



**Programme for Government  
'Our Shared Future'  
Family Carer Scorecard 2024**

Assessing the implementation of the  
Programme for Government from the  
perspective of family carers

**December 2024**

## Family Carer Scorecard 2024

With the dissolution of the 33<sup>rd</sup> Dáil on November 8<sup>th</sup>, the Family Carer Scorecard 2024 is the third and final assessment of the Government's progress in implementing the 18 commitments for family carers contained in the Programme for Government, 'Our Shared Future', agreed by the coalition parties in June 2020.<sup>1</sup>

When reflecting on the achievements of the outgoing government, progressive change can be seen in some areas, while in others there has been no progress or things have gotten worse for family carers. Family Carers Ireland recognises the immense challenges presented by the COVID-19 pandemic during the early years of the Government's term in office, which stymied its efforts to implement the Programme for Government and hindered progress in the delivery of some commitments. Despite the pandemic however, welcome progress has been made in relation to the creation of the new Long-Term Carers Contribution Scheme, which gives carers caring more than 20 years access to the State Pension (Contributory), and a Family Carer Register. There have been substantial increases in the income and capital disregard for Carer's Allowance and Government has finally ratified the Optional Protocol of the United National Convention for People with Disabilities (UNCRPD).

However, significant challenges remain for family carers. The cost-of-living crisis continues to impact on caring households grappling to meet the increasing costs of care. The ongoing housing crisis is impacting on caring households and people with disabilities who want to live independently but can't access appropriate housing. The failure to provide regular, appropriate and quality respite has left many carers to care alone, 365 days a year, without a break. Day services, which are a lifeline to people with a disability and their families, have barely returned to pre-pandemic levels. Perhaps of most concern is the failure to address the crisis in children's disability services, leaving thousands of children floundering on waiting lists, without the Assessment of Need they are entitled to and without the interventions they so desperately need.

As we mark the end of this Government, it is clear that there are some of the commitments made in the Programme for Government to family carers that have not received sufficient urgency or attention. Family Carers Ireland will continue in our efforts to ensure the next Programme for Government contains ambitious commitments for carers and we will monitor their implementation through a new series of Family Carer Scorecards.

### Family Carers Ireland's perspective of highs and lows during the review period:

#### Highs

- Increase in the Carer's Allowance income disregard from €665 to €1,250 (couples) and from €332.50 to €625 (single carers)<sup>2</sup> and an increase in the capital disregard from €20,000 to €50,000.
- Increase in the annual Carer's Support Grant from €1,700 to €2,000.<sup>3</sup>
- Introduction of the Long-Term Carer Contributions Scheme giving people caring 20+ years access to the State Pension (Contributory) and creation of a Family Carer Register (available at MyWelfare.ie).
- Ratification of the UNCRPD Optional Protocol.
- Introduction of the Work Life Balance and Miscellaneous Provisions Act 2023 giving carers in employment a right to five annual unpaid carer leave days and the right to request flexible working.

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<sup>1</sup> Department of the Taoiseach, 'Programme for Government: Our Shared Future', 2020.

<sup>2</sup> Carer's Allowance income disregards will increase from €900 to €1,250 (couples) and €450 to €625 (single carers) in July 2025.

<sup>3</sup> Carer's Support Grant will increase to €2,000 in 2025.

- €600k in funding towards the enhancement of respite support.
- €400k Dormant Accounts funding to support carers to engage in employment or education; the production of digital resources for young carers and a campaign to help carers self-identify.

### **Lows**

- Failure to fully fund the Carer Guarantee.
- Continued under-resourcing of appropriate respite care across the life course.
- Referendum on Family and Care.
- Failure to provide timely Assessments of Need to thousands of children as is their right under the Disability Act 2005.
- Failure to deliver on every child's constitutional right to an appropriate school place.
- Failure to publish a refreshed National Carers' Strategy.
- Failure to deliver the long-awaited statutory home support scheme first committed to in 2017.
- Ongoing issues in relation to access and quality of CAMHS.
- The housing crisis and worsening cost of living pressure on households.
- Impact of the continuing chronic shortage of Home Support Workers on family carers who are being forced to care alone and unsupported.
- Failure to introduce the Transport Support Scheme committed to in 2013 and continuation of two-tier Disabled Drivers and Disabled Passengers Scheme that is only available to people with profound physical disabilities.

## Our Approach

Family Carers Ireland has examined the Programme for Government and selected 18 commitments for inclusion in the Scorecard based on several criteria:

- The commitment directly impacts family carers, defined as someone who is providing an ongoing significant level of care to a person in need of that care in the home due to illness, disability or frailty.
- The commitment is clear and measurable.
- If achieved, the commitment has the potential to significantly improve the quality of life of family carers and those for whom they care.

The 18 commitments cover the needs of all family carers, including those caring for a child, adult or older person; those receiving social welfare support and those not; and include a range of policy areas to reflect the many issues that can affect carers' lives.

The Family Carer Scorecard 2024 sets out the findings of an online survey undertaken by Family Carers Ireland between 23<sup>rd</sup> October and 4<sup>th</sup> November 2024. The survey was completed by 939 family carers. A link to the survey was sent to Family Carers Ireland's membership and disseminated via social media and through [www.familycarers.ie](http://www.familycarers.ie). The survey comprised of 21 questions. Question 1 was a screener question to ensure the survey was completed by people who were providing care at that time or had provided care within the last 12 months. The remaining 20 questions related to each of the 18 commitments in the Programme for Government (commitments 5 and 6 were broken into two parts (a) and (b)). These questions followed a standard format and included a paragraph and/or table presenting a summary of the evidence relating to the commitment followed by a question asking the respondent to assign the 'rating they feel reflects the level of progress made in implementing that commitment during the review period.'<sup>4</sup> The rating allotted to each of the 18 commitments in the Family Carer Scorecard is the rating that was most frequently assigned by family carers in the survey. See appendix 1 for a typical example of a question included in the online survey and the data provided.

### Scorecard Framework

<b>Commitment Achieved</b>	<b>Making a real difference for family carers</b>
<b>Good Progress</b>	<b>Positive results for family carers</b>
<b>Limited Progress</b>	<b>Some progress but slow pace/delayed start</b>
<b>No Progress</b>	<b>Nothing has been achieved</b>
<b>Regressive</b>	<b>Things have gotten worse</b>

The evidence presented was taken from a number of sources:

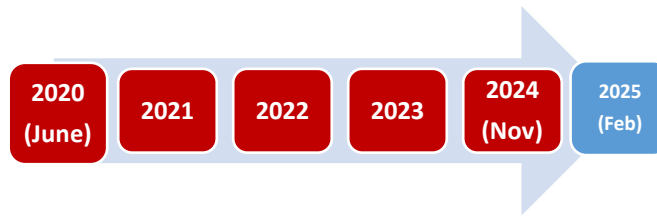
- An analysis of policy documents, responses to Parliamentary Questions, HSE National Service Plans, Department of Health Disability Capacity Review to 2032, Department of Public Expenditure and Reform (DPER) Public Service Performance Reports and relevant annual reports.
- Evidence gained from family carers and stakeholders working within the caring sector.
- Engagement with relevant Government departments and statutory agencies.

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<sup>4</sup> In the Family Carer Scorecard 2024 survey the questions relating to commitment 5 and 6 were broken into two parts (a) and (b) as each commitment refers to two distinct policy areas. This decision was made following feedback from carers in the preparation of the 2023 scorecard.

### Review Period 2020-2024

The period under review in the Family Carer Scorecard 2024 is from June 2020 when the Government was formed and the Programme for Government agreed, until November 2024 when the Government was dissolved pending a General Election on November 29<sup>th</sup> 2024.



### Limitations of Consultation Method

Family Carers Ireland acknowledges a number of methodological limitations that should be noted when considering the ratings assigned in the Family Carer Scorecard 2024.

