

Submission to the Public Consultation on the Review of the Disability Act 2005

October 2026

Introduction

Care Alliance Ireland welcomes the opportunity to contribute to the public consultation to inform the long-overdue review of the Disability Act 2005 and its framing within the National Human Rights Strategy for Disabled People 2025–2030¹ and Ireland’s obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Care Alliance Ireland is a national charity working to improve the recognition and support of family carers in Ireland. Our network includes over 100 member organisations working directly with family carers across a wide range of care situations, including organisations supporting disabled people and their families, such as Inclusion Ireland, St Michael’s House, Irish Wheelchair Association, Special Olympics Ireland, and the Jack & Jill Foundation, in addition to condition-specific organisations (for example, The Alzheimer Society of Ireland). We note that many of our member organisations may have made their own submissions reflecting their specific areas of expertise, and this submission is provided as a complementary, sector-wide perspective focused on the experience of family carers.

Care Alliance Ireland’s mission is to enhance the wellbeing of family carers so that they are better able to care for their loved ones. It is from this perspective

¹ Department of Children, Disability and Equality, *National Human Rights Strategy for Disabled People 2025–2030* (3 Sept 2025): <https://www.gov.ie/en/department-of-children-disability-and-equality/campaigns/the-national-human-rights-strategy-for-disabled-people-2025-2030/>

the carer’s own wellbeing, alongside their role in supporting the person they care for that we make the observations below.

We support the principle of *“nothing about us, without us”* as it applies to this review: that those most directly affected by the Act must be central to its reform². That principle is rooted in, and remains primarily about, the voice of disabled people themselves and their representative organisations, whose lived experience and expertise must lead this process. We make this submission on the understanding that the perspective of family carers is properly supplementary to that primary voice, informed by carers’ own direct experience of how assessment, service delivery and accessibility function in practice, but never substituting for the disabled person’s own participation or the input of Disabled Persons’ Organisations.

Summary of Key Recommendations

For the sake of brevity, we have summarised our key recommendations by Part of the Act. Each is set out in more detail in the sections that follow.

Part 1

- **Align the definition of disability with the UNCRPD**, and add a statement of guiding principles affirming an ecological model of disability.
- **Amend Section 5** so that funding aligns with the UNCRPD principle of progressive realisation, with any reductions justified and reported annually to the Oireachtas.

² University of Galway (2026), The Disability Act 2005 at 21: Reflecting, Reforming, Reimagining: https://research.universityofgalway.ie/ws/portalfiles/portal/28948135/The_Disability_Act_2005_at_21_Reflecting_Reforming_Reimagining_Online_dps.pdf

Part 2

- **Meet the existing six-month Assessment of Need timeframe**, with interim targets and public reporting, and reimburse families who pay privately when statutory timelines are missed.
- **Amend Section 11(7)(e)** to establish minimum service guarantees, so that assessed needs translate into services.
- **Consider a Carer’s Needs Assessment**, where appropriate, linked to the Assessment of Need process.
- **Support family carers acting on behalf of a family member** in complaints and appeals, and shift the burden of enforcement onto public bodies.

Part 3

- **Require consultation with family carers** and their representative organisations on sectoral plans and accessibility codes of practice, and set clearer minimum thresholds for what is “practicable”.

Overarching

- **Recognise family carers in the Act** as partners in care, with regard to their knowledge and expertise, alongside, and *never* in place of, the disabled person’s own voice. Refer to the National Carers’ Strategy (2012) and the 2026 IHREC review of the Act’s compliance with the UNCRPD (*Overarching; Part 1*).
- **Make respite a required consideration** in service statements and sectoral plans, delivered as community-based and in-home supports in line with the disabled person’s will and preferences (*Overarching; Part 2*).
- **Introduce a statutory duty to collect and publish data** on unmet need among disabled people and family carers.

