

13 January 2023

Follow up to attendance at HSCS Committee, 5 December 2022 (Panel 1)

Dear Convener,

Following your letter of 6 December 2022, the ALLIANCE is pleased to provide additional written responses to questions that were not asked during the Committee evidence session on 5 December 2022. We appreciate the extension to the original deadline, and hope that these responses can usefully inform the Committee's work on the National Care Service (Scotland) Bill.

General views on the Bill

How would the implementation of the Bill impact upon the voluntary sector? Are there any particular changes to the Bill you would wish to see to minimise any potential negative impacts or to maximise potential benefits to the voluntary sector from the creation of a national care service?

The third and independent sectors are one of the biggest strengths of our social care system, and they must be acknowledged, valued and sustainably funded within the National Care Service. Third and independent sector providers have long highlighted difficulties in engaging with local and integration authorities' commissioning processes. Some of the issues raised with the competitive tendering is that it hinders, rather than helps, partnership working and can contradict the values of personal choice and control embedded in Self-directed Support (SDS) and social care legislation.¹ Similarly, we support the role of community-based health and social care, including the vital work of the third and independent sectors, Community Links Practitioners, social work professionals, care workers, and allied health professionals alongside community health workers.

There are an estimated 11,760 voluntary organisations operating within the social care sector in Scotland, and a further 1,988 operating within healthcare.² The vast majority of these social care organisations are local (89% of third sector

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organisations overall, and 98% of community groups), providing tailored support to the people they serve.³ In 2021, 49,182 social care and support staff were employed within the voluntary sector in Scotland, with a further 11,560 healthcare staff.⁴ That figure does not include volunteers – and Volunteer Scotland estimate that 200,000 volunteers provide support within the voluntary sector more broadly across the country.⁵

Even when discussing social care providers more narrowly (excluding organisations that provide, for example, communication support to people accessing social care), Audit Scotland estimate that the voluntary and private sectors deliver the majority of social care services in Scotland, representing “20 and 57 per cent of registered services respectively”.⁶ In some parts of the sector, such as palliative and end of life care, the third sector provides a much higher proportion of support available to people. It is also worth noting that overall, the Care Inspectorate consistently rates third sector social care provision as providing higher quality of care than for-profit organisations.⁷

Despite the vital role they play in delivering social care in Scotland, the third and independent sectors are not mentioned explicitly at any point in the Bill. As such, there is no duty placed upon care boards to involve the third and independent sectors as equal partners, and definitions of community planning partners as outlined in Part 2 of the Community Empowerment (Scotland) Act 2015 do not ensure that third and independent sector providers of social care and support will be included in planning processes.⁸ This omission risks losing vital insight and expertise, and could perpetuate existing inequalities in terms of provision, resourcing, and workforce pay and conditions within social care in Scotland.

The ALLIANCE understands the third and independent sectors as providers of care and support who are not included within the statutory sector. This includes both for-profit and non-profit providers, and organisations that rely on volunteers to provide care and support. Our use of the term also encompasses wider community-based support services for people, as well as organisations providing personal care at home. It is important that legislation and guidance reflects this broader use of the term.

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We propose that care boards should be required by primary legislation to engage with partners across the social care landscape, to ensure representative input from key stakeholders. This should include third and independent sector involvement in strategic planning as equal partners, access to care records (where appropriate), and inclusion in definitions of independent advocacy.

The right to breaks

Does the Bill as introduced guarantee the right to breaks for unpaid carers who need them? What measures should be considered to give unpaid carers the right of redress if they do not receive breaks or a carer's assessment?

The ALLIANCE believes that breaks from caring are an essential form of support for unpaid carers and welcomes the commitment to ensuring access to short breaks in the Bill. Unpaid carers, disabled people, and people living with long term conditions have all outlined the importance of short breaks, and of everyone being able to access them. However, many people spoke about problems accessing short breaks, even when it was included in their personal outcomes plan, and the subsequent difficulties that could cause. The process of accessing short breaks should be simple, transparent, and equitable, and properly resourced. Furthermore, any assessment process should not be linked to Carer's Allowance. Planning for the National Care Service should include estimates for encouraging and commissioning the provision of new services, specifically around short breaks, but also across the social care landscape more broadly. There should also be specific regional analysis of provision, to ensure equitable access across Scotland – including in rural and island communities.

While we welcome the commitment to ensuring unpaid carers have access to breaks from caring, attendees at the ALLIANCE engagement event raised concerns about the language used in Section 38 (Rights to breaks for carers). In particular, the reference to “sufficient breaks from providing care” is open to interpretation and could lead to variation in provision across different care boards and localities. Similarly, respondents suggested that the language of “short breaks” is open to interpretation and could indicate that breaks are only provided in line with options funded via Shared Care Scotland (rather than a more flexible variety of options).

