

Cathaoirleach and members of the Committee, I would like to start by thanking you for the invitation to contribute here today. I want to commend the deputies and senators who have engaged on these matters to date and for taking the time to consider the submission that I wrote to you all late last year.

I am a public representative, a local councillor elected in 2019 onto South Dublin County Council. It was my first time to run for election and I am sure like you all, it was and remains a huge honour to have won the trust of the people in my local community. I work very hard every day to ensure that the people that I represent have a voice at the decision-making table. Including disabled people.

I am a disabled woman. You will have read in my submission that I acquired my disability during my 20s. It took me a long time to be able to accept this, to say it out loud and not to feel shame. As we all know, people with disabilities in the past were simply written off. They were segregated from society, left in the shadows and considered something to be shameful of. The state supported this by providing institutions to hide children and adults that were considered 'less than'.

The stigma remains to this day. While a lot has changed since those very dark days, moving from a medicalised system towards a more progressive social model, the stigma and the state continue to work to prevent disabled children and adults from accessing and participating with the world in a meaningful way.

I call this structural violence which is defined as "*a form of violence wherein social structures or social institutions harm people by preventing them from meeting their basic needs.*" I ask you to consider how you felt when I read aloud this definition. Do you agree? Or do you feel uncomfortable or defensive? I can assure you that disabled people and their families feel this structural violence each and every day. We feel utterly let down by the state. I will use my time here today to outline why this is.

How do we know that the state is complicit in structural violence against people with disabilities, which makes up around 13.5% of our population? We have any number of examples, and I will outline just a few of those today.

The first relates to the is UN Convention on The Rights of Persons with Disabilities. Ireland signed up to this Convention in 2007, yet only ratified it eleven years later in 2018. We know there are issues with a number of pieces of existing legislation that either requires significant review such as the *Disability Act 2005* or legislation that Acts that are not fully implemented such as the *Education for Persons with Special Educational Needs Act 2004*.

The Optional Protocol remains unratified, which crucially offers individuals a complaints mechanism which allows a person to make a case before the UN to determine whether or not the state is living up to its commitments under the Convention. Without the Optional Protocol, we have no way to hold the state to account. The Optional Protocol cannot wait, and I would urge the Committee to consider the impact this is having on children and adults with disabilities across the country.

Another example relates to diagnosis and service provision. The new Assessment of Needs system is not fit for purpose. I have been through this process under the old system with my son. We had to fight for proper diagnostic testing which concluded that my son is autistic. Throughout this time, I was advised that a diagnosis was not important and that I was 'labelling my child'. If my child hurt his arm, I think we would all agree it would be better to know if the pain was caused by a sprain or whether a bone was broken. The Doctor would order tests, including an X-Ray. A sprain would be treated very differently to a fracture. Tests and treatment, whether it be a cast or even surgery, would all be carried out very quickly. Yet when it comes to disability, whatever form that is, we are told that there is no need to get a full picture. I spent years researching online before we finally got a diagnosis. With a diagnosis, we were able to understand his sensory issues around noise, food and touch, his core weakness, his executive functioning challenges, why he feels anxious and overwhelmed in the classroom. Knowing this helped us understand our son so much more. We were able to know what his needs are. This is not 'labelling' our children. The idea of 'labelling' is rooted in stigma. The thought process being that the diagnosis will follow our child, that somehow, we should be ashamed of it, that it might hurt him down the line. It will only hurt him down the line if the state continues to do

very little to combat this stigma. And while diagnosis is crucial, it would be remiss of me not to talk about the lack of services available to our children.

My son was referred for an Assessment of Need in 2014. By the time he completed that process, like so many others, he had aged out of Early Intervention. Services given during that crucial time have a much greater chance of being effective due to brain development and plasticity they experience during those years. He missed out like thousands of children who are left waiting while there are not enough therapists or resources provided. My son was then added to the School Age Team in 2016. He is still waiting to be seen five years later. He was first referred into this system at the age of three. He is now ten years old and has yet to meet anyone from Chamber House in all that time.

