



Family Carer Scorecard 2023

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

December 2023



Family
Carers
Ireland

No one should have to care alone

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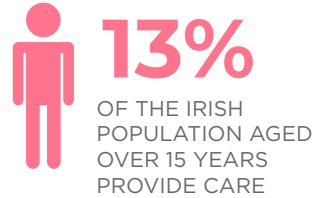
FAMILY CARER SCORECARD 2023

The Family Carer Scorecard 2023 is an assessment of Government’s progress in implementing the commitments for family carers contained in the Programme for Government, ‘Our Shared Future’, agreed by the coalition government in June 2020.¹ Family Carers Ireland has examined the Programme for Government and has selected 18 commitments for inclusion in the scorecard which are clear and measurable, most relevant and have the potential to significantly improve the quality of life of family carers and those for whom they care.

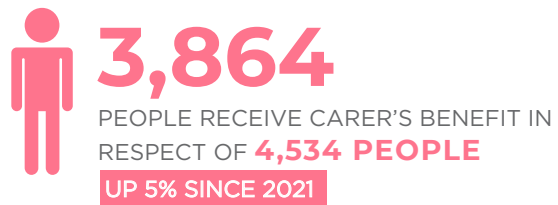
Family Carers Ireland recognises the immense challenges presented by the COVID-19 pandemic which have stymied Government’s efforts to implement the Programme for Government and have undoubtedly hindered progress in the delivery of some commitments. While it is understandable that momentum may have been lost, it is important to note that the Programme for Government was agreed in the months following the outbreak of COVID-19 and, as such, inaction due to the pandemic is not an acceptable reason for a lack of progress. It is also important to recognise that despite the damage inflicted by the pandemic, welcome progress has been made in relation to access to the State Pension (Contributory) for long-term family carers, increasing the income and capital disregard for Carer’s Allowance and the piloting of a statutory home support scheme. With the Government now approaching its final year in

office, it is imperative that we refocus and redouble our efforts towards ensuring that the ambitions of the Programme for Government are realised.

WHO CARES?²



CARERS IN RECEIPT OF SOCIAL WELFARE:



¹ Department of the Taoiseach, ‘Programme for Government: Our Shared Future’, 2020.

² Statistics are taken from Census 2016, 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.

Between 2016 and 2022, the number of people providing regular unpaid care increased by 53%. During the same intercensal period, the proportion of carers providing unpaid care for 43 hours or more increased from 21% to 29%.³

METHODOLOGY

The Family Carer Scorecard 2023 is Family Carers Ireland’s second analysis of Government’s progress in implementing the 18 commitments for family carers contained in the Programme for Government, ‘Our Shared Future’, agreed in June 2020. The first Family Carer Scorecard was published in December 2021. These 18 commitments were selected based on several criteria:

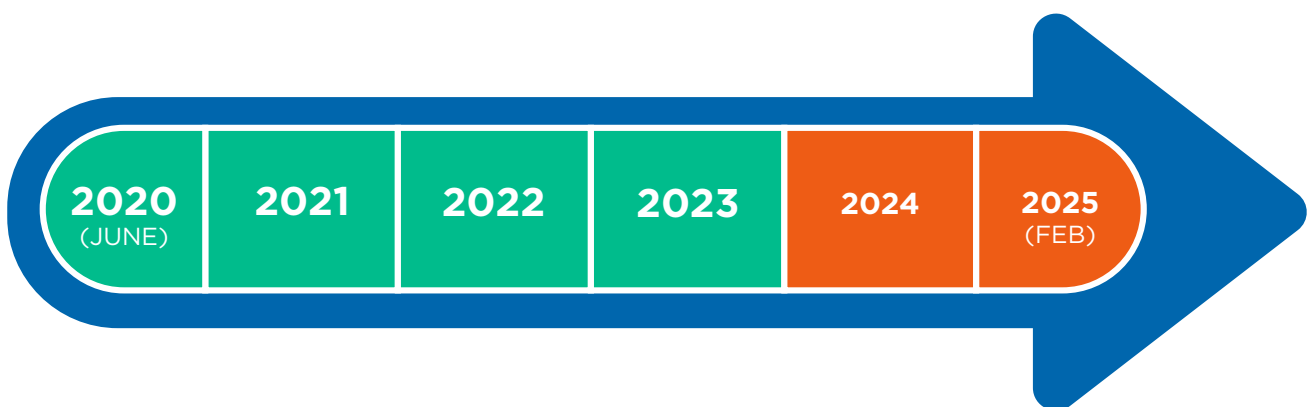
- The commitment directly impacts family carers, defined as someone who is providing an ongoing significant level of care to a person in need of that care in the home due to illness, disability or frailty.
- The commitment is clear and measurable.
- If achieved, the commitment has the potential to significantly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

The 18 commitments cover the needs of all 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 evidence used to assign scores to each of the 18 commitments is based on:

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

REVIEW PERIOD



³Census of Population 2022.

SCORECARD FRAMEWORK



The scorecard framework consists of five colour-coded ‘scores’ assigned to each commitment to reflect the level of progress that has been made during the review period. This framework was created by the National Carers’ Strategy Monitoring Group in 2013 and was used to produce annual National Carers’ Strategy Scorecard Reports until 2018. After that time, it was accepted that the 42 actions contained in the National Carers’ Strategy had been exhausted and that the annual progress reports compiled by the Department of Health in relation to the strategy would no longer be produced. In the absence of a refreshed National Carers’ Strategy, as committed to by Government, Family Carers Ireland now apply this methodology to scoring progress in relation to the implementation of the Programme for Government.

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

ASSIGNING SCORES

Six regional ‘Listening to Carers’ forums were hosted by Family Carers Ireland during October and November 2023 in Offaly, Kilkenny, Limerick, Dublin, Cork and Galway. A seventh virtual forum was held on November 17th to facilitate the views of carers who could not attend the in-person events. In each forum, a presentation was delivered showing the evidence relating to the implementation of each of the 18 commitments. Using Slido and Zoom polls, the 165 family carers in attendance were then asked to assign one of five colour-coded scores to each of the 18 commitments based on the evidence that had been presented. The score assigned to each commitment reflects the highest number of votes by participating family carers (a ‘modal’ rating). In seven cases the modal rating received more than 50% of the votes cast. A further 9 commitments received at least 40% of the votes cast. The remaining two commitments received 38% / 39% of votes. The scores in respect of commitments 9 and 11 displayed a bimodal distribution.

SUMMARY OF FAMILY CARER SCORECARD 2023

Of the 18 Programme for Government commitments assessed, none received a score of ‘Commitment Achieved’. Three commitments received a ‘Good Progress’ score, meaning that there have been positive results for family carers; five commitments received a ‘Limited Progress’ score, meaning that there have been steps in the right direction but this progress is slow and requires an increase in the pace of implementation; six 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, four commitments received a ‘Regressive’ score, meaning that the situation has worsened for family carers during the review period.

2021	Regressive (5)	No Progress (7)	Limited progress (4)	Good progress (2)
2023	Regressive (4)	No Progress (6)	Limited progress (5)	Good progress (3)

Highs

- Introduction of Long-term Carer Contributions in January 2024 that will give carers (caring 20+ years) access to the State Pension (Contributory).
- Launch of a new Family Carer Register by the Department of Social Protection allowing full-time family carers to register their caring role.
- Announcement that Government will hold a referendum on equality and care.
- Increase in the income disregard for Carer’s Allowance from €665 to €900 (couple) and from €332.50 to €450 (single carers).⁴ The capital disregard has increased from €20,000 to €50,000.
- Work Life Balance and Miscellaneous Provisions Act 2023 which gives an entitlement to five unpaid days leave for medical care purposes per year and the right to request flexible working for parents and carers.⁵
- Pilot of the Family Carer Needs Assessment tool in CHO2.
- 600,000 in funding towards the enhancement of respite supports.
- 400,000 Dormant Accounts funding to support family carers to engage in employment or education; the production of digital resources for young carers and a campaign to help carers self-identify.

Lows

- Children with additional needs continued to be denied the assessments and therapeutic supports they need, forcing families to pay privately.
- While efforts are being made to improve the system, too many children with additional needs remain without an appropriate school place.
- Failure to publish a refreshed National Carers’ Strategy.
- Continued under-resourcing of appropriate respite care across the life course.
- Delay in establishing the long-awaited statutory home support scheme first committed to in 2017.
- Impact of the continuing chronic shortage of Home Support Workers on family carers who are being forced to care alone and unsupported.
- Notwithstanding the allocation of €1.9m in recurring funding towards the Carers’ Guarantee, this falls short of the €5m necessary to fully eliminate the postcode lottery.

⁴As announced in Budget 2024 the Carer’s Allowance disregards will increase from €750 to €900 (couples) and €350 to €450 (single carers) in June 2024.

⁵The right to request flexible working has not yet commenced. The WRC is currently developing a Code of Practice.

SCORES TABLE

Programme for Government Commitment	2021	2023
Deliver a 'Carers Guarantee' proposal that will provide a core basket of services to carers across the country, regardless of where they live	No Progress	Limited Progress
Extend free GP care to carers in receipt of the Carer's Support Grant	No Progress	No Progress
Review and update the National Carers' Strategy	Regressive	No Progress
Establish a commission to examine the care of older people	Limited Progress	No Progress
Introduce a statutory home support scheme to provide equitable access to quality, regulated home care/increase home support hours for older people	Limited Progress	Regressive
Deliver increased home support and personal assistance hours for disabled people	No Progress	Limited Progress
Extend the remit of the NTPF to secure timely assessment for both child and adult psychological services	Regressive	No Progress
Reduce the waiting times for assessment of need under the Disability Act 2005	Good Progress	Regressive
Provide additional residential places and new emergency residential places for disabled people	Regressive	Limited Progress
Provide additional respite nights for disabled people	Regressive	Regressive
Expand adult day services and support for adults with physical, sensory and intellectual disability and autism throughout the country	Regressive	Regressive
Examine options for a pension solution for carers in recognition of the enormous value of their work	Good Progress	Good Progress
Protect core social welfare rates / recognise the importance of ancillary benefits and eligibility criteria to vulnerable groups	Limited Progress	Good Progress
Enhance the demand-led Seniors Alert Scheme and ensure it adapts to changing demographics and technological advancements	No Progress	No Progress
Ensure each child with a special educational need has an appropriate school place in line with their constitutional right	Limited Progress	Limited Progress
Increase the Home Carer Tax Credit	No Progress	Good Progress
Maintain support for the Housing Adaptation Grant Scheme	No Progress	Limited Progress
Ensure appropriate mix of housing, including universally designed units and accommodation for older people/disabled people	No Progress	No Progress

Deliver a ‘Carers’ 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 has led to a postcode lottery where access to essential supports such as respite, training and peer support is determined by where a carer lives rather than what they need. The Carers’ Guarantee proposal was developed by Family Carers Ireland to ensure the uniform delivery of a core basket of services to all carers regardless of where they live.

