

An Comhchoiste um Nithe a Bhaineann le Míchumas

Maoiniú Míchumais a Ailíniú le Coinbhinsiún na Náisiún Aontaithe ar Chearta Daoine faoi Mhíchumas: Aighneacht Réamh-Bhuiséid i gcomhair Bhuiséad 2025

Meitheamh 2024

Joint Committee on Disability Matters

Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities Budget 2025 Pre-Budget Submission

June 2024

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Related information

Publications

All publications for this committee are available on the Oireachtas website

Committee videos

Footage of Committee proceedings can be found on the Committee videos page

Contact details

The contact details for the Committee can be found on the Committee page

Terms of reference

Read the terms of reference for the Committee

Committee Membership

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Michael Moynihan TD, Fianna Fáil

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Senator Erin McGreehan, Fianna Fáil

Senator Fiona O'Loughlin, Fianna Fáil

Senator Mary Seery Kearney, Fine Gael

Cathaoirleach's Foreword

The Committee continue to focus on key funding initiatives for delivery under Budget 2025 that will drive strategic change, reform, and enable meaningful implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The Committee believe that transitioning to a needs-led and rights-based disability services as required by the UNCRPD must include an All of Government response with a key focus on mainstreaming early intervention and responding to unmet need to develop care pathways across health, education, employment, and community that work for people with disabilities. The lack of coordination of inclusion across sectors, ensures that persons with disabilities right to live independently in the community is not realised.

The development of funding distribution in line with the UNCRPD is critical. Funding redistribution must be undertaken in tandem with strengthening the link between expenditure and activity across services and service providers, to help improve monitoring and in turn value for money in disability services. The supporting steps towards this can be taken by developing UNCRPD compliant Equality Budgeting.

The forthcoming budgetary choices will be an indicator of the State's commitment to the UNCRPD and the fulfilment of its human rights obligations for persons with disabilities. An urgent All of Government approach is critical to enable individuals with disabilities live the life they want.

Michael Moynihan T.D.

Michael llognihan

Cathaoirleach to the Committee on Disability Matters

Executive Summary

The Joint Committee on Disability Matters recommend:

- A holistic approach to funding disability service providers is required which supports pay parity, the development of universally accessible facilities, and appropriate training to support a rights-based approach across all **Disability** Services.
- The development, funding, and resourcing of a model of early intervention for Children's Disability Services (0-5yrs) which is mainstreamed across health and education services to reduce regression and deliver improved quality of life outcomes.
- A new needs-based, grant-aided vehicular adaptation scheme to replace the
 Disabled Drivers and Disabled Passengers Scheme which has outdated
 criteria for primary medical certificates is required as a matter of priority, and
 in the interim, the criteria for the Primary Medical Cert should be revised.
- Adoption of Universal Design as a key strategy, as set out by the UNCRPD, for the design and development of products, services, ICT, and buildings (including housing) that are accessible and usable to the widest range of users possible regardless of age, size, disability, or ability.
- A framework to transition the provision of Personal Assistance Services to a
 statutory basis which must be resourced, and adequate funding allocated to
 ensure national delivery of these services and related administrative
 supports as an essential part of ensuring disabled people can exercise their
 right to independent living in line with their own will and preferences.
- Provision to target the transition between primary, secondary, and further **education** as well as appropriate financing of specialist supports for persons with disabilities.
- Ratification of the Optional Protocol.

Introduction

The Committee publishes its fourth pre-budget submission with the aim of informing the budget process for 2025 in a way that is beneficial for the State. The Committee has published this report based on its own knowledge, information received and its engagement with stakeholders. A copy of this report will issue to the Department of Children, Equality, Disability, Integration and Youth, Department of Education, Department of Finance, Department of Health, Department of Higher and Further Education, Research, Innovation and Science, Department of Housing, Local Government and Heritage, Department of Public Expenditure, NDP Delivery and Reform, and the Department of Social Protection.

The Committee believe that the Department of Children, Equality, Disability, Integration and Youth have a significant opportunity to transition disability services to a social approach where equity/equality, person centred/individualised approach and the UNCRPD can form the basis of delivery. The Committee look forward to the publication of the successor whole of government strategy to the National Disability Inclusion Strategy.

The Committee recommend that the Department of Health, the Health Service Executive (HSE), and the Department of Children, Equality, Disability, Integration and Youth work together to develop a model of funding distribution in line with the UNCRPD and strengthen the link between expenditure and activity across services and service providers, to help improve monitoring and in turn value for money and accountability of person-centred services.

