

# Health and Social Care Alliance Scotland (the ALLIANCE)



## ALLIANCE response to the National Care Service (Scotland) Bill

2 September 2022

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# Future of Social Care

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to share our views with the Scottish Government on the National Care Service (Scotland) Bill. The opportunity to improve social care is welcome – and should draw heavily on the experiences and expertise of disabled people, people living with long term conditions, unpaid carers and the third sector. The ALLIANCE believes that it is essential to embed equality, human rights, and co-production in the proposed National Care Service in order to achieve transformational and positive change that works for everyone.

Over the years, the ALLIANCE has heard from a significant number of people and organisations across Scotland with direct experience of social care, and our response draws on this rich and substantial information.

This includes around 1,000 disabled people, people living with long term conditions, and unpaid carers via *My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland*,<sup>1</sup> extensive engagement for the Independent Review of Adult Social Care,<sup>2</sup> work on the revised Self-directed Support Guidance, and our 2021 response to the National Care Service for Scotland consultation. *My Support My Choice* was the most recent and comprehensive reflection of people's experiences of accessing Self-directed Support (SDS) and social care in Scotland prior to COVID-19. Our response is also informed by an ALLIANCE consultation event on the National Care Service (Scotland) Bill, held on 19 August 2022, and supplementary data from our members.

The National Care Service offers an opportunity to improve people's experiences of community health and social care - if implemented in a way that responds to the concerns and experiences of people accessing services and the workforce, and the recommendations in the Independent Review of Adult Social Care. Any programme of improvement needs to consider the support and resources required to allow this to happen. Furthermore, improvement activity overseen by the National Care Service must start with those areas of improvement which will realise the principles and values of choice, control, and human rights. It is also essential that the development of the National Care Service is attentive to the importance of integration across systems and does not unintentionally reduce integration across health and social care services.

Social care should be seen as an investment in citizenship. We have an opportunity to embed citizen involvement, human rights and co-production in re-designing services. We need to have support services that are readily available when a person needs to access them, enshrine people's right to independent living, and become much more proactive in providing preventative and early intervention services. To see that progress and ambition realised, it is imperative that the National Care Service (Scotland) Bill is fit for purpose.

## General questions about the Bill

Question 1. The Policy Memorandum accompanying the Bill describes its purpose as being “to improve the quality and consistency of social work and social care services in Scotland”. Will the Bill, as introduced, be successful in achieving this purpose? If not, why not?

As introduced, the National Care Service (Scotland) Bill (thereafter “the Bill”) has the potential to improve the quality and consistency of social work and social care services in Scotland and lead to improved outcomes for people. However, while there is much welcome material, there are a significant number of areas in which there is not sufficient detail in the Bill as it stands to ensure that the National Care Service (NCS) will match the ambitions of the Independent Review of Adult Social Care. In particular, further checks and balances must be built in throughout primary legislation to ensure that the intentions behind the Bill are realised.

Without further detail and explicit commitments to delivering social care that prioritises people’s human rights, in legislation rather than regulation, we cannot state that the Bill will enable transformative change and improvement across social care. It must ensure that support services are readily available when a person needs to access them, protect people’s right to independent living, and ensure that Scotland is much more proactive in providing preventative and early intervention support and services for people. It must also ensure there are robust and independent accountability mechanisms that allow people to raise an issue where their rights are not being protected, respected, and fulfilled. Accountability processes must be transparent, with effective redress and action available if systems fail.

Question 2. Is the Bill the best way to improve the quality and consistency of social work and social care services? If not, what alternative approach should be taken?

The Bill offers a significant opportunity to improve the quality and consistency of social work and social care services in Scotland. However, as with any legislation, implementation and robust accountability mechanisms, including evaluation measures, are key to ensuring the success (or otherwise) of the proposals. Fundamentally, the Bill must enshrine the right to access social care and support, and for disabled people, people living with long term conditions, and unpaid carers to be involved in decision making at every level. Without this included as a right in primary legislation, it will be more difficult to address current inequality of access to social.

The ALLIANCE recommends that in addition to the material outlined in the Bill (e.g. Section 36, “Care Records”), the Scottish Government must ensure robust and fully transparent national data collection. Data gathered should monitor and evidence the impact of changes stemming from the implementation of the National Care Service,

and be used to ensure equitable access to social care. In *My Support My Choice*, a shared research project between the ALLIANCE and Self Directed Support Scotland, we found that there are concerning gaps in national and regional data gathering and analysis around social care.<sup>3</sup> Disaggregated data gathering and intersectional analysis, including monitoring personal outcomes, is essential to develop fully realised policies and practices that prioritise equal access to SDS and social care for everyone. Such work should follow human rights principles of equality, non-discrimination, participation and accountability.

To avoid gaps and improve analysis, we recommend the Bill should create a duty for systematic and robust data gathering by local and national public bodies on people who access social care, disaggregated by all protected characteristics, as well as other relevant socio-economic information like household income and the Scottish Index of Multiple Deprivation (SIMD). Further detail on data gathering should be included in legislation at regulation level, in line with the principles of consent, choice and ownership.<sup>4</sup>

Equalities monitoring data should be gathered, including demographic groups outwith the protected characteristics, to ensure a robust human rights based approach – so the rights of those who are potentially most at risk of health and social care inequalities, and have least access to services, are protected. For example, this may include (but is not restricted to) unpaid carers, care experienced people, survivors of trauma and/or abuse, and victims of crime.

It is important that this collection of data on people's experiences of social care is regular, sustained, and spans the entire population of people accessing social care and support in Scotland (longitudinal and national data collection). The questions to capture people's experiences should allow for personalised, qualitative responses as well as quantitative data analysis, and should be developed in co-production with people who access services and their families and unpaid carers. Decisions taken based on evidence from data collection and analysis should be clearly communicated to the public, people accessing care, and the workforce.

This prioritisation of both qualitative and quantitative data is essential if people's personal outcomes and rights are to be monitored and measured with a view to ensuring continuous improvement and progressive realisation of people's rights. A mixed methods approach that embeds a human rights based approach (as is used by the Care Inspectorate, or in *My Support My Choice*) would help to ensure that appropriate weight and priority is given to people's experiences alongside nationwide statistics. A rigorous approach to data collection is essential to meet the aspirations of the National Care Service in terms of delivering improvement to social care.

