

## A New Social Contract for Care: Pre-Budget Submission **2025**

Proposals to support family carers in Budget 2025





## **Budget 2025:** Summary of Budget Priorities

## **Social Protection**

- Increase the weekly Carer's Allowance income disregard to €1,250 (couples) and €625 (single carers) in Budget 2025, with a similar increase in Budget 2026 with the full abolition of the means test and the introduction of a Family Carer Payment by 2027.
- Establish a Family Carer Payment Implementation Group to oversee the development of the new payment. This should begin in 2024 and ensure that all practical issues regarding the implementation of the new payment for carers are addressed, including the transfer of secondary benefits (e.g Carer's GP Card, Carer's Support Grant, Free Travel), the full Family Carer Payment awarded to those on Half-Rate Carer's Allowance and legislation to protect the payment from exportability.<sup>1</sup>
- The rate of Carer's Allowance and Carer's Benefit should be increased to €325 in recognition of the significant and unavoidable costs of care faced by caring families.
- The Carer's Allowance means test should be based on net, not gross, income, in line with the assessment of earnings under Carer's Benefit which is based on earnings less income tax, USC, PRSI, superannuation (pension payments), Pension Levy, Union Dues, Subscriptions to Friendly Societies and health insurance premiums.
- Increase the weekly travel allowance allowed in the Carer's Allowance means test from €15 to €50 to reflect the rate of fuel inflation.
- Increase the 18.5-hour ceiling for people in receipt of Carer's Allowance who want to undertake training or education, while providing full-time care.

- Include Carer's Allowance as a qualifying payment for the Fuel Allowance scheme.
- Carers who care for two or more people should receive a full-rate Carer's Allowance instead of a half-rate payment for the second person.
- Carer's Benefit is not a means-tested payment, so the current earnings limit of €450 per week for those who want to continue to work for up to 18.5 hours makes little sense and is unfair to workers who need the scheme but cannot access it because of their earnings. FCI calls for the removal of the earnings limit so that the scheme is available to all workers.
- Extend eligibility of Carer's Benefit to include people who are self-employed.
- Increase the annual Carer's Support Grant from €1,850 to €2,000.
- Increase the monthly payment of Domiciliary Care Allowance (DCA) from €340 to €400.
- Extend eligibility for the Free Travel Scheme to include children in receipt of DCA.
- Reinstate the policy of disregarding Carer's Allowance and Carer's Benefit in the means assessment for the Working Family Payment.
- Continue to provide funding to support carers in employment and help carers who want to return to employment through the Dormant Accounts Fund programme measure 'Support for Family Carers and Young Carers'.

## Health



- Undertake an audit of respite needs in each Regional Health Area in line with the Population Based Funding Allocation model, a core component of the Regional Health Area Implementation Plan. FCI is also calling for a national respite register 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 needs by age group and condition type.
- Adequately fund the number and type of respite places required for older people, children with additional needs and people with a disability as identified through Population Based Planning and in line with the investment identified in the Disability Capacity Review to 2032, i.e. €16m to €20m annually.
- Ringfence respite places to ensure they cannot be re-designated as step-down, rehabilitation or transitional care facilities.
- Allocate funding to meet the demand implications of the Statutory Home Support Scheme, which the ESRI predict could see the demand for home support hours increase from 18.56 million in 2019 to almost 42 million hours following the scheme's introduction - a 126 per cent increase <sup>2,3</sup>.

- Immediate action is needed to address the staffing crisis in homecare and disability services 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 (DSP).
- Ensure no child with scoliosis must wait more than four months for spinal surgery and provide the funding necessary to implement the recommendations of the Paediatric Spinal Taskforce.
- Introduce a Transport Support Scheme, committed to in 2013, as a replacement for the Mobility Allowance and Motorised Transport Grant.
- Commit the additional €3.1m in annual funding required to fully deliver the proposals contained in the Carers' Guarantee.
- Ensure that the funding parameters for Regional Health Authorities include adequate minimum provision for local carer supports in each region.

<sup>2</sup> ESRI (2021) 'Demand for the Statutory Homecare Scheme'.

<sup>&</sup>lt;sup>3</sup>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.

## Children, Equality, Disability, Integration & Youth



- Provide immediate financial relief for parents 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).
- 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.
- Publish a costed and time-bound implementation strategy for the Disability Capacity Review and a cross-departmental strategic workforce development plan.
- Allocate funding to support children's transition from child to adult services, specifically towards:
  - the employment of a 'transition lead' in each CDNT 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 to provide clarity about where and when services will be delivered post-transition.
  - implementation of the recommendations of the Youth Mental Health Transitions Group.

