

National Carer Organisations briefing: National Care Service (Scotland) Bill Stage 1 debate

The National Care Service (Scotland) Bill

The delivery of effective social care support is critical to supporting unpaid carers and those they care for and, as such, the National Carer Organisations are broadly supportive of the development of a National Care Service, in particular in delivering the vision from the Independent Review of Adult Social Care. Throughout the review of adult social care and the consultation and coproduction of a national care service, unpaid carers have been emphatic that something must change and that the current system is not working. This reflects not only the experience of unpaid carers throughout the pandemic, and the current challenges they face, but their experiences over many years. Unpaid carers felt that the pandemic shone a light on issues with social care that were long-standing, and often ignored.

This briefing has been produced following the Stage 1 report on the Bill from the Health, Social Care and Sport Committee and highlights some areas that the Committee focused on within that report.

Key Points

The National Carer Organisations believe:

- unpaid carers must be specifically referenced as voting members on JJBs and the new National Care Service Board, with a minimum of two unpaid carers on each board.
- the Scottish Government must address the question of how we can enable people to access services when and how they need them, before they reach crisis point, while managing a finite resource
- the Scottish Government must set out a clear timescale and plan for the removal of social care charging and consider opportunities to deliver this ahead of the National Care Service.
- the effectiveness of a new right to a break for unpaid carers hinges not only on the right itself but also on the necessary investment, resources, commitment and leadership to develop a sustainable short break sector.
- there should be an additional duty on local authorities on the face of the Bill, to secure the provision of services that ensures there is sufficient availability and variety of short breaks provision in place to meet the rights of unpaid carers to a break from their caring responsibilities, including having regard to the diverse needs of circumstances of carers.
- the right to a break should be underpinned by a national improvement strategy led by a national taskforce.
- the proposed resourcing of the right to a break from caring is at odds with the stated ambition and the preventative agenda.
- any reference to "from providing care for the cared-for person" is removed to enable carers to choose the type of break they wish that meets their outcomes, including with the person they care for.
- defining 'sufficient' in respect to a right to a break on the face of the Bill, rather than secondary legislation, would strengthen the position of rights holders, giving a necessary level of accountability and scrutiny to the term.

- would also like to see further clarity on 'sufficient' through regulations and guidance including a set of
 principles that could apply and illustrative examples. There is a stark difference between breaks that are
 sufficient only to prevent a carer from reaching crisis point and being unable to care, and regular, flexible,
 and planned breaks.
- the Scottish Government considers progressing Annie's Law outwith the provisions of the National Care Service bill and extending these rights to healthcare settings

Membership and Voting Rights of Enhanced IJBs and the National Care Service Board

An important principle of the National Care Service is *that 'services provided by the National Care Service are to be designed collaboratively with the people to whom they are provided and their carers.'* This collaborative approach must start at the top, with meaningful representation of people with lived experience on the National Care Service Board and on local Integration Joint Boards.

• The National Carer Organisations believe that it is vital therefore that unpaid carers are specifically referenced in the Bill as voting members of Integrated Joint Boards and of the new National Care Service Board and membership of both boards should include a better balance of people with lived experience, with a minimum of two unpaid carers. One individual is not sufficient to represent the diverse range of caring roles and to deliver the principle of designing services collaboratively.

Access to Support and Social Care Charging

The Independent Review of Adult Social Care recommended *that 'People must be able to access support at the point they feel they need it and for barriers to this, such as the current eligibility criteria and charging regime, to be fundamentally reformed and removed, to allow a greater emphasis on prevention and early intervention'*

In their Joint Statement of Intent in 2021, the Scottish Government and COSLA committed to 'An end to charging for non-residential services as soon as possible' and 'The overhaul of the current mechanism of eligibility criteria to ensure an approach to social care support that is based on human rights and needs' Neither of these commitments have been delivered and this Bill provides no further information on the timescales, processes or costings for implementation.

This is set in the context of waiting lists getting longer, eligibility thresholds getting higher and charges for services increasing, while further cuts to social care budgets are being made, as we speak, as part of budget negotiations.

While these barriers to accessing support remain in place, unpaid carers are required to take on more caring tasks and to care for additional hours, with less support and to the detriment of their own health and wellbeing.