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We suggest that primary legislation should clearly outline that every unpaid carer has a right to regular breaks (with a set period wherein unpaid carers should expect to access breaks from caring as a minimum level of provision). Regulation should then provide further detail and nuance, co-produced by people with lived experience (including unpaid carers of all ages).

People also reported that some local authorities specified designated centres for the provision of short breaks, rather than allowing people to choose which arrangements suited them best and refused to fund short breaks outwith those providers. This caused problems in terms of respecting people's choices, but also prompted longer waiting lists for spaces at those designated centres – particularly around typical holiday periods. Respondents highlighted the need for people to be able to use their short break budgets flexibly, as long as they could demonstrate that activities met their personal outcomes and were within budget.

Flexible, regular access to short breaks for all unpaid carers should be strongly encouraged because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers. However, people also highlighted that provision needs to accommodate and be appropriate to people with complex support requirements – it must be both sufficient and flexible enough to enable breaks that are fit for purpose.

During our Independent Review of Adult Social Care engagement activities, we heard that the experiences of people accessing care during short breaks can often be inadequate, with some individuals being allocated a place in a care home which was inappropriate for their requirements or age. With limited choice and lack of appropriate solutions, often unpaid carers did not feel able to take up opportunities for short breaks (as suitable care was not available). Some people we spoke to felt that care homes operate as a business so do not have beds readily available for short stays as it doesn't make "business sense" if the aim is to maximise capital.⁹

It was also shared with the ALLIANCE that when a supported person presents so-called challenging behaviour, this increases the barriers to accessing short breaks. Paid carers may no longer be willing to come in and support and care homes decline

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to take people, leaving psychiatric or dementia units in hospitals as the only option available. The system as it stands is not equitable or available to all.

Finally, it is essential that young carers are not left out of any arrangements for accessing short breaks, and that they are consulted about their requirements – which may differ from those of adult carers. It is also important that young carers and the persons for whom they care have a right to separate assessments, and secondary legislation should make clear that different short break options are available to different members of the same family.

Data and information sharing

To what extent are you confident that the Bill as introduced will lead to the creation of a nationally-consistent, integrated and accessible electronic social care and health record?

Care records have the potential to meet some of the concerns the ALLIANCE has heard from members about the current disconnect between health and social care record keeping, and the frustration of having to repeat information. However, we recommend that Section 36 of the Bill should be amended in order to ensure the creation of a nationally-consistent, integrated and accessible electronic social care and health record that is fit for purpose.

The Bill should make it clear that 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. If implemented properly, a

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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, with the ability to either make or request edits and changes, and that there are clear methods and pathways available for them to request corrections if information has not been recorded properly.

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.¹⁰

In 2021, in partnership with Scottish Care and VOX (Voices Of eXperience), the ALLIANCE consulted a range of people to develop human rights principles in digital health and social care. We suggest that any record keeping system developed as part of the National Care Service should comply with those key principles.¹¹

Furthermore, despite the vital role they play in delivering social care in Scotland, the third and independent sectors are not mentioned explicitly at any point in either the Bill or the accompanying explanatory notes and are not clearly delineated as included under the definitions provided of the "National Care Service". As such, Section 36 (Care records) of the Bill does not ensure that third and independent sector providers of social care and support will be able to access and contribute to care records where appropriate. This omission risks reducing the effectiveness of care records and could adversely affect the quality of care that people receive and the accuracy of data collection and analysis.

We suggest that 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. 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 graduated access to information. Significant work and co-design is required to ensure

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appropriate connectivity between relevant records to ensure that care records are fit for purpose.

At present, Section 36 of the Bill outlines information sharing requirements for professionals working within the National Care Service and the National Health Service. To create a care record system that is person centred, this section of the legislation should be amended to outline measures to ensure citizen control of and access to their data, and a digital choice approach. This section of the legislation should also be amended to outline measures to ensure that third and independent sector providers and workers should have the ability to access the care records (not only employees of the NHS, local authorities, and Health and Social Care Partnerships), if appropriate and with permission of the individual in question.

Any data collection process should not place significant cost or labour demands on third and independent sector providers, and providers should be properly resourced to cover those costs. The Bill should place a requirement on Ministers to ensure in regulation that there is appropriate infrastructure and workforce development to enable citizen access and control of data, and high-quality data collection, storage and analysis.

Planning and co-design

Are there aspects of the development of a national care service you would prefer to see detailed on the face of the Bill rather than left to the co-design process? Or vice versa (i.e. provisions on the face of the Bill that would be better developed through co-design)? What role can third sector organisations play in the planning and co-design of the National Care Service?

