



Introduction

The National Carer Organisations (NCO) welcome the opportunity to comment on the call for evidence from the Scottish Parliament Health and Sport Committee on the Scottish Government's draft Stage 2 amendments to the National Care Service (Scotland) Bill.

The National Carer Organisations are Carers Trust Scotland, Carers Scotland, the Coalition of Carers in Scotland, MECOPP, Shared Care Scotland, and the Scottish Young Carers Services Alliance.

Together we have a shared vision that all of Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The National Carer Organisations aim to achieve this through the representation of unpaid carers and amplifying their voices at a national level.

We believe we can deliver more for unpaid carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to unpaid carers.

National Care Service Strategy

1. What is your view of the proposed National Care Service strategy (see proposed new sections 1A to 1E)?

Strongly support

Tend to support

Partly support and partly oppose

Tend to oppose

Strongly oppose

Undecided / no opinion

Unpaid carers, particularly those with protected characteristics such as those from minority ethnic communities, have experienced inconsistent delivery of services to provide support such as for short breaks from caring. This varies between local authority and in essence means that the quality of services differs across Scotland. Work by MECOPP in 2023 for instance showed that only 15 out of 30 local carer strategies reviewed included strategic outcomes to address the specific needs of BME unpaid carers (such as identification of carers and provision of appropriate services)¹. Other work by MECOPP has indicated issues with services such as not being culturally appropriate or language barriers². With there being these issues, it is imperative that the strategy put in place addresses these issues.

While it does state in the principles that 'opportunities are to be sought to continuously improve the services provided by the National Care service in ways which... advance equality and non-

¹ MECOPP (2023), 'Local Carers Strategies and Action Plans: A Review', <https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/646f804e13cf995603e31f36/1685028943149/MECOPP+Briefing+Sheet+16.pdf>

² MECOPP (2017), 'Informal Caring within Scotland's Black and Minority Ethnic Communities', <https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/6397558e2f0aca3c17eed4f5/1670862226396/Briefing+sheet+03.pdf>

discrimination,' we would argue that there should be a more robust line. Replacing 'advance equality and non-discrimination' with 'advance equality, non-discrimination and human rights outcomes in relation to those services' would more explicitly ensure that there are outcomes designed to support those with protected characteristics under the Equality Act.

National Care Service Board

2. What is your view of the proposal to create a National Care Service Board, and the provisions about the role and functions of the Board (see in particular new Chapter 1B of Part 1, and new schedule 2C)?

Strongly support

Tend to support

Partly support and partly oppose

Tend to oppose

Strongly oppose

Undecided / no opinion

The Board could allow for better consistency in the delivery of services for unpaid carers, but we would also note the need for ensuring that equalities are robustly dealt with by the National Care Service Board, which we would suggest be considered in defining its role.

1. Local Autonomy with joint accountability

The results of consultation work showed that while there was a desire for greater shared accountability, there was also a preference for retaining local autonomy and a concern that a national service would not reflect local needs.

"I think the social care works better and is more accountable and accessible at a local level. National services are too remote and do not reflect local needs."

A balance must be struck between centralisation and localism. While national standards and accountability can drive improvements, decisions must be made as close to people and communities as possible. This is particularly the case for rural and island communities who must have specific representation within the structures of the National Care Service.

2. Carers as Equal and Expert Partners

Members of the Carers Collaborative group, who are carer representatives on Integrated Joint Boards (IJBs), were keen for clarification on what 'influence' unpaid carers would have on the National Board. Will members from health, local authorities, and Scottish Government have more power as they are seen as the main 'decisionmakers'.

The National Carer Organisation's feel strongly that in order for the National Board to be meaningful, impactful and effective in decision making, the recommendation from the Independent Review of Adult Social Care that '*Carers must be represented as full partners on the Integration Joint Boards and on the Board of the National Care Service*' must be a key priority.