This data should be published regularly and made available to the public (after following standard research ethics around anonymity for respondents), with a duty

placed on Ministers and care boards to respond to any evidence of poor outcomes or inadequate access to care for people. There is currently no commitment in the Bill to capturing such information routinely nor rendering this information publicly available; this absence should be amended in subsequent parts of the legislative process.

Analysis of results should be published and available to the general public on at least an annual basis, and include intersectional analysis to monitor how policies are working in practice for different population groups across Scotland. This would enable targeted action to ensure everyone has access to high quality social care and support (while still following standard research ethics regarding participant anonymity). Relevant organisations should be appropriately and sustainably resourced to carry out this data collection and analysis at national and local levels (including third and independent sector providers). This analysis should include use of Equalities and Human Rights Impact Assessments as practical tools to inform policy and assess its impact.

Furthermore, we recommend that the secondary legislation should include a requirement for the National Care Service to develop robust and sustainable processes to support citizens to understand and – if they are then happy to do so – consent to their anonymised data being collected and used to inform this analysis (or to provide sustainable funding for other organisations to deliver such a programme). These actions would increase public understanding of and trust in data collection for health and social care, and would support wider public health.

While the Bill offers welcome opportunities, it is not the sole means of improvement and change. The ALLIANCE has long supported calls for the abolition of care charging; a concern which has become more acute within the current cost of living crisis, which disproportionately affects disabled people, people living with long term conditions, and unpaid carers. We suggested that action on these items should be happening while the Bill is progressing throughout Parliament.

**Question 3. Are there any specific aspects of the Bill which you disagree with or that you would like to see amended?**

There are several sections of the Bill where the draft legislation could be strengthened to ensure people have equitable access to the care and support they require. Our key proposed amendments to Part 1 are detailed below, as outlined in the structure of the Bill:

1. The National Care Service principles (Section 1(e)) should make explicit reference to people's right to independent living and inclusion in the community. Commitments to the promotion of the "dignity of the individual" and advancing "equality and non-discrimination" are welcome, but the independent living movement offers a clearer definition of rights, as outlined in international human

rights conventions (e.g. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD)).<sup>5</sup>

2. Section 4(3)(a) (Establishment and abolition of care boards): care boards should be required to have multiple lived experience representatives to be considered quorate. These representatives should include 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 is not a meaningful commitment to participation and empowerment, or human rights based approaches. Furthermore, people's participation and involvement in decision making needs to be embedded through these processes – not only within care boards, but also within related subgroups and connected meetings. Provision should also be made for full and appropriate support to enable people with lived experience to participate in decision-making at all levels (e.g. drawing on the learning from the People Led Policy Panel).
3. Strategic planning by Scottish Ministers (Section 6) and care boards (Section 7) should include a commitment to more than public consultation; plans should be co-produced with people with lived experience, where people accessing services are part of planning and decision-making at all levels. Both consultation and co-production activity should be fully accessible, with appropriate support provided to ensure people can participate in the process. Similarly, plans should explicitly draw on data collection and intersectional analysis of people's experiences of care, to ensure evidence-based policy and plans that target groups of people who do not have equitable access to social care. This would be enabled through the duty for national data collection as described in our response to question 2.
4. The third and independent sectors, and the role of volunteers, should be explicitly considered as key and equal partners throughout the legislation, and named in both the explanatory policy memoranda and regulation. Examples of this include naming the third and independent sectors as "community planning partners" (Section 8) and stating explicitly that they should be included in the list of groups who can have access to people's care records (with permission and as appropriate). 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.
5. The commitments to ethical commissioning mentioned in the Bill are welcome. However, Section 10 (Meaning of ethical commissioning strategy) should be

strengthened, with primary legislation providing a clear definition of ethical commissioning and the principles of ethical commissioning, to aid in consistent implementation. This section is also an opportunity to strengthen the Bill's commitment to fair work and human rights budgeting.

6. Section 11 (The National Care Service Charter) should commit to co-producing the Charter, with disabled people, people living with long term conditions, and unpaid carers as key decision-makers in deciding what is included in the final document. This section could also be strengthened by detailing in Section 11 a commitment to independent living. Finally, while much of the proposed content of the Charter is welcome, there is nothing in the legislation to indicate consequences if the Charter is not fulfilled or who would be held responsible. 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 if systems fail.

The legislation should also include a requirement for Ministers to publish the Charter whenever it is revised, and to co-produce changes with people with lived experience (not just consult).

7. Section 13 (Independent advocacy) is welcome but lacks detail. It is essential that a definition of independent advocacy is provided within primary legislation, to enable consistent implementation of these important services (and particularly to ensure that services are fully independent). We recommend that the legislation should use the definition of independent advocacy as offered by the Scottish Independent Advocacy Alliance (SIAA). 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.<sup>6</sup>

There should also be a legislative duty 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.

8. Section 18 (Transfer of care board's functions in an emergency) requires further detail to ensure that human rights based approaches are followed in the event of an emergency. It should be clearly laid out in legislation that emergency transfers should be short term and time limited. Furthermore, while contingency planning should be included in legislation, we suggest it is important that this section outline that Ministers should have a duty to refer to the principles set out in Section 1 even in the event of emergency transfer of functions – particularly

regarding the expertise of lived experience representatives from care boards. We also suggest that this section should be amended to provide a clear definition of “emergency”, to strengthen transparency and public accountability of process.

We know from evidence provided to the COVID-19 Inquiry that a number of practical problems 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.

