



National Carer Organisations response to: Wellbeing and Sustainable Development (Scotland) Bill

Introduction

The National Carer Organisations welcome the opportunity to submit a response to Scottish Government's *Wellbeing and Sustainable Development (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.

Consultation questions and response

Question 1: *Is a statutory definition of 'wellbeing' required?*

Yes

Question 2: *Do you have any views on how 'wellbeing' can be clearly defined in legislation?*

We would agree that a legal definition of wellbeing is important as it will provide greater clarity and specificity around public sector duties and help improve accountability. For Scotland's estimated 800,000 unpaid carers¹, it is important that

¹ Scottish Government (2022), 'Scotland's Carers Update Release: December 2022', <https://www.gov.scot/publications/scotlands-carers-update-release-december-2022/>

this definition would help build on the principles of equity, long-termism and citizen engagement.

We would support the following definition made by a number of organisations who are members of a group convened by Scotland's International Development Alliance: *“Collective wellbeing is the progressive realisation of social, economic, environmental and democratic outcomes which enable people to meet their needs, as identified through consultation with the people of Scotland, pursued in a way that reduces inequalities in wellbeing between different groups. It also recognises the importance of protecting the interests and needs of future generations and fostering intergenerational equity.”*

Following on from this, we agree with the National Performance Framework's approach of measuring wellbeing through a number of National Outcomes. We would argue that the definition of wellbeing must encapsulate those in our society that face additional challenges and barriers towards their own individual wellbeing, such as unpaid carers. The National Outcomes would be strengthened in that respect by including a new National Outcome on Care to fully value and invest in those experiencing care and all of those who provide it on both a paid and unpaid basis.

Scotland's estimated 800,000 unpaid carers provide invaluable care to their cared-for person/s with daily activities that they would be unable to manage without this support. This can include someone living with a disability, long-term or terminal illness, a mental health problem or an addiction, or someone who needs additional support as they grow older.

There are many reasons to back setting up a new National Outcome on Care, and there are significant details on this from the 'A Scotland That Cares' campaign which is backed by more than 60 organisations². The need for a new National Outcome on Care is also underpinned by the importance of unpaid care to our economy, which saves Scotland £12.8 billion per year in social care costs and a further £320 million in healthcare costs³. Furthermore, the impact unpaid care has on women who provide most care, the link to poverty, the unheard voices of unpaid carers and the scale of caring responsibilities all work hand-in-hand to underscore how having a National Outcome on Care can make an impact. A blueprint has already been put in place for this with proposed indicators on how to measure this⁴, including:

- 1) Quality of life of unpaid carers, care workers, and those experiencing care
- 2) Quality of care for all
- 3) Financial wellbeing of unpaid carers, care workers, and those experiencing care
- 4) Voice and influence of care workers, unpaid carers and those experiencing care

² A Scotland that cares (2023), 'Invaluable, But Invisible: Why Scotland needs a new National Outcome on Care', https://ascotlandthatcares.org/wp-content/uploads/2023/10/AScotlandThatCares_Invaluable-But-Invisible_Oct-2023_DigitalVersion.pdf

³ Ibid.

⁴ UWS-Oxfam Partnership (2021), "Towards an Scotland that cares: A new National Outcome on care for the National Performance Framework", <https://oxfam.app.box.com/s/v65fhy5rx7yicfbjuo29ulg5h9qliq5x>

- 5) Access to education and training
- 6) Adequacy of funding for care
- 7) Job quality of social care and childcare workers

Unpaid carers' barriers towards individual wellbeing are numerous. They often face increased financial challenges, with 28% of unpaid carers surveyed in 2023 reporting that they were struggling to make ends meet⁵. Unpaid carers also face challenges with their physical and mental wellbeing, with 54% of unpaid carers reporting that their physical health and suffered due to their caring role and 36% of unpaid carers reporting thoughts related to self-harm and suicide⁶. 79% of adult unpaid carers and 89% of young carers experienced an impact on their emotional well-being due to their caring role⁷.

For unpaid carers who have one or more protected characteristics, these challenges can be exacerbated which often leads to poorer health and financial outcomes. Recent reports indicate growing numbers of adults with learning disabilities being cared for by elderly relatives, with 875 adults with a learning disability aged 45 or older living with a parent carer in 2018 in Scotland, with some of these people also being reported to be in a mutual-caring position with an older relative⁸. LGBT unpaid carers also face additional challenges, with LGBT young adult carers being twice as likely to report their health being 'just ok' or 'poor' compared to young adult carers overall⁹. BME unpaid carers face other barriers, such as economic barriers with 49% reporting that their caring role had adversely impacted their work or chances of employment¹⁰.

In the creation of a legislative definition of wellbeing, we would argue that there needs to be a focus in ensuring inclusivity so that those such as unpaid carers who are more likely to face worse outcomes are fundamentally supported by any definition of wellbeing. This should also include unpaid carers with protected characteristics such as those described previously. By adding a new National Outcome on Care, this would assist with this definition.

Question 3: Is a statutory definition of 'sustainable development' required?

