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About Carers NI

1. Carers NI is Northern Ireland's membership charity for unpaid carers. We work to represent and support the near 300,000 people in Northern Ireland who provide unpaid care for ill, older or disabled family members or friends – fighting for increased recognition and support for all carers and to ensure they have a voice in policymaking.

Introduction

2. There are near 300,000 unpaid carers in Northern Ireland, meaning one in five adults here have some sort of caring role. ^[1] Even before the Covid-19 pandemic, the care provided by unpaid carers was worth £4.6bn per year in Northern Ireland. ^[2] This only increased during the pandemic as many social care services were disrupted and reduced, and research in November 2020 estimated that the value of care provided by carers in Northern Ireland during the pandemic was £19m per day – equating to a staggering £6.93bn for a full year. ^[3]
3. The simple reality is that Northern Ireland's Health and Social Care system, and wider public finances, would collapse without unpaid carers. Too many, for too long, have been unable to access the support they need from social care services, so the reform of adult social offers an opportunity to deliver a better, more robust system that we cannot afford to miss.
4. Unpaid carers must be treated as strategic partners as this process develops. They have unrivalled knowledge and experience of the social care system, built up from years of living within it day-and-daily. Based on this lived experience, they also have a raft of recommendations and ideas to improve the system, and that voice must be listened to during the next steps of reform.
5. Carers NI welcomes the opportunity to respond to the Department of Health's consultation on the reform of adult social care. We undertook an extensive programme of engagement with unpaid carers from across Northern Ireland to inform this response, to ensure that we were truly reflecting their lived experience, concerns and views. This included an online survey, a series of virtual focus groups and consultative events. The rest of this consultation response includes both quantitative and qualitative data that was gathered through this engagement, along with wider research and evidence from Carers NI.
6. While the consultation document includes proposals on a wide range of important themes and issues, we have only responded to those to which we feel we have something meaningful to contribute.

¹ Carers Week research report 2022.

² Buckner, L and Yeandle, S (2015). Valuing carers: The rising value of carers' support.

³ Carers UK (2020). Unseen and undervalued: The value of unpaid care during the COVID-19 pandemic.

Strategic priority 1: Sustainable system building

Proposed action 1: Adult social care legislation

7. Carers NI is disappointed that, while the need to develop a cohesive legislative basis for adult social care provision is recognised in the consultation proposals, measures to put the rights of unpaid carers on a legal footing are not set out explicitly. The Power to People report was very clear that the lack of a legal right to support services for carers, based on identified need, is a significant anomaly in Northern Ireland, and we would urge the Department to make a clear commitment to introducing legislation to correct that.
8. The case for this could not be better evidenced. Pre-pandemic, one in five carers in Northern Ireland did not receive any support at all in their caring role. Among those who did, many had been experiencing a reduction in the amount of care received from statutory health and social care (HSC) services even before the Covid-19 pandemic disrupted the system so significantly. In our engagement with carers, the most pressing theme identified overall was the lack of support they received and the need for greater access to services to help them provide care, take a break from caring and prevent them being pushed to a position of exhaustion and burnout.

“We have never had support outside of a hospital environment; basically discharged and left to deal with the situation at home by ourselves. Have never seen or spoken to a social worker.”

“My physical and mental health is poor due to lack of support as a carer, finding things, fighting for things, the time it takes to address anything.”

“I’m at rock bottom and so fearful for the future and what lies ahead. There is no light at the end of the tunnel. I feel quite angry sometimes and abandoned. The anxiety I feel is all-consuming both mentally and physically.”

“The years of caring responsibilities without support or breaks has taken a physical and mental toll. I don’t know how much longer I can keep giving from a nearly empty box.”

“It does affect my mental health as feel like a hamster on a wheel. I’ve had 2 days off in the last 8 years.”

“I feel isolated and very alone. I find caring such a challenge. In general, there is very little means of support for carer. You’re just left to get on with it.”