9. Section 36 (Care records). 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. That said, we recommend that this section should be amended to make the following clear:
  - a. Citizens should have, as a right, access to and control of their own care records (via a digital choice approach). A “digital choice” approach to data records would mitigate digital exclusion and promote and protect the rights of people accessing services.
  - b. 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.<sup>7</sup>
  - c. 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. Section 37(4) (Information standards) should also be amended accordingly to include third and independent sector providers.
  - d. Any data collection process should not place significant cost or labour demands on third and independent sector providers, and/or should be properly resourced to cover those costs. This comment also applies to Section 27 (Information standards).
  - e. The Bill should be clear in acknowledging the role of Personal Assistants (PAs) within the social care workforce, and explicit in detailing which sections of the legislation – and particularly those pertaining to additional duties, such as Sections 36 and 37 – apply to PAs rather than providers. Furthermore, details in regulation involving Personal Assistants should be co-produced with both PAs and people employing PAs.

Question 4. Is there anything additional you would like to see included in the Bill and is anything missing?

### **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 a national dataset on people’s experiences and outcomes after accessing social care (with intersectional analysis), and clear accountability for action therein. Disaggregated data gathering and intersectional analysis is essential to develop fully realised policies and practices that prioritise equal access to SDS and social care for everyone, following human rights principles of equality, non-discrimination, participation and accountability and monitor whether people’s outcomes are being met. It should also be made clear who is responsible for national 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.

### **Training and evaluation**

Similarly, while the section on “Training” empowers Ministers and care boards to provide people with relevant training, no further detail is provided. The ALLIANCE proposed that this section of legislation should be strengthened to place a duty (“must”) on care boards and Ministers to provide training and support for the workforce and unpaid carers, rather than the optional “may” provide training. We also suggest that this section should be expanded to include a commitment to the sustained provision of human rights training for all duty bearers and people who access services. Without investment to build capacity amongst the workforce, effectively implementation of human rights based approaches is unlikely to be realised in practice.

The above action may also require the creation of a new body to oversee training and evaluation, or the empowerment of an existing body to take responsibility for that remit. In either case, appropriate resourcing should be provided to ensure effective implementation.

Within training and evaluation processes, staff wellbeing and welfare should also be considered and tracked as key concerns for the sustainability of social care and support in Scotland. This should include work to support social care and social work professionals, and evaluate gaps in provision that require dedicated recruitment and training efforts to ensure future sustainability (e.g. ensuring that there are enough deafblind communicator guides). Given known pressures on the workforce, it is important that measures to ensure staff wellbeing and welfare are included within the National Care Service.

## Right to rehab

The ALLIANCE also supports calls from Chest Heart & Stroke Scotland (CHSS) and others to include the right to rehabilitation within the Bill. We welcome the Scottish Government's manifesto commitment to ensuring a right to rehab, and suggest that the Bill is a key opportunity to embed this within health and social care planning and legislation. This sits alongside welcome commitments to Anne's Law and visits to or by care home residents in Section 40 of the Bill, and our wider comments on the importance of including independent living in the Bill.

We suggest that the Bill should make explicit mention of Article 26 (Habilitation and rehabilitation) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which states that:

"1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation."<sup>8</sup>

Rehabilitation should be offered to support people living with long term conditions, to support people transitioning from hospital to home, and to support recovery from a health event. Providing a definition of habilitation and rehabilitation within primary legislation, with explicit reference to Article 26, would also be useful in promoting a clear definition to health and care services and providing people with lifelong care. A

system to monitor the implementation of the right to rehabilitation should also be included under the sections of the Bill pertaining to Ministerial responsibility and accountability.

### **Eligibility criteria**

Apart from modifications to existing legislation in Part 3, there is no mention of eligibility criteria in the Bill – either the replacement of them with an alternative approach to assessment, focused on individual requirements and human rights, or of their continuation. Given that eligibility criteria are one of the key barriers to people accessing social care in Scotland, and particularly to early intervention and preventative care and support (as outlined in the Independent Review of Adult Social Care and *My Support My Choice*),<sup>9</sup> this absence is remarkable.

The ALLIANCE supports calls from the Scottish Human Rights Commission to define eligibility criteria in a manner that is compliant with human rights standards. If the National Care Service is to be effective and meet the ambitions of the Independent Review of Adult Social Care, and to offer equitable access to social care across Scotland, it is essential that primary legislation is explicit in ending the use of current eligibility criteria, the associated regional variation, and the focus on crisis response over preventative care. Such an action would also be in keeping with Social Work Scotland's Standards 2 ("early help and support") and 8 ("worker autonomy") to ensure best practice in delivering Self-directed Support.<sup>10</sup> Eliminating eligibility criteria would also enable the meaningful implementation of Article 19 of the United National Convention on the Rights of Persons with Disabilities (Living independently and being included in the community).<sup>11</sup>

Reform of eligibility criteria is urgently required within primary legislation – both to ensure the effective implementation of preventative care and human rights based approaches, and to reform the scope of social work. Such an action would also assist in meeting some of the challenges currently facing social work in Scotland – as starkly outlined in the *Setting the Bar for Social Work in Scotland* report (2022), and in responses to the Bill by Social Work Scotland and the Scottish Association for Social Work.<sup>12</sup> As the Independent Review of Adult Social Care summarised:

“Social workers and their representative organisations told us about their frustrations with this process [eligibility criteria], which put social workers in the position of gatekeeping budgets on behalf of cash-strapped Local Authorities, and prioritising cost and eligibility considerations above working with people to plan their support and to ensure access to high quality support. As one social worker put it to us: It's the equivalent of NHS staff having to make a case for funding every time someone needs a blood test.”<sup>13</sup>

### **The role of social work**

It is also remarkable that the role of social work professionals is not detailed in the Bill. Given social workers' importance for the delivery of social care and support, and the references within the Independent Review of Adult Social Care to social work professionals as having a "critical role"<sup>14</sup> to play in the delivery of social care, this seems a clear omission, and one that should be amended.

Question 5. The Scottish Government proposes that the details of many aspects of the proposed National Care Service will be outlined in future secondary legislation rather than being included in the Bill itself. Do you have any comments on this approach? Are there any aspects of the Bill where you would like to have seen more detail in the Bill itself?

While it is understandable that the Scottish Government intends to use secondary legislation to outline much of the detail of the National Care Service, the ALLIANCE believes that too much reliance is being placed on future regulations. As outlined in our responses to questions 3 and 4, there are several areas of the Bill where we recommend amendments to primary legislation at this stage, to ensure that people's rights are realised. It is particularly important that those elements that outline people's human rights are included in primary legislation, rather than regulations, to ensure appropriate scrutiny, input from people with lived experience, and that ongoing and sustainable checks and balances are firmly in place.

