

## **Submission to the Joint Committee on Disability Matters**

*N.B. I have used the questions that were provided as a framework but have only dealt with the three that I feel are most pertinent to my understanding of issues raised by the committee. I have taken the first question on its own and the final two questions together.*

*Question: Are you a DPO or a Self-Advocate? Please provide as much detail as you can on why you are considered a DPO or Self Advocate.*

I was born in Glasgow, Scotland in 1969 with a congenital birth deformity of the left leg that eventually led to an above-knee amputation. Originally offered a place for children with special needs and learning disabilities (not uncommon for physically disabled children in the 1970s), my father fought to have me placed in a regular primary school.

His advocacy allowed me to attend a mainstream school. I went on to be the first person from my comprehensive school in Scotland to attend Oxford University where I graduated with a degree in Economics and Politics. I also hold a Masters from an Ivy League university in the US, none of which would have been possible without access to a mainstream education and proper supports in terms of education and health.

I moved to Ireland with my wife and daughter in 2004. Last year I was honoured to be granted Irish Citizenship. Citizenship carries with it responsibilities and well as rights and and that is why I have decided to advocate for the many

amputees, as well as others with permanent physical disabilities such a spinal injury, who are currently being failed by the Irish government and state.

My reason for making this submission is simple. While living in Ireland I have spoken to many amputees and others with permanent physical disabilities. Their experiences of dealing with the state, and particularly the HSE have not only appalled me, but stand in stark contrast to the compassion, empathy and understanding of people in Ireland.

I also compete in combat sports. and am proud to now officially represent Ireland internationally. In Paris in 2023 I became the only amputee in the world to become a European Champion in Brazilian Jiu Jitsu while competing against able-bodied athletes.

Access to sport and recreation is another area that is critical for people with disabilities and this also requires the support of the state.

*Question: What are the key issues that you believe are affecting your human rights and having equal opportunities like everyone else in your local area?*

*Question: What are the solutions that you believe would help make things better and that Government should be supporting?*

Many of the most important issues facing disabled people in Ireland are not local issues. Neither are they regional issues.

***These are national issues. They are issues of legislation and government policy, particularly as they relate to the Departments of Health, Social Protection and Transport.***

Framing them as local or regional issues has been a major part of why they are not dealt with (e.g. the postcode lottery for HSE provision of prosthetic limbs for amputees). This has led to a situation of disabled rights that often revolve around access to support being dealt with on an ad hoc basis by TDs who are forced to raise cases for individual constituents when they are refused a Medical Card or their Medical Card is withdrawn.

Rather than deal with a vague raft of issues, I would like to highlight one issue relating to amputees that I hope will illuminate a broader range of issues for committee members when it comes to implementation of the UNCRPD in Ireland.

Ireland is the only country in the EU that does not guarantee provision of prosthetic limbs beyond the first prosthetic limb or limbs.

The amputation of a limb is a permanent disability. This might seem obvious but given stories from amputees who have dealt with the HSE withdrawing their Medical Card it's apparently worth highlighting.

Prosthetic limbs are an ongoing need. For children, who are still growing, this can be a bi or tri-annual need. An adult amputee may need one every year or at a much longer interval. I have had prosthetic legs that I have worn for six or seven years before they had to be replaced.

In Ireland amputees who need a prosthetic limb or limbs to function can either:

- i. Apply for a means-tested discretionary medical card that may not be granted and if it is can be withdrawn at any time. This provision is coupled with an often lengthy and inefficient system of arbitrary sanctioning by non-medical staff in the HSE who are not qualified to decide what an amputee requires. The HSE regularly argues with qualified prosthetists over what they will sanction or it will take many months for them to sanction at all. In the meantime an amputee can be left with no limb or an unsafe limb.
- ii. Privately fund the limb(s) themselves.
- iii. If they have it, use private medical insurance offered by VHI who will contribute up to €6,200 per year under certain plans. The typical cost of a prosthetic leg for an above-knee amputee would be above this so amputees with VHI have to work with clinics to schedule the limb being built and fitted so that the cost is split over two insurance periods.

iv. Raise money via crowdfunding sites such as GoFundMe or have private individuals help them out. I know of one instance where an Irish sports star paid for orthotics for one young disabled man so that he could train martial arts.

Amputees in Ireland continue to be failed by a means-tested, and overly bureaucratic system that is morally indefensible, expensive to operate and causes untold stress and anxiety to amputees and their families. The treatment of children and teenagers who have a limb amputated and struggle to access appropriate prosthetic limbs is particularly shameful.

Provision of prosthetic limbs that allow amputees to play a full part in their community and society should be universal and non means-tested, whether that is by an adjustment in how the Medical Card is granted (and removing any need for review), by a different mechanism such a separate category of Medical Card, or by a statutory right.

The economic case for ending means-testing and discretionary Medical Cards in this instance (and I would strongly argue for others with permanent disabilities such as spinal injury) is clear. Some amputees would like to work but are scared to move into employment because they fear losing their Medical Card and thus their access to vital support. Others who are in employment face constant stress and anxiety surrounding their Medical Card being withdrawn.

Cost is often raised as a factor but I would argue that when it comes to government spending on health as a country we are penny wise and pound foolish. The HSE and government don't collect figures, but extrapolating from NHS England data, the amputee population in Ireland that require prosthetics limbs is tiny.

Even if we leave aside the moral argument, any basic cost-benefit analysis will show that an amputee with a prosthetic can stay active, be less isolated, engage in education and employment. Not only are their health outcomes going to be significantly better, but they will be net contributors.

I've given you one easily actionable example but there are many more in terms of transport, housing, the interface between people with disabilities and the HSE, meaningful social welfare supports, etc.

Let me ask this committee the following:

Why should the parent of a child who's had one of their limbs amputated have to battle HSE bureaucrats when that child's Medical Card is withdrawn?<sup>1</sup>

Why should an amputee who is working as a tradesman have someone in an HSE office refuse to sanction a particular knee unit that he needs to get up and down safely at work because they will only sanction a 'basic' prosthetic?

Why should a gold medal Irish Paralympian who is highly educated and working have to worry that his next pay rise or next promotion might result in his Medical Card being withdrawn leading to a choice between a prosthetic limb or paying his mortgage?<sup>2</sup>

In conclusion, people with disabilities in Ireland need a floor, not a ceiling. That requires them to be listened to and the issues they face being taken seriously by the state and government.

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<sup>1</sup> <https://www.rte.ie/news/primetime/2020/1210/1183626-amputees-ireland-prosthetics-hse/>

<sup>2</sup> *ibid*

I'd like to thank all the members of the committee for soliciting this feedback.  
My schedule allowing I'd be happy to appear in person and speak with them at the meeting in the Seanad Chamber on the 8th of April.

David Young

15th March, 2024