

An Comhchoiste um Nithe a Bhaineann le Míchumas

Maoiniú ar Mhíchumas a chomhfhogasú le Coinbhinsiún na Náisiún Aontaithe um Chearta Daoine faoi Mhíchumas Buiséad 2024 Aighneacht Réamh-Bhuiséid

Iúil 2023

Joint Committee on Disability Matters

Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities Budget 2024 Pre-Budget Submission



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Senator Fiona O'Loughlin, Fianna Fáil



Senator Mary Seery Kearney, Fine Gael

FOREWORD

The Committee to continue to focus on key funding initiatives for delivery under Budget 2024 that will drive strategic change and reform and enable meaningful implementation of the UNCRPD and deliver rights for people with disabilities.

The Committee calls on the Government to provide funding under Budget 2024 to provide service and support developments for people with disabilities, which have been identified as being urgently needed under the Disability Capacity Review and for the urgent publication of the Disability Services Action Plan.

The lack of responsibility and coordination of inclusion across sectors, the dependence on long term residential care, an absence of community, mental health, and rehabilitative supports along with segregation from employment, ensures that adults with disabilities right to live independently in the community is not realised.

Requiring urgent attention under Budget 2024 is Children's Disability Services and developing, funding, and resourcing a model of early intervention, where intervention happens early in a child's life (0-5yrs) and is mainstreamed across health and education services to reduce regression and deliver improved quality of life outcomes.

The development of a model 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 first steps towards this can be taken by developing UNCRPD compliant Equality Budgeting. An urgent All of Government approach is critical to enable individuals to live the life they want.

Michael Moynihan

Michael blognihan

Cathaoirleach to the Joint Committee on Disability Matters

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INTRODUCTION

The Joint Committee on Disability Matters publishes its third pre-budget submission with the aim of informing the Budget process 2024 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 Public Expenditure and Reform, Department of Finance, Department of Children, Equality, Disability, Integration and Youth, Department of Health, Department of Education, Department of Higher and Further Education, Research, Innovation and Science and Department of Housing, Local Government and Heritage.

The Committee believe that the completion of the transfer of functions from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth, will facilitate 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 HSE and 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

RECOMMENDATIONS

- 1. In expectation of ratification of the Optional Protocol to the UNCRPD ensure funding in Budget 2024 to ensure efficient operation of access to the complaints process and scrutiny of the UN Committee.
- 2. The Committee believe that there is an urgent need to create equity in the system and recommend urgent redistribution of funding in Budget 2024 in line with the UNCRPD to deliver better outcomes for people with disabilities, and maximise people's capacity, independence, and quality of life.
- 3. Equality Budgeting must be developed to deliver CRPD compliant budgeting. The Committee recommends 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.
- 4. 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 DPOs. This should include funding for
- (a) additional direct consultation with DPOs to bring it in line with UNCRPD consultative requirements and to ensure they have the financial capacity to engage with multiple public bodies and processes.
- (b) direct core institutional funding and resourcing should be made available to self-representative groups of people with disabilities who wish to become DPOs and DPO's to enable them to build capacity and progress their organisational goals as well as achieve the governance and other standards required.
- (c) specific resourcing of self-representative groups or organisations of disabled children and young people to ensure that legislation and service provision

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

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.

5. Development of the Disability Consultative Forums in line with Article 4 (3) of the UNCRPD so that people with disabilities have a meaningful consultative mechanism to participate in strategic change.

Equality and non-discrimination

RECOMMENDATION

- 6.. Budget 2024 must include 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 in the UNCRPD Implementation Plan and to strengthen the governance role of IHREC in monitoring the compliance of Departments and Public Bodies.
- 7. Specific funding should be made available to self-representative organisations of disabled women and girls, of disabled members of the LGBTQIA+ community, and of 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.
- 8. Allocate sufficient funding and resourcing to ensure that all provisions of the Irish Sign Language Act 2017 maybe enacted and implemented in a timely manner.

Accessibility

RECOMMENDATIONS

All of Government National Plan for Accessibility

9. The Committee recommended in their recent report 'Ensuring independent living and the UNCRPD', the development for an All of Government National Plan for Accessibility and monitoring framework to ensure full inclusion, in consultation with people with disabilities and their DPOs and agree annual targets across all the

sectors. Budget 2024 must ensure funding for All of Government National Plan for Accessibility for people with disabilities in line with the UNCRPD.