- In 2024 ratings were assigned by 939 family carers using only an online survey disseminated to members of Family Carers Ireland and via social media.
- The online survey was disseminated to members of FCI or carers within FCI’s network reach, which is not necessarily representative of the general population of carers.
- The age profile of people who complete an online survey is likely to be different to the general population of carers due to different levels of access to the internet or different levels of familiarity with engaging with online surveys. Any age difference amongst the cohort consulted could have impacted on the ratings assigned to commitments that affect a specific age-cohort or category of carer (e.g. parents of children with additional needs or older carers).
- Using an online survey reduced the ability to clearly articulate some complex policy areas or respond to carers’ questions.

## Summary of Family Carer Scorecard 2024

Of the 18 Programme for Government commitments assessed, none received a score of 'Commitment Achieved' or 'Good Progress'. Thirteen commitments received a 'Limited Progress' score, meaning that there have been steps in the right direction but progress is slow; four commitments received a 'No Progress' score, meaning that there was no evidence that any change has taken place that would have an impact on family carers' lives. Finally, three commitments received a 'Regressive' score, meaning that the situation has worsened for family carers during the review period.

Note: Following feedback from carers, it was agreed that commitments 5 and 6 should be broken into two parts (a) and (b) as each commitment refers to two distinct policy areas. This means that 20 scores have been assigned in the Family Carer Scorecard 2024, while 18 were assigned in the 2021 and 2023

## Family Carer Scorecard Scores 2024

2024	Regressive (3)	No Progress (4)	Limited Progress (13)
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### Who Cares?<sup>5</sup>

**A family carer is someone who provides care to a child or adult with additional needs, a physical or intellectual disability, frail older people, those with palliative care needs or people living with a chronic illness or experiencing mental health difficulties.**

- **13%** of the Irish population aged over 15 years provide care.
- Extrapolation to the national population means Ireland has some **499,904 family carers**.
- Family carers provide an average of **38.7 hours of care each week** which means that, collectively, they provide **19m hours of unpaid care each week**.
- The **annual replacement cost of the care provided by family carers is approximately €20bn**.
- 13% of children aged 10-17 years provide care. Extrapolation to the national population means there could be as many as **67,000 young carers** in this age cohort.

#### **Carers in Receipt of Social Welfare:**

- **97,407** people receive Carer's Allowance, of which 45,845 receive Half-rate Carer's Allowance.
- **4,118** people receive Carer's Benefit.
- **133,684** people received the Carer's Support Grant in 2024.
- **55,995** children receive Domiciliary Care Allowance.

<sup>5</sup> Statistics are taken from a number of sources: Census 2022, the Irish Health Survey 2019 and the Health Behaviours in School-aged Children Survey 2018. The replacement value is based on an hourly replacement rate of €20.

## Ratings Table

No	Programme for Government Commitment	2024
1	Deliver a 'Carer Guarantee' proposal that will provide a core basket of services to carers across the country, regardless of where they live	No Progress
2	Extend free GP care to carers in receipt of the Carer's Support Grant	Limited Progress
3	Review and update the National Carers' Strategy	No Progress
4	Establish a commission to examine the care of older people	Limited Progress
5	(a) Introduce a Statutory Home Support Scheme to provide equitable access to quality, regulated home care and (b) increase home support hours for older people	No Progress
		Limited Progress
6	(a) Deliver increased home support and (b) personal assistance hours for disabled people	Limited Progress
		No Progress
7	Extend the remit of the National Treatment Purchase Fund (NTPF) to secure timely assessment for both child and adult psychological services	Regressive
8	Reduce the waiting times for assessment of need under the Disability Act 2005	Regressive
9	Provide additional residential places and new emergency residential places for disabled people	Limited Progress
10	Provide additional respite nights for disabled people	Limited Progress
11	Expand adult day services and support for adults with physical, sensory and intellectual disability and autism throughout the country	Regressive
12	Examine options for a pension solution for long-term family carers, the majority women, in recognition of the enormous value of their work	Limited Progress
13	Protect core social welfare rates / recognise the importance of ancillary benefits and eligibility criteria to vulnerable groups	Limited Progress
14	Enhance the demand-led Seniors Alert Scheme and ensure it adapts to changing demographics and technological advancements	Limited Progress
15	Ensure each child with a special educational need has an appropriate school place in line with their constitutional right	Limited Progress
16	Increase the Home Carer Tax Credit	Limited Progress
17	Maintain support for the Housing Adaptation Grant Scheme	Limited Progress
18	Ensure an appropriate mix of housing types is provided, including universally designed units and accommodation for older people and disabled people	Limited Progress

## **Analysis of the Progress made during the Review Period on Implementing the 18 Commitments**

- 1. Deliver a ‘Carer Guarantee’ proposal that will provide a core basket of services to carers across the country, regardless of where they live.**

**Responsibility:** Department of Health

**Why this is important to family carers:** Inconsistent and inadequate funding to the caring sector over many years created a postcode lottery where access to essential supports such as respite, training and advocacy was determined by where a carer lived rather than what they needed. The Carer Guarantee is a proposal committed to in the Programme for Government to abolish the postcode lottery and ensure the uniform delivery of a core basket of services to all carers regardless of where they are located.

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In 2019, Family Carers Ireland developed a ‘Carer Guarantee’ proposal setting out how, with additional annual funding, the organisation could ensure the uniform delivery of a core basket of services (peer support, training, emergency respite, advocacy and information) to family carers across the country, thus eliminating the postcode lottery that has long characterised carers’ access to services. Delivery of the Carer Guarantee was committed to in the Programme for Government.

In 2021, €2m in annual funding was committed to the Carer Guarantee by the Department of Health. Despite a firm commitment from the Taoiseach in June 2024 that he *‘intends to implement the Carer Guarantee’*, Family Carers Ireland is extremely disappointed with the announcement in Budget 2025 of just €600,000 of the additional €3.3m needed.<sup>6</sup> Having reached the end of its term, this government has failed to deliver the Carer Guarantee in full, as the €2.6m annual funding provided to date is not enough to ensure that all carers can access the same supports regardless of where they live.

**Carer Rating: No Progress**

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<sup>6</sup> Dáil Debate, June 18th, 2024 accessed at [https://www.oireachtas.ie/en/debates/debate/dail/2024-06-18/4/#spk\\_69](https://www.oireachtas.ie/en/debates/debate/dail/2024-06-18/4/#spk_69)



## 2. Extend free GP care to carers in receipt of the Carer's Support Grant.

**Responsibility:** Department of Health

**Why this is important to family carers:** The association between physical and psychological health and being a family carer is well established, with growing evidence that caring is a social determinant of health.

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The introduction of the Carer GP Visit Card for carers in receipt of Carer's Allowance and Carer's Benefit in 2018 was a welcome step in recognising the health and wellbeing needs of family carers. However, the decision to limit access to the Carer GP Visit Card to only carers in receipt of Carer's Allowance or Carer's Benefit means that 6,481 full-time family carers, who only receive the annual Carer's Support Grant, are excluded<sup>7</sup>. It also imposes a means test on carers' access to the GP Visit Card by virtue of the means test applied to Carer's Allowance. This is at odds with the Government's plan for the universal rollout of free GP care and counter to the universal access afforded to the over 70s and children under 8 years who are rightly not means-tested.

In August 2023, free GP care was extended to include all children under 8 and in September and November 2023, the income limits for the GP Visit Card were increased, making free GP care available to an additional 500,000 people. While the increases in earning thresholds will benefit some family carers, it is disappointing that there has been no progress in extending eligibility specifically to include the 6,481 full-time family carers who receive the annual Carer's Support Grant as a standalone payment, as was committed to in the Programme for Government.

**Carer Rating: Limited Progress**

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<sup>7</sup> Department of Social Protection figures provided to FCI in February 2024 show that 6,481 full-time carers received the Carer's Support Grant as a stand-alone payment in 2023.

### 3. Review and update the National Carers' Strategy.

**Responsibility:** Department of Health

**Why this is important to family carers:** Ireland's first National Carers' Strategy published in 2012 provided the strategic direction for future policies, services and supports provided for family carers by government departments and agencies. The strategy was designed around a core vision to recognise and respect carers as key care partners and support them to maintain their own health and well-being, care with confidence and participate as fully as possible in economic and social life. Oversight of the strategy was led by the Department of Health, with individual government departments leading on action areas under their remit.