In 2019, Family Carers Ireland developed a ‘Carers’ Guarantee’ proposal setting out how, with additional annual funding of €5m, 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 helping to eliminate the postcode lottery that has long characterised carers’ access to services.

Recurring funding of €2m was secured in Budget 2021 for implementation of the Carers’ Guarantee. €1.9m of this funding was made available to Family Carers Ireland, while the remaining €100,000 is supporting the development and delivery of online supports through Care Alliance Ireland. The €1.9m allocation to Family Carers Ireland has enabled the organisation to begin to provide a more standard package of support to family carers across Ireland and extend services to approximately 5,000 additional family carers. Family Carers Ireland is delivering these supports through its nationwide network of Support Hubs using a three-tier public health model of carer support: universal access support, targeted community support and intensive support.

As part of the 2023 Estimates Process, the Department of Health sought additional funding of €2m for the Carers’ Guarantee which, if successful, would bring the total allocation to €4m, closer to the €5m initially proposed. This would allow Family Carers Ireland to establish a comprehensive network of family carer groups, both in person and online, organised geographically and by condition and

would enable the rollout of a carer identification programme. Family Carers Ireland estimates this additional funding would enable the organisation to provide one-to-one intensive support to an additional 10,000 family carers and support and engage with thousands more through our universal self-directed supports and carer identification campaign. The additional funding would also allow Family Carers Ireland to deliver an enhanced range of targeted supports including additional training and information sessions, face to face groups and online communities, as well as increased counselling hours and emergency respite packages.

As of November 2023, Family Carers Ireland has not received confirmation regarding this additional €2m. With the ongoing funding crisis within the health service, it is highly unlikely that this additional funding will be secured to deliver the Carers’ Guarantee.

What’s needed to progress this commitment:

The annual allocation of €1.9m has allowed Family Carers Ireland to begin to make progress in delivering the Carers’ Guarantee, however it is critical that the additional €2m funding sought by the Department of Health is secured if the organisation is to deliver fully on the commitments made in the original proposal. Critically, if Family Carers Ireland is to deliver the Carers’ Guarantee at the existing level of service, then funding levels must be benchmarked against inflationary pressures.



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. Despite this strong correlation, many family carers can't afford to visit their GP because of the costs involved - a phenomenon that has become even more prevalent with the cost of living crisis.

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 first step in recognising the health and wellbeing needs of family carers. However, the decision to limit access to only carers in receipt of Carer's Allowance or Carer's Benefit means that 5,696 full-time family carers, who only receive the annual Carer's Support Grant, are excluded.⁶ 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.

Budget 2022 extended free GP care to all children under 7 years, and in August 2023 eligibility was broadened to all children under 8. In September and November 2023, the income limits for the GP Visit Card were increased to include an additional 215,000 people earning less than the median household income.

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 carers in receipt of the Carer's Support Grant, as committed to. The failure to do so shows a disregard for the immense contribution made by the 5,696 full-time carers whose only recognition from the State is the annual Carer's Support Grant and ignores the adverse health effects they are likely to experience because of their caring role.



What's needed to progress this commitment:

In order to reach a greater number of full-time carers and in keeping with Government's own policy of universal access, the Carers GP Visit Card should be made available to all carers in receipt of the non-means tested Carer's Support Grant. This can be done outside of the Budgetary process so family carers should not have to wait until Budget 2025 to have the Carers GP Visit Card extended to include them.



⁶5,696 fulltime carers receive the Carer's Support Grant as a stand-alone payment.

Review and update the National Carers' Strategy.

Responsibility: Department of Health

Why this is important to family carers:

The National Carers' Strategy demonstrates the Government's commitment to family carers. It sets out in a single document the actions that will be undertaken across relevant government departments to improve the lives of carers. These actions cover the gamut of carer needs including recognition, financial support, home support, respite, transport, information, advocacy, housing, training and employment.

At a meeting between the Department of Health and Family Carers Ireland in September 2019, it was agreed that the actions contained in Ireland's first National Carers' Strategy, published in 2012, had been exhausted and no further annual progress reports would be compiled. Following the publication of the Programme for Government in June 2020, which renewed the commitment to update the National Carers' Strategy, Family Carers Ireland made a written submission to the Department of Health outlining the actions we believe the refreshed National Carers' Strategy should contain based on the commitments for carers set out in the Programme for Government. However, despite having received assurances in December 2020 that the refreshed strategy was a priority and would be published, this has not yet materialised.

Responding to a Parliamentary Question in July 2021 regarding progress towards the publication of a refreshed National Carers' Strategy, Minister for Health Stephen Donnelly reaffirmed his commitment to the publication of 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, as Minister for Health. To this end, 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 in this area, including relevant government departments, representative organisations and those who advocate on behalf of family carers.”

(PQ 36088/21).



As of November 2023, 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.

What's needed to progress this commitment:

Given the current period of significant health reform, including the focus on Sláintecare and the creation of a statutory home support scheme (both of which are dependent on the support of family carers), as well as demographic change, healthcare advances, long-term care policy and cost-containment pressures, it is critical that a refreshed National Carers' Strategy and action plan are developed and funding is ringfenced for its delivery. To progress this commitment, the Department of Health must immediately engage with representative organisations and agree a timeline towards the strategy's publication. As we approach the final phase of this Government, immediate action is needed if this commitment is to be achieved.

Establish a commission to examine the care of older people.

Responsibility: Department of Health

Why this is important to family carers:

The pandemic shone a light on the fracture lines in our health and social care system and the 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.

Weaknesses in our long-term care system were exposed by the pandemic, with older people and those in the poorest health most severely affected. We now have a better understanding of the dangerous architecture on which our current system of long-term care is built, its overreliance on nursing homes, the lack of integration between home and residential care and the incentivisation towards nursing homes in the absence of a statutory home support scheme. The establishment of a Commission on Care would take onboard the lessons learned from the pandemic and reassess how care for older people is provided while supporting people's choice to age in place.

On October 3rd, 2023, Minister for Health Stephen Donnelly and Minister of State for Mental Health and Older People Mary Butler announced the establishment of a Commission on Care for Older Persons, which is expected to get underway in January 2024. Minister Butler confirmed that the commission will examine the provision of health and social care support for older persons and make recommendations to Government on their strategic development. As part of the work of the commission, a cross-departmental group will be established to consider whether the supports for positive ageing across the life course are fit-for-purpose and to develop a costed implementation plan for options to optimise these supports.

While Family Carers Ireland welcomes the establishment of the commission, we note that it had been due to convene in 2022. Responding to a Parliamentary Question in June 2020, Minister Butler



noted that

“ It is currently envisaged that the scoping work for a commission will be significantly progressed this year in order that it may be established in 2022 ”

(PQ 5897/21).

Notwithstanding this delay, the newly announced Commission on Care for Older Persons provides an opportunity for us to future-proof our health and social care provision and set out a clear vision for the future of long-term care, how it will be delivered, how needs will be assessed and supported and how the system will be resourced.

What's needed to progress this commitment:

With 80-90% of care in the community provided by family and friends, it is imperative that the terms of reference for the Commission on Care for Older Persons include an examination of the role and reliance of family carers in the provision of long-term care. The commission should bring together all stakeholders to modernise the long-term care sector and better align all care settings including care in the home, nursing homes and residential and palliative care settings.

Given that care is provided across the life course, it would be illogical for the Commission to focus only on the care of older people, but rather should include the care of adults of all ages. This is in keeping with the decision to extend the statutory home support scheme to include all adults with care needs.

Introduce a statutory home support scheme which will provide equitable access to high-quality, regulated home care/increase home care 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.

A statutory scheme for the financing and regulation of home support services is a key Sláintecare proposal and a long-standing Government priority. The scheme, which will include adults of all ages, aims to ensure that users of home support services are provided with a standard, high-quality level of care which is safe, effective and person-centered. Work on the development of a statutory home support scheme commenced in 2017 following an announcement by then Minister for Mental Health and Older People Helen McEntee.

Responding to a Parliamentary Question on October 3rd 2023,⁷ Minister for Health Stephen Donnelly confirmed that work is ongoing within his department across four areas to progress the statutory home support scheme:

i. Regulation: The department is currently developing a regulatory framework for providers of home support services. This will comprise primary legislation for the licensing of home support providers, regulations which will set out the minimum requirements that a home support provider must meet to obtain a license and HIQA national standards. The Heads of Bill are currently being drafted and are expected to be brought to Government for approval before the end of the year. The draft regulations are at an advanced stage informed by a public consultation which concluded in August 2022. A report on the findings of the public consultation was published in January 2023. In addition, HIQA has initiated the process of developing standards for home care and home support.

ii. Examination of funding options: Home support services are currently fully funded by the Exchequer, however, the department is examining potential options for a new funding model for home support. The ESRI undertook a programme of work on behalf of the department on the potential demand for, and cost of, home support which culminated in two reports. The department has also commissioned a rapid response from the EU Observatory on Health Systems and Policies which explores the impact of user charges on home care sustainability in Ireland. This report was published in March 2023. No final decision on future funding has been made and further research is currently underway.

iii. Reformed model of service delivery: In 2022, a pilot was initiated in CHO4 to test a reformed model of delivery for home support. A draft evaluation of the pilot has been completed. The HSE has begun the recruitment of 128 interRAI Care Needs Facilitators. The process for the development of a home support IT system is underway. The HSE is undertaking a recruitment process for a number of key posts to support the establishment of a National Home Support Office. Funding is provided for 15 full-time jobs of which four have been appointed, including the Head of Service. A proposed location in Tullamore for the National Home Support Office is being sourced by the HSE.

iv. Strategic Workforce Advisory Group (SWAG): The cross-departmental SWAG was established in March 2022 to examine and



⁷PQ [42269/23]

make recommendations to address the chronic shortage of workers in the home support and long-term residential care sectors. The group's final report was published in October 2022 and contained 16 recommendations. Implementation of the recommendations is being overseen by a cross-departmental implementation group chaired by the Department of Health. The department is engaging with recommendation owners to define an implementation plan. A meeting of the group took place on June 29th. The implementation group will meet quarterly and publish progress reports thereafter. Recommendation 9 has been implemented. Work is underway on all recommendations, with a further four at an advanced stage.

