



Pre-Budget Submission 2024

to Department of Health; Department of Education & Department of Children,
Equality, Disability, Integration and Youth

Care Across the Life Course

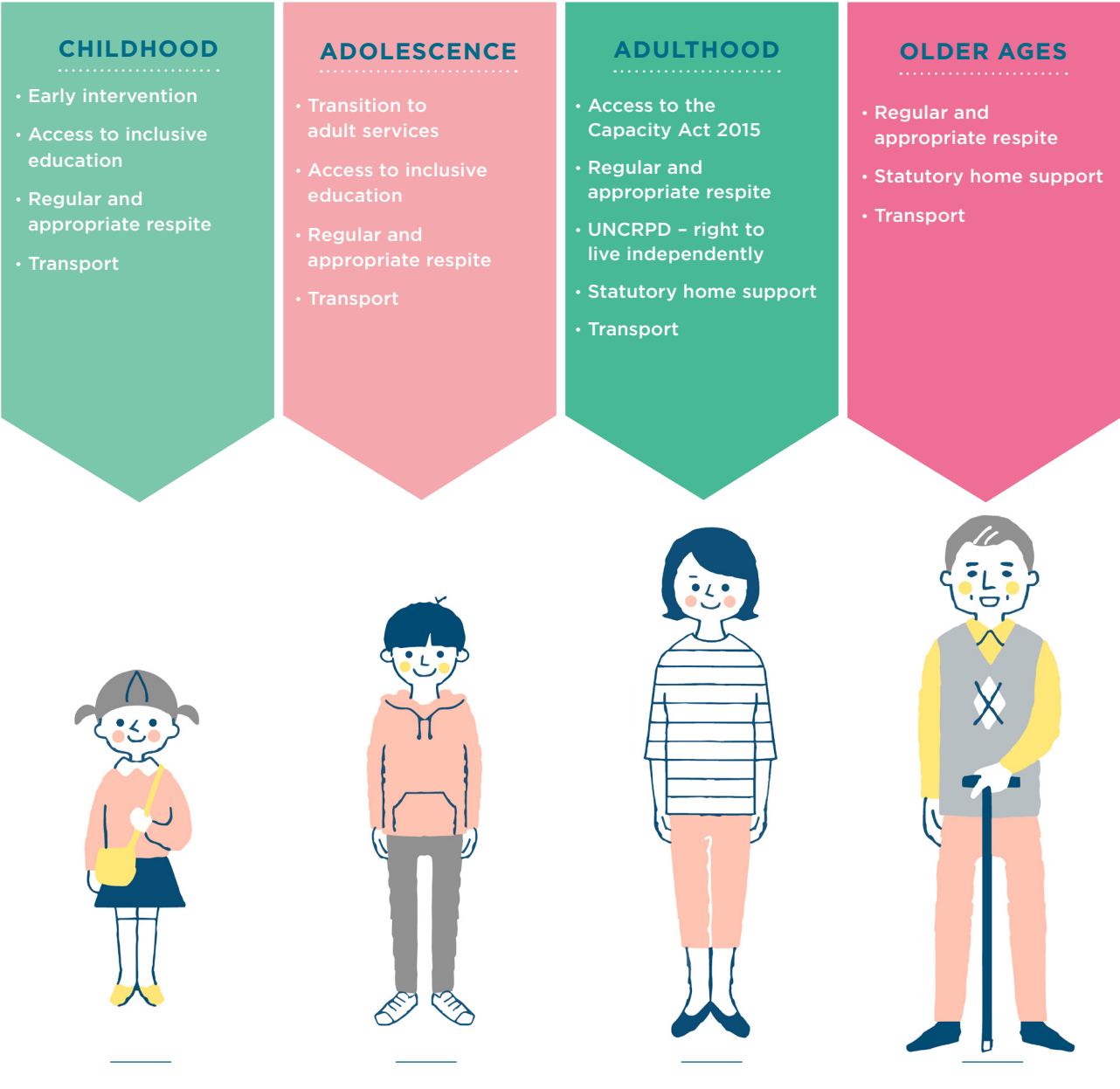




INTRODUCTION

Children with additional needs grow up to be adults with additional needs. By failing to plan ahead and ensure supports are in place for these children and adults across the life course, the State is flouting its constitutional obligations, denying them their right to reach their full potential and forcing many families into financial hardship and poor health.

