

Family Carer Scorecard 2021

Assessing the implementation of the Programme for Government '*Our Shared Future*' from the perspective of family carers.



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FAMILY CARER SCORECARD 2021

The Family Carer Scorecard 2021 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. Family Carers Ireland has examined the Programme for Government and has selected 18 commitments for inclusion in the scorecard which are clear and measurable, are 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 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 carer pensions, increasing the income and capital disregard for Carer’s Allowance and the piloting of a statutory homecare scheme. With the Government having now completed the first quarter of its term 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 CARES¹?



13%

OF THE IRISH POPULATION AGED OVER 15 YEARS PROVIDE CARE



EXTRAPOLATION TO NATIONAL POPULATION MEANS IRELAND HAS SOME **499,904** FAMILY CARERS



THE ANNUAL REPLACEMENT COST OF THE CARE PROVIDED BY FAMILY CARERS IS APPROXIMATELY **€20BN**



FAMILY CARERS PROVIDE **AN AVERAGE OF 38.7 HOURS** OF CARE EACH WEEK WHICH MEANS THAT, COLLECTIVELY, CARERS PROVIDE **19M HOURS OF UNPAID** CARE EACH WEEK



13.3%

OF CHILDREN AGED 10-17 YEARS PROVIDE CARE. EXTRAPOLATION TO NATIONAL POPULATION MEANS THERE COULD BE AS MANY AS 67,000 YOUNG CARERS IN THIS AGE COHORT

CARERS IN RECEIPT OF SOCIAL WELFARE:



118,813

RECIPIENTS OF THE ANNUAL CARER’S SUPPORT GRANT



90,260

CARERS RECEIVE CARER’S ALLOWANCE



3,600

CARERS RECEIVE CARER’S BENEFIT

Almost one million additional people in Ireland provided some form of unpaid care as a result of the pandemic². This is on top of the 500,000 unpaid carers who were already caring before the outbreak, bringing the total to over 1.4 million – more than a quarter of the Irish population.

¹ 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.

² Behaviour and Attitudes Survey 2020.

METHODOLOGY

The Family Carer Scorecard 2021 is Family Carers Ireland’s first analysis of the progress in implementing the commitments for family carers made in the Programme for Government ‘Our Shared Future’ agreed in June 2020. Family Carers Ireland reviewed all commitments related to family carers in the Programme for Government and selected 18 to track over the course of this Government’s term in office. Commitments were shortlisted based on several core criteria:

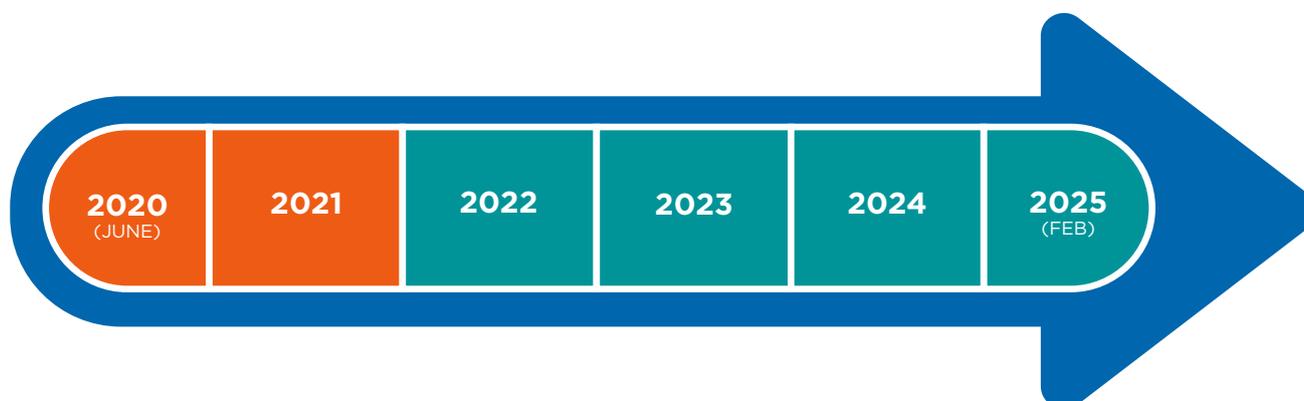
- The commitment directly impacts on family carers, defined as someone who is providing an ongoing significant level of care to a person in need of that care in the home due to illness, disability or frailty.
- The commitment is clear and measurable.
- If achieved, the commitment has potential to significantly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

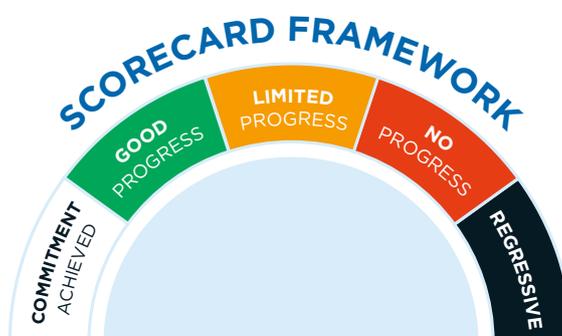
The 18 commitments selected cover the needs of all carers, including those caring for a child, adult or older person; those receiving social welfare support and those not; and include a range of policy areas to reflect the many issues that can affect carers’ lives.

The methodology used to assign scores to each of the 18 commitments was based on:

- An analysis of policy documents, responses to Parliamentary Questions, HSE National Service Plans, Capacity Review up to 2032, sector reports and academic literature.
- Evidence gained from family carers and stakeholders working within the caring sector.
- Engagement with relevant Government departments and statutory agencies.
- Three virtual ‘Listening to Carers’ forums held in November 2021, during which the 71 family carers in attendance were asked to assign one of the five colour-coded scores to each of the 18 commitments. Voting was cast using Zoom Polls. Where the score assigned to an individual commitment was at odds with the analysis provided through policy evidence, it was referred to Family Carers Ireland’s Research and Policy Committee for consideration and final decision.

REVIEW PERIOD





The scorecard framework, which assigns one of five colour-coded ‘scores’ to each commitment to reflect the progress that has been made during the review period, was established 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 will 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

SUMMARY OF FAMILY CARER SCORECARD 2021

Of the 18 Programme for Government commitments assessed, none received a score of ‘Commitment Achieved’. Two commitments received a ‘Good Progress’ score, meaning that there have been positive results for family carers; four 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; seven 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, five commitments received a ‘Regressive’ score, meaning that the situation has worsened for family carers during the review period.

Regressive (5)	No Progress (7)	Limited Progress (4)	Good Progress (2)
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Lows

- Closure of vital supports during lockdown left carers to care alone, around the clock and without the support of formal services, family or friends.
- The regression and anxiety experienced by many children with special needs during the pandemic losing skills that they and their families worked hard to develop.
- Failure to recognise family carers in the provision of PPE and roll-out of the vaccination programme.
- Family carers who had to give up work to provide care to a disabled, sick or older person ‘voluntarily’ during the pandemic were not eligible for PUP, but parents without childcare were.
- Continued under-resourcing of appropriate respite care across the life course.
- Failure to publish a refreshed National Carers’ Strategy despite a commitment that it was a priority for 2021.
- Shortage of homecare workers has meant that even where home support hours have been funded, families are not receiving them because a homecare worker isn’t available.

Highs

- Pilot of the Family Carer Needs Assessment tool in CHO 2.
- Pilot of the Statutory Homecare Scheme.
- Citizens’ Assembly recommendations on gender equality and recognition of family carers.
- Recommendations from the Commission on Pensions with regard to the creation of a dedicated pension for long-term carers.
- Increase in the Carer’s Support Grant from €1,700 to €1,850 in Budget 2021.
- €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.
- First increase in 13 years announced in Budget 2022 to the income and capital disregards for Carer’s Allowance.

SCORES TABLE

Programme for Government Commitment

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
Extend free GP care to carers in receipt of the Carer's Support Grant	No Progress
Review and update the National Carers' Strategy	Regressive
Establish a commission to examine the care of older people	Limited Progress
Introduce statutory homecare scheme to provide equitable access to quality, regulated home care/increase Homecare Hours for older people	Limited Progress
Deliver increased Home Support and Personal Assistance hours for people with a disability	No Progress
Extend the remit of the NTPF to secure timely assessment for both child and adult psychological services	Regressive
Reduce the waiting times for assessment of need under the Disability Act 2005	Good Progress
Provide additional residential places and new emergency residential places for people with a disability	Regressive
Provide additional respite nights for people with a disability	Regressive
Expand adult day services and supports for adults with physical, sensory and intellectual disability and autism throughout the country	Regressive
Examine options for a pension solution for carers in recognition of the enormous value of their work	Good Progress
Protect core social welfare rates / Recognise the importance of ancillary benefits and eligibility criteria to vulnerable groups	Limited Progress
Enhance the demand led Senior Alert Scheme and ensure it adapts to changing demographics and technological advancements	No Progress
Ensure each child with a special educational need has an appropriate school place in line with their constitutional right	Limited Progress
Increase the Home Carer Tax Credit	No Progress
Maintain support for the Housing Adaptation Grant Scheme	No Progress
Ensure appropriate mix of housing, including universally designed units and accommodation for older people/people with disabilities	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: Despite the clear advantages of caring for people in their own homes, inconsistent funding has led to a postcode lottery where access to essential supports such as homecare, respite and training is determined by where a person lives rather than what they need. The Carers Guarantee is needed to ensure the uniform delivery of a core basket of services to all carers regardless of their address.