Unpaid carers don't always have the confidence to speak out in board meetings, which is why it is vital that we get rid of hierarchies and not replicate the current structure and inequalities that currently exist in many of the IJBs. In order for quality social care to be a right for everyone, those with lived experience and frontline staff must be equal members, with voting rights, on both the National and Local Care Boards.

3. Responsibility and Scale of Representative Roles

Members of the Carers Collaborative wanted to reiterate that being a representative on a Board is a ‘job’ and that it won’t just involve attending meetings, but also preparing for the meetings and attending other meetings related to the work of the Board, as well as attending carer engagement groups and forums.

Board members who are there in their professional capacity are supported by their organisation in terms of receiving briefings prior to the meetings. Unpaid carer representatives will require a similar level of support. For example, briefings and opportunities to discuss issues before they go to the meetings.

The current remit for an IJB carer representative role is vast and can involve attending several additional meetings/sub committees. It often equates to a full-time occupation. If that is the expectation for lived experience representatives on the National Board then that needs to be made clear, and unpaid carers need better support to fulfil that role.

4. Supporting and Resourcing Lived Experience Representatives

The Carers Collaborative scope the experience of unpaid carer representatives on an annual basis, including how they are supported and resourced and what measures need to be put in place to improve their experience and the effectiveness in the role.

The Carers Collaborative’s joint report, published in May 2024 [‘More than Equal’](#) sets out a set of recommendations, supported by resources, to support and strengthen the contribution of representatives with lived experience on IJBs. This includes actions under four thematic headings:

- Strengthen recruitment and representation
- Build capacity
- Support equity of involvement
- Evaluate impact

The National Carer Organisations believe that in order for lived experience representatives to be valued as ‘full partners’ the recommendations in ‘More than Equal’ must be fully resourced.

5. Direct Funding to the Third Sector

We note that Ministers have been clear on their intention to introduce legislation to give Scottish Ministers the powers to directly fund National Care Service Local Boards for specific purposes. The National Carer Organisations would like to see this function extended to enable the National Care Board to have the ability to directly fund third sector organisations to deliver care and support services. There is some precedent with this in the way funding is directed to breaks for unpaid carers through the Short Breaks fund, facilitated by Shared Care Scotland and delivered by the Third Sector. In contrast, where funding has been routed through Local Authorities, such as funding for implementation of the Carers (Scotland) Act, much of this has not been used for direct support for unpaid carers. The National Carer Organisations would like to see this included in the functions for the National Care Board to enable funding to be more targeted, to directly benefit supported people and unpaid carers.

6. Investment in Services

The development of a National Care Service will require considerable investment. However, unpaid carers connected with our organisations were keen to emphasise that they wished to see the majority of additional resources made available for the reform of social care being directed to frontline services, rather than being spent on structures and processes.

7. Membership of the National Care Board

There was consensus from the Carers Collaborative that there should be a cohort of unpaid carers, rather than one unpaid carer representative on the National Care Board. The job of being an unpaid carer representative is very time and energy consuming. Having a cohort of carers that feed into the National Care Board would provide unpaid carers with the peer support that is currently missing from IJBs.

Members of the Carers Collaborative also noted that because of the intensive and time-consuming nature of the role, there are many vacancies across Scotland, with at least ten IJBs failing to appoint an unpaid carer representative and at least six people who are currently in position expressing the desire to leave the post as soon as a replacement can be found.

“Carers are passionate about affecting change, but you will lose carers if they are not supported to stay in the role.”

The National Carer Organisations believe that unpaid carer representatives need to be part of a larger network and that needs to be built in as part of the unpaid carer representative role. Just as unpaid carer representatives on local boards will need to have a local reference group of unpaid carers, so must unpaid carer representatives on the National Care Service Board. For example, it would make sense for the national unpaid carer representatives to link with the local carer representatives through the Carers Collaborative.