• We must not set up a system which does more of the same. The National Carer Organisations believe that the Scottish Government must address the question of how we can enable people to access services when and how they need them, before they reach crisis point, while managing a finite resource. At this stage the National Care Service Bill fails to do so.

Secondly, unpaid carers and disabled people are more likely to live in poverty. Over a quarter of unpaid carers (28%) are living in poverty compared with 20% without such responsibilities and research by Carers Scotland¹ indicates that 41% of unpaid carers in receipt of Carers Allowance are struggling to make ends meet, with 44% cutting back on food and heating. Nearly a third (31%) of disabled people are living in poverty - 12 percentage points higher than people without disabilities - and households *with someone with a disability* are more likely to be living in poverty (13 percentage points higher) and to be in deep poverty².

Delays in removing non-residential social care charges mean disabled and older people and their unpaid carers are forced to continue to wait, with charges increasing locally and in the face of an ongoing cost of living crisis. Whilst the Scottish Government's policy to freeze Council Tax, intended to support households with cost-of-living challenges, those with disabilities and their unpaid carers continue to face a growing "care tax" for their everyday needs.

• The Scottish Government must set out a clear timescale and plan for the removal of social care charging and the National Carer Organisations believe that there are opportunities to deliver this removal at a greater pace ahead of the national care service, including for example, working towards their phased reduction, in partnership with COSLA and local authorities.

The Right to a Break from Caring

The National Carer Organisations welcome the commitment to a right to a break from caring as a vitally important component of the National Care Service legislation. By legislating this responsibility, Scotland aims to acknowledge the invaluable contribution of unpaid carers to society, promoting their wellbeing and resilience by guaranteeing their right to essential breaks from caring duties.

Additionally, we welcome the level of detail within this part of the Bill and acknowledge the widespread support³ from all sectors.

However, we have several concerns on the implementation of this right as regards funding; definitions within the Bill; and the resourcing of short breaks provision. These concerns are reflected in the evidence that we gave to the Health and Sport Committee and in their subsequent report⁴.

• We firmly believe that the effectiveness of this new right for unpaid carers hinges not only on the right itself but also on the necessary investment, resources, commitment and leadership to develop a sustainable short break sector.

Short breaks capacity building and resourcing

There is no specific duty contained within the Bill to ensure there is enough availability and choice of short breaks provision, particularly replacement-care-type break provision, to meet the needs of carers who will have a right to a break.

¹ State of Caring in Scotland – The financial impact of caring in 2023, Carers Scotland (October 2023)

² UK Poverty 2024, Joseph Rowntree Foundation (January 2024)

³ https://www.gov.scot/publications/national-care-service-consultation-analysis-responses/pages/4/

⁴ Stage 1 report on the National Care Service (Scotland) Bill | Scottish Parliament

There is increasing evidence of the need for this. The Care Inspectorate inquiry into adult social care highlighted this as a key weakness and Scottish Government's own figures suggest the number of carers currently accessing short breaks through an assessed route is as low as 3%. Looking to the future, we are extremely concerned by the numbers of respite care and day services closing due to financial insecurity and unsustainability and how this will impact on carers access to breaks from caring. This is disproportionately affecting those with more complex levels of need.

The precarity of the short breaks and respite sector is such that the legal right to a break may not have the transformative effect that it aspires to as services will simply not exist to support its delivery.

- Consequently, the National Carer Organisations would propose an additional duty on local authorities on the face of the National Care Service Bill, to secure the provision of services that ensures there is sufficient availability and variety of short breaks provision in place to meet the rights of unpaid carers to a break from their caring responsibilities. In carrying out this duty, the local authority must have regard to the diverse needs and circumstances of carers. Placing it within the context of the Bill recognises that building short breaks and respite capacity and variety is an integral and necessary part of this new right.
- Furthermore, given the scale of the challenges facing the short breaks sector, and opportunities for greater coordination and collaboration, we believe that the new right to a break should be underpinned by a national improvement strategy, led by a national task force.

Funding a Right to a Break

We are concerned that the original and revised Financial Memoranda for the Bill understate the level of funding required to achieve this important extension in rights for Scotland's unpaid carers.

The evidence of the impact of and need for breaks on carers health and wellbeing is undisputed, however carers consistently report barriers to accessing the breaks that they need with only 3-4% of carers accessing breaks through statutory services. This is further put at risk by increased pressure on local authority budgets and by under-funding the new right to a break.