9. This situation has only deteriorated since the Covid-19 pandemic began, with many services reduced or closed in March 2020 and yet to fully return. Nearly half of carers in Northern Ireland have faced a reduction in day services and over a third have experienced reduced access to short breaks.^[4]

“I have lost all day care, lost my one visit a day from my care workers. The support has been non-existent and I have become somewhat of a recluse as I can’t get a proper break.”

10. When we asked carers what difference it would have made to them to get support early in their caring journey, answers included:

“I don’t think I’d be as strung out. I’m battling to recover from exhaustion and depression. Over the years and before Covid, I was alone most of the time every day. When I asked for help, I got very little.”

“We wouldn’t have been in limbo for 6 years with the whole family developing mental health difficulties such as anxiety and depression. Things have got worse rather than better due to the lack of support.”

⁴ Carers NI (2022). State of Caring 2021: A snapshot of unpaid care in Northern Ireland.

11. Closely linked to this, one in seven carers in Northern Ireland told our last State of Caring survey that they had not requested a Carers Assessment because they did not feel it would be beneficial to them. ^[4] In far too many cases, carers have grown disillusioned at having taken the time to go through an assessment only to receive no additional support afterwards.

“The Carers Assessment is nothing more than a tick box exercise. I have had 18 Carer Assessments and every single one recognises my need for regular breaks, yet in 18 years, I have only ever received 3 single day breaks from caring.”

“My needs were identified but remain unmet.”

12. The social care reform process offers a critical opportunity to deliver a legal right to support for our carer population. Legislation in other jurisdictions, such as the Care Act in England, are by no means perfect – but do provide protections and entitlements for unpaid carers that do not exist in Northern Ireland. We would strongly advocate for legislation that enshrines the rights of unpaid carers to social care support from their Health Trusts, as was envisaged in the Power to People report – including the right to regular breaks from caring.
13. This must be accompanied by a major funding boost for the social care system, so that capacity, staffing and resource levels match demand and all unpaid carers, and the people they support, can access the services they need.

Proposed action 2: Review of third party top-up fees for care homes

Proposed action 6: Revised system of regionally consistent tariff setting for adult social care services

14. Carers NI supports these proposals. Our members highlighted the crippling impact of high social care costs, including for care services in their own home and care home fees. This was contributing to the financial pressure they faced (see paragraph 20-22) and reduced the choice of services available to them.

“I would like to have placed my mum in a home with toilet facilities in her room but due to third party charges I could not afford this. The care homes in my area were charging from £110 a week upwards for such facilities and as her sole carer I was unable to meet these weekly costs. My choice was therefore extremely limited.”

“I live 90 miles from my mum and I am now with her four days and nights per week. I know I am probably going to burn out. I cannot pay what it costs for multiple night sits. If the care system in place gave two nights care per week that would make a huge difference.”

“Care has to be more affordable. I can't afford the help I need. One night of care was quoted by the hour. I can't afford that.”

“A relative had to enter a care home. His home had to be sold to pay for his care needs. He stated: ‘I should have committed a crime, then the government would have jailed me and I'd get care for free’.”

15. In the context of the wider cost of living crisis, this situation seems to be getting worse, with 65% of local carers telling us in February 2022 that the cost of care services had increased during the previous six months. ^[5]
16. Tariff setting for social care services must be fair, standardised and set at a level that people can afford to pay, with regular reviews that take account of rising inflation and cost of living pressures. We would also be in favour of setting a weekly cap on the amount that people are asked to pay for their social care services, as exists in Wales.

⁵ Carers NI (2022). Under pressure: Caring and the cost of living crisis in Northern Ireland.

17. We find it particularly egregious that care home top-up fees may be applied for what most people would consider to be basic necessities, such as private bathrooms. The review should ban top-up charges of that, and a similar, nature.