While we acknowledge the efforts underway in relation to special education provision and commitments to finally address the egregious waiting times for an Assessment of Need (AON), these efforts alone are not enough. Government must use Budget 2024 to begin a radical overhaul of the special education and disability sector. The Budget 2024 allocation should be increased significantly to ensure the provision of adequate financial and human resources for disability and education across the life course, to meet the investment targets set out in the Disability Capacity Review and to improve timely access to AONs and therapeutic interventions.



CHILDHOOD

EARLY INTERVENTION: MAKING SURE CHILDREN WITH ADDITIONAL NEEDS GET THE SUPPORT THEY NEED EARLY AND OFTEN IN THE YEARS WHEN IT MAKES THE GREATEST DIFFERENCE

The Programme for Government (PfG) pledges to prioritise the delivery of earlier diagnostic interventions, reduce AON waiting times and improve service accessibility¹. FCI has welcomed these commitments, however, three years on and despite increased investment in special education and disability services, few children with additional needs and their families have experienced any positive change.

Under the Disability Act 2005, children with additional needs have a constitutional right to an AON. However, at the start of 2023, some 4,600 children were on a waiting list for an assessment. Of these, 3,155 have been waiting more than three months. We know these figures underestimate the actual number of children in need of and waiting for an AON.

Too often, children referred for early intervention face endless delays, may not get any or all of the recommended services or will simply age out of services. In March 2023, 17,157 children were waiting for initial contact with a Children's Disability Network Team (CDNT). 10,696 of these have been waiting for over 12 months, an increase of 836 since December. Over 102,500 children are waiting for a primary care disability intervention. A failure to provide children with early intervention misses a critical window of opportunity and increases the risk of significant developmental delays and ultimately costs the State exponentially in the long term.

Denying children with additional needs their rights is not only an attack on that child, but it is also detrimental to their family, who are forced to pick up the pieces and fill the many deficits in our broken health and education system, often at a significant personal cost. Research by FCI, UCD and the College of Psychiatrists of Ireland published in 2019 found that in a survey of over 1,100 carers, almost half had been diagnosed with mental ill-health, 67% suffered from physical ill-health and 75% are worried about their health and well-being².



The failure of the State to meet its obligations also has significant financial implications, forcing many families to pay privately for assessments and interventions that they can't afford. A study by the Vincentian Partnership for Social Justice carried out before the cost-of-living crisis and published in 2022 shows that **a household caring for an adolescent child with a profound disability faces additional weekly costs of €244 when compared to a non-caring household**³. A significant proportion of this cost is because families have to pay privately for services that are supposed to be publicly available.

¹ Government of Ireland. (2020). Programme for Government: Our Shared Future. Pg.78. Online. Available at: <https://www.gov.ie/en/publication/7e05d-programme-for-government-our-shared-future/>

² Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin (2019) Paying the Price: The Physical, Mental and Psychological Impact of Caring, Ireland: Family Carers Ireland.

³ MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. The additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent with a profound intellectual disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland.

BUDGET PRIORITIES:

- Budget 2024 must provide immediate financial relief for parents and family carers who have been forced to pay privately for assessments and therapies by allowing the cost to be either reimbursed or paid for through the National Treatment Purchase Fund (NTPF)⁴.
- Allocate funding in Budget 2024 to extend the NTPF to include timely assessment for both child and adult psychological services (as committed to in the PfG) and extend it to include occupational therapy, speech and language therapy and physiotherapy until backlogs are cleared.
- Funding must be set aside in Budget 2024 to address the damning findings of the Mental Health Commission's interim report on the review of Child and Adult Mental Health Services (CAMHS), specifically the need for an urgent review of all open cases across all CAMHS teams and for the immediate regulation of CAMHS under the Mental Health Act 2001.

