



Inclusion Ireland

The National Association for People
with an Intellectual Disability.

Joint Committee on Autism. January 24th 2023.

Inclusion Ireland Opening Statement

Good morning.

My name is Derval McDonagh and I am the Chief Executive Officer of Inclusion Ireland. I would like to sincerely thank the committee for inviting Inclusion Ireland to the session today.

I am joined by two colleagues: Sarah Jane Lavin and Angela Locke Reilly. Sarah is a member of our board of directors and Angela is an advocacy project worker at Inclusion Ireland. They both bring their experience in different ways to the committee today and I will ask them to introduce themselves shortly.

A brief piece about Inclusion Ireland. We are a national, civil society organisation focused on the rights of people with intellectual disabilities. Our sole purpose is to work towards the full inclusion of people with intellectual disabilities by supporting people to have their voices heard and advocating for rights under the United Nations Convention on the Rights of Persons with Disabilities. At Inclusion Ireland we work in a number of ways;

- We provide an information service. We are particularly focused on providing information in accessible ways to people with intellectual disabilities and their families.
- We campaign for policy and legislative changes.
- We work in solidarity with disabled people and their representative organisations in holding the Government and state agencies to account for their progress under UNCRPD.
- We research issues affecting people with intellectual disabilities and their families and publish reports based on people's lived experience.
- We work for changes in how services are provided; pushing for a move away from a "charity" model and towards a rights based model of support.

Inclusion is a word which is over-used and under delivered- on. It is fundamentally about community, belonging and upholding human rights. It is about valuing people for who they are and systematically dismantling the barriers that people face in having a good life. It is not about “fixing” people , it is about fixing systems. There are many autistic children and adults in Ireland who also identify as having an intellectual disability. We want to make sure that the committee considers the intersectional issues people face. We know that sometimes autistic people who have an intellectual disability are overlooked, de-valued and are often not seen or heard. This is particularly true of people who are non- speaking and who face multiple barriers in accessing their rights and in having a good life. We know this needs to change.

Today we could talk about every article of the UNCRPD from article 5-30 but we would need a 24 -hour committee meeting, an hour for every relevant article. What we will say is that we believe this committee and any committee where work is focused on disabled people should consider the UNCRPD as the prism through which to view their task. With all of the issues facing people today, it is challenging to wade through what is important. The UNCRPD lays out a framework and helps us all to think strategically about the kind of future we want as a society, one where every citizen enjoys equal rights, a seat at the table and a good life.

For today’s opening statement we will focus on two articles: Article 24 (Education) and Article 19 (Living independently and being included in the community). We are happy to discuss any other article of the convention and policy solutions which may pave the way for a more equal society.

Article 24 Education

The right to an inclusive education is spelt out clearly in the UNCRPD.

Sadly, we know that a fully inclusive model of education is a distant dream for many autistic children who have intellectual disabilities.

At Inclusion Ireland, working towards a vision where all children get to go to school together is a core pillar of our work. In November we hosted a conference bringing together disabled people, Disabled Persons Organisations, families, teachers, special needs assistants, the Ombudsman for Children, the Irish Human Rights and Equality Commission, policy makers, department officials, advocates and politicians. It is our strongly held belief at Inclusion Ireland that working collectively is where we can bring real change.

What is clear from consulting with people experiencing the system and working within the system is that right now many children:

- Must travel long distances to access their right to education

- Only have segregated options available to them as the supports are not there in mainstream.
- Do not get the services and supports they need in accessing their rights (for example access to therapeutic interventions)
- Families have to “fight” for a school place and often end up choosing an option because they do not trust that their child will get support in their local school.
- Lack of guidance on seclusion and restraint
- Lack of guidance in special schools for children leaving school.
- Lack of ambition and vision for some children leaving school (Only 17% of people with intellectual disabilities are employed)

This year, the EPSEN act is under review. This is an opportunity to reflect as a society and at Government level on the kind of education system we want for children. For too long the “charity” model mentality has permeated the education system. It is not a charitable act to give a child a place in school, it is their constitutional right. We need to flip the narrative around disabled children as “problems to be fixed” and start thinking about school communities as simply better when the entire community is included.

There are many stories we hear about the transformative effect of inclusive classrooms and school environments where inclusion works. All children benefit from that not just disabled children. Inclusion however doesn’t mean “fitting a child in” to the system as it currently stands, it is about reimagining what schools could and should look like. We want to see vision from our political system. In twenty years time when we stand before the UNCRC committee again as we are doing today in Geneva, we should feel proud of the gains we have made. Although it may seem like an insignificant request- we are calling on Government to change the name of the “EPSEN ACT” to the Inclusive Education Act. This spells out publicly and clearly that we are taking our obligations seriously around developing an inclusive education model. There is nothing “special” about access to education-it is a right; one which all children should enjoy equally, no matter the level of support they need or the barriers that need to be overcome.

