



NOTE OF PROCEEDINGS

National Carers' Strategy - Annual Carers' Forum 2024

Wednesday 22 May 2024

Chartered Accountants House, Pearse Street, Dublin 2

& Online live stream: [link on Gov.ie](#)

Background

The Annual Carers' Forum is hosted by the Department of Social Protection as part of its commitments under the National Carers' Strategy (NCS). The purpose of the Forum is to provide carers with a voice at policy level. It also provides an opportunity for engagement between officials and people experiencing care issues first-hand.

Introductions

Teresa Leonard, Deputy Secretary General, Department of Social Protection opened the Forum and welcomed those attending in person and those viewing the Forum online. She highlighted the importance of the event as it enables the voice of carers to feed directly into department policy and provides a valuable opportunity for engagement between officials and people experiencing the issues first-hand. She said that events such as the Forum, the Disability Consultative Forum, meetings with the Community and Voluntary Pillar and the annual Pre Budget-Forum really help to inform the Department's thinking in relation to developing policies. For carers, she said that this event is an opportunity to highlight their issues and concerns but also a chance to get out and to share and interact with other carers.

She recognised that the last number of years have been a very difficult time financially for everyone, and particularly family carers, and that the Department has strived to respond to carers' needs through improvements to the various income support measures provided. She noted the increase in carer payment recipients over recent years with an 11.3% increase from 2020 (86,831 recipients) to 96,670 today. There are currently 3,887 people getting Carer's Benefit, an increase of over 13.4% from 3,426 in 2020. On average, 419 new claims for Carer's Allowance are received each week and processing times have significantly improved at 6 weeks currently compared to 7 weeks in 2020 and 14 weeks in 2019. Spending on the various carer payments in 2024 is expected to amount to over €1.7 billion.

Ms Leonard acknowledged the hard work and commitment of carer representative groups and thanked those present – Family Carers Ireland and Care Alliance Ireland – for their assistance with today's event and looked forward to their presentations. She noted that Care Alliance Ireland would be presenting on their Online Family Carer Support Group which provides support to family carers online and was established during the first COVID-19 lockdown and which now has about 8,000 members. Family Carers Ireland will present on their Caring Employers Programme, which is funded by the Department through Dormant Accounts, outlining the key elements of the programme, including surveys and focus groups and the importance of growing the programme. She said that

Family Carers Ireland will also take this timely opportunity to outline their Budget asks for 2025. Ms Leonard said that, over the years, she has witnessed the strong relationship and open dialogue between the Department and the carer's organisations and that engagement has led to positive outcomes for all and she looks forward to continuing this relationship into the future. She said that the Forum aims to capture carer issues that are wider than just income supports and thanked colleagues from other government departments for their attendance and contributions today.

Finally, Ms Leonard stated that she was particularly pleased that Minister Humphreys was able to take time out to address today's Forum later in the morning. The Ministers attendance demonstrates her personal commitment to advancing the issues affecting family carers. She then invited Care Alliance Ireland and Family Carers Ireland to make their presentations.

Presentations

Zoe Hughes, Senior Research & Policy Officer, Care Alliance Ireland (CAI)

The Online Family Carer Support Group Ireland – 4 Years On

An overview and update of the *Online Family Carer Support Group Ireland* was provided. Established in March 2020 during the COVID-19 lockdown, this project aims to provide carers with trustworthy information, peer support between carers and a signpost to other services and organisations while increasing the confidence and wellbeing of participants and decreasing social isolation.

- Using the Facebook platform, this professionally moderated group uses high levels of privacy settings and offers peer support and advice, professional guidance and referrals and a range of group activities such as book and gardening clubs and educational talks.
- There are currently 8,047 members with ongoing increases of 7 new members a day. Retention rate is 97% and extremely high engagement levels – approximately 90% of members are 'active'.
- Member polls have shown that over 93% of members have found the group helpful in their own situation with over 96% reporting a positive experience in the group.
- The group actively collaborates with other organisations, referring carers as appropriate and undertaking joint courses and activities.
- Research by the University of Limerick, *Social Identity and Online Support Groups: A Qualitative Study with Family Caregivers (July 2023)* included interviews with members of the group and the results were very positive and demonstrated the positive impact of being a member of the online support group.
- While initially funded in 2020 by the Community Foundation of Ireland and The National Lottery, recurring funding was granted by the HSE in 2021.
- The group is accessible online, 24/7, without the need to travel or find replacement care and the member can choose how they want to interact. The group has no waiting lists to join and

the project costs approximately €20 per client per year. There is no cost to members to join the group.