In Budget 2021, €2m was allocated as a first step towards delivering a Carers Guarantee, providing a more standard package of supports to family carers in every region, in tandem with the community and voluntary sector. *'My Department is actively engaging with the HSE and with representative groups on this matter to ensure the funding will improve equity of access to carer supports across the country.'* (Minister for Health responding to PQ 46938/21).

In 2019, Family Carers Ireland developed a 'Carers Guarantee' proposal, setting out how, with additional annual funding, the organisation could ensure the uniform delivery of a core basket of services to family carers across the country, regardless of where they live, thus helping to eliminate the 'postcode lottery' that has long characterised carers' access to services.

Family Carers Ireland welcomes the €2m committed to the Carers Guarantee in Budget 2021, however this welcome is qualified for two reasons. Firstly, the €2m falls short of the €5m that we believe is the absolute minimum required to deliver the Guarantee. This means that only some of the core services encompassed in the Guarantee will be available until 2023 at the earliest. Secondly, while the €2m was allocated in Budget 2021, some 14 months ago, only €100,000 of it had been allocated by November 2021.

Family Carers Ireland met with the HSE on 1st December, 2021 during which a commitment was given to allocate the funding to organisations in the caring sector as part of their 2022 service level agreement (SLA). While we welcome this development for next year, the failure to spend



the money available this year means that the only possible assessment of the situation at the end of 2021 is a score of 'No Progress'.



In Budget 2021, €2m was allocated as a first step towards delivering a Carers Guarantee, providing a more standard package of supports to family carers in every region, in tandem with the community and voluntary sector. My Department is actively engaging with the HSE and with representative groups on this matter to ensure the funding will improve equity of access to carer supports across the country. ”

(MINISTER FOR HEALTH RESPONDING TO PQ 46938/21).

What's needed to progress this commitment:

The Programme for Government commits specifically to the delivery of the Carers Guarantee which implies that it will be delivered in the format proposed by Family Carers Ireland. Notwithstanding the issues which have delayed the drawdown of the €2m funding assigned to the Carers Guarantee in Budget 2021, Family Carers Ireland trust that the recent commitment made to allocate the funding through the 2022 SLAs of organisations in the sector will be honoured, with recurring annual funding. Family carers who care, often around the clock, need to know that Government recognises and values them and will give them the right support, if and when they need it, regardless of where they live.

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 associations between physical and psychological health and being a family carer are well established, with growing evidence that caring should be considered a social determinant of health. Despite this strong correlation, many family carers cannot afford to visit their GP because of the costs involved. It is imperative that carers' own health and wellbeing is supported in order to sustain their capacity to continue to provide care.

The introduction of GP Visit Cards 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 carers. However, the decision to give access to free GP care only to carers in receipt of Carer's Allowance or Carer's Benefit means that almost 25,000 full-time family carers are excluded³. 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 Government's plan for the universal roll-out of free GP care and counter to the universal access afforded to the over 70s and children under 7 years who are rightly not means tested. In order to reach a greater number of full-time carers and in keeping with Government's own policy of universal access, the Programme for Government committed to extending the Carers GP Visit Card to all carers in receipt of the non-means tested Carer's Support Grant. While Budget 2022 confirmed that free GP care will be extended to all children under 7 years, with the intention of eventually extending cover to all children under 12, there was no mention in either Budget 2021 or Budget 2022 of including family carers in receipt of the Carer's Support Grant. The decision to extend free GP care to some 62,257⁴ 'healthy' children⁵, but not to the 24,953 full-time family carers who only receive the Carer's Support Grant, shows a disregard for the adverse health effects which research has consistently shown they are likely to experience as a result of their caring role.

SCORE

NO PROGRESS

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 2023 to have the Carers GP Visit Card extended to include them.



³24,953 is the difference between the number of carers who received the Carer's Support Grant in 2021 and the 93,860 carers who receive either Carer's Allowance or Carer's Benefit.

⁴According to Census 2016, 62,257 children were aged under 1 year. These children will now be aged 7 and under.

⁵Children in receipt of DCA qualify for a full Medical Card.

Review and update the National Carers' Strategy

Responsibility: Department of Health

Why this is important to family carers: Carers need to be recognised and valued. They need access to information and support; help to balance their caring responsibilities with paid employment and to preserve their own health and wellbeing. A refreshed National Carers Strategy is critical to this because it sets out the practical actions Government will take over the coming years to empower, value and support family carers and is a mark of Government's commitment to them.

The National Carers' Strategy sets out in a single document all the actions that will be undertaken by Government, across relevant departments, to improve the lives of family carers. These actions cover the gamut of needs of family carers and those for whom they care, including value and recognition, access to appropriate homecare and respite, financial supports, transport, information, advocacy, housing, training, employment and the right to a life of their own away from their caring role.

At a meeting with 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, have been exhausted and no further annual progress reports would be compiled by the Department. 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 outlining the actions we believe the refreshed Carers' Strategy should contain based on the commitments for carers set out in the Programme for Government. No follow-up engagement ensued. Despite having received assurances from the Department in December 2020 that the refreshed strategy was a priority and would be published in 2021, this has not materialized.

Responding to a Parliamentary Question in July 2021 regarding progress towards the publication of a refreshed National Carers' Strategy, the Minister for Health confirmed that preparatory work in respect of the Strategy had not yet commenced.



“ **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 2021, Family Carers Ireland are not aware of any preparatory work having commenced on the National Carers' Strategy, nor have we been consulted.

The responses given to other Parliamentary Questions regarding the Strategy also raise concern in that they conflate and confuse two separate Programme for Government commitments - the review of the National Carers' Strategy and the Carers Guarantee which aims to eliminate the postcode lottery in carer supports. This confusion

undermines Government's credibility with regard to these separate Programme for Government commitments and demonstrates a lack of understanding regarding each.

“
€2million was allocated in Budget 2021 to further the National Carers' Strategy in 2021 with a focus on improving equity of access to supports for carers
 ”

(PQ 46939/21).

In light of the agreement in September 2019 that the original National Carers' Strategy has been exhausted, alongside the commitment that the refreshed strategy was a priority for the Department and would be published in 2021, the lack of consultation or the commencement of preparatory work, this commitment has been assigned a score of 'Regressive'.

What's needed to progress this commitment:

Given the period of significant health reform that we are now in the midst of, including the renewed focus on Sláintecare and the creation of a statutory homecare scheme (both of which are predicated on the provision of care in the home), as well as the changes that have been brought about by the COVID pandemic, it is critical that a refreshed National Carers' Strategy and action plan for the period 2022 - 2027 is developed alongside ringfenced funding for its delivery. In order to progress this commitment, the Department of Health must immediately engage with representative organisations and agree a timeline towards the Strategy's publication.



Establish a commission to examine the care of older people

Responsibility: Department of Health

Why this is important to family carers: The COVID pandemic has 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 will provide an opportunity to reassess how we care for older people, the value placed on the unpaid care provided by family and friends and how we can break the imbalance between home and residential care.

The fracture lines in our long-term care system have been exposed by COVID-19, 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 care is built, its over-reliance on nursing homes, the lack of integration between home and residential care and the incentivization of nursing homes in the absence of homecare legislation. Family Carers Ireland welcomes the commitment to establish a Commission on Care which would take the lessons learned from the COVID-19 pandemic and re-assess how care for older people is provided while supporting people's choice to age in place.

Family Carers Ireland acknowledges the progress that has been made on the implementation of recommendations arising from the COVID-19 Nursing Homes Expert Panel, which will ultimately improve standards of care in nursing homes, and in the establishment of a statutory Home Support Scheme which should significantly increase support for people in their own homes. We also note the Minister for Older People and Mental Health's confirmation that 'preliminary scoping work on the establishment of a commission on care has commenced' but that the 'ongoing priority focus in 2021 is ensuring the continued implementation of the recommendations of the COVID-19 Nursing Homes Expert Panel' (PQ 39327/21).

Responding to a Parliamentary Question in June 2020 the Minister 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).