- Tackle the chronic shortage of health professionals across the health service by creating a bursary to help fund students' education in specialised disciplines. Following graduation, these professionals would be required to remain working in the public health service for a minimum of 10 years.
- Ratify the UNCRPD Optional Protocol to ensure disabled people have access to the Committee on the Rights of Persons with Disabilities to vindicate their rights.
- Provide funding for the additional 1,900-3,900 residential places which the Disability Capacity Review has shown are needed by 2032 with an estimated cost of €320m (min. scenario) to €550m per year<sup>4</sup>.
- Allocate funding to provide a pathway for the 1,320 people under 65 who are living in a nursing home to a more appropriate home of their choosing and work to prevent any further admissions.

<sup>&</sup>lt;sup>4</sup> Department of Health (2021) Disability Capacity Review to 2032: A Review of Disability Social Care Demand and Capacity Requirements up to 2032.

## Education

- 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 and delivering its constitutional obligation to give every child a right to an appropriate education.
- Provide comprehensive rights-based training for teachers and SNAs that includes universal design for learning, rights-based approaches for supporting children in crisis and how to make sure the school environment is accessible for all children.
- Increase funding and resources to make the Summer Programme available in every special school.

## Housing, Local Government & Heritage

- Increase Exchequer funding towards the Housing Adaptation Grant Scheme and increase the maximum grant limits, income thresholds and disregards available to reflect the spiralling costs of living and building costs and increase annual funding to the scheme in line with need and demand.
- Standardise rents under the Differential Rent Scheme to ensure fairness and geographic equity. Specifically, Carer's Allowance should be disregarded at the basic social welfare rate; Half-Rate Carer's Allowance should be disregarded in full and Disability Allowance received by children aged between 16 and 18 years should be disregarded in full across all local authorities.
- Provide funding to support the roll-out of 'Changing Places' toilets across public buildings.





## Environment, Climate & Communications



 Introduce a rebate to offset the additional waste collection charges that will be incurred by households where incontinence care is provided due to pay-by-weight collection pricing, and ensure all climate action policies are disability and carer-proofed and do not negatively impact those not able to adapt to these changes.

## Finance



- Provide a statutory payment for employees who avail of the five unpaid leave days for medical care purposes legislated for under the Work-Life Balance and Miscellaneous Act 2023, on a similar basis to the existing provision for five days statutory sick pay.
- Make Carer's Allowance exempt from tax.
- Extend eligibility for the Home Carer Tax credit to include single working carers and increase it to €2,000.
- Increase the Dependent Relative Tax Credit to €1,000.
- Allow taxpayers to claim tax relief on the cost of employing a home carer while also receiving the Dependent Relative Tax Credit or the Incapacitated Child Tax Credit.
- The credits received while on Carer's Allowance should be the same value as paid PRSI contributions.

## **Cross Department Priorities**



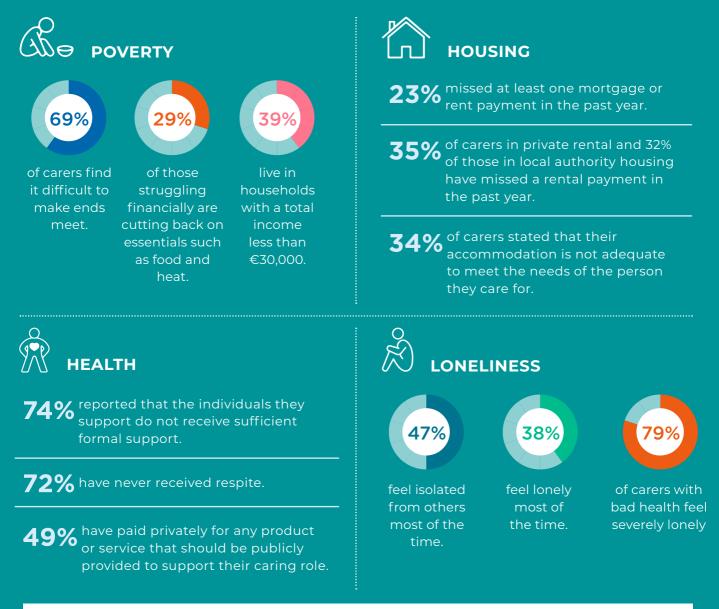
- Extend the Carer's GP Visit Card to include full-time family carers who receive the annual Carer's Support Grant as a standalone payment (DSP / DoH).
- Extend the payment of Carer's Benefit (and Carer's Leave) for an additional six months for carers who are unable to return to work due to their caring responsibilities (DSP/DCEDIY).
- Realign eligibility thresholds across all departments and agencies in line with any increases to social welfare payments to avoid the unintended loss of other supports, e.g.
   Fuel Allowance, Medical Cards, social housing and housing grants (all depts).
- Introduce legislation and ringfenced funding to give full-time family carers the right to appropriate, free and regular respite, in line with the statutory leave entitlements afforded to paid employees (DoH / DCEDIY).
- 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 and ending the four-over-seven-day rule which prevents part-time home support workers from claiming part-time Jobseeker's Allowance (DSP / DoH).