Proposed action 3: Review of social care charging arrangements

18. Carers NI welcomes the fact that a new charging system has not been introduced for domiciliary care in Northern Ireland, although we recognise that that seems to be the ultimate direction of travel. It is critical that the future review of charging arrangements for domiciliary care includes the voices and experiences of unpaid carers.

19. Under any future charging arrangements, we also think it is important that:

- Any new means-testing system is airtight in exempting those households that cannot afford to pay for domiciliary care without a negative impact on their financial stability and quality of life.
- A weekly cap is introduced on the amount that people are asked to pay for their social care services, as exists in Wales.
- Any domiciliary care services that are introduced to support an unpaid carer, following an identified need in a Carers Assessment, are provided free of charge, as is the case in Scotland.

20. Many unpaid carers in Northern Ireland are already facing severe financial pressure due to the costs linked to their caring role, and this would only be exacerbated by additional charges for domiciliary care. Last year, 29% of local carers said they were struggling to make ends meet,^[6] and this is largely driven by the high extra costs they face as a result of their caring role and the inability of many to work. For example, carers face higher energy, travel and food bills due to the needs of the person they care for; the enormous cost of equipment and home adaptations so the cared-for person can remain in the home; and much more.

21. We must also recognise that many carers are already paying for social care support in Northern Ireland. In 2019, 86% of local carers said they were regularly using their own income or savings to pay for care or support services, equipment or products for the person they care for.^[7] Additional charges for domiciliary care services will therefore create an even greater financial burden that many unpaid carers simply cannot afford, especially in the context of the growing cost of living crisis.

22. Failure to protect these households from new domiciliary care charges will inevitably result in more and more people going without the services they need, putting an even greater care burden on unpaid carers. Many unpaid carers are being pushed to exhaustion and burnout even with the support of domiciliary care services in the home, so this situation would be a recipe for disaster that must be avoided.

Proposed action 4: Review the current balance in the mixed economy of care

23. Carers NI welcomes the commitment to review the balance in the mixed economy of care in Northern Ireland. We agree with the Department's assessment that current arrangements are driving a cost-focused and transactional system of provision, and our members highlighted a number of ways in which this is manifesting.

24. Firstly, carers told us that, in too many cases, care services are based around short, task-focused and inflexible appointment times rather than personalised and holistic support. This

⁶ Carers NI (2022). State of Caring 2021: A snapshot of unpaid care in Northern Ireland.

⁷ Carers NI (2019). State of Caring 2019: A snapshot of unpaid care in Northern Ireland.

often doesn't meet the needs of the cared-for person and puts more pressure on their unpaid carers.

"The carers that I've personally seen going into homes and within 5 to 8 minutes are exiting the property. This has got to end. How do you get to know and trust someone that appears for 5 minutes? You would just about have time to boil a kettle!"

"It would be good to have flexibility. Four 15-minute visits a day didn't suit mum's needs or us as a family, but that was all that was offered."

25. Carers also highlighted that the current mixed economy leaves the availability of services severely limited, or non-existent, in some parts of Northern Ireland – particularly in rural areas.

"In rural areas, the carers only work until 9pm. My father had a catheter and it was emptied at approximately 7pm each night [with a] bag fitted. This had to last until 9am the next morning."

"[We need] more flexibility on working hours. Many people require night visits which are not available in rural areas."

"Services in Tyrone are woefully lacking. My son has to travel 2 hours by bus to and from his placement in Derry."

26. We would argue that properly addressing the issues above requires not only an assessment of the balance in the mixed economy of care, but also an understanding of the true cost of care – to allow services to be commissioned and delivered in a sustainable way that meets the needs of care recipients and their unpaid carers. This equally applies to Proposed action 36 in the consultation document, on the removal of limits on the amount or cost of social care services someone may receive, and Carers NI also supports that recommendation in the context of the points we have raised here.