A score of 'Limited Progress' was assigned to this commitment in recognition of the ongoing implementation of the recommendations made by the Nursing Homes Expert Panel and the scoping work that has commenced towards the establishment of the commission in 2022. We wish to emphasise however, the urgent need for the commission and warn that it should not be delayed beyond 2022.

What's needed to progress this commitment:

The pandemic has accelerated the need for a renewed focus on our health and social care systems, and has given us an opportunity to reassess the value we place on informal care – which is timely given the significant long-term care challenges that lie ahead due to population ageing. With between 80-90 per cent of care in the community provided by family and friends, it is imperative that the Commission on Care is established and its terms of reference include an examination of the role, reliance and recognition of family carers in the provision of long-term care. Given that care is provided across the lifecourse, it would be illogical for the commission to focus only on the care of older people, but rather should focus on the care of adults of all ages. This is in keeping with the decision to extend the statutory homecare scheme to include all adults with care needs.

Introduce a statutory homecare scheme which will provide equitable access to high quality, regulated home care / Increase Homecare 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 where 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 reform proposal and a long-standing Government priority. The scheme aims to ensure that all users of home support services are provided with a standard, high-quality level of care which is safe, effective and person-centered. The regulatory framework underpinning the scheme will comprise of (i) primary legislation for the licensing of public and private home support providers; (ii) minimum requirements (regulations); and (iii) HIQA National Standards for Home Support Services.

Responding to a Parliamentary Question in October 2021, the Minister for Older People and Mental Health confirmed that work is on-going within the Department to progress the development of the new scheme. Specifically, the Minister noted the following progress:⁶

- Government approval to draft a General Scheme and Heads of a Bill to establish a licensing framework for home support providers - currently being progressed with a view to bringing it through the Houses of the Oireachtas.
- Public scoping consultation undertaken by HIQA to inform the development of National Standards for Home Support Services.
- Funding secured to progress the roll-out of interRAI as the standard assessment tool for care needs in the community.
- Pilot of a reformed model of service delivery for homesupport scheduled to commence in November 2021 in CHO 8 (Longford/Westmeath). However, the Minister notes that recruitment issues associated with the backfilling of posts

has impacted on the release of interRAI Care Coordinators in CHO 2 (Galway), 4 (South Lee) and 7 (Dublin West) which has delayed the pilot in these three sites until January 2022.

- Funding for 130 posts for the national rollout of interRAI with recruitment to commence in 2021.
- A National Home Support Office to be established before the end of 2021.

While Family Carers Ireland welcomes the Minister's update, much of the progress named relates to 'early-stage' components of the scheme, which according to the Sláintecare Implementation Strategy and Action Plan 2021-2023 should already have been completed, with the scheme ready for full implementation in 2022. We also note that some items remain outstanding for 2021 including the establishment of a National Home Support Office; the recruitment of interRAI coordinators and the commencement of three of the four pilot sites. We also note that the previous commitment that '*mobilisation of the Home Support pilot would commence at the end of August 2021*' has not been achieved.⁷

We welcome the Department's commissioning of three reports to be undertaken by the ESRI to inform the development of the statutory home support scheme and the piloting of a Family Carer Needs Assessment in CHO2.

Home Support Hours

Family Carers Ireland acknowledges the increased investment in supporting access to home support hours pending the introduction of the scheme including the €150m funding secured in Budget

⁶PQ 51619/21

⁷<https://www.gov.ie/en/press-release/11c2f-minister-for-mental-health-and-older-people-announces-selection-of-four-sites-for-new-home-support-pilot/>



2021 for 5 million additional home support hours which will be maintained for 2022. As of the end of September 2021, 15,061,610 home support hours were delivered nationally to 53,335 people. This is approximately 2 million more hours compared to the same period in 2020. Also, at the end of September 2021, there were 393 people waiting for funding for new or additional home support, while 4,933 people were approved for home support but awaiting a carer to be assigned. In relation to Delayed Discharges with specific regard for those who are waiting to return home with home support, as of the end of October 2021, the number stands at 105 nationally. (PQ: 51472/21 / PQ: 51473/21). This figure also includes people with a disability.

While steady progress is being made in relation to the creation of a statutory home support scheme, progress has been slow, with a number of the targets set out in the Sláintecare Implementation Report missed. Given these delays and the waiting list for home support, the commitment has been assigned a score of 'Limited Progress'.

What's 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 13 years, families have had to accept a system which incentivises residential care and spends twice as much on nursing homes as 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 due to COVID and the

cyber-attack 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 homecare⁶. The legislation must recognise the intertwined relationship between the person receiving care and their family members or friends who provide the bulk of this care. If carers are to continue to play an integral role in keeping their loved ones at home, then they too must be supported. The scheme should be available to all adults with care needs and frame a whole of government approach to home care, creating a statutory context that includes aids and appliances, housing adaptation grants, transport and respite breaks as part of a comprehensive basket of services.

The delivery of the statutory home support scheme is dependent on having access to a skilled pool of homecare workers available across the country. Even before the statutory home support scheme is launched, the acute shortage of homecare workers is having a detrimental effect on the sector, with homecare providers frequently unable to deliver funded Home Care Packages due to a lack of staff. This is not limited to rural communities, but is increasingly experienced in towns and cities, where staff simply aren't available. Family Carers Ireland is calling for proactive efforts to be made by Government to promote employment and attract workers to the homecare sector. This has included a call for domestic or care work to be include as an eligible category in the issuing of work permits by the Department of Jobs, Enterprise and Innovation, which unfortunately remains unchanged.

⁶ESRI 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 per cent increase. It is important to note, these projections are based only on the demand generated by older people aged over 65 and do not include demand from younger adults with care needs who will also be provided for under the scheme.

Deliver increased Home Support and Personal Assistance Hours for People with a Disability

Responsibility: Department of Health

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 from the community.” Personal Assistance and Home Support hours are critical to this.

The HSE provides a range of assisted living services including Personal Assistance and Home Support hours to support individuals with a disability to maximise their capacity to live full and independent lives. Personal Assistance and Home Support hours are provided either directly by the HSE or through a range of voluntary service providers. The majority of specialised disability provision (80%) is delivered through non-statutory sector service providers. Services are accessed through an application process or through referrals from public health nurses or other community-based staff. Resource allocation is determined by the needs of the individual, compliance with prioritisation criteria, and the level of resources available. Both schemes are discretionary, meaning they are resource rather than demand led.

In the 2021 National Service Plan, the HSE states that its priority is to ‘continue to deliver high quality Personal Assistance and Home Support Services to 10,000 people with disabilities including 1.71 million PA hours and over 3 million Home Support Hours’. This includes the allocation of an additional 40,000 Personal Assistance hours. Unfortunately, due to the cyber-attack on the HSE in May, data is only available for Q1 2021. The same target - to provide

Personal Assistance hours to 10,000 people with a disability - was made in the 2020 Service Plan but fell short, reaching 9,465 people.

While the number of adults in receipt of Personal Assistance hours increased between 2019 and 2020, figures show a possible downturn for 2021. Average hours have remained relatively constant at 12.3 hours in 2018 and 12.8 hours in 2020. We note that the Minister for Health, in response to a Parliamentary Question asked on November 2nd 2021, confirmed that €600,000 had been spent on increasing Personal Assistance hours by 40,000; however more complete data for 2021 are not yet available⁹.

Figures for Home Support show that the number of adults receiving hours under the scheme have decreased consistently since 2018, reducing from 7,447 to 6,636 between 2018 and 2021. Average hours however have increased modestly from 7.5 hrs in 2018 to 8.3 hrs in 2020.



SCORE

NO PROGRESS

⁹ PQ 52973/21

¹⁰ Information provided by the HSE Disability Services on October 5th 2021.

Number of adults with a Physical and Sensory Disability in Receipt of PA Services including no. of hours ¹⁰

	2018		2019		2020		2021 Q1 only	
	Adults	PA Hrs	Adults	PA Hrs	Adults	PA Hrs	Adults	PA Hrs
National	2,553	1,636,883	2,548	1,652,030	2,673	1,781,310	2,457	419,753

Number of adults with a disability in receipt of Home Support hours ¹¹

	2018		2019		2020		2021 Q1 only	
	Adults HS	HS Hrs	Adults HS	HS Hrs	Adults HS	HS Hrs	Adults HS	HS Hrs
National	7,447	2,930,000	7,130	3,010,000	6,792	2,939,541	6,636	709,879

We note that €55m was secured in Budget 2022 to collectively provide for disability supports for school leavers, Personal Assistance hours, addressing decongregation for people with disabilities in nursing homes and rolling out ‘Progressing Disability Services for Children and Young People’. Details of what proportion of the €55m allocation will support Personal Assistance hours specifically will become clear following publication of the HSE’s National Service Plan 2022. Assigning a score to this commitment is complicated by both COVID-19 and the cyber-attack. However, while Family Carers Ireland acknowledges the intention of the Department and HSE to increase Personal Assistance and Home Support hours, family carers assigned a score of ‘No Progress’ as any benefit from recent announcements has yet to be felt on the ground.

