

Introduction

Thank you, Chairperson and Committee members, for the invitation to speak to you today. I am a self-advocate with lived experience. I was diagnosed with a progressive non treatable neurological condition in 2006. I was fortunate to have a successful career in the private sector and I continued to work until 2018 at which time my condition had progressed significantly. I believe that being abled bodied until my mid 30's, I can clearly see both sides

When I finished work, I thought I could use my skill set and lived experience to volunteer and I was appointed to the Disability Stakeholders Group (DSG) in 2018 and reappointed in 2021

With regard to "How have my human rights been supported", I would say in summary that there is a lot more work to be done in compliance with UNCRPD which is also evidenced in the publication of the Committee's report in January 2024

1. (Art 19 and 23) Independent living – home care and personal assistant services should not be a geographical or budget lottery and disabled people should receive the supports they require to live independently rather than be at the mercy of what others think we need.

I recommend that home care packages become person centred with flexibility and that personal assistant services become an automatic entitlement and provided for in primary legislation before the current Dail ceases

2. (Art 9 and 20) Transport – A frequent and reliable public transport service with accurate information is imperative. Bus design (narrow turning space when entering the bus, only one wheelchair space, rules insisting I cannot face forward) etc. must be reviewed. The hazards of crossing a cycle lane to enter and exit a bus are well documented and I wholeheartedly share these concerns and fear it is only a matter of time before there is a fatality.

The rules for advance notification on Dart and Irish Rail are ableist.

There is a huge problem regarding wheelchair accessible taxis and even though there may be increased numbers, the day-to-day user experience of receiving a reliable and suitable wheelchair accessible taxi are far from ideal

I recommend a complete review of transport services and have one that is fit for purpose for all members of society. The current approach has failed

3. Infrastructure – shared spaces, dangerous footpaths, poor dishing, kissing gates, lack of wheelchair parking spaces and disabled bays have no dishing to safely get on the footpath, lifts out of order have been detailed on other occasions. Poorly designed footpaths and dishing also impact my ability to be independent in my community. If it is poor for me, it is also poor for families with buggies and older people.

(Art 29) I have previously appeared before this committee regarding the challenges of postal voting and physical attendance to vote and there is more work to be done. Infrastructure issues also lead to difficulties when trying to vote.

4. Leaving one's home – many buildings, shops and social settings and ATM's are not designed for wheelchair users and this lack of universal design can cause us to be excluded and marginalised by society. The simplest of excursions outside of the home requires planning like a military operation and there is no room for spontaneity

I recommend that universal design become mandatory especially for any building and social setting

5. (Art 25) Health – I have been trying to get a dexa scan for the last few months. 13 radiology centres and counting cannot facilitate a hoist transfer from my wheelchair to the dexa scan machine. Another challenging experience is trying to get a dental appointment where I can remain in my chair. The HSE could facilitate such an appointment but as I do not have a medical card, they could not see me. After much ringing around, I located a private dental practice where I could be treated whilst remaining in my chair.

I recommend that all procurement processes include a mandatory requirement that the equipment, and environment etc is suitable for all

The wheelchair accessible toilets in hospitals and the toilets on the wards in hospitals are generally unsuitable for wheelchair users

I recommend that all healthcare facilities follow universal design and have at least one changing places bathroom in each location

6. Cost of disability – it is without doubt more expensive to be disabled than able bodied. The long-term illness card does not cover all medications a disabled person might need as the medication list is limited to the long-term illness itself rather than other conditions that might develop because of an illness for which the long-term illness card is provided. If a clinician prescribes something, it should be provided. Being immobile results in significant heating costs as it is difficult to stay warm in standard heating settings. Electricity costs also increase because of charging wheelchairs, electric beds, hoists, breathing apparatus etc. The deposit return will add to my cost of living as I do my shopping online and cannot return the empty bottles easily

I recommend that all disabled people automatically receive a medical card, free public transport and a cost of disability payment as detailed in the Indecon Cost of Disability report published in December 2021. I would also mention that not all disabled people receive payment from DSP and they should be included in any cost of disability payment

7. (Art 27) - Employers need to create an inclusive environment where all staff are given opportunities to reach their full potential. Disabled people are innovative, solutions orientated and offer a unique perspective which is an asset that is often overlooked. We are not a problem to be solved. Diversity and Inclusion is more than words, it is the day to day environment, language and culture. Policies and procedures are meaningless unless they translate into jobs and roles where disabled employees are valued, encouraged and have career progression (if they so wish)

I recommend that all employers action their words regarding diversity and inclusion

8. Law and order – an increased Garda presence is needed on our streets as I do not feel safe especially in the city centre. Parking on footpaths and across dishing is widely abused and the existing road traffic regulations must be enforced. The removal of wheelchair accessible parking spaces in towns and cities is also a personal security risk as well as an accessibility challenge. Safety on public transport is also a concern
9. Family life – a disabled family member affects the whole family not just the individual and the role of family needs to be more valued by Government, employers and

society. Many disabled people cannot visit the homes of family or friends as their homes may not be accessible and this can lead to the disabled person feeling that everything revolves around them

I think it is vitally important that UNCRPD is implemented in an expeditious manner. The long standing issues can no longer be put to one side. All Government officials and public servants must work together with a sense of urgency to implement UNCRPD. Lack of resources, human or financial, can no longer be cited as a reason for non-progress as we have seen how Government can respond in other situations. Disability related matters are at crisis point and have been for a long time. Missed deadlines and ticking the box without consideration if something is fit for purpose can no longer be acceptable and people must be held to account. Ireland is regarded as a wealthy country but sadly there is little evidence of this if you are disabled which is a shocking reflection of our country in 2024

I as a disabled person have had to become more resilient, highly organised, solutions focussed while trying to remain positive in a world that would exclude me if it could. No decisions should be made for me or any disabled person without our input especially at the start of any process

I hope that the contributions presented today will further advance progress in improving the lives of disabled people as prescribed by UNCRPD. Thank you again for the invitation and I look forward to further discussions during the Q&A.