⁵ Carers Scotland (2023), 'State of Caring 2023: The financial impact of caring in Scotland', <https://www.carersuk.org/media/3lefbisc/state-of-caring-in-scotland-2023-finances-fv.pdf>

⁶ Carers Scotland (2023), 'State of Caring 2023: A health and social care crisis for unpaid carers in Scotland', <https://www.carersuk.org/media/4upje0ot/state-of-caring-2023-a-health-and-social-care-crisis-for-carers-in-scotland-online.pdf>

⁷ Scottish Government (2023), 'Carers Census, Scotland, 2022-23', <https://www.gov.scot/publications/carers-census-scotland-2022-23/>

⁸ MECOPP (2019), 'Scotland's Carers: An overview by disability and longterm condition', <https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/639758cecd61966dde153278/1670863055635/Briefing+sheet+12.pdf>

⁹ MECOPP (2019), 'Informal Caring within the LGBT Community', <https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/639759252f0aca3c17ef8c09/1670863141538/Briefing+sheet+13.pdf>

¹⁰ 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>

Yes

Question 4: *Do you agree with our proposal that any definition of sustainable development should be aligned with the common definition: “development that meets the needs of the present without compromising the ability of future generations to meet their own needs”?*

Yes

Question 5: *Do you have other views on how ‘sustainable development’ can be clearly defined in legislation?*

It is important that sustainable development both takes in the needs of future generations as well as wellbeing and equity now. Unpaid carers face a number of challenges and continue to play an important role in our society. We would therefore support the proposed definition: “Sustainable Development can be defined as the development of human societies based on fair shares of planetary boundaries, and which equitably support the capability of present and future generations across the world to meet their needs.” We would hope that policymaking in this would therefore consider the needs of unpaid carers in sustainable development work in Scotland.

Question 6: *What future wellbeing issues or challenges do you think legislation could help ensure we address?*

As discussed, there are 800,000 unpaid carers in Scotland and the legislation is an opportunity to set up a new National Outcome on Care. Scotland has an ageing population, with 22.9% of the population projected to be pensionable age in 2043 compared to 19% in 2023¹¹. This means that the demands on unpaid carers will increase, as will their importance to the economy of Scotland, where they save £12.8 billion in social care costs. A report by the European Commission in 2022 found that the estimated value of unpaid care accounts for 2.4% of GDP across Europe¹².

Without greater support and investment into care, there is a danger that this will have the effect of impacting the wider collective wellbeing of Scotland. Already the current economic challenges are having a significant impact on the wellbeing of unpaid carers – almost half (46%) for instance have cut back on seeing friends and family, taking away a valuable support for them as unpaid carers¹³. The mental health impact on unpaid carers is enormous, with 82% reporting feelings of hopelessness¹⁴.

Research has also shown that BME unpaid carers, the peak age of caring is considerably younger than for white people, with the most common age bracket being 21-40 years old¹⁵. This means for many in BME communities, they will have

¹¹ Scottish Government (2021), “A Scotland for the future: opportunities and challenges of Scotland’s changing population”, <https://www.gov.scot/publications/scotland-future-opportunities-challenges-scotlands-changing-population/pages/6/>

¹² European Commission (2022) “Economic Value of Informal Long Term Care”.

¹³ Carers Scotland (2023), ‘State of Caring 2023: The financial impact of caring in Scotland’.

¹⁴ Carers Scotland (2023), ‘State of Caring 2023: A health and social care crisis for unpaid carers in Scotland’.

¹⁵ MECOPP (2017), ‘Informal Caring within Scotland’s Black and Minority Ethnic Communities’.

caring responsibilities for a longer period, which means this can lead to significant impacts in their economic and health outcomes.

Unpaid carers are already facing significant wellbeing pressures, and with demographic projections showing that the importance of unpaid carers will increase, it is extremely important that this legislation takes into account this future challenge. We would strongly urge that as part of this, a National Outcome of Care is considered as a priority.

Question 7: *We are aware that the term ‘sustainable development’ has been set out in various legislation of the Scottish Parliament since devolution in 1999, and that careful consideration will need to be given to how any new definition will impact on these. What impact, if any, would the proposed definition have on other areas of legislation?*

N/A

Question 8: *How should a legal duty be defined to ensure that public authorities uphold sustainable development and the interests of future generations?*

We would argue that the duty to “have regard to the National Outcomes” in the Community Empowerment (Scotland) Act 2015 should be amended to utilise more tangible, directional and affirmative language relating to the delivery of the National Outcomes, wellbeing and sustainable development. If combined with a new National Outcome on Care, this would help ensure that public authorities take account of, and effectively work towards wellbeing, sustainable development, and the delivery of the National Outcomes.

We would support the following rephrased duties requiring public authorities to “*promote and deliver sustainable development while protecting the wellbeing of current and future generations ensuring that they take all reasonable steps to support the realisation of the National Outcomes, minimise trade-offs, and resolve policy conflicts in a way that does not undermine sustainable development or the wellbeing of current and future generations*”

Question 9: *Are there specific areas of decision making that should be included or excluded from the Bill?*

Areas of decision making to include:

We would argue that any decision making that involves the rights and wellbeing of unpaid carers should be included in this Bill and would be concerned that excluding different areas of decision making from the Bill would threaten the coherence and clarity of the legislation and impede effective implementation.”

