

Consultation Response: Northern Ireland Executive. Our Plan: Doing What Matters Most. Draft Programme for Government 2024 – 2027

October 2024

ABOUT CARERS NI

Carers NI is Northern Ireland's membership body for unpaid carers. We work to represent and support over 220,000 people who provide unpaid care for ill, older or disabled family members or friends.

SUMMARY OF KEY POINTS

- Carers NI welcomes the publication of a Programme for Government and long-term strategic planning.
- However, we are disappointed that unpaid carers are not mentioned at all in the plan and their priorities are not clearly addressed. In a dedicated carers event hosted by The Executive Office (21 October 2024) carers said they feel invisible in this plan.
- Unpaid carers want to be recognised within the Programme for Government. They want “the plan” to start addressing the challenges they face every day.
- **Tackling poverty; a commitment to funding and urgent action to reform the social care system, including support for unpaid carers; and delivery of improved employment rights legislation for carers within this mandate are priority areas for unpaid carers.**
- For many unpaid carers in Northern Ireland providing care to family members, friends or neighbours who are ill, disabled or older, comes at a significant personal cost. This comes in the form of loss or damage to educational or employment opportunities; careers; finances; health and wellbeing.
- Unpaid carers have specific challenges and needs and should be included as a standalone category in the wellbeing dashboard, rather than amalgamated into the broader category of “those with dependents”.
- Carers NI would value clarity around the actions that are built into the plan and ask what assessment/tracker tools will be used to measure success. For many areas we feel improved matrices need developed which better reflect the priorities the plan is trying to tackle rather than just measuring what is readily available.
- The commitment to cut waiting times is welcome however the health and social care system needs to be viewed as a whole. Investment purely in cutting waiting times for operations, procedures or appointments will not solve the wider problems within our health and social care system and will not address many of the pressures felt by unpaid carers. Carers have asked does this priority include cutting waiting times for community care packages and multidisciplinary support? Will investment be made in primary care and community care services to enable people to be cared for in the community and take the pressure off unpaid carers?
- Timeline: After the main consultation closes on 4 November and the deadline has passed for the 2 December impact assessment process; a consultation analysis will be drafted to help inform the final version of PfG. Carers would like a confirmation from TEO that it will come back to Carers NI after all the responses are submitted and the newly updated version is ready.

INTRODUCTION

Carers NI welcomes the publication of the draft Programme for Government 2024-2027. Northern Ireland is facing many societal challenges and has been without a clear agenda for change and long-term planning for too long. Long absences of a functioning government at Stormont have consolidated that lack of progress. These long periods of stasis have also severely delayed transformation of NI's public services which are so desperately needed. To make any advancement we need a clear strategic plan, with clearly defined targets alongside appropriate needs-based funding formulas and multiyear budgets.

Transformation of public services will require cross departmental co-operation and collaboration, something which has been lacking in the past. This is especially important for unpaid carers who need co-ordinated support across multiple departments to make tangible differences to their daily lives.

Upon the restoration of the Northern Ireland Executive in early 2024 Carers NI issued a rapid survey to our members asking about their priorities for the incoming government. This response is based upon that survey and a consultation event for unpaid carers held in October 2024.

LIFE FOR UNPAID CARERS IN NORTHERN IRELAND

There are over 220,000 people providing unpaid carer for ill, disabled or older family members, friends or neighbours in Northern Ireland – representing around 1 in 8 adults.¹ They are a diverse group spanning from child and young adult carers to working age carers and through to carers of pension age.

They support people with health conditions like cancer, stroke, progressive neurological conditions and visual impairment, mental ill-health, learning disabilities, terminal illnesses, and more. For some, their caring role may be for a few hours per week, but for many it is much more and often involves caring around the clock.

For many unpaid carers, the care they provide comes at significant personal cost in educational and employment opportunities, careers, finances and health and wellbeing. One in four (28%) local carers are living in poverty in Northern Ireland. Much higher than those without caring responsibilities (17%) and higher than carers across the rest of the UK (24%). For those carers in receipt of Carer's Allowance, the main social security benefit and essentially the safety net for carers, this figure rises to nearly one in two (46%).²

When we surveyed carers in 2023 nearly one in three (30%) told us they are struggling to make ends meet. More than one in five (21%) said they are struggling to afford the cost of food and nearly one in three (31%) said they are cutting back on essentials like food and heating to get by.³

¹ NISRA. Census 2021

² Carer Poverty Commission. Policy measures to tackle poverty amongst unpaid carers in Northern Ireland. 2023

³ Carers NI. State of Caring. The impact of caring on finances in Northern Ireland. 2023

“I am at breaking point due to the abject poverty I am forced to live in while caring for my parent, who has dementia. My debts are increasing at an alarming rate as my quality of life continues to decrease. I feel depressed... I have been abandoned.”

“Yesterday I had breakfast cereal for three meals, so that my cared-for person could have their required lunches for the week.”

Unpaid caring is also a major driver of mental and physical ill health within Northern Ireland. Carers are also struggling to access any form of respite or a break from caring. Our 2023 State of Caring survey shows:

- One in four carers described their mental health as bad or very bad.
- A large majority (76%) said they had continued providing care despite feeling like they were at breaking point.
- Nearly a third (29%) told us they feel lonely always or often.
- Over half (52%) of carers told us their physical health has suffered due to caring
- 21% said they had experienced injuries as a result of their caring role.
- More than one in three (39%) said they had put off health treatment because of their caring role.⁴

“I’m always tired. Completely worn out. I’m doing the role of three people and it’s so difficult. I’ve no independence.”

“I am rarely out of the house, as it is not safe to leave my husband on his own.”