With regard to material that we would hope to see included within future secondary legislation, the ALLIANCE offers the following comments:

### **Fair work**

The mentions of fair work in Section 1(g) are welcome, but no further detail is offered on the effective implementation and funding of this work. This single mention of fair work is not likely to prompt substantive improvement. Significantly more detail should also be provided in regulation if the National Care Service is to address current inequalities in care work.

To achieve the best quality care, the Scottish Government must prioritise recruiting, training, paying, and valuing social care staff better. Terms and conditions should be equitable across all sectors – including across services provided by the statutory sector and the third and independent sectors, and across children's social care support and adult services. The latter is particularly pertinent given that the hourly rate for sessional workers within children's social care is currently lower than for equivalent work within adult social care.

The implementation of fair work should include work to enable people working in care to have access to flexible working and to options for career progression pathways, and must avoid rolling back to the institutionalised settings of the past to meet the financial challenges of today. This action must be a key part of any work to develop the National Care Service, and the ALLIANCE recommends focusing on the principle of maximum available resource as one way in which the legislation could deliver its commitment to human rights based approaches. The Fair Work Convention have highlighted that failure to address these issues will have broader consequences, for example low pay will significantly contribute to inequality in women's working conditions and Scotland's gender pay gap.<sup>15</sup>

The ALLIANCE also supports Volunteer Scotland's proposal that as part of the commitment to Fair Work, the National Care Service legislation should include an explicit statement that volunteers will not be used to carry out duties normally performed by paid staff or to disguise the effects of staff shortages. Volunteer Scotland and the Scottish Trades Union Congress developed the Volunteer Charter identifying the key principles for "assuring legitimacy and preventing exploitation of workers and volunteers"; we recommend that the National Care Service should align with the principles of the Charter, as part of work to ensure fair work and sustainable care and social care in Scotland.<sup>16</sup>

## **Right to Food**

The ALLIANCE strongly recommends that a commitment to the right to food should be included in secondary legislation. Such an action would ensure that the role of food within social care is appropriately acknowledged. Legislation should include the mention of appropriate provision of food within national and care board strategic plans. It would also continue the welcome commitments in the Good Food Nation (Scotland) Act in support of the right to food (e.g. care boards producing Good Food Plans), in line with international human rights treaties. Plans should acknowledge and respond to people's right to access nutritious, sustainable and safe food, in a culturally appropriate manner.

## **Care charging**

The ALLIANCE remains committed to the removal of care charges, to ensure that care is free at point of delivery, and supports calls from Scotland Against the Care Tax (SACT) to end care charging. Care charges are not mentioned in the Bill, but remain an area where change is essential to improve the quality and consistency of social work and social care services.

During our Independent Review of Adult Social Care engagement sessions, participants identified local authority applications for charging around care to be particularly complicated. They identified the document "Charging for Residential

Accommodation Guidance”, which supports the charging procedures, to be extremely long, offering guidelines as opposed to rules or laws, and suggested it represents the discrepancy in the approach to charging for social care which exists across Scotland.

The consensus was that there is inconsistency across the country and the review needs to look closely at the level of financial contributions individuals are being asked to pay in order to access social care support. There needs to be clarity on what people are charged for and why, as well as what is a proper social care cost, especially around those with dementia. In Scotland, nearly all elements of charging have been removed from the healthcare system so there needs to be a close examination of the social care system with regards to charging people for care and investigate whether this is still necessary or appropriate.

Social care as currently arranged means that some people must pay more to enjoy the same human rights as others. Non-residential care charges increase financial pressures on people who access care, and potentially causes people to forego essential services – particularly in light of the current cost of living crisis.

This difficulty is compounded by the fact that local authorities and health and social care partnerships can make their own decisions on charging, which leads to varying quality in the experience of social care across Scotland. Scotland should be working urgently towards making all social care universally free at the point of use. In the meantime, the ALLIANCE welcomes the Scottish Government’s commitment to end non-residential care charges and recommends that this takes place in the current parliamentary term.

### **Care records**

The ALLIANCE has made a range of proposals regarding care records (Section 36) in our response to earlier questions. In addition to those comments, we also 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 appropriate connectivity between relevant records to ensure that care records are fit for purpose.

### **Right to inclusive communication**

Finally, and importantly, primary legislation should ensure that there is an obligation placed on every duty bearer within the National Care Service to ensure inclusive communication. While we welcome the statement in the National Care Service principles that “the National Care Service, and those providing services on its behalf, are to communicate with people in an inclusive way”,<sup>17</sup> this single reference should be threaded throughout primary legislation to ensure compliance. In particular, the sections on strategic planning, complaints, care boards, care records, rights to breaks for unpaid carers, and visits to or by care home residents should include an obligation on duty bearers to ensure that people have access to inclusive communication in a timely manner. Such actions would be in line with Article 9 of the United Nations Convention on the Rights of Persons with Disabilities, which states that:

“1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.”<sup>18</sup>

Question 6. The Bill proposes to give Scottish Ministers powers to transfer a broad range of social care, social work and community health functions to the National Care Service using future secondary legislation. Do you have any views about the services that may or may not be included in the National Care Service, either now or in the future?

The ALLIANCE understands that Scottish Government is undertaking a programme of research and consultation to inform the decisions outlined in section 30 (Consultation before bringing children’s and justice services into the NCS). It is essential that the Scottish Government ensures that these plans are clearly communicated to the public, with transparency and accountability, and that all plans are properly co-produced. That co-production work should be transparent to the public and to the social work and social care workforce, and include people with experience of accessing and delivering current services (and their families), with appropriate support for them to fully engage in the co-production process.

Question 7. Do you have any general comments on financial implications of the Bill and the proposed creation of a National Care Service for the long-term funding of social care, social work and community healthcare?

### **Third sector**

The third sector is one of the biggest strengths of our social care system, and it 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 SDS and social care legislation.<sup>19</sup> 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 have long been calls for greater investment in social care as part of the shift from acute services towards preventative, community-based support. While the national social care budget has grown, thanks in part to campaigning by Scottish civil society, it is widely recognised that more financial investment is needed.