Proposed action 5: Reform how adult social care is planned and delivered within the new Integrated Care System (ICS) model

27. Carers NI supports this recommendation and believes the reform of adult social care and delivery of the new Integrated Care System should be intimately linked. As this process moves forward, we would like to see the role of unpaid carers properly codified in the ICS, making explicit the permanent and strategic role of unpaid carers in designing and delivering the objectives of the new systems and commissioning processes. This contribution should be fully compensated.
28. Linked to this, we believe it is important to place on record our concerns around the role of unpaid carers in the proposed Area Integrated Partnership Boards (AIPBs). AIPBs will play a key role within the new system – holding overall responsibility for strategic area planning and local delivery – but there is space for just one carer representative on each Board. This set up would leave each person with the task of reflecting the diverse views, experiences and needs of the carer population – an impossible undertaking, as we have already seen with the existing Integrated Care Partnerships.
29. Carers NI would like to see a carer forum being established to sit alongside each AIPB and support the input of unpaid carers into the work and decision-making of each Board. We would be happy to explore the ways in which Carers NI could assist with the establishment and/or operation of such a forum.

Strategic priority 2: A valued workforce

Proposed action 9: Improving pay, terms and conditions for the lowest paid social care staff

Proposed action 10: Continue developing a Social Care Workforce Strategy

30. Carers NI supports both of these proposals. Our engagement with carers across Northern Ireland highlighted the importance of creating a larger, higher paid and more skilled and experienced social care workforce – both to provide better care for patients and take pressure off their unpaid carers.

31. Carers repeatedly emphasised that the current situation – where low pay and poor T&Cs result in high turnover of social care staff – is not conducive to the high-quality and consistent care they want for the person they're caring for.

“They should be better rewarded and valued. There should be a major recruitment campaign with a clear career path, appropriate remuneration and status rolled out as soon as possible to ensure that everyone is getting the social care they need.”

“Better funding and conditions are vital to ensure recruitment and retention of good carers. It should not just be a stepping stone, rather a real career.”

32. We would argue that, while immediate priority should be given to increasing remuneration and improving T&Cs for the lowest paid social care staff, this should ultimately extend to the entire workforce.

Strategic priority 3: Individual choice and control

Proposed action 24: Development of a co-produced regional strategic “In Control” action plan

33. When we engaged with Carers NI members and other unpaid carers across Northern Ireland, many expressed support for the principle and/or concept of Self-Directed Support (SDS). While it will always remain the case that some households will prefer to have services directly arranged by their Health Trust – and that option should remain for anyone that wants it – for others, SDS can offer greater levels of control and personalisation of care services.

34. However, many carers also told us that the reality of the SDS system does not match the theoretical benefits it can or should provide, inevitably putting greater pressure on them and/or creating a care gap that they, or other family members/friends, had to fill. The primary issues they raised included:

- The high administrative burden of becoming an employer, managing budgets and navigating a complex system with little information or support available.

“It would add more stress and anxiety. There is already a lot of paperwork without adding more. We need support, not more work.”

“I would prefer not to have to deal with sending work remits, invoices etc. Could there not be a service to sort this all out, as being an unpaid carer takes up most of my time?”

- Challenges finding suitably experienced and qualified staff due to shortages across Northern Ireland.

“Getting appropriate staff to employ was extremely difficult, so Direct Payments were unsuitable for us.”

“It’s impossible to recruit employees to work with complex challenging vulnerable adults.”

“The pool of people who are skilled and experienced [enough] to provide the required care and support is not available.”

- Regular turnover of staff causing lack of continuity of care and, as a result, worse outcomes for the care-receiver.

35. Beyond these issues, our engagement with carers also showed there is lack of awareness or understanding of SDS as an option among many households, and countless examples of carers being dissuaded from considering SDS due to the complexity of accessing the system. When we asked carers about the barriers to using Direct Payments, typical answers included:

“Don't know how to access it or what I could use it for.”

“Have never been made aware that this was available to us.”

“It seems so complicated. I haven't been able to work out how to use it.”