What’s needed to progress this commitment:

The Department of Health’s Capacity Review to 2032 found that data on unmet need for the Personal Assistance and Home Support services have not been systematically recorded, however the report estimates that the level of unmet need is significant. The additional costs of demographic change are 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 for those who currently receive minimal hours has been costed at €30m a year. In order to progress this commitment and support all adults with a disability who require either Personal Assistance 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 people with a disability to realise their rights.



¹¹ Information provided by the HSE Disability Services on October 5th 2021.

Extend the remit of the 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 care they desperately 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 outcomes.



In September 2021 some 8,832 people were on a waiting list for HSE psychology services, with 3,986 waiting more than one year; 7,849 of those on the waiting list are children (88 per cent). Of these children, almost half (47 per cent) have been waiting more than one year (PQ 48458/21). The allocation of €4m in August 2021, to help reduce the

number of children waiting more than 12 months to access Primary Care Psychology is welcome, with early progress shown in 2021 figures. That said, the number of children on the waiting list remains unacceptably high.

Psychology waiting list – September 2021

Year	Children Waiting	Waiting >1yr	Adults Waiting	Waiting >1yr	Total
2020 (Oct)	8,893	4,807	1,553	449	10,446
2021 (Sept)	7,849	3,747	783	239	8,832

In October 2021, 2,625 children were on a waiting list for Child and Adolescent Mental Health Services (CAMHS), with 170 waiting for more than one year.¹² By year end this is likely to be on par with the 2020 waiting list figure of 2,755 children and above the waiting list in 2019 of 2,327 children.

In responding to a Parliamentary Question on October 7th 2021, which asked the Minister for Older People and Mental Health about the progress being made with regard to the Programme for Government commitment to extend the NTPF to secure timely assessment for both child and adult psychological services, the Minister's response confirmed that no progress has been made in advancing this commitment. She stated:

“

As psychological assessment services are generally provided in community, not acute hospital settings, they would not meet current NTPF criteria. Any

change in the function of the NTPF to include the provision for treatment for patients outside of the acute hospital setting would require primary legislation. Therefore, the operational and legislative implications of this need to be considered. ”

(PQ 49037/21).

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. For this reason and the continued delay in children's access to critical psychological services, this commitment has been assigned a score of 'Regressive'.

¹² Figures do not include waiting list from CHO 6 due to the cyber-attack.

What's needed to progress this commitment:

Evidence has consistently shown the severe shortage of psychologists across the mental health and disability sector. The Disability Capacity Review to 2032 estimated a minimum of doubling of the number of psychologists in child disability services alone would be needed to meet demand. The number of psychologists in Child and Adolescent Health Services (CAMHS), as recommended by A Vision for Change, only reached approximately 32% of the recommended levels. The HSE Report of the National Psychology Team Project¹³ published in 2021 estimated an additional 321.8 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 €4m allocation to address psychology waiting lists and the recruitment of additional staff, 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 psychology 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. Children, particularly those with disabilities, have been most severely affected by the blanket withdrawal of services during the COVID crisis. Every effort must now be made to ensure the long-term impacts of the withdrawal of services are minimised.



¹³ <https://www.hse.ie/eng/staff/jobs/eligibility-criteria/psychology-report-jan-2021.pdf>

Reduce the waiting times for assessment of need under the Disability Act 2005

Responsibility: Department of Health

Why this is important to family carers: An Assessment of Need is the first critical step in a child’s journey towards securing the health and educational supports they may need. Early diagnosis, early action and early treatment are key to positive outcomes. Delay in accessing an Assessment of Need is not only injurious to the future wellbeing of the child, it is also likely to have a ripple effect that will require additional funding and support at a later stage.



The Disability Act 2005 provides for Assessments of Need for people with disabilities. Any child born on or after 1 June 2002 and thought to have a disability is eligible to apply for an Assessment of Need, which will detail his or her health needs arising from any disability. Since the Act’s commencement in 2007, there have been significant year-on-year increases in the number of children applying for both an Assessment of Need and disability services generally, leading to extensive waiting lists. This is despite the Disability Act setting out statutory timelines under which Assessments of Need must be completed:

- Assessment Officer must commence the assessment process no later than **three months** after the completed application has been received. (Stage one)
- Completed assessment report must be forwarded to the Liaison Officer within a **further three months** from the date on which the assessment commenced. (Stage two)
- Service Statement must be completed within **one month following receipt of the assessment** report by the Liaison Officer. (Stage three)

In August 2020 the HSE secured €7.8m in once-off Sláintecare funding to address Assessments of Need overdue on June 30th 2020, with the Department of

Health giving assurances that the implementation of the Standard Operating Procedure for Assessment of Need and the reconfiguration of all children’s disability services to Children’s Disability Network Teams (CDNTs) will ensure that further backlogs do not occur once the waiting lists have been cleared. During 2020, each CHO developed a plan to address their backlog of overdue Assessments of Need through (i) overtime initiatives for existing therapists at weekends / evenings (ii) procurement of private assessments and (iii) the short-term recruitment of additional staff. The impact of COVID restrictions also required clinicians to deliver some assessments remotely.

Significant progress has been made and it is anticipated that most of the CHO areas will have eliminated all of their backlogs by the end of 2021. At the time of writing (November 2021), six CHOs have cleared all overdue assessments. The table below shows the progress made up to the end of September 2021 in relation to the backlog of assessments, which has reduced from 6,558 in June 2020 to 520 at end of September 2021. Across the country, 92% of overdue assessments have been cleared. (Note: These activity data refer only to assessments that were overdue at 30/6/2020).

	Overdue assessments 30th June 2020	Outstanding assessments 30th September 2021	% reduction
Total	6,558	520	-92%

In addition, 100 new posts have been allocated under the HSE National Service Plan 2021. These posts should enable each CHO area to determine the discipline and grade required to address the gaps in their Children's Disability Network Teams. The 2021 allocation of posts is being assigned to the CHO areas in two tranches of 50 posts to further strengthen the capacity of Network Teams.

What's needed to progress this commitment:

Family Carers Ireland acknowledges the significant progress that has been made in clearing waiting lists for overdue Assessments of Need during the review period. We note that overdue assessments were a consequence of demand for assessments coupled with insufficient staff to meet this demand¹⁴. The Minister has emphasised that the €7.8m in Sláintecare funding allocated in August 2020 to address waiting lists was 'once-off and strictly time bound' and as such won't be repeated¹⁵. For this reason, it is imperative that the HSE ensure that the Children's Disability Network Teams are adequately resourced, including resources to cover periods of staff leave, and that the new Standard Operating Procedure, currently under review, is sufficiently robust to ensure that waiting lists are not allowed to accumulate in the future.

While this commitment has been assigned a score of 'Good Progress', we are conscious of the concern expressed by families and people working in the disability sector with regard to the robustness of the Assessments of Need undertaken during the clearing process, with concerns that the assessments were not as rigorous as they should be, and that they do not provide a diagnosis for the child. If this is the case, then any apparent progress achieved by clearing the backlog of overdue assessments will be ineffectual and will simply lead to problems elsewhere in the system or further down the line.



¹⁴ Initially it was envisaged that the provisions in Part 2 of the Disability Act would only apply to persons under 5 years of age; however, a successful challenge to the legislation in the case of HSE v Dykes [2009], expanded the class of applicants to all children born after 1st June 2002.

¹⁵ PQ 37504/21.

Provide additional residential places and new emergency residential places for people with a disability

Responsibility: Department of Health

Why this is important to family carers: There is a growing number of people with a disability moving from institutional settings to community-based housing, and many more living at home with family who would like to live independently. The UNCRPD is clear that people have the right to live independently in the community, and it is important that the proper supports are in place for people to realise their rights.

Residential services make up the largest part of the Disability funding disbursed by the HSE – over 60% of the total budget of €2.2 billion in 2021. Approximately 90 service providers provide residential services to over 8,000 individuals throughout the country. The bulk of these are provided by the 50 highest funded agencies (comprising both Section 38 & Section 39 organisations) – some 6,300 places or 75 per cent of places. The HSE itself provides 1,300 or 16 per cent of the places.

Residential Places:

Accurate figures, in relation to the number of residential places available for the last 3 years were difficult to secure and multiple sources were relied on to populate the table below, including direct correspondence with the HSE (figures for 2021), HSE Service Plans and HSE Annual Reports. An analysis of figures shows a downward trend in the number of residential places available between 2019 and 2021, albeit figures for 2021 are only available up to September. It is also the case that the annual target set in the HSE Service Plan has not been achieved, including during the review period.