When compared to the Sláintecare Action Plan 2021 – 2023, the minister's update reveals the extent to which the development of the statutory home support scheme is behind schedule. Much of the progress listed relates to 'early-stage' components of the scheme which, according to the Sláintecare Action Plan, should have been completed. While the pandemic has understandably affected the introduction of the scheme, it should not have delayed it by years. The original Sláintecare Implementation Plan in 2018 committed to the establishment of the scheme by the end of 2021.⁸ As we approach the end of 2023, it seems unlikely that the scheme will be introduced before 2025.

Given the chronic shortage of Home Support Workers and its impact on the delivery of home support hours, it is concerning that there appears to be no urgency in relation to the implementation of

the SWAG recommendations, with only one meeting of the implementation group having taken place since the publication of the report in October 2022. The HSE announcement of a recruitment freeze on Home Support Workers in October 2023, at a time when the sector is already in crisis, undermines the recommendations of the SWAG and gives little hope to the 6,432 people currently on a waiting list for home support.

In relation to the Home Support regulations, there has been a softening of the language used in some sections when compared to previous drafts, for example with regard to minimum training requirements. Because the regulations provide the baseline for the home support legislation this is likely to impact the delivery of the statutory home support scheme.

Home Support Hours for Older People

The Programme for Government commits to increasing home support hours for older people. While there has been an upward trend in the delivery of home support hours during the review period, the Public Service Performance Review Reports for 2020, 2021 and 2022 show that actual delivery of hours has consistently fallen short of the targets set. In 2022, the last year for which figures are available, only 88% of targeted home support hours were delivered. The shortfall is even more pronounced in intensive home care package hours, where in 2022 only 61% of target hours were delivered. The report for 2022 also shows that just 80 people were in receipt of intensive home care packages in 2022, which is 34% of the Department's target of 235 people.

Home Support Hours⁹

Year	Target Hours	Actual Hours	% Target
2023	23.9m / 22m	12.4m (up to 31st July)	-
2022	23.7m	20.8m	88%
2021	22.3m	20.7m	93%
2020	18.9m	17.8m	92.6%

Intensive Home Care Packages

Year	Target Hours	Delivered Hours	% Achieved
2023	360,000	-	-
2022	360,000	219,678	61%
2021	360,000	246,374	68%
2020	360,000	276,025	77%

⁸ Page 50: <https://www.gov.ie/pdf/?file=https://assets.gov.ie/9914/3b6c2faf7ba34bb1a0e854cfa3f9b5ea.pdf#page=null>

⁹ Public Sector Performance Review Reports 2020 – 2022.

Recent improvements to the terms and conditions of Home Support Workers are welcome, however, to allow the HSE to offer an increased rate to home support providers, the Department of Health sanctioned an adjustment to the National Service Plan target to provide 23.9 million home support hours in 2023, to a revised target of 22 million hours – a reduction of 1.9m hours. With 6,432 people currently on a waiting list for home support, a reduction in the provision of hours will only exacerbate this backlog further and may see existing clients facing cuts to their current home support allocation.

What is needed to progress this commitment:

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 14 years, families have had to accept a system that incentivises residential care and spends twice as much on Fair Deal than on home care, despite Government policy to support people to be cared for at home. The momentum lost in the creation of the statutory home support scheme must be regained. The establishment of the scheme should

be given utmost priority with an agreed timeline towards its introduction and appropriate funding made available to meet the demand implications of introducing a statutory entitlement to home support.¹⁰

The delivery of the statutory home support scheme is dependent on having access to a skilled pool of workers across the country. Even before the scheme is launched, the acute shortage of workers is having a detrimental effect on the sector, with home care providers frequently unable to deliver funded home support hours due to a lack of staff. Urgent efforts are needed to promote employment and attract and retain workers in the home care sector.

In 2023, Government will spend €1.5bn¹¹ on Fair Deal compared to €723m on home care.¹²



¹⁰ ESRI predict that following the creation of the scheme, the number of hours provided through publicly funded home support could increase from 18.56 million hours pre-COVID in 2019, to almost 42 million hours - a 126% increase. These projections are based only on the demand generated by older people over 65 and do not include demand from younger adults with care needs who will also be provided for under the scheme.

¹¹ PQ [32967/23]

¹² <https://www.gov.ie/en/press-release/2c486-ministers-for-health-announce-increased-rates-of-funding-for-state-funded-home-support-providers/#:~:text=In%202023%20the%20overall%20home,a%20more%20viable%20career%20option.>

Deliver increased home support and personal assistance hours for disabled people.

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

Why this is important to family carers:

The right to live independently and to be included in the community is set out in Article 19 of the UNCRPD. State Parties to the CRPD, including Ireland, are obliged to “take effective and appropriate measures” to facilitate the full enjoyment of this right, including by ensuring that disabled people have “access to a range of in-home, residential and other community support, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation.” Personal assistance (PA) and home support hours are critical to this.



Note: Since March 2023, responsibility for specialist disability services transferred from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth. The HSE has retained responsibility for the delivery of specialist disability services.

The HSE provides a range of assisted living services including PA and home support hours to support individuals with a disability to maximise their capacity to live full and independent lives. PA and home support hours are provided either directly by the HSE or through a range of voluntary service providers.

PA Hours

The tables below show the number of PA hours provided to disabled people from 2018 - 2022. While the number of PA hours delivered has increased between 2018 and 2022, the number of hours has decreased during the period of this Government, falling by 2%. The number of recipients of PA

hours has remained relatively unchanged. The average hours received by clients also remains relatively unchanged, however Disabled Persons’ Organisations (DPOs) continue to highlight the inadequacy of PA hours and are campaigning for the daily allocation of hours to increase as well as the need to include many more disabled people within the scheme.¹³

It should be noted that there is a discrepancy between the figures provided by the HSE in the table below when compared to those in the Public Service Performance Reports for 2022 prepared by the Department of Public Expenditure and Reform. The department report that the number of PA hours delivered in 2022 was 1,175,000 hours, significantly less than the 1,746,136 hours reported in the HSE Service Plan. Worryingly, the department’s figures show that while target hours were over-achieved in both 2019 and 2020, the actual number of PA hours delivered in 2022 was 31% less than targeted.

Personal Assistance 2018 - 2022 ¹⁴

	2018	2019	2020	2021	2022	% change 2020-2022
Personal Assistance Hours	1,639,481	1,652,030	1,781,310	1,700,309	1,746,136	-2%
Recipients	2,535	2,551	2,673	2,613	2,669	-0.15%
Avg. hrs per day	1hr 46m	1hr 46m	1hr 50m	1hr 47m	1hr 47m	-2%

¹³ Independent Living Movement Ireland ‘Not in the Driving Seat’ November 2023.

¹⁴ HSE National Service Plans 2018 - 2022

PA hours provided to persons with a physical and/or sensory disability ¹⁵

Year	Target Hours	Actual Hours	% Target
2023	1.77m	-	-
2022	1.7m	1.175m	69.1% ¹⁶
2021	1.74m	1.70	97.7%
2020	1.63m	1.78m	109.2%
2019	1.63m	1.65m	101.2%

In a recently published ESRI report examining PA services, the authors note that “there is a crucial lack of evidence on current PA service provision in Ireland. There is little understanding of how eligibility is determined, how PA services are provided, the outcomes of this provision for PA service users and what data are collected on PA applicants and service users”. ¹⁷

Home Support Hours for People with Disabilities

Home support hours have increased during the review period, however, when considered in the context of the reduction in service delivery during COVID-19 in 2020 and 2021, the baseline figure of 2,929,541 hours in 2020 was a low starting point. Average home support hours per recipient have increased during the period 2020 – 2022 by 8%, however the number of recipients of Home Support Hours has only increased by 5.5%.

Home Support Hours 2018 - 2022 ¹⁸

	2018	2019	2020	2021	2022	% change 2020-2022
Home Support Hours						
Hours	3,138,939	3,036,182	2,939,541	2,949,806	3,369,146	+15%
Recipients	7,522	7,321	6,792	6,902	7,146	+5.5%
Avg. hrs per day	1hr 14m	1hr 14m	1hr 19m	1hr 17m	1hr 29m	+8%

The Disability Action Plan 2024 – 2026, recently announced by Minister of State for Disability Anne Rabbitte, will include actions for the expansion and reform of specialist community-based disability services including PA and home support. The HSE has also announced that it intends to establish a working group to address current issues in relation to PA services, which will develop a model of service and access criteria. This group will include representatives of primary stakeholders including disabled people.

What is needed to progress this commitment:

The Department of Health’s Disability Capacity Review to 2032 found that data on unmet need

for PA and home support services has not been recorded, however, the report estimates that the level of unmet need is significant. The additional cost of demographic change is estimated at €4m a year by 2022, €10m a year by 2027 and €15m a year by 2032. An indicative package to provide greater access and additional levels of support to those who currently receive minimal hours has been costed at €30m a year. To progress this commitment and support all adults who require either PA or home support hours, it will be necessary for the department to undertake research to establish the level of unmet need and thereafter allocate an appropriate budget that allows disabled people to realise their right to live independently.

¹⁵ Dept. Public Expenditure and Reform Public Service Performance Reports 2019 -2022.

¹⁶ Please note, the HSE Service Plan 2023 suggests that the target for PA Hours was achieved in 2022. Similarly, the reply to PQ 35365/23 states that PA hours delivered in 2022 exceeded the target by 2%. However, this information is contradicted by the Public Services Performance Report 2022 published by DPER.