The funding specifications outlined in the Financial Memoranda for the National Care Service Bill allocate resources for additional carer breaks in two ways: personalised breaks determined through assessments conducted by local authorities to address individual carers' needs, and 'easy access breaks' provided by third-sector carer organisations and based on the existing Short Breaks Fund Scheme.

We are also concerned with several issues about the funding required for local authorities and integration authorities to implement the right to a break, according to the original and revised FM, which COSLA and Social Work Scotland has identified in a recent letter and report to the Scottish Parliament's Finance and Public Administration Committee⁵.

⁵ <u>https://www.parliament.scot/-/media/files/committees/finance-and-public-administration-</u> committee/correspondence/2024/ncsbillfm_cosla_swstoconvener_12feb24.pdf

This letter highlights areas of concern including anomalies in the unit costs calculations, the delayed start to funding for short breaks, the absence of any costings for additional carer assessments likely to arise from the right, and the slow growth in investment.

• In short, the proposed resourcing of the right to a break from caring is at odds with the stated ambition and the preventative agenda.

Definitions

In Section 38 2, 1 the Bill refers to "the outcome that the adult carer is able to take sufficient breaks from providing care for the cared-for person." This appears in the Keeling Schedule for the Carers Act in several places (*Section 8 Adult carers: identification of outcomes and needs for support (3), (4)*

We have significant concerns that this definition of 'sufficient breaks from *providing care for the cared-for person'*, may exclude the possibility of the carer and cared-for person having a break from routine together. This level of specificity around 'providing care for the cared-for person' could be interpreted as implying a very traditional form of respite/break where the supported person has residential/building-based respite away from the carer and could lead to a lack of flexibility on how carers are supported to meet their own outcomes.

• To reduce the potential for misinterpretation, the National Carer Organisations would propose that any reference to "from providing care for the cared-for person" is removed.

We have welcomed the opportunity to participate in the Regulations and Guidance group and in discussions regarding the definition of the term 'sufficient' as outlined in the legislation related to the right to a break from caring.

We are pleased with the progress the group has made towards a more robust definition and welcome the links that are being made to Article 24 of the International Declaration of Human Rights, and the use of positive language in the draft definition.

- The National Carer Organisations are still of the view that clearly defining 'sufficient' on the face of the Bill, rather than relying on secondary legislation, would strengthen the position of rights holders, giving a necessary level of accountability and scrutiny to the term.
- The National Carer Organisations would also like to see further clarity on 'sufficient' through regulations and guidance including a set of principles that could apply and illustrative examples. We reiterate that there is a stark difference between breaks that are sufficient only to prevent a carer from reaching crisis point and being unable to care, and regular, flexible, and planned breaks which allow a carer to thrive and live a full and vital life alongside their caring responsibilities.

Anne's Law

The national carer organisations are fully supportive of the provisions to provide for the designation of an essential caregiver within care homes with the same access rights as staff. We recognise the campaigning of family members of people in care homes and the distress and trauma of being separated from family during the pandemic and the impact on both their physical and emotional wellbeing.

• The National Carer Organisations note the Health, Social Care and Sport Committee's recommendation to consider extending such rights to healthcare settings and believe that the Scottish Government should actively consider this option.

Furthermore, we believe that there are opportunities to progress the delivery of Annie's Law at greater pace.

The National Carer Organisations recommend that the Scottish Government considers progressing Annie's
Law outwith the provisions of the National Care Service bill. This could include, for example, appending to
other upcoming legislation or seeking to make change by regulation. This would ensure the prompt, and
needed, enshrinement in law of the rights both of unpaid carers and families – and the human and
economic, social and cultural rights of individual care home residents themselves.

Further information

The National Carer Organisations have produced a detailed list of proposed stage 2 amendments, which may be subject to change following the Scottish Government's publication of their own amendments. A copy of these can be provided by Joe McCready (joe.mccready@carerscotland.org).

The National Carer Organisations are Carers Scotland, Carers Trust Scotland, the Coalition of Carers in Scotland, MECOPP, Shared Care Scotland and the Scottish Young Carers Services Alliance. We operate locally and nationally across Scotland and together we have a shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care.

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