New Emergency Residential Places:

As with the availability of residential places, figures in relation to the number of new emergency residential places were difficult to secure and

multiple sources of information were relied on, including responses to parliamentary questions, HSE Service Plans and Annual Reports. In the 2021 National Service Plan, the HSE were allocated funding to develop an additional 44 emergency places. At end of September 2021 (latest data available), 64 new emergency residential places were developed. Similarly, the target of 56 new emergency residential places set for 2020 was exceeded.

It is important to note that the Capacity Review up to 2032, commissioned by the Department of Health, found that access to residential care has fallen since the 2008 recession and supply has not kept up with population growth, in part due to some centres not meeting regulatory standards. 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 (page 52). For this reason, and due to information deficits regarding the number of people waiting for a residential place, a score of 'Regressive' was assigned.



	2019		2020		2021	
	Target	Actual	Target	Actual	Target	Actual
Residential places	8,568	8,190	8,353	8,065	8,130	8,090
New emergency places	90	80	56	86	44	64

What's needed to progress this commitment:

Demand for residential care significantly exceeds supply. Since the onset of the recession in 2008, rather than increase in line with population growth, the provision of residential places for people with disabilities has actually fallen. Firstly, the introduction of HIQA standards and inspections of residential disability services in 2013 has reduced the supply of beds; for example, sharing a bedroom is no longer acceptable. Secondly, there are no new admissions to institutions or residential centres as part of the policy to close congregated settings. The outcome has been the emergence of significant waiting lists for residential care, leaving people with complex care needs to be cared for by elderly parents, and younger people with complex medical needs or behavioural issues being denied the intensive supports they need. With such limited places, it is only those in the most extreme situations who are getting a residential place. In order to provide the necessary number of residential places to meet the level of demand projected in the Capacity Review, Government must invest some €550m annually.



Provide additional respite nights for people with a disability

Responsibility: Department of Health

Why this is important to family carers: Respite has been identified as one of the most necessary and effective strategies to preserve and improve the well-being and quality of life of family carers.¹⁶ It is therefore deeply concerning that family carers have no entitlement to any time away from their caring role. Just like the people they care for, family carers also need support to maintain their own health and well-being. Respite care, which provides caregivers with the opportunity for a temporary rest from their caregiving duties, can relieve their stress, renew their energy and restore a sense of balance to their lives.

The HSE and its funded agencies provide respite care to children and adults with disabilities. 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, and according to available resources. 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. As a vital part of the continuum of services for families, respite potentially helps prevent residential placements, preserves the family unit and supports family stability.

The provision of residential respite services has come under increasing pressure in recent years due to a number of impacting factors. An increase in the number of children and adults who are seeking respite due to the increasing population; an increase in the age of people with a disability resulting in people presenting with more complex needs; and the regulation of service provision as set by HIQA who require agencies providing respite to comply with regulatory standards. These standards specify a requirement for personal and appropriate space which has had a direct impact on capacity as respite

beds within a residential setting, e.g. vacated by residents who go home at weekends or for holidays, can no longer be used for respite. Implementation of the national policy on congregated settings is also affecting capacity. As a consequence, the numbers of people with disabilities in receipt of residential respite services and the corresponding number of respite nights has reduced considerably.

Prior to COVID-19, 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 per cent below target, and respite nights 48 per cent below target. The delivery of Respite Services continued to operate during the pandemic, albeit at a reduced capacity; some centres remained open, while others were temporarily re-purposed as isolation facilities. The table below provides details of the number of overnights and the number of day only respite sessions accessed by people with a disability in 2019, 2020 and to date (end of September) 2021.



Year	No. of overnights (with or without day respite)			No. of day only respite sessions		
	2019	2020	2021 (to Q3)	2019	2020	2021 (to Q3)
National	164,506	87,177	66,894	33,172	21,032	11,120

Note: Figures for 2020/2021 are provided through PQ 55064/21. Figures for 2019 are based on the HSE Service Plan 2020

¹⁶ Lund DA, Utz R, Caserta MS, Wright SD. Examining what caregivers do during respite time to make respite more effective. *Journal of Applied Gerontology*. 2009;28(1):109–131. doi: 10.1177/0733464808323448. [Google Scholar].

In 2020, the HSE committed to provide 144 intensive transitional support packages for children with high support needs, to include residential respite interventions and access to extended day/ weekend and summer day-based activities. By the end of 2020, a total of 857 intensive home support packages were actually delivered – six times what was planned - indicative of the requirement for additional in-home services to compensate for the reduction in the delivery of traditional respite during the pandemic.

More recently, the HSE Service Plan 2021 commits to providing nine additional centre-based respite houses, one in each CHO, providing 10,400 additional respite nights along with a range of alternative respite projects including Saturday clubs, breakaway schemes and summer schemes. In responding to a Parliamentary Question on November 22nd 2021¹⁷, the HSE gave the following update with regard to the progress being made towards the establishment of these 9 new respite houses.

Progress on the new Centre-based Respite Services

CHO 1	Completed a review of respite needs and has agreed to use the funding to provide a respite service for children in the Sligo-Leitrim area. They will shortly commence the procurement process for the service. In the interim, time-related savings will be used to enhance the level of respite being provided through existing respite services for children and adults in Donegal and Sligo. They will also procure increased day respite through existing providers. Due to open Qtr. 2, 2022, action plan updated 5.11.2021. Procurement process under way.
CHO 2	CHO 2 have revised their plan in conjunction with service providers and Disability Managers to use the entire allocation of funding for respite between 1/8/21 – 31/12/21. The review of where to allocate funding focused on current emergency cases, business cases and service needs. The proposal has endeavoured to be fair and equitable to all individuals and to support various respite options and be person centred. A new respite service in Galway East sector will also be developed.
CHO 3	CHO 3 had a facility ready for opening once the revenue funding was allocated. This service for children with complex needs, being provided by St Gabriel's, commenced in May 2021.
CHO 4	A respite service for adults will be developed in Cork by the Brothers of Charity and is scheduled to open in Q4 2021.
CHO 5	Delta Services Carlow are currently in the process of arranging some minor building works to ensure the building complies with H&S standards. They plan to open the Unit the first week in December, 2021.
CHO 6	The capital works required for the new respite house have gone out to tender. It is planned that the respite house developed by HSE - Southside Residential Intellectual Disability Service for adults at Respite House Bakers Corner, Co Dublin will be operationalised in Q1 2022.
CHO 7	A development plan is in place for the provision of respite for children, with a component to focus on the needs of children with complex behaviour support needs. CHO7 hopes to operationalise one section of the property (i.e. self-contained apartment) towards the end of December 2021, with a view to a full opening on a phased basis in Q1 2022.
CHO 8	Developed a proposal to open a respite service for adults in a house owned by the HSE in Offaly. To allow time for Estates to complete the necessary works and for HIQA registration to be completed it is anticipated that the service will be ready to open in November.
CHO 9	CHO 9 has developed a respite service for children called “The Hamlet” based in Swords, Co Dublin. The Hamlet, which is now open, is a bespoke house developed to provide specialist respite services to children and families in the area. Minister Rabbitte was invited to ‘officially’ open the house in October, 2021.

¹⁷ PQ 55064/21.

While Family Carers Ireland acknowledges the efforts being made to improve respite provisions, the €600,000 awarded to Family Carers Ireland to provide emergency respite to family carers during the pandemic and the unavoidable impact of COVID-19, given the significant reduction in actual respite delivery and the crisis experienced by many family carers throughout the pandemic, family carers voted overwhelmingly for a score of 'Regressive', illustrating that carers' access to respite has deteriorated greatly during the review period.

What's needed to progress this commitment:

Family Carers Ireland believes full-time family carers should have a right to a minimum of 20 days respite each year, in line with the statutory entitlement afforded to other workers and are calling for this to be included in the statutory homecare scheme legislation. It is deeply concerning that despite the critical importance of respite, there is no national database or figures

on respite availability. We believe 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 need by age group and condition type.

Family Carers Ireland understands that to address the growing requirement for respite services, the current estimates process is proposing €10m investment and targeted alternative models of respite provision such as extended days, weekends, in-home and overnight respite. While welcome, the amount sought does not address the latent unmet need for respite. The Capacity Review to 2032 suggests that €16m to €20m is needed annually to meet the unmet need for respite in 2017 but with latent unmet need this is likely to be significantly higher.



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 & Youth

Why this is important to family carers: Day services are a lifeline for many people with a disability and for their families. These essential services provide support, routine and respite. The Government must provide the resources to allow the full reopening of day services for people with disabilities who avail of them.