The Committee believe that transitioning to a needs-led and rights-based disability services as required by the UNCRPD must include an All of Government response with a key focus on mainstreaming early intervention and responding to unmet need to develop care pathways across health, education, employment, and community that work for people with disabilities.

Optional Protocol and general provisions

- Budget 2025 should consider ring fenced funding to ensure efficient operation of access to the complaints process and scrutiny of the UN Committee in expectation of ratification of the Optional Protocol to the UNCRPD. (Set out in the <u>Programme for Government Our Shared Future</u>).
- 2. The Committee believe that there is an urgent need to create equity in the system and recommend redistribution of funding in Budget 2025 in line with the UNCRPD to deliver better outcomes for people with disabilities, and maximise people's capacity, independence, and quality of life.
- 3. People with disabilities experience the most disadvantage yet they are not protected from economic shocks and are disadvantaged further. They are excluded from economic models, even though they can contribute to society. The Committee recommend mainstreaming disability across all economic recovery models, plans and strategies.
- 4. Equality Budgeting must be further developed to deliver CRPD compliant budgeting. The Committee recommend that all projects or programmes that are allocated Government funding should be compelled to use the principles of Universal Design. All departments must update their budgetary key metrics accordingly and in line with CRPD compliant budgeting.
- 5. There is need for the forthcoming budget to commit to funding a national policy and framework on the recognition and consultation of people with disabilities and their Disabled Persons Organisations (DPOs) as highlighted at

¹ <u>Disability inclusive or CRPD compliant budgeting? – Center for Inclusive Policy (inclusive-policy.org)</u>

the Committee's public meeting, 8 April 2024; <u>here</u>. This should include funding for

- (a) additional direct consultation with DPOs to align with UNCRPD consultative requirements and to ensure they have the financial capacity to engage with multiple public bodies and processes.
- (b) self-representative groups of people with disabilities who wish to become DPOs to enable them to build capacity and progress their organisational goals.
- (c) specific resourcing of self-representative groups or organisations of disabled children and young people to ensure that legislation and service provision regarding children is aligned with the UNCRPD. Creation of fora to enable children and young people with disabilities, parents of children with disabilities and appropriate civil society stakeholders are consulted on all matters which affect them.
- 6. It is important that development of Disability Consultative Forums is in line with Article 4 (3) of the UNCRPD so that people with disabilities have a mechanism to move from consultation to co-creation of policy.

Equality and non-discrimination

- 7. Budget 2025 must consider funding to support the expansion of Irish Human Rights and Equality Commission's (IHREC) role to ensure the prominence of the Public Sector Equality and Human Rights Duty (the Duty) in the UNCRPD Implementation Plan and to strengthen the governance role of IHREC in monitoring the compliance of departments and public bodies.
- 8. Specific funding should be made available to self-representative organisations of disabled women and girls, of disabled members of the LGBTQIA+ community, and migrant and ethnic minority people with disabilities so that they may monitor and

report on the effectiveness of equality legislation and national strategies impacting these groups, who are at heightened risk of violence, unemployment, poverty, and social exclusion.

- 9. The Committee's recent report 'Towards Harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities' sets out the importance of ensuring Disability Impact Assessments (DIAs) are undertaken on all draft bills to support mainstreaming of disability within all sectors, in line with the Convention and the Duty. Funding will be required to support the publishing of these assessments as part of public consultations to ensure that people with disabilities are aware of the impact on their rights.
- 10. Allocate sufficient funding to ensure that all provisions of the Irish Sign Language Act 2017 may be enacted and implemented in a timely manner.

Accessibility

Recommendations

All of Government National Plan for Accessibility

11. The Committee recommended in their report 'Ensuring Independent Living and the United Nations Convention on the Rights of Persons with Disabilities', the development for an All of Government National Plan for Accessibility and a monitoring framework to ensure full inclusion, in consultation with people with disabilities and their DPOs. Budget 2025 must ensure funding for All of Government National Plan for Accessibility for people with disabilities in line with the UNCRPD and agree annual targets across all the sectors.

Built Environment

12. The UNCRPD sets out Universal Design as a key strategy for the design and development of products, services, ICT, and buildings that are accessible and usable to the widest range of users possible regardless of age, size, disability, or

ability. Budget 2025 should ensure all investment is aligned with Universal Design principals.