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In 2019, it was agreed that the actions contained in the National Carers' Strategy had been exhausted and no further annual progress reports would be compiled. The Programme for Government agreed in 2020 committed to review and update the National Carers' Strategy.

Responding to a Parliamentary Question in July 2021, the Minister for Health affirmed his commitment to publish a refreshed National Carers' Strategy.

*"The Programme for Government contains a firm commitment to progress the review and update of the National Carers' Strategy, and this is a priority for me... my department will undertake preparatory work this year in relation to the design, scope and workplan for delivering a review of the Strategy. Furthermore, my department is committed to keeping all the key stakeholders informed in relation to our progress, including relevant government departments, representative organisations and those who advocate on behalf of family carers."*<sup>8</sup>

Responding to a parliamentary question in September 2024, the Minister confirmed that work on updating the strategy had not commenced, stating:

*"Before commencing work on updating the National Carers' Strategy, consideration is being given regarding the approach and the breadth of stakeholder consultation. A review of the Strategy, carried out by Care Alliance Ireland and University College Cork in 2021, found that over 90% of carers felt the actions in the Strategy were still relevant and wanted them retained. In March, I established with Minister Humphreys an inter-departmental group examining supports for family carers. ... The inter-departmental group will report its findings in Q3 2024."*<sup>9</sup>

As of November 2024, a refreshed National Carers' Strategy has not been published nor is Family Carers Ireland aware of the commencement of any preparatory work within the department.

**Carer Rating: No Progress**

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<sup>8</sup> PQ36088/21 27<sup>th</sup> July 2021

<sup>9</sup> PQ 25386/24 13<sup>th</sup> June 2024

#### 4. Establish a commission to examine the care of older people.

**Responsibility:** Department of Health

**Why this is important to family carers:** The pandemic exposed the fracture lines in our health and social care system and its heavy reliance on residential care for older people. The establishment of a Commission on Care for Older Persons will provide an opportunity to reassess how we care for older people, how we can break the imbalance between home and residential care and how to create positive ageing strategies across the life course.

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On October 3<sup>rd</sup>, 2023, the Minister for Health and Minister of State for Mental Health and Older People announced the establishment of a Commission on Care for Older Persons. The commission is charged with examining the provision of health and social care services and support for older people and with making recommendations to the government for their strategic development. The first meeting of the commission took place on March 21<sup>st</sup>, 2024.

The commission is chaired by Professor Alan Barrett (Chief Executive Officer, Economic and Social Research Institute) and is comprised of independent experts in the areas of geriatrics, gerontology, health economics, health policy and management, primary care, health ethics, health technologies, and ageing and disability, as well as representation of the community and voluntary sector and older people. It is supported by a secretariat from the Department of Health.

The work of the commission will be advanced through three consecutive modules. Module 1 will consider the effectiveness, adequacy and efficiency of the care and support currently provided within the health and social care system, and the plans to meet the evolving needs of our ageing population. Module 2 will examine the broader policy options for older people's care, as determined in Module 1, and will develop a costed and detailed implementation plan for the selected options. In Module 3, a cross-departmental group will be established to consider whether the mainstreaming of ageing across government and civil society is effective in supporting citizens' healthy, positive, and autonomous ageing across the life course.

The first two modules will be of six months' duration while the final module will run for 12 months with the commission expected to complete its work in early 2025. Funding of €1.2 million was secured in Budget 2024 to support the work of the commission.

**Carer Rating: Limited Progress**

**5. (a) Introduce a Statutory Home Support Scheme which will provide equitable access to high-quality, regulated home care and (b) increase home support hours for older people.**

**Responsibility:** Department of Health

**Why this is important to family carers:** A well-resourced home support scheme would provide people with the choice to receive care more appropriately in their homes and communities and end the current legislative anomaly whereby people have an entitlement to nursing home support under the provisions of Fair Deal but no equal entitlement to be cared for at home.

**5(a) Introduce a Statutory Home Support Scheme**

Government first committed to introduce a Statutory Home Support Scheme 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 work is ongoing by the Department of Health in relation to drafting regulations, examining funding options, reforming the model of service delivery, piloting the interRAI assessment tool and addressing chronic staff shortages in the care sector, the Statutory Home Support Scheme will not be introduced during the term of this Government.

The Department of Health projects that following the enactment of the General Scheme of the Health (Amendment) (Licensing of Professional Home Support Providers) Bill, published in May 2024, it will take a further three years for the new system to become fully operational. This three-year implementation period includes a 12-month commencement period and a 24-month transitional period.

**5(b) Increase Home Support Hours for Older People**

The Programme for Government commits to increasing the number of home support hours for older people. While there has been an upward trend in the delivery of home support hours during the review period, increasing by 26%, the Public Service Performance Review Reports for 2020 - 2023 show that the number of hours delivered has consistently fallen short of the targets set by the HSE in its annual Service Plan. In 2023, the last year for which figures are available, 92% of targeted home support hours were delivered. It should be noted that in 2023, the Department of Health sanctioned an adjustment to the National Service Plan target to provide 23.9m home support hours to a reduced target of 22m hours – a reduction of 1.9m hours. This was done to allow the HSE to fund improvements to the terms and conditions of home support providers and workers agreed in 2023. The 92% achievement rate is based on the original target of 23.9m hours.

**Home Support Hours for Older People<sup>10</sup>**

	2020	2021	2022	2023	% change 2020-2023
Home Support Hrs	17.5m	20.5m	20.8m	22.1m	+26%
Target Hrs	18.9m	21.9m	23.7m	23.9/22m	-
% target	93%	94%	88%	92%	-

<sup>10</sup> Public Sector Performance Review Reports 2020 – 2023.

**Waiting List:** The number of older people on a waiting list for home support hours has reduced by 40% during the review period, falling from 7,881 people waiting in 2020<sup>11</sup> to 4,702 people waiting in May 2024.<sup>12</sup>

### Intensive Home Care Hours

While the number of Home Support Hours for older people increased during the review period, the number of Intensive Home Support Hours decreased by 24%. The Public Service Performance Review Report shows that in 2023, only 58% of the targeted intensive hours were delivered. The report also shows that only 74 people were in receipt of an Intensive Home Care Package in 2023 – just 31% of the target of 235 people.

### Intensive Home Care Hours

	2020	2021	2022	2023	% change 2020-2023
Intensive Home Care Hours	276,025	246,374	219,678	210,550	-24%
Target Hours	360,000	360,000	360,000	360,000	-
% target	77%	68%	61%	58%	-

<b>Carer Rating: No Progress (a)</b>
<b>Carer Rating: Limited Progress (b)</b>

<sup>11</sup> PQ53114/19 17<sup>th</sup> December 2019.

<sup>12</sup> PQ30331/24 10<sup>th</sup> July 2024.

**6. (a) Deliver increased home support and (b) personal assistance hours for disabled people.**

**Responsibility:** Department of Health/Dept of Children, Equality, Disability, Integration and Youth<sup>13</sup>

**Why this is important to family carers:** The right to live independently and be included in the community is set out in Article 19 of the UNCRPD. State Parties, including Ireland, are obliged to facilitate the full enjoyment of this right by ensuring disabled people have “*access to a range of in-home, residential and other community support, including personal assistance necessary to support independent living.*”

**6 (a) Home Support Hours for People with Disabilities**

The number of home support hours delivered to people with a disability increased during the review period by 21%, a total of 605,397 hours. Recipients of home support hours increased by 3%, with 234 more people receiving home support hours in 2023 than in 2020. The HSE National Service Plan (NSP) 2024 commits to delivering 3.48m home support hours this year. The latest figures show that at the end of Q1 2024, 951,427 hours were delivered, 9.4% ahead of the NSP target and 15% ahead of the same period last year. The number of people in receipt of home support at the end of Q1 is 7,023, 4% less than the NSP target of 7,326.

**Home Support 2020 - 2023<sup>14</sup>**

		2020	2021	2022	2023	% change 2020-2023
<b>Home Support Hours</b>	Hours	2,939,541	2,949,806	3,369,146	3,544,938	+21%
	Recipients	6,792	6,902	7,146	7,026	+3%

**6(b) Personal Assistance Hours**

The number of PA hours delivered decreased between 2022 and 2023 by 5% falling from 1,781,310 hours to 1,686,227 – a reduction of 95,083 hours. The number of recipients of PA hours increased modestly by 2% or 55 additional recipients.