“I was told it was too much paperwork and I would have to jump through hoops to get it. I was discouraged from pursuing it further.”

36. In the context of all of the issues above, it is vital that the In Control action plan includes measures to provide greater information and administrative support to households considering Self-Directed Support. For example, we would be supportive of the introduction, as suggested by our members, of dedicated SDS navigators in each Trust area to help overcome some of the challenges in the system and ensure all carers are aware of the options it provides.

Strategic priority 5: Supporting carers

37. Carers NI welcomes the fact that unpaid carers have been identified as a strategic priority in the social care reform process. We have a number of comments and suggestions on the proposals under this theme.

Proposed Action 30: Evaluation of the Caring for Carers Strategy to inform a new strategic approach

38. We are disappointed with Proposed Action 30 and believe that evaluating the 2006 Caring for Carers Strategy is an unnecessary and time-consuming step that will uncover little-to-no new evidence and only serve to further delay the new strategic approach that carers need.
39. The case for this new strategic approach is well known and has been firmly established for years. Carers have grown deeply frustrated at the slow pace of change in the social care reform process – the Power to People report alone was published nearly 5 years ago – and this is only likely to grow if decisive action is held up by the launch of another review.
40. Carers NI wants to see the immediate development of a new Carers Strategy for Northern Ireland. We welcome many of the priority areas identified in paragraph 7.11 of the consultation document – which are discussed in greater detail below – and would like to see these proposals progressed within a new strategy without delay.
41. We warmly welcome the proposal to develop a new HSC carer support pathway as part of a new strategic approach to carers. This pathway should cover the direct care, support and advice that carers need to look after their own wellbeing and get regular breaks from caring.
42. Similarly, we believe the proposed Carer Navigation System is desperately needed. When consulting with our members, many expressed exasperation at the extreme complexity of health and social care structures and highlighted how challenging it is for them to access and coordinate the support the cared-for person needs. While social workers have a role to play here, feedback from carers suggests that having a social worker does not always provide adequate help.

“Navigating the system from a standing start is a nightmare. You are dealing with the illness or disability of your loved one, struggling financially, trying to maintain family and work life and taking care of your own mental and physical wellbeing. You have to find out everything for yourself and be extremely proactive to get anything done.”

“The care system is a maze for the ordinary person. A suitably qualified and knowledgeable member of staff should be allocated to individuals, at an early stage, to guide, advise and advocate for their care needs.”

“[Carers need] someone who can be a point of contact should they need assistance or have a query. Both myself and my husband would have benefited from this instead of me having to run around sourcing information and help by myself.”

43. We believe there is merit in exploring the possibility of households being allocated a social care keyworker as part of the new Navigation System.
44. We welcome the Department’s commitment to including measures related to carer wellbeing in Programme for Government (PfG) outcome assessments, but also would argue that carers should be recognised within the PfG Outcomes Framework as well. The draft Outcomes Framework published last year does not say a single word about unpaid carers, and given the multi-billion pound contribution they make each year in Northern Ireland, that was very disappointing. Many unpaid carers feel that they are not properly recognised or valued by our government or health service – this perception is only reinforced when they are left out of the Executive’s most important strategy document.

