

Thank you for inviting me to address the committee today.

Every year another 130-150 babies join the population of people with Down syndrome living in Ireland.

Babies and children with Down syndrome need therapies to help them reach their potential.

According to our recent research, almost half of all children with Down syndrome had no therapy at all in the last year, and even when children do get therapy, it is not at the intensity and dosage that they need.

Down syndrome is diagnosed before or immediately after birth. Early diagnosis means that you don't need to wait for babies to start showing developmental delays. You have the opportunity to provide targeted therapy from birth, with potentially life changing results. Why is there no plan for this?

Before the pandemic, in 2019, the average number of Speech and Language therapy sessions for a child with Down syndrome was just five. Not five a week or even five a month, but five a year. This is well below the dosage required according to research, and it has only got worse. Two thirds of children with Down syndrome received **no** Speech and Language therapy at all last year, according to our research, and in some CHOs, it was 80% of children.

We have been told that money is not the issue, so someone needs to figure out what the issue is. Why are we spending money on services which are failing to meet the needs of children with Down syndrome?

In the 1980's, average life expectancy for someone with Down syndrome was around 25 years. It's now around 60. The HSE, by failing to provide therapy in childhood, are kicking the can down the road. They are not just impacting on the lives of children with Down syndrome right now, they are storing up social and economic costs for the future.

People with Down syndrome are often underestimated because of their communication difficulties, and without effective, individualised therapy, they can become increasingly frustrated and isolated. Failing to provide therapy has huge impacts on access to education, social inclusion and quality of life, and these in turn impact physical and mental health.

Therapy is not happening because the system is simply not working. Resources are being spread so thinly that they are far below the level needed to be effective. Statutory assessments are being resourced from the same pot as therapy, and when one **has** to be provided and the other would be nice to provide, it's easy to see what will happen. Parents are getting phone calls from therapists asking them to describe their child's progress so that unmanageable waiting lists can be triaged. Most families are only being offered indirect therapy, such as parent training, despite there being no evidence that this effects change on speech and language skills for children with Down syndrome. Therapists are leaving, some because the service they are asked to provide doesn't line up with their professional ethics. We saw what happened when the HSE ignored ethical concerns from therapists about the revised Assessment of Need.

The state has a responsibility to provide effective therapy to support development and prevent further disabilities under Article 25b of the UNCRPD. This is not happening.

Focusing in on Speech and Language therapy, we also need to consider the discriminatory nature of the system. Children with developmental speech and language disorders who **don't** have intellectual disabilities **are** offered direct therapy. There is no suggestion of moving to a less direct model for these children. But if your child has a speech and language disorder associated with Down syndrome, they are facing much longer waiting lists, which may be triaged based on a phone call. They are extremely unlikely to be offered direct therapy.

This is state-designed discrimination. Children with Down syndrome have the right to receive the same range, quality and standard of health care and programmes as provided to other people. This is a breach of Article 25a of the UNCRPD

The HSE has said that one of the issues is that there are not enough therapists to fill posts. However, most teams are not openly recruiting. The allied healthcare section on the HSE jobs website recently had only two areas recruiting for senior SLTs to work on disability teams. It is disingenuous to say there are no therapists out there if you're not actively looking, or incentivising therapists to return to the workforce.

We have been told that issues we are raising are temporary while the HSE make the system better for everyone, and that we somehow fail to understand. But we understand that children are not getting the therapy that they need. The HSE is failing to take into account both the needs of children and families, and the research evidence, and as a consequence, the state is failing to meet its obligations under article 25 of the UNCRPD. We need to stop putting the lives and futures of hundreds of children at a disadvantage by failing to provide therapy, or by providing advisory services that are not based on best evidence, and have little or no chance of changing outcomes.

Last year was the 50th anniversary of the founding of Down Syndrome Ireland. We found some archived magazines from the early 1970s and the biggest issue then was lack of therapy. We were failing children 51 years ago, and we're still failing them now.

I will leave you with a couple of quotes from parents of children with Down syndrome:

*"I firmly believe not one therapist could pick my son out of a line-up and even if they could they'd struggle to tell me anything about his strengths, interests and challenges."*

*"We have and are receiving no service and I do not expect this to change. They are just rearranging the deck chairs on the Titanic again...nothing ever improves."*

To summarise, what we need is:

- Complete overhaul of recruitment and retention processes which are not fit for purpose.
- An increase in staffing to the levels recommended by professional bodies when this model was initially proposed and provision of the structures and support staff for therapists to work effectively.
- The provision of separate, additional, ring-fenced resources for assessments of need, and a change in the law to make provision of services identified in the assessment a statutory requirement.
- Individualised therapy provision at dosages high enough to make an impact, rather than just parent training or short blocks of therapy with long breaks between, neither of which have been shown to be effective.
- An end to discrimination, by increasing therapy for children with Down syndrome and other disabilities, not by reducing therapy for others.
- A real commitment to meeting the state's obligations under UNCRPD article 25.