The HSE NSP 2024 commits to delivering 1.85m PA hours this year. The latest figures available show that by the end of Q1 2024, 459,413 PA hours were delivered, 0.7% less than the NSP target of 462,501. However, it is 5.8% more than during the same period last year. In Q1, the number of people in receipt of PA hours was 2,867, 4.6% ahead of the NSP target of 2,740.

**Personal Assistance 2020 - 2023<sup>15</sup>**

		2020	2021	2022	2023	% change
<b>Personal Assistance</b>	Hours	1,781,310	1,700,309	1,746,136	1,686,227	-5%
	Recipients	2,673	2,613	2,669	2,728	+2%

<b>Carer Rating: Limited Progress (a)</b>
<b>Carer Rating: No Progress (b)</b>

<sup>13</sup> Responsibility for specialist disability services transferred from the Dept of Health to the Dept of Children, Equality, Disability, Integration and Youth in March 2023. The HSE retain responsibility for specialist disability services.

<sup>14</sup> PQ 29157/24 11<sup>th</sup> July 2024.

<sup>15</sup> PQ 29157/24 11<sup>th</sup> July 2024.

7. **Extend the remit of the National Treatment Purchase Fund (NTPF) to secure timely assessment for both child and adult psychological services.**

**Responsibility:** Department of Health

**Why this is important to family carers:** Each waiting list statistic represents a child or adult waiting for a psychological intervention while potentially deteriorating clinically. As well as having a detrimental impact on their mental health, a failure to provide psychological support can impact physical health and prevent children from reaching their full potential.

The NTPF is a government body established to decrease waiting lists in the public healthcare system. It funds the private treatment of long-waiting public patients on an inpatient/day case waiting list for surgery. Given long-standing delays in access to psychological services, particularly for children, the Programme for Government commits to amend the National Treatment Purchase Fund (Establishment) Order 2004 to include child and adult psychological assessments.

In 2023, when asked about progress to extend the NTPF to include psychological assessments, the Minister for Health confirmed that no progress had been made and cast doubt as to whether this would be achieved. He stated: *“Notwithstanding Primary Legislation would be required there are other core factors that may militate against a role for the NTPF... The NTPF could potentially play a role in the future. However, there are foundational issues that need systematic reform...”*<sup>16</sup>

**Psychology Waiting Lists:** In February 2024, 21,132 people were waiting for a psychology service, an increase of 102% since 2020 when 10,466 people were waiting. 18,368 of those waiting are young people aged under 18 – a 107% increase since 2020 when 8,893 were on the waiting list. Of the children waiting for psychology services, 7,472 (41%) have been waiting for more than 1 year - a 55% increase since 2020.

**Psychology waiting list 2020 -2024<sup>17</sup>**

Year	Children	Waiting >1yr	Adults	Waiting >1yr	Total
2020 (Oct)	8,893	4,807 (54%)	1,553	449	10,446
2021 (Sept)	9,533	4,415 (46%)	1,858	517	11,391
2023 (April)	15,698	5,823 (37%)	2,924	844	18,622
2024 (Feb)	18,368	7,462 (41%)	2,764	1,119	21,132
% change	+107%	+55%	+78%	+149%	+102%

**Child and Adolescent Mental Health Service (CAMHS):** There are currently 3,882 children on a waiting list for CAMHS, a 41% increase since 2020. 14% are waiting for more than one year.

**Number of children on CAMHS waiting list 2020 – 2024<sup>18</sup>**

	2020	2021	2022	2023	2024	% change
Children waiting	2,755	2,625	3,556	4,434	3,882	+41%

**Carer Rating: Regressive**

<sup>16</sup> PQ 42872/23 4<sup>th</sup> October 2023.

<sup>17</sup> [Figures provided by the HSE February 2024.](#)

<sup>18</sup> PQ 15437/24 April, 2024.

## 8. Reduce the waiting times for Assessment of Need (AON) under the Disability Act 2005.

**Responsibility:** Department of Health/Department of Children, Equality, Disability, Integration and Youth

**Why this is important to family carers:** An Assessment of Need (AON) is the first critical step in a child’s journey towards securing the health and educational support they need. Early diagnosis and intervention are key to achieving long-term positive effects on symptoms and later skills. Delay in accessing an AON is not only injurious to the present well-being of the child but is likely to have a ripple effect that will require far greater funding and support for the child at a later stage.

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Any child born on or after 1 June 2002 and thought to have a disability has a right to an AON under the Disability Act 2005. Since the Act's commencement in 2007, there have been significant year-on-year increases in the number of children applying for both an AON and disability services, leading to extensive waiting lists. This is despite the Act setting out statutory timelines under which AONs must be completed.

- Stage 1: Assessment Officer must commence the assessment process (no later than 3 months after application is received).
- Stage 2: Completed assessment report must be forwarded to the Liason Officer (within a further 3 months from the date the assessment commenced).
- Stage 3: Service Statement completed (within 1 month following receipt of the assessment report by the Liaison Officer).

### Children waiting for an AON

The Programme for Government pledges to prioritise the delivery of earlier diagnostic interventions, reduce AON waiting times and improve service accessibility. Family Carers Ireland has welcomed these commitments however, almost five years on and despite increased investment, few children with additional needs and their families have experienced any positive change.

At the end of Q1 2024, 9,924 children were on a waiting list for an AON. This is a 112% increase since 2020. These figures mask the true extent of children who need an assessment as thousands do not appear on the waiting list because their families have been forced to pay for a private assessment.

### Children waiting for an Assessment of Need 2020 - 2024<sup>19</sup>

No. Children waiting for AON	2020	2021	2022	2023	2024	% change 2020-2024
	4,674	5,899	6,755	8,472	9,924	+112%

### Targeted Initiative focused on long-waiting families

In June 2024, the HSE launched a new initiative to target families who have been waiting the longest for an AON. Under this initiative, the HSE will fund private clinicians to undertake AONs for long-waiting families. It is estimated that the funding of €6.89m will allow the HSE to procure up to 2,500 additional AONs during Q3 and Q4 2024.

**Carer Rating: Regressive**

<sup>19</sup> PQ 26194/24 reply received 25<sup>th</sup> June 2024.



**9. Provide additional residential places and new emergency residential places for disabled people.**

**Responsibility:** Department of Children, Equality, Disability, Integration and Youth

**Why this is important to family carers:** In June 2011, the report *Time to Move on from Congregated Settings* was published. It identified that in 2008, approximately 4,000 individuals with disabilities were living in congregated settings, defined as “where ten or more people reside in a single living unit or are campus-based”. The report was adopted as policy and implementation began to end congregated living and replace it with a new model for residential support, where disabled people are supported to live ordinary lives in ordinary places. It is now policy that no more than four disabled people would share a home in any residential setting. These are referred to as residential places.

Residential services make up the largest part of disability funding disbursed by the HSE, accounting for 58% of the total disability budget. Approximately 90 service providers provide residential services to over 8,472 individuals throughout the country, with a smaller number (approx. 13%) provided by the HSE.

While there has been a 3% increase in the number of residential places available between 2020 and 2023, increasing from 8,139 to 8,400 places, this does not match the level of demand for residential places due to demographic changes, a rise in the number of disabled people, the increase in age and life expectancy and the changing needs of disabled people as identified by the Disability Capacity Review up to 2032. Emergency residential places are put in place by the HSE to respond to the most urgent cases on its waiting list. Between 2020 and 2023, the number of emergency places increased by 86%.<sup>20</sup>

**Residential and new emergency placements 2020 - 2024<sup>21</sup>**

	2020	2021	2022	2023	2024 (May)	% change 2020 - 2023
Residential places	8,139	8,146	8,282	8,400	8,472	+3%
New emergency places	86	91	103	160	63	+86%

While an 86% increase in the number of emergency residential places may appear positive, it is critical that the health service plans ahead to ensure that community-based models of residential care are available to people with disabilities when they want and need them, rather than relying on emergency places which cost substantially more. The failure to provide adequate residential places forces many disabled people who need residential support to live in situations that are not of their choosing. Similarly, parents, who are often elderly, struggle to continue to provide care for an adult child within their home because no appropriate residential place is available. The closure of congregated settings has not been replaced with a sufficient pipeline of new, funded community-based supports for those coming into adulthood or whose needs (or those of their carers) change and who now require residential support.