 Deliver therapeutic support for children with additional needs within the school environment. Funding currently provided to the National Council for Special Education for 39 therapy posts per year as part of the School Inclusion Model should be increased and regularised in Budget 2025 with rollout across all schools. Children with higher support needs, regardless of where they attend school, should also be able to access therapies (DoE / DCEDIY / DoH).



## Why we campaign for better recognition and support for Ireland's family carers

Findings from FCI's State of Caring 2024 survey, completed by 2,127 current family carers, show:



#### **WHO CARES?**

Across Ireland, 500,000 people provide unpaid care for a family member, friend or neighbour with additional care needs such as older people, those living with long-term illness or disability.. Thousands of us take on new caring responsibilities every day – it can happen unexpectedly, or gradually, but almost all of us will experience care at some point in our lives.

Over the last decade, the number of carers and the volume of care they provide has increased substantially. Since 2011, the Census has recorded a 60% increase in the number of people who provide unpaid care and the number of people who care for more than 43 hours per week has more than doubled. The value of unpaid care is now worth a staggering €20 billion a year – equivalent to the annual budget of the HSE, and without which our health and social care systems would collapse.

## **A New Social Contract for Care** Proposals to improve recognition and support for family carers in Budget 2025

While every year is important politically, 2024 stands out. With the referendums on family and care held in March, local and European elections in June and a General Election announcement imminent, alongside the annual budget process, 2024 is a year when our elected representatives have ample opportunities to take concrete action to better recognise, support and compensate family carers.

The State has reached a critical juncture in its support for unpaid carers. While defeated, the referendum on care ignited a national conversation about the crucial issues surrounding care and disability. It brought to light the challenges faced by family carers and those receiving care and highlighted the need for a more ambitious, progressive and rightsbased care system. While the reasons for the comprehensive No vote are complex, the result is an unequivocal wake-up call that the State cannot be complacent in its obligation to support the hundreds of thousands of its citizens who provide unpaid care.

The proposal to hold a referendum on care was one of a number of recommendations put forward by the Citizens' Assembly on Gender Equality. The assembly was adamant about the need to place much greater value on care work, expressing a high level of ambition for change in how the State recognises, compensates and supports carers. Amongst its proposals, the assembly recommended the reform of Carer's Allowance including changes to the means test and individualisation; increasing the number of hours carers can work or study; reimbursing the costs associated with care; increasing the Carer's Support Grant; increasing respite provision and providing a dedicated pension solution for family carers.

FCI acknowledges the significant progress made in improving access to the State Pension (Contributory) for long-term carers and increases in the income and capital disregard for Carer's Allowance. However, we believe much more needs to be done. Our 2025 Pre-Budget Submission continues our call for a new social contract for care, by fundamentally reforming how the State categorises, compensates, and values family carers. Our proposals are ambitious but reasonable.

Government must not underestimate the public's appetite for change. Instead, it must listen and learn from the referendum, moving beyond mere lip service to meeting the Irish people's demand for genuine progress and concrete action. We must use Budget 2025 to begin to transform what has now become an antiquated and paternalistic model of support for carers into a mutual and equal partnership where carers are valued for their immense contribution; they receive fair compensation for the care they provide; are not excluded from supports due to their means; and have timely access to the health and social services that they and their loved one(s) need when, where and how they are needed.