The HSE provides and funds a range of day services and rehabilitative training to approximately 19,000 adults with disabilities in almost 1,000 locations across the country.¹⁸ These services are essential for the adults with disabilities who avail of them and for their families. For the duration of the COVID pandemic, day service capacity has been 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 are now working 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 COVID, with full restoration of services expected by October 22, 2021. At the time of writing (November 2021) no information was available on the level of capacity that has actually been achieved by October 22nd.

An analysis of the HSE National Service Plan for 2018, 2019, 2020 and 2021 shows the impact of the pandemic on day services, with the number of people in receipt of day services falling from 20,772 in 2018 to 15,693 in 2020. Due to the ongoing restrictions, many service users will have received supports remotely during the pandemic.

HSE National Service Plan 2018, 2019, 2020, 2021

	2018		2019		2020		2021	
	Target	Actual	Target	Actual	Target	Actual	Target	Actual
People in receipt of day services - work/ work like activities	2,752	2,513	2,513	2,513	2,290	2,237	2,290	Not avail
People receipt other day services	19,672	20,772	22,272	22,281	23,547	15,693	18,420	Not avail

With regard to funding required to support the resumption and restoration of adult disability day services during COVID-19, the following additional funding was allocated:

2020

- €5m towards additional locations required to support service users; IT equipment to support remote service provision and costs of increased transport journeys due to social distancing guidelines.

- €7.5m to provide additional staffing to enable day service staff that had been redeployed to residential services to return to their day service locations.

- Funding for the additional costs of infection prevention and control measures and PPE.

¹⁸ PQ7635/21.

2021

- €30m for additional staffing.
- €17.4m for new day placements for young people leaving school and rehabilitative programmes.

According to the Capacity Review to 2032, meeting continuing demographic need 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 required by 2032.

Capacity Review to 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

While COVID-19 and the ongoing restrictions associated with the pandemic have undoubtedly affected the ability to provide day services in the traditional way, reductions in the HSE targets for meeting the needs of day service users is contrary to the need identified in the Capacity Review and as such this commitment has been assigned a score of 'Regressive'.

What's needed to progress this commitment:

The reduction in supports during lockdown has had a severe impact on people with disabilities and their families, with resilience levels decreasing in the absence of vital supports from day services. People with disabilities are reported to have 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 people with a disability or a greater reliance on family members or carers, as was clearly outlined 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 don't have a day service or receive a reduced service.

While transport is not considered a 'core health service'¹⁹ it is vital to enabling many people with a disability to access day services. While approximately 8,000 adult day recipients are provided with transport to access their day service, some 11,000 people aren't, meaning they rely on public transport or transport provided by family and friends. We note that both the Mobility Allowance and 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 Passengers Scheme which only people who are severely physically impaired are eligible to apply for. Family Carers Ireland continues to call for the establishment of a replacement Transport Support Scheme to meet the needs of people with disabilities as committed to in 2013 when the original schemes were withdrawn.

¹⁹ 50832/21

Examine options for a pension solution for 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 direct consequence of their years spent providing care. Family carers want to be recognised not penalised for their caring years and have their contribution valued in the same way as paid contributions.



For many years, Family Carers Ireland has lobbied for an equitable State Pension system that recognises rather than penalises family carers, and values the immense contribution they make through their years of caregiving, in the same way we value social insurance 'contributions' paid through PRSI. We therefore welcome the Programme for Government commitment to address the long-standing pension anomaly affecting long-term family carers and the subsequent recommendations contained in the Report of the Commission on Pensions. Specifically, the Commission recommends:

- i. That long-term carers (defined as those caring for more than 20 years) should be given access to the State Pension Contributory by having retrospective contributions paid for them by the Exchequer when approaching pension age for any gaps in their contribution history arising due to caregiving.
- ii. The contributions would be exclusively for State Pension Contributory purposes, and would be recognised as paid contributions both for the purposes of the qualifying for the State Pension Contributory and for the purposes of calculating pension rate entitlement under the Total Contributions Approach. This addresses the barrier for long-term carers who, because of the length of their caring lives, are unable to acquire the necessary 520 paid PRSI contributions or who qualify for a reduced rate of pension.

- iii. Relevant Government Department(s), in conjunction with key stakeholders, will examine options for the creation of a statutory 'Family Carer Register' which could, in time, facilitate the identification of long-term family carers for State Pension Contributory purposes as well as assisting in the planning and delivery of services for family carers.

These recommendations reflect the proposals submitted by Family Carers Ireland to the Commission on Pensions both in written and oral form in February and March 2021 and as such a score of 'Good Progress' has been assigned.

What's needed to progress the commitment:

Family Carers Ireland welcomes the Commission on Pensions recommendations for long-term carers, which if implemented will address the legacy issues associated with carers' access to the State Pension system. We understand that the Commission's report will now be referred to the Cabinet Committee on Economic Recovery and Investment for consideration, with a view to bringing a recommended response and implementation plan to Government by the end of March 2022. In order for the Programme for Government commitment to address the pension anomaly affecting family carers to be achieved, it is necessary that all the recommendations relating to long-term carers be approved and urgently implemented.

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: For many families, taking on caring responsibilities results in long-term financial hardship, with the loss of income from employment exacerbated by higher household costs. Protecting and expanding income support schemes is vital for ensuring family carers can continue to care. The commitment to ‘protect’ rather than ‘increase’ or ‘expand’ social welfare rates or address means testing does not go nearly far enough.



The Programme for Government commitment in relation to social welfare rates is disappointing and seeks only to maintain the status quo, rather than move towards establishing a benchmark for the adequacy of adult and child welfare payments. Nonetheless, notable changes in carer payments were announced during the term of this Government. In Budget 2021 and Budget 2022 the following changes were announced:

- Increase in the annual Carer’s Support Grant from €1,700 to €1,850.
- Increase in the Carer’s Allowance income disregard from €665 to €750 (couples) and from €332.50 to €350 (single people).
- Increase in the capital disregard for Carer’s Allowance from €20,000 to €50,000.
- €5 increase in weekly social welfare payments including Carer’s Allowance and Carer’s Benefit.

- Domiciliary Care Allowance and Carer’s Allowance will continue to be paid for 6 months (rather than 3 months) for children who go into hospital.

The changes to the Carer’s Allowance income and capital disregards announced in Budget 2022 will benefit some 45,000 family carers currently on a reduced rate of Carer’s Allowance and thousands more who will now become eligible for the scheme. While Family Carers Ireland welcomes these changes, it is disappointing that they will not take affect until June 1st 2022.

It is also disappointing that despite the changes announced in relation to the Fuel Allowance, Carer’s Allowance has not been included as a qualifying payment, despite the additional heating costs incurred as a consequence of providing full-time care in the home.

Case 1 Couple:

One partner works full-time and earns €1,000 gross per week. The other partner is a full-time carer for their disabled child. They have savings of €100,000.

Current means test:	Qualify for CA of €29 per week.
New disregards:	Qualify for CA of €141.50 per week

Increase of €112.50 per week

Case 2 Single person:

Works part-time and earns €400. Cares for his mother. Has savings of €50k

Current means test:	Qualifies for a CA of €144 per week
New disregards:	Qualifies for CA of €219 per week

Increase of €75 per week



What's needed to progress the commitment:

The establishment of the Pandemic Unemployment Payment (PUP) at €350 per week validated the inadequacy of existing social welfare rates. 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 €224²⁰, €16 more than basic social welfare rates, is untenable. In fact, of the 90,000 carers receiving Carer's Allowance, half receive a reduced rate due to other means and are therefore likely to receive even less than the basic social welfare rate²¹. It is disappointing that the Programme for Government commitment in relation to social welfare rates seeks to protect core social welfare rates, rather than to index social welfare and begin to tackle the scale of poverty, inequality and social exclusion being experienced by so many people in Ireland today.

Family Carers Ireland is currently working with the Vincentian Partnership for Social Justice to establish a Minimal Essential Standard of Living (MESL) for households where full-time care is provided. Pending the completion of this research, and in line

with the recommendations made by the Vincentian Partnership²², Family Carers Ireland has called for Carer's Allowance and Carer's Benefit to be increased by €8 per week²³. While we note the €5 increase announced in Budget 2022, this falls short of what is needed to bridge the gap between the rate of Carer's Allowance/Carer's Benefit and the real costs facing caring households.

Social Assistance payments are defined in law under the Social Welfare (Consolidation) Act 2005. They are one of three categories of welfare alongside Social Insurance and Universal payments and are characterised by the imposition of a means test and the application of the Habitual Residence Condition (HRC). While Family Carers Ireland accepts the logic of the categorisation of Carer's Allowance as a Social Assistance payment on the basis that it is neither PRSI based nor universal, it is increasingly clear that this classification does not recognise the uniqueness of family carers within the social welfare system and as such is hampering efforts to make the scheme accessible to genuine full-time carers who we believe should qualify.

