

Family Support in Context of Disability: an Undue Burden?



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Outline



1. Setting the scene.
2. The role of macro systems and structures.
3. The utility of a rights-based framework.
4. What experiences of family support in the context of disability tells us about current state and implementation of rights.
5. Moving forward: connecting family support and rights discourse.

Introducing my co- presenter, Robyn



'Families' – the focus

- Families that include a child/ren or young person(s) with a disability
- Families that include an adult(s) with a disability
- Families where a parent(s) has a disability



A spectrum of 'caring'

The Context



1,109,557 people in Ireland (22% of the population), indicated they had a disability compared to 2016 (**643,131**) (**Census 2022**).



Over 500,000 people in Ireland are family carers (Family Carers Ireland 2022).



Ireland ratified the UN Convention on the Rights of the Child (CRC) in 1992 and the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2018.



The Role of Macro Systems and Structures in Supporting or Hindering Families in the Context of Disability

From State to Family Responsibility



- Global shift towards deinstitutionalisation and community supports has shifted the burden of responsibility onto families in order to reduce the burden (and cost) on the state.
- Systems and institutions not designed BY or FOR people with disabilities and their families. Policies and services have tended to be based on non-disabled or ableist assumptions of what a 'normal' and 'good' citizen looks like.



Lack of Adequate Supports and Services

- Studies show lack of adequate supports for children with disabilities and their families (OCO 2023, 2021).
- Fragmented or ineffective service provision for adults with disabilities and families (.g. Brennan et al 2023, Daly et al 2015, Marsack-Topolewski and Graves, 2020).
- Disempowerment of families and silencing of the individual with the disability (e.g. Courtin et al 2014, Stefánsdóttir et al 2022).
- Reliance on informal, ad hoc supports and networks.

The Additional Costs of Disability & Caring

- Extra costs of achieving same standard of living as children, adults and families without disabilities.
- 2021 estimate to be between €8,700 - €12,300 a year in Ireland. Taking account recent high levels of inflation, this has likely increased to a range of €10,379 – €14,673 (Indecon 2024).
- May include disability specific goods such as home adaptations or specialised care services, or higher levels of spending on more 'regular' goods and services (electricity and heating).





The Value of a Rights-Based Framework

The Importance of Rights

- Children and adults with disabilities are rights-holders under UN Convention on Rights of Child (CRC) & UN Convention on Rights of Persons with Disabilities (CRPD).
- The State, and those employed by the State as primary duty-bearer.
- ‘Rights play a key role in making visible that which has been suppressed’ (Freeman, 2007).
- Explicit recognition of children and adults with disabilities as rights-holders is critical since it disrupts the mainstream narrative of as burdensome and in need of protection or cure (Byrne and McNamee, forthcoming).



Rights and Family Support

- ‘the family is... entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities...’ (**Preamble to CRPD**)
- ‘States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.’ (Article 23 CRPD)
- ‘States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families,... and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.’ (**Article 28 CRPD**)

Informing Decision Making Processes

- ‘In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, **States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities**, through their representative organizations’ (Article 4.3 CRPD)
- ‘States Parties shall ensure that children with disabilities have **the right to express their views freely on all matters affecting them**, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.’ (Article 7.3 CRPD)



“Human rights claims express not merely aspirations, suggestions, requests, or laudable ideas, but rights-based demands for change.”

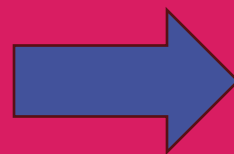
Donnelly (2003, p.12)



**Making Rights
Connections: What
can we learn about
the state of rights
around family
support and
disability?**

1.The CRPD: A Critical Entitlement Framework

- ‘The real value of the Convention therefore will be revealed in how government, human rights organisations, services and organisations of and for people with disabilities internalise their values, principles and rules’ (Quinn 2009: 245).



To what extent are the values and principles of the CRPD and CRC manifest in services and supports , and what are the barriers to the realisation of these rights across services and supports...?