¹⁷ March 2023 Esri Working Paper No. 747 - Economic and Social Research Institute. Available at <https://www.esri.ie/system/files/publications/WP747.pdf> (Accessed: 25 October 2023).

¹⁸ HSE National Service Plans 2018 - 2022

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 service that they need while potentially deteriorating clinically. As well as having a devastating impact on their mental health, a failure to provide urgently needed psychological support can impact significantly on physical health and prevent children from reaching their full development potential.

The National Treatment Purchase Fund (NTPF) is a government body which was established to decrease waiting lists in the Irish public healthcare system. The NTPF works with public hospitals to provide funding for the treatment of long-waiting patients who are on an inpatient/day case waiting lists for surgery. The key criteria of the NTPF is the prioritisation of the longest waiting patients first. Given the long-standing issue in relation to access to psychology services, particularly for children, the Programme for Government contains a commitment to amend the National Treatment Purchase Fund

(Establishment) Order, 2004 to include child and adult psychological assessments.

In April 2023, 18,622 people were waiting on primary care psychology services. This is an increase of 78% since 2020 when the waiting list was 10,466. 15,698 of those waiting are young people below the age of 18 – up from 8,893 in 2020, a 77% increase. Of the children waiting for psychology services, 5,823 (37%) have been waiting for more than 1 year. This is a 21% increase in the number of children waiting more than 1 year since 2020.



Psychology waiting list 2020 -2023 ¹⁹

Year	Children Waiting	Waiting >1yr	Adults Waiting	Waiting >1yr	Total
2020 (Oct)	8,893	4,807	1,553	449	10,446
2021 (Sept)	9,533	4,415	1,858	517	11,391
2023 (April)	15,698	5,823	2,924	844	18,622
% change	+77%	+21%	+88%	+88%	+78%

According to the HSE, there are currently 4,434 children on a waiting list for Child and Adolescent Mental Health Services (CAMHS), which is a 61% increase since 2020.

Number of children on CAMHS waiting list 2020 - 2023

	2020 ²⁰	2021 ²⁰	2022 ²¹	2023 ²²	% change
Children waiting	2,755	2,625	3,556	4,434	+61%

¹⁹ PQ 25720/23 asked by Deputy Mark Ward on 30th May 2023.

²⁰ PQ 47739/21 asked by Deputy Mark Ward 19th October, 2021.

²¹ PQ 18198/22 asked by Deputy Marian Harkin on 25th April 2022.

²² PQ 18208/23 asked by Deputy Mark Ward on 20th April, 2023.

In responding to a Parliamentary Question on October 4th, 2023, which asked the Minister for Health Stephen Donnelly about the progress being made regarding the Programme for Government commitment to extend the NTPF to include psychological assessments, the minister's response confirmed that no progress has been made and cast doubt as to whether this would be achieved during the lifetime of this Government. He stated:

“

Notwithstanding the fact that primary legislation would be required to expand the NTPF's role there are other core factors that may militate against a role for the NTPF... Firstly, the nature of private capacity in the context of hospitals versus community services... People using HSE primary care therapies are likely to have more complex needs and, therefore, require several services at the same time, provided through a multidisciplinary team. In essence, they have a longer-term relationship with health services rather than an episodic relationship, and as such it would be necessary to cost and profile 'bundles' of work. In addition, careful consideration would need to be given to the impact of the purchasing of private capacity on long-term expansion of public capacity within primary care, and ensuring appropriate skill mix to meet the needs of people including children with more complex needs. The NTPF could potentially play a role in the future. However, there are foundational issues that need systematic reform...²³

”

The minister's response is concerning as it implies that the extension of the NTPF to include psychological services, albeit requiring legislative change, will need to be considered, despite having been committed to in the Programme for Government.

While Government has made efforts to address waiting times, through measures including the Primary Care Psychology Waiting List Initiative, the Waiting List Action Plan and increased funding,

as the figures above show, the crisis in accessing psychology services continues to worsen.

Speaking in the Dáil in May 2023 following a Labour Party motion on autism and disability services, Minister of State for Disability Anne Rabbitte proposed that either the HSE urgently address and resolve the issues presented in the motion by August or else she would bring a proposal to budget to sanction the use of the NTPF to allow families to buy assessments and therapies from private providers. Since then, six Regional Assessment Hubs have been established which means the minister did not have to enforce her ultimatum.²⁴

What's needed to progress this commitment:

There is a chronic shortage of psychologists across the mental health and disability sector. The Disability Capacity Review to 2032 estimated a minimum doubling of the number of psychologists in child disability services alone is needed to meet demand. The number of psychologists in CAMHS, as recommended by A Vision for Change, only reached 32% of the recommended levels. The HSE Report of the National Psychology Team Project²⁵ published in 2021 estimated an additional 321 psychologists were required in mental health services alone to meet demand.

While Family Carers Ireland recognises the efforts being made to address waiting lists, including the Psychology Waiting List Initiative and Regional Assessment Hubs, we are sceptical that this can be achieved through the public system alone. Rather we are calling for the extension of the NTPF to include not only psychological assessments but also other essential supports, such as speech and language, occupational therapy and physiotherapy, to clear the waiting lists for each of these essential therapies.

²³ PQ 43489/23 asked by Deputy Mattie McGrath on October 10th, 2023.

²⁴ Access to Autism and Disability Assessments and Supports: Motion [Private Members] – Dáil Éireann (33rd Dáil) – Wednesday, 24 May 2023 – Houses of the Oireachtas

²⁵ <https://www.hse.ie/eng/staff/jobs/eligibility-criteria/psychology-report-jan-2021.pdf>

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 may need. Early diagnosis and early intervention are key to positive outcomes. Delay in accessing an AON is not only injurious to the future wellbeing of the child but is also likely to have a ripple effect that will require far greater levels of funding and support at a later stage.



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 Disability Act setting out statutory timelines under which AONs must be completed.

	Action	Timeline
Stage 1	Assessment Officer must commence the assessment process	No later than 3 months after the application has been received
Stage 2	Completed assessment report must be forwarded to the Liaison Officer	Within a further 3 months from the date on which the assessment commenced
Stage 3	Service Statement must be completed	Within 1 month following receipt of the assessment report by the Liaison Officer

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, three years on and despite increased investment in disability services, few children with additional needs and their families have experienced any positive change. At the start of 2023, 7,144 children were on a waiting list for an assessment. Of these, 77% have been waiting more than three months. These figures underestimate the actual number of children in need of and waiting for an AON due to parents being forced to pay privately for these assessments.

Children waiting for an Assessment of Need 2018 - 2023²⁶

2018	2019	2021	2021	2021	2021	% change 2020-2023
5,060	6,596	4,674	5,899	6,755	7,144	+53%

²⁶ PQ 35084/23 asked by Deputy David Cullinane on July 13th 2023.

Responding to a Parliamentary Question regarding addressing the backlog in AONs, Minister of State for Disability Anne Rabbitte noted the funding allocated in Budget 2023 to facilitate additional assessments through a suite of measures including the establishment of dedicated AON assessment teams; private procurement and overtime initiatives for existing staff; and recruitment of administrative resources to free up therapists to assist with assessments. The minister also noted that the department has begun engagement with the HSE to consider what options might exist in respect of a proposal for a time-bound and quality assured reimbursement scheme.²⁷

High Court Ruling 2022

In August 2020, the HSE secured €7.8m in once-off Sláintecare funding to address overdue AONs. During 2020, each CHO developed a plan to address their overdue assessments using a combination of overtime, procurement of private assessments and the recruitment of additional staff. The impact of COVID-19 restrictions also required clinicians to deliver some assessments remotely. In addition, a 90-minute cap was placed on clinical assessments. During 2020/2021, the HSE cleared almost all overdue assessments, with 92% of overdue assessments cleared by September 2021. This progress was recognised in the Family Carer Scorecard 2021 with a score of 'Good Progress'. However, the report also expressed concern with the way these assessments were being undertaken and warned that if not sufficiently robust, then any apparent progress achieved by clearing the backlog would be ineffectual and would lead to problems further down the line.

In March 2022, the High Court ruled that the HSE's standard operating procedure did not comply with the Disability Act 2005 because it only consisted of 90-minute assessments and failed to properly examine the nature and extent of the child's disability. As a result, the assessments that had been completed during the clearing process are considered invalid.

What is needed to progress this commitment:

Family Carers Ireland acknowledges the efforts that have been made to clear waiting lists, albeit clear from the lack of impact on numbers that a different approach is needed. As noted in the previous section of this scorecard, Family Carers Ireland believes that the NTPF should be extended to include access not only to psychological assessments but also to the other therapeutic interventions children with additional needs require.

Even before the cost of living crisis the additional costs associated with caring for a child with complex needs was estimated to be approximately €244 per week. A significant proportion of this cost is because families must pay privately for services that are supposed to be publicly available.²⁸ Considering its failure to deliver on children's constitutional right to an AON, Family Carers Ireland believes the State must 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 NTPF.



²⁷ PQ 25682/23 asked by Deputy Jennifer Murnane O'Connor on May 23rd, 2023.

²⁸ MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. The additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent with a profound intellectual disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland.

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:

Under the UNCRPD, disabled people have the right to live independently in the community and have access to the appropriate services to support them.



Residential services make up the largest part of disability funding disbursed by the HSE - 60% of the total disability budget of €2.2bn in 2022. Approximately 90 service providers provide residential services to over 8,000 individuals throughout the country. These places are delivered predominantly by Section 38 and Section 39 organisations (78%). The HSE itself provides 13% of the places, while 9% are provided by private-for-profit agencies.

While there has been a small increase in the number of residential places available (2.5%) between 2020 and 2023 from 8,139 places to 8,343 places, this does not match the increased 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. A further challenge relates to the latent unmet need for residential care. The Disability Capacity Review to 2032 found that access to residential care has fallen since the 2008 recession and supply has not kept up with population growth. The resulting shortfall is estimated to range from a minimum of 800 up to 2,300 places. The report estimates that an average of about 90 new residential places are needed every year from 2020 to 2032 to cater for changes in the size and age structure of the disabled population.

Residential and new emergency placements 2020 - 2023 ²⁹

	2020	2021	2022	2023 (YTD Aug)	% change
Residential places	8,139	8,146	8,282	8,343	+2.5%
New emergency places	86	91	103	96	+12%

The lack of funding to meet increased demand means that the residential supports that are put in place are often provided on an emergency basis. This 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 alternative residential place is available.

