



Submission by the Disability Federation of Ireland and the Centre for Disability Law and Policy (CDLP) at the National University of Ireland to the 25th Session of the UPR Working Group April – May 2016

The Disability Federation of Ireland (DFI) works for the interests and the expectations of people with disabilities to be fully included in Irish society. It is an umbrella body, comprising organisations that represent and support people with disabilities and disabling conditions. There are over 120 organisations as affiliates or associates of DFI who have been consulted in the drafting of this submission.

The Centre for Disability Law and Policy (CDLP) at the National University of Ireland Galway was formally established in 2008. The Centre's work is dedicated to producing research that informs national and international disability law reform, guided by the principles of the United Nations Conventions on the Rights of Persons with Disabilities (CRPD). The Centre's Director, Professor Gerard Quinn, led the delegation of Rehabilitation International during the negotiations of the CRPD in New York.

1. Assisted Decision-Making (Capacity) Legislation

The Assisted Decision-Making (Capacity) Legislation has not been passed. This legislation is central not only to the lives of people with intellectual and neurological disabilities, mental health conditions, and older people with specific conditions, but also to their family members, friends, carers, and ultimately to all Irish citizens.

The current formal (ward of court) system and informal restrictions on decision making denies many people with disabilities in Ireland their right to decide on where they live, their relationships, their education and their health related choices.¹

Enacting this long overdue legislation is essential in realising the commitment to people with disabilities, made in the Programme for Government 2011 - 2016², where it was stated that this would be developed 'in line with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)'. The current Assisted Decision-Making (Capacity Bill) 2013 does not fully accord with the right to legal capacity as set out in Article 12 of the UN CRPD.

2. Ratification of the UN CRPD

The government must promptly ratify the Convention and deal with the necessary legislative reforms following ratification.

3. Impact of Austerity Measures

Families in Ireland where the head of the household was not at work due to illness or disability had the lowest average annual disposable income in 2013.

People with disabilities have been recognised as one of the marginalised groups who have been disproportionately impacted by austerity measures in areas such as social welfare³, housing, health, and education⁴. The Committee of the ICESCR also noted there has been no human rights-based approach in assessing the impact of austerity measures before or during their implementation.

4. Activation and Access to the Labour Market

People with disabilities are not on the Live Register and therefore are excluded from mainstream activation measures which would support their entry / re-entry into the labour market.⁵

¹ Expert reference group on Disability Policy *Report on Disability* 2010

² Department of the Taoiseach (2011) Programme for Government 2011 – 2016.

http://www.taoiseach.gov.ie/eng/Work_Of_The_Department/Programme_for_Government/

³ Disability Allowance, Blind Pension, Invalidity Pension, and Carer's Allowance cut by an average of 8% from 2009. Respite Care Grant cut by 19% in 2013, with no restoration yet. Expenditure on Exceptional Needs payments reduced from €64.9 million in 2010 to €19.2 million in 2014. This represents a reduction of over 70%.

⁴ Committee of the International Covenant on Economic Social and Cultural Rights Concluding Observations on the Third Periodic Report from Ireland, June 2015.

⁵ People with disabilities who are on disability / illness payments are unable to access programmes including the Youth Guarantee, Momentum, Gateway and Community Employment.

Specialist supports should be made available to support people with disabilities access mainstream programmes.

Mainstream employment services and policies, e.g. Intreo, National Action Plan for Jobs do not cater for / include people with disabilities who are seeking work.