Parents are forced to become protestors, lawyers and warriors to stand any chance of getting the support their child is legally entitled to.

REALISING EVERY CHILD'S RIGHT TO AN INCLUSIVE EDUCATION

All children, including those with additional needs, have a constitutional right to be educated in a place and manner that is appropriate to their needs. However, we know families who are struggling to secure an appropriate school place for their child(ren) both at primary and second level. During the current school year, some 618 children with special educational needs are receiving home tuition because they do not have an appropriate school place. FCI welcomes the review of the Education for Persons with Special Educational Needs Act (EPSEN) Act 2004, the reform of the Summer Programme and the activation of emergency legislation which compels schools to open special classes. However, these initiatives alone are not enough. Opening new school places does not in itself create inclusive education, but rather must be accompanied by future planning, funding, staff resources, staff training and cultural change to embed educational inclusivity as the new norm.

BUDGET PRIORITIES:

- Fund a ten-year plan towards a fully inclusive model of education. Similar to Sláintecare, this plan should have cross-party support and commit to achieving the State's obligations under the UNCRPD.
- The review of the EPSEN Act 2004 must update the Act's provisions to better reflect contemporary understandings of disability and best practices for inclusive education.
- Increased funding and resources should be made available for the school Summer Programme to be available in every special school across the country.
- Publish a costed and time-bound implementation strategy for the Disability Capacity Review and a cross-departmental strategic workforce development plan.

⁴ Reflects the wording of the Labour Party motion on autism and disability services. May 24th 2023.

ADOLESCENCE - ADULTHOOD

MANAGING THE TRANSITION FROM CHILD TO ADULT SERVICES

Moving from child to adult services is a key transition point for young people with additional needs and can be challenging. It is clear from the families FCI works with that they find the transition process emotional, stressful and confusing and describe the process as falling off a cliff or being given up on when they reach 18. Young people and their families need additional support to ensure that the handover of care is effectively coordinated and planned for in the years before the child reaches 18, which best practice suggests should begin no later than when the child is aged 13. An effective transition should be coordinated, planned and person-centred involving the young person and their family. It should ensure continuity of care, optimise health, minimise adverse events and ensure that the young person achieves their potential.

BUDGET PRIORITIES:

ALLOCATE FUNDING IN BUDGET 2024 TOWARDS:

- resources in each Children's Disability Network Team (CDNT) to allow the HSE to employ a 'transition lead' to oversee the provision of supports for young people and their families as they transition from child to adult care;
- co-produced individual transition plans created by young people, their families and the service provider to ensure clarity about where and when services will be delivered and the key contacts;
- the implementation of the recommendations made by the Youth Mental Health Transitions Specialist Group.

Transition should be an ongoing process, not a single event, and tailored to suit the child's unique needs.



ADULTHOOD - OLDER AGES

THE RIGHT TO LIVE INDEPENDENTLY

For many family carers, their greatest worry is what will happen to their loved one(s) when they are no longer able to provide care due to their own illness or death. While the UNCRPD commits countries that have ratified the treaty to realise the right of persons with disabilities to live independently, this can only be achieved if it is accompanied by investment in an appropriate mix of housing supports, grants, additional residential places, universally designed units and support services.

BUDGET PRIORITIES:

- Provide funding for the additional 1,900 (min. scenario) – 3,900 residential places which the Disability Capacity Review has shown are needed by 2032 with an estimated cost of €320m (min. scenario) to €550m per year⁵.
- Allocate funding to help the 1,320 people aged under 65 who are currently living in a nursing home to a more appropriate home of their choosing and work to prevent any further admissions of adults under 65⁶.
- Increase the maximum grant limits, income thresholds and disregards available under the Housing Adaptation Grant Scheme to reflect the spiralling costs of living and building costs and increase annual scheme funding in line with demand.
- Standardise rents under the Differential Rent Scheme to ensure fairness and geographic equity. Specifically, we are calling for Carer's Allowance to be disregarded at the basic social welfare rate; Half-Rate Carer's Allowance to be disregarded in full and Disability Allowance received by children aged between 16 and 18 years to be disregarded in full across all local authorities.