**Carer Rating: Limited Progress**

<sup>20</sup> Comparison was made between 2020 and 2023 as the data for 2024 is not in respect of the full year.

<sup>21</sup> PQ 28042/24. Reply received July 2nd 2024.

## 10. Provide additional respite nights for disabled people.

**Responsibility:** Department of Children, Equality, Disability, Integration and Youth

**Why this is important to family carers:** Access to regular, appropriate and quality respite is critical to sustaining family carers and is an integral element of carer support. It is deeply concerning that family carers have no entitlement to respite, meaning many care full-time, 365 days a year, without a break.

Respite can occur in a variety of settings and for various lengths of time, depending on the needs of the individual and their family or carer. Respite can be centre-based or provided in other ways, e.g. in-home, home-to-home, family support, etc. Respite is a vital element of the continuum of services to support family carers and helps prevent residential placements, preserves the family unit, supports family stability and improves quality of life.

While the Programme for Government commits to increasing respite nights for disabled people, the availability of respite has come under pressure in recent years due to a variety of factors including an increase in demand due to a rise in the number of people living with disability and chronic conditions, the need for specialist respite for children and adults with complex care needs and HIQA regulations. These regulations stipulate minimum requirements for personal space and privacy which has impacted on the availability of respite. For example, a room or bed in a residential setting vacated by a person who goes home at weekends or on holidays can no longer be used for respite.

### Recipients of Respite

During the review period, the number of disabled people receiving respite increased from 3,652 in 2020 to 6,086 in 2023.<sup>22</sup> Funding increased by 49% from €70,677,000 in 2020 to €105,703,000 in 2023.

### Respite funding 2020 - 2023<sup>23</sup>

Respite	2020	2021	2022	2023	% change
Funding for Disability Respite	€70,677,000	€87,423,000	€96,465,000	€105,703,000	+49%

### Number of Day-Only Respite Sessions and Centre-Based Respite Nights

The delivery of both day-only and respite nights increased during the review period (2020 – 2024) by 81% and 73% respectively. A comparison between 2020 and 2023 figures masks a reduction in day-only respite in 2021 and 2022. However, this is understandable given the closure of respite during the COVID-19 pandemic. It should also be noted that while figures are positive for the review period, the quantum of both day-only and overnight respite is only now beginning to be restored to pre-pandemic levels.<sup>24</sup>

### Day-Only Respite Sessions<sup>25</sup>

	2020	2021	2022	2023	2024	% change 2020-2023
Target	33,712	20,958	22,474	24,444	40,400	+20%
<b>Actual</b>	<b>20,958</b>	<b>14,826</b>	<b>23,244</b>	<b>38,000</b>	-	<b>+81%</b>
% target	62%	71%	103%	155%	-	-

<sup>22</sup> HSE National Service Plans.

<sup>23</sup> PQ: 36215/24 asked by Deputy Pauline Tully. Reply given October 2<sup>nd</sup> 2024.

<sup>24</sup> Day-only respite was 33,712 in 2019. Respite nights were 158,441 in 2019.

<sup>25</sup> HSE National Service Plan 2020-2024.

**Respite Nights 2020-2024<sup>26</sup>**

	<b>2020</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024 (July)</b>	<b>% change 2020-2023</b>
Target	166,183	85,336	92,552	129,012	160,000	-3.7%
<b>Actual</b>	<b>87,177</b>	<b>94,606</b>	<b>133,572</b>	<b>151,123</b>	<b>76,863</b>	<b>+73%</b>
% target	52%	111%	142%	117%	Incomplete Year	-

**Carer Rating: Limited Progress**

<sup>26</sup> PQ: 36215/24 Reply received October 2<sup>nd</sup>, 2024, and data from Public Services Performance Reports 2020 – 2023.

**11. Expand adult day services and supports for adults with physical and sensory disabilities, intellectual disability and autism throughout the country.**

**Responsibility:** Department of Health/Department of Children, Equality, Disability, Integration and Youth

**Why this is important to family carers:** Day services are a lifeline for many disabled people and their families. It is a Government priority to support disabled people to live ordinary lives in ordinary places by (i) replacing residential institutions and campuses with community-based housing in line with Article 19 of the UNCRPD and (ii) providing more person-centred day services in line with the New Directions policy.

Adult day services are HSE-funded programmes that provide day services to disabled people aged 18 and over. Day services are provided to 19,300 people across 1,091 locations by 97 service providers. The average full-year cost of a new day placement is €32,615.<sup>27</sup> New Directions is the HSE's approach to supporting disabled people who use day services. It sets out 12 supports that should be available to disabled people using day services and proposes that day services should take the form of individualised, outcome-focused supports that allow adults using those services to live a life of their choosing in accordance with their own wishes, needs and aspirations.

**People in receipt of day service 2020-2024<sup>28</sup>**

	2019	2020	2021	2022	2023	2024 (to date)	% change 2020-
People in receipt of day services	22,281	16,762	17,734	18,423	18,963	19,300	+15%

An analysis of HSE data shows the impact that the pandemic had on day services, with the number of people in receipt of day services falling from 22,281 in 2019 (before the pandemic) to 16,762 in 2020. While the number of people attending day services during the review period increased by 15%, the number of recipients of day services in 2020 was at a low level due to the pandemic. When the number of recipients in 2024 is compared to those attending a day service in 2019, there is a 13% reduction. This means that the level of day services provided prior to the pandemic has not been fully restored.

**Autism Innovation Strategy**

In August 2024, Government launched the Autism Innovation Strategy which includes 83 actions to be implemented over an 18-month period. The strategy places the lived experiences of autistic people and families at the core of the oversight structures and promotes a human-rights based approach to the inclusion of autistic people in Irish society. The 83 actions contained in the strategy fall under four pillars (i) building an autism-affirming society (ii) equality of access to public services (iii) accessible, inclusive communities and (iv) building capacity. Many of the actions centre around improving accessibility, knowledge, and awareness about the needs of autistic people in schools, the workplace, other public spaces, and within the healthcare service. The strategy also sets out plans for the accurate collection of data on autism through surveys and research projects.

**Carer Rating: Regressive**

<sup>27</sup> PQ: 30719/24. Reply received July 23<sup>rd</sup> 2024.

<sup>28</sup> PQ: 36217/24. Reply given on September 25<sup>th</sup> 2024.

## 12. Examine options for a pension solution for long-term family carers, the majority of whom are women, in recognition of the enormous value of their work.

**Responsibility:** Department of Social Protection

**Why this is important to family carers:** For decades, family carers, the majority women, were denied a State Pension or received a reduced pension because of their years spent caring. Family Carers Ireland has lobbied to ensure carers are recognised, not penalised for their caring years and have their contribution valued in the same way as paid PRSI contributions.

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For many years, Family Carers Ireland has lobbied for an equitable State Pension system that recognises rather than penalises family carers and values the immense contribution they make through their years of caring, in the same way we value social insurance ‘contributions’ paid through PRSI. We therefore welcomed the Programme for Government commitment to examine solutions to address the pension anomaly that has disadvantaged long-term carers for decades and the subsequent recommendations put forward by the Commission on Pensions. Based on the commission's recommendations, the Department of Social Protection developed a new Long-Term Carer Contributions Scheme to give full-time carers caring for 20+ years access to the State Pension (Contributory). Since the scheme's launch in January 2024, 2,186 carers have been awarded over 20 years of Long-Term Carer Contributions - 1,487 of these carers are aged over 66 years. At the beginning of October 2024, a total of 8,822 carers have registered their caring role on the Family Carer Register on MyWelfare.ie.