Despite contributing an estimated £3.4 billion to the Scottish economy, with a gross value added (GVA) greater than that of agriculture or the arts,<sup>20</sup> social care is commonly portrayed as a drain on public resources. A recent report by the Women's Budget Group notes that "investment of 1% of GDP in the care sector would produce 2.7 times as many jobs in the economy overall as an equivalent investment in construction."<sup>21</sup>

The Feeley Review estimated that the total cost of its recommendations would amount to additional expenditure of £0.66bn per year, approximately 0.4% of Scottish GDP. It noted that increased expenditure is essential to achieve a rights based system and will have a positive impact – amongst others – on women's employment and the gender pay gap. It recommended "[c]areful consideration of options for raising new revenues to increase investment in adult social care support."<sup>22</sup>

At the ALLIANCE's Independent Review of Adult Social Care engagement events, participants stated that there needs to be an increased involvement of communities in commissioning, with the encouragement of community partnerships and a shift towards an enhanced asset based approach. By involving communities more in the commissioning of services and support it would be possible to make better use of the range of resources available to support a person to live well.

Participants felt that the role of the third sector is one of the biggest strengths of our social care system, with a person centred ethos providing high quality, diverse support. Those who took part felt "totally different" services could be procured if the third sector had an earlier and meaningful input to the commissioning process. It was suggested that an opportunity and additional duty for third sector organisations could be to get involved in collaborative commissioning, taking shared ownership of the

commissioning process. Increasing the role of the third sector and local communities could help to change the narrative of social care if the current commissioning processes were overhauled.

If the third sector was properly resourced and valued, it could spend less time on locating and competing for funding, concentrating on working better collaboratively, 'pulling together a synergy of specialisms' which could be commissioned.<sup>23</sup> The ALLIANCE, along with Volunteer Scotland and a range of our members, calls on the Scottish Government to plan for the effective inclusion and financing of the third and independent sectors within the National Care Service. Demand for services is increasing, as are operating costs, yet the money available to many organisations providing vital services is decreasing. Those whose core funding comes from the public sector are often subject to either fixed funding, which is declining in real terms due to high inflation, or reduced funding. The expertise of the third sector, community and volunteer organisations is significant, and should be properly acknowledged, valued, and sustainably resourced by the proposed National Care Service.

To give one example of the core role that the third sector plays in health and social care, commissioning and procurement models should consider the significant role played by the third sector in palliative and end of life care.<sup>24</sup> Adult voluntary hospices are major providers of specialist palliative care in many (but not all) areas of Scotland. Any new arrangements should take account of this fact, and not assume that all mainstream healthcare provision is provided by the NHS.

The ALLIANCE supports calls from the Scottish Partnership for Palliative Care for new market oversight and commissioning arrangements to ensure the financial sustainability of hospice provision. In the absence of hospice-provided services (which the public helps fund through donations) the state would face a substantial bill to fill the gap. As organisations which provide leadership, innovation, education, advice and support around death, dying and bereavement, hospices should be engaged as key partners in strategic commissioning processes.

### **Inclusive and accessible communication**

Ensuring that inclusive and accessible communication is embedded across all parts and stages of social care should be a key part of the responsibilities of the National Care Service, and costed accordingly. Services like Contact Scotland BSL are invaluable to people with sensory loss for inclusive communications and should be valued and sustainably funded; but there are many more examples of good communication practice that could be usefully expanded, as well as areas where accessible communication is limited in scope and availability.

The ALLIANCE recommends the use of systems such as Contact Scotland (which has seen a marked increase in use during the pandemic)<sup>25</sup> should be extended,

sustainably funded, and appropriately resourced to continue providing their vital service as part of plans for the National Care Service, with staff trained in signposting people to it. Finally, the National Care Service should acknowledge and fund the specialist skills required to train people in specific social care roles, such as sighted guides and deafblind communicator guides – especially given the restrictions placed on people’s ability to use tactile communication during the pandemic, and the resulting reductions in emotional support, increased risk of social isolation and loneliness, and reduced access to communication.

### **Allied health professionals**

ALLIANCE members have highlighted the role of allied health professionals (AHPs) for people accessing social care, and the need for their important work to be acknowledged, financed, and planned for within the National Care Service. In 2021 Alison Keir, Professional Practice Lead Scotland for the Royal College of Occupational Therapists (RCOP), summarised the position of the College as follows:

“We are hopeful that the outcome of the consultation will recognise the need for a fundamental shift towards early intervention and re-ablement. AHPs, including occupational therapists, will be central to this shift. In the short-term this will require greater resources, but investing in people and addressing these problems sooner can save money in the long-term. It is the chance to be truly transformative in our approach to support in Scotland.

As people age or become ill, they begin to lose the ability to complete daily activities in a particular order. Once we know where a person is on their ageing journey we map out services, products and support that will help that person to maintain, or even recover, daily abilities. If we focus on re-ablement and switch to community-based support, we can relieve the pressures on primary and acute care.”<sup>26</sup>

### **Resourcing new systems**

Much of the proposals within the National Care Service involve new processes and systems (data collection, care records, a national complaints systems, evaluation measures, training facilities). All of this must be properly and sustainably resourced to ensure its success and effectiveness – including plans for training and career progression within the social care workforce.

While the mention of fair work in the Bill is welcome, further detail is needed on introducing associated systems change. If social care work is to be properly valued, there must be plans to acknowledge and encourage career development and specialisation, with associated training and funding. For example, Guide Communicators and BSL interpreters train for several years to reach the levels of

competency required to support people who are Deaf or deafblind, yet there is no competency framework to acknowledge that specialism within care work.

Question 8: The Bill is accompanied by the following impact assessments:

- [Equality impact assessment](#)
- [Business and regulatory impact assessment](#)
- [Child rights and wellbeing impact assessment](#)
- [Data protection impact assessment](#)
- [Fairer Scotland duty assessment](#)
- [Island communities impact assessment](#)

Do you have any comments on the contents and conclusions of these impact assessments or about the potential impact of the Bill on specific groups or sectors?

