

Submission by Voice of Vision Impairment
To Oireachtas Joint Committee on Disability Matters
Topic: The Rights – Based Approach and Disability Legislation
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1. Introduction

A Chathaoirligh agus a bhaill eile den Chomhchoiste,

On behalf of Voice of Vision Impairment, I would like to thank you for your inviting us to submit on the topic of this module of the Committee.

While this module is intended to review the adequacy and effectiveness of the State's legislative framework on disability; in the briefing letter, a certain framing, through related themes, was suggested, including inadequacies of specific current legislation, and the general over-arching necessity to move beyond an individualist, purely anti-discrimination approach.

While these suggestions are all very welcome in framing the discussion; covering all the suggested themes adequately, especially while also allowing time for our own suggested framing of the discussion, means that I must apologise for this submission effectively being two papers rolled into one:

- * Part 1 – Direct Responses to Suggested Themes.

* Part 2 – The CRPD’s and VVI’s Priorities for Ireland’s Disability Legislative Framework.

So, please forgive us for this submission being twice as long as we all would have preferred. I am, of course, happy to present to you a much abridged form, and take any questions, as ever.

Part 1 – Direct Responses to Suggested Themes.

2. Assessment of Impairments and Support Needs.

2.1. Specific Focus on EPSON.

2.2. Assessment in General.

2.3. Employment.

2.4. Role of DPOs in Individual Assessments.

2.1. Particular Focus on EPSON and EPSON-Related Part of Disability Act.

Before getting into the most significant rights-related theme from VVI’s perspective, I’ll just make a few quick observations on the ‘disability assessment’ point which was mentioned in the briefing letter.

As a parent, I have experienced problems relating to EPSON (2004) for non-visual-impairment-related needs of my children, and the EPSON system is clearly not fit for purpose – including the de facto marginalisation of DPOs in the legislation;¹ and the damage being done as a result of this is incalculable and inexcusable. There are few components of life more critical than appropriate education.²

However, I also say the following, and do so as an autistic person too. I would suggest that the fact that EPSON, specifically, is

¹ UN Convention on the Rights of People with Disabilities (CRPD), General Comment 7, para. 85.

² CRPD, GC4.

so central to the general “rights” perspective of this committee, and the fact that there is even a separate Joint Oireachtas Committee on autism, itself, could be, at least in part, to the power of the voice of non-disabled carers for disabled people.

Many on the Joint Committee draw on a rich experience and strong motivation from loved ones who are close to them with lived experience of being disabled; and such motivation is a brilliant asset to have in the Oireachtas, and on relevant committees, etc.

However, while non-disabled voices are, of course, invaluable and crucial, the Human Rights model, as explained by the UN Committee, unwaveringly prioritises the voice of disabled people themselves,³ either through their representative organisations (DPOs), or, particularly in the case of people with intellectual disabilities, through self-advocacy organisations (albeit heavily supported by carers).⁴

While there is no doubt whatsoever that EPSON and autism, respectively, are very important areas that must be addressed, their prioritisation, in terms of focus, at the possible expense of the bigger picture of a general framework for the Human Rights of disabled people, may be a reflection of how far the culture in Ireland remains divergent from the Human Rights model of disability which puts the (organised) voice of the disabled person (including disabled children), above all others in matters relating to disability.

The only prioritisation in the CRPD is that of the General Principles, in Articles 2 and 3, and the General Obligations in Article 4, especially the cross-cutting Article 4 (3) regarding DPO rights.⁵

w2.2. Assessment in General.

³ Cf. GC7, paras. 3, 10, 13, 14, 23, 56, etc.

⁴ GC7, para. 12 (c, d).

⁵ GC7, para. 68-8.

Regarding the definitional components of the paper (Waddington & Priestly, 2020), mentioned in your Committee briefing letter; from a visually impaired perspective, VVI's position shows how technical, Human Rights, and social model perspectives can be made to work together.