SUPPORTING FAMILY CARERS TO ACCESS THE ASSISTED DECISION-MAKING (CAPACITY) ACT 2015

The Assisted Decision-Making (Capacity) Act 2015 was fully commenced on April 26th 2023, providing a new legal framework to support persons who may have difficulty in making certain decisions. In the few short months since its commencement, it has become clear that many families who care for a person who lacks capacity are finding it difficult to apply for a Decision-Making Representative Order (DMRO) due to the financial costs involved. These costs relate to both the cost of applying to the Circuit Court and securing the necessary medical reports from healthcare professionals. While legal aid may be available, it is only available where a person's income (after certain deductions) is less than €18k and their capital assets less than €100k. The issue is further compounded for family members who need to make an emergency application to the High Court where costs will be substantially higher and beyond the financial reach of most. While engagement with the 2015 Act is voluntary, it is likely that as custom and practice develop over time, healthcare and other professionals are unlikely to engage with a family carer who does not have an official decision support arrangement in place. As such, the costs of applying for a DMRO will become unavoidable for some carers.

⁵ Department of Health (2021) Disability Capacity Review to 2032: A Review of Disability Social Care Demand and Capacity Requirements up to 2032.

⁶ Ombudsman (2021) 'Wasted Lives: Time for a better future for younger people in Nursing Homes'.

BUDGET PRIORITIES:

- The right of access to justice is accepted as a constitutional principle and a right under the European Convention on Human Rights. Urgent adjustments should be made to the means test for legal aid to ensure that more families qualify. Adjustments should take into account the rising costs of living and the costs associated with providing full-time care, e.g. the purchase of an adapted vehicle.
- Ensure the Legal Aid Board is adequately resourced so that waiting times to access legal aid – currently up to 35 weeks in certain parts of the country – can be reduced and the means test made considerably less restrictive.

STATUTORY HOME SUPPORT SCHEME: RECEIVING THE RIGHT CARE, IN THE RIGHT PLACE, AT THE RIGHT TIME

Government first committed to the introduction of a Statutory Home Support Scheme in January 2017 with the subsequent Sláintecare Implementation Strategy, published in 2018, targeting the passing of legislation for statutory homecare by 2021. While the importance of the scheme has been amplified by the pandemic, the crisis has also caused its delay, with the scheme now unlikely before 2024. While this delay is understandable, the commencement of the scheme must now be given the utmost priority. Direct action must be taken in Budget 2024 to fund the demand implications the introduction of the scheme will bring and for measures to address the ongoing recruitment and retention crisis within the homecare sector. Government has a commitment to provide sustainable quality services as outlined in the PfG and the Disability Capacity Review, however, this can't happen if organisations are unable to recruit and retain the staff needed to deliver their existing funded services.

BUDGET PRIORITIES:

- Funding must be made available in Budget 2024 to meet the demand implications of introducing a Statutory Home Support Scheme, which the ESRI predict could see the demand for home support hours increase from 18.56 million hours in 2019 to almost 42 million hours - a 126% increase^{7,8}.
- Immediate action is needed to address the staffing crisis in the homecare and disability sectors which is threatening their viability, including:
 - a formal agreement to address the pay disparity of Section 39 organisations;
 - ending the four-over-seven-day rule which prevents part-time home support workers from claiming part-time Jobseeker's Allowance.

According to a **Department of Health** survey, **94%** of respondents surveyed felt that people who receive homecare should have more of a say in the range of services that are provided for them and **88%** felt that people who receive homecare should have a choice over who provides their care⁹.