## **Eight Pillars of Change**

Government must be ambitious in Budget 2025. Many of the challenges experienced by family carers relate to long-standing structural issues, often due to policies or decisions made years or even decades ago. We need to challenge the status quo and shed practices and policies that no longer serve us or fail to deliver the results intended. Therapy waiting lists, delays in Assessments of Need, the lack of school places for children with additional needs, the consistent inadequacy of respite care and the inability to deliver home support hours are casualties of policies that urgently need to be overhauled. The pandemic highlighted the State's ability to adapt and respond rapidly when needed. This agility, creativity and innovation must not be lost. In Budget 2025, we call on Government to deliver eight pillars of change:



# Abolition of the Carer's Allowance means test

#### **Department of Social Protection**

01

Despite improvements in recent years, the Carer's Allowance means test remains one of the most contentious issues amongst family carers. Thousands of full-time family carers, caring for people medically in need of full-time care, do not qualify for Carer's Allowance or receive a reduced rate due to their relatively modest household income. We believe the scheme, which was created 34 years ago, is overly restrictive, gender-biased and no longer fit for purpose.

FCI acknowledges the efforts made by Minister Humphreys and her department to increase the income and capital disregards for Carer's Allowance in Budget 2022 and Budget 2024, and the minister's commitment to review the entire system of means tested payments for carers. However, we believe a much more fundamental change is needed. FCI is calling for a transition from the outdated means tested Carer's Allowance scheme towards a more equitable and gender-balanced scheme for carers - one that reflects the reality of contemporary caring relationships and that values and fairly compensates the immense contribution made by carers, acknowledging the State's reliance on them.

Our priority for Budget 2025 remains consistent with the proposal set out in our 2024 submission – to incrementally increase the Carer's Allowance income disregard in Budget 2025 and Budget 2026 with the full abolition of the Carer's Allowance means test and the introduction of a Family Carer Payment (i.e. Participation Income) for full-time family carers by 2027. Under the Family Carer Payment, all existing eligibility criteria attached to the Carer's Allowance scheme would remain except the means test.<sup>5</sup> This ambitious change requires the department to approach its categorisation and assessment of carers in a new and progressive way. We believe that the ambition, motivation and political will exists to achieve this.



Respondents who completed the State of Caring 2024 survey identified the abolition of the Carer's Allowance means test as the most important policy change they want to see implemented by Government

<sup>&</sup>lt;sup>5</sup> FCI is calling for an increase in the 18.5 hours a carers is allowed to study while in receipt of Carer's Allowance for those who want to pursue training or education and who continue to provide full-time care.

Disregard	2024 (Current)	Budget 2025	Budget 2026	2027	
Single	€450	€625	€750	Full abolition means test	
Couple	€900	€1,250	€1,500		

Roadmap for the abolition of the means test Budgets 2025 - 2027

#### How much will this cost?

- In 2024, a Parliamentary Budget Office (PBO) analysis estimated a full-year cost of €375.3million to abolish the Carer's Allowance means test.<sup>6</sup>
- This is in line with the cost estimated by FCI in 2023 of €389m p.a<sup>7</sup>.
- These estimates are considerably less than €1.2bn suggested by the Department in 2022<sup>8</sup>.

#### WHAT IS A PARTICIPATION INCOME?

A Participation Income is a form of State income support that enables and values certain forms of unpaid work. A Participation Income is similar to a Universal Basic Income however the main difference is that individuals have to do something societally valuable in exchange for the money they receive. Care work is often referenced as one of the most deserving forms of unpaid work suited to a Participation Income. **Both NESC and the Oireachtas Committee on Gender Equality recommend that consideration be given to a Participation Income for carers.** 

For more information, see FCI and Maynooth University's report 'Towards a Participation Income for Family Carers'.<sup>9</sup>

- Increase the weekly Carer's Allowance income disregard to €1,250 (couples) and €625 (single carers) in Budget 2025, with a similar increase in Budget 2026 with the full abolition of the means test and the introduction of a Family Carer Payment by 2027.
- Establish a Family Carer Payment Implementation Group to oversee the development of the new payment. This should begin in 2024 and work to ensure that all practical issues regarding the implementation of the new payment for carers are addressed, including the transfer of secondary benefits (e.g Carer's GP Card, Carer's Support Grant, Free Travel), the full Family Carer Payment awarded to those on Half-Rate Carer's Allowance and legislation to protect the payment from exportability.<sup>10</sup>

<sup>&</sup>lt;sup>6</sup> Parliamentary Budget Office reference 2024-001-01 as requested by Deputy Denis Naughten.

<sup>&</sup>lt;sup>7</sup> FCI (2023) 'Estimating the Cost of Abolishing the Carer's Allowance Means Test'.

<sup>&</sup>lt;sup>8</sup> PQ (50414/22)

https://familycarers.ie/media/3314/towards-a-participation-income-for-family-carers-summary-report.pdf

<sup>&</sup>lt;sup>10</sup> Exportability refers to payments that can be paid while the recipient is living outside of Ireland.