²⁰ Maximum rate of Carer's Allowance will increase to €224 on January 1st 2022.

²¹ Department of Employment Affairs and Social Protection (2019) Policy Review of Carer's Allowance.

²² Vincentian Partnership (2020) https://www.budgeting.ie/download/pdf/vpsj_mesl_pre-budget_submission_2021.pdf

²³ Increasing Carer's Allowance from €219 to €227 would be the first annual step in reaching income adequacy during the lifetime of this Government based on the Minimal Essential Standard of Living (MESL). See www.budgeting.ie.

Enhance the demand led Senior Alert Scheme and ensure it adapts to changing demographics and technological advancements

Responsibility: Department of Community and Rural Development

Why this is important to family carers: Ageing in place means having the ability to live in one's home and community safely, independently and comfortably 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 Senior Alert Scheme would help give peace of mind to families and carers.

The Seniors Alert Scheme (SAS) provides funding for a personal monitored alarm, connected to a contact centre, to enable older persons of 65 or older and of limited means 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, voluntary and not-for-profit organisations registered with Pobal.

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.²⁴ Despite this recommendation, and the obvious opportunities to expand the Seniors Alert Scheme in light of significant technological developments in the area of assistive technology, the scheme has not changed during the review period. Eligibility for the scheme remains confined to persons over 65 years.

It is also notable that despite demographic changes, the number of older people availing of the scheme has decreased from 19,384 participants in 2019 to 16,939 in 2020 (-13 per cent). Figures for 2021 up to the end of September suggest that the decline could be even greater this year.



Year	Participants Senior Alert Scheme
2019	19,384
2020	16,939
2021	11,154 (Sept 30)

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 well-being of many thousands of vulnerable older people across Ireland. Family Carers Ireland notes that 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. In order to progress this commitment, the scheme should be extended to include a range of assistive technologies alongside the traditional personal and pendent alarm systems. We also believe the scheme should be extended to include vulnerable adults of all ages.

²⁴ www.telecare.ie/wp-content/uploads/2017/10/TQG_review_of_the_delivery_model_of_the_seniors_alert_scheme.pdf

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 children with additional needs - have a constitutional right to an education. A failure to provide an appropriate school place is a perversion of the Constitution and a breach of the child's rights.



Home Tuition

During the academic year 2020/2021, a total of 1,434 children with special needs were in receipt of home tuition as they did not have a school place appropriate to their assessed level of need²⁵. The purpose of the Home Tuition Scheme is to provide funding towards the provision of a compensatory educational service for children who, for a number of specific reasons, are unable to attend school. Home tuition is not an alternative to school but rather is intended to be a short-term intervention.

For children with Autism aged from 2.5 years to 3 years, the number of tuition hours available is 10 hours per week. From 3 years, for children with Autism and for children with special educational needs over 4 years, the number of available tuition hours is 20 per week. Complete data for the current academic year 2021/2022 are not yet available, however there has been a reduction of 18 children in receipt of home tuition between 2019/2020 and 2020/2021.

No. of children in receipt Home Tuition Funding 19/20, 20/21, 21/22 (As of the 28/10/21)

	2019/20	2020/21	2021/22 (Oct)
Age 2.5yrs-6yrs (Special Educational Needs)	731	775	422
Age 6yrs+ (Special Educational Needs)	79	86	35
Medical	277	227	45
Mental Health	365	346	71
Total	1452	1434	573 (Oct)

Special Needs Assistants

Budget 2022 provided for an additional 1,165 Special Needs Assistants (SNAs) to provide support to children with special educational needs, bringing the planned number of SNAs to 19,169 by the end of December 2022. This represents an increase of 13 per cent in the number of SNAs provided during the term of the current Government.

Special Needs Assistant Allocations	Number
2018/19 school year	14,973
2019/20 school year	15,948
2020/21 school year	17,014
2021/22 school year	18,004
2022/23 school year Planned	19,169

²⁵ PQ53445/21



Special Classes

For the 2021/22 school year, 2,118 special classes have been provided. This is an increase of 269 classes from the previous school year and will provide approximately 12,700 special class places, including 1,600 new special class places.

Responding to a parliamentary question in June 2021, the Minister of State at the Department of Education confirmed that data are not available as to the number of pupils who are currently on reduced timetables.²⁶

July Provision/Summer Programme

In May 2021 the Department of Education announced a four-fold increase in the number of children eligible to participate in the 2021 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, including special schools which had previously ran the programme. The budget for the 2021 programme was also doubled, from €20 million in 2020 to €40m in 2021. Despite the significant expansion of the Summer Programme, responding to an FOI request in Q4 2021, the Department confirmed that the most up-to-date figure available for the overall cost of the school-based summer programme in 2021 is €15.28m. Figures for the cost of the home-based Summer Programme are not yet available. Despite this, the spend on the school-based programme alone indicates a significant underspend on the €40m budget allocated to the programme.

Family Carers Ireland acknowledges the significant increase in SNAs and the investment in additional special classes with initial signs of a reduction in children receiving Home Tuition. While we welcome

the expansion of the Summer Programme and the significant increase in its budget, it is worrying that this doesn't appear to have had a commensurate impact on the operation of the scheme. Crucially, a key piece of legislation, the Education for Persons with Special Educational Needs (EPSEN) Act 2004, remains only partially commenced. Almost 20 years on, not all parts of this Act are in full effect. The EPSEN Act provides that children with special needs should be educated in an inclusive mainstream environment, unless to do so would not be in the best interests of the child. However, the provision to prepare a tailored, annually-reviewed, individual Education Plan for a pupil following assessment of need is not yet operational, nor has the Special Education Appeals Board - the independent mechanism for review and redress - been established.

What's needed to progress this commitment:

All children, including those with special needs, have a constitutional right to an education and the State has a role in vindicating that right. Home tuition is not a substitute for an appropriate school place. The child is missing out on the social skills, mixing with other children and the benefits that come from that. While we acknowledge the efforts being made by the Government with regard to increased investment in special education, SNA, capital projects and the publication of guidelines on the use of reduced timetables, the failure to provide appropriate school places for all children remains an issue. The Department of Education must create a pathway to a system where all children vindicate their right to education through the introduction of increased monitoring, better planning for future demand and the completion of reforms to which the Government has already said it is committed but which have yet to be achieved.

²⁶ PQ34121/21.

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 by up to €1,600. The Home Carer Tax 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.



While the Programme for Government presents the commitment to increase the Home Carer Tax Credit in the context of supporting stay-at-home parents, the tax credit also benefits family carers who are married or in a civil partnership and are jointly assessed for tax, where one spouse/partner works in the home caring for a dependent person.

While the Home Carer Tax Credit has doubled since 2015, it has not increased during the period of the Programme for Government and has remained at €1,600 since January 2020. The maximum income allowable for the carer has also not increased during the review period and remains at €10,400²⁷.

Year	Credit	Max Carer Income
2022	1,600	10,400
2021	1,600	10,400
2020	1,600	10,400
2019	1,500	10,200
2018	1,200	9,600
2017	1,100	9,400
2016	1000	9,200
2015	810	6,700

What's needed to progress this commitment:

While the Programme for Government commitment to increase the Home Carer Tax Credit is welcome, Family Carers Ireland is concerned that the Home Carer Tax Credit appears to be the only care-related tax relief considered by Government as a support to help carers and parents. By focusing on the Home Carer Tax Credit only, Revenue are failing to address the many anomalies that exist within the suite of tax reliefs available to carers. Current arrangements wrongly deny any meaningful tax relief to single carers or those caring for a relative other than a child. For example, an Incapacitated Child Tax Credit of €3,300 is available to the parents/guardian of a child, including an adult child,

who is permanently incapacitated, either physically or mentally. However, the only tax relief available to a single person caring for their mother or a non-child relative is the Dependent Relative Tax Credit of just €240 – which was increased from just €70 in Budget 2021. It is also a cause of frustration for family carers that the Home Carer Tax Credit of €1,600 is only available to married couples or those who are jointly assessed for tax, meaning single carers cannot avail of it. While Family Carers Ireland welcomes the commitment to increase the Home Carer Tax Credit, this in itself is not enough to address the anomalies for family carers that exist within the current tax system.

²⁷ Under the terms of the Home Carer Tax Credit the carer is allowed to work, however if their earnings exceed €10,400 the family are not eligible for the credit.

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 provides a suite of supports to older people and people with a disability to assist them to carry out works, repairs and accessibility upgrades to their homes to enable them to remain living at home. The scheme is an important element of Government's ageing in place and housing for people with disability policy statements.