The closure of congregated settings means

that previous residential support options are no longer available as new need comes on-stream. Congregated settings have 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.

In its response to a Parliamentary Question, the HSE illustrates the impact of Government’s policy to move away from residential settings:

²⁹ PQ 44179/23 asked by Deputy Marian Harkin on October 10th 2023.



Residential capacity will reduce as a result of the loss of places in congregated settings due to deaths, which cannot be re-utilised. This is in keeping with Government policy, which is to move away from institutionalised settings (i.e. Time to Move On from Congregate Settings) where the State is actively implementing a policy that will have a bed reduction impact. In addition, capacity levels are also negatively impacted as a result of regulatory requirements and inspections

(PQ 8774/23)



Residential places by CHO ³⁰

CHO	Residential Places (Dec 2022)
CHO1	695
CHO2	900
CHO3	802
CHO4	1,114
CHO5	914
CHO6	544
CHO7	1,144
CHO8	916
CHO9	1,253
Total	8,282

What is needed to progress this commitment:

Demand for residential places significantly exceeds supply. Since the onset of the recession in 2008, rather than increasing in line with population growth, the provision of residential places for disabled people has fallen. With such limited places, it is only those in the most extreme situations who get a residential place. In order to provide the necessary number of residential places to meet the level of demand projected in the Disability Capacity Review to 2032, Government must invest €550m annually. There is also an urgent need for a multi-annual investment programme to address the unmet need for residential care.

Disability Support Application Management Tool

HSE Disability Services use a Disability Support Application Management Tool (DSMAT) which allows CHOs to record and manage requests for support and ensure that the application process is equitable and transparent. The DSMAT provides a uniform listing process for each CHO by presenting

a detailed profile of adults and children who require support. It captures detailed information on home and family circumstances, key diagnoses and support needs due to the extent and intensity of the disability. In the absence of a statutory framework providing entitlement to services, the DSMAT is not a chronological waiting list. Rather, it supports the CHO in its decision-making process regarding the prioritisation of services subject to budgetary constraints. This means that services are allocated on the basis of the greatest presenting need and associated risk factors.



³⁰ PQ 8774/23 asked by Deputy Denise Mitchell | March 1st 2023.

Provide additional respite nights for disabled people.

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

Why this is important to family carers:

Living independently is a goal that we all share, however, some disabled people require the full-time care and support of others. In these situations, it is critical that regular and appropriate respite is in place to enable and sustain family carers in their caring role.

The HSE and its funded agencies provide respite care to disabled adults and children. Respite can occur in a variety of settings for various lengths of time, depending on the needs of the individual and their family or carer. Respite is not always centre-based and can be provided in a number of other ways, e.g. in-home; home-to-home; family support, etc. Respite is a vital element of the continuum of services to support disabled people and their families. Access to appropriate and regular respite helps prevent residential placements, preserves the family unit, supports family stability and improves quality of life.

The availability of residential respite has come under increasing pressure in recent years due to several factors including an increase in demand, 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 had an impact on capacity. 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. Implementation of the national policy on congregated settings is also affecting capacity. Consequently, the number of respite nights available has reduced.

Recipients of Respite

According to the Capacity Review to 2032 there is a significant level of unmet need for respite care. During the review period, the number of disabled people receiving respite increased from 3,652 people in 2020 to 5,758 in 2023. However, it should again be noted that while this is an increase, the figure has decreased since 2018 when the number of people receiving respite was 6,059.³¹



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

Prior to the pandemic, the HSE's National Service Plan 2020 committed to provide 33,712 day-only respite sessions and 166,183 respite nights. Actual delivery fell far short of this, with day respite 38% below target and respite nights 47% below target. The delivery of respite services continued to operate during the pandemic, albeit at an understandably reduced capacity. While the delivery of day respite sessions and respite nights increased during the review period (2020 - 2022) by 11% and 50% respectively, the targets and baseline hours in 2020 were at an extremely low level due to the pandemic. When the number of day respite sessions and respite nights is compared with 2018 service levels, delivery has reduced by 29% and 16% respectively. The tables below provide details of the number of day-only respite sessions and respite nights provided to disabled people between 2018 - 2022.

³¹ HSE National Service Plans.

Day-Only Respite Sessions 2018 - 2022

	2018	2019	2020	2021	2022	% change 2020-2022	% change 2018-2022
Target	42,552	32,662	33,712	20,958	22,474	-33%	-47%
Actual	32,622	33,712	20,958	14,826	23,244	+11%	-29%
% target	77%	103%	62%	71%	103%	-	-

Source: HSE National Service Plans

Centre-Based Respite Nights 2018 - 2022

	2018	2019	2020	2021	2022	% change 2020-2022	% change 2018-2022
Target	182,506	182,506	166,183	85,336	92,552	-44%	-49%
Actual	156,752	158,441	87,177	94,606	131,057	+50%	-16%
% target	86%	87%	52%	111%	142%	-	-

Source: Public Services Performance Report 2018 - 2022

In 2021, the HSE committed to providing nine new respite houses for children with additional needs, one in each CHO, providing an additional 10,400 respite nights per year. An update on the establishment of each of these centres was included in the Family Carer Scorecard 2021. While no further update has been provided, the additional nights and day-only sessions provided across these nine respite centres should be included in the figures set out in the tables above.

The HSE National Service Plan 2023 commits to establishing five additional respite services and increase one existing service from part-time to full-time opening to provide 7,872 additional nights to 278 people each year. The HSE also commits to providing an additional 265 day-only respite packages to 180 people per year. Data is not yet available on the progress made in relation to this.

What is needed to progress this commitment:

The Disability Capacity Review to 2032 shows that €16m to €20m is needed annually to meet the unmet need for respite, however, with latent unmet need, this is likely to be significantly higher. Family Carers Ireland believes all full-time family carers should have a right to at least 20 days of respite each year, in line with the statutory entitlement afforded to other workers. It is deeply concerning that despite the critical importance of respite, there is no national database or figures on respite

availability. Family Carers Ireland believes that a national respite register should be established to allow family carers to register their need for respite along with the age and details of the person for whom they care. This would provide a geographical inventory of respite needs by age group and condition type.

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 ordinary housing in the community 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 approximately 18,000 disabled people in almost 1,000 locations. 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.

Day Service Capacity

During the COVID-19 pandemic, day service capacity was greatly reduced due to the continued restrictions imposed by social distancing and the medical vulnerability of many service users. In line with Government's publication of 'Reframing the challenge, continuing our recovery and reconnecting' in August 2021, day service providers worked to fully restore adult disability day services

and provide all service users with the same level of day service that they had been receiving prior to the pandemic, with full restoration of services expected by October 2021.

An analysis of HSE National Service Plans 2018 to 2023 shows the impact that the pandemic had on day services, with the number of people in receipt of day services falling from 20,772 in 2018 to 15,693 in 2020, notwithstanding that some of these service users would have received support remotely during the pandemic.

While the number of people in receipt of day services during the review period increased by 17%, the number of recipients of day services in 2020 was at an exceptionally low level due to the pandemic. When the number of recipients in 2022 is compared to the 2018 figure, recipient numbers have reduced by 12%. This means that the level of day services provided prior to the pandemic has not been fully restored



People in receipt of day service 2018 - 2022³²

2018	2019	2020	2021	2022	% change 2020-2022	% change 2020-2022
20,772	22,281	15,693	17,500	18,300	+17%	-12%

³² Public Service Performance Reports 2018 – 2022.



Disability Capacity Review to 2032

According to the Disability Capacity Review to 2032, meeting continuing demographic needs for day services is likely to require an annual stepwise increase in spending. On different assumptions

about the annual exit rate from day services, the combined additional costs of demographic demand and unmet need could fall within a range of an extra €90m to €280m a year by 2032.

Additional costs of adult disability day services demographic and unmet need

	Demographic Change			Unmet Need €m	Total €m
	Low €m	Medium €m	High €m		
2022	8	31	40	30	38-70
2027	32	109	144	30	62-174
2032	62	191	255	30	92 - 285

What’s needed to progress this commitment:

The reduction in support during lockdown has had a severe impact on disabled people and their families, with resilience levels decreasing in the absence of vital support from day services. Disabled people are reported to have experienced an increase in anxiety levels, behaviours of concern and isolation during the period that day services were closed. The resumption of adult day services must not mean a reduction in service hours or supports for disabled people or a greater reliance on family members or carers, as was suggested in the ‘Framework for the Resumption of Adult Disability Day Services’ published in May 2020. Across the document, reference was made to services operating at reduced capacity with an increased reliance on families to provide transport and a ‘new normal’ in service delivery. While the pandemic has undoubtedly changed how day services are delivered, it must not be used as a reason to dampen the expectation that all people who need a day service will have an appropriate place. Services

must expand to meet the needs of the growing population and include the many people who currently do not have a day service or receive a reduced service.

While transport is not considered a “core health service”³³ it is vital to allow many disabled people to access their day service. Approximately 8,000 adult day recipients are provided with transport, however some 10,000 are not, meaning they rely on public transport or transport provided by family and friends³⁴. Both the Mobility Allowance and Motorised Transport Grant were withdrawn in 2013 and have yet to be replaced, meaning the only transport scheme available to families is the Disabled Drivers and Disabled Passengers Scheme which is only available to people who are severely physically impaired. Family Carers Ireland continues to call for the establishment of a replacement Transport Support Scheme to meet the needs of disabled people as committed to in 2013 when the original schemes were withdrawn.

³³ PQ50832/21 asked by Deputy David Stanton on October 19th, 2021.

³⁴ Most recent data on access to transport for users of day services is taken from the ‘Framework for the Resumption of Adult Disability Day Services’ 2020.

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, have been denied a State pension or receive a reduced pension as a consequence of their years spent providing care. Family carers should be recognised not penalised for their caring years and have their contribution valued in the same way as paid PRSI contributions.

Family Carers Ireland has lobbied consistently over many years for an equitable State Pension system that recognises rather than penalises family carers and values the immense contribution they make through their years of caregiving, in the same way we value social insurance 'contributions' paid through PRSI. Family Carers Ireland therefore warmly welcome the Programme for Government commitment to address the pension anomaly that has disadvantaged long-term carers, the subsequent recommendations put forward by the Commission on Pensions and the efforts of the department to create a new way of assessing long-term carers' entitlement to the State Pension (Contributory).