The ALLIANCE welcomes that the Scottish Government have carried out a range of impact assessments, including an island communities impact assessment. However, we have reservations that at times the impact assessments discuss the possible impacts of items that are not explicitly outlined in the Bill (but only implicitly mentioned within the principles and aims). Further work is needed to ensure that the Bill is improved to ensure that there are sufficient amendments and safeguards to ensure improvements for people who access, or wish to access social care.

The equality framework provided for by the provisions of the Equality Act 2010, Public Sector Equality Duty, and Scotland Specific Duties, forms an important element of a human rights based approach. Improvement should therefore also be planned and measured in alignment with equality, including use of Equality Impact Assessments (EIAs) and Human Rights Impact Assessments (HRIAs). The Scottish Human Rights Commission and Equality and Human Rights Commission have developed a means to combine EIAs and HRIAs, called Equality and Human Rights Impact Assessments (EQHRIAs) which are not included in the list above.<sup>27</sup> This is a practical tool that should be used both at the early stages to inform policy, and after the policy has been implemented to assess its impact.

The concept of “continuous improvement” is aligned to – and complemented by – the principle of “progressive realisation” of rights,<sup>28</sup> which is found in the International Covenant on Economic, Social and Cultural Rights (also reflected in Recommendations 31 and 39 of the Independent Review of Adult Social Care).<sup>29</sup> This means that deliberate steps are taken immediately and on an ongoing basis towards the full realisation of people’s rights. Given that Scotland is proposing to incorporate the International Covenant on Economic, Social and Cultural Rights, International Convention on the Elimination of All Forms of Racial Discrimination, and other international human rights law into Scots law, this is a timely opportunity to

ensure that Scotland's community health and social care services – including their improvement frameworks – are suitably “future proofed”.

### Questions about the Financial Memorandum

**Question 1: Did you take part in any consultation exercise preceding the Bill and, if so, did you comment on the financial assumptions made?**

The ALLIANCE submitted a lengthy response to the original 2021 consultation.<sup>30</sup> In our response, we commented on a range of financial assumptions – particularly highlighting the need to sustainably fund the vital work of the third and independent sectors within wider investment in social care. We also recommended the use of ethical commissioning models, fair work, and of human rights budgeting approaches.

**Question 2: If applicable, do you believe your comments on the financial assumptions have been accurately reflected in the financial memorandum (FM)?**

The ALLIANCE welcomes the mention in the Bill of ethical commissioning, human rights based approaches, and fair work. However, in all three instances, we suggest that more could be done to strengthen the commitment to these approaches in the legislation. We also suggest that the financial memorandum does not provide sufficient detail on funding plans to assure the sector of sufficient investment to see the proposals implemented – particularly given the significant impact of the cost of living crisis on the third and independent sectors, as evidenced by recent work by SCVO.<sup>31</sup> It is particularly important that the costs of accommodating new processes within the National Care Service (such as care records and data collection) are considered within the financial memorandum.

In taking forward this and future year's budgets, non-regression means the Scottish Government must ensure that any changes in spending do not result in people's existing human rights, such as the rights to independent living and equal participation in society for disabled people, being eroded. Maximum use of available resources means the government has a duty to ensure that adequate funding is available to ensure the progressive realisation of human rights. We recommend that budget planning for the National Care Service should begin with people's outcomes, and then identify the resources required. Scottish Government should not assume that the level of current spend equates to current need, if we are to deliver care and support in a preventative manner and address unmet need.

**Question 3: Did you have sufficient time to contribute to the consultation exercise?**

The consultation exercise has a relatively tight turnaround time given the breadth and importance of the consultation topic. This has adversely affected our and our

members' ability to respond to some sections of the consultation exercise. The timescale for responding to the Bill has been similarly short, especially given summer recess.

Question 4: If the Bill has any financial implications for you or your organisation, do you believe that they have been accurately reflected in the FM? If not, please provide details.

The creation of a National Care Service during this parliamentary term offers an opportunity to improve the lives and experiences of disabled people, people living with long term conditions, and unpaid carers. It will also be one of the biggest public sector reforms taken in recent decades, with significant financial implications. In moving forward with a National Care Service, spending plans must be human rights based and recognise third and independent health and social care organisations as equal and valued delivery partners, resourced by additional, sustainable, ongoing, and secure funding. In addition, as the ALLIANCE noted in our response to the Resource Spending Review Framework consultation, it is important to reflect on the lessons learned from the slow pace of the health and social care integration agenda.<sup>32</sup>

We would also re-emphasise the points made in that response relating to support for third sector organisations. The financial situation facing third sector organisations has been difficult for a number of years, particularly as a result of short-term funding arrangements which often do not provide for full cost recovery or build in inflationary adjustment costings. These pre-existing pressures are now being further exacerbated by the cost of living crisis, including by the rising costs of energy supply, and fuel costs (both of which severely impact care providers and Personal Assistants, and in turn people accessing social care).

The contribution of the third sector to Scotland's people, society and economy remains unrecognised and undervalued. There are over 40,000 third sector organisations in Scotland, with an estimated combined annual turnover of more than £6 billion (2018 figures).<sup>33</sup> The sector is also a major employer – for example, SCVO estimates that there are over 100,000 paid staff working in Scotland's voluntary sector, and a further 200,000 volunteers providing support in 2020.<sup>34</sup>

During COVID-19, the ALLIANCE's Community in Action<sup>35</sup> initiative documented how community and third sector organisations responded flexibly and at pace to provide lifeline services and support for people across Scotland. However, the impact of the pandemic has been stark, far-reaching, and in some cases poses a threat to their very survival.<sup>36</sup> Throughout the pandemic, loss of income and increased demand for services has significantly impacted organisations' ability to plan and deliver future services. Findings from 'Scotland's Third Sector Tracker' highlight that almost half (48%) of all organisations surveyed saw a decrease in turnover compared with pre-

pandemic levels.<sup>37</sup> At the same time, costs have increased in responding to the pandemic, including workforce related costs, such as additional staff wellbeing support and cover for sickness absence.<sup>38</sup>

These trends are likely to continue for third sector organisations, particularly for those working with people who have been disproportionately affected, including disabled people, people living with long term conditions, and unpaid carers. The consequences for those that rely on their vital support is hard to overstate. The longer term survival of third sector health and social care organisations is at stake, and the crucial services and the support they deliver remains just as vital as we continue through COVID-19 recovery; sustainable, ongoing and protected funding and support should reflect that to ensure that essential services continue to reach people and keep staff in secure employment.