The Programme for Government commits to 'maintaining support for the Housing Adaptation Scheme' - a more modest commitment than that made by the previous Government who sought to 'invest significantly in the scheme'²⁸ That said, funding for the Housing Adaptation Grant Scheme has increased modestly since 2020, albeit funding levels have never recovered to their peak of €77m in 2010.²⁹ While average grant values have remained

relatively stable, this should be considered in relation to inflation and the significant increase in the cost of building products. While it has improved in recent years, there is evidence of failures within Local Authorities to draw down the totality of funding allocated to them, despite waiting lists for the scheme. We also note that as of July 1st, just 27 per cent of the 2021 allocation for the Housing Adaptation Grant Scheme has been drawn down.

HAGs funding and drawdown 2014 - 2021

	Housing Aid Older People €'000	Housing Aid Disability €'000	Mobility Aid Grant €'000	Total Grants	Total HAGs Drawdown €'000	Total Exchequer Funding	% Drawdown	Average Grant €
2014	13,498	17,386	5,570	7,547	36,454	38,410	95%	4,830
2015	11,267	20,841	6,284	7,596	38,391	25,321	66%	5,054
2016	12,647	20,867	6,548	8,010	40,062	45,000	89%	5,001
2017	13,254	27,857	7,295	9,080	48,406	47,844	101%	5,269
2018	13,904	29,739	7,601	9,413	51,244	53,000	97%	5,630
2019	15,426	32,246	7,593	10,023	55,265	57,000	97%	5,513
2020	12,762	26,653	5,960	8,137	45,375	59,000	77%	5,575
2021					16,369 (July)	60,000		

* Total exchequer funding does not include the 20 per cent contributed made by the Local Authority.

We acknowledge the impact that COVID-19 has had on Local Authorities' ability to draw down funds during the review period, with Government restrictions curtailing the activities of authority staff, preventing Occupational Therapists from assessing applicants' homes and halting construction projects, thus making it difficult to draw any meaningful

assessment of progress. That said, we note the commitments made in the 'Housing Options for Our Ageing Population: Policy Statement 2019' - still an active document - to increase the funding, review the guidelines and streamline the application process for the HAG scheme as well as publishing annual data on waiting lists, which

²⁸ Programme for Partnership Government (2016).

²⁹ <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>

to date have not been delivered despite having a deadline of Q4, 2019. While some early progress was noted in the First Report of the Implementation Group overseeing the Policy Statement, including initial work on a revised application form and a review of waiting lists, no further progress has been reported, nor has the new application form been operationalized. We note the more recent commitment contained in the Housing for All strategy (2021) to review the Housing Adaptation Grant Scheme (objectives 6.4/7.4) and the Minister's confirmation this will include a review of the existing grant limits and income thresholds and will be undertaken in 2021.³⁰ While welcome, it is disappointing that the review originally committed to in 2019 was not completed. It is also concerning that the Housing for All Progress Report Q3 2021 makes no reference to the review or the Housing Adaptation Grant Scheme.

With regard to the target set in Rebuilding Ireland to achieve 10,000 Housing Adaptation Grants drawdown in 2017 (p. 96), we note that this ambition was reached only once during the last decade in 2019. However, we accept that the failure to achieve the target since 2020 can be attributed to the ongoing restrictions associated with COVID-19.

Finally, we note that funding for the Disabled Persons Grant Scheme and Improvement Works in Lieu of Local Authority Housing Scheme has increased from €15,075,000 in 2019, to €18m in 2020 and now stands at €23m in 2021.

In light of the missed opportunities to review the HAGs, the relative stagnancy of funding in light of the rising costs of building and an ageing population and ongoing operational issues, this commitment has been assigned a score of 'No Progress'.

What's 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 Housing Adaptation Grant Scheme 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 Adaptation 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, with the report stating *'applicants could be subject to considerable inequity based on location, in that the level of funding available to them in one authority may differ greatly from that in a neighboring authority'*³¹. 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.

In light of rising inflation, the spiraling cost of living and price increases in building products due to Brexit, Family Carers Ireland welcomes the Minister's commitment to review existing grant limits and income thresholds. We believe that due to the ongoing housing crisis, this review should put an end to the unfair assessment of the income of other adults living in the household not in full-time education.



³⁰ Response to Parliamentary Question 47287/21.

³¹ <https://igees.gov.ie/wp-content/uploads/2020/02/Focussed-Policy-Assessment-of-Housing-Adaptation-Grants.pdf>

Ensure that an appropriate mix of housing types is provided, including universally designed units, and accommodation for older people and people with disabilities

Responsibility: Department of Housing, Local Government and Heritage

Why this is important to family carers: Under the UNCRPD, people with disabilities have an equal right to access housing and to receive the supports necessary to enable them to live in their own home. Equally, older people have a right to live in a place of their choosing. If appropriate housing is not planned for and ultimately not available, then older people and people with disabilities are forced to live in unsuitable accommodation or placed inappropriately in residential care.



The Programme for Government pledges a vision of an age friendly Ireland. The approach taken is to support older people and people with a disability to live in their own homes and communities with dignity and independence, for as long as possible. This vision is central to the overarching principles of the WHO's Age Friendly Framework and core to the joint departmental Housing Options for our Ageing Population Policy which is to ensure that older people will have greater choice by developing a range of housing options that are suited to their needs, so they can plan ahead and, insofar as possible, choose the right home for them.

Government's 'Housing for All - a New Housing Plan for Ireland' was published in September 2021 and 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 7 relate to improving housing for older people and 6 relate to improving housing options of people with a disability. The actions below are due to be completed by the end of 2021, including:

- Delivery of a new National Housing Strategy for People with a Disability 2022 - 2027;
- Local Authority Housing Delivery Action Plans will set out how dedicated social housing provision appropriate to the needs of older people and people with a disability will be delivered matching the scale and extent of the housing need identified;
- Completion of a review on the range of housing grants available to assist with meeting specific housing needs, including the Housing Adaptation Grant Scheme, and the implementation of relevant changes;

- Nomination of Disability Friendly Housing Technical Advisors in each Local Authority.

At the time of writing (November 2021), Family Carers Ireland understands that while work is being undertaken on these actions, none of the four have been completed despite the deadline of Q4 2021. We note that in 2020, all 31 Local Authorities have appointed an Age Friendly Technical Advisor as committed to in the Housing Options for Our Ageing Population policy statement of February 2019, but Technical Advisors for people with a disability have yet to be appointed. We also note the Minister's reply to a parliamentary question in October 2021 which suggested the new Housing Strategy for People with a Disability 2022-2027 should be in place by January 2022.³²

In relation to social housing, the Summary of Social Housing Assessments Report 2020 shows a 10 per cent reduction in the number of households on a waiting list for social housing between 2019 and 2020 (down from 68,693 in 2019 to 61,880 in 2020), and a 16 per cent reduction in the number of people waiting for more than 5 years. The reduction in the number of people with a disability on the waiting list is proceeding at a much slower rate of 3 per cent. There is an almost 4 per cent reduction in the number of people on a waiting list for social housing who are aged 65 years and over.

Finally, we acknowledge the amendment made to the national social housing application form in April 2021 which, for the first time, allows a person applying to their local authority for social housing to request wheelchair accessible accommodation. Up until April 2021, requesting wheelchair liveable accommodation in a social housing application was not possible which could account for the under-representation of people with disabilities on waiting lists.

³² PQ 47716/21

Unfortunately, while Government have set out their ambition to create more housing options under their Housing for All strategy, no evidence of more accessible housing for older people or people with a disability has been demonstrated during the review period and so a score of 'No Progress' has been assigned. We are hopeful that the ambitions set out will be realised in a more positive score in future scorecards.

What's needed to progress this commitment:

Housing for All is an ambitious document which, if implemented in full by 2030, has the potential to move us closer to achieving a more sustainable housing system that works for all in society including older people and people with a disability. Even at this early stage however, we are at risk of not delivering on some of the actions contained in the plan in the timeline specified - including the publication of the new Housing Strategy for People with a Disability due by the end of 2021; the review of the suite of housing grants and the commencement of the implementation of recommendations; the assigning of Disability Friendly Technical Housing Advisors and the publication of Local Authority Housing Delivery Action Plans which are aligned to population housing needs.

In order 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 live in nursing homes not appropriate to their needs³³ and recognise the close connection between health and housing supports including the introduction of a statutory home support scheme, the delivery of the Carers Guarantee and the expansion of community-based care in line with the Sláintecare Implementation Plan.

Family Carers Ireland also believes that 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.³⁴



³³ Wasted Lives: Time for a better future for younger people in Nursing Homes (2021) Office of the Ombudsman.

³⁴ <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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