Many carers want to be in employment to bring in much needed wages but often struggle to balance their caring role with paid employment due to poor workplace support and a lack of replacement care. This can lead to exhaustion, stress and poor health. Carers NI’s research shows one in three carers leave work to care, one in four cut back on their hours and others take on jobs they are overqualified for or turn down promotions. This has implications for carers’ finances, career progression and social connections⁵.

“I ended up having to take redundancy because they wouldn’t accommodate my caring needs along with work. I initially asked if I could reduce my hours from 32 hours/week to two and a half days and they said no. Then I asked for hybrid working and they said no to that. Then I asked for a career break, and they said no to that too. In the end the redundancy package came up and I had no choice but to take it.”

Unpaid carers are currently propping up our health and social care system. They save the Executive £5.8 billion per year in care costs⁶, yet they feel unrecognised, unsupported and many are at breaking point. They cannot continue like this. They need the NI Executive to recognise the challenges they face and to move at pace to resolve them.

⁴ Carers NI. State of Caring. The impact on caring on health in Northern Ireland. 2023

⁵ Carers NI. Delivering carer’s leave in Northern Ireland. 2024

⁶ Carers NI and the Centre for Care. Valuing Carers Northern Ireland. 2023

PRIORITIES FOR UNPAID CARERS

Unpaid carers want to be recognised within the draft Programme for Government. They want “the plan” to start addressing the challenges they face – what matters to them. But in the current draft they are not mentioned at all, and their priorities are not clearly addressed. Carers believe it is essential that government is transparent about how the plan’s nine priority areas were chosen and that they should listen to the views of those who feel they are excluded.

“We need our elected representatives to start working on our behalf. We are struggling with everything. They just don’t seem to understand what it’s like.”

Below are a list of **priorities** that unpaid carers told us are important to them and which should be included within any final version of NI’s Programme for Government that runs to 2027.

1. **Tackling poverty:** As detailed above the poverty rates amongst unpaid carers are shockingly high and many carers are being forced to make extremely difficult choices on a daily basis to get by. Tackling this poverty must be a priority within the Programme for Government.

What is needed: A clear cross departmental anti-poverty strategy addressing the deficiencies in our social security system, the barriers preventing carers taking on employment and the high extra costs associated with caring is needed within this plan and mandate.

2. **Reform of the social care system:** Chronic under funding and a lack of long-term planning has seen severe deterioration in community care services across the province. Shortages of care packages and staff are putting greater pressure on the shoulders of unpaid carers who are having to fill in the gaps in service provision. This is leading to poor health and wellbeing amongst carers many of whom are receiving little or no breaks, respite or support to look after their own health and wellbeing.

Northern Ireland has an aging population. This will mean in the future more people will become carers in their lifetime and often be caring at an older age. It is therefore essential the Programme for Government addresses the current poor provision of social care, the lack of support for carers and plans for the future.

We acknowledge the good work being undertaken within the Social Care Collaborative Forum to develop proposals for reform. However, action is urgently required.

What is needed: Transformation of social care services must be a priority, be properly funded and move at pace. This must include a comprehensive new cross-departmental carers’ strategy which includes support for carers to look after their own mental and physical wellbeing.

3. **Employment rights legislation to support carers to balance employment and care:** Many carers want and indeed need employment. They value having an identity outside of their caring role. They cherish the careers they’ve spent so long working

toward. And they rely on their wage packets to meet the high costs of supporting someone who is unwell during an ongoing cost of living crisis. However, balancing paid work and caring responsibilities is difficult.

Supportive workplace cultures and workplace rights enshrined in law will help carers manage their caring roles without using holiday leave and are extremely important to carers.

What is needed: Improved employment rights legislation needs to be delivered within the current mandate and include flexible working from day 1 and paid carer's leave to ensure carers are supported to enter and remain in employment.

- 4. Supporting carers to return to work:** Carers NI welcomes the commitment to grow an inclusive economy with good jobs for everyone and opportunities to help disadvantaged groups into employment. However much in this section focuses on helping women with children return to work. Carers NI's research clearly shows how carers (of whom 60% are women) struggle to balance work and caring responsibilities⁷. We also welcome the commitment to introduce new employment rights legislation and a good work charter within the Programme for Government

What is needed: We would like to see better inclusion and recognition in this section around the need to support carers to return to work both when balancing employment and care and for those for whom the caring role had ended.

In addition, the affordable childcare proposals within the Programme for Government must include a commitment to improving childcare options for children with SEN. This is a vital enabler to allow parental carers to take on employment.

TARGETS, DELIVERY AND MONITORING: Many of the actions included within the Programme for Government are vague. Carers NI would value clarity around the actions and clear targets and timescales for delivery built into the plan. For many areas we feel improved matrices need developed which better reflect the priorities the plan is trying to tackle rather than just measuring what is readily available. We would also ask that unpaid carers are included as a standalone category within the wellbeing dashboard rather than being amalgamated within all those with dependents. Data should be disaggregated to improve transparency as unpaid carers represent a different group, with specific needs and should not be grouped with those with purely parental responsibilities for dependents.

CONCLUSION: Carers NI welcomes the publication of the draft 2024-2027 Programme for Government and the concept of long-term strategic planning. However, we would urge the Executive to consider the issues that are important to unpaid carers in Northern Ireland. Unpaid carers are the backbone of our health service but they feel unrecognised and unsupported. Many are suffering poverty and mental and physical ill health as a result of caring. We would ask that the Executive includes tackling poverty as a priority area in the plan; commit to funding and urgent reform of the social care system, including support for unpaid carers; and deliver improved employment rights legislation for carers within this

⁷ Carers NI. Career or Care. 2024

mandate. We would also ask that unpaid carers are recognised and included as a standalone category in the wellbeing dashboard.

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