The National Carer Organisations also believe that further consideration must be given to how the views and experiences of young carers are appropriately represented on the National Care Board, ensuring to uphold these children and young people’s rights under the UNCRC to be meaningfully engaged on matters that impact them

Creation of local boards and removal of other integration models

3. What is your view of the proposal to establish National Care Service local boards and to remove other integration models (see in particular Chapter 1A of Part 1, and new schedules 2A and 2B)?

Strongly support

Tend to support

Partly support and partly oppose

Tend to oppose

Strongly oppose

Undecided / no opinion

Overall, we are supportive of the proposals, but feel that there can be improvements.

1. Strengthening Existing Boards

The Audit Scotland report into IJBs found that *‘Integration Joint Boards (IJBs) face a complex landscape of unprecedented pressures, challenges and uncertainties. These are not easy to resolve and are worsening, despite a driven and committed workforce. The health inequality gap is widening, there is an increased demand for services and a growing level of unmet and more complex needs.’*

They also noted the impact this has on unpaid carers, due to increasing reliance on the unpaid care they provide and the expectation that they will need to fill the gaps present in our health and social care services. *‘Unpaid carers are increasingly relied on as part of the system but are also disproportionately*

affected by the increased cost-of-living. Without significant changes in how services are provided and organised, these issues will get worse as demand continues to increase and the workforce pool continues to contract.'

While the National Carer Organisations agree with the move to reform IJBs, rather than replace them, the emphasis must be on learning lessons from IJBs so the new NCS Local Boards represent an improvement rather than a continuation of the current challenges.

The current provisions for the creation of NCS Local Boards do not adequately address how current issues with IJBs will be resolved, such as addressing challenges with the workforce, ensuring adequate provision of quality services and delivering a greater consistency of experience across Scotland.

2. Carers as Equal Partners in Care

Unpaid carer representatives highlighted that they do not always feel like 'equals' at the IJB meetings. The IJB meetings are seen as a place to rubber stamp decisions that have already been made elsewhere.

The full involvement of unpaid carers and people who use services **as equal partners** in the codesign of the national care service is a pre-requisite for improving social care. Managing competing interests and ensuring that people who use services and their unpaid carers are heard equally and their views and experiences given the weight they deserve will be a key measure of successful codesign. Consideration must also be given to how young carers are represented and heard through co-design processes and through unpaid carer representation.

We note that the Scottish Government has set out its intention to provide enhanced support measures for lived experience representatives. As mentioned previously, the Carer Collaborative's recent report, published in May 2024 '[More than Equal](#)' includes a set of recommendations, supported by resources, to strengthen the support and contribution of representatives with lived experience on IJBs. We believe that in order for lived experience representatives to be valued as 'full partners' the recommendations in 'More than Equal' must be fully resourced.

3. Voting rights

We welcome the commitment to all members of the Board, including unpaid carer representatives, being given full voting rights. Although it is not the only barrier to full participation not having voting rights contributes to them not being fully included as equal and valued members of IJBs.

4. Membership of Local Care Boards

Unpaid carers highlighted that there needs to be more than one carer representative on the NCS Local Boards due to recruitment and succession issues and to give carers practical and emotional support to attend the meetings. '*we need at least two carer representatives to reduce the burden of meetings and commitments on carers*'. This commitment needs to be included on the face of the Bill or within secondary legislation.

Further attention must also be given to how young carer's views and experiences are appropriately represented on Local Care Boards, ensuring they are valued and their rights are upheld.

5. Advancing Equalities and Human Rights

Unpaid carers with protected characteristics face inconsistent delivery of services across Scotland, as shown by analysis of local Carers Strategies often not having outcomes to support BME unpaid carers. The National Carer organisations would suggest that there should be reference to local Care Boards' responsibilities in advancing equalities and human rights.

Monitoring and improvement and commissioning

4. What is your view of the proposed new provisions on monitoring and improvement (see new sections 12K and 12L) and on commissioning (see new section 12M)?