From January 1<sup>st</sup>, 2024:

- Full-time carers caring for 20+ years will be given Long-Term Carer Contributions in recognition of their caring years.
- Long-Term Carer Contributions will be treated the same as PRSI paid through employment.
- Care provided during these 20+ years will satisfy the statutory requirement to have at least 520 PRSI contributions (10 years) to qualify for the State Pension (Contributory). Even if a person doesn't have any paid PRSI contributions, they can still use their Long-Term Carer Contributions to help them qualify for a State Pension (Contributory).
- Once Long-Term Carer Contributions are awarded, they can be added to any paid PRSI contributions from employment.

### **Applying for Long-Term Carer Contributions and Registering Caring Periods**

In September 2023, the Department of Social Protection opened a Family Carer Register allowing full-time family carers to formally register their caring role. Carers do not have to be a long-term carer to register. All full-time family carers are strongly encouraged to register, even if they are receiving a care-related social welfare payment, have cared for a relatively short time or continue to provide care. By registering, their caring periods will be formally recorded and this will help protect them from having gaps in their PRSI record when they reach retirement age – even if that is many years from now.<sup>29</sup>

**Carer Rating: Limited Progress**

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<sup>29</sup> Registration is through MyWelfare.ie.

### 13. Protect core social welfare rates / recognise the importance of ancillary benefits and eligibility criteria to vulnerable groups.

**Responsibility:** Department of Social Protection

**Why this is important to family carers:** Taking on full-time caring responsibilities can result in long-term financial hardship, with the loss of income from employment exacerbated by higher household costs. Increasing social welfare rates to mitigate the rising costs of living as well as valuing the immense contribution of family carers is critical to ensuring they are protected from financial hardship and have a decent standard of living.

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The language used in the Programme for Government to “protect” rather than increase core social welfare rates is disappointing and aspires only to maintain the status quo. Nonetheless, significant improvements have been achieved across carer schemes during the review period, specifically:

#### *Core social welfare rates<sup>30</sup>*

- Increase in the maximum weekly Carer’s Allowance payment from €219 to €260 (+19%).
- Increase in the weekly rate of Carer’s Benefit from €220 to €261 (+19%).
- Increase in Domiciliary Care Allowance from €309.50 to €360 per month (+16%).
- Increase for Qualified Children (IQC)<sup>31</sup> rates have increased by €14 for children under 12 (+39%) and by €22 for children over 12 (+55%).
- Increase in the annual Carer’s Support Grant from €1,700 to €2,000 (+18%).

#### *Income disregards/means-testing<sup>32</sup>*

- Increase in the Carer’s Allowance income disregard from €665 to €1,250 for couples and from €332.50 to €625 for single people (+88%).
- Increase in the capital disregard for Carer’s Allowance from €20,000 to €50,000 (+150%).
- New means test disregard for Fuel Allowance for people aged over 66 - €524 (single) and €1,048 (couple). Means assessment threshold for Fuel Allowance for under 66s increased from €120 to €200
- Half-rate Carer’s Allowance is now disregarded in the means assessment for Fuel Allowance.
- In 2024, the Minister for Social Protection established an Interdepartmental Group with the Department of Health to review the system of means-testing carer payments. The group is due to report its recommendations in Q4 2024.

#### *Ancillary supports*

- Carer’s Allowance was made a qualifying payment for Fuel Allowance.
- Domiciliary Care Allowance and Carer’s Allowance will be paid for six months (rather than three months) for children who go into hospital
- Free Travel Scheme extended to people who are medically certified unfit to drive.
- Free Travel companion pass will be extended to all people aged over 70.
- Carer’s Benefit extended to include the self-employed.

#### *Cost of living measures*

- Carers received energy credits totalling €1,300

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<sup>30</sup> Figures listed include increases announced in Budget 2025 that are due to come into effect in January 2025.

<sup>31</sup> Increase for Qualified Child payment has been renamed ‘Child Support Payment’.

<sup>32</sup> Changes to income disregard announced in Budget 2025 will come into effect in July 2025.

- Carers in receipt of the Carer's Support Grant have received a total of €1,300 in once-off cost of living measures, in addition to three double-week payments for those receiving Carer's Allowance.

*Long-Term Carer Pension*

- Since January 2024, long-term carers caring 20+ years can access the State Pension (Contributory) through the new Long-Term Carer Contributions Scheme.

***Example of the impact of Budget announcements on the Carer's Allowances means test since 2020:***

**Case 1 - Couple:** Annemarie works full-time and earns €1,500 gross per week. Her partner John is a full-time carer for their child who has autism. They have savings of €100,000.

Means test in 2020 / 2021:

John does NOT qualify for Carer's Allowance.

New disregards in 2022:

John does NOT qualify for Carer's Allowance.

***New disregards announced in Budget 2024:***

***Qualifies for €5.50 per week***

***New disregards announced in Budget 2025:***

***Qualifies for approx. €192 per week***

**Carer Rating: Limited Progress**

#### 14. Enhance the demand-led Seniors Alert Scheme and ensure it adapts to changing demographics and technological advancements.

**Responsibility:** Department of Rural and Community Development

**Why this is important to family carers:** Ageing in place means being able to live at home and in your own community safely, regardless of age, income or ability level. While feeling secure and having access to security pendants is important, it is not the only way technology can be used. Offering a broader range of assistive technologies to people of all ages through the Seniors Alert Scheme would help give peace of mind and support positive ageing.<sup>33</sup>

The Seniors Alert Scheme (SAS) provides funding for a personal monitored alarm connected to a contact centre to enable older people to continue to live securely in their homes. The scheme is funded by the Department of Rural and Community Development via Pobal, with equipment made available through community organisations. The scheme is demand-led, so expenditure is driven by demand.

While the number of new approvals and expenditure on the Seniors Alert Scheme has increased during the review period by 2% and 20% respectively, the scheme itself has not changed or been enhanced as committed to in the Programme for Government. A *Review of the Delivery Model of the Seniors Alert Scheme* published in 2017 recommended that the services provided by the scheme be extended from its “narrow ‘alarm and security’ focus to embrace broader aspects of health and well-being” with “additional funding sourced from other government bodies to facilitate the move from social alarms to telecare”,<sup>34</sup> Despite this recommendation, and the obvious opportunities to expand the scheme to reflect the significant advancements in the application, availability and affordability of assistive technologies, the scheme has not changed or adapted during the review period and eligibility remains confined to persons over 65 years.

##### **Seniors Alert Scheme new approvals and expenditure 2020–2024<sup>35</sup>**

	2020	2021	2022	2023	2024 (March)		% change 2020-
New Approvals	16,719	14,225	15,577	17,032	4,867		+2%
Expenditure	€5.1m	€4.8m	€4.6m	€6.1m	-		+20%

**Carer Rating: Limited Progress**

<sup>33</sup> If the Senior Alert Scheme was extended to include adults of all ages, the name of the scheme would need to be changed.

<sup>34</sup> *Review of the Delivery Model of the Seniors Alert Scheme*, Telehealth Quality Group 2017.

<sup>35</sup> Seniors Alert Scheme Annual Reports published by Pobal and PQ 18850/24 April 30<sup>th</sup> 2024.



**15. Ensure each child with a special educational need has an appropriate school place in line with their constitutional right.**

**Responsibility:** Department of Education

**Why this is important to family carers:** Despite having a constitutional right to an education, families across Ireland continue to struggle to secure a school place for their child(ren) both at primary and second level. However, providing a school place alone does not satisfy the State's constitutional obligation to provide an equitable education to all children. Even children who have a school place can experience a lack of appropriate support in school, have a reduced timetable, not have access to necessary technology or communication devices or may experience an inaccessible school environment.

**Special Education Provision**

There are currently 134 special schools nationwide, 124 supported by the National Council for Special Education (NCSE), seven attached to hospitals and three attached to the Child and Adolescent Mental Health Service (CAMHs). It is estimated that a further 300 new special school places may be required nationwide each year for the coming years.

The number of Special Needs Assistants (SNAs) to provide support to children with additional needs has increased by 28% during the review period. The announcement of an additional 1,600 SNAs in Budget 2025 will bring the total number of SNAs to over 23,000 in 2025, the highest number of SNAs ever allocated. The number of Special Education Teachers (SETs) has also increased, rising from 13,620 in 2020/2021 to 14,600 in 2024/2025, a 7% increase. Budget 2025 announced the recruitment of an additional 768 SET in 2025.