The positive impact of longer term funding for third sector organisations was highlighted in a recent ALLIANCE report which gathered learning from projects which received five year funding via the “Transforming Self Management” round of the Self Management Fund.<sup>39</sup> This longer term funding for the Self Management Fund aimed to impact the ability of organisations to effect sustainable change to deliver supported self management to people in Scotland living with long term conditions. The report highlights how long term, secured funding enhanced the sustainability of self management practice and delivery, and in turn, the positive impact on individuals’ lives. Longer term funding made project activity more sustainable by allowing organisations more time to develop project engagement and respond to challenges, supporting improved trust in organisations, providing a consistent and reliable delivery of services, and reaching a larger scope of individuals.

As stated in our initial response to the Resource Spending Review Framework consultation,<sup>40</sup> current plans to incorporate several international human rights treaties into Scots Law offer an opportune time to embed human rights budgeting principles – including in the Bill. In particular, decisions on public finances should have due regard to two of the key principles of progressive realisation of human rights, those of “non-regression” and “maximum use of available resources.”

In taking forward this and future year’s budgets, non-regression means the Scottish Government must ensure that any changes in spending do not result in people’s existing human rights, such as the rights to independent living and equal participation in society for disabled people, being eroded. Maximum use of available resources means the government has a duty to ensure that adequate funding is available to ensure the progressive realisation of human rights. It should therefore carefully consider how to use the tax and revenue powers it has at its disposal, and whether maintaining current tax policies are the best means of maximising resources.

On the issue of fiscal transparency, we would reiterate the recommendation that the Scottish Government adopt a human rights budgeting approach, which is outlined in more detail by the Scottish Human Rights Commission.<sup>41</sup> Being clear about the human rights impacts of spending decisions is essential both to understanding the progress the government is making towards its own aspirations on human rights.

**Question 5: Do you consider that the estimated costs and savings set out in the FM are reasonable and accurate?**

No. The Fraser of Allander Institute and Social Work Scotland have carried out separate analyses of the costs involved in the National Care Service. We concur with their findings that the information in the Financial Memorandum of the Bill is not sufficient to support effective Parliamentary scrutiny. In particular, we highlight the statement by Emma Congreve and co-authors that “no costing has yet been produced for the health and social care record which is also part of the legislation.”<sup>42</sup>

Within the Financial Memorandum it is unclear what funds, if any, are allocated towards the sustainable funding of services provided by the third and independent sector (including the running costs of volunteer-based services). While third and independent sector providers are mentioned as being part of the National Care Service within the Bill, it is equally important that effective resourcing is provided to enable them to carry on their vital work within the social care landscape in Scotland. More detail is required on this front to indicate what is and is not included in the estimates contained within the Financial Memorandum.

In particular, the ALLIANCE and our members are concerned by the following statement within the Financial Memorandum:

“56. It is not anticipated that the establishment of the NCS and care boards, and the transfer of functions to those bodies, will have any financial implications for any other public bodies, businesses or third sector organisations, or for individuals.”<sup>43</sup>

Given that Scotland does not currently track unmet need within social care, it is difficult to see how this statement is sustainable. The Bill and the Financial Memorandum should both reflect the need to improve data collection around unmet need, and subsequent action to meet that need. Emma Congreve and co-authors also highlight this issue in the Fraser of Allandale Institute’s analysis:

“[W]e have very little understanding on unmet need in Scotland. New provision to meet at least some of this need will be required to meet the vision of all people being able to access timely, consistent, and high-quality health and social care support across Scotland. If we cannot quantify how many people will draw on new support it will not be possible to cost and plan.”<sup>44</sup>

At the very least, the Financial Memorandum must accommodate costs for third and independent sector providers to comply with the information standards and data sharing elements of the Bill. It should also ensure that third and independent sector organisations are provided with either access to or funding for the relevant software and/or equipment used to access care records, and any training included for care staff working within the National Care Service. This should include Personal Assistants and volunteers in relevant care roles, as well as persons employed centrally or by the third and independent sector. If people accessing social care are to be able to access and manage their care records directly (following best practice in human rights approaches to health and social care record keeping) then funding should also be dedicated to ensuring equitable access and appropriate training where required.

The ALLIANCE also supports Volunteer Scotland's calls to ensure that volunteers – while a valuable asset to the health and social care landscape – are not expected to substitute for paid care provision. Funding should also be dedicated to ensuring the equity of terms and conditions for social work and social care staff across the sectors – and the financial memorandum should plan for these additional costs. The latter is particularly pertinent given that the hourly rate for sessional workers within children's social care is currently lower than for equivalent work within adult social care.

While the ALLIANCE and our members welcomes the commitment to ensuring all carers have access to short breaks, we are concerned that the Financial Memorandum does not include explicit provision for the expansion of short break facilities. At present many unpaid carers are unable to access short breaks, not because they are not considered eligible (although variance on that front is also a concern), but because there is not enough suitable provision for the person for whom they care. The Financial Memorandum 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.

As mentioned earlier in this response, data collection and analysis – and action on findings to improve people's experiences of social care – are essential to the effective implementation of the Bill. There is currently not enough detail in the Financial Memorandum about how data collection and analysis will be funded across the National Care Service, nor who will be responsibility for this work (although the ALLIANCE welcomes the commitments to co-productions within the relevant sections of the Financial Memorandum).

Finally, the ALLIANCE suggests that the funds allocated to the establishment and running of care boards must, if we are to see co-production properly embedded,

include funding for the payment and remuneration of lived experience representatives on every care board, and for proper facilitation and support of their engagement. This should include (although not be restricted to) funding for accessible communications on the decisions and plans of the care board, and any assistive technology or support costs required to enable lived experience representatives to take part in and contribute to the work of the care boards. Learning from current groups such as the People Led Policy Panel should be at the forefront of this planning work to establish and estimate the ongoing costs of care boards – and is particularly important given known limitations to the current accessibility and engagement work of Integrated Joint Boards.

