

# Submission to the Scottish Government consultation on a National Care Service

## Summary for carers



## Background

[The independent review of adult social care \(Feeley report\)](#) was published in February 2021 and set out a bold and ambitious vision for transforming the lives of people with social care needs and unpaid carers. The Scottish Government [responded with a consultation paper](#) in August 2021, setting out their proposals in response to the recommendations in the review and asking for people's views.

Between August and October the Coalition of Carers in Scotland facilitated a series of 7 engagement events with carers and staff from carer support organisations. Over 130 people participated in our discussions.

We also hosted two surveys to ensure we heard from as wide a range of carers as possible. Our survey on the government's response to a right to breaks from caring received 997 responses and our survey on the proposal for a National Care Service received 424 responses.

Carers told us of a social care system that is broken and that increasingly relies on the labour of unpaid carers. Many carers told us that they have not had a break for years, that they are exhausted and that their mental and physical health has been severely affected.

*"We are preventing a tsunami of need from overwhelming public services. That comes with costs to us, to our families"<sup>1</sup>*

Radical change is needed. We heard from carers that they want to be able to move with ease through a system which is preventative and based on human rights, where people do not have to 'battle' or 'fight' to access support. As one carer said '*We need **rights not fights***'

Our [full submission to the consultation can be found here](#). This document summarises what carers and carer support staff told us and our key recommendations to the National Care Service consultation.

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<sup>1</sup> All the quotes in this document are from our engagement events and surveys

## A right to breaks from caring

*I'm sitting here with tears in my eyes hoping that this can bring about real change. ...I am utterly exhausted and no longer feel I'm giving my best because I'm just so worn down with never getting a break."*

### What Carers Told Us

Carers were strongly in favour of having a right to breaks from caring. Many carers said they had not had a break since the pandemic, or even before and they said they were 'exhausted' and 'close to breaking.' Even carers who had been allocated a social care budget had not been able to access a break, due to the lack of available social care provision.

In our polls, the majority of carers (80%) thought that all carers should be entitled to breaks from caring, rather than only those carers with a more intensive caring role. In response to the government's options on how a right to a short break should be delivered, overall carers favoured the proposal to provide all carers with a minimum entitlement to breaks from caring and in addition, to provide carers who have a more intensive caring role with an additional amount, according to need (39%)

Carers who responded to our survey were clear that in order for a right to short breaks to become a reality, there needs to be a mix of respite options, providing adequate provision and catering to different needs.

Specific mention was given to the needs of children and adults with a learning disability, carers from minority ethnic communities and carers living in rural and island communities. These were felt by many to be groups who particularly struggle to find suitable support. The needs of working carers was also raised, as they require both replacement care to enable them to work, but also breaks from caring outside their working hours.

*"Respite must be suitable for the person being cared for. There's no point in allocating respite hours or weeks if the appropriate care cannot be provided. Having a 'right' and having 'access' to care are two completely separate things."*

Carers told us that breaks from caring need to be regular and consistent and that the process for accessing a break must be simple, fair and transparent. Lengthy assessments and form filling will dissuade some carers from accessing support. Carers must not have to 'fight' and 'challenge' to get breaks from caring

### Our recommendations for a right to breaks from caring

- Carers are providers of services and must be viewed as such with legislation extended to provide a right to breaks from caring
- All carers who need a break should be able to access one
- We support the option put forward by the government to provide all carers with a minimum entitlement, whilst recognising that carers with a more intensive caring role will require more substantial support