Strongly support
Tend to support
Partly support and partly oppose
Tend to oppose
Strongly oppose
Undecided / no opinion

We have concerns that there is no specific reference to equalities and human rights outcomes in both monitoring and improvement aspects of the National Care Service Board's work. Unpaid carers, including those with protected characteristics, such as those from minority ethnic communities and those who are female, face a number of equalities barriers and issues. It is imperative for unpaid carers that work is undertaken to try and ensure a more consistent approach to equalities issues across Scotland in terms of caring.

National Chief Social Work Adviser and the National Social Work Agency

5. What is your view of the proposed new provisions to designate a National Chief Social Work Adviser and for the creation of a National Social Work Agency (see new section 26A)?

Strongly support
Tend to support
Partly support and partly oppose
Tend to oppose
Strongly oppose
Undecided / no opinion

Amendments to the Public Bodies (Joint Working) (Scotland) Act 2014

6. What is your view of the proposed amendments to the Public Bodies (Joint Working) (Scotland) Act 2014, as set out in the marked-up version of the Act?

Strongly support
Tend to support
Partly support and partly oppose
Tend to oppose
Strongly oppose
Undecided / no opinion

Areas of further work

7. What is your view of the Scottish Government's proposed approach to addressing the areas of further work outlined in the Minister's covering letter?

Direct funding

Strongly support
Tend to support
Partly support and partly oppose
Tend to oppose
Strongly oppose

Undecided / no opinion

Inclusion of children's services

Strongly support
Tend to support
Partly support and partly oppose
Tend to oppose
Strongly oppose

Undecided / no opinion

The National Carer Organisations continue to believe that the Scottish Government should at a minimum consider the particular risks to families at a time of transition to adult services and whether this model provides the smooth, coordinated and supportive approach that young people and their families need.

Inclusion of Justice Social Work

Strongly support
Tend to support
Partly support and partly oppose
Tend to oppose
Strongly oppose

Undecided / no opinion

Anne's Law

Strongly support
Tend to support
Partly support and partly oppose
Tend to oppose
Strongly oppose
Undecided / no opinion

The National Carer Organisations are in support a full and faster implementation of Anne's Law into legislation. Older and disabled people and their families and unpaid carers suffered greatly from the separation they experienced during the pandemic and the right to maintain connections, including that of a person who is designated as an essential visitor. However, the time taken to deliver this commitment remains disappointing. And, as noted in the MS Society in their response "Given that the

law has cross party support in parliament, this legislation should have been able to move much more quickly through the parliamentary process and already have been on the statute books in Scotland.”

The National Carer Organisations welcome that the Minister in her letter indicated that the Scottish Government is reviewing the best way to take this forward. We would support whatever is the quickest method of putting Anne’s Law on the book.

Draft National Care Service Charter

8. What is your view of the initial draft of the National Care Service Charter?

Strongly support

Tend to support

Partly support and partly oppose

Tend to oppose

Strongly oppose

Undecided / no opinion

1. Children and Young People

The National Carer Organisations echo the views of the Scottish Children and Young People’s Commissioner that there has been insufficient consideration of children and young people, including young carers, in its development. Their response indicates that officials that there may be consideration of a separate children’s charter. However, we believe that in order to deliver a cohesive and consistent approach, based on whole family support, that this could be a missed opportunity.

The National Carer Organisations and local carers services support many parent carers, conferred with rights under the National Care Service Charter and in the Carers Charter, but who are caring for children and young people. Research by Carers Scotland³ found that only half (50%) of parent carers said that services met the needs of they or their child, with a similar proportion saying that these need increased choices of support services. Just 30% felt that they could rely on social services. The rights of children and young people are inextricably linked.

Alongside this, at least 30,000 children and young people under 16 provide unpaid care for a family member in Scotland. These young people must have the right to participate in decisions that will affect them and a significant number will be caring for an adult family member who will be receiving services under the umbrella of the National Care Service.

Therefore, it is difficult to see how a charter which does not fully address the rights of children and young people could deliver effectively the rights of either parent carers or young carers.