5. Social Protection

Problems exist with eligibility and assessment procedures for disability / illness payments that have resulted in a high number of refusals for the Disability Allowance⁶, followed by appeals for this payment.⁷ Barriers have also been experienced with the application for Domiciliary Care Allowance where the assessment process has not given due weight to the medical evidence supplied by the applicant and their multidisciplinary team.⁸

6. Education

Research in Ireland in 2014 has indicated that children with disabilities are more likely to be placed in special education settings when socio-economic stresses are present.⁹

The Government must publish a plan for the implementation of the EPSEN Act 2004, as promised in the Programme for Government 2011 in collaboration with the Health Service Executive (HSE), Department of Education and Skills, the Department of Children and Youth Affairs / Tusla, to ensure alignment with the Outcomes Framework of the Progressing Disability Services for Children and Young People aged 0 – 18 years, and the ‘Better Outcomes, Better Futures’.

Children with disabilities are children first and have the right to the experience of pre-school¹⁰ equal to that of their peers. It is essential that a formalised structure at county level is provided to ensure that the HSE’s Children’s Services, relevant local disability organisations and local child care providers can plan for the integration of children with disabilities into the free pre-school year scheme.

7. Housing

Inadequate housing in the community remains a significant barrier to community living, not only for people with disabilities moving out of congregated settings, but

⁶ The disability allowance is a weekly allowance paid to people with a disability who are aged between 16 and 65 years.

⁷ Submission to the Joint Committee on Education and Social Protection on Medical Eligibility Criteria for Illness and Disability Related Payments. DFI, 24th April, 2015.

⁸ Cousins, M. (2014) Decisions and appeals in Irish social welfare law: recent case law. Available at: http://works.bepress.com/mel_cousins/73

⁹ McCoy, S., Banks, J., Frawley, D., Watson, D., Shevlin, M. and Smyth, F. (2014). Understanding Special Class Provision in Ireland: Findings from a National Survey of Schools, Dublin/Trim: ESRI/NCSE.

¹⁰ The government introduced a free pre-school year in January 2010.

also for people with disabilities who are already living in inappropriate situations in the community¹¹.

Delays in moving people out of congregated settings, including the growing number of younger people with disabilities inappropriately placed in nursing homes, is unacceptable. Those inappropriately placed also include a number of Deaf people who communicate through Irish Sign Language and are placed in services, including congregated settings, with no access to communication.

There has also been growing evidence of abuse reported in some residential centres, as well as criticisms of 'outdated models of care, negative culture towards residents, and a failure to recognise and protect vulnerable residents'.¹²

8. Health

Some people with acute medical conditions, or lifelong conditions including intellectual disabilities, lost their medical card as an outcome of a review which took place between 2012 and May 2014.¹³ The medical card is a key cost of disability measure for people with disabilities to cover the costs associated with their condition- including general medical services, therapies, transport, and the expense of medical aids and appliances. Removing this support compromises people's capacity to meet other basic costs of living.

There is also a large unmet need for services as demonstrated by growing waiting lists. This is unacceptable¹⁴.

A properly resourced primary and community care infrastructure is required. The current configuration of health and social care services within the Health Service Executive does not adequately support community living for people with disabilities.

Current legislative provisions in health (Disability Act) have resulted in assessment of need and service statement processes which are ineffective, overly diagnostic in

¹¹ For example, in inaccessible housing. Funding for the State's Housing Adaptation Grant Scheme was cut by 56% between 2010 and 2014. The Housing Adaptation Grant Scheme is the backbone of community support for people with disabilities and although there was a recent increase 10% to this Scheme in 2015, it remains far removed from previous levels and, indeed, even further from requisite provision. Accessible social housing, such as it is, may also be located a significant distance from vital community supports such as transport.

¹² Letter from Health Information and Quality Authority (HIQA) to Health Service Executive (HSE), 10 July 2015.

¹³ "In 2011 the HSE centralised the administration of the scheme and in 2012 commenced a review of all card holders. By the end of 2013, the HSE had reviewed almost 1 million card holders and the proposal is that the entire medical card population will have been subject to review by the end of 2014. In 2014 and arising from a huge negative reaction by the public, the Government stalled the review of those medical cards that were allocated on a discretionary basis." Houses of the Oireachtas (2014) Public Accounts Committee (PAC) Report on the Review of Medical Card Eligibility, October 2014.