Built environment

- 10. 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. The Expenditure Report for Budget 2023 does not highlight how Universal Design will be used as a key strategy and there is a need in Budget 2024 to ensure all investment is aligned with Universal Design principals.
- 11. Appropriate funding for Housing Adaptation Grants, alongside a review of current retrospective 'draw-down' processes for these grants. Consider adjusting the administration of the grant so that qualifying applicants may be granted funds against reasonable professional estimates for the adaptation work required upon successful completion of their application, rather than the current system whereby expenses are only recoupable after the fact, to remove unnecessary barriers to housing adaptation for those who qualify.

Transport

- 12. The Committee continue to call for a comprehensive needs-led Transport Support Scheme (to replace the Mobility Allowance and Motorised Transport Grant) as a matter of priority and to reinstate the Primary Medical Cert (PMC) process.
- 13. Budget 2024 must develop additional measures to deal with additional cost that people with disabilities experience accessing transport as well as ensuring that all investment in transport infrastructure supports accessibility and inclusion.
- 14. There are challenges in accessing funding for School Transport including barriers to drawing down the grant from the Department of Education. Budget 2024 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

- 15. Additional funding for people with disabilities must be allocated under Budget 2024 to expand the Housing Adaptation 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 to ensure non-discrimination in the grant's administration
- 16. Budget 2024 must ensure Universal Design is being incorporated in housing delivery and provide targeted funding to ensure that all new social housing, and affordable housing is future proofed for people with disabilities as well as delivering innovative supported housing options.
- 17. 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 process and align with the UNCRPD. In addition, Budget 2024 must support the establishment or retrofitting of accessible emergency accommodation.

Independent living

18. The Committee continue to recommend the elimination of placing people with disabilities in congregated settings.²

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

- 19. The Equality Budgeting objectives and performance indicators regarding decongregation in the Revised Estimates for the Department of Health are welcomed. The indicator tracking the percentage of people with disabilities living in community-based residential placements needs to be developed to accurately track decongregation process in line with Article 19, and as highlighted above.
- 20. The Committee recommended a right to independent living be established in domestic law in their recent report 'Ensuring independent living and the UNCRPD'. 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 for this right including funding
 - 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, including 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) The HSE must undertake a review of other residential settings for people with disabilities with multiple occupants as recommended by the Working Group under the Time to Move on from Congregated Settings report (2011). There is a need to develop appropriate pathways to ensure these individuals can access the same levels of community-based support and inclusion and that a clear pathway for exiting such schemes is explained and made available to those who wish to exit.
 - d) A framework to transition the provision of Personal Assistance Services to a statutory basis must be funded and resourced, 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.
- 21. Funding must be allocated for a programme for the number of 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 as recommended in Time to Move on from Congregated Settings Report (2011).

Disability allowance

- 22. In its Pre-Budget Submission 2022 and 2023, the Committee 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
- 23. The Committee recommend that an independent a report is prepared into the feasibility and impact of transferring Disability Allowance, and other State administered disability-related payments and supports, from a Means Tested framework to a Universal Payment for those who qualify within the next 12 months, to inform the drafting of Budget 2025. This report should be prepared in conjunction with the Department of Social Protection as well as IHREC and other appropriate stakeholders with a role to play in monitoring Ireland's CRPD implementation.
- 24. Introduce benchmarking of disability related payments and supports as recommended by the 2021 ERSI report on 'Poverty, Income Inequality and Living standards in Ireland'.
- 25. Ensure that all disability-related payments, such as the Blind Pension, Invalidity Pension have been brought into alignment with the Disability Allowance in all aspects, including in how they interact with other schemes and grants, and that this alignment is ensured into the future to guard against differential treatment by impairment type.

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. The exclusion from the Medical Card Scheme and resultant cost is causing a great deal of stress and medical poverty. 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.

Artists Basic Income

28. Budget 2024 needs to consider how issues regarding the interaction between the new pilot payment and existing payments will be addressed in conjunction with other relevant Departments.