45. While we are strongly supportive of the development of a Carers' Register, we do not believe the Department's proposal would be any more robust than those registers that are already held by each Health and Social Care Trust. The unsuitability of these registers in policy delivery was illustrated clearly by the unsuccessful introduction of the proposed carer Covid-19 payment in 2021.
46. For the new Carers' Register to be a success, something much more robust is required. While getting this right will be challenging, we would advocate for an approach based on the following core components:
- a) A legal duty on all health and social care professionals, in every sector across Northern Ireland, to ask every patient and/or client they support *does a family member or friend provide unpaid care for you?*, after which information would be passed on about joining the new Carers' Register.
 - b) Greater training for health and social care professionals on recognising and identifying carers.
47. Ideally, carers would be able to join the register via a short and straightforward form, providing basic details about themselves, their circumstances and how much care they provide. This should be available digitally and in print.
48. Combined with the data on carers that already exists, e.g. recipients of Carers Allowance, GP carer lists, we believe this approach would ensure a much more comprehensive and complete Carers' Register for Northern Ireland.
49. It is also important to begin thinking about the services and supports that would be offered to carers who join the register. While a full list should be co-produced and designed with carers, our initial thoughts are that this should include: the offer of an adult carer support plan or young carer statement, as have been introduced in Scotland; an annual carer 'MOT'/check-up; information and advice on finances, including benefits maximisation sessions; access to a central information bank on services for carers from GPs, HSCTs, other statutory stakeholders and the community and voluntary sector; access to a 'carer buddy', i.e. someone with lived experience of caring who can provide advice, and is compensated for their time in return.
50. We welcome the proposals around raising greater awareness of the contribution of unpaid carers and the importance of health and social care staff involving them. This should include a statutory duty to treat carers as partners in care and involve them in care planning and decision-making. During consultation with our members, we were very disappointed at the number of carers who recounted experiences of not being listened to, and having their advice ignored, in these situations.

"I felt dismissed as the carer. I was almost made to feel like I was in the way by the company providing care."

"We know the people we care for the best and should be listened to more."

"As a carer, I know my son best and understand what he needs. Carers should be involved at every step with decisions."

"Family Carers know the patient best. They should have equal say in all aspects of the caring situation. When you had a problem, no one took our views into account as we weren't trained professionals."

"Families know the person needing support, but I found that healthcare staff made decisions which didn't take the personality of the person into account and the family's knowledge was ignored. Family should be more involved rather than decisions being made by officials."

51. Regarding Section 75, we agree that more needs to be done to ensure explicit recognition of carers. At present, carers are sometimes considered under the protected group of *persons with dependents*, but this is not universal and focus tends to concentrate on parent carers only. While it is right to consider parent carers in this context, the same should also apply to all other groups of unpaid carers too. Failure to do so has resulted in an undermining of carer's rights and protections in the policymaking process.
52. We would welcome actions under a new Carers Strategy to promote the recognition of all carers as a Section 75 group, however the intervention that will make the biggest difference is an amendment to the Northern Ireland Act itself. This could either add unpaid carers as a new protected grouping, or change the language of the *persons with dependents* grouping, to make it explicit that this relates to all unpaid carers in Northern Ireland.
53. Finally, in addition to the points above, the other areas already identified in paragraph 7.11 of the consultation document and the wider recommendations we have made throughout this consultation response, we would also suggest that a new strategic approach to carers should cover:
- Measures to help carers plan for the future, including for emergency situations and the time when they are no longer able to provide care.
 - Actions to address loneliness and social isolation among the carer population.
 - Greater mental health support for unpaid carers, including dedicated mental health funding that is ringfenced for carers.
 - Greater services for carers' physical health needs, including health screening and access to flexible appointments to take account of the demands on their time.
 - Action to facilitate true co-design with unpaid carers in the policymaking process, not just co-production once all of the strategic decisions have already been made.
 - The reopening and boosting of day services, respite support and short breaks in every Health and Social Care Trust in Northern Ireland.
 - An action plan to help more people identify themselves as carers and signpost them to sources of support.
 - Post-caring support, including support, where applicable, for bereavement, employability and financial help.

Proposed action 31: Establishment of a cross-departmental Senior Officials' Group

54. Carers NI warmly welcomes this proposal and believes it is a vital step in delivering a more strategic, cross-government approach to carer policy in Northern Ireland. There is a wealth of evidence demonstrating that the major challenges impacting on unpaid carers are not experienced in the vacuum of a single policy area – matters of carers' health, wellbeing, financial stability and more are all closely linked. To take just one example, our research has shown that carers who are struggling to make ends meet financially are being forced to cut back on essentials like nutritious meals and heating, which inevitably has a detrimental impact on their physical health.
55. It is critical that the new cross-departmental group has genuine power, the ability to influence policy and access at the highest levels of government. For instance, we would be supportive of the group being allocated a dedicated slot to present to meetings of the Executive on a bi-monthly basis – providing an opportunity to raise awareness of its work among Ministers, highlight the challenges facing carers and discuss potential policy solutions. It will be incredibly disappointing for carers if the group is established and then descends into a forum for talking without concrete action or delivery.