¹⁴ 21,821 people remained on waiting lists for speech and language assessments and interventions (April, 2015). More than 15,300 people were waiting for assessment by an occupational therapist, with 2,409 children waiting for over a year. 28,749 people were waiting for a physiotherapy assessment in April 2015. April 2015, Figures provided through a Parliamentary Question to Roisin Shortall TD. (PQ Ref. No. 18511/15). There is a growing waiting list for Personal Assistant services (207) and home help services (296). (Health Research Board (2014) Annual Report of the National Physical and Sensory Disability Database Committee 2013. In addition, those who currently receive this service report an insufficient number of hours that do not come anywhere close to what is required for independent living.

approach, and not conducive to people with disabilities accessing health services and related supports.¹⁵

9. Access to Justice

Two recent reports highlight the need to reform the laws of evidence and procedure to ensure that people with disabilities can give evidence and testify on an equal basis with others. Both reports indicated that there were significant barriers for people with disabilities in accessing justice from the police investigation stage through the post-trial phase.¹⁶

10. Crimes against People with Disabilities

In the past year there have been two disturbing reports detailing abuse of people with disabilities in residential facilities.¹⁷ In addition to these institutional abuses there have been several high profile cases of attacks against people with intellectual disabilities.¹⁸ These attacks and a recent report¹⁹ highlight the need for comprehensive hate crime legislation in Ireland.

11. Transport

Availability of accessible, affordable transport is a priority.

Key statutory supports, the Mobility Allowance and the Motorised Transport Grant that provided people with disabilities a payment to support their transport needs were abolished in February 2013.²⁰

¹⁵ Centre for Disability Law and Policy, NUI Galway Review of the Operation of the Disability Act 2005, Submission (2010) Section 6

¹⁶ Jennifer Kline and Dr. Eilín Flynn, *Access to Justice for Children with Cognitive Disabilities-Ireland Country Report*, Centre for Disability Law and Policy and Mental Disability Advocacy Centre, (April 2015) 17. Available at <http://www.nuigalway.ie/cdlp/projects/access_to_justice.html>. (Last accessed 19 June 2015); Shane Kilcommins et. al., *An International Review of Legal Provisions and Supports for People with Disabilities as Victims of Crimes*, Irish Council for Civil Liberties (December 2013). Available at <<http://www.iccl.ie/news/2014/01/30/new-report-highlights-protection-gaps-for-crime-victims-with-disabilities.html>> (last accessed 18 August 2015).

¹⁷ Carl O'Brien, 'Residents restrained 770 times at Meath care home, inspectors find,' *The Irish Times* (11 December 2014). Available at <<http://www.irishtimes.com/news/social-affairs/residents-restrained-770-times-at-meath-care-home-inspectors-find-1.2034433>> (last accessed 19 June 2015); Carl O'Brien, 'The Irish Times (18 December 2014). Available at <<http://www.irishtimes.com/news/social-affairs/new-allegations-of-mistreatment-at-co-tipperary-disability-centre-1.2043084>> (last accessed 19 June 2015); 'Shocking Prime Time doc shows elderly, fragile women being hit, kicked and dragged across the floor,' *TheJournal.ie* (9 December 2014). Available at <<http://www.thejournal.ie/aras-attracta-home-abuse-rte-1822665-Dec2014/>> (last accessed 19 June 2015).

¹⁸ Elaine Keogh, 'Man with learning disability attacked in Dublin park,' *The Irish Times* (17 April 2015). Available at <<http://www.irishtimes.com/news/crime-and-law/man-with-learning-disability-attacked-in-dublin-park-1.2179426>> (last accessed 18 August 2015). 'Cork teens force autistic boy to expose himself and eat twigs,' *TheJournal.ie* (31 March 2015). Available at <<http://www.thejournal.ie/cork-down-syndrome-boy-2023328-Mar2015/>> (last accessed 18 August 2015).