## *O2* A fair and adequate income



#### **Department of Social Protection**

Both the Citizens' Assembly and the Oireachtas Committee on Gender Equality made unequivocal recommendations regarding the reform of Carer's Allowance, including the need to increase the income disregards and earnings thresholds, the need to disregard the costs associated with care and increase the hours a carer is allowed to work or study as well as the possible introduction of a Participation Income for carers.

Research by the Vincentian Partnership for Social Justice published in April 2022, shows that even before the cost of living crisis, income supports for family carers are inadequate in supporting low-income households caring for a child with a profound intellectual disability to meet a Minimum Essential Standard of Living (MESL) .<sup>11</sup> These households, which are representative of many caring situations, incur additional average weekly costs of €244 compared to a similarly composed household with no disability or care needs. Worryingly, the additional costs are not only due to direct costs, such as medical care or transport, but also the hidden costs of caring that are often unaccounted for in Government policy, including the costs forced on families when 'public' services are not available leaving families with little choice but to pay privately, if they can.

The Vincentian Partnership's research also shows that the disadvantage experienced by caring households does not end as income increases. Even caring households with higher incomes have significantly less disposable income to meet the need for contingencies such as car or house repairs, medical expenses, or unexpected bills. These families, who often have to depend on a single income due to their caring responsibilities, face a multitude of financial battles as they are ineligible for almost all carer supports, yet face the same devastating costs of caring without recognition or support from the State.



of carers who completed the State of Caring 2024 survey are struggling financially.

29% of these carers have had to cut back on essentials including food and heat to make ends meet.

<sup>&</sup>lt;sup>11</sup> MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland.

- Pending the introduction of a Family Carer Payment, the rate of Carer's Allowance and Carer's Benefit should be increased to €325 in recognition of the significant and unavoidable costs of care faced by caring families.
- The Carer's Allowance means test should be based on net, not gross, income, in line with the assessment of earnings under Carer's Benefit which is based on earnings less income tax, USC, PRSI, superannuation (pension payments), Pension Levy, Union Dues, Subscriptions to Friendly Societies and health insurance premiums.
- Increase the weekly travel allowance allowed in the Carer's Allowance means test from €15 to €50 to reflect the rate of fuel inflation.
- Increase the 18.5-hour ceiling for people in receipt of Carer's Allowance who want to undertake training or education, while providing full-time care.
- Include Carer's Allowance as a qualifying payment for the Fuel Allowance scheme.
- Carers who care for two or more people should receive a full-rate Carer's Allowance instead of a half-rate payment for the second person.
- Carer's Benefit is not a means tested payment, so the current earnings limit of €450 p.w for those who want to continue to work for up to 18.5 hours makes little sense and is unfair to workers who need the scheme but cannot access it because of their earnings. FCI calls for the removal of the earnings limit so that the scheme is available to all workers.

- Extend the payment of Carer's Benefit (and Carer's Leave) for an additional six months for carers who are unable to return to work due to their caring responsibilities.
- Extend eligibility of Carer's Benefit to include people who are self-employed.
- Increase the annual Carer's Support Grant from €1,850 to €2,000.
- Extend the Carer's GP Visit Card to include full-time family carers who receive the annual Carer's Support Grant as a standalone payment (joint action with DoH).
- Increase the monthly payment of Domiciliary Care Allowance (DCA) from €340 to €400.
- Extend eligibility for the Free Travel
  Scheme to include children in receipt of DCA.
- Reinstate the policy of disregarding Carer's Allowance and Carer's Benefit in the means assessment for the Working Family Payment.<sup>12</sup>
- Realign eligibility thresholds across all departments and agencies in line with any increases to social welfare payments in Budget 2025 to avoid the unintended loss of other supports, e.g. Fuel Allowance, Medical Cards, social housing, housing grants.

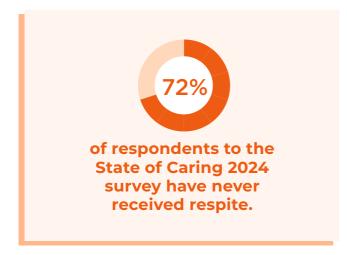
<sup>&</sup>lt;sup>12</sup> Prior to Budget 2012, both Carer's Benefit and Carer's Allowance were excluded from the assessment of income for the Family Income Supplement (now Working Family Payment).