56. In order to be truly led by the voices and experiences of carers, we also believe that holding bi-monthly engagement sessions with carers should be part of the group's terms of reference. Carers should be offered the help and support they need to take part in this process, such as training and replacement care options.

Proposed action 32: Introduction of an independent Carers' Champion role

57. Carers NI warmly welcomes this proposal, which was strongly supported by the carers we consulted with. Like the cross-departmental officials' group, it is important that the Champion role be properly resourced and given the access needed to be a true voice for carers at the top of government. We would expect the Carers' Champion to be recruited at a senior level and to have a fully funded policy, research and communications team to support their work.

Strategic priority 6: Primary of home

Proposed action 33: Review of NISAT and its application

58. When engaging with carers about the use of NISAT for Carers Assessments, we received mixed feedback. Some felt the tool was not fit for purpose and that a bespoke alternative should be developed that is designed and used only for Carers Assessments. Other carers had a more favourable view of NISAT and said it is a comprehensive tool but, in too many cases, it isn't being used properly.
59. In both readings, the end result is that many carers do not feel their holistic needs are being fully considered whenever they go through a Carers Assessment. This is reinforced by our last State of Caring survey,^[4] where, among carers in Northern Ireland who had had a Carers Assessment in the last 12 months:
- 63% did not feel their need to have regular breaks from caring was thoroughly considered in the assessment.
 - 37% felt their ability to have time to themselves was poorly considered.
 - 75% felt that demands linked to the other responsibilities they faced alongside caring, such as looking after children, were not sufficiently considered.
 - Less than half felt that their assessment thoroughly considered what needed to be put in place to support the person they care for in the event of an emergency.
 - 70% felt the impact of caring on their employment/prospects of employment was not thoroughly considered.
60. Carers NI is supportive of the proposed review of the NISAT and would advocate for a dedicated workstream within that review to look at use of the tool for Carers Assessments, whether the tool is fit for purpose for Carers Assessments and how the issues highlighted above can be addressed.
61. Whatever the outcome, we would also argue for renewed training to ensure all relevant HSC staff have the required competence and confidence to use the NISAT, or whatever replaces it, for Carers Assessments.

Proposed action 44: Expand the availability of supported housing

Proposed action 45: Promote best practice design principles across all types of housing

62. Carers NI supports both of these proposals. Access to good quality and appropriate housing, and the right housing adaptations, were among the priority areas identified by carers when we asked them about reform of the social care system.^[4]
63. For some carers, finding a supported housing arrangement is a critical step in giving the cared-for person more independence and a better quality of life, but the lack of supply and long waiting lists are a big barrier. We spoke to one carer who had been waiting over 15 years to access supported housing for his disabled child.
- “My son will eventually have to go into supported living, but there is a shortage of places locally.”*
- “I feel that the supported housing model needs further investment. Surely, it's got to be better for individuals who can live relatively independently, with some support in place, to do so?”*
64. Other carers prefer to have the person remaining at home with them, but delivering adaptations to meet their needs – especially adaptations that are required as a result of physical disability or mobility issues – are incredibly expensive.

“We recently spent our own money to build an extension, downstairs bathroom and bedroom for my disabled mother. We had no access to funding or a grant.”