13. Budget 2025 must ensure Universal Design principles are incorporated in housing delivery and provide targeted funding to ensure that all new social and affordable housing is future proofed for people with disabilities as well as delivering innovative supported housing options.

Transport

- 14. The Committee continue to call for a new needs-based, grant-aided vehicular adaptation scheme. It also indicates that a replacement for the Disabled Drivers and Disabled Passengers Scheme is required as a matter of priority and in the interim, the criteria for the Primary Medical Cert are revised.
- 15. Budget 2025 must develop additional measures to deal with cost that people with disabilities experience accessing transport as well as ensuring that all investment in transport infrastructure supports accessibility and inclusion.
- 16. There are challenges in accessing funding for school transport including barriers to drawing down the grant from the Department of Education. Budget 2025 needs to address the additional measures required to support children who must travel to school outside their local area until such times as places become available for them.

Independent and adequate standard of living and social protection

Recommendations

Universal Design, planning, and housing delivery

- 17. Specific funding for people with disabilities must be allocated under Budget 2025 to expand the Housing Adaptation Grant (the Grant) to enable;
 - (a) independent and accessible living for individuals who choose to live with their own family or opt for long-term placement with another family.
 - (b) individuals to access the Grant as an individual without the rest of the household income being included as part of the means test.
 - (c) expansion of the Grant to include adaptations for sensory accessibility and other disability-related structural accessibility needs not currently covered under the Grant.
 - (d) amendment of the Grant criteria so that the funds are paid on a phased basis to ensure the Grant is available to all those who need it, including those without access to savings or lines of credit to cover the cost of the required adaptation.
- 18. The funding allocation must include a requirement for Local Authorities to ensure that accessibility and Universal Design thinking underpin the built environment and information provision at all stages of the planning and development process and align with the UNCRPD. In addition, Budget 2025 must support the establishment or retrofitting of accessible emergency accommodation.
- 19. Long term planning and funding harmonisation between Department of Health and Department of Housing, Local Government and Heritage is required to support the move away from institutionalism and provide rights-based care to disabled people and the elderly to ensure long term sustainability of care.

Independent living

- 20. The Committee continue to recommend the elimination of placing people with disabilities in congregated settings.²
- 21. The Equality Budgeting objectives and performance indicators tracking the percentage of people with disabilities living in community-based residential placements need to be further developed to accurately track the decongregation process in line with Article 19.
- 22. The Committee recommended a right to independent living be established in domestic law in their report 'Ensuring Independent Living and the United Nations Convention on the Rights of Persons with Disabilities'. This will ensure that people with disabilities have a right to independent living as well as appropriate community inclusive accommodation and adequate supports. Additional funding must be allocated including:
 - a) For the development of a national plan for the realisation of this right including support for agencies to re-configure their services to support the right to independent living.
 - b) To ensure that the people who remain in congregated settings, and those individuals who have been moved to smaller congregated settings, are given a choice of where they want to live, in consultation with family and supporters.
 - c) To ensure that the HSE undertake a review of other residential settings for people with disabilities with multiple occupants. There is a need to develop appropriate pathways to ensure these individuals can access the same levels of community-based support and inclusion. In addition, a clear pathway for

² Article 19 – Living independently and being included in the community | United Nations Enable

- exiting such schemes is explained and made available to those who wish to exit.
- d) To support a framework to transition the provision of Personal Assistance Services (PAS) to a statutory basis, and adequate funding allocated to ensure delivery of these services and related administrative supports nationally as an essential part of ensuring disabled people can exercise their right independent living in line with their own will and preferences.
- 23. Funding must be allocated for people with disabilities still living in mental health settings, nursing homes, residential centres for persons with autism and other relevant multiple occupancy settings for their accommodation and support needs.

Disability related payments

- 24. The Committees Pre-Budget Submissions 2022, 2023 and 2024 recommended that a cost of disability payment is introduced to ensure the same standard of living for people with disabilities as non-disabled people and ensure alignment with Article 28 of the UNCRPD.³ This would ensure that the welfare support for people with disabilities would include the cost of disability.⁴
- 25. Funding should be provided for an exploratory report into the feasibility and impact of transitioning the Disability Allowance, Blind Pension and any other relevant payments from current means tested frameworks to a unified universal payment allocated based on qualifying criteria. The scope of this review should include a robust projected impact report on what effect removing means testing is likely to have on bringing levels of un/underemployment, poverty and social exclusion experienced by disabled people in Ireland into line with EU averages.