Family Carers

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

Homecare and personal assistance

- 30. The Committee are aware that there is a significant gap in demand versus supply regarding Personal Assistance Service (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 2024 must address these aspects of PAS development in Ireland.
- 31. Budget 2024 must ensure funding to enable people with disabilities live independent lives and that current pathways to accessing Personal Assistance in Ireland be expanded, with a view to establishing an appropriately funded and

standardised national statutory Personal Assistance system in keeping with Article 19 of the UNCRPD. In addition, funding allocated to consider whether the PAS pilot be extended to children.

32. 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

RECOMMENDATIONS

- 33. Funding must be targeted to develop the transition for children with special educational needs between primary and secondary school.
- 34. Home schooling must be funded to ensure access for children with disabilities where required.
- 35. Financing for SEN supports, and staff must also be ring-fenced from the general school budget.
- 36. Department of Education must develop a plan for the July Summer Provision
 This plan must include additional measures to use any unspent budget allocation for
 additional programmes for children who cannot access the July Summer provision.
- 37. Provision be made in Budget 2024 to ensure all students 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.
- 38. Budget 2024 must consider support for people with disabilities who leave education and enter day services. Consideration of the necessary resources is required to support better regulation of the day service sector.
- 39. 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.

- 40. The Reasonable Accommodation Fund is sufficiently resourced so that all complete applications may be granted and that it is available to all people who need support in access. 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.
- 41. An upwards adjustment in the income disregard for those people with disabilities engaged in employment, uncoupling of the medical card and disability related supports from income restrictions and a relaxation on the time limit placed on people with disabilities as regards engagement with employment support services and sufficient budgeting for PAS.
- 42. Funding is required for Master Programme's for the following disciplines; phycology, occupational therapy, speech and language therapy and dietetics to begin to resource Disability Services and improve the quality and quantity of the services.

Health and life

RECOMMENDATIONS

43. 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 cost-effectiveness and value for money.⁵ The Committee are of the view that funding strategy and governance in disability services needs to be strengthened in this way.

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. 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.
- 45. Publish the three-year Action Plan for Disability Services covering 2022-25 and Progressing Disability Services (PDS) roadmap to deliver meaningful systems change in consultation with DPOs and people with disabilities. Both plans must include provision for collaboration across Departments and agencies to tackle unmet need and elimination of wait lists (outlined above).
- 46. Funding recommendations in the Disability Capacity Review report, and the Cost of Disability report commissioned in 2019 by Government need to be implemented on a departmental basis
- 47. Additional funding to be allocated to HSE Disability Services and CDNTs for 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.

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 Progressing Disability Services (PDS) Model.

The Committee believe that there is urgent need in Budget 2023 to ensure full resourcing of the PDS model to meet the demographic demand and unmet need as highlighted in the Disability Capacity Review along with additional innovative measures to reform the HSEs recruitment model.

RECOMMENDATIONS

48. The PDS model must continue to be fully funded and dedicated year-on-year investment in the 91 Children Disability Network Teams (CDNT's) must be allocated to achieve fully resourced CDNT's to support early intervention between years 0-5.

Palliative care/nursing homes

49. There is a need for Budget 2024 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

50. Additional funding must be targeted in Budget 2024 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 for these services.

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

RECOMMENDATIONS

Gender-based support

51. There is a need to allocate 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.

Participation in public and political life

RECOMMENDATIONS

- 52. Budget 2024 must incorporate measures under the Electoral Reform Commission, Department of Housing, Local Government and Heritage for the production and dissemination of accessible independent information regarding candidates for elections to public office, referenda, and other matters for the public vote as needed, including information on how to vote and amend information on the Register of Electors.
- 53. 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, modelled on the UK's Access to Elected Office Fund.

Statistics, national implementation, and international cooperation

RECOMMENDATIONS

- 54. Budget 2024 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.
- 55. There is need for further 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.
- 56. Further funding allocation is needed to improve data collection and disaggregation on gender, sexual, racial, and ethnic identities to ensure adequate full

⁶ Article 31 – Statistics and data collection | United Nations Enable

and robust data collection which allows meaningful action to be taken in complying with General Comment 7 of the UNCRPD.⁷

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



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