Detailed Submission

T +353 1 874 7776
E info@carealliance.ie
W www.carealliance.ie

 [@CareAllianceIrl](https://twitter.com/CareAllianceIrl)
 [Care Alliance Ireland](https://www.linkedin.com/company/care-alliance-ireland/)

A Coleraine House
Coleraine Street
Dublin 7, Ireland
D07 E8XF

Registered Company No
461315
Charity Registration No
20048303
CHY No 14644



We have structured our response using the Department’s template, adapted for clarity. Our comments focus primarily on the areas of the Act with the greatest bearing on family carers, in particular *Part 1 (Preliminary and General)*, *Part 2 (Assessment of Need, Service Statements and Redress)*, and *Part 3 (Access to Buildings and Services and Sectoral Plans)*, together with several overarching recommendations relevant across the Act as a whole.

We believe that, on the whole, the Disability Act 2005 is no longer fit for purpose. The ambition of the Act, when enacted over 20 years ago, was commendable. However, time and society move on, as has our understanding of disability, and how disability can be experienced across society. Disability cannot, and should not, be examined and addressed in isolation from intersecting identities such as gender, sexuality, nationality, culture, and religion. Our proposals for change outlined below, and any changes to this existing Act (or any replacement Act which is developed through ongoing consultation with disabled people and their families) must consider this intersectionality. The UNCRPD recognises this diversity within disability.

Our main concern is that while the Act is rightly centred on the rights and needs of the disabled person, it does not formally recognise the role, contribution or needs of family carers. This is despite the fact that family carers are, in practice, central to how assessment, service delivery and support actually function for many disabled people and their families. We believe this review is an opportunity to address that gap.

Our recommendations are grounded in the experience of family carers and our member organisations of how the Act operates in practice, and in Ireland’s obligations under the UNCRPD. The Convention’s Preamble recognises 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”³, and under Article 19 (living independently and being included in the community), the CRPD Committee maintains that where care is provided by family members, the State must extend support to them as well. We draw on the recent *Review of the compliance of the Disability Act 2005 with the UN Convention on the Rights of Persons with Disabilities*, prepared for the Irish Human Rights and Equality Commission⁴ (the ‘IHREC review’), which found that this obligation is not adequately captured by the current Act. While the review rightly centres the rights of disabled people, its findings on independent living, enforcement and the design of services bear directly on families, and we refer to them throughout this submission.*

Part 1: Preliminary and General

What is working

- Part 1 provides a necessary foundation for the Act, setting out definitions and enabling provisions for funding measures.

What is not working

- The Act’s definition of disability (Section 2) attributes disability solely to the individual’s impairment, without reference to the environmental or attitudinal barriers that contribute to it. This reflects a largely medical model. Care Alliance Ireland favours an ecological model, which combines elements of both the medical and social models to take a holistic view of disability: never in isolation from society, and with due regard to the impact

³ UN Convention on the Rights of Persons with Disabilities (2006), Preamble para (x) and Article 28(2)(c): <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

⁴ Review of the compliance of the Disability Act 2005 with the UN Convention on the Rights of Persons with Disabilities, Centre for Disability Law and Policy, University of Galway (2026): <https://www.ihrec.ie/publications/review-of-the-compliance-of-the-disability-act-2005-with-the-un-convention-on-the-rights-of-persons-with-disabilities>



impairments can have on a person’s daily life⁵. This approach better reflects the experience of people with significant support needs, and of the families who support them. We also favour the UNCRPD definition of disability which acknowledges that the definition of disability is an evolving concept, which *‘results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’*. We suggest that the definition of disability in any piece of legislation utilise this definition in order to be fully aligned with the UNCRPD.

