

I would like to thank the Chairperson and the Joint Committee on Disability Matters for the invitation to attend the Seanad Chamber, to discuss my role in self-advocacy under UNCRPD.

I have had significant input in a personal capacity as well as through the Public Participation Network (PPN) secretariat at County, national level, as well successive national civic Forums and various European entities.

I received a Global award for Social Impact at the UNESCO HQ in Paris in March of this year as well as other accolades.

I wish to outline, how my human rights have been supported;

Areas such as travel, some housing supports in addition to a number of avenues to channel ones advocacy through are welcomed.

However the fact that one has had to go outside of the State on three separate occasions, to reinforce primary Human rights, speaks volumes about our values and the associated impacts on citizens!

In addition to lived experiences, the need for these was reaffirmed following feedback after media participation, these include;

- Firstly, representation to the European commission and parliament was made in March of 2021, a year after representation for Government formation, to reinforce the **civil rights** of the Disability sector. This was confirmed in a letter by the EUROPEAN COMMISSION SECRETARIAT-GENERAL, on Citizens, Equality, Democracy & Rule of Law on the 30th of April 2021. See attached.

As outlined in the letter by the European commission “It aims to enforce the civil rights of the several millions of persons with disabilities in Europe and abroad.”

- Secondly, representation to the office of the Director of the World Health Organisation (WHO) **to ensure that policy is adequately aligned, robust and holistic in nature!** This focused on social Inclusion, the Disability sector, mental well being and childhood alienation.

On return from a TASC meeting at the Buswells hotel, on the 7th of October of 2021, in which seven European countries were represented, It was confirmed by an authentic source that members of the Judiciary were due to receive training on mental health the following day!

- Thirdly representation to Sara Minkara, who is the United States, special advisor on International Disability rights, led to media coverage on behalf of Government confirming “**Disability rights are Human Rights**” two months later in September 2023.

I wish to focus on each of the following areas;

1. Health care including mental health.

The revelations by the RTEs Health correspondent in March of 2022, showed;

“Last year, Hospital mistake claims rose above 105K, including almost 50,000 relating to clinical care.” By any standard, these figures are exorbitant.

[Hospital mistake claims rose above 105,000 last year \(rte.ie\)](https://www.rte.ie/health/2022/03/22/hospital-mistake-claims-rose-above-105000-last-year/)

Time lines for high end medication, needs to be reviewed. **Having to wait close to a decade after such is authorised by the European commission, is not acceptable!**

There has not been the required urgency with the chronic disease management program (CDM) as only four conditions were listed by last summer!

There are clear variations between the approach of public and private practitioners in the area of mental health care, with private practice adopting a much more holistic approach.

Much of this culture was dealt with by the advisory team to the State in 2006, during the formation of see.change.ie, (Ireland's organisation dedicated to ending mental health stigma) with an emphasis on emotional well being.

However some of the primary institutions of the State have not adhered to such advice, respected medical verification, or shown the required regard for how people may be impacted on numerous fronts, including with chronic pain!

2. Social Inclusion

There needs to be a significant transformation here on multiple fronts:

- There has not been the appropriate alignment between the State, the local authorities and related stakeholders to activate funding with the appropriate transparency through the likes of the Wheel and Leader funding. There needs to be significant incentivisation of sectors to facilitate the activation of funding as securing a LEAD ENTITY is a prerequisite.

3. Legal and Court services

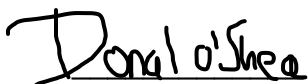
- Civic society led on the appointment of a Supreme Court judge by the minister for Justice, to review the civil legal services in May of 2022, as there were clear variations between public and private practice, these are recurring themes which have undermined human rights!
- Provisions have now been made for vulnerability and for domestic cases to be concluded within thirty months. Forty three NGOs had called for this through FLAC. This also frees up significant time through the courts.
- Civic society led on the reform of the criminal Justice strategy, the focus centred on social inclusion, equality and minority groups and the minister for Justice announced radical reforms to family law six weeks later on the 30th of September 2020.

In conclusion, there have been very clear failings, with a culture which is too frequently dysfunctional and has shown little regard for the impact of Disability.

In undermining the Disability sector, the State has undermined our Democracy!

In doing so, it has desecrated the memories of so many who paid the ultimate price during the formation of our State and the principles upon which it was founded.

Serious consideration must now be given to having an International delegation go through each of these areas to ensure that they are adequately robust and authentic in nature, to respect and advance Human rights.



Donal O' Shea

3rd of April 2024