# *03* A right to respite

Department of Health /Department of Children, Equality, Disability, Integration & Youth

FCI believes all full-time family carers should have a right to regular and appropriate respite breaks needed to sustain a healthy balance between caring and their personal wellbeing. Access to regular respite is repeatedly identified as a priority by carers and should be viewed as integral to carer support.

It is deeply concerning that family carers have no entitlement to respite or a break from their caring role, meaning many full-time carers care 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.



- Introduce legislation and ringfenced funding to give full-time family carers the right to appropriate, free and regular respite, in line with the statutory leave entitlements afforded to paid employees.
- Undertake an audit of respite needs in each Regional Health Area in line with the Population Based Funding Allocation model, a core component of the Regional Health Area Implementation Plan. FCI is also calling for a national respite register 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 needs by age group and condition type.
- Adequately fund the number and type of respite places required for older people, children with additional needs and people with a disability as identified through Population Based Planning and in line with the investment identified in the Disability Capacity Review to 2032, i.e. €16m to €20m annually.
- Ringfence respite places to ensure they cannot be re-designated as step-down, rehabilitation or transitional care facilities.



## 04 Deliver the Statutory Home Support Scheme

#### Department of Health

The legislative gap between a person's right to nursing home care and the discretionary basis for home support is long-standing, having been created with the introduction of the Nursing Home Support Scheme (Fair Deal) in 2009. During these 15 years, families have had to accept a system that incentivises residential care and spends twice as much on Fair Deal than on home support. This is despite Government policy to support people to be cared for at home and the consistently voiced preference of people to live and be cared for in their own homes and communities.

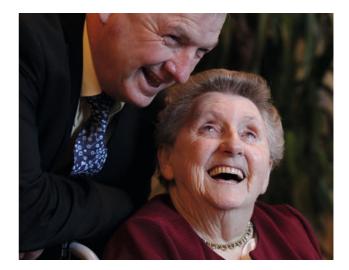
Government first committed to the introduction of a Statutory Home Support Scheme seven years ago in January 2017 with the subsequent Sláintecare Implementation Strategy, published in 2018, targeting the introduction of the scheme by 2021. Unfortunately, the scheme has yet to be introduced. While we accept the complexities involved in creating a statutory home support scheme, its commencement must be given the utmost priority with direct action taken in Budget 2025 to fund the demand implications of a statutory scheme and for measures to address the ongoing recruitment and retention crisis within the homecare sector.



In 2023, Government spent €1.5bn on Fair Deal, compared to €723m on homecare.

#### **Budget 2025 Priorities**

- Allocate funding to meet the demand implications of the Statutory Home Support Scheme, which the ESRI predict could see the demand for home support hours increase from 18.56 million in 2019 to almost 42 million hours when the scheme is introduced - a 126 per cent increase<sup>13,14</sup>.
- Immediate action is needed to address the staffing crisis in homecare and disability services 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 parttime Jobseeker's Allowance (DSP).



<sup>13</sup> ESRI (2021) 'Demand for the Statutory Homecare Scheme'.

<sup>&</sup>lt;sup>14</sup> 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.

## 05 Fully fund the Carers' Guarantee

#### **Department of Health**

The delivery of the Carers' Guarantee is a commitment in the Programme for Government; however as we approach the end of this government's term in office, we are at serious risk of failing to deliver the guarantee in full, as the €2m annual funding provided to date falls far short of what is required. The additional €3.1m per annum required to deliver the Carers' Guarantee must be secured if all the commitments contained in the original proposal are to be delivered.

- Commit the additional €3.1m in annual funding required to fully deliver the proposals contained in the Carers' Guarantee.
- Ensure that the funding parameters for Regional Health Authorities include adequate minimum provision for local carer supports in each region.



## *06* Prioritise support for children with additional needs

Department of Education / Department of Children, Disability, Equality, Integration & Youth

Children with additional needs grow up to be adults with additional needs. By failing to plan ahead and ensure supports are in place as these children grow into adulthood, the State is flouting its constitutional obligations and denying these children their right to reach their full potential.

The Programme for Government pledges to prioritise the delivery of earlier diagnostic interventions, reduce Assessment of Need (AON) waiting times and improve service accessibility<sup>15</sup>. FCI has welcomed these commitments, but, four 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.