- The term “family carer” does not appear anywhere in the Act, despite being used and defined in Government policy such as the National Carers’ Strategy (2012)⁶. The University of Galway’s national survey for its 2026 report on the Act found that family members and carers were the second-largest group of respondents (54 of 156)⁷, yet the Act itself does not recognise them as a distinct stakeholder group with their own needs.
- Neither Part 1 nor the wider Act makes any reference to working in partnership with families, nor does it recognise them as holders of expertise and knowledge in their own right. This is inconsistent with the National

⁵ Care Alliance Ireland (2017), Discussion Paper 6: Disability and Family Carer Policy – Challenges and Responses: <https://www.carealliance.ie/userfiles/file/Discussion%20Paper%206%20Disability%20and%20Family%20Carer%20Policy.pdf>

⁶ Department of Health, *National Carers’ Strategy* (2012), which defines a “family carer” as someone “who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty.” <https://assets.gov.ie/static/documents/national-carers-strategy.pdf>

⁷ University of Galway (2026), The Disability Act 2005 at 21: Reflecting, Reforming, Reimagining: https://research.universityofgalway.ie/ws/portalfiles/portal/28948135/The_Disability_Act_2005_at_21_Reflecting_Reforming_Reimagining_Online_dps.pdf

Carers’ Strategy (2012)⁸, which recognises carers as partners in care and explicitly invites people with disabilities, their families and carers to participate as stakeholders with insight and expertise to offer. In addition, the UNCRPD (Article 23) recognises the right of disabled people to respect for home and family life, and this includes ensuring that, where appropriate, family of origin and of choice are treated with equal respect as key parts of disabled people’s lives.

- The funding provision at Section 5 requires the Minister to allocate funding but leaves the amount entirely to the Minister’s discretion (“such amount as he or she considers appropriate”), and confirms the Act creates no obligation to fund beyond what is already allocated. In practice, this allows resourcing to fall well short of what is required to give real effect to the rights the Act sets out. This is in direct conflict with Article 4(2) of the UNCRPD⁹, which requires the State to take steps “to the maximum of its available resources” towards progressively realising these rights. Progressive realisation is a legal standard rather than a discretion; it requires a visible trajectory of improvement and bars unjustified backsliding. Section 5 as it stands sets no floor, offers no way to test whether funding reflects the maximum available resources, and has no safeguards against cuts.

⁸ Department of Health, *National Carers’ Strategy* (2012): <https://www.gov.ie/en/publication/a1e44e-national-carers-strategy/>

⁹ UN Convention on the Rights of Persons with Disabilities, Article 4:
<https://social.desa.un.org/issues/disability/crpd/article-4-general-obligations>

Recommendations

- That the review align the Act’s definition of disability with the UNCRPD definition¹⁰, which recognises the interaction between impairment and barriers, to reduce inconsistency across Irish legislation and better reflect the range of needs and circumstances of disabled people.
- That the review consider how the Act, or its accompanying policy framework, could formally recognise family carers as partners in care whose role should be identified and supported, consistent with the National Carers’ Strategy (2012)¹¹ and with Article 19 of the UNCRPD, under which the State’s duty to support independent living extends to family members who provide care. Suggested wording: *"In performing functions under this Act, regard shall be had to the role of family carers as partners in the provision of care and support, and to their knowledge and expertise regarding the needs of the person they support."*
- That a statement of guiding principles be added to the Act¹², affirming an ecological model of disability that recognises both the impact of impairment and the barriers society creates, and recognising disabled people and their families as experts in their own needs and circumstances.

¹⁰ UN Convention on the Rights of Persons with Disabilities, Article 1: *"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."*

<https://social.desa.un.org/issues/disability/crpd/article-1-purpose>

¹¹ Department of Health, *National Carers’ Strategy* (2012): <https://www.gov.ie/en/publication/a1e44e-national-carers-strategy/>

¹² As recommended by the Ombudsman for Children’s Office, *Unmet Needs* (2020), Section 5 (Recommendations): https://www.oco.ie/app/uploads/2020/10/15438_OCO_Assessment_of_Need_Report_Interactive.pdf

- That Section 5 be amended to align with the progressive realisation principle under the UNCRPD (Article 4(2))¹³, not removing budgetary discretion over how resources are spent, but requiring that funding decisions reflect reasonable steps to the maximum of available resources, and that any reduction be justified and reported to the Oireachtas. Suggested wording: *"Any measure that reduces the level of funding or services provided under this Act shall be objectively justified by reference to the totality of resources available to the State, and the Minister shall report annually to the Oireachtas on progress towards realisation of rights under this Act."*

International Good Practice Examples

- Germany’s Federal Participation Act (Bundesteilhabegesetz, 2016)¹⁴ and its later corrective law, the Family Relief Act (Angehörigen-Entlastungsgesetz, 2019)¹⁵.
- Sweden’s Act concerning Support and Services for Persons with Certain Functional Impairments (LSS, 1993)^{16,17}.