On January 1st 2024, the Department of Social Protection will introduce a new method of calculating a long-term carer's entitlement to the State Pension (Contributory). The new 'Long-Term Carer Contributions' scheme will make it easier for long-term family carers to qualify for the State Pension (Contributory) when they reach pension age. A long-term carer is someone who has cared for more than 20 years. From January 1st 2024:

- Full-time carers caring for 20+ years will be given Long-Term Carer Contributions (the carer must have registered these caring years with the department).
- Long-Term Carer Contributions will be treated in the same way as PRSI paid through employment.
- The 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).



To enable the identification of carers who have been caring for more than 20 years, the department has created a new Family Carer Register, which was launched on September 1st 2023. Using MyWelfare, ie, carers can formally register their caring role with the department. They do not have to be a long-term carer to register. All full-time family carers are encouraged to register, even if they are already receiving a care-related social welfare payment, have cared for a shorter period of time or continue to provide care.

Family Carers Ireland commends the department for their work in developing a robust, transparent and equitable solution to the long-standing pension anomaly that unfairly penalised carers for many decades. We are confident that when the Long-Term Carer Contribution scheme comes into effect in January 2024, no full-time family carer who has been caring for more than 20 years will be denied a pension or receive a reduced rate pension due to their time spent caregiving.

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.

The language used in the Programme for Government commitment to “protect” rather than increase core social welfare rates is disappointing and appears only to aspire to maintain the status quo, rather than move towards establishing an adequate benchmark for social welfare. Nonetheless, notable improvements have been achieved in carer schemes during the review period, specifically³⁵:

Core social welfare rates:

- Increase in the maximum weekly Carer’s Allowance payment from €219 to €248
- Increase in the weekly rate of Carer’s Benefit from €220 to €249
- Increase in Domiciliary Care Allowance from €309.50 to €340 per month
- Increase for Qualified Children (IQC) rates have increased by a total of €10 for children under 12 and by €14 for children over 12
- Increase in the annual Carer’s Support Grant from €1,700 to €1,850.

Income disregards/means testing³⁶

- Increase in the Carer’s Allowance income disregard from €665 to €900 (couples) and from €332.50 to €450 (single people)
- Increase in the capital disregard for Carer’s Allowance from €20,000 to €50,000
- New means test disregard for Fuel Allowance for people aged over 70 - €500 (single) and €1,000 (couple). Means assessment threshold for Fuel Allowance for under 70s increased from €120 to €200



- Half-rate Carer’s Allowance is now disregarded in the means assessment for Fuel Allowance.

Ancillary supports

- Domiciliary Care Allowance and Carer’s Allowance will continue to 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 from July 2024.

Cost of living measures

- Since 2020, carers in receipt of the Carer’s Support Grant have received a total of €900 in once-off cost of living measures, in addition to two double-week payments for those on Carer’s Allowance.

In addition to the Budget announcements relating to core social welfare payments, on January 1st 2024, the department will also introduce a new Long-Term Carer Contributions scheme which will make it easier for long-term carers to qualify for the State Pension (Contributory).

In Budget 2024, Minister for Social Protection Heather Humphreys announced that she proposes to establish a new Interdepartmental Working Group with the Department of Health to examine and review the entire system of means tests for carer payments.

³⁵ Note: Changes in rates announced in Budget 2024 will come into effect in January 2024.

³⁶ Note: Changes to income disregard announced in Budget 2024 will come into effect in June 2024.

The changes to the Carer’s Allowance income and capital disregards announced in Budget 2022 and Budget 2024 will benefit thousands of family carers who were either on a reduced rate of Carer’s Allowance or who will now become eligible for the scheme.

Examples of the impact of Budget 2022/2024 announcements on the Carer’s Allowances means test:

Case 1 Couple:	
Annemarie works full-time and earns €1,000 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:	Qualify for Carer’s Allowance of €29 per week
New disregards in 2022:	Qualify for Carer’s Allowance of €141.50 per week
New disregards announced in Budget 2024:	Qualify for Carer’s Allowance of approx. €182 per week

Case 2 Single Person:	
Dan works 18 hours and earns €500 per week. He also cares full-time for his mum. He has savings of €50,000.	
Means test in 2020 / 2021:	Qualify for Carer’s Allowance of €73.50 per week
New disregards in 2022:	Qualifies for Carer’s Allowance of €201 per week
New disregards announced in Budget 2024:	Qualifies for max rate Carer’s Allowance of €248 ³⁷ per week

Adequacy of Social Protection Rates

Family Carers Ireland has lobbied extensively for improvements in the capital and income disregards for Carer’s Allowance and welcomes the increases announced in Budgets 2022 and 2024. However, a critical component of a progressive welfare system is one that keeps pace with inflation and makes sure welfare rates are appropriately benchmarked to ensure income adequacy. In 2020, the maximum rate of Carer’s Allowance for carers under 66 was €219. The equivalized rate today according to the CSO Consumer Price Index Inflation Calculator is €261. This means that even when the new maximum rate of Carer’s Allowance of €248 is introduced in January 2024, it remains €13 behind the rate of inflation.

What is needed to progress this commitment:

Family Carers Ireland acknowledge the significant improvements that have been made to carer schemes in recent years. However, the expectation that family carers will provide full-time care, at least 35 hours each week to those medically assessed as in need of full-time care, for just €16 more than basic social welfare rate is untenable. Family Carers Ireland is calling for the 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. In 2023, the Parliamentary Budget Office estimated the cost of abolishing the Carer’s Allowance means test would be an additional €397m p.a.³⁸ This reform of Carer’s Allowance should also include a benchmark against which a Family Carer Payment would be established to ensure it remains adequate and reflects the immense contribution of family carers.

³⁷ New disregards will not come into effect until June 2024.

³⁸ Parliamentary Budget Office Reference 2023-008-1, as requested by Deputy Pauline Tully March 31st 2023.

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 an important aspect of this, it is not the only way technology can be used to support people to age in place. Offering a broader range of assistive technologies to more people through the Seniors Alert Scheme would help give peace of mind and support positive ageing.



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 with confidence, independence and peace of mind. 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.

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”, harnessing a range of new technologies.³⁹ Despite this recommendation, and the obvious opportunities to expand the scheme to reflect the significant advancements in the 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. It is also notable that despite demographic changes, the number of new approvals for the scheme has decreased from 16,719 participants in 2020 to 15,577 in 2022. Total expenditure has also decreased during the term of this Government, falling from €5,134,519 in 2020 to €4,600,000 in 2022 (a decrease of 10.4%). This downward trend makes little sense at a time when the older population has increased.

What’s needed to progress this commitment:

The Seniors Alert Scheme is highly valued and recognised as having made a positive contribution to the security and wellbeing of many thousands of older people. However, the scheme has not changed since 2017 when eligibility was extended to include people not living alone and included free monitoring for the first year. To progress this commitment, the scheme should be expanded to include a range of assistive technologies alongside the traditional personal and pendant alarm systems. Family Carers Ireland also recommends that the scheme be extended to include vulnerable adults of all ages.

Seniors Alert Scheme new approvals and expenditure 2018 – 2022⁴⁰

	New Approvals	Allocation	Expenditure
2018	19,228	€2.3m	€6,984,000
2019	19,109	€2.3m	€5,342,804
2020	16,719	€2.3m	€5,134,519
2021	14,225	€2.3m	€4,800,000
2022	15,577	€2.3m	€4,600,000

³⁹ www.telecare.ie/wp-content/uploads/2017/10/TQG_review_of_the_delivery_model_of_the_seniors_alert_scheme.pdf

⁴⁰ Senior Alert Scheme Annual Reports published by Pobal.

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:

All children, including those with additional needs, have a constitutional right to be educated in a place and manner that is appropriate to their needs. However, many families struggle to secure an appropriate school place for their child(ren) both at primary and second level. Denying children with additional needs their rights is not only an attack on that child, but it is also detrimental to their family.

All children, including those with additional needs, have a constitutional right to be educated in a place and manner that is appropriate to their needs. Government has made a commitment to ensure that each child with additional needs has an appropriate school place. However, families are still struggling to secure an appropriate school place for their child(ren) both at primary and second level. This section examines the supports offered by the Department of Education to help children and their families access education.

Home Tuition

The Home Tuition Grant Scheme provides funding towards the provision of a compensatory educational service for children who, for a number of reasons, are unable to attend school. Home

tuition is not an alternative to school but rather is intended to be a short-term intervention. Therefore, the aim is to reduce home tuition, as this implies that fewer children are reliant on the scheme as they have secured an appropriate school place.

During the academic year 2020/2021, a total of 1,437 children with additional needs were in receipt of home tuition funding as they did not have a school place appropriate to their assessed level of need. The total number of children availing of home tuition funding has more than halved during the review period, reducing by 52% in 2023/2024 to 690. Of note is the significant and welcome reduction in the number of children availing of home tuition funding due to medical (-77%) and mental health (-71%) reasons.



No. of children in receipt Home Tuition Funding 2019 - 2023⁴¹

	2020/21	2021/22	2022/2023	2023/2024	% change
Age 2.5yrs-6yrs	776	812	692	463	-40%
Age 6yrs+ (school age no placement)	86	69	77	75	-13%
Medical	228	195	186	53	-77%
Mental Health	347	387	418	99	-71%
Total	1,437	1,463	1,373	690	-52%

⁴¹ PQ44248/23 October 11th, 2023.



The number of Special Needs Assistants (SNAs) to provide support to children with additional needs has increased by 20% during the review period. The announcement of an additional 1,216 SNAs in Budget 2024 brings the allocation of SNAs to its highest-ever level. The number of Special Education Teachers (SETs) has also increased, rising from 13,620 in 2020/2021 to 15,129 in 2023/2024, an 11% increase.

While information is still pending regarding the number of students supported in special classes during the current academic year, the information that is available shows a 37% increase between 2020/2021 and 2022/2023. Similarly, there has been a modest increase in the number of students supported in special school placements of 7% between 2020/2021 and 2022/2023.