Worse again, we were unable to afford much private therapy throughout this time. I cannot begin to describe how devastating it is to watch my smart, funny and kind little boy grow up, knowing that he may never reach his full potential because the healthcare system in this country is abysmal and because we didn't have the disposable income necessary to pay for private therapy. There are thousands of families just like mine across the country. I know you hear from them every day. You listen to our stories when you knock on our doors. And yet here we are today. I hope the Committee will give this area significant attention as your work continues.

Another example of structural violence relates to access to education. When we consider Article 24 of the Convention, we have too many examples where the state is letting us down. Children with disabilities and additional needs face barriers to education from the very start. While some improvements have been made in Early Education, we know that over 500 children were unable to access a primary school place suitable for their needs in 2019. I have dealt with families whose children are 6, 7 and 8 years old, desperate to find a school place for their child, denied over and over again. We have no idea how many children are on reduced timetables. We know that too many children are without suitable in-class support with little or no access to a Special Education Teacher or SNA. Too many schools still have no special classes set up. And when a disabled child makes it through their school years, a report published yesterday by the NDA

and the ESRI tells us that there are still too many barriers in place for disabled students to transition from post-primary to third level education. How can we expect our children to engage and participate in the world with access to education?

Another example relates to income for disabled people. In relation to social welfare payments such as the Invalidity Pension, Disability Allowance, Primary Medical Certificates, Domiciliary Care Allowance, Carers Benefit/Carers Allowance, the state offers in most cases a means tested, below the poverty line payment which also fails to consider the additional costs that having a disability can incur. When the pandemic hit in 2020, with hundreds of thousands of workers unable to work, the Government provided a €350 a week payment. It was understood that this really was the bare minimum needed for people and families to cover basic necessities. Yet many other cohorts, including disabled people did not see any rise in their payments.

I don't know if anyone here on the Committee has ever had to survive on payments of just over €200 a week. I have. For a very long time. During the 2008 crash, my husband lost his job, through no fault of his own. I had recently been diagnosed with otosclerosis and was unable to access audiology services. We then experienced cuts to social welfare payments, rather than increases. We could not manage on such a low income, often having to choose between heating the home or paying the electricity bill. We have spent many, many years living in poverty, as have our children. Poverty grinds you down. It is death by a thousand cuts. With no end in sight and the state failing to provide any safety net for families like ours, we ended up losing our home, something I never thought could happen.

Poverty negatively impacts both the individual and society. There is a wealth of evidence to demonstrate that countries who work hard to eradicate poverty, do better more generally. Poverty is a social problem created by the state and which can be tackled with interventions and resources to both the individual and to their local community. Despite this too many disabled people experience poverty. We know that the most effective way of reducing poverty is to access education and work. Article 27 of the Convention recognises the right of people

with disabilities to work on an equal basis with others. Yet Ireland has one of the lowest employment rates for people with disabilities in the EU. When an intersectional approach is taken, imagine how much more difficult it might be to access employment if you are disabled and also a person of colour, a migrant, a Traveller, a woman, a queer person, an older person.

I would urge the Committee to give strong consideration towards the provision of Personal Assistants for disabled people. A PA would help empower the disabled person, provide them with opportunities to interact with the world, possibly engage in education and may even allow them to enter the work force if they want to. A PA could help in providing autonomy, independence, and freedom to a disabled person and is very different to home services. This is especially important when considering the *Decision Making Capacity Act 2015* and could be a real game changer for thousands of disabled people.

I will end on that note and ask all members of this committee to consider how your work and recommendations can make meaningful and lasting systemic change, to move from oppressor to ally and to ensure that the rights of disabled people under the Convention are centred, respected and protected by the state. Policy must be poverty proofed and an intersectional approach will help ensure that all people are considered when considering policy changes. I would also ask the Committee to please listen to disabled people and involve us in this process as much as possible.

I would like to take this opportunity to thank all members of the Disability Matters committee here this morning for listening and I am happy to answer any questions you may have.