<https://vvi.ie/our-policies/accessible-communications-policy/3-language-and-terminology/>

It goes without saying that for reasons of honesty and objectivity, Budgetary concerns should have zero impact on definitions of impairments or support needs. It would be more honest, for example, to accurately state that particular needs are not suppliable under a current system for reasons of budgetary priorities etc., than to try to change definitions and criteria in order to minimise the numbers being supported. However, the more honest approach should also include cost benefit analyses of the hidden and longer-term social and personal costs of non-provision of necessary supports.

One example of where the technical definition of visual impairment is at odds with the social model is that of people who, even with corrective lenses, do not have enough sight to drive a motorised vehicle; but they are not seen to be blind enough to receive compensatory supports, such as eligibility to the Free Travel Scheme. At the other end of the spectrum, some of our members have fields of vision so narrow, that it is clear to any lay-person that to all intents and purposes, they are visually impaired – and yet, they are denied access to supports such as the Blind Pension because they can read down to a certain letter on an eye chart, through the very narrow field of vision they have left.

2.3. Employment.

Regarding employment, as per the 2016 Census, 76% of people of working age with a severe visual impairment are out of (formal)

work. We know of no country in the world where this figure is under 70%. So, while we, of course, reaffirm the right of all visually impaired people to work; in reality, the likelihood is that most visually impaired people in Ireland of working age right now will never be officially employed, and, so, ways must be found to make sure that visually impaired people are not punished, shamed, or seen in an undignified light as a result of what is clearly institutionalised discrimination.

It is not fair to hold up a standard of expectation while that standard, for the most part, is practically unattainable for the majority of a group. As such, a two-pronged approach is necessary: doing what is possible to create a level playing-field for visually impaired people in the jobs market; while at the same time making sure that there is zero practical or notional stigma attached to visually impaired people who find themselves unable to find or hold down a job.

Not helping the massive unemployment rate of visually impaired people in Ireland is a system which lifts most of the barriers to getting necessary assistive technology only when the visually impaired person gets a job in the first place. This means that there is a 'catch 22' in operation, with visually impaired people not being able to better prepare for the jobs market via regular use of such technology, and remaining very much socially marginalised in the meantime.

2.4. Role of DPOs in Individual Assessments.

Finally, regarding Waddington & Priestly (2020), we would have some concerns regarding the peer-to-peer role envisaged for DPOs regarding self-assessment for needs and services, on the following grounds:

* as a Human Rights organisation, a DPO should never become an instrument of the State, for example, in a sort of service-provision

role, such as systematically working with individuals to help in the evaluation their support needs.

* while there can certainly be shared understandings among many in an impairment group, technical measurements of impairments do not necessarily correlate to support needs. For example, someone who loses their sight later in life, or someone with few or no social/family supports or other resources, may have greater support needs. A lot of training along the Human Rights model of disability would be needed in order to make sure that the expertise from one person's lived experience does not negatively impact on another's.

Part 2 – The CRPD's and VVI's Priorities for Ireland's Disability Legislative Framework.

3. Reasonable Accommodation and Universal Design.

3.1. Reasonable Accommodation.

3.2. Universal Design.

Beginning with the over-arching framing, from the perspective of Human Rights and international law: rather than saying that there is a need "to move beyond anti-discrimination legislation to align with the UNCRPD," a clearer way would be to say that 'legislation urgently needs to make both reasonable accommodation and universal design parallel realities'.⁶

3.1. Reasonable Accommodation.

Reasonable accommodation recognises the disabled individual as a rights-holder, and acknowledges that each disabled individual is their own expert in appraising their own barriers to equal participation, and that they can hold institutions to account for

⁶ GC7, paras. 17, 70, 77, etc.

discriminating against them – i.e., failing to facilitate equality of opportunity by effectively denying those rights.

