

**Joint Committee  
on  
Disability Matters**

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**OPENING STATEMENT**

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8<sup>th</sup> April 2024**

## **Introduction**

Good morning or good afternoon Chair and members of the committee. Thank you for this invitation.

This opening statement is with reference to the following question:

### **How have your human rights been supported?**

Ireland has clearly demonstrated its responsibility on an international level by signing up to the United Nations Convention for the Rights of People with Disabilities (UNCRPD): a human rights treaty for people with disabilities, although this is ultimately progress it is still not enough.

I am a self-advocate but also a member of a support group called: 'Amputee Ireland and Beyond'. I have a limb impairment, lower right arm, so I am talking about my own experience but also I will refer to the experiences of eight participants interviewed for my Master's Degree entitled:

The impact of Irish national and international Health policies [including the UNCRPD] and services on the quality of life of amputees and those with limb impairments in Ireland.

I feel that having a disability and being a disabled researcher adds value and experience to my research; being disabled is special, we get to see a very different side to humanity: this should be valued as insightful and beneficial. Traditionally, disability was not regarded as a human rights issue, it was seen as a medical issue requiring medical solutions and for support through welfare and charity for those who cannot be cured or corrected (Lawson, 2005:462). It is hoped that this is no longer the approach we have towards disability that at last modern legislation will hopefully take us away from historical harms and discrimination.

So, for my experience, well I no longer wear a prosthetic but I have done so in the past. Most of my life has been spent in the UK; access to prosthetic healthcare in the UK came from the NHS, which was of a high standard in my experience. Accessing prosthetics for anything, any sport, and any hobby was easy, they would happily make a prosthetic if it meant you could enjoy life more.

I was not aware of the difficulty in accessing services and prosthetics in Ireland with all of its processes and necessary approval from resource management boards, especially for leisure activities. I applied for a prosthetic for violin playing but was not successful, based on the policy that states ‘Prosthesis for “everyday mobility use” (HSE South, 2013) only, where if it is not for daily use it is not seen as worthwhile. Leisure activities are not seen as necessary unless you fund the prosthetic yourself. The WHO may disagree with this asserting that:

‘Assistive technology is also a means by which to exercise human rights. The UN Convention on the Rights of Persons with Disabilities (2) recognizes this. It requires states to provide necessary assistive technology to enable people with disabilities to exercise their rights to education, work, leisure, participation in the cultural life of the community etc., and freedoms of opinion and expression.’

(WHO and UNICEF, 2022)

This quote came from the ‘Global Report on Assistive Technology’. This report has ten great recommendations to improve assistive technology systems, encourages universal health coverage, and would aid in supporting the UNCRPD.

My Masters focused specifically on the health service and the importance of support and assistance including the need of assistive technology, required by many amputees and those with limb impairments. The Irish Human Rights and Equality Commission points out that: ‘While discrimination reported by people without disabilities is most likely to occur in the labour market, discrimination reported by people with disabilities is most likely to be in accessing health services’ (Banks et al, 2018:30) and this discrimination they experience is likely to have had: ‘serious or very serious effects on them compared to those with no disability’ (ibid)

The impact of not being able to access services quickly and efficiently is massively impacting amputees and it is not the case that everything is terrible or awful, as some of the participants I interviewed had good experiences but that there is no one standard or ‘no national standards that apply to the provision of services to people who have had amputations’ (Delea et al 2015:2) and no national statistics recommended by the UNCRPD that would aid improvements.

Many discussions were had about the endless bureaucracy experienced within the various government departments and health services trying to access treatment abroad schemes, primary health certificates and prosthetics and aids and even trying to get blue badges for arm amputees. One participant referred to the HSE like this:

*I mean it's it's like, you know, the HSE take your independence and your freedom and put it in a box and throw away the key*

(Baker, 2023:55)

Another referred to the lack of support:

*‘There is no one, what’s the word I’m looking for, there is no one to contact. If I have a problem with something. There's no one there, Like a shoulder to cry on or ‘... ‘ a favourite voice or something nowhere to go’*

(Baker, 2023:59)

Also on applying for prosthetics through a resource allocation board and waiting long periods while experiencing blisters and pain:

*The HSE for four months has refused because in their opinion I have a leg that is semi-functional, why does it need to be changed.*

There are quite a few references to a ‘wall of silence’, feeling like a ‘second thought’ and ‘backwards’ (Baker, 2023:62) with reference to the HSE service, feelings of isolation and lack of independence when it comes to accessing services or getting services that actually benefit the patient holistically: ones that are not merely ticking boxes.

I am unsure whether I have answered your question fully, I would like to suggest that this service has the potential to be excellent if the system was more centralised. What if you registered your disability especially when the disability is physical: for example amputation and then use the registration to access all the other departments easily: here’s your blue badge, your medical card etc.

I understand under the National Disability Inclusion Strategy 2017-2021 that has a great list of goals, it states that: ‘We will work together to ensure joined up public services for persons with disabilities’. (Justice.ie, 2017:18). This goal will be of great assistance in further supporting human rights and accessing good public services in Ireland.

The sociologist Max Weber warned: ‘of the possibilities of bureaucracies becoming an ‘iron cage’ in which individuals find their freedom of action constrained and their activities over-regulated by rigid procedure’ (Cockerham, 2015:124) This can only delay the potential of the UNCRPD.

Thanks for listening.

**Referencing**

Baker, D (2023) The impact of Irish national and international Health policies and services on the quality of life of amputees and those with limb impairments in Ireland, Unpublished Master's Thesis, Maynooth University.

Banks, J., Grotti, R., Fahey, É. and Watson, D., 2018. *Disability and discrimination in Ireland: Evidence from the QNHS Equality Modules 2004, 2010, 2014*. ESRI and The Irish Human Rights and Equality Commission.

Cockerham, W.C., 2015. Max Weber: Bureaucracy, formal rationality and the modern hospital. In *The Palgrave handbook of social theory in health, illness and medicine* (pp. 124-138). London: Palgrave Macmillan UK.

HSE South prosthetics and orthotics Group, (2013) Prosthetics, HSE South report publication.

Justice.ie, 2017, The National Disability Inclusion Strategy 2017-2021, Available at: [162923\\_96990962-f41f-4844-b784-e9ccf8cbfa42.pdf](https://www.justice.ie/publications/162923_96990962-f41f-4844-b784-e9ccf8cbfa42.pdf) Accessed on: 3<sup>rd</sup> April 2024

Lawson, A., (2005). Disability, Degradation and Dignity: The Role of Article 3 of the European Convention on Human Rights. *N. Ir. Legal Q.*, 56, p.462.

Lee, G, (2017) Disability- A Human Rights Perspective, Law Society Gazette, Available at: <https://www.lawsociety.ie/globalassets/documents/gazette/gazette-pdfs/gazette-2017/march2017-gazette.pdf#page=31> Accessed on: 3<sup>rd</sup> April 2024

Magee, C., Murphy, T., Turley, M., Feely, M., Iriarte, E.G. and McConkey, R., 2018. 19 stories of social inclusion—Ireland: stories of belonging, contributing and connecting. *Dublin: National Disability Authority*.

World Health Organization and the United Nations Children's Fund (UNICEF), 2022, Global report on assistive technology. Geneva. Licence: CC BY-NC-SA 3.0 IGO.