The number of students supported in special classes increased by 59% between the 2020/2021 and 2023/2024 school years. There has been an 11% increase in the number of students supported in special school placements during the same period.

**Number of SNAs, SETs and students supported in special class and special school placements.<sup>36</sup>**

Academic Year	Special Needs Assistants <sup>37</sup>	Special Education Teachers	Number of students supported:	
			Special Classes	Special School Placements
2020/2021	17,032	13,620	10,436	7,900
2021/2022	18,004	13,765	12,289	8,158
2022/2023	19,169	14,418	14,352	8,424
2023/2024	20,788	14,551	16,548	8,784
2024/2025	21,900	14,600 <sup>38</sup>		
% change	+28%	+7%	+59%	+11%

<sup>36</sup> National Council for Special Education Annual Reports.

<sup>37</sup> PQ 36451/24 18<sup>th</sup> September 2024.

<sup>38</sup> PQ 38923/24 1<sup>st</sup> October 2024.

## Home Tuition

The Home Tuition Scheme provides a compensatory educational service for children who are unable to attend school. It is not an alternative to school but is intended to be a short-term intervention. Any downward trend in the number of children availing of home tuition is welcome as this implies they have secured a school place. During the school year 2023/2024, 1,392 children received home tuition because they did not have a school place (this excludes children aged under three years). Overall, the number of children receiving home tuition reduced modestly by 9% during the review period. However, there has been a 57% increase in children with special education needs receiving home tuition.

### **No. of children in receipt of home tuition funding 2020-2024<sup>39</sup>**

	2020/21	2021/22	2022/2023	2023/2024	% change
Early Intervention <3yrs	106	110	98	65	-39%
Age 3yrs+	670	702	694	682	+2%
Medical	228	195	186	178	-22%
Mental Health	347	387	418	397	+14%
SEN - School Age No Place	86	69	77	135	+57%
No School Place	159	91	174	185	+16%
<b>Total</b>	<b>1596</b>	<b>1554</b>	<b>1647</b>	<b>1457</b>	<b>-9%</b>

### **Summer Programme (formerly July Provision)<sup>40</sup>**

In 2021, the department announced a four-fold increase in the number of children eligible to participate in the Summer Programme, increasing from 23,000 to 81,000 students, and for the first time allowed all schools to host the programme. The budget was doubled from €20m in 2020 to €40m in 2021. This €40m budget has been maintained through to 2024. The department undertook a comprehensive review of the Summer Programme in 2023 focused on encouraging more schools and staff to participate. These efforts have resulted in a 124% increase in the number of children who have participated.

### **Number of children who have taken part in the Summer Programme since 2020**

No. students	2020	2021	2022	2023	% change
Primary School Scheme	-	6,103	8,372	17,695	+190%
Post Primary School	2243	2228	2787	3830	+71%
Special School Scheme	-	-	-	2437	-
Special Class/Special School	3892	5587	5758	-	+48%
Home-Based	9716	13321	13883	12772	+31%
DEIS L&N Summer Camp	7000	10738	11211	14498	+107%
<b>Total</b>	<b>22851</b>	<b>37977</b>	<b>42011</b>	<b>51232</b>	<b>+124%</b>

## Review of the EPSEN Act 2004

A review of the Education for Persons with Special Education Needs (EPSEN) Act 2004 was initiated by the Department of Education in December 2021 to modernise the Act and reflect the experiences of students, staff and families. This review is due to be concluded in the fourth quarter of 2024.<sup>41</sup>

**Carer Rating: Limited Progress**

<sup>39</sup> PQ27874/24 20<sup>th</sup> July 2024.

<sup>40</sup> PQ34453/24 9<sup>th</sup> September 2024.

<sup>41</sup> PQ18958/24 30<sup>th</sup> April 2024.

## 16. Increase the Home Carer Tax Credit

**Responsibility:** Department of Finance

**Why this is important to family carers:** The Home Carer Tax Credit is an important support to families balancing paid employment and care by reducing the amount of tax they pay by the amount of the credit. The credit is available to married couples or couples in a civil partnership jointly assessed for tax.<sup>42</sup> The Home Carer Tax Credit is one of a number of tax reliefs available to caring families. As such, this commitment could have been strengthened by also committing to increase the other care-related tax credits.

The Home Carer Tax Credit has increased by 22% between 2020 and 2024, notwithstanding the Budget 2025 announcement to increase it by €150 will not come into effect until January 2025. The maximum income allowable for the carer has increased during the review period from €10,400 to €10,800 (4%).<sup>43</sup> In 2023, the Minister for Finance confirmed that 67,000 taxpayers benefit from the Home Carer Tax Credit.<sup>44</sup>

While not included as a Programme for Government commitment, it is notable that both the Incapacitated Child Tax Credit and the Dependent Relative Tax Credit have also been increased. The Incapacitated Child Tax Credit was increased for the first time in over a decade in Budget 2024 from €3,300 to €3,500. It was increased again in Budget 2025 by €300, bringing it to €3,800 (January 2025). This is available to the parent or guardian of a child or adult who is permanently incapacitated, either physically or mentally, and where there is a reasonable expectation that the child will be unable to maintain themselves when over 18.

The Dependent Relative Tax Credit, while not as generous as the other credits, increased by 336% during the review period, rising from just €70 to €305. The Dependent Relative Tax Credit is available to people who maintain a dependent relative who has an income of less than €17,404.

### Increase in Tax Credits for Carers 2020 – 2025.

Tax Credit	2020	2021	2022	2023	2024	2025	% change
Home Carer	€1,600	€1,600	€1,600	€1,700	€1,800	€1,950	+22%
Incapacitated Child	€3,300	€3,300	€3,300	€3,300	€3,500	€3,800	+15%
Dependent Relative	€70	€245	€245	€245	€245	€305	+336%

**Carer Rating: Limited Progress**

<sup>42</sup> FCI continues to lobby for the Home Carer Tax Credit to be available to single people and those not married or in a civil partnership.

<sup>43</sup> A carer can work while the household receives a Home Carer Tax Credit however their earnings must not exceed €10,800.

<sup>44</sup> PQ 33344/23 6<sup>th</sup> July 2023.

## 17. Maintain support for the Housing Adaptation Grant Scheme.

**Responsible:** Department of Housing, Local Government and Heritage

**Why this is important to family carers:** The Housing Adaptation Grant Scheme (HAGS) provides a suite of supports to older and disabled people to assist them in carrying out works, repairs and accessibility upgrades to their homes. The scheme is an important element of the Government’s ageing in place and housing for people with disability policy statements.

The Programme for Government commits to “maintaining support for the Housing Adaptation Scheme” - a more modest commitment than that made by the previous Government which sought to “invest significantly in the scheme.”<sup>45</sup> Nonetheless, funding for the HAGS has increased during the review periods, rising by 26% between 2020 and 2024. Family Carers Ireland notes the long-standing failure of local authorities to draw down the totality of funding allocated to them, despite waiting lists for the scheme, and therefore we welcome the reversal of this trend over recent years, with all funding drawn down in 2022 and 2023 with funding top-ups provided by the department.

Funding for the HAGS had reduced significantly during the austerity years starting in 2011. However, there has been a year-on-year increase in funding during the review period with funding levels slowly returning to 2010 levels when funding was at its highest of just under €100 million.

### HAGS funding and drawdown 2020 – 2024<sup>46</sup>

Year	Housing Aid Older People €'000	Housing Aid Disability €'000	Mobility Aid Grant €'000	Total Grants	Total HAGs Drawdown €'000	Total Exchequer Funding €000	% Drawdown
2020	12,762	26,653	5,960	8,137	45,377	59,000	77%
2021	19,184	31,062	6,246	10,283	56,492	60,000	94%
2022	24,258	38,085	6,375	12,487	68,717	65,000	106%
2023	29,522	40,770	4,988	13,698	75,279	66,500	113%
2024	-	-	-	-	-	74,500 <sup>47</sup>	
% change	+131%	+53%	-16%	+68%	+66%	+26%	

*\*Total Exchequer funding does not include the 20% contributed by the Local Authority*

### Review of HAGS

‘Housing for All – A New Housing Plan for Ireland’ commits to review the full suite of housing adaptation grants for older people and disabled people. A public consultation to inform this review was launched in March 2022 and considered income thresholds, grant limits, and the application and decision-making processes. In September 2024 the Department of Housing published the Report on the Review of the

<sup>45</sup> Programme for Partnership Government (2016).