⁷ ESRI (2021) 'Demand for the Statutory Homecare Scheme'.

⁸ These projections are based only on the demand generated by older people aged over 65 and do not include demand from younger adults with care needs who will also be provided for under the scheme.

⁹ Irish Department of Health, Report on the findings of the public consultation on home-care services, June 2018. <https://assets.gov.ie/9990/1e6ec3b04d8a4c1480c6637ccee471c88.pdf>



CHILDHOOD – ADOLESCENCE – ADULTHOOD – OLDER AGE

A RIGHT TO RESPITE

Living independently is a goal that we all share, however, some people with a profound disability require the full-time care and support of their family. This can affect the whole family and, in some cases, can put a severe strain on family life. In these situations, it is critical that a whole of family approach is taken and supports are in place to enable and sustain family members in their caring role.

An essential element of this is access to regular and appropriate respite both within and outside the home. Respite provides relief from the daily demands of caring and allows parent carers to spend time with their other children, which is critically important. It also allows the person receiving care to have a break from their family carer and home environment whilst providing an opportunity for socialisation and specialised care. Access to regular respite has also been shown to reduce the need for full-time residential care. It is deeply concerning therefore that family carers have no entitlement to respite, which means that many carers care 24/7, 365 days a year without a break. While we acknowledge the efforts of the Government to improve respite provision, access to regular respite remains a pipe dream for the majority of caring families.

BUDGET PRIORITIES:

- Give all full-time family carers the right to a minimum of 20 days respite each year. This does not imply reducing respite to those who have been assessed as needing more respite days or who before now received more frequent respite but rather will give a right to at least 20 days of respite each year free of charge.
- We are calling for a national respite register to be established to allow family carers to register their need for respite along with the age and details of the person for whom they care. This would provide a geographical inventory of respite need by age group and condition type.

ACCESS TO TRANSPORT SUPPORT

Family Carers Ireland is disappointed that the PfG makes no mention of the introduction of the long-awaited Transport Support Scheme, which has been promised since 2013 when both the Mobility Allowance and Motorised Transport Grant were withdrawn on the grounds of age discrimination. The failure to replace these schemes has led to the illogical situation whereby those who received a Mobility Allowance prior to 2013 have been allowed to keep it while others now equally in need are locked out. It also means that the only transport support available to families is the Disabled Drivers and Disabled Passengers Scheme, which is available only to those with a severe physical disability, with absolutely no support available to those with an intellectual disability or cognitive impairment. This prioritises the transport needs of people with physical disabilities over those with an intellectual/cognitive disability which we believe could be subject to legal challenge.

BUDGET PRIORITIES:

- Address the ten year delay in providing transport support for people with disabilities by introducing the long-awaiting Transport Support Scheme to replace the Mobility Allowance and Motorised Transport Grant.
- Extend eligibility for the Primary Medical Certificate and the Disabled Drivers and Disabled Passengers Scheme to include people with a non-physical disability.



The manner in which people with disabilities continue to be denied access to personal transport supports is nothing short of shameful. Everyone agrees that something needs to be done but no one seems to be willing to take action.” *Ger Deering, Ombudsman, June 14th 2023*



FULLY FUND THE CARERS' GUARANTEE OF NATIONWIDE ACCESS TO BASIC SUPPORTS

The Programme for Government 'Our Shared Future' (2020) included a commitment to develop a Carers' Guarantee proposal that *“will provide a core basket of services to carers across the country, regardless of where they live”* (p76). In 2022, the Government allocated a recurring annual budget of €2m as the first phase of realising this commitment. As 2024 will be the final full year of this government, FCI calls on it to commit the additional €3m annually required to fully fund the guarantee.

BUDGET PRIORITIES:

- Commit the additional €3m annually required to fully fund the Carers' Guarantee in 2024.
 - Ensure that the funding parameters for Regional Health Authorities include adequate minimum provision for local carer supports in each region.
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