In March 2024, a record 8,900 children were overdue an AON. Of these, 7,000 have been waiting more than three months. In 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. In 2023, 102,500 children were waiting for a primary care disability intervention. The 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 neglectful of that child, but it is also detrimental to their family, who are forced to pick up the pieces and fill the many deficits in a broken health and education system, often at a significant cost. Before the cost of living crisis, the additional costs associated with caring for a child with complex needs were estimated to be  $\in$ 244 per week. A significant proportion of this cost is because families are forced to pay privately, if they can, for services that are meant to be publicly available.<sup>16</sup>

Despite having a constitutional right to be educated in a place and manner that is appropriate to their needs, families across Ireland continue to struggle to secure an appropriate school place for their child(ren) both at primary and second level. During the current school year, some 690 children with special educational needs are receiving home tuition because they do not have a school place. While FCI welcomes the review of the Education for Persons with Special Educational Needs Act (EPSEN) Act, the reform of the Summer Programme and the activation of emergency legislation compelling schools to open special classes, 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.

<sup>&</sup>lt;sup>15</sup> 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/

<sup>&</sup>lt;sup>16</sup> MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland.

#### **Budget 2025 Priorities**

- Provide immediate financial relief for parents 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) <sup>17</sup>.
- 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.
- Publish a costed and time-bound implementation strategy for the Disability Capacity Review and a cross-departmental strategic workforce development plan.
- Allocate funding in Budget 2025 to support children's transition from child to adult services, specifically towards:
  - the employment of a 'transition lead' in each CDNT 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 to provide clarity about where and when services will be delivered post-transition.
  - implementation of the recommendations of the Youth Mental Health Transitions Specialist Group.
- Tackle the chronic shortage of health professionals across the health service by creating a bursary to help fund students' education and training in specialised disciplines. Following graduation, these professionals will be required to remain working in the public health service for a minimum of 10 years.

- Ensure no child with scoliosis must wait more than four months for spinal surgery and provide the funding necessary to implement the recommendations of the Paediatric Spinal Taskforce.
- 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 and delivering its constitutional obligation to give every child a right to an appropriate education.
- Deliver therapeutic support for children with additional needs within the school environment. Funding currently provided to the National Council for Special Education for 39 therapy posts per year as part of the School Inclusion Model should be increased and regularised in Budget 2025 with rollout across all schools. Children with higher support needs, regardless of where they attend school, should also be able to access therapies.
- Provide comprehensive rights-based training for teachers and SNAs that includes universal design for learning, rights-based approaches for supporting children in crisis and how to make sure the school environment is accessible for all children.
- Increased funding and resources should be made available for the school Summer Programme to be available in every special school across the country.
- Ratify the UNCRPD Optional Protocol to ensure disabled people have access to the Committee on the Rights of Persons with Disabilities to vindicate their rights.

<sup>17</sup> Reflects the wording of the Labour Party motion on autism and disability services. May 24th 2023.

07

# Deliver housing, transport and climate justice

Department of Housing, Local Government & Heritage / Department of Health / Department of the Environment, Climate & Communications.

Article 19 of the UNCRPD obliges State Parties to the convention to take effective measures to support people with disabilities to live independently alongside the support they need. This can only be achieved if it is accompanied by investment in an appropriate mix of housing supports, residential places, universally designed units, home supports, personal assistance services and accessible transport options.

Accessibility is one of the general principles upon which the UNCRPD is based. Good quality accessible transport can help to maintain a person's independence and autonomy and ensure that all parts of the community in which a person lives are accessible. While accessible public transport is critical, it is important to recognise the thousands of older people and people with disabilities who cannot use public transport due to their restricted mobility or because they are unable to get from their home to the transport stop. The Mobility Allowance and Motorised Transport Grants were both designed to support people in this situation by providing a monthly cash payment towards accessible transport options such as taxis or a grant towards the purchase of an adapted vehicle. Both schemes were withdrawn without warning in 2013 and have yet to be replaced, meaning the only transport scheme is the Disabled Drivers and Disabled Passengers Scheme which is only available to people who are severely physically disabled. FCI continues to call for the creation of a replacement Transport Support Scheme to

meet the needs of disabled people of all ages as committed to in 2013 when the original schemes were withdrawn.

While FCI welcomes initiatives to reduce waste and address climate change, consideration must be given to how climate action policies can disproportionately impact older people, disabled people and family carers. We draw specific attention to the proposals recently outlined in the Moving Together Transport Strategy which would see local authorities overseeing congestion charges to alleviate car dependency and promote public transport. For many people with complex care needs, public transport is not an option and, as such, provisions must be made to provide exemptions for disabled people and their carers to ensure they are not financially penalised. Similarly, Government must consider the disproportionate impact of payby-weight bin charges. While most households can mitigate these charges by sorting their waste and recycling, households with a person(s) requiring and disposing of incontinence care products cannot.