Part 2: Assessment of Need, Service Statements and Redress

¹³ UN Convention on the Rights of Persons with Disabilities, Article 4:

<https://social.desa.un.org/issues/disability/crpd/article-4-general-obligations>

¹⁴ Library of Congress, *Germany: Act to Strengthen the Disabled’s Participation in Society Enters into Force* (Jan 2017):

<https://www.loc.gov/item/global-legal-monitor/2017-01-12/germany-act-to-strengthen-the-disableds-participation-in-society-enters-into-force/>

¹⁵ Germany’s Family Relief Act (Angehörigen-Entlastungsgesetz) (2019): <https://www.bmas.de/DE/Service/Gesetze-und-Gesetzesvorhaben/angehoerigen-entlastungsgesetz.html>

¹⁶ Ehliasson, K. and Markström, U. (2020) ‘Revealing the Ideas in the Swedish Social Services Act Regarding Support to Individuals with Disabilities’, *Scandinavian Journal of Disability Research*, 22(1), pp. 393–402. Available at: <https://doi.org/10.16993/sjdr.720>.

¹⁷ <https://www.regeringen.se/pressmeddelanden/2026/05/tydliga-och-hallbara-regler-for-personlig-assistans/>

What is working

- Part 2 establishes a clear statutory entitlement to an Assessment of Need (AoN) and, where needs are identified, to a service statement setting out how they will be met.

What is not working

- In practice, the three-month-to-commence, three-month-to-complete structure set out in the 2007 Regulations made under Section 21 of the Act¹⁸ is persistently not met, leaving families providing unsupported care in the interim, often at significant personal cost. The average duration of the AoN process is currently 27 months against the statutory six-month limit¹⁹. The IHREC review notes that, according to the CRPD Committee, supports provided under Article 19 must not be subject to waitlists²⁰.
- Service statements remain subject to the resource-constraint provision at Section 11(7)(e)²¹, which ties the content of a service statement to the Executive’s approved service plan for the year. This contrasts with Section

¹⁸ Disability (Assessment of Needs, Service Statements and Redress) Regulations 2007, S.I. No. 263 of 2007:

<https://www.irishstatutebook.ie/eli/2007/si/263/made/en/pdf>

¹⁹Oireachtas Library & Research Service (2026), Policy and Legislative Briefing Paper: General Scheme of the Disability (Amendment) Bill 2025, ‘Demand and waiting times for Assessment of Need’, pp. 13–14:

https://data.oireachtas.ie/ie/oireachtas/libraryResearch/2026/2026-05-29_general-scheme-of-the-disability-amendment-bill-2025_en.pdf

²⁰ Review of the compliance of the Disability Act 2005 with the UN Convention on the Rights of Persons with Disabilities, Centre for Disability Law and Policy, University of Galway (2026), Article 19 – Living independently and being included in the community(p.20): <https://www.ihrec.ie/publications/review-of-the-compliance-of-the-disability-act-2005-with-the-un-convention-on-the-rights-of-persons-with-disabilities>

²¹ Disability Act 2005, Section 11(7)(e): “in the case of a service to be provided by or on behalf of the Executive, the need to ensure that the provision of the service would not result in any expenditure in excess of the amount allocated to implement the approved service plan of the Executive for the relevant financial year [...]”

