



NOTE OF PROCEEDINGS

National Carers Strategy - Annual Carers' Forum 2023

Wednesday 17 May 2023

Chartered Accountants House, Pearse Street, Dublin 2

& Online live stream: YouTube Platform

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 the Department places a high value on events such as the Forum and other engagements such as the Disability Consultative Forum and the Pre Budget-Forum. She recognised that with Covid and the Cost-of-Living crisis, the last number of years have been a very difficult time for everyone, and particularly family carers and that the Department has responded to carers' needs through improvements to the various income support measures provided. She noted the increase in carer payment recipients over recent years with a 15% increase from 2018 (79,914 recipients) to over 92,000 today. On average, 422 claims for Carer's Allowance are received each week and processing times have significantly improved at 6 weeks currently compared to 14 weeks in 2019. Spending on the various carer payments in 2023 is expected to amount to almost €1.6 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 Re-Emerge Project which provides support to family carers returning to employment and that this project has been funded by DSP utilising funding from Dormant Accounts. She stated that many of the carer representative organisations have availed of Dormant Accounts funding over the last number of years and piloted some very innovative projects. In December, the Minister announced almost €700,000 in funding to 7 projects under the Dormant Accounts Action Plan 2022. These projects are designed to increase the employment, including self-employment, and education and training opportunities for carers and young carers. 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 this engagement has led to positive outcomes for all and she looks forward to continuing this relationship into the future. She thanked colleagues from other government

departments for their attendance and contributions to the Forum which aims to capture carer issues that are wider than just income supports.

Finally, Ms Leonard thanked Minister Humphreys for taking time out to address today's Forum. She said that the Minister takes a very personal interest in carer issues and is a true advocate for family carers. She then invited the Minister to address the Forum.

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

The Minister for Social Protection, Heather Humphreys, T.D., welcomed all attendees in person and online to this very special event in the Department's annual calendar. The Minister 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, a number of significant improvements within the social welfare system for carers have been made. While she would like to do more, the Minister stressed that there are competing demands across government at Budget time, but good progress has been made and carers remain a top priority.

The Minister noted that there are currently 93,035 people in receipt of Carer's Allowance – almost double the number in 2010 when there were 50,000 people getting this payment. She outlined the significant improvements made to carer payments as part of Budget 2023 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.

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 rising dramatically. The Cost-of-Living crisis was especially difficult for carers and the Minister ensured that they were prioritised in the government response. She outlined provisions to date including a double payment for carers last October; a €500 payment for those getting the Carer's Support Grant paid in November, the Christmas Bonus double payment to carers and a further €200 payment for carers which was made most recently in April.

The Minister acknowledged that the Carer's Allowance means test is an issue which has been raised consistently by carers over the years. 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. She explained that the reason the disregard was raised by slightly more for a couple was to try and help the person who has to give up work but was missing out because of their partner's income. 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. The Minister also confirmed her commitment to carrying out a broad review of means testing this year which will help to inform future policy decisions.

In acknowledgment of the important role that family carers play in society; the Minister stated her commitment to pension provision for those caring for over 20 years. This will be done by attributing social insurance contributions to long-term carers to cover gaps in their record and by establishing a register of family carers for this purpose. The Minister confirmed that her officials are currently working to implement these reforms so that the pension for carers can be in place by January 2024.

The Minister noted that the issues affecting family carers are much broader than the income supports provided by her department. Issues include accessing services, waiting lists for appointments, transport to and from medical appointments and accessing much needed respite services. The Department of Health is committed to improving such supports for family carers and the Programme for Government commits to delivering a 'Carers Guarantee' proposal that will provide a core basket of services to carers nationwide. This commitment which is being led by the Minister for Health is consistent with the National Carers' Strategy. 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.

The Minister also stated that a Family Carers Needs Assessment pilot programme is being carried out over a two-year period from September 2021 to September 2023 in Community Healthcare West, which aims to gather data to assist with planning health care services and developing new policies which are inclusive of 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. Finally, she expressed the hope that all attendees will have an informative and productive morning and she thanked all the carers present for taking time out of their busy lives to take part in this important Forum.

