The Health and Social Care Alliance Scotland (the ALLIANCE)

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Care Reform (Scotland) Bill
Stage 3 debate briefing

10 June 2025

Key Points

- The ALLIANCE recommends MSPs vote in favour of the Care Reform (Scotland) Bill at Stage 3.
- The ALLIANCE also believes the Bill is an opportunity missed. Cross-party work to advance transformational change in social care over the long term must start now.
- The ALLIANCE recommends MSPs vote in favour of amendment 2, which would ensure citizens right of access and control care records pertaining to them.
- The ALLIANCE recommends MSPs vote in favour of amendments 72 and 73, which would provide a clear definition of independent advocacy.

Final vote on the Bill

The ALLIANCE recommends that MSPs vote in favour of the Care Reform (Scotland) Bill at Stage 3.

The Bill contains a number of provisions that have the potential to further people's human rights and improve the health and social care services they need. These include a right to breaks for carers, Anne's Law, and improving access to independent advocacy.

However, the ALLIANCE also believes the Bill is an opportunity missed. When it was introduced in June 2022 as the National Care Service (Scotland) Bill, it represented an opportunity for long-overdue transformational change in social care, and an opportunity to implement the recommendations of the Independent Review of Adult Social Care (the Feeley Review).

The ALLIANCE is disappointed by the dropping of large parts of the Bill, including all the legislative commitments. While we have been consistently clear the Bill did not meet the need for the transformational change people needing social care support have called for, and required substantial amendment, the removal of all commitments from primary legislation to

social care system reform leaves an uncertain future. It remains unclear what social care reforms will be delivered and when.

As we described in our recent joint paper with partner organisations, 'The National Care Service – Where Now?'[1], the last four years demonstrate that significant cross-party support, collective institutional effort and meaningful stakeholder involvement will be essential to advance reform over the long term. The work to ensure this happens must start now.

Group 1: Health and Social Care Information

The ALLIANCE supports amendment 2, in the name of Jackie Baillie, and recommends MSPs vote in favour of it.

Care records proposed in the Bill should follow best practice in human rights based approaches to data, and a digital choice approach. The amendment would provide that regulations made under the Bill must include:

- Citizens' rights to access and control care records pertaining to them, including the ability to decide who should have access to different types of information in their care record.
- Guardians' rights to access and control the care records of the person for whom they care and hold Guardianship.
- Citizens' rights to access and control care records digitally or in other formats.

Citizens or guardians should have, as a right, access to and control of their own (or those who they hold a guardianship for) care records, using a digital choice approach. A digital choice approach to data records means that people can choose whether to access and edit information digitally or in alternative formats and would help to mitigate digital exclusion and promote and protect the rights of people accessing services.

One of the weaknesses of the current system is that health and social care records are not shared across connected services and sectors, nor do they necessarily evolve with them as they age and transition from childhood to

adulthood, requiring people to repeatedly explain their situation and requirements – which can include having to repeatedly recount traumatic experiences. Nor is there currently a role for the person to record their will and preferences when it comes to their care and support.

If implemented properly, a single planning process with integrated care record keeping would enable better conversations about people's care and support planning and a more compassionate approach. However, it is essential that the person accessing support has control over and access to their own records, and that there are clear methods and pathways available for them to request corrections if information has not been recorded properly.

Secondary legislation should ensure compatibility between the design of care records and existing regulation and guidance around health records (with edits to the latter where required). For example, primary care and community and hospital health records are separate and are not shared routinely outwith the NHS. Additionally, it is important to ensure coherence with implementation of the Mental Health Law Review.

Commented [SR1]: Should we acknowledge coherence with the mental health law review implementation too, since the proposals here were around human rights based assessments and noting people's will and preferences?

It is also important to clarify whether care records will include everyday detail (e.g. updates from daily visits from a carer), high-level information only (e.g. diagnoses and key health and care requirements), or a combination of the two with gradiated access to information. Significant work and co-design is required to ensure appropriate connectivity between relevant records to ensure that care records are fit for purpose.

Data sharing should follow human rights principles in digital health and social care, ensuring people have access to and control of their data and who can access and edit it. This could include following the model of personal data stores, as outlined in the ALLIANCE response to the Data Strategy for Health and Social Care.[2]

Amendment 53, in the name of Mark Ruskell, also addresses the issue raised, though we understand there are concerns about it being within legislative competence.

Group 11: Independent information, advice and advocacy

The ALLIANCE supports amendments 72 and 73, in the name of Mark Ruskell, and recommends MSPs vote in favour of them.

We welcome the commitment to independent advocacy contained in the Bill and it being retained despite the remainder of the original Part 1 of the Bill being removed. Independent advocacy is vital in ensuring that people are properly supported to access health and social care, and to ensure that their will and preferences are understood, and to holding public bodies accountable when people's human rights are not met.

Independent advocacy can also have a preventative role, prevent situations of conflict or poor practice from escalating, and enables people to stay engaged with services that are struggling to meet their needs. Independent advocacy is closely aligned to the realisation of human rights, the prevention of crisis and prioritisation of early interventions, and co-production.

The amendments would provide a clear definition of independent advocacy in primary legislation, reducing confusion about what the term means and ensuring consistent delivery of services. If a clear definition is not provided in primary legislation, Scotland is likely to see inconsistent delivery of independent advocacy – leading to the perpetuation of ongoing problems with varied delivery of services across different health and social care partnerships and areas.

Amendments 72 and 73 would ensure a clear definition is provided and ensure that the advocacy provided is genuinely independent. This is informed by the definition of independent advocacy offered by the Scottish Independent Advocacy Alliance (SIAA) and agreed by their membership. This states that independent advocacy should:

- Have structural, financial and psychological independence from others
- Provide no other services, has no other interests, ties or links other than the delivery, promotion, support and defence of independent advocacy.[3]

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.

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[1] CCPS, Coalition of Carers in Scotland, Glasgow Disability Alliance, the ALLIANCE, Inclusion Scotland, Scottish Care, "The National Care Service – Where Now?' (April 2025). Available at https://www.alliance-scotland.org.uk/blog/news/the-national-care-service-where-now/
[2] The ALLIANCE, "ALLIANCE responds to Data Strategy for Health and Social Care" (2022), available at: https://www.alliance-scotland.org.uk/blog/news/alliance-responds-to-data-strategy-for-health-and-social-care/.
[3] Scottish Independent Advocacy Alliance, "What is independent advocacy?". Available at: https://www.siaa.org.uk/what-is-independent-advocacy/.