8(5)²², which requires the assessment itself to disregard cost or capacity to provide. In practice, this means an assessed need does not automatically translate into an actual guaranteed service. The IHREC review identifies this as a clear gap in compliance with Article 19, which requires the State to guarantee an enforceable legal right to support disabled persons to live independently in the community²³. The Ombudsman for Children has found that many parents, once their child’s needs are assessed, struggled to secure any or all of the services identified, and the Ombudsman’s 2020 report documents a case in which a child’s assessed need for therapy went unmet for five years²⁴.

- The complaint and appeal mechanisms under Sections 14–20 can be difficult for family carers to navigate, particularly where they are acting on behalf of a family member while also managing caring responsibilities.
- There is no equivalent statutory mechanism for identifying or assessing the needs of the family carer alongside the disabled person’s assessment, despite the carer’s needs and capacity being central to what support a family can sustain. This reflects the Act’s individual-centred approach, discussed under Part 1, and is again inconsistent with treating families as partners in care.

²² Disability Act 2005, Section 8(5): “An assessment under this section shall be carried out without regard to the cost of, or the capacity to provide, any service identified in the assessment as being appropriate to meet the needs of the applicant concerned.”

²³ Review of the compliance of the Disability Act 2005 with the UN Convention on the Rights of Persons with Disabilities, Centre for Disability Law and Policy, University of Galway (2026), Article 19 – Living independently and being included in the community(p.20): <https://www.ihrec.ie/publications/review-of-the-compliance-of-the-disability-act-2005-with-the-un-convention-on-the-rights-of-persons-with-disabilities>

²⁴ Unmet Needs: A report by the Ombudsman for Children’s Office on the challenges faced by children in Ireland who require an assessment of their needs (2020):

https://www.oco.ie/app/uploads/2020/10/15438_OCO_Assessmnet_of_Need_Report_Interactive.pdf

Recommendations

- That the HSE commit to meeting the existing statutory six-month timeframe for Assessment of Need, with clear interim targets and public reporting on progress. The immediate goal must be closing the gap between what the law already mandates (six months) and what is currently being delivered (~27 months).
- Building on Cara’s Fund²⁵, that a reimbursement mechanism be regularised for families who incur costs securing a private Assessment of Need or related services where the public system has failed to meet its statutory timeline, consistent with the existing Treatment Abroad Scheme, recognising that the cost of public-system delays currently falls on families, and that those without the means to pay privately are left waiting longest.
- That Section 11(7)(e) be amended to establish minimum service guarantees, bringing resource constraints into alignment with the UNCRPD principle of progressive realisation (see Part 1). Existing allocations should not act as an automatic limit; the State should be required to demonstrate that it is using the maximum available resources to meet assessed needs. Despite rising demand for assessment²⁶, all efforts must be made to align provision of services with the assessed needs of disabled people when identified in the AoN.

²⁵ See <https://tippfm.com/news/health/caras-fund-reaches-e50-million/> Accessed October 8th 2026.

²⁶ Oireachtas Library & Research Service (2026), Policy and Legislative Briefing Paper: General Scheme of the Disability (Amendment) Bill 2025, ‘Demand and waiting times for Assessment of Need’, pp. 13–14:
https://data.oireachtas.ie/ie/oireachtas/libraryResearch/2026/2026-05-29_general-scheme-of-the-disability-amendment-bill-2025_en.pdf



- That respite be explicitly provided for as a required consideration within service statements under Section 11, rather than being left to local discretion, in recognition of its role in sustaining family caregiving capacity. By respite, we mean community-based and in-home supports, such as in-home help, short breaks with a support family, or supported community and leisure activities, arranged in line with the disabled person’s own will and preferences. We share the concern raised in the IHREC review that services currently offered under service statements, including residential and respite care, may further isolation and segregation of disabled people, contrary to Article 19²⁷.
- That complaint and appeal procedures under Sections 14–20 include a specific provision for supporting family carers acting on behalf of another person. Such support may take the form of clearer guidance, accessible formats, or a named point of contact, recognising the practical burden already carried by the person raising the complaint. Crucially, we support the IHREC review’s call for enforcement and monitoring mechanisms that shift the burden away from individuals and families asserting their rights and onto public bodies’ duty to deliver them.
- That an element assessing the carer’s needs be introduced, linked to the AoN process under Part 2, so that the carer’s own support needs, and their expertise regarding the person they support, are identified and addressed alongside the disabled person’s assessment. This reflects the principle, established in the National Carers’ Strategy (2012), that carers are partners