Catherine Cox, Head of Communications & Policy and Sue O’Grady, Marketing Manager, Family Carers Ireland

Building a Community of Caring Employers

An overview of Family Carers Ireland’s *Carer Pathways* programme was provided along with an outline of the FCI ‘asks’ for Budget 2025.

- An overview was provided of the work of Family Carers Ireland and some national estimates on the numbers of carers, gender breakdown and numbers who are caring and in paid employment. The importance of the work life balance by supporting carers in employment was emphasised.
- Carer Pathways is funded by Dormant Accounts and aims to upskill and empower family carers to re-enter or remain in paid employment through targeted interventions. It also aims to future-proof workplaces for family carers by providing targeted programmes of support such as the Caring Employers project.
- Launched in 2019, Caring Employers is a bespoke programme that tailors its approach to individual employers and their caring employees. This is done through initial learning what the employee’s challenges are, focus groups and selected practical virtual events.
- Results of a survey of 54 respondents from 2 organisations were presented, 34 of whom identified as family carers. Of those, 30 were caring for 1 person, 6 for 2 people and 2 were caring for 3 people. 44.7% were caring for a parent or parent-in-law, 36.8% caring for a son or daughter (in-law), while 10.5% were caring for a spouse or partner.
- Practical workplace supports include People Manager Workshops which educate about carers, their challenges and how managers can and should support them. Webinars are also provided in areas such as carer rights and entitlements, elder care/dementia care and coping with bereavement. The CARE TALK Series are practical webinars open to all member employees.
- The benefits of being a Caring Employer were outlined. Recognition and adoption of carer policies resulting in staff retention and resultant savings in recruitment costs, experience loss, mentoring and productivity loss due to staff turnover.

Budget 2025 priorities from Family Carers Ireland were outlined including:

- Increased income disregards in the means test for Carer’s Allowance for couples and single carers with the full abolition of the means test and the introduction of a Family Carer Payment by 2027.
- Increased rates to Carer’s Allowance, Carer’s Benefit, Carer’s Support Grant and Domiciliary Care Allowance. Removal of the income limit for those on Carer’s Benefit.

- Carer's Allowance to be included as a qualifying payment for the Fuel Allowance scheme. Extend GP Visit Card to those getting Carer's Support Grant. Extend Free Travel to children for whom Domiciliary Care Allowance is in payment.
 - Removal of the 18.5-hour work/training limitation for those getting Carer's Allowance who wish to undertake care specific training or education to help them secure employment after their caring role ends.
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Workshops & Plenary Session

The groups in each workshop were asked to discuss their theme and each reported back on three issues to the Plenary Session following the workshops.

Workshop 1: DSP information, operational and policy issues including DSP income supports & life after caring

3 issues fed back for consideration to the Plenary Session:

1. Abolish the Carer's Allowance means test.
2. Increase Carer's Allowance rate (improve adequacy of payment).
3. Recognising the cost of disability and the costs of care and have a more person-centred approach (needs of care recipients and of carers). Acknowledge levels of care.

Other issues raised at this workshop included:

- Means test for Carer's Allowance needs to be completely abolished and replaced with a participation income.
- The cost of disability needs to be acknowledged. The costs associated with the care of children with disabilities are exceptionally high and not acknowledged (e.g., private assessments, adapted vehicles, specialist clothing etc). Current rate of Carer's Allowance is wholly inadequate to deal with such costs.
- The means test removes the financial independence of a carer in a relationship and fails to see them as a person in their own right.
- The above needs to be particularly considered in the context of domestic/financial abuse situations where a carer is dependent on their partner.
- 18.5 hour/week employment limit was mentioned as discriminating against carers.
- The question was asked why two parents caring for a child full-time should only receive only one Carer's Allowance payment.
- Carer's Allowance should be a qualifying payment for Fuel Allowance.
- Lack of awareness around the Long-Term Carers Contribution Scheme launched in January was highlighted and lack of information regarding eligibility.
- The complexity and level of detail required on application forms was mentioned as being onerous.
- Process needs to be more person-centred.