- [The Covid-19 SDS Guidance](#) should become permanent and part of legislation and It should be implemented consistently across Scotland. Both social care recipients and carers must be trusted to have choice and control over the support they access.
- Options for support should include being able to employ a relative. The Scottish Government should explore the Burgenland pilot project in Austria which has been underway since 2019 and will be evaluated over the coming months.
- There needs to be a range of short break services to ensure all carers have equal access to breaks from caring. As well as short break services this should include investment to make mainstream community support more accessible. This diverse marketplace needs to be in place before a right is enacted
- There is clear evidence of the impact a lack of breaks has had on carers' health and wellbeing and the ongoing impact is has on their ability to access basic human rights. This situation needs to be addressed now, we cannot wait for legislation, but must begin to invest now and move towards a right incrementally
- A right to short breaks will require significant funding. We need to value the role unpaid carers play and recognise that both social care and health service would be in crisis without their contribution., We need to move towards targeted investment so that commitments made nationally are properly funded. To quote Derek Feeley *"Not only are carers indispensable, they are also human beings and need time off like the rest of us. That's an investment I think we ought to make"*
- The right to breaks from caring cannot be delivered unless other deficits in the social care system are addressed, including valuing and increasing the care workforce and commissioning services which meet people's needs.

## Proposals for a National Care Service

*"Any NCS needs to be properly funded, informed by people who will use it and have compassion, good relationships and rights at its heart"*

### What Carers Told Us

Carers told us that they found it difficult to give their views on the Scottish Government's proposals for a National Care Service, as they felt they lacked detail. In addition, many carers struggled to imagine how setting up a National Care Service would improve their lives and preferred to focus on changes that need to happen at a local level in relation to direct service provision.

That said, the majority of people who took part in our polls indicated that they were in favour of the development of a National Care Service, although this support often came with conditions. Of the 424 people who responded to our survey, a slim majority of 52% supported the development of a National Care Service, although a higher proportion of people attending our engagement events supported the proposal, with an average of 87%

The most common reason carers gave for supporting the development of a National Care Service was that they felt let down by the current system and would prefer that responsibility for social care shift to national government to ensure greater accountability.

They were also hopeful that a National Care Service would ensure more consistent standards and help to end the 'postcode lottery'

*"I support a National Care Service because my local authority has failed me and no one is willing to accept accountability"*

However, not all carers agreed that the responsibility for social care should move away from local authorities, as they expressed concerns that an NCS would be less responsive to local needs. This was particularly the case for people living in rural and island communities

*"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"*

Carers were clear that decisions on the delivery of social care should be made locally, as close to the users of social care services, their carers and communities as possible. While an NCS should be able to drive forward more consistent standards and improvements, services and support must be delivered locally.

### **Our Recommendations for a National Care Service**

- We are concerned that the government's proposals are too focused on structures and processes and not human rights and enabling people to live their best lives.
- The involvement of carers and people with lived experience as equal partners in the new structures and processes, both nationally and locally is a prerequisite to improving social care
- 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
- The development of a NCS will require considerable investment. However, our members 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
- The proposed scope of the NCS is very broad and goes far beyond the remit and recommendations of the Feeley report. We agree with our members that the government should consider developing the NCS on an incremental basis, starting with adult social care and then including other areas once more consideration has been given to the implications of widening the scope.
- Given the proposed relationship between the NHS and the proposed NCS, while we welcome a greater drive towards integration at a national level, the NCS must not follow the medical model, but must have human rights as its heart.

### **Access to Care and Support**

*"I have dealt with scores of agencies and individual professionals. It's exhausting and actually, traumatising. Forced to relieve difficulties over and over again in return for help that doesn't quite fit"*

## What Carers Told Us

Carers were clear that access to care and support should be simple, fair and transparent and focussed on people's outcomes.

Lengthy assessments and form filling will dissuade some carers from accessing support. Carers must not have to 'fight' and 'challenge' to get a support for them and the people they care for.

It is essential that carers are involved in the support planning for the people they care for. Both because carers often have a contribution to make in relation to the preferences and needs of the person they care for and because the support plan needs to reflect the carer's role in the provision of care and how much care they are willing and able to provide.

In relation to eligibility criteria, it is not entirely clear whether the government intends to remove eligibility criteria entirely, remove eligibility thresholds, or simply change the process and parameters for applying eligibility criteria. But carers are clear that people should not have to justify their need for support. Eligibility criteria must be removed if the government is serious about adopting a human rights approach to the provision of social care.