¹⁹ Jennifer Schweppe et al., *A Life Free From Fear-Legislating for Hate Crime in Ireland: An NGO Perspective*, University of Limerick (April 2014). Available at <<http://www.ul.ie/news-centre/news/hate-crime-highlighted-as-major-concern-for-irish-ngos-in-recent-ul-report>> (last accessed 18 August 2015).

²⁰ In the case of the Mobility Allowance, the Ombudsman drew the attention of the Department of Health to the fact that the upper age limit was illegal in February 2009. Successive governments, however, failed to address the problem.

The Motorised Transport Grant and Mobility Allowance were effective cost of disability measures, however over two years later, there has yet to be any announcement on the new provisions being devised by this Government.

This has left those in receipt of these supports uncertain about the future and afraid to take up work for fear of losing their entitlements. Other individuals, who prior to the cuts would have been eligible, have had to absorb the extra mobility costs associated with their disability.

12. Lack of Disaggregated Information and Data

The lack of disaggregated information relating to economic, social, and cultural rights for people with disabilities has been criticised. For example, the ICESCR has highlighted this lack of data in relation to unemployment statistics, and thus the difficulties in determining the actual extent of challenges posed to people with disabilities in progression / return to employment.²¹ Lack of data is also evidenced in relation to the Department of Environment, Community, and Local Government's social housing allocations in urban centres, which does not require data collection about disability-specific housing allocations.²²

13. Recommendations

1. Enact legal capacity legislation that respects Article 12 of the UN CRPD²³.
2. Ireland must ratify the UN CRPD and introduce a rights based approach to supports provision for people with disabilities.
3. Adopt a human rights based approach in assessing the impact of austerity measures on people with disabilities.
4. Blockages to mainstream activation measures should be removed, and targeted measures to support people with disabilities enter / re-enter the labour market should be provided.
5. The assessment process for disability / illness payments is problematic. More fundamental reform of the initial adjudication system is required.
6. Medical cards should be issued based on medical needs, not on income²⁴.
7. Publish a plan for the implementation of the EPSEN Act 2004.

²¹ Committee of the International Covenant on Economic Social and Cultural Rights Concluding Observations on the Third Periodic Report from Ireland, June 2015.

²² DFI, September, 2015. Letter to the Assistant Secretary for Housing, Housing Division, Department of the Environment, Community and Local Government.

²³ The enactment of this legislation should be accompanied by advocacy supports, accessible information and communication systems and opportunities for people to develop decision-making skills. Resource allocation to enact this legislation should focus on identifying and providing supports and should not be based on assessment of capacity, as is called for by the UNCRPD committee. General Comment no 1 (on Article 12, CRPD) 2014 paragraph 25 (i) The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.

²⁴ Inequalities exist in access to health care, for example, with free GP (General Practitioner) care available for children aged under six, while eligibility for a medical card for families with older children with disabilities is dependent on a means test.

8. Overhaul and revise the Disability Act provision for assessment of need and service identification / allocation for children and persons with disabilities.
9. Ensure robust transparent systems of governance and management are in place to introduce individualised resource allocation for the provision of disability supports and services to replace block grant system.
10. A review of the Housing Adaptation Scheme should be undertaken, as well as arrangements for adaptations for social housing. The exclusions, and long delays are causing serious hardship.
11. Comprehensively resource community living for people with disabilities, including provision for the extra costs of disability, people have to endure.
12. Provide replacements for the Mobility allowance and Motorised Transport Grant, including the availability of affordable and accessible transport.
13. Make the reality of living with a disability visible in how statistics are compiled.
14. Introduce legislation to officially recognise Irish Sign Language.
15. Ensure accountability in relation to those involved in perpetrating abuse on people with disabilities in residential services.
16. Introduce robust Hate Crime legislation as well as investing in the expansion of civil legal aid.