Areas of decision making to exclude:

N/A

Question 10: *What issues, if any, may result from strengthening the requirement to have regard to the National Outcomes?*

We would argue that rather than looking at what issues may result from strengthening the requirement to have regard to the National Outcomes, it should instead be looking at what issues might arise from not strengthening this requirement.

As discussed previously, there are many challenges that will impact the wellbeing of society due to demographic pressures. Unpaid carers will continue to play an increasingly important role going forward, and strengthening National Outcomes (by for instance creating a National Outcome for Care) to support carers is paramount. Without doing risks leading to wellbeing – whether it is health, social or economic – being put in jeopardy for a significant proportion of our society.

We would therefore ask that the Bill does not just include new duties, but also puts in place a support ecosystem. This would include providing necessary guidance on how to resolve trade-offs between different National Outcomes, defining ways of working, and the use of both current or new bodies to support duty-bearers.

Question 11: *Should any duty apply to the Scottish Government?*

We would agree that a duty for the Scottish Government and its Ministers should be made explicit. This would ensure a greater consistency in approach and ensuring that all Scottish Government Departments and Public Bodies would need to pay regard to, and be accountable towards, the National Outcomes.

In any work to introduce a new National Outcome on Care, we would also argue there should be a legal duty for professionals within the NHS to identify unpaid carers, in order to ensure adequate support is provided.

Question 12: *Do you have any views on the range and type of organisations that any duty should apply to?*

We would argue that all public bodies in Scotland, particularly those that have involvement in supporting both unpaid carers and cared for people should have a duty on wellbeing applied to them. This is important in ensuring a consistency in approach that often does not currently exist.

For unpaid carers, a lack of consistency often has detrimental impacts on their wellbeing. For BME unpaid carers, accessing Self Directed Support often involves additional hurdles such as being able to get accessible information or recruitment of staff that meets their linguistic or cultural needs¹⁶. This issue is exacerbated by the

¹⁶ MECOPP (2017), “Self Directed Support and Scotland’s Black and Minority Ethnic Communities”, <https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/639756d706b13822dd49a7ed/1670862554276/Briefing+sheet+05.pdf>

fact that in early 2023, only 15 local carers strategies from 32 local authorities contained strategic outcomes to address the specific needs of BME unpaid carers¹⁷.

A strengthened duty to local authorities and Health and Social Care Integrated Joint Boards would help ensure greater consistency in improving the wellbeing of unpaid carers, particularly if a new National Outcome on Care was introduced. This could help ensure that the type of inconsistency mentioned above would be avoided. Future public bodies such as those involved in the National Care Service should also be included in this.

Question 13: *Do you have any views on how we can better report the achievement of wellbeing objectives which supports clear accountability and scrutiny of public bodies in Scotland?*

We would argue that the most important aspect of this is ensuring a consistency of approach. When undertaking scrutiny of wellbeing objectives, indicators under each of the National Outcomes should be fully measured and we would argue that this should be expanded to include a National Outcome on Care. This scrutiny should include all public bodies whose work is based on supporting the wellbeing of the Scottish public. This should also be built into the proposed National Care Service, which aims to deliver standards and consistency across Scotland.

Requiring Ministers to report more regularly on progress towards the National Outcomes to Scottish Parliament and allowing Scottish Parliament time to scrutinise reports would assist in this. Another option that may be considered is complementing this with an institution that can provide independent assessments on Scotland's progress towards wellbeing and sustainable development, such as having a Future Generations Commissioner.

Question 14: *What additional steps are needed to ensure collaboration and working across boundaries?*

We would support the approach described in *Annex I: Strengthening ways of working*, which utilises the example of the *Well-Being of Future Generations (Wales) Act 2015*, in particular in regards to the principle of integration, collaboration and involvement of the community. Many of the wellbeing issues faced by unpaid carers are due to the lack of consistency and different approaches taken across the country. By working towards greater alignment in public bodies, this would increase the opportunity to improve on wellbeing.

Question 15: *Do you have any views on whether any duty related to ways of working could create conflicts with duties currently placed on you?*

N/A

¹⁷ MECOPP (2023), "Local Authority Carer Strategies and Action Plans: A Review", <https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/646f804e13cf995603e31f36/1685028943149/MECOPP+Briefing+Sheet+16.pdf>

Question 16: Do you have any views on the additional resource implications necessary to discharge any wellbeing duty in your organisation?

N/A

Question 17: Should Scotland establish an independent Commissioner for Future Generations?

Yes

Question 18: In what ways could an independent Commissioner for Future Generations increase the accountability, scrutiny and support for decision making?

It is important that in determining accountability, it is guaranteed by specifying who is accountable (potentially all public bodies), to whom, in respect of what responsibilities and with what potential sanction. We would ask that this pays due regard to the National Outcomes, particularly any potential new National Outcome on Care, to ensure that those such as unpaid carers are taken into account in all scrutiny functions.

Question 19: Are there alternative ways we can increase the accountability, scrutiny and support for decision making?

N/A

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