*"The amount of forms we need to fill in put us off asking. We constantly need to fight. We are tired. We don't have the energy to prove our existence"*

## Our recommendations in relation to Access to Support

- Support planning should build on outcomes focused best practice, including the good conversation model
- The work of carers centres in undertaking Adult Carer Support Plans should be retained and built on. The government should consider devolving responsibility to the third sector for other forms of support planning
- The process for support planning in relation accessing a right to breaks from caring must be simple, fair and transparent. Lengthy assessments and form filling will dissuade some carers from accessing support.
- It is our view that the use of eligibility criteria is not compatible with a preventative or human rights based approach. The government should consider other methods to facilitate access to social care to ensure people do not have to focus on deficits and risks and are supported to live their best lives

## Commissioning of Services

*"Money is useless if there's nothing to spend it on. The same as hours, you can legislate entitlements, but entitlements are useless without actual service provision"*

## What Carers Told Us

Commissioning is an area of concern for unpaid carers and the staff that support them. Carers told us that they were often unable to access the services they needed because of

gaps in provision in their local areas. Commissioning is therefore a key element of improving social care.

In addition, local carers centres who are members of COCIS have told us over many years that current commissioning processes rarely contribute to good outcomes for social care recipients and unpaid carers. They are not collaborative or focused on the needs of the local population and are time-consuming and bureaucratic, requiring small grass-roots organisations to take valuable time away from service provision.

### Our recommendations in relation to the commissioning of services

- There are good examples of outcomes focused commissioning. We should be drawing on best practice.
- We support the principle of collaborative commissioning. People who use social care and unpaid carers should be equal partners in the process of commissioning and decisions must be taken as closely as possible to people and their communities
- While we support the development of a structure of standards and processes for commissioning, these must not stand in the way of the development of smaller grass-roots organisations.

## Valuing people who work in social care

*“Difficulty with this is staffing. Already receive SDS which is used for activities to allow us respite, but have not received this for several weeks due to staffing issues. Adequate pay and conditions for social care sector is essential to retain staff as we have had numerous workers introduced then leave within the last few years.”*

### What Carers Told Us

As with the previous section on commissioning, carers told us how the current pandemic has exposed shortages in the workforce to the level that social care provision is now almost unsustainable. They also told us of staff going the extra mile and providing excellent support, despite poor working conditions and low pay

In our discussions we heard many examples of how carers with an agreed package were unable to use it, due to the lack of social care staff. If social care is to improve and expand, workforce issues must be addressed.

### Our recommendations in relation to people who work in social care

- At our engagement sessions with staff they were strongly in favour of a Fair Work Accreditation scheme with 93% of people supporting this proposal. When asked ‘What do you think would make social care workers feel more valued in their role?’ 100% of staff said ‘Improved terms and conditions, including measures such as improvements to sick pay, annual leave, maternity/paternity pay, pensions, and development/learning time’
- A key message that came through our discussions was the importance of valuing the third sector and understanding the expertise of staff and the specialist nature of

third sector organisations. The third sector must be viewed as equal partners to statutory partners with access to long-term, sustainable and adequate funding to enable them to continue to play their vital role in the delivery of social care support.

## Conclusion

We welcome the government's focus on social care and the promise of radical change and improvement, alongside greater investment. While we absolutely agree that this requires a long-term view, we want to make the point that carers can't wait for legislation to be enacted.

As came across very strongly in our discussions with carers, they report that they are exhausted, that many have not had a break since the start of the pandemic or even before and their health and wellbeing is at breaking point. We need sustained investment in social care and carer support as a matter of urgency, or the cost to individuals, society as a whole and the economy will only increase.

We hope that this will be just the start of the discussion and that there will be a greater effort to engage carers and people with lived experience before important decisions are made and set in legislation. We would urge the government not to rush this and to establish a collaborative process with organisations like ourselves in the next stage of developing their proposals.

## Further information

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