²⁷ Review of the compliance of the Disability Act 2005 with the UN Convention on the Rights of Persons with Disabilities, Centre for Disability Law and Policy, University of Galway (2026), Article 19 – Living independently and being included in the community(p.20): <https://www.ihrec.ie/publications/review-of-the-compliance-of-the-disability-act-2005-with-the-un-convention-on-the-rights-of-persons-with-disabilities>

in care rather than incidental to it, and gives effect to Article 19 of the UNCRPD, under which the State must extend support to family members who provide care, including support to make housing modifications and access assistive devices and technologies²⁸. The carer’s assessment should therefore consider these practical supports, not only the carer’s personal wellbeing. A useful model that may be considered has already been piloted by the HSE, in the form of the Carer’s Needs Assessment within the interRAI Needs Assessment in older persons’ services²⁹.

- That the ongoing AoN reforms be assessed for their impact on family carers specifically (for example, on carers’ capacity, wellbeing and financial circumstances), not solely on the volume and speed of assessments completed for the disabled person, and that reform resolve the current bottleneck at the assessment stage through increased capacity rather than narrowing applicants’ rights.
- *Note: We understand that currently there are efforts being made to reform the AoN process through the Disability (Amendment) Bill 2025. We would like to impress upon policymakers that these reforms should not be seen as adequately addressing the identified difficulties with this process being experienced by disabled people and their families.*

International Good Practice Examples

²⁸ Review of the compliance of the Disability Act 2005 with the UN Convention on the Rights of Persons with Disabilities, Centre for Disability Law and Policy, University of Galway (2026), Article 19 – Living independently and being included in the community(p.20): <https://www.ihrec.ie/publications/review-of-the-compliance-of-the-disability-act-2005-with-the-un-convention-on-the-rights-of-persons-with-disabilities>

²⁹ O’Sullivan, L., McDermott Scales, L., Duffy, C., Vereker, N. and Dhondt, K. (2017), ‘Carers Needs Assessment Development – A Republic of Ireland led International Joint Working Project to Support Delivery of Integrated Care’, International Journal of Integrated Care, 17(5), A288 (Conference abstract): <http://dx.doi.org/10.5334/ijic.3601>

- Iceland’s Act on Services for Disabled People with Long-Term Support Needs (No. 38/2018)³⁰.
- England’s Care Act 2014³¹.
- The Carers (Scotland) Act 2016³².

Part 3: Access to Buildings and Services and Sectoral Plans

What is working

- Part 3 establishes an enforceable framework requiring public bodies to make buildings, services and information accessible, backed by a complaints mechanism (Section 38), independent inquiry officers, and recourse to the Ombudsman (Section 40).
- Section 38 already permits a complaint to be made on behalf of a disabled person by someone referred to in Section 9(2) (including a spouse, parent, relative or guardian), giving family carers a limited existing role in enforcement.

What is not working

- Where public services and information are not fully accessible, family carers frequently act as intermediaries or advocates for the disabled person, which adds to the practical burden of caring and can obscure the underlying accessibility gap.