Currently, reasonable accommodation complaints can be made under two separate legal mechanisms. The first is the Equal Status Act (2000), a system which is effectively inaccessible to those with least resources and supports. The second, relating to public bodies alone, is the Disability Act (2005, Part 3), which is not fit for purpose for several reasons, including:

- * the Ombudsman does not take the Disability Act (Part 3) seriously (in our experience)
- * Neither the Ombudsman nor the National Disability Authority (NDA) are taken seriously by public bodies (i.e., the Disability Act has no teeth)
- * there is no consistency in terms of quality or definition of role of an Access Officer under the Act. Some Access Officers are part-time, with the position as an add-on; others are their own Equality Officer – i.e., investigate complaints about themselves; and many public services have no Access Officer at all.

The Equal Status Act is currently under review by the Dept. of Justice, but voices of disabled people, through their DPOs, have, to date, been aggregated with all other voices, rather than being prioritised with regard to disability-specific issues.

In both the Equal Status Act review, and an overhaul (or total replacement) of the Disability Act, the State is obliged to “closely consult and actively involve” DPOs (CRPD, Article 4 (3)), and, indeed, to prioritise our views and opinions in all or any consultations on such reviews.⁷

⁷ Cf. GC7, paras. 13, 14, 15, 23, 56, etc.

3.2. Universal Design.

Universal design is a general principle in Article 2 of the CRPD. It is mentioned in the Disability Act (S52); and there are two half-hearted nods to it in the same Act (SS26-7), but effectively, Ireland continues to completely ignore universal design, including through the total absence of disability-proofing of policies and legislation.

The Irish Human Rights and Equality Commission (IHREC) Act (2014, S42), could have been an opportunity to ensure universal design, but it has been shown so far to have no teeth, and even IHREC haven't joined the dots between the disability component of the this 'Public Sector Duty', and Ireland's CRPD obligations to prioritise DPOs in consultations in such regard. So, the IHREC Act (2014), is a damp squib from a disability perspective.

The EU Website Accessibility Directive (2016) held out hope that visually impaired people would have accessible websites and apps by public bodies, through universal design. However, the transposition of the Directive to Irish law in 2020 was modelled on the Disability Act (NDA led), so is not Human Rights based – and so is ineffective and non-binding.

The European Disability Act (2019) was another Directive promising to give visually impaired people access to all sorts of machines such as ATMs and point-of-sale terminals. The State, after prioritising DPOs in consultations, was supposed to have transposed this Directive to Irish law in June, 2022 – but the legislation has not happened, and any VVI communications to the relevant Department, regarding consultations, have been effectively ignored. But, how can this be of any surprise when Ireland steadfastly refuses to apply the Human Rights (accountable and binding) approach to disability.

Expertise on universal design is, perhaps, the most important function of Disabled Persons Organisations – being consulted and listened to on every policy and plan, so that hundreds of thousands

do not have to make the choice, on a regular basis, between firefighting their most recent encounter with discrimination; or just buckling under that discrimination and suffering in silence.

As a DPO, two of VVI's core principles are:

- * subsidiarity in the State's consultations with disabled people – decisions made at the lowest level possible – so that, for example, a visually impaired person, themselves, is the primary voice listened to in matters specific to their own situation, such as deciding what supports they require; and the collective voice of DPOs being the expert consultees at higher levels.
- * VVI tries to prioritise the perspectives of those with least resources and supports.

In this way, DPOs are supposed to be representative from a Human Rights perspective – as opposed to a majoritarian perspective, and we are not only the only representative organisations of disabled people, but we must be seen as Human Rights Defender organisations.⁸

See detailed legal opinion commissioned by VVI, as sent to your Committee in August, 2021.

<https://vvi.ie/legal-opinion-for-vvi-as-a-dpo-for-all-dpos/>

4. Incorporation of DPO Rights into Irish Law.

The paradigm which Ireland has ratified, in the CRPD, is so alien to traditional practice in this country, and is so diametrically opposed to the way things continue to be done here; that a rapid education is urgently needed for decision-makers to make sure that the Human Rights model is built into the structure of the Irish system – i.e., incorporated into Irish law. Anything falling short of this urgent need

⁸ Cf. GC7, para. 29.

is a waste of all our times, and an unnecessary continuation of the suffering and marginalisation of disabled people in this country.