At present, the ALLIANCE has eleven proposed amendments that we would like to see on the face of the Bill rather than left solely to the co-design process. These are as follows:

1. Lived experience representation on care boards (Section 4(3)(a))

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The ALLIANCE welcomes the sections in the Bill that enable care boards to pay care board and sub-committee members; the lack of proper remuneration has been a key barrier to lived experience representation on Integrated Joint Boards (IJBs) under the current funding model. However, we agree with our members that it is vital that the legislation requires every care board to include within their membership lived experience representatives, to ensure that disabled people, people living with long term conditions, and unpaid carers are included in decision making.

We propose that care boards should be required by primary legislation to fill *at least* two lived experience representative posts within their membership to be considered functional; and recommend that care boards should aim for more than that number, to enable good attendance and involvement.

Lived experience members should be open to disabled people, people living with long term conditions, unpaid carers, and people from other groups in society who access social care. Representation of unpaid carers should include people who provide unpaid care for children and young people and adults. Boards should ensure full voting rights for representatives who access services and unpaid carers, and their attendance (properly reimbursed) should be a pre-requisite for quorate meetings and decision-making. Leaving these items as optional possibilities for care boards will perpetuate existing inequalities in social care decision making and not meet the requirement of ensuring rights holders are empowered to take part in decision making which affects their lives. Adequate provisions should be put in place to support active lived experience attendance at meetings.

An explicit obligation will support the realisation of the objectives stated in the United Nations Convention on the Rights of Persons with Disabilities (particularly Article 29 – participation in political and public life) and assist with the implementation of PANEL principles.¹²

2. Including the third and independent sectors as community planning partners (Section 8)

An amendment to ensure the National Care Service (Scotland) Bill acknowledges the third and independent sectors as key and equal partners in the delivery of social

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care thought the legislation. Examples of this include naming the third and independent sectors as “community planning partners” (Section 8). Without this alteration, third and independent sector providers of care and support may not be included in planning processes – and vital insight and experience will be lost. We propose that care boards should be required by primary legislation to engage with partners across the social care landscape, to ensure representative input from key stakeholders.

3. Citizen access to and control of care records (Section 36)

As outlined earlier in this letter, the ALLIANCE would welcome an amendment to ensure that the care records proposed by the National Care Service (Scotland) Bill 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.

4. Third and independent sector access to care records (Section 36)

The ALLIANCE also proposes a second amendment to Section 36 (care records), to ensure that third and independent sector providers of care and support (including personal assistants and support workers) can access and use care records where appropriate. The amendment would require regulations made under the Bill provide for:

- Social care workers’ access to the care records of people for whom they care, subject to permission from those individuals. This should include third and independent sector providers of social care and support, and personal assistants.

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- Provision to support citizens, unpaid carers, and the workforce to access care records, with appropriate infrastructure and workforce development to enable data collection, entry, control, and storage.

5. Strategic planning by Scottish Ministers (Section 6) and care boards (Section 7)

The ALLIANCE welcomes the sections in the Bill that commit to strategic planning and public consultation by Scottish Ministers (Section 6) and care boards (Section 7). However, we agree with our members that it is vital that the legislation requires every Ministers and care board to include within their planning processes lived experience representatives, to ensure that disabled people, people living with long term conditions, and unpaid carers are included in active decision making – not just consultation. To provide clarity on this issue, we also suggest the Ministers should define co-production within primary legislation, with direct input in decision-making as a key distinction raised between co-production and consultation.

We propose that Ministers and care boards should be required by primary legislation to co-produce plans, by ensuring that at least two lived experience representatives are present in care boards and relevant planning groups; and recommend that care boards should aim for more than that number, to enable good attendance and involvement. Consideration should also be given to the support which lived experience representatives will require in order to be able to engage with a wider community of interest.

Lived experience members should be open to disabled people, people living with long term conditions, unpaid carers, and people from other groups in society who access social care. Representation of unpaid carers should include people who provide unpaid care for children and young people and adults. Boards should ensure full voting rights for representatives who access services and unpaid carers, and their attendance (properly reimbursed and accessible) should be a pre-requisite for quorate meetings and decision-making. Leaving these items as optional possibilities for care boards and Ministers will perpetuate existing inequalities in social care decision making.



An explicit obligation will support the realisation of the objectives stated in the United Nations Convention on the Rights of Persons with Disabilities (particularly Article 29 – participation in political and public life) and assist with the implementation of PANEL principles.¹³

6. Ethical commissioning (Section 10)

The ALLIANCE welcomes the references to ethical commissioning in Section 6 (Strategic planning by Scottish Ministers) and Section 7 (Strategic planning by care boards) of the Bill. These sections state that strategic plans must set out plans for ethical commissioning strategy in relation to the delivery of services.