As per the agenda, presentations followed these opening addresses, then workshops on key issues, with the day concluding with a plenary session.

Presentations

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

Re-emerge: The Next Chapter is for you

An overview of the *Re-emerge Project* was provided. This project focusses on supporting carers by increasing opportunities for career progression and employment skills while decreasing isolation and increasing the confidence and wellbeing of participants.

- The project end goal is to have 16 carers progressing to further education, 80 engaged in employment training and 12 returning to paid employment.

- The project is open to family carers returning to employment as well as those who have recently returned to employment with the aim of increasing retention.
- The course is delivered online and participants will be offered a training budget, replacement care costs, assistive technology, wellbeing interventions as well as 1-2-1 supports in IT and life coaching.
- Activities include access to mental health support groups, mindfulness/meditation, confidence building and peer interaction. Physical health supports include nutritional education, yoga and exercise classes.
- The project will collaborate with a number of Irish not for profit organisations over the course of the programme, such as current collaboration with Siel Bleu, Ciunas Centre and Empower.
- The first group of participants started in April and registration is ongoing until end June 2023.

Catherine Egan Morley, Head of Carer Supports & Maggie Lally, Regional Manager, Intensive Supports, Family Carers Ireland

Intensive Support Service – An Overview and Case Study

An overview of Family Carers Ireland *Intensive Support Service* was provided along with a case study. This service focusses on support for carers experiencing the most complex caring situations.

- Established in September 2022, this service provides carers with support access to Transdisciplinary Teams, comprising support specialists in Children/Young Adults with Additional Needs, Older People, Mental Health and Addictions.
- National coverage is provided and the current waiting time for the service is 12 weeks due to demand.
- Between January and March 2023, 1,124 carer needs assessments were completed; 389 cases were assessed as requiring intensive support; 202 carers commenced Intensive Support; 1,000 interventions were delivered, and 1,270 hours of counselling were delivered. 110 emergency respite referrals were received, 50 of which were delivered.
- A case study was presented outlining the challenges facing a parent with a child who has significant additional needs and the supports provided to them by this service.
- The approach adopted by the service in this case involved the assignment of a dedicated Support Manager, identification of carer support needs, psychotherapeutic support provision, group based and individualised training and mentoring provision and referral for emergency respite.
- The issues for policy makers to consider were outlined including the need for earlier intervention, improvements to assessment provision, more carer support at post-assessment and diagnosis stage, high costs of private assessments and therapies, better services integration and improved access to Home Care and respite.

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. Caring should be seen as a job with minimum wage, similar to the artist's minimum wage pilot scheme. The discussions also centred around what happens after a period of caring stops (perhaps due to the death of the caree) and how the carer might not be able to access jobseeker supports because of a lack of social insurance contributions.
2. There were many calls for means test for Carer's Allowance to be abolished. This was linked to the first point above where carers felt they were doing a service for the State and their family income should not determine whether they qualify for support or not.
3. There was a lot of discussion about the frontline staff who carer's encounter when applying for social welfare supports and how they need to show more empathy towards carers who are very vulnerable. Many of the group had encountered excellent and very caring staff within DSP but felt that some staff required more training.

Other issues raised at this workshop included:

- A complete review of Carer's Allowance should be carried out with open and transparent input from stakeholders.
- Free Travel is not useful for carers in rural areas where public transport is not readily available. Many carers living in rural areas have no option but to drive and they have care related transport costs, such as diesel.
- Application forms for carer supports should be reviewed with simplification in mind.
- The application forms are not suitable for complex diagnoses and don't cater for rare diseases.
- The Appeals process can be difficult to understand.
- Carer's Allowance rates are not high enough, especially for lone parents. It was said that if lone parents are in financial difficulty, then this affects the whole family.
- Burial costs are significant and there are no post-death services provided when a carer is particularly vulnerable. Concerns and lack of knowledge were expressed about Community Welfare Officer supports around burial costs.

- Carers should be given contributions, not credits, to enable carers to avail of for example Illness Benefit or jobseekers benefit after caring has ended.
- Basic Income for the Arts was set at €325, and PUP was set at €350. Carer's Allowance rate should at least be equivalent.