Number of SNAs, SETs and students supported in special class and special school placements.^{42,43}

Academic Year	Special Needs Assistant	Special Education Teachers	Number of students supported in:	
			Special Classes	Special School Placements
2020/21 school year	17,014	13,620	10,436	7,899
2021/22 school year	18,004	13,765	12,289	8,183
2022/23 school year	19,169	14,418	14,352	8,424
2023/24 school year	20,385	15,129		
% change	+20%	+11%		

Summer Programme (formerly July Provision)⁴⁴

The Summer Programme is run by the Department of Education for primary and post-primary students with complex needs and those at the greatest risk of educational disadvantage. In May 2021, the department announced a four-fold increase in the number of children eligible to participate in the Summer Programme, rising from 23,000 students to more than 81,000 students. For the first time, all schools in the State were allowed to host a Summer Programme. The budget for the 2021 programme was also doubled from €20m in 2020 to €40m in 2021. This €40m budget has been maintained through to 2023. Despite the significant expansion of the Summer Programme, responding to a Freedom of Information (FOI) request in Q4 2021, the department confirmed that the most up-to-date figure available for the overall cost of the school-

⁴² National Council for Special Education Annual Report 2022.
⁴³ PQ[4612/22] asked by Deputy Jennifer Carroll MacNeill February 1st 2022.
⁴⁴ PQ[20388/23] asked by Deputy Emer Higgins on May 3rd 2023.

based summer programme in 2021 was €15.28m indicating a significant underspend on the €40m budget allocated to the programme⁴⁵.

The department undertook a comprehensive review of the Summer Programme in 2022/2023, primarily focused on encouraging more schools and staff to participate. Family Carers Ireland contacted the department seeking data in relation to the take up of the 2023 Summer Programme, however, have been informed that at the time of writing (November 2023) no data relating to the 2023 Summer Programme has yet been released.

Review of the EPSEN Act 2004

Family Carers Ireland acknowledges the review of the Education for Persons with Special Educational Needs (EPSEN) Act 2004 currently underway. The EPSEN Act provides that children with additional needs should be educated in an inclusive mainstream environment, unless doing so would not be in the best interests of the child. However, almost 20 years after its enactment, the provision to prepare an annually-reviewed, Individual Education Plan for students following an assessment of need is not yet operational, nor is the Special Education Appeals Board - the independent mechanism for review and redress.

While the consultation paper states that the purpose of the review is to ensure that the law in this area is “adequate”, Family Carers

Ireland encourages the department to be more ambitious. The review should not only update the Act’s provisions to better reflect contemporary understandings of disability but should also seek to reform Ireland’s education system into a world-class model of inclusive education.

What is needed to progress this commitment:

Family Carers Ireland acknowledges the progress that has been made during the review period in relation to special education provision. We welcome the review of the EPSEN Act, the reform of the Summer Programme and the activation of emergency legislation which compels schools to open special classes. However, these initiatives alone are not enough. Opening new school places does not in itself create inclusive education, but rather must be accompanied by future planning, funding, staff resources, staff training and cultural change to embed educational inclusivity as the new norm. Family Carers Ireland believes the Department should develop and 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.



⁴⁵ DES-FOI-2021-00517

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 tax credit for working carer families by reducing their tax liability. The credit is not the only tax relief available to caring families however, and as such this commitment could be strengthened by extending the commitment to include other important tax reliefs and credits.

The Home Carer Tax Credit has increased by 12.5% during the review period. The announcement made in Budget 2024 to increase the Home Carer Tax Credit by €100 will come into effect in January 2024. The upper income limit in respect of the credit will also be increased from €10,600 to

€10,800⁴⁶ per annum as of 1 January 2024. By way of illustrating the impact of this change, in 2023 the Minister for Finance Michael McGrath confirmed that the €100 increase to the Home Carer Tax Credit in 2023 benefited 67,000 taxpayers.⁴⁷



Year	Credit	Max Carer Income
2024	1,800	10,800
2023	1,700	10,600
2022	1,600	10,400
2021	1,600	10,400
2020	1,600	10,400

While not included as a Programme for Government commitment, it is notable that both the Incapacitated Child Tax Credit and the Single Person Child Carer Credit were also increased in Budget 2024. The Incapacitated Child Tax Credit was increased for the first time in over a decade from €3,300 to €3,500. 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 Single Person Child Carer Credit increased by €100 from €1,650 to €1,750. The credit is available for people who live with and care for a child for the whole or greater part of a year (more than six months). Claimants of the credit are also entitled to an increased rate band of €4,000, which is an additional €4,000 at the 20% tax rate.

What is needed to progress this commitment:

While the Programme for Government committed only to increasing the Home Carer Tax Credit, the increase in the Incapacitated Child Carer Tax Credit and the Single Person Child Carer Credit are equally important and acknowledge the broad range of caring situations and relationships. Family Carers Ireland urges Government to continue to consider these and the other tax reliefs available to caring households, including the Dependent Relative Allowance and tax relief on employing a home carer. In relation to the earning threshold for the Home Carer Tax Credit, it is important that the threshold rises in line with wage increases and inflation.

⁴⁶ The Home Carer Tax Credit allows the carer to work, however if their earnings are above €10,600, then the family are not eligible for the credit.

⁴⁷ PQ [33344/23]

Maintain support for the Housing Adaptation Grant Scheme.

Responsibility: 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 people and disabled people to assist them in carrying out works, repairs and accessibility upgrades to their homes. The scheme is an important element of Government's ageing in place and housing for people with disability policy statements.

Population ageing and the increase in the number of people living with a disability or chronic condition represent some of the most significant demographic and societal challenges facing policymakers in terms of planning for the long-term care needs of the population. The number of people over the age of 65 is expected to reach 1.4 million by 2040, or about 23% of the total population, while the number of people living with a disability is expected to increase by 20% by 2026⁴⁸. These demographic changes, aligned with Government policy to rightly re-orientate the delivery of healthcare towards care in the home, will inevitably increase society's reliance on the HAGS, bringing with it a commensurate need for a substantial increase in funding and a reform of the policy fundamentals underpinning the scheme.

HAGS Funding

The Programme for Government commits to "maintaining support for the Housing Adaptation Scheme" - a more modest commitment than that made by the previous Government who sought to "invest significantly in the scheme."⁴⁹ That said, funding for the HAGS has increased significantly, by 41% since 2020, surpassing the previous funding peak of €77m in 2010⁵⁰. The amount of funding allocated to the scheme should however be considered relative to population ageing, high inflation and the significant increase in the cost of building products. 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 welcome the reversal of this trend over recent years, with all funding drawn down in 2022 including a €3.7m top-up.



HAGS funding and drawdown 2020 - 2023⁵¹

	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						83,000 ⁵²	
% change	+74%	+28%	-16%	+33%	+34%	+41%	

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

⁴⁸ CSO Population Projections as set out in Housing Options for Our Ageing Population, DHLGH and DoH.

⁴⁹ Programme for Partnership Government (2016).

⁵⁰ <https://www.gov.ie/en/collection/0906a-other-local-authority-housing-scheme-statistics/#housing-adaptation-grants-for-older-people-and-people-with-a-disability-private-houses>

⁵¹ Department of Housing.

⁵² PQ33199/23 asked by Deputy Sean Canney on July 6th, 2023.

Review of HAGS

'Housing for All – A New Housing Plan for Ireland' commits to reviewing 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. Unfortunately the findings of this review have yet to be published. Responding to a Parliamentary Question in July 2023, the Minister of State at the Department of Housing Kieran O'Donnell confirmed that this review has been completed and that "an active body of work is underway with the Department of Public Expenditure, National Development Plan Delivery and Reform. We hope to bring them to a conclusion as quickly as possible. Thereafter, along with announcing what has been agreed, we will publish the report."⁵³

This delay is disappointing given the previous commitments made in the 'Housing Options for Our Ageing Population' 2019 policy statement to increase the funding, review the guidelines and streamline the application process for HAGS as well as publish annual data on waiting lists. We acknowledge the progress made on the rollout of the revised application form and streamlined process, which was highlighted in the Second Report of the Implementation Group, however, the Final Report of the Implementation Group⁵⁴ makes no mention of the progress made in relation to the

publication of annual data on waiting lists.

Disabled Persons Grant Scheme and Improvement Works in Lieu Scheme

Local Authorities are funded by the department under the Disabled Persons Grant Scheme (DPGS) to carry out adaptations and extensions to existing social housing to meet the needs of disabled people living in these homes. The Improvement Work in Lieu of Local Authority Housing Scheme (IWILS) allows the local authority to improve privately owned accommodation which is unsuitable for disabled people instead of providing them with local authority housing.

While funding allocations for both the DPGS and IWILS have increased significantly during the review period, increasing from €13.5m in 2020 to €24.6m in 2022 (82%), only 71% of this funding was drawn down in 2021 and only 69% in 2022. In our work with family carers across Ireland, we note growing frustration amongst older people and disabled people who are tenants in local authority properties and who, despite having very significant mobility and health needs, cannot secure an adaptation of their home through the DPGS. There also appears to be considerable confusion regarding how the scheme is administered and where tenants can seek recourse or make an appeal when, despite years of waiting, funding is not provided for the adaptation of their home.

Funding for DPGS and IWILS 2018 - 2022⁵⁵

2018		2019		2020		2021		2022	
Allocation	Drawdown	Allocation	Drawdown	Allocation	Drawdown	Allocation	Drawdown	Allocation	Drawdown
€14m	€17m	€15m	€16.9m	€13.5m	€18.1m	€23.7m	€17m	€24.6m	€17m

Adequacy of HAGS Grant Limit

Currently, the maximum grant limit under HAGS is €30,000, which can cover up to 95% of approved costs of works. However, the spiraling cost of living and building material price increases, coupled with labour shortages within the sector, has contributed to record levels of building inflation which means maximum grant limits fall far short of what is required to meet the actual costs involved in home adaptations. Even before the cost of living crisis, figures from the Society of Chartered Surveyors of Ireland show the annual rate of construction inflation hit 13.4% between January and December 2021. An analysis by Family Carers Ireland through records received by FOI request in 2021 shows that

the average cost of an extension is significantly more than the current maximum cap of €30,000. For example, the average cost of an extension in Westmeath rose from €56,565 in 2018 to €60,297 in 2021. Even if a family received the full Housing Adaptation Grant of €30,000, which would only be provided if the household income was below €30,000 (or €40,000 if, for example, there were two children under 18 in the household), the shortfall of almost €30,000 would have to be met by the family. This places enormous financial pressure on households already struggling to meet the additional costs associated with caring and disability.