The Procurement Reform (Scotland) Act 2014 introduced welcome changes to existing legislation, introducing a sustainable procurement duty to public authorities, focusing on improving people’s outcomes and reducing inequality.¹⁴ It also removed the pre-requisite to award contracts via competitive tendering processes.

However, at present there are a wide variety of interpretations of what “ethical commissioning” entails. If a clear definition is not provided in primary legislation, Scotland is likely to see inconsistent delivery of ethical commissioning – leading to the perpetuation of ongoing problems with varied delivery of services across different care boards and areas.

Primary legislation should clearly define what is meant by ethical commissioning, beginning with the additional information laid out in the policy memorandum for the Bill and the recommendations of the Independent Review of Adult Social Care.

7. National Care Service Charter and accountability measures (Sections 11 and 12)

Section 11 (The National Care Service Charter) and Section 12 (Further provision about the charter) of the Bill contains welcome commitments to human rights, including discussion of the importance of input from people accessing and delivering social care and support.





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However, while much of the proposed content of the Charter is positive, and in line with PANEL principles,¹⁵ there is nothing in the legislation to indicate consequences if the Charter is not fulfilled, or to detail who would be held responsible should that occur. If we are to see meaningful implementation of the Charter, and of human rights based approaches to the National Care Service more broadly, the accountability processes must be clear, with effective redress and action available to people if systems fail.

As such, we propose that primary legislation should place accountability for the implementation of the Charter with Scottish Ministers, who should have due regard for human rights treaties and a duty to report annually on the delivery of the Charter and any steps taken to combat problems in delivery. Ministers may in turn detail in regulation responsibilities placed on public bodies and providers to ensure that the rights detailed in the Charter are met, and what consequences will follow and redress is available should that not be the case.

We also suggest that Section 11(4) could cause considerable confusion. That part of the Bill states that:

“(4) Nothing in the charter is to—
(a) give rise to any new rights,
(b) impose any new responsibilities, or
(c) alter in any way an existing right or responsibility.”

Within the present system, there are a range of examples where people do not have a legal right to redress or access to services – but where, if the National Care Service is to deliver on a commitment to human rights based approaches and the recommendations of the Independent Review of Adult Social Care, change is needed to improve people’s experiences.

For example, at present people’s options within the current complaint system can be extremely limited if they wish to challenge decisions about their care; people do not have a sustained right to family visits within residential care settings (as outlined in “Anne’s Law”); unpaid carers have variable access to short breaks; authorities do not have a duty to collect, analyse, or share a wide range of useful information and data

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on people's experiences of social care. The National Care Service aims to improve consistency of practice and delivery in all of the above examples – and in doing so, will give people new rights in law, and outline additional responsibilities on public bodies and providers of social care and support. To avoid potential confusion and variance in practice across Scotland, we recommend the removal of Section 11(4) from the Bill.

8. Independent advocacy (Section 13)

The ALLIANCE welcomes the references to independent advocacy in Section 13 (Independent advocacy) of the Bill. Independent advocacy is vital in ensuring that people are properly supported to access health and social care, and to holding public bodies accountable when people's human rights are not met. Independent advocacy can also have a preventative role, and 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 with the principles of the Bill, particularly with regard to the realisation of human rights, the prevention of crisis and prioritisation of early interventions, and co-production.

Independent advocacy is mentioned in both the Social Care (Self-directed Support) (Scotland) Act 2013 and the Mental Health (Care and Treatment) (Scotland) Act 2003, as a key part of the delivery of social care and support. The 2013 Act states that independent advocacy is a key part of providing people with information about Self-directed Support.¹⁶

Due to the discretionary aspect of information sharing about independent advocacy in the 2013 Act, local practice on social workers informing people about independent advocacy is variable across Scotland. The National Care Service (Scotland) Bill offers an opportunity to strengthen those existing legislative commitments, by requiring Ministers to make provision for independent advocacy services within the NCS, and in turn ensuring that these vital services are properly resourced, included in strategic planning, and a duty to share information about local services is included for social work professionals as part of their work.

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The ALLIANCE recommends that there should be a legislative duty on Ministers and care boards to ensure that every care board covering a specific geographical area should ensure that there is adequate provision of independent advocacy services within that area, with sustainable funding. We know from consultation with the Scottish Independent Advocacy Alliance (SIAA), that in local authorities and Health and Social Care Partnerships where independent advocacy is included within strategic planning that local independent advocacy services can provide more sustained support to people and in turn improve their outcomes.