The UN Committee, in its clarification of Articles 4 (3) and 33 (3) of the CRPD, has stated that DPOs must be closely consulted and actively involved in all decisions affecting disabled people, and this being meant in the broadest sense.⁹ The UN Committee has also clarified that the views and opinions of DPOs must be prioritised in all such consultations.¹⁰ As if the message wasn't already strong enough, the UN Committee points out that DPOs must be distinguished from all other civil society organisations in such consultations, even to the extent that DPOs have separate DPO-only spaces in consultations at **all levels and branches** of government.¹¹

Not only is the DPO system compliant with Ireland's Human Rights obligations, but it is also the most efficient and effective system. Whereas interviewing a thousand disabled people in a consultation would be unwieldy and not a good way to ascertain the needs of those with least resources and supports, having well-resourced and Human-Rights-based DPOs enables disabled voices to coalesce in collective expertise, and to include all spectrums and social statuses of their constituency, so that every branch and every level of government can easily ask advice from a coherent, consistent and legitimate (DPO) voice, and including all relevant DPOs (e.g., national, local etc.).

Disability-proofing of all policies and legislation, by DPOs, is to be so systematic that there should be sanctions for non-compliance, and collective remedies including suspension or quashing of procedures not complying with Article 4 (3).¹² DPOs need also to be able to bring class actions on behalf of their impairment

⁹ GC7, paras. 18-20.

¹⁰ GC7, paras. 13-4, 23, 47, etc.

¹¹ GC7, para. 49.

¹² GC7, para. 66.

constituencies where the CRPD has been ignored – as it is systematically being ignored by Ireland, currently.¹³

To this end, States are required to adopt an “anti-discrimination framework,”¹⁴ which includes legislation, regulations, and policies, making obligations towards DPOs mandatory.¹⁵ Such DPO-specific legislation should also require other civil society organisations (including disability service-providers) to closely consult with and actively involve DPOs in their own work relating to the CRPD.¹⁶

Of course, the formulation of legislation specifically relating to the implementation of Articles 4 (3) and 33 (3), must, itself, be predicated on close consultation and active involvement of DPOs.¹⁷

Similarly, DPOs must be given priority regarding monitoring of the implementation of the CRPD, and the independent monitoring framework (i.e., IHREC in Ireland’s case).¹⁸

5. Absence of Universal Design (some current examples)

Barriers faced by visually impaired people tend to break down into two types:

- * communication barriers
- * barriers to safe and accessible mobility and travel

VVI’s Manual on Accessible Communication (VVIMAC) comprehensively deals with the former. We can go into this in greater detail at a later date,

¹³ GC7, paras. 65-7.

¹⁴ GC7, para. 16.

¹⁵ GC7, paras. 53, 94 (e).

¹⁶ GC7, para. 14.

¹⁷ GC7, para. 15.

¹⁸ GC7, paras. 14, 34-41, etc.

<https://vvi.ie/our-policies/accessible-communications-policy/>

Regarding barriers to safe and accessible travel and mobility, visually impaired people are facing an immediate shock and crisis as a result of the CRPD being utterly ignored in the pushing through of certain policies.

If we want Ireland to be a country tolerable to older people – and we all are getting older – all plans and policies must be disability-proofed.

The Dept. of Public Expenditure and Reform (DPER) currently has €665bn in planned spending on the National Development Plan, and key to this is the UN Sustainable Development Goals, 2030, and the National Climate Action Plan.

The UN Committee is clear that the CRPD is central to the planning and implementation of the 2030 Sustainable Development Goals;¹⁹ and that DPOs must be very much strengthened in this regard, so that disability-proofing is mainstreamed in all related plans and implementation.²⁰

Instead, DPOs have been totally marginalised from anything to do with the Sustainable Development Goals by the State, and even were this to change overnight, much of the implementation is already underway, and to all intents and purposes, disabled people will remain excluded as far as 2030 is concerned.