³⁰ Review of the compliance of the Disability Act 2005 with the UN Convention on the Rights of Persons with Disabilities, Centre for Disability Law and Policy, University of Galway (2026), section on Disability Acts under Other Jurisdictions (Iceland) (p.43): <https://www.ihrec.ie/publications/review-of-the-compliance-of-the-disability-act-2005-with-the-un-convention-on-the-rights-of-persons-with-disabilities>

³¹ Care Act 2014, s.10: <https://www.legislation.gov.uk/ukpga/2014/23/section/10/enacted>

³² Carers (Scotland) Act 2016: <https://www.legislation.gov.uk/asp/2016/9/contents>

- The accessibility duties throughout Part 3 (Sections 25, 26, 27 and 29) are consistently qualified by “practicability” and cost. For example, accessibility of services supplied to a public body does not apply where it “would not be justified having regard to the cost.” As with the funding provision identified in Part 1, this leaves considerable discretion as to what is actually delivered, with no clear minimum threshold.
- Section 31(2) requires Ministers to consult “persons representative of persons with disabilities” before publishing a sectoral plan, with no equivalent naming of family carers or carer representative organisations, despite carers’ direct experience of where accessibility gaps place a burden on disabled people and their families.
- Family carers’ existing role under Section 38 is limited to raising complaints after an accessibility failure has occurred; there is no mechanism for carer input at the planning or standard-setting stage, where accessibility gaps could be identified and addressed proactively.

Recommendations

- That accessibility codes of practice under Part 3 explicitly consider the interaction between disabled people and their support networks, ensuring services are directly accessible to the person wherever possible, while also facilitating carer involvement where that is required or wanted.
- That Section 31(2) be amended to explicitly require consultation with family carers and carer representative organisations, alongside persons representative of persons with disabilities, in the preparation of sectoral

plans. Suggested wording: *"such persons representative of persons with disabilities and of their family carers/supporters as he or she considers appropriate."*

- That the review consider establishing clearer minimum thresholds for what constitutes "practicable" under Sections 25–29, to reduce the scope for the qualifier to be used as a basis for non-provision rather than a genuine constraint, consistent with the UNCRPD's requirement to use the maximum available resources for progressive realisation.
- That family carers be given a defined route for proactive input into accessibility standards and codes of practice (not only a reactive complaints role), recognising their first-hand knowledge of where accessibility failures place a burden on disabled people and their families.

Overarching Recommendations

In addition to the Part-specific comments above, we would ask the review to consider the following issues, which cut across the Act as a whole:

1. Statutory recognition of family carers as partners in care

- The reviewed Act should include an explicit statement recognising the role, contribution and rights of family carers, and their expertise regarding the needs of the person they support. This is consistent with the National Carers' Strategy (2012)³³ and with the whole-of-Government, cross-departmental approach set

³³ Department of Health, *National Carers' Strategy* (2012): <https://www.gov.ie/en/publication/a1e44e-national-carers-strategy/>

out in the National Human Rights Strategy for Disabled People 2025–2030³⁴, which the reviewed Act should actively support rather than sit apart from. It would also address the gap identified in the IHREC review, which finds that the State’s Article 19 obligation to support family members who provide care is not adequately captured by the current Act³⁵. In advocating statutory recognition of family carers, we do not seek to detract from the priority of keeping disabled people at the centre of the Act, or to encourage a paternalistic approach. The aim is to create space for carers to be recognised legislatively alongside disabled people, while understanding that there is a significant cohort of disabled people who do not require care from family or friends, but rather require the right support, in the right way, at the right time – and of their choosing – to live their lives independently. However, we must also recognise that there is a cohort of disabled people who do require this level of care, and whose preference it is to receive that from family members. Those family members deserve recognition as core partners in that care.

2. Respite

- Access to respite is consistently raised by our member network as one of the most significant unmet needs of family carers, with direct consequences for carer wellbeing and capacity for sustained caregiving. We recommend that respite be explicitly named as a required consideration wherever the Act provides for service statements or sectoral plans (see our comments on Part 2), rather than being left to local discretion. Consistent with Article 19, this should

³⁴ Department of Children, Disability and Equality, *National Human Rights Strategy for Disabled People 2025–2030* (3 Sept 2025): <https://www.gov.ie/en/department-of-children-disability-and-equality/campaigns/the-national-human-rights-strategy-for-disabled-people-2025-2030/>

³⁵ Review of the compliance of the Disability Act 2005 with the UN Convention on the Rights of Persons with Disabilities, Centre for Disability Law and Policy, University of Galway (2026), Article 19 – Living independently and being included in the community(p.20): <https://www.ihrec.ie/publications/review-of-the-compliance-of-the-disability-act-2005-with-the-un-convention-on-the-rights-of-persons-with-disabilities>

mean community-based and in-home supports that sustain family life and the disabled person’s inclusion in the community, designed around the disabled person’s own wishes.