Furthermore, there is the opportunity to 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 care boards and areas.

We recommend that the legislation should use the definition of independent advocacy in line with that offered by the Scottish Independent Advocacy Alliance (SIAA), and agreed by their membership of independent advocacy organisations and groups. 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.¹⁷

9. Limitations on transfer of care board functions in an emergency (Section 18) and on transfer of care board functions due to service failure (Section 19)

Section 18 (Transfer of care board's functions in an emergency) and Section 19 (Transfer of care board's functions due to service failure) are understandable contingency measures to include within the Bill to ensure that Ministers are fully accountable for the delivery of the National Care Service. While it is to be hoped that neither Section is required in practice, it is reasonable to outline in primary legislation



measures to enable direct Ministerial input in instances where radical intervention is required.

However, we are concerned that the Bill as drafted does not place sufficient limitations on Ministerial interventions in the event of emergency or service failure. We suggest that it is important that the transfer of care board functions should be both short term and time limited; as evinced by the COVID-19 pandemic, states of emergency can continue for years rather than weeks or months, and the legislation as it stands enabled Ministers to retain control of care boards for as long as “an emergency exists”. Section 20 (Emergency intervention order) of the Bill stipulates a maximum time period of 12 months; a similar level of detail should be included in Sections 18 and 19.

Furthermore, we suggest that Sections 18 and 19 of the Bill require further detail to ensure that human rights based approaches are followed by Ministers in the event of an emergency or service failure. The Bill should state explicitly that Ministers should have a duty to refer to the principles set out in Section 1 of the Bill, and the Charter of Rights and Responsibilities, in the event of transfer of care board’s functions due to emergency or service failure – particularly regarding the expertise of lived experience representatives from care boards. We know from evidence provided to the COVID-19 Inquiry that a wide range of practical problems and inequalities in the pandemic response were caused by early decisions being made without input from disabled people, people living with long term conditions, and unpaid carers. As such, it is particularly important that the National Care Service learns from that experience and embeds safeguards to ensure that experts by experience are included in decision making processes in emergency as well as everyday scenarios.

Finally, we also suggest that regulation should provide a clear definition of “emergency”, to strengthen transparency and public accountability of process around Ministerial intervention in care board function.

10. Intersectional data collection and analysis

While the sections on “Research” and “Care records” contain much welcome content, there is no concrete commitment within the Bill to collecting or analysing a

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national dataset on people's experiences of social care, nor to including that information within strategic planning by Ministers or care boards.

At present, data collection on social care is variable across each local authority and Health and Social Care Partnership. This causes substantial difficulties for analysts looking to collect and analyse social care data – and, in turn, for Ministers, local authority, and health and social care staff to effectively plan and deliver high quality social care, based on people's requirements and experiences. Without measures in place in primary legislation to ensure good data collection and intersectional analysis, the National Care Service will struggle to evidence and respond to people's needs across Scotland. This challenge is particularly acute given the problems highlighted in the Independent Review of Adult Social Care and in *My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland*, which demonstrated that some groups of people receive poorer access to social care, compounding existing health inequalities (including people with learning disabilities, people from Black and ethnic minority communities, people with lived experience of mental health problems, disabled women, and people with sensory loss.¹⁸ Data gaps continue to challenge the implementation of SDS improvements.

Disaggregated data gathering and intersectional analysis are essential to develop fully realised policies and practices that prioritise equal access to, and outcomes from accessing, social care for everyone, following human rights principles of empowerment, non-discrimination and equality, participation, and accountability. The ALLIANCE recommends that primary legislation should make clear that Ministers and care boards are responsible for carrying out data collection and intersectional analysis and including it within strategic planning.

We also suggest that further detail should be provided in regulation about the scope of national data collection and intersectional analysis, the publication of data, the frequency of reporting, and action to reduce inequalities and improve people's experiences of care based on that data and analysis.



11. Complaints service and dealing with complaints (Sections 14 and 15)

The ALLIANCE welcomes the commitment in the Bill to ensuring an effective complaints system by which people can seek redress where necessary. However, we suggest that at present primary legislation could be strengthened in Section 15 by stating that Scottish Ministers “must” (rather than “may”) by regulation make provision about the handling of relevant complaints (including the remedies that are to be available). Such an amendment would ensure that complaints systems and redress are prioritised in the National Care System, responding directly to key concerns raised within the Independent Review of Adult Social Care around the existing complaints systems.

Thank you for the opportunity to provide evidence to the Committee. If you have any further questions, please do not hesitate to contact us.

Yours sincerely,

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