- Reviews reported as a source of considerable anxiety.
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- General feeling of people feeling degraded or having to beg in terms of looking for State supports.
- Need to improve overall administration e.g., including processing delays, submitting applications, consistent advice on phone queries.
- Need to continue the ongoing consultation and dialogue on issues.
- SUSI Grants: The application process for the SUSI grant where student children can see the details of family finances, was described as degrading. It was also mentioned that the Carer Support Grant is considered as means when applying for the SUSI grant. DSP said they would follow this up with the relevant department.

Workshop 2: Carer Health and Well Being/ Access to Health and Social Care Supports and Services

3 issues fed back for consideration to the Plenary Session:

1. Equity of access – there are regional disparities in access to some services and supports. The quality of your care should not vary based on where you live.
2. Address waitlists – some people have been on waiting lists for services for significant periods of time and are now afraid their children will age out. In some instances, they may have to go private and pay out of pocket to get basic services.
3. Carers' voice – carers' voices should be considered throughout the patient's journey, and in the formation and implementation of policy for supports and services (co-design), including respite services.

Other issues raised at this workshop included:

- A family carer outlined how where you live can impact your situation. She lives in a rural area where there is a big centre for people with autism, but those services were not always available elsewhere. There is inconsistency and inequity with the provision of some services and supports.
- A suggestion that assessments should be outsourced to address the waiting lists for services.
- Services and supports should be designed with carers. Currently, some carers report that respite services cause more stress to carers as they do not consider the patient or carers' needs.
- Calls were also made to introduce a right to a minimum of 20 days of respite care per year for full time carers.
- There needs to be a list of supports and services available. People can only find out information from other parents through word of mouth. For example, it was suggested that the Children's Disability Network Team (CDNT) should give parents this information. Finding information becomes a full-time job for carers.
- There needs to be flexibility in the system. The respite for people caring for an autistic child or a spouse with dementia will look very different. There is no one carer.

- Frustration that advocacy groups have been calling for change for years. If policymakers listen to carers, it must then lead to the implementation of policy/ change that impacts carers.

Workshop 3: Housing Supports and Transport for Older People/People with Disabilities

3 priority issues fed back for consideration to the Plenary Session:

1. Funding, there is no joined up thinking across departments, between Education, Health and Transport. People can't get funding for support packages, personal budgets not working. Need to increase money for grants in line with rising building costs.
2. Have a liaison officer to advocate or make individualised plans to make applying for the different aspects of grants a smoother process. Carers don't have the time or energy to deal with surveys, builders, quotes etc.
3. Transport – more services, infrastructure and improvements to accessibility. Larger signs for partially sighted people and have signs at an accessible height for wheelchair users. More wheelchair spaces in buses, currently there is only one.

Other issues raised at this workshop included:

- The Differential Rent Scheme, there are different approaches from different local authorities, no consistency.
- The criteria for Primary Medical Certs has been changed, there are severe strict rules around the Primary Medical Certs.
- Dublin Bus App has been changed; it is not accessible.
- Mobility Allowance was abolished in 2013, there has been no replacement.
- Have strong vibration at traffic lights for visually impaired.

Workshop 4: Supports for Young Carers

3 priority issues fed back for consideration to the Plenary Session:

1. A multi-department national awareness campaign is needed to highlight and recognise the role young carers play. This should be linked in with a Public Young Carers Forum to give a voice to all young carers including those under 18.
2. Permanent annual funding for young carer projects in all organisations and youth groups to ensure services are available in all areas of the country.
3. Financial support is needed for young carers that is not dependent on the person being cared for declaring their illness. Evidence from a GP or other medical professional could support this when the person being cared for doesn't accept that they have an illness.

Other issues raised at this workshop included:

- Lack of a central repository/area where young people can access information on all of the supports available to them. Currently, they have to research everything themselves and it can be too long of a process to find out what supports are available and then to get them.

- Lack of support in schools. While there is some level of support from teachers in primary/secondary school that are aware of the household situation but no support in third level colleges. In third level you are very much on your own. Where a student is 10 minutes late, they are marked as absent, and their SUSI grant reduced. It was felt that there should be screening to establish if students are carers and support put in if they are. There should be more public speakers in colleges to raise awareness about caring as it's a taboo subject at present. Young carers felt peer support among other students who are carers would be helpful. It was also suggested that both schools and colleges need dedicated mental health professionals to develop individual care plans and link students into the available services.
- Working and juggling caring is difficult. It was felt young carers were penalised for working e.g., support with rent is reduced. Also, as soon as they finish college, they are assessed on the basis of the own income rather than parents who may be on Social Welfare and felt no allowance was made for them being carers. It was felt work is good for their mental health.
- Young carers don't always identify as carers so it's important to find a way to do so.
- Social workers are available for the person being cared for but not for the young carer. Young carers need support and advice too.