2. Rights and Responsibilities

The National Carer Organisations agrees with the views of the Scottish Children and Young People’s Commissioner over the framing of the charter as one of “rights and responsibilities”. We support their response that: *“This is not an approach which is compatible with human rights, for adults (particularly disabled adults) or children. Human rights are innate, they are not earned and they cannot be lost. They are not contingent on meeting obligations or responsibilities. The conflation of rights with responsibilities undermines the commitment made by Scottish Ministers to a human rights-based approach.”*

³ State of Caring survey 2023

3. Protected Characteristics

The National Carer Organisation support the rights-based approach within the Charter including the rights to be treated without discrimination, including unfair treatment because of any protected characteristic. However, this needs to go further.

(a) Advancing Equality of Opportunity

Firstly, in addition to committing to not treating those with protected characteristics unfairly, the National Carer Organisations would recommend reference to *advancing equality of opportunity* for those with protected characteristics, reflecting this requirement of public bodies under the Equality Act.

(b) Associative Discrimination

Secondly, the National Carer Organisations recommend that it explicitly reference the rights of unpaid carers under section 13 of the Equality Act.

The law in relation to associative discrimination under the Equality Act 2010 is not widely known or understood and often is considered only to relate to employment. However, in recent research⁴ around one in ten unpaid carers said that they had been treated unfairly or unfavourably when receiving services from the NHS (13%) or social services (10%). Given this lack of understanding and the lack of visibility of the rights of unpaid carers under the Equality Act 2010, it is vital that any newly created service actively seeks to protect unpaid carers from discrimination.

The National Carer Organisations therefore recommend that the Committee seek assurances that the Charter will extend this explicit reference to protect the rights of unpaid carers under the Equality Act.

Other Comments

9. Do you have any other comments on the Scottish Government's proposed draft Stage 2 amendments to the National Care Service Bill?

1. The Right to a Break from caring

The National Carer Organisations are disappointed by the noticeable absence of further detail on the right to a break from caring in Stage 2 of the National Care Service Bill. This new right has the potential to be transformative for Scotland's unpaid carers and lead to positive outcomes for unpaid carers of all ages, cared-for people, and the wider health and social care sector.

The ability of the new right to fulfil its potential hinges not only on the right itself but also on the necessary investment, resourcing, commitment and leadership to develop a sustainable short break sector that can meet the diverse needs and circumstances of all unpaid carers. This was recognised by the Health, Sport and Social Care Committee in their Stage 1 report on the NCS Bill which noted:

"The Committee welcomes provisions in the Bill detailing the rights to breaks for carers, but remains concerned these implementation gaps will persist unless the right to breaks is matched by action to:

- *increase appropriate respite (and supportive) care provision and associated funding, and*
- *improve flexibility and responsiveness to individual needs and circumstances."*

The Committee also asked the Scottish Government to provide clarity on how the right to breaks for unpaid carers will be funded and what steps it will take to ensure any associated implementation gap is avoided. However, this remains unanswered.

⁴ Making caring the 10th protected characteristic: Research Report, Carers UK 2024

We would therefore urge the committee to continue to ask for clarity on what steps are being taken to understand the scale of the challenge, how an implementation gap will be addressed, and how the right will be delivered in order that it can reach its full potential.

The right to a break from caring is a fundamental part of the legislation which has wide support in principle from all sectors across Scotland. We know from consultation with unpaid carers and carer support organisations that this right is vital and we cannot afford to delay its implementation.

The National Carer Organisations would therefore urge committee to consider separate legislation for the right to carers' breaks, similar to Anne's Law, to prevent prolonged delays.

In order to strengthen the right to a break legislation, we would also reiterate that the following amendments should be considered:

An additional duty should be placed 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 all unpaid carers, including young 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.

Definitions on right to a break

Providing care for the cared-for person

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.”*

We are concerned that this definition of ‘sufficient breaks from providing care for the cared-for person’, may exclude the possibility of the unpaid 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 unpaid carers are supported to meet their own outcomes.