⁵³ PQ 33199/23 asked by Deputy Sean Canney on July 6th 2023.

⁵⁴ Interdepartmental/Agency Implementation Group, 'Final Report of the Implementation Group', 2022.

⁵⁵ Department of Housing: See: <https://www.gov.ie/en/publication/061cd-disabled-persons-grant-and-improved-works-in-lieu-schemes-allocation-and-drawdown/?referrer=www.gov.ie/en/publication/c472d-disabled-persons-grant-and-improved-works-in-lieu-schemes-allocation-and-drawdown-2011-2020/>

Income thresholds

Income thresholds for the HAGS are outdated and bear no resemblance to the actual disposable income of households where high-level care is provided. Because the means test is applied to gross rather than net income and does not apply disregards to mortgage repayments, dependent children, college fees, Fair Deal contributions, medical costs, etc., it does not reflect the reality faced by families who are struggling to make ends meet. The decision to include the income of other adults living in the household over the age of 18 if not in full-time education is unfair and penalises older parents who, due to the housing crisis, have little choice but to allow adult children to remain living with them temporarily.

Family Carers Ireland welcomes the announcement by the Minister for Housing Darragh O'Brien in July 2023 that fixed tracked hoists are now covered under the HAGS⁵⁶.

What is needed to progress this commitment:

Ireland's demography is changing with the old-age dependency rate predicted to significantly increase in the coming years, which will inevitably increase the reliance on the HAGS and bring with it a commensurate need for an increase in funding. The commitment to "maintain" rather than increase funding for the scheme is, therefore, an inadequate policy response. Rather, funding for the scheme should increase in line with demographic demand, with the scheme reviewed to address existing anomalies and operational issues.

Family Carers Ireland agrees with the recommendations made in a Policy Analysis of the Housing Adaption Grant Scheme in 2020 including the need to align the scheme to demographic projections, the opportunity for greater efficiencies through the use of technology and the need to streamline administration processes and data collection across all local authorities. Of particular importance is the need to address the geographic inequity in average grants awarded under the scheme. The variance seen in the levels of grant funding provided by local authorities raises questions regarding the autonomy afforded to local authorities and the inconsistencies that can arise in the delivery of the scheme.

Considering rising inflation, the spiraling cost of living and price increases in building products, the review of HAGS should lead to an increase in maximum grant limits; an increase in income thresholds as well as a broader range of disregards and put an end to the unfair assessment of the income of other adults living in the household not in full-time education.



⁵⁶ <https://www.gov.ie/en/press-release/8d927-fixed-track-hoists-now-covered-under-housing-adaptation-grants/>

Ensure that 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 that Ireland delivers on the rights 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.

According to Census 2022, there were 1,109,557 people who experienced a long-lasting condition or disability, accounting for 22% of the population. Of these, 1,035,415 (94%) live in private accommodation. A total of 29,245 people reside in a nursing home (24,527) or residential centre for people with a physical or intellectual disability (4,718).

Housing for All

Government’s ‘Housing for All - a New Housing Plan for Ireland’ published in 2021 sets out how during the period 2022-2030, Government will improve Ireland’s housing system and deliver more homes of all types for people with different housing needs. The plan contains 213 actions, of which 6 relate to improving housing options for disabled people and 7 relate to improving housing for older people. There has been welcome progress in relation to the implementation of these actions, most notable of which is the publication of a National Housing Strategy for Disabled People in 2022. As noted in the previous section, the delay in publishing the findings of the department’s review of the HACS is disappointing, particularly given that it commenced in early 2022.

SCORE

NO PROGRESS



Housing for All – Progress in the delivery of action for disabled people and older people

Actions: Disabled people		Status
7.1	Deliver a new National Housing Strategy for Disabled people (2022 – 2027) following stakeholder and public consultation and with a range of actions which will detail co-ordination and alignment of housing, health and community support.	Complete
7.2	Local Authority Housing Delivery Action Plans will set out how dedicated social housing provisions appropriate to the needs of disabled people will be delivered matching the scale and extent of housing need identified for disabled people.	Complete
7.3	Local Authorities will consider the housing needs of disabled people through the Housing Need and Demand Assessment Framework and feed that into their Housing Strategies as part of their Development Plan process.	Ongoing
7.4	Review the range of housing grants available to assist with meeting specific housing needs, including the Housing Adaptation Grant for Disabled people, and implement relevant changes (Q4 2022).	Pending
7.5	Nominate Disability Friendly Housing Technical Advisors in each Local Authority.	Complete
7.6	Housing and Disability Steering Groups will report quarterly on the implementation of their local strategic plans regarding housing for disabled people to the Chief Executive and the Strategic Policy Committee.	Complete

Actions: Older People		Status
6.1	Continue to support the development of the Age Friendly Homes portal and website, which promotes awareness of Age Friendly housing.	Ongoing
6.2	Local Authority Housing Delivery Action Plans will set out how dedicated social housing provision appropriate to the needs of older people will be delivered matching the scale and extent of housing need for older people identified.	Complete
6.3	Local Authorities will consider the housing needs of older people through the Housing Need and Demand Assessment Framework and feed that into their Housing Strategies as part of their Development Plan process.	Ongoing
6.4	Review the range of housing grants for the suitable adaptation of existing housing (Q4 2022).	Delayed
6.5	Continue delivery of the Age Friendly housing and public realm training modules to cross-sectoral stakeholders to promote greater awareness and foster knowledge transfer across the sector.	Ongoing
6.6	Support pilots of innovative forms of housing redesign/reorganisation to deliver additional rental accommodation supply along with support for older homeowners.	Ongoing
6.7	Implement the actions under the Housing Options for our Ageing Population Policy Statement, having regard to the Reports of the National Implementation Group.	Ongoing

National Housing Strategy for Disabled People 2022-2027

The National Housing Strategy for Disabled People 2022 - 2027 was published in January 2022 and the implementation plan for the strategy in June 2023. The strategy is a five-year plan which sets out ambitions with regard to housing with related supports for disabled people. The development of the strategy, and the suite of documents that accompany it, are informed and underpinned by the UNCRPD. The vision for the strategy 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. To further enable equal access for disabled people to housing with integrated support services”. There will be a formal review of the implementation plan commencing mid-2024 for completion by Q4 2024.

Summary of Social Housing Assessments Report

In relation to social housing, a comparison of the ‘Summary of Social Housing Assessments Report 2020 and 2022’ shows a 6.5% reduction in the number of households on a waiting list for social housing between 2020 and 2022, down from 61,880 to 57,842. There was a small increase in the proportion of households whose basis of need for housing was a mental health disability increasing from 2.5% to 2.8%, and a physical disability increasing from 2.4% to 2.5%. However, there was a slight reduction in the number of households whose basis of housing need related to an intellectual disability (2.6% to 2.5%). The number and proportion of households with an accommodation requirement due to a disability or to older age has remained relatively steady with 6.6% and 3.1% of households recorded in these categories respectively.

Local Authority Housing Allocations to disabled people since 2016⁵⁷

Disability	2016	2017	2018	2019	2020	2021	2022
Physical	682	833	761	1,231	1,038	1,121	1,089
Sensory	88	118	155	239	222	338	389
Mental	194	365	318	632	521	597	695
Intellectual	215	199	167	296	312	338	299
Classification ⁵⁸	27	64	142				
Total	1,206	1,579	1,543	2,398	2,093	2,394	2,472

Younger adults in nursing homes

The HSE reported in June 2020 that there were 1,320 people under 65 years living in a nursing home and supported under the Fair Deal scheme. In 2023, this figure has dropped by just 20 people and now stands at 1,300⁵⁹. ‘Wasted Lives’, a report published by the Ombudsman in 2021, showed that hundreds of 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.⁶⁰ The Ombudsman’s investigation identified systemic issues, compounded by a fractured funding model, which undermines the rights of disabled people. The Ombudsman

noted that the commitment in the Programme for Government to implement a statutory home support scheme will be necessary to address the current bias in favour of institutional settings. In May 2023, the HSE launched a national survey of people aged under 65 and living in a nursing home. The survey is an attempt to address the lack of information held by the HSE in relation to younger people in nursing homes and will be used to create a database to identify disabled people inappropriately living in nursing homes and to make sure that the most appropriate health and social care supports are provided in the most appropriate setting. The survey will close in November 2023.

⁵⁷ Source: National Housing Strategy for Disabled People 2022-2027 Implementation Plan.

⁵⁸ Classification of need was initially included to account for situations where the applicant or household member had a disability but that was not the basis of need on which they were allocated a social housing tenancy.

⁵⁹ <https://healthservice.hse.ie/staff/news/staff-news-listing-page/national-survey-of-people-aged-65-and-under-in-nursing-homes/#:~:text=There%20are%20approximately%201%2C300%20people,and%20a%20service%20provider%20survey.>

⁶⁰ 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>.

What is needed to progress this commitment:

The 'National Housing Strategy for Disabled People 2022-2027' is an ambitious document that, if implemented in full and on time, has the potential to move Ireland closer to achieving an equitable system of housing support for disabled people. To progress this commitment further, Government must address other issues identified in the Programme for Government including securing appropriate accommodation for the 1,300 adults under the age of 65 who currently live in a nursing home and substantially increase funding for PA, home support hours and residential places to enable disabled people to live independently. Family Carers Ireland also believes that in order to ensure an appropriate mix of housing is provided, greater emphasis and

investment should be placed on supported housing projects which provide housing with care and support, primarily for older people. It can enable people to live independently for longer and is an alternative housing option that falls between living independently in the community and nursing home/residential care. Work from multiple sources, including The Housing Agency, has demonstrated a lack of supply in the provision of this form of housing in the State.⁶¹



⁶¹ <https://www.housingagency.ie/sites/default/files/publications/Thinking-Ahead-Supported-Housing.pdf>



Family Carers Ireland is *the* national charity supporting the 500,000 family carers across the country who care for loved ones such as children or adults with physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental ill-health or addiction.

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