3. Data and evidence

- We recommend that the reviewed Act include a statutory duty to collect and publish regular data on unmet need affecting both disabled people and their family carers, to support transparent monitoring of progress under the UNCRPD’s principle of progressive realisation, and to provide an evidence base for future resourcing decisions, including anticipating the additional demand created by Ireland’s ageing population, among both disabled people and older family carers themselves.

4. An ecological model orientation, applied consistently

- Several of the specific gaps identified above (Part 1’s impairment-based definition of disability; Part 2’s absence of a carer’s needs assessment; Part 3’s lack of carer consultation in sectoral planning) share a common root: an Act that views the disabled person in isolation from both the barriers they face and the people who may support them. We recommend the review adopt, as a guiding principle across all Parts, an ecological model of disability that recognises both the impact of impairment and the barriers society creates, treats disabled people and their families as experts in their own circumstances, and family carers as partners rather than incidental parties. This also supports a universal design approach, which benefits the whole population because disability and caregiving are not fixed categories – anyone may become disabled, and anyone may become a family carer, at any point in life.

Conclusion

Care Alliance Ireland welcomes this review as a genuine opportunity to modernise the Disability Act 2005 in line with the UNCRPD and the ambitions of the National Human Rights Strategy for Disabled People 2025–2030³⁶. Across Parts 1, 2 and 3, our concerns point to a consistent gap: the current Act is structured around the individual disabled person and does not formally recognise the role, contribution or expertise of family carers, who are, in practice, central to how assessment, service delivery and accessibility actually function for many disabled people and their families. This is in no way to suggest that family carers should become a focus of the Act; far from it. However, to erase the existence of family supports from the lives of disabled people across Ireland does a disservice to all.

Our recommendations are intended as practical, implementable steps, from statutory recognition of family carers as partners in care, to concrete provisions on carers’ needs assessments, respite, data and transparency, and an ecological approach to disability. These structural changes would strengthen the Act’s alignment with the UNCRPD’s principle of progressive realisation and with Article 19’s requirement that the State support families who provide care. We believe they are also needed to better support both disabled people and the family carers who care for them.

We would welcome the opportunity to discuss any of the points raised in this submission further, and would be glad to participate in targeted focus groups during Stage 2 of the consultation process.

³⁶ Department of Children, Disability and Equality, *National Human Rights Strategy for Disabled People 2025–2030* (3 Sept 2025): <https://www.gov.ie/en/department-of-children-disability-and-equality/campaigns/the-national-human-rights-strategy-for-disabled-people-2025-2030/>

Prepared by: Áine Evans

Submitted by:

Liam O’Sullivan

CEO

ndo@carealliance.ie

087 207 3265

Statement on the Use of Generative AI

In line with our commitment to transparency, Care Alliance Ireland discloses that Claude, a generative AI tool developed by Anthropic, was used to assist in preparing this submission, specifically for background research, content presentation and editing. AI was not used to generate the organisation’s policy positions, and no confidential or personal data was entered into the tool. All outputs were critically reviewed by a number of staff and all factual claims and references were independently verified. Responsibility for the final content rests entirely with Care Alliance Ireland.

T +353 1 874 7776
E info@carealliance.ie
W www.carealliance.ie



[@CareAllianceIrl](https://twitter.com/CareAllianceIrl)



[Care Alliance Ireland](https://www.linkedin.com/company/care-alliance-ireland/)

A Coleraine House
Coleraine Street
Dublin 7, Ireland
D07 E8XF

Registered Company No
461315
Charity Registration No
20048303
CHY No 14644