To avoid regressing to a more rigid definition of breaks, the National Carer Organisations propose a simple modification and that any reference to ‘from providing care for the cared-for person’ is removed, leaving the phrase to read *“the outcome that the adult carer is able to take sufficient breaks.”*

Defining sufficient

We have welcomed the opportunity to participate in the Scottish Government’s 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 an unpaid carer from

reaching crisis point and being unable to care, and regular, flexible, and planned breaks which allow an unpaid carer to thrive and live a full and vital life alongside their caring responsibilities.

2. Independent Advocacy

The National Carer Organisations welcome the commitment to rights to information on independent advocacy, but agree with the Equality and Human Rights Commission Scotland that the primary legislation should be amended to introduce a statutory right to independent advocacy for those using services and their unpaid carers. This would be in line with other legislation, including social security, which recognised the importance of a right to such advocacy in enabling individuals to access their rights.

We believe that the legislation should be amended to set in statute a right to independent advocacy for disabled people, older people and unpaid carers. This is vital to enable people to access their rights and receive support through assessment, service delivery and complaints. As noted by the Equality and Human Rights Commission Scotland *“independent and specialist advocacy can also be an important reasonable adjustment to ensure everyone can access services equally.”*

3. S14: Complaints

The National Carer Organisations have raised consistently the need for a more effective and streamlined complaints system for people who use services and their unpaid carers. We do not believe that either the Bill in its current form or the draft charter adequately responds to concerns raised by people who use services that they are often unable to have issues resolve nor redress provided.

We are disappointed that the amendments at Stage 2 do not respond to the concerns of people who use services and unpaid carers. In its response, the Scottish Public Services Ombudsman, sets out concerns from members of the public about their experience of complaining. These range from uncertainty about who to contact, feeling that they are not being listened to when they do complain, through to for some, fear of a potential negative impact from complaining. This reflects the experiences of many carers the National Carer Organisations are in contact with.

We reiterate from our previous submissions, that it is important to make the system as smooth as possible, unpaid carers have said that the current system lacks both trust and transparency and leaves them with issues unresolved. To bring about a trusted complaints procedure, we recommend a completely new complaints process is developed to enable complaints to be assessed against the principles of the National Care Service Bill.

- Has the decision/issue negatively impacted about the realisation of human rights for the individual or their unpaid carer?
- Has the decision resulted in a detriment to carers with one or more protected characteristics?
- Has the decision/issue impacted upon an individual or their unpaid carer’s ability to thrive and/or reach their potential?

This includes individuals and their unpaid carers having the ability to complain about the allocation of social care resources, how any assessment of eligibility is decided upon and whether they have been able to have the choice and control they wish over how their needs and outcomes are met.

The National Carer Organisations also believe that it is appropriate for the key elements of whether decisions impact upon the realisation of human rights, ability to thrive or reaching potential to be extended to be included in both the NCS, local authority and NHS complaints procedures.

This Bill is an opportunity to legislate to require a new human rights-based complaints system that truly has the laudable principles of the National Care Service at its heart. individuals at its heart, that is simple to access, provides independent advocacy and enables.

4. Timescales on Adult Carer Support Plans

The Carers Act places a duty on Ministers to bring forward regulations to prescribe timescales for the preparation of Adult Carer Support Plans and Young Carers Statements in relation to unpaid carers of terminally ill cared-for persons. We would propose extending this to include all carers, but still recognising that the current timescales for unpaid carers of terminally ill persons would still apply.

The removal of eligibility criteria on the right to a break from caring is very welcome, however it is a risk that waiting lists for Adult Carer Support Plans or Young Carer Statements could be used as an alternative means of managing the level of demand and provision of services, potentially becoming a means of gatekeeping or a rationing device. While this is potentially of detriment to those with a higher level of need, it is concerning that this new right will be delivered through an assessment process which largely remains the same and is already known to be limiting timely and appropriate support for carers.

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