

Age Scotland
Causewayside House
160 Causewayside
Edinburgh EH9 1PR

16 January 2022

Dear Convener,

Re Follow-up to your attendance at HSCS Committee 13 December 2022

Thank you for your letter of 14th December 2022, and for the opportunity to provide further commentary on the questions from committee members. I have provided written responses to these as follows.

General hopes and fears

- How would you like organisations such as yours to be represented on care boards?

We are committed to there being representation of the third sector on National Care Boards with full voting rights. This has also been a consistent recommendation of Audit Scotland since 2015. The pandemic has shown the vital role that the third sector plays in service delivery, often stepping in to fill gaps left by the statutory sector. They are not merely a value add, but a core part of the mixed economy of delivery of social care and should be recognised as such.

Scotland has a diverse and thriving third sector made up of small grass roots organisations and larger nationals. We believe that mechanisms should be put in place to enable the involvement of the sector in the National Care Service across this diversity. We would hope to see representation of national third sector organisations at National Care boards, and of smaller organisations at a local level. We also believe that there is considerable scope for smaller community based organisations to play a role in this project, not only through TSIs but in their own right.

- What challenges have you experienced in working with IJBs? What lessons would you draw from these experiences for the creation of a national care service?

Our members have shared a range of challenges with us with respect to working with IJBs. For the third sector, particularly small community-based organisations, there has been a lack of understanding or appreciation for the vital role that they play in delivering social care. While there are undoubtedly good practice examples, such as in Angus and East Lothian where the Health and Social Care Partnership have worked to support the development of Meeting Centres for people with experience of dementia. These provide

vital forms of hyper-localised post diagnostic support (see [here](#)) to people in the early to moderate stages of dementia. However, we have seen as many examples of poor practice, where the third sector is either ignored, or expected to compete for contracts under unbalanced procurement processes that are often disproportionate the amount of funding requested. This takes attention away from front line service delivery and fails to make the most of the expert community knowledge these assets bring.

From the perspective of people living with dementia and unpaid carers, we have regularly heard that IJBs have not recognised the experience and expertise that those with lived experience bring to their work. This is compounded by members with lived experience not having full voting rights. Our members have also cited a lack of support in order to fulfil the role of a lived experience rep on the board. Carers have expressed frustration that they receive expenses to cover the cost of care during meetings but not to enable them to prepare for meetings. This puts them at a significant disadvantage to other members of these bodies and does not recognise the complex realities of providing care. Other challenges shared with us have included boards refusing to cover personal assistance but not administrative or secretariat support to board members. As I shared in evidence to the committee, our members have called for a pooled approach to the new Care Boards enabling those with lived experience to balance their involvement against caring and self-management. This can also enable those with lived experience to benefit from peer support giving them a stronger voice and enabling them to better articulate their views. I would also reiterate my point to the committee, around the importance of training board members in recognising and understanding the vital contribution that people with lived experience bring to the table.

- What do you understand to be the purpose and objectives of creating a national care service? To what extent are the principles in the Bill an accurate reflection of that purpose and those objectives?

We broadly support the purpose and objectives articulated in the bill as well as those outlined by Feeley. What is not yet clear is whether the structure as proposed will deliver on those objectives. There are also questions around the cost and financing of the proposals that are a cause of concern. Our members have articulated to us the urgency of reform. Improvements in access to much needed services as well as realisation of the principles are more important than the implementation of structures.

- Are the principles in the Bill suitably aligned with the principles in other legislation and policy such as that relating to Self-directed Support and health and social care integration?

Our members believe that there is clear congruity between the principles of the Bill and other legislation, particularly SDS. However, alignment with principle is not the same as practical alignment or delivery. We want to see explicit links being made to other services involved in delivery and prevention such as housing. There also needs to be genuine read across with strategies such as carers and dementia. This goes beyond oblique references in policy documents but must involve practical steps that will be taken to enable these connections to be made with staff working proactively in partnership on the ground. This

might involve exploring different ways of working including supporting grass roots organisations to deliver service provision with adequate financial support to do so.

Anne's Law

- What is your understanding of why the Anne's Law provisions of the Bill as introduced might not afford a named family member or friend the same access to a loved one as a staff member?

As we have already shared with the committee in our written evidence, we are concerned that under the current provisions of the bill there may still be scope for the Minister, under advice from Public Health Scotland to restrict access of family members in the event of future lockdowns. We continue to be concerned about the ongoing use of lockdowns in care homes to manage the spread of winter viruses such as flu and norovirus. The health and wellbeing of residents is paramount, but having regular and guaranteed access to family members is a vital part of enabling wellbeing.

Unpaid carers and breaks for carers

- To what extent are you satisfied that these proposed amendments to the Carers (Scotland) Act 2016 alone will be sufficient to support people in their caring roles?

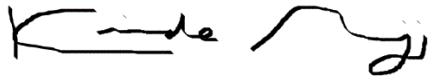
The sections of the Bill relating to support for carers are among the most detailed. However, we are conscious of ongoing gaps between policy aspiration and delivery, and this must be considered in terms of how the provisions will be enforced. Since our inception in 2019 the topic that has been raised with About Dementia by our members has been the mismatch between the provisions of the Carers Act and delivery on the ground. We believe that the new provisions need to have some teeth and there needs to be accountability and clear mechanisms for carers to seek recourse if their needs are not met.

- Are other amendments required to the Bill to strengthen support for carers, considering the invaluable contribution they make?

In addition to what has been outlined we believe that carers should be entitled to financial support to enable them to undertake development or training either linked to their caring responsibilities or future employability. Unpaid carers have shared with us that they often feel under skilled and undervalued, particularly when they face changes over their caring journey when they become responsible for issues such as moving and handling, medication, or nutrition. Such vital skills are among the first that the care workforce are trained on and it is core to their roles, however there is no equivalent support for unpaid carers. Likewise, carers at the end of their caring journey have shared that they often feel de-skilled and unfit to return to the labour market particularly if this gap in participation has been of more than a year or so. We have called for the creation of a carers' development fund to provide access to training and support at these key junctures in a carers' journey.

Thank you again for the opportunity to give evidence to the committee. Please do not hesitate to contact me should you have any further questions.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Kainde Manji'. The signature is fluid and cursive, with the first name 'Kainde' written in a slightly larger, more prominent hand than the last name 'Manji'.

Dr Kainde Manji
Head of Dementia, Age Scotland