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:

- Respite services must be improved. Respite is required for emergencies, medical appointments, planned events (such as weddings or funerals) as well as a break for carers themselves. Far more hours/overnights of respite care are needed than currently available. Lack of respite care is especially difficult for those caring for more than one person and those carers who don't have family or other support in times of crisis. An example was given of a disability respite service recently closed for refurbishment without any clarity as to whether, or when, it will reopen, and this has caused huge anxiety for family carers.
- Assisted Decision Making legislation is welcome but involves costs in setting up Enduring Power of Attorney or in setting out what level of decision-making a person should be entitled to, to ensure that the person being cared for is supported and to ensure the carer is not accused of taking advantage of them.
- Emotional stress and worry can lead to personal health issues for many carers.
- Carer isolation and not having access to a well-informed single point of support contact. Examples were given of excellent Public Health Nurses who helped with home help hours and respite care while other health professionals didn't know where to get help and were learning from the carers themselves.
- An electronic health record would benefit both health professionals and carers and the roll-out of same should be accelerated. Some carers find it challenging making numerous phone calls and emails which are time-consuming and stressful.

Other issues raised at this workshop included:

- Lack of staff to support carers; constant turnover of staff; lack of co-ordination between services and a geographic lottery regarding service provision.
- Carer feelings of isolation, desperation, stress, being a burden on their family (when support available) and being alone (where family or friend support not available).
- Covid-19 risks for carers made them more isolated.
- Charges for respite care.
- With an increasing population there will be more carers and they need to be provided for.

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

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

1. Transport: A community-based transport system as recommended in the Value for Money report. Participants recalled the old RTP model that could be updated and utilised. Vehicles should belong to the community. Best practice model in Canada was noted (Wheely). Schemes needed for carers reliant on cars e.g., to purchase electric vehicles and for the existing Fuel Grant to be extended from petrol diesel and LPG to include electricity used for driving.
2. Housing: Provision of age and condition-appropriate housing for people with cognitive disabilities in the area that they are from.
3. A more integrated approach to service provision is needed between communities, local government and government departments.

Other issues raised at this workshop included:

Housing:

- Assessments for Housing Adaptation Grants need to be standardised around the country.
 - Assessments by Occupational Therapists are being paid for by individuals or some county councils provide this assessment.
 - There is central guidance on medical prioritisation as well, but practice still varies. Department of Housing is currently reviewing adaptation grant limits and outcome is expected later this year.
- Regarding the differences in availability of grants and amounts, Department of Housing representatives confirmed that budget is there for all county councils, but some may not exhaust their budget. In these cases, money goes to a different county council. Financing of fixed-track hoists is in progress. Legislation is being drafted. Repairs will not be covered.
- There is insufficient supported living for young people with intellectual disabilities. They are often offered placement in nursing homes or to live on their own or far away from their families or support systems – these do not suit young people with intellectual disabilities. Good examples: Scotland and Canada. An Irish example: supported living in Navan run by Enable Ireland.

Transport:

- There was a consensus that the current system of public transport does not work for people with disabilities. People were not satisfied with the services currently provided. A number of questions and complaints were articulated to the officer representing the National Transport Authority.
- In many cases, the bus cannot take more than one wheelchair user. Low-floor buses do not work everywhere, and buses would need lifts as well.
- Some argued that hiring private operators do not serve local communities well. It is not on-demand, it is not flexible. Scheduled buses are not sufficient. It was also the experience of attendees that community public transport is often the first to cut funding for at times of recession.

- Arguments were made in favour of community transport. It was recommended that local communities should own the buses purchased for the community and service for disabled people should include on demand and door-to-door services, not just scheduled buses.
- There are community and NGO-led initiatives like ACTS that provide services. Consideration should be given to financing what's already working for the local communities. The old Rural Transport Programme was brought up as an approach that would require updates but could be a good direction for future development.
- Mobility Grant could be brought back. Support could be introduced to encourage the use of e-vehicles, including not penalising people with savings set aside for vehicle adaptation works in means-testing processes.