There is, underway, via the National Transport Authority and Transport Infrastructure Ireland, an avalanche of plans that are disablement by design. I could go into detail here on how DPOs have been marginalised, rather than prioritised, by explicit decisions by

¹⁹ GC7, para. 9.

²⁰ GC7, para. 32, 94 ®.

the NTA, and by structural ignoring of the CRPD in the case of the Dept. of Transport and Transport Infrastructure Ireland. The immediate cause of this is the persistent lack of guidance from the Dept. of Disability etc. (DCEDIY) regarding obligations of public bodies under Articles 4 (3) and 33 (3) of the CRPD. Indeed, DCEDIY, itself, appears to be caught in the headlights, and is currently sitting on its hands regarding such obligations, until it gets reports from the NDA, so that it can begin on a CRPD implementation strategy/plan, as early as January, 2024.

Meanwhile, while the CRPD obligations are being systematically ignored by the State, tremendous damage is being pushed through at an alarming rate.

In the meantime, current legislation and policy proposals should be adhering to Article 4 (3) by close consultation and involvement with DPOs, at least to take the edge off the worst excesses.

One example is of a Planning Bill currently in the early stages, going through the Houses of the Oireachtas. The last Planning Act was in 2000, with a Planning Regulations Act in 2001. So, opportunities to get planning right, such as this, only happen every 25 years or so.

VVI is routinely told by local authority planners that their hands are tied in terms of creating built environments that are safe and accessible for visually impaired people – for example, as set out in our Manual of Accessible Planning for Pedestrians (MAPP).

<https://www.vvi.ie/mapp/>

As far as planners are concerned, their parameters have nothing to do with DPOs – who they see as being no different to any other NGO (contrary to the CRPD), and instead, they say they are

bound by guidelines such as Design Manual for Urban Roads and Streets (DMURS) – which had some NDA, but no DPO input – and they even refer to “Access for All by the Irish Wheelchair Association, which is a service provider – i.e., absolutely not a DPO (as well as having nothing to do with visual impairment).

The point here is that, under the current system, local authority planners can currently pick and choose whatever accessibility features they themselves happen to like, where the Human Rights model would legally bind them to properly engaging with DPOs, and to being held to account for disablist planning decisions.

In 2013, the NDA published a disability-proofing template for planning, and it intends revising this. But I would suggest that such a revision would be a total waste of time, since it is, being the NDA, only advisory, and not based in Human Rights law – i.e., not binding. In other words, as if it hasn't already been obvious, the NDA is not a DPO and nor can it ever try to replicate a DPO; but it should itself be, as a public body, prioritising the views and opinions of DPOs in everything it does.

6. Conclusion.

While VVI absolutely agrees with the authoritative assertions that “the Disability Act undermines disability rights and must be updated,” this, by itself, does not even approach the magnitude of the shift Ireland needs to make, as per its obligations under the CRPD.

In short, the best motivations and intentions in the world are no substitute for the incorporating of the CRPD's Human Rights model into Irish law, as Ireland has agreed to do with the ratification of the CRPD, in 2018. Taking alternative routes will inevitably just lead us around in circles not fit for purpose – as all approaches taken to date have shown.

In the meantime, while the State remains oblivious to its obligations to DPOs and the incorporation of the CRPD into Irish law, tremendous damage continues to be done on a wholesale and daily basis. This damage will be very costly to repair, and such remedies will be too late for many or most.

As an immediate, interim, measure, at least, the Oireachtas has nothing whatsoever to lose, and lots of potential gains and long-term savings etc., if TDs and Senators a). reach out to DPOs on massive issues, such as those relating to the National Development Plan; or B). at the very least, to make sure that the views and opinions of DPOs are prioritised in the disability-proofing of legislation, regulations, and policies etc.