We call for:

- A fully costed multi annual plan which has cross government support. This plan should spell out incrementally the pathway towards a fully inclusive model of education. We need to invest in our school communities. The issues disabled adults experience, often stem from an underinvestment in their futures as children.

- Invest in mainstream schools; give them the resources they need to support every child in their community. Build trust amongst families that their child will get the support they need in their local school; this will prevent the need and the push for more separate education for disabled children. This support needs to include access to Alternative and Augmentative Communication systems, adequate physical space and incorporating principals of universal design for learning.
- Invest in teacher and SNA training. This training should focus on neuroaffirmative, child's rights-based approaches. In November 2022 we consulted with teachers and SNAs about the barriers to inclusion. One of the top issues highlighted was training both at a primary degree level but also at continuous professional development level and within school every day learning. Many school staff and leaders reported the lack of time for reflective practice and sharing expertise.
- Gathering of better data to plan properly for disabled children.
- Statutory guidelines on elimination of seclusion and restraint.
- Clear plan on investing in our Children's Disability Network Teams (CDNTs). In our 2022 report on Progressing Children's Disability Services, we called for a comprehensive workforce planning strategy repeatedly. With 1/3 of the CDNTs vacant currently, the resources are simply not there to support children the way they need to be supported. This is immensely frustrating and heart breaking for children and their families.

In his report on school places in 2022, the Ombudsman for children stated "All decisions made and actions taken from this time forth should be about building a strong, inclusive education system, which is fully supportive of all our children equally". We echo that call.

Article 19 Living Independently and being included in the Community

We all know that Ireland faces a housing crisis right now. Disabled people have faced a housing crisis for decades. This is apparent in these statistics and facts:

- 2400 people still living in large group homes of 10 or more people. Many of these individuals are autistic and have intellectual disabilities. Imagine not having choice and control about where you live or who you live with? This is the reality for some of our citizens today. We have closed many institutions over the last number of

decades and yet institutional living still remains a reality for some disabled people.

- Thousands of people living at home with family members and ageing carers for decades longer than they should have to. The National Federation of Voluntary Service Providers reported in August 2022 that there are now over 1500 people with intellectual disabilities living with primary carers who themselves are over 70 years of age, approximately 485 of whom are over 80. (Up from 1250 reported in 2019).

The disability capacity review spelt out the real unmet need of people with intellectual disabilities. We are awaiting the publication of the implementation plan. Without this, we lurch from crisis to crisis. What is needed is a fully costed plan with multi-annual funding so that people can vindicate their rights to live in accessible, affordable, appropriate homes, with their own front door key. Institutional thinking and living has no place in 21st century Ireland. It is, quite simply discrimination that if you happen to have high support needs (e.g need intensive support to live in your own home) the likelihood of you getting your own front door key is incredibly low. People should not have to stay living with their families if their expressed wish (whether that's verbally or non-verbally) is to move out. If people and families choose to stay living together, then they should have access to real and meaningful support so that families can be families and carers can be carers.

There was not time in the opening statement to also mention other significant issues facing disabled people such as the cost-of-living crisis, access to justice, employment, access to mental health services etc. We are happy to discuss many or all of these with the committee.

On a final note, what is needed more than anything is solidarity and understanding. We want to hear less about "them" and more about "us" as a society.

We want to hear less about "independence"; and more about the recognition that we are all interdependent, we rely on each other as a community for support, to belong, to be included.

We want to hear less about "awareness" and more about acceptance and celebration of difference. This is not to deny the support that people need, but to respect that in our differences there is real value. 1/3 of our board at Inclusion Ireland have a lived experience of Intellectual Disability. Having this dynamic makes sure that we stay focused as an organisation on what is important; people's lives.

So let's be visionary, let's invest in an Inclusive Ireland.

I will now ask Sarah Jane to introduce herself and highlight some of the issues she experiences.

My name is Sarah Jane Lavin.

I am 54 years old.

I am currently living with my Mum in Clane Co. Kildare.

My school experience was not great. There was no support or guidance during my school years. This made school difficult for me. After school I went to work with my mum. This was a catering job. I enjoyed this job and enjoyed the people and the environment in this job. My dream job would be to be a paid advocate.

At the moment I am living at home with my mum. I would love a place of my own. At the moment the housing list is very long. The forms were very complicated to fill out. I think the age for applying for a house should be lower than 55.

I think public transport timetables should be easier to read, I think they are very hard to follow. The signs on the buses should be easier to read and clearer. The buses are not reliable and are very rarely on time.

Getting to know autism. Trying to get people to understand more about autism is important. Make the world more autism friendly. It makes me feel like there is a barrier between me and the world. People need to be more open minded when it comes to autism. It is good to be different. Thank you so much for listening.

I will now ask Angela Locke Reilly to introduce herself.

My name is Angela Locke-Reilly. I am a parent to Jacob who is autistic and has Down syndrome and high support needs. I also have run a large support group for parents of children with additional needs for many years so am familiar with a wide range of topics relating to autistic and neurodivergent children and supporting them as a parent.