<sup>46</sup> [Department of Housing.](#)

<sup>47</sup> [PQ21249/24 May 14<sup>th</sup> 2024.](#)

Housing Adaptation Grants for Older People and People with a Disability. Amongst the recommendations included in the report are proposals to:

- increase the grant limits by over 30% and the income thresholds by 25%;
- amend the means test to exclude the income of adult children living in the home, increase deduction for children from €5,000 to €6,250, increase deduction for full-time carers from €5,000 to €6,250, introduce a deduction for housing mortgage/rent expenses up to €6,250, introduce a deduction for residential care fees up to €12,500; introduce a deduction for cost of care in the home (up to €12,500 or €6,250 if full-time carer deduction claimed).
- Explore the capacity to move towards an online application process.

These changes are expected to come into effect in Q1 2025.

**Carer Rating: Limited Progress**

**18. Ensure an appropriate mix of housing types is provided, including universally designed units, and accommodation for older people and disabled people.**

**Responsibility:** Department of Housing, Local Government and Heritage

**Why this is important to family carers:** Article 19 of the UNCRPD requires Ireland to deliver the right of persons with disabilities to “live in the community with choices equal to others” and to “have the opportunity to choose their place of residence and where and with whom they live”. If appropriate housing is not planned for and ultimately not available, then older people and disabled people are forced to live in unsuitable accommodation or placed inappropriately in residential care.

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**Local Authority Housing Allocations**

The number of allocations to households where disability is the primary basis of need across all local authorities increased by 34% between 2020 and 2022. There was an increase in the number of housing allocations across all disability types except intellectual disability, for which allocations reduced by 11%.

**Local Authority Housing Allocations to disabled people 2020-2022<sup>48</sup>**

Disability	2020	2021	2022	2023	% Change
Physical	1,038	1,121	1,089	1,424	+37%
Sensory	222	338	389	428	+93%
Mental	521	597	695	668	+28%
Intellectual	312	338	299	278	-11%
<b>Total</b>	<b>2,093</b>	<b>2,394</b>	<b>2,472</b>	<b>2,798</b>	<b>+34%</b>

**Summary of Social Housing Assessments Report**

The Summary of Social Housing Assessment Report (SSHAR) is a statutory assessment to count the total number of households that qualify for social housing support across the country but whose housing need is not currently being met. A comparison of the SSHARs between 2020 and 2023 shows a marginal increase of 0.4% in the number of households on a waiting list for social housing whose basis of need is disability. While some types of disability have seen a reduction, namely those seeking housing based on medical need or compassionate grounds (-28%) and those with other forms of disability (-9%), all other categories of disability have increased.

**Unmet Need for Social Housing 2020-2023**

Household member has:	2020	2021	2022	2023	% change 2020-2023
Intellectual disability	1,597	1,656	1,455	1,628	+ 2%
Mental health disability	1,550	1,477	1,621	1,604	+3%
Physical disability	1,493	1,418	1,430	1,550	+4%
Medical/compassionate	743	642	897	533	-28%
Sensory disability	362	347	356	457	+26%
Other form of disability	55	62	69	50	-9%
<b>Total</b>	<b>5,800</b>	<b>5602</b>	<b>5828</b>	<b>5822</b>	<b>+0.4%</b>

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<sup>48</sup> The Housing Agency: Journey to Independent Living accessed October 17<sup>th</sup> at: <https://www.housingagency.ie/journey-independent-living>

## Capital Schemes

Housing for disabled people is also funded under capital schemes in local authorities including through Capital Assistance Scheme (CAS). CAS provides funding to Approved Housing Bodies for the provision of independent living accommodation to meet the needs of vulnerable groups including disabled people. The number of units of housing delivered under CAS for disabled households decreased from 102 units in 2020 to 93 units in 2023. CAS, which received funding of €220m in 2023, is among the key measures to support the delivery of housing for disabled people under the National Housing Strategy for Disabled People 2022-2027.

	2020	2021	2022	2023	% Change
No. Units of CAS for Disabled Households	102	121	112	93	-9%

## Wasted Lives - Younger adults in nursing homes

'Wasted Lives', a report published by the Ombudsman in 2021, showed that 1,323 young and middle-aged disabled people are being forced to live in nursing homes because of a lack of State support to enable them to live independently.<sup>49</sup> Following efforts to transition younger adults out of nursing homes and into the community, the HSE reported in May 2024 that there are now 1,242 young adults living in a nursing home, meaning that 81 people have transitioned into the community since the Ombudsman's report in 2021. A further 51 individuals are in active planning for potential discharge.<sup>50</sup>

## National Housing Strategy for Disabled People 2022-2027

The National Housing Strategy for Disabled People 2022–2027 was published in January 2022 (under the auspices of Housing for All) followed by the publication of an implementation plan in June 2023. The strategy, underpinned by the UNCRPD, sets out the actions the Government will take to provide appropriate housing and related support for disabled people. Its vision is to *"facilitate disabled people to live independently with the appropriate choices and control over where, how and with whom they live, promoting their inclusion in the community."* A review of the implementation plan is due in Q4 2024. At the time of writing, the report has yet to be published.

## Ratification of the UNCRPD Optional Protocol

On the 8<sup>th</sup> October 2024 government announced its decision to accede to the Optional Protocol to the UNCRPD. On November 6<sup>th</sup> Minister for Children, Equality, Disability, Integration and Youth and Minister of State for Disability, announced that the formal process for accession has now been completed and the Optional Protocol to the UNCRPD will come into effect in Ireland on the 30<sup>th</sup> of November 2024. This means that from November 30<sup>th</sup> people in Ireland will be able to rely on the "communication procedure" in the Protocol to bring to the UN Committee's attention alleged breaches of rights under the Convention, usually on the condition that all domestic remedies have been exhausted.

**Carer Rating: Limited Progress**

<sup>49</sup> Time for a better future for younger people in nursing homes. (n.d.). Available at: <https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf>.

<sup>50</sup> HSE: Under 65s Ombudsman's Report. Implementation Progress Update May 2024.

**Next Steps**

The Family Carer Scorecard 2024 is the third and final assessment of Governments' progress in implementing the Programme for Government 'Our Shared Future' from the perspective of family carers. These scorecards are a valuable tool in helping us better understand if and to what extent family carers are feeling the impact of Governments efforts to improve care and disability policies. The scorecard also acts as a proactive and positive platform for discussion and engagement between Family Carers Ireland and Government. As we look forward to the formation of a new Government in early 2025, and the agreement of a new Programme for Government, Family Carers Ireland will continue the process of monitoring progress to ensure Government is held to account in delivering on its commitments for Irelands family carers.



## Appendix 1: Example of a question included in the Family Carer Scorecard Survey 2024.

### 8. Reduce the waiting times for Assessment of Need (AON) under the Disability Act 2005

#### Children waiting for an AON

The Programme for Government pledges to prioritise the delivery of earlier diagnostic interventions, reduce AON waiting times and improve service accessibility.

At the end of Q1 2024, 9,924 children were on a waiting list for an AON. This is a 112% increase since 2020. These figures do not include the many families who have had to pay privately for an assessment.

No. Children waiting for AON	2020	2021	2022	2023	2024	% change 2020-2024
	4,674	5,899	6,755	8,472	9,924	+112%

#### Targeted Initiative focused on long-waiting families

In June 2024, the HSE launched a new initiative to target families who have been waiting the longest for an AON. Under this initiative, the HSE will fund private clinicians to undertake AONs for long-waiting families. It is estimated that the funding of €6.89m will allow the HSE to procure up to 2,500 additional AONs during Q3 and Q4 2024.

What score would you assign this Programme for Government commitment based on the information provided?

- Commitment Achieved
- Good Progress
- Limited Progress
- No Progress
- Regressive