if required.

All of these need to be provided in an environment of inclusion and respect.

These elements that reflect and protect individuals' rights, as enshrined in the UNCRPD, must be at the core of legislation.

While some may argue that the rights of people with autism can be included under general disability legislation, we believe that autism specific legislation is the only means of ensuring the rights of autistic people are adequately protected.

The Irish Society for Autism has long campaigned for the rights of Autistic people. We have also campaigned through Autism Europe and the World Autism Organisation.

**Autism is not a health issue: it is a human rights issue.**

It is time now to finally enshrine the rights of Autistic People in law.

Tara Matthews,  
Irish Society for Autism,  
October 2023.

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