#### **Budget 2025 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 year<sup>18</sup>.
- Allocate funding to provide a pathway for the 1,320 people under 65 who are living in a nursing home to a more appropriate home<sup>19</sup> of their choosing and work to prevent any further admissions.
- Increase Exchequer funding towards the Housing Adaptation Grant Scheme and increase the maximum grant limits, income thresholds and disregards available to reflect the spiralling costs of living and building costs and increase annual funding to the scheme in line with need and 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.

- Introduce a rebate to offset the additional waste collection charges that will be incurred by households where incontinence care is provided due to pay-by-weight collection pricing, and ensure all climate action policies are disability and carer-proofed and do not negatively impact those not able to adapt to these changes.
- Provide funding to support the roll-out of 'Changing Places' toilets across public buildings and spaces.
- Introduce a Transport Support Scheme committed to in 2013 as a replacement for the Mobility Allowance and Motorised Transport Grant.



<sup>&</sup>lt;sup>18</sup> Department of Health (2021) Disability Capacity Review to 2032: A Review of Disability Social Care Demand and Capacity Requirements up to 2032.

<sup>&</sup>lt;sup>19</sup> Ombudsman (2021) 'Wasted Lives: Time for a better future for younger people in Nursing Homes'.

## 80

## Support carers in employment

#### Department of Social Protection / Department of Finance / Department of Public Expenditure & Reform

It is estimated that one in nine Irish employees juggle paid employment with caring responsibilities at home. Evidence shows that without support, the challenges employees face in combining work and care are stressful and can lead workers to reduce their hours, forgo promotion opportunities or quit their jobs altogether, with lifelong consequences on their incomes and careers. While many employers recognise that they can ill afford to lose key staff like this and that there is a business imperative to support families to balance work and care, it is only through a combination of support both within and outside of the workplace that carers in employment can be supported to remain in work and those who have been forced to leave work can be supported back to employment if/ when the time is right. FCI acknowledges the funding that has been made available through the Dormant Accounts Fund programme measure 'Support for Family Carers and Young Carers' that is specifically targeted to support carers in employment and provide employment related training.

The Work-Life Balance and Miscellaneous Provisions Act 2023 introduced new duties on employers to show flexibility in working arrangements for family carers and gives carers the right to five unpaid days for medical care purposes each year. This is in addition to the provisions already included in the Carer's Leave Act 2001. However, there is more that can and should be done. As a major employer themselves, Government should champion the case for supporting working carers and provide information that will help employers to understand how they can support carers in their workforce. Government must also ensure that home support, day services and respite are available to enable people to combine work and caring.

Tax credits and reliefs are a critical policy response to support caring households by reducing the amount of tax they pay. FCI welcomes the increases announced to the Home Carer Tax Credit and the Incapacitated Child Carer Tax Credit in Budget 2024. However, we continue to draw attention to a number of anomalies in the current suite of tax credits/reliefs available to caring households. Specifically, current arrangements wrongly deny any meaningful tax relief to single carers or those caring for a relative other than a child. An Incapacitated Child Tax Credit of €3,500 is rightly available to the parents/guardian of a child, including an adult child, who is permanently incapacitated, either physically or mentally. However, the only tax relief available to a single person caring for their mother or another non-child relative is the Dependent Relative Tax Credit of just €245. Equally, the Home Carer Tax Credit of €1,800 is only available to married couples or those jointly assessed for tax, meaning single carers cannot avail of it.

- Continue to provide funding to support carers in employment and help carers who want to return to employment through the Dormant Accounts Fund programme measure 'Support for Family Carers and Young Carers'.
- Provide a statutory payment for employees who avail of the five unpaid medical care purpose days legislated for under the Work-Life Balance and Miscellaneous Act 2023, on a similar basis to the existing provision for five days statutory sick pay.
- Make Carer's Allowance exempt from tax, in line with Jobseeker's Allowance and Disability Allowance.
- Extend eligibility for the Home Carer Tax credit to include single working carers and increase it to €2,000.
- Increase in the Dependent Relative Tax Credit to €1,000.
- Allow taxpayers to claim tax relief on the cost of employing a home carer while also receiving Dependent Relative Tax Credit or the Incapacitated Child Tax Credit.
- The credits received while on Carer's Allowance should be the same value as paid PRSI contributions.



## NOTES






Family Carers Ireland National Office, Market Square, Tullamore, Co. Offaly, R35 PW50 Freephone Careline 1800 24 07 24

www.familycarers.ie



CHY 10962