³ Article 28 – Adequate standard of living and social protection | United Nations Enable

⁴ Department of Social Protection, Cost of Disability report, pp. xvii. Available here; gov.ie - The Cost of Disability in Ireland - Research Report (www.gov.ie)

Medical cards

- 26. The Committee recommend an examination of the medical card means testing criteria as a significant majority of those diagnosed with chronic or long illnesses will continue to work and contribute to the wider community. This review must consider the challenges caused by the interaction between primary and secondary social welfare supports.
- 27. Targeted funding must be allocated to support the cost of prosthetics and their replacement and maintenance needs to be considered as well as the need to introduce entitlement to medical cards on a mandatory basis for amputees.

Family Carers

28. The Committee's prebudget Submission 2022, 2023 and 2024 called for a review of relevant family carers payment to ensure that family carers are not placed at undue risk of consistent poverty. Budget 2025 must consider thresholds in line with individualised demand and need, particularly regarding the care of children.

Personal Assistance Service and Homecare

- 29. Budget 2025 must ensure funding to enable people with disabilities live independent lives by establishing a standardised national statutory PAS in keeping with Article 19 of the UNCRPD. In addition, funding should be allocated to consider whether the PAS pilot be extended to children.
- 30. The Committee are aware that there is a significant gap in demand versus supply regarding PAS. Lack of access to the service is a significant barrier to independent living, education, and employment for an individual but there is also a significant impact on the family. Budget 2025 must address these aspects and move from the PAS pilot to full rollout of the service.
- 31. Funding must be made available to ensure that the statutory entitlement to homecare can be urgently introduced, along with comprehensive regulation of the homecare sector.

Education and employment

- 32. Funding must be targeted to develop the transition for children with special educational needs between primary, secondary school and further education.
- 33. Home schooling must be funded to ensure access for children with disabilities where required.
- 34. Financing for Special Educational Needs (SEN) supports, and staff must also be ring-fenced from the general school budget.
- 35. Provision be made in Budget 2025 to ensure all students and employees have access to appropriate assistive technology (such as AAC devices) as required. Ensure the appropriate funding is in place for the maintenance of such supports.
- 36. Funding the Department of Further and Higher Education, Research, Innovation and Science to expand its role as the model of rights-based service provision to enable transition between educational services, including part-time educational services.
- 37. Budget 2025 must consider support for people with disabilities who leave education and enter day services subject to the outcomes of the Day Service Policy Review. Consideration must be given to resources required to support better regulation of the day service sector.
- 38. The Reasonable Accommodation Fund must be sufficiently resourced. Access to the fund must be extended to those post-secondary educational institutions currently exempt on financial grounds, or that an equivalent fund be established, to ensure that disabled students can access all forms of post-primary education to an equal standard, and that their educational options are not limited by considerations of accessibility, including for education-related work placements.

39. Funding is required to identify and remove barriers which will allow increased participation and career progression for employees, self-employed and entrepreneurs with disabilities across public and private sectors.

Health and life

- 40. Irish Government Economic and Evaluation Service (IGEES) highlight in their 'Spending Review 2021 Social Care for People with Disabilities: Trends in Expenditure and Delivery of Services' that more than 80% (over €1.3bn) of the expenditure in disability services in 2018 was on residential and day care, and that opportunities exist to strengthen the link between expenditure and activity across services and service providers, to help improve monitoring and in turn costeffectiveness and value for money. The Committee is of the view that funding strategy and governance in disability services needs to be strengthened in this way.
- 41. The Committee recommend that specific funding is directed to ensure the equal accessibility of gender-related healthcare services, such as Breast and Cervical Screening and sexual and reproductive healthcare services, to women and girls with disabilities. Universal programmes like Sláintecare need to align with the UNCRPD and deliver rights-based outcomes.
- 42. The <u>Action Plan for Disability Services</u> covering 2024-26 and the <u>Progressing Disability Services (PDS) roadmap</u> must support collaboration across departments and agencies to tackle unmet need and elimination of wait lists.
- 43. A holistic approach to funding disability service providers is required which supports pay parity, the development of universally accessible facilities, and appropriate training to ensure a rights-based approach across all disability services.