2. Families with Disabled Members Experience Discrimination

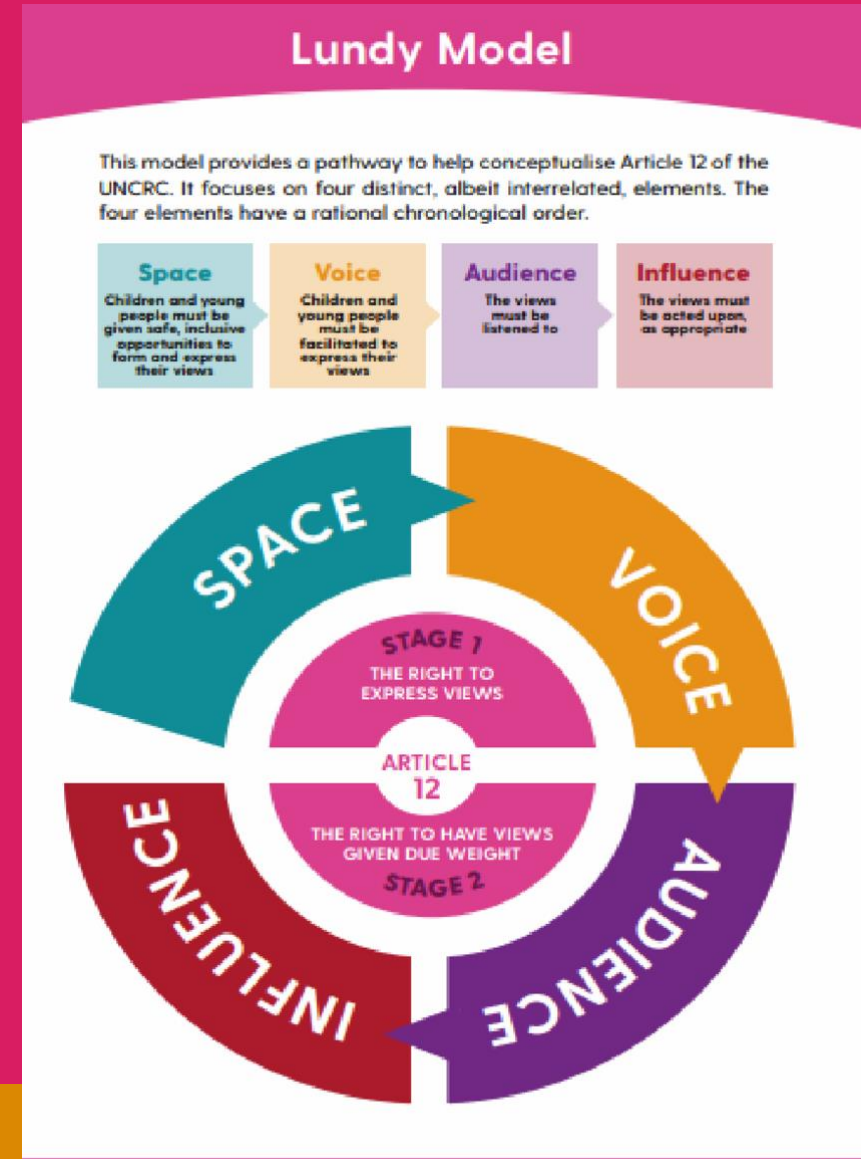
- Families experience complex forms of discrimination, that is, institutional and systemic discrimination, both directly and indirectly.
- They also experience intersectional discrimination – which arises from the particular intersection disability with other identity categories – e.g. gender, age, socioeconomic status, ethnicity etc.
- The protection of human dignity , respect, and equality are central to the interpretation of the CRPD.

3. Undue Burden and Responsibility on Families

- Burden – ‘a heavy load, that is difficult to carry’ (Oxford Dictionary).
- Narrative that this is due to the individual family member and the nature of their disability. Reflects medicalised/deficit-based discourse.
- In human rights terms, the primary obligation remains on the state to implement rights – rights as entitlements, not a gift or privilege.
- Many examples of families taking on the role of duty-bearer rather than rights-holders.

4. Co-Production and Voice

- Outlined by both Art 12 CRC, and Art 4.3/Art 7.3 CRPD
- Requires States to take positive action to involve children and adults with disabilities in the development of policies and services and in ‘all matters affecting them’.
- Voice = not always verbal.
- Dearth of evidence of children/adults with disabilities and family members being meaningfully asked for their views on family support



Key Takeaways



Families that include children and/or adults with disabilities are experiencing significant challenges.



This is reflection of a general failure to effectively implement the rights of children and adults with disabilities, and **a lack of understanding** on the nuances of rights.



PWD and their families must be empowered as rights-holders, including the right to express their views and for these to be acted upon.

Moving Forward

- 1** Applying rights-based framework, shifting support from language of need to one of (human) rights.
- 2** Returning the responsibility for rights to where it belongs, and as affirmed by human rights law – to duty-bearers.
- 3** Voice – supporting children and adults with disabilities, and family members to express their views on policies and provisions in a sustained manner.
- 4** Policymakers, practitioners and academics all have a critical ongoing role to play as advocates and allies, and in facilitating access to rights for PWD and families.

Thank you

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