Online Event Feedback

While the Workshops above were taking place, attendees at the online event were also posting comments on carer issues online. The following are some of the comments raised:

- Why is there not a database for children born with lifelong conditions (that are never going to be cured) that links directly to their claims for allowances?
- I was refused the Carer's Support Grant when DCA finished at 16 – diagnosis doesn't go away; he actually needs more care as he gets older.
- Current claims are processed by nameless, faceless people with no experience of disability/mental health issues which means that already stressed parents are doubly stressed.
- Had a review of my Carer's Allowance – voluntarily reported an increase in my husband's wages. It was horrendous, took over 2 to 3 months and didn't sleep a wink. Caring for 2 disabled children. Letter that came looking for more information was threatening in nature made it worse – took a toll on my mental health. You are made to feel like a criminal.
- Lack of access to respite.
- Fact is a lot of people apply for these allowances because of inadequate services. If the services were properly run and more easily accessible, the need for such allowances might reduce.

Address by the Minister for Social Protection, Ms Heather Humphreys, TD

The Minister for Social Protection, Heather Humphreys, T.D., acknowledged the hugely important role which family carers play in Irish society and stated that she and the Government are committed

to supporting carers and have made this commitment in both the Programme for Government and in the National Carers' Strategy. Since her appointment as Minister, she said that she has listened to and done her best to support carers and there have been a number of significant improvements within the social welfare system as a result and her intention is to do more.

The Minister noted that the combined spend on carer income supports this year is over €1.7 billion and that there are currently over 96,400 people in receipt of Carer's Allowance – over double the number in 2015. She outlined the significant improvements made to carer payments and added that, in her very first Budget in the Department of Social Protection, she increased the Carer's Support Grant to €1,850 – it's highest level ever which will be paid to all carers next month (June).

In acknowledging the financial burden that the families of sick children face, the Minister said that a number of changes have been made to the Domiciliary Care Allowance payment over the last three years. The period during which DCA can be paid for children in hospital was extended from 3 to 6 months, and with effect from last year, the payment is available for babies who remain in an acute hospital after birth for a period of 6 months. In the last week, the Minister stated that she was pleased to have signed legislation to extend this period to 18 months. While she acknowledged that these changes only affect a small group of people, but she knows that it means a great deal for these families.

The Minister highlighted some of the positive measures introduced for carers in Budget 2024 including a €12 increase in the weekly Carer's Allowance and Carer's Benefit payments – weekly Carers payments have been increased by €29 in the last three years. Domiciliary Care Allowance also increased to €340 per month – this payment has increased by €30.50 under this Government.

The Minister recognised that the past year or so has been very difficult for many families in Ireland with the costs of food and energy rises, and especially difficult for carers, and the Minister ensured that they were prioritised in the Government's response. She outlined provisions to date including a €400 payment for people receiving the Carer's Support Grant paid in November last, carers provided with the Christmas Bonus Double payment and a further double payment was made to carers earlier this year.

In the coming weeks, Government will begin the process once again of devising the annual budget, the Minister said. While there are a lot of competing demands across Government at Budget time, she said that very good progress for carers has been made in recent years and provided an assurance that she will be once again be advocating strongly on behalf of carers in the context of the upcoming Budget.

The Minister acknowledged that the Carer's Allowance means test is an issue which has been raised consistently by carers over the years as well as again today. As part of Budget 2022, she was the first Minister in 14 years to make changes to the Carer's Allowance means test, increasing the weekly earning disregard to €750 for a couple and to €350 for a single person. In Budget 2022, she increased the amount of savings disregarded in the means test from €20,000 to €50,000 and stated that the current disregards for carers are the highest of any payment in the entire social welfare system. As part of Budget 2024, the Minister made further changes. From June, a couple can have weekly

earnings of €900 per week and still qualify for the full carers allowance payment. This change to the means test will help more carers to qualify for a payment.