65. It is well established that building new homes that are truly accessible is much more cost effective than trying to retrofit the existing housing stock, but this takes time and, regardless, people should be entitled to remain in their family home if that is their wish. In this context, the financial support available to unpaid carers and families to help pay for home adaptations needs to be significantly improved and easier to access. For example, a recent investigation found that waiting times for adaptations to be approved and completed under the Disabled Facilities Grant was more than three years in some parts of Northern Ireland.^[8] This is unacceptable and leaves carers and other family members to try to pay for the adaptations out of their own pocket.

⁸ ‘Disabled people trapped waiting years for vital home adaptations’ *The Bureau of Investigative Journalism*, 05.04.22. Available at: <https://www.thebureauinvestigates.com/stories/2022-04-05/disabled-people-trapped-waiting-years-for-vital-home-adaptations>.

Summary of Carers NI recommendations

- The Department of Health should commit to new legislation that enshrines the rights of unpaid carers to social care support from their Health Trusts.
- A major funding boost for the social care system should be delivered, so that capacity, staffing and resource levels match demand and all unpaid carers, and the people they support, can access the services they need.
- Tariff setting for social care services must be fair, standardised and set at a level that people can afford to pay, with regular reviews that take account of rising inflation and cost of living pressures.
- The review of third-party top-up fees for care homes should ban top-up charges for necessities like private bathrooms.
- The future review of social care charging arrangements should include the voice/experience of unpaid carers.
- Any future charging arrangements for domiciliary care must be airtight in exempting those households that cannot afford to pay for domiciliary care without a negative impact on their financial stability and quality of life; include a weekly cap on the amount that people are asked to pay for their social care services; and continue to provide for free any domiciliary care services that are introduced to support an unpaid carer following an identified need in a Carers Assessment.
- To support the review of the mixed economy of social care, the true cost of care must be established, so that services can be commissioned and delivered in a sustainable way that meets the needs of care recipients and their unpaid carers.
- The permanent and strategic role of unpaid carers in designing and delivering the objectives of the new Integrated Care System must be formally codified, with carers fully compensated for their contributions.
- A carer forum should be established to sit along new Area Integrated Partnership Boards, to support the input of unpaid carers into the work and decision-making of each Boards.
- Remuneration and terms and conditions for all social care staff must be improved.
- The In Control action plan must include measures to provide greater information and administrative support to households considering Self-Directed Support, including SDS navigators in each Trust area.
- A new Carers Strategy for Northern Ireland should be commissioned without delay.
- Along with the priority areas identified by the Department in the consultation document, a new Carer Strategy should also cover: planning for the future; loneliness and social isolation; mental and physical health support; the reopening and boosting of day services and respite; carer self-identification; post-caring support; and more.
- Households should be allocated a social care keyworker as part of the new Carer Navigation system.
- Along with measures related to carer wellbeing in Programme for Government (PfG) outcome assessments, carers should be recognised within the overarching PfG Outcomes Framework.
- Carers should be identified for the new Carers' Register through a duty on health and social care professionals, rather than relying solely on proactive/voluntary registration from carers.

- Joining the new Carers' Register should entitle carers to a range of services and supports, including an annual check-up, financial and welfare advice and more.
- As part of the exercise to raise greater carer awareness among health and social care staff, a statutory duty should be introduced to treat carers as strategic partners in care and involve them in care planning and decision-making.
- Section 75 of the Northern Ireland Act should be amended to explicitly recognise all unpaid carers as a protected group.
- The new cross-departmental Senior Officials' Group, and independent Carers' Champion, should have the resources and top-level access they need to be able to truly effect policy change for unpaid carers. They should also engage regularly with unpaid carers to ensure their work is driven by the voice and experience of the carer population.
- The review of the NISAT should include a dedicated work stream to look at use of the tool for Carers Assessments and whether the tool is fit for purpose for Carers Assessments.
- All relevant HSC staff should be given additional training on using the NISAT, or whatever replaces it, for Carers Assessments.
- The barriers and waiting times to accessing supported housing in Northern Ireland should be removed and carers should have greater access to financial support/grants to help pay for housing adaptations.

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