Workshop 4: Supports for Young Carers

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

1. Support advocacy and financial support needs of young carers. An Advocacy Service should be made available to young carers. Examine the range of financial supports available and, where conditionalities are creating barriers, seek to address them.
2. Identify young carers and listen to them. Define what a young carer is, find mechanisms to identify them and their particular needs, listen to them and use social media to reach out to them, where appropriate.
3. Make funding to support services for young carers secure and permanent and ensure that all services are available across the country. In this regard, good practices led by some CYPSC which are currently reliant on short-term funding were highlighted.

Other issues raised at this workshop included:

- Need to ensure inter-agency and intra-agency collaboration. Many departments, agencies and organisations have a relevant role and mandate, but better coordination and improved visibility is needed.
- Consider the issue of young carer's own healthcare needs and the supports that they may need, individually, in addition to their role as carer.
- Issues affecting young carers directly were raised such as the education system not 'wrapping around' them, for example, with bans on phone access in school (not tenable when in caring role), late/nonattendance at class, constraints around attending exams and access to transport etc.
- It was suggested that many issues being raised around young carers such as isolation, educational disadvantage, financial issues, health and wellbeing are longstanding ones. It was proposed that a rights-based approach is needed.
- Fora such as the Annual Carers' Forum need the presence and perspective of young carers and, in setting out the timeframe for such events consideration should be given to their availability and needs, for example, pre-exam season, cover for care for the day, transport, internet/laptop access etc.

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 issues they raised:

- The Carer's Allowance means test should be abolished.
- The means test should not be based on gross income. When caring for a child with complex medical needs, outgoings should be considered such as mortgage, sibling needs and other necessities.
- Carer's Allowance needs to be reformed to be based on needs rather than on means.
- Carers should receive payment for the work that they do.
- The application form for Carer's Allowance needs to be simplified using Plain English. Many carers are overwhelmed, and the application process can be stressful.
- A replacement for the Mobility Allowance is needed, which was closed in 2013 with the promise of a new scheme.
- Carers should get priority when learning to drive, getting a driver's licence and insurance as they need to drive as a necessity for care.
- We need to see radical reform of Housing Adaptation Schemes with a significant increase in the maximum amount afforded which is now €30,000 whereas the cost of adaptation is closer to €60,000.
- Carer's Allowance should be paid to some families on the One-Parent Family Payment as there are challenges where there's more than 1 child in the family and 1 has complex needs, especially where a parent has died. There is very little support in the community for children with ID/ASD even with ID nurses in hospital or GPs or dentists.
- Also, the lack of childcare for children with special education needs.
- The home care system needs a rehaul. Cost of care is €30 an hour locally from a care company where the worker only gets €15 if they're lucky.
- Many mothers would, if given the choice, rather have access to childcare and be at work for a few hours to get out of the house rather than be forced (societally) into a carer's role.

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 participants for their openness and the difficult and personal stories they shared. He stressed that Government needs to hear these stories without reserve. 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 and, for those who were unable to attend, a note on the day's proceedings will be made available.

Mr Hession thanked Zoe Hughes of CAI for her presentation on the Re-Emerge Project and was impressed with the planned employment outcomes as well as the 'softer' outcomes such as confidence building which are equally important for participants. While the Department is primarily tasked with providing income supports, it also provides some funding from the Dormant Accounts Fund which funds this project, and the Department is delighted to do so. He also thanked Catherine Egan Morley and Maggie Lally from FCI for their presentation and noted the importance of Government departments hearing personal stories such as that shared as part of the presentation.

He thanked colleagues from other Government Departments in attendance today for their active participation. He stressed that today's event is not just a discussion forum but that many of the points and ideas expressed today may lead to real change in policy. He cited by way of example the change to carer hours that had come out of a previous forum.

Finally, he thanked his colleagues who had organised today's event, the venue team at Chartered Accountants House, the technical team presenting the day's event online as well as Family Carers Ireland and Care Alliance Ireland for their assistance in today's event. He stressed that the Department is always open to hearing ways of improving future events.

End of Forum