The Minister stated that, while Carers Allowance now has the highest income disregards in the social welfare system, she is conscious that no matter where the line is drawn on the means test, there are still some families who will fall on the wrong side of it. However, she has set up an Interdepartmental Working Group to examine and review the system of means test for carers payments and have asked this group to report back to her before this year's Budget.

In acknowledgment of the important role that family carers play in society; the Minister stated that she has delivered on the Programme for Government commitment to provide a pension solution for long-term carers.

From January 2024, a new Long-Term Carers Contribution scheme was introduced. She said that this significant reform enables long term carers, who have been caring for incapacitated dependants for 20 years or more, to qualify for the State Pension Contributory. It will do this by attributing the equivalent of paid contributions to long-term carers to cover gaps in their contribution record. These contributions will be treated the same as paid contributions for State Pension (Contributory) entitlement only and can be used to satisfy the minimum 520 contributions condition. She said that she knows this reform is a reassurance and relief to the many carers across the country who have spent their lives caring for loved ones. In particular, she thinks of those many mothers who have had to give up their jobs to care for a severely disabled child into adulthood and found themselves reaching pension age without any income. She thanked department officials working behind the scenes to make these changes happen.

The Minister noted that the issues affecting family carers are much broader than the income supports provided by her department. Those providing full-time care have other varied needs and the Government response needs to be holistic. The Programme for Government commits to delivering a 'Carers Guarantee' proposal that will provide a core basket of services to carers nationwide, regardless of where they live. In Budget 2021, €2m was allocated to the HSE under the National Carer's Strategy with a view to improving equity of access to supports for carers. €1.9 million provided to Family Carers Ireland to deliver a mixture of community and individual supports to approximately 5,000 additional family carers and €100,000 is supporting the delivery of online supports through Care Alliance Ireland by means of an online support group, which was presented on earlier in the morning.

Family Carers Ireland have called for an additional investment of €3.1 million to complete the carers' guarantee and that the Department of Health have undertaken to consider the Carers' Guarantee request in the context of the estimates and budgetary process.

A Family Carers Needs Assessment pilot programme was carried out over a two-year period from September 2021 to September 2023 in Community Healthcare West. Dormant Accounts funding was used to test the implementation of the programme across various care groups, including carers of people with dementia, older people, physical and sensory disability, intellectual disability and mental health. The pilot, which was carried out with Family Carers, examined the role of the Family Carer, how caring affects them, and how much care they can realistically provide while still allowing for

involvement in other activities. The InterRay Family Carers Needs Assessment identified the types of support family carers need to support them in their caring role and seeing how these can be met. The project's final evaluation report was published in March 2024. The HSE and the Department of Health are considering what next steps may be required to further support family carers.

The Minister noted the opportunity that today's Forum brings for officials and carers to engage directly. Since her appointment as Minister for Social Protection, she has placed a high value on these engagements. She said that priorities raised at previous events have resulted in concrete improvements for carers over the years and that today's event continues this process of open communication and dialogue. She thanked all attendees for taking time out of their busy lives to engage in the Forum. Finally, she stated that she wants to recognise the huge contribution that Family Carers make to our society and the Government's commitment to further enhancing the supports available to them.

Concluding Remarks

Rónán Hession, Assistant Secretary at the Department for Social Protection with responsibility for Carers Policy, closed the Forum and thanked all attendees for their attendance and contributions to the workshops. He thanked attendees who had travelled today and taken time from their busy lives to attend as well as those who joined the forum online. He said that this Forum is very valuable from the Department's point of view as it enriches our understanding of the issues for carers.

Mr Hession thanked Zoe Hughes of CAI for her presentation on the Online Family Carer Support Group and noted that many of the issues raised in previous forums such as lack of confidence and need for peer support are met by this project.

He also thanked Catherine Cox and Sue O'Grady from FCI for their presentation on the Caring Employers programme and noted that the Department works closely with employers. He was struck by the fact that the very qualities demanded of a full-time carer, such as tenacity and multi-tasking, are the very strengths that employers value.

He thanked colleagues from other Government Departments in attendance for their active participation. He stressed that the event is not just a discussion forum but that many of the points and ideas expressed today may lead to real change in policy and that the senior people who can make those changes are in attendance today.

Finally, he thanked his departmental colleagues who had organised today's event, the venue team at Chartered Accountants House and the technical team presenting the day's event online. He especially thanked Family Carers Ireland and Care Alliance Ireland for their assistance in today's event.

End of Forum