⁵ IGEES, 'Spending Review 2021 Social Care for People with Disabilities: Trends in Expenditure and Delivery of Services'. Available here; 204304 8705b33b-6972-4df3-b558-9cbdefa0b037 (1).pdf

44. Additional funding to be allocated to HSE Disability Services and Childrens Disability Network Teams (CDNTs) for dedicated administrative support, so that some of the clinicians and other professional practitioners' time currently spent on administration may be redirected to reducing waiting times and providing direct clinical support to service users.

45. The Attention Deficit Hyperactivity Disorder (ADHD) in Adults National Clinical Programme has had a range of positive impacts in those Community Health Organisation (CHO) areas where it is currently being delivered. This Committee recommends funding is continued to complete its roll-out, and further recommends that additional funding is allocated to create and deliver a similar public pathway to autism assessment and support for adults in Ireland.

Children's Disability Services

The Committee remain concerned about the significant negative impact on children with disabilities through the lack of early intervention and because of the disruption and regression caused by inconsistent implementation across health and education services of the PDS Model.

The Committee believe that there is urgent need in Budget 2025 to ensure full resourcing of the PDS Model to meet the demographic demand and unmet need as highlighted in the '<u>Disability Capacity Review'</u> along with additional innovative measures to reform the HSEs recruitment model.

Recommendations

46. The PDS Model must continue to be fully funded and dedicated year-on-year investment in the 91 CDNTs must be allocated to achieve fully resourced CDNTs to support early intervention between years 0-5.

Palliative care/nursing homes

47. There is a need for Budget 2025 to immediately strengthen end-of-life care and nursing support for children with complex disabilities and increase funding in this area so that families who need this service can access it.

Mental health

48. Additional funding must be targeted in Budget 2025 to ensure full capacity of teams as outlined under 'the Mental Health Services for Adults with Intellectual Disabilities: National Model of Service' and targeting unmet need for these services.

Freedom from exploitation, violence, and abuse and autonomy and integrity

Recommendations

Gender-based support

- 49. There is a need to allocate additional ring-fenced funding to gender-based support services to make them accessible. The Committee further recommend that specific funding is made available to DPOs, with particular focus on DPOs of women and girls, and women's groups within existing DPOs, to produce guidance and policy relating to the contributory and protective factors for gender-based violence against people with disabilities.
- 50. The Committee have highlighted that the lack of a regulatory framework for adult safeguarding is concerning and is a significant gap in protecting the rights of disabled people. The Committee's recent report on 'Ensuring rights-based adult safeguarding in Ireland' makes many recommendations which will require consideration for significant funding in Budget 2025 and beyond.

Participation in public and political life

Recommendations

51. The Committee recommend that funding is allocated to support a scheme which will assist disabled candidates to stand for election at all levels of public office.

Statistics, national implementation, and international cooperation

The Central Statistics Office (CSO) carried out the twenty-sixth census on the night of Sunday, 03 April 2022. Over 1.1 million people or 22 percent of the population reported having experienced at least one long-lasting condition or difficulty. The findings show that 407,342 people or 8% of the population experienced long-lasting conditions and difficulties to a great extent, while a further 702,215 people or 14% of the population did so to some extent.

- 52. Budget 2025 must ensure that funding is targeted for ensuring that CSO data is aligned with the UNCRPD particularly Article 31⁶ to enable improved data collection and disaggregation and funding a data disaggregation action plan.
- 53. There is need for funding for improved data collection and disaggregation, to enable parameters used to capture this information to be reviewed in conjunction with DPOs to ensure adequacy and completeness.
- 54. Further funding allocation is needed to improve data collection and disaggregation on gender, sexual, racial, and ethnic identities to ensure adequate full and robust data collection which allows meaningful action to be taken in complying with General Comment 7 of the UNCRPD.⁷

⁶ <u>Article 31 – Statistics and data collection | United Nations Enable</u>

⁷ General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention.

APPENDIX

UNCRPD Categorisation

Categorisation	Articles
General provisions of the Convention	Articles 1–4
Equality and non-discrimination	Article 5
Accessibility	Articles 9, 21, 30
Independent and adequate standard of living and social protection	Articles 19, 20, 26, 28
Employment	Article 27
Education	Articles 7, 24
Health and life	Articles 10, 23, 25

Freedom from exploitation, violence, and abuse	Articles 6, 16
Autonomy and integrity	Articles 12, 14, 15, 17
Participation in political and public life	Article 29
Statistics, national implementation, and international cooperation	Article 31, 32, 33