**Question 6: If applicable, are you content that your organisation can meet any financial costs that it might incur as a result of the Bill? If not, how do you think these costs should be met?**

Many ALLIANCE members have raised concerns about the impact of the current economic environment on their ability to delivery services. The cost of living crisis is likely to result in more people having to rely on third sector support and services. We are not confident that the Bill adequately commits to providing sustainable funding for the third and independent sectors, and the vital care services they provide. In particular, it is essential that the Scottish Government ensures that there is funding (that takes into account rising costs/inflation) available to enable the third and independent sectors to comply with data and training requirements outlined in the Bill, and wider sustained funding to ensure community investment in social care.

### **National Care Service principles (Section 1)**

**Question: Section 1 defines the National Care Service principles. In providing comments on this section of the Bill, please consider:**

- Whether you agree with these principles as drafted?
- Whether there is anything in the principles you would disagree with or wish to amend?
- Whether there is anything important missing from these principles?
- Whether an alternative approach would be preferable?

Broadly speaking, the ALLIANCE welcomes the principles outlined in Section 1 of the Bill. In particular, we welcome the explicit commitment to the realisation of human rights, and to advancing equality and non-discrimination. However, as outlined in our response to earlier questions in this consultation, we believe that this section could be further strengthened.

The National Care Service principles (Section 1(e)) should make explicit reference to people's right to independent living and inclusion in the community. Commitments to the promotion of the "dignity of the individual" and advancing "equality and non-discrimination" are welcome, but the independent living movement offers a clearer definition of rights, as outlined in international human rights conventions (e.g. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD)).<sup>45</sup>

The mentions of fair work in Section 1(g) are welcome, but no further detail is offered on the effective implementation and funding of this work. This single mention of fair work is not likely to prompt substantive improvement. Significantly more detail should also be provided in regulation if the National Care Service is to address current inequalities in care work.

To achieve the best quality care, the Scottish Government must prioritise recruiting, training, paying, and valuing social care staff better. Terms and conditions should be equitable across all sectors. The latter is particularly pertinent given that the hourly rate for sessional workers within children's social care is currently lower than for equivalent work within adult social care. This should include work to enable people working in care to have access to flexible working and to options for career progression pathways, and must avoid rolling back to the institutionalised settings of the past to meet the financial challenges of today. This action must be a key part of any work to develop the National Care Service, and the ALLIANCE recommends focusing on the principle of maximum available resource as one way in which the legislation could deliver its commitment to human rights based approaches. The Fair Work Convention have highlighted that failure to address these issues will have broader consequences, for example low pay will significantly contribute to inequality in women's working conditions and Scotland's gender pay gap.<sup>46</sup>

Finally, while much of the proposed content of Section 1 (The National Care Service principles) is welcome, there is nothing in the legislation to indicate consequences if those Principles are not fulfilled. If we are to see meaningful implementation of the Principles, and of human rights based approaches to the National Care Service more broadly, the accountability processes must be clear, with effective redress available if systems fail. Data collection and publication, as previously discussed in this response, is one pillar of work to ensure progress and action. An independent body, who would be responsible for scrutiny and the identification of areas where people's rights are not being realised is another key action to ensure public accountability. The National Care Service should draw on learning from the Scottish Mental Health Law Review and the Social Security (Scotland) Act 2018 in developing these sections of the Bill and associated proposals.

## Accountability to Scottish Ministers (Sections 2 and 3)

Question: Sections 2 and 3 establish Scottish Ministers' overarching responsibilities for the National Care Service, namely to "promote in Scotland a care service designed to secure improvement in the wellbeing of the people of Scotland" and to monitor and improve the quality of services provided by the National Care Service. These provisions have the effect that the National Care Service will be directly accountable to Scottish Ministers.

In providing comments on these sections of the Bill, please consider:

- Whether you agree with Scottish Ministers being given these overarching responsibilities?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

There is a clear need for strong accountability on the delivery of social care in Scotland. Current systems are not working for many people. Ministerial accountability, if delivered with transparency and in line with PANEL principles<sup>47</sup> could potentially improve systems. In practice, accountability and engagement with human rights based approaches need to be threaded throughout the leadership of social care at all levels to see effective change. There should be scope within the Bill for the creation of an independent authority whose role is to hold Ministers to account for their decisions.

Accountability in health and social care requires a wide range of representation in leadership roles from across the sectors. A key finding from our report *Framework for Community Health and Social Care Integrated Services (2020)* is that "integration requires a collaborative, cross-sector approach and leaders have a responsibility to engage with partners across the health and social care system before making any decisions", with better transparency about who is appointed to such leadership positions.<sup>48</sup> However, it is essential that accountability, and the development of the National Care Service more widely, is linked to long-term planning; social care should not be limited to political terms and election cycles, even if ministerial responsibility becomes a key part of accountability processes. Independent mechanisms, and clear routes for complaints and redress, are essential parts of ensuring ongoing public accountability.

In relation to transparency, *My Support My Choice* highlights that "work is needed to ensure systematic good practice and consistent transparency across several elements of SDS/social care [...] People should not have to resort to Freedom of

Information requests or court action to acquire information about their SDS/social care.”<sup>49</sup> People explained that as a result of lack of transparency they were often not part of the decision-making process concerning their care arrangements, and also that it impacted their ability to make a complaint if they wanted to. A key recommendation in *My Support My Choice* around complaint procedures is as follows:

“Social work professionals should also pro-actively inform service users, families and unpaid carers on a regular basis about how they can challenge decisions, access independent advocacy and support, local authority complaints procedures and the independent oversight of the Scottish Public Services Ombudsman (SPSO).”<sup>50</sup>

Any system that transfers responsibility for the National Care Service to Ministers must ensure a full and transparent system of accountability, with longevity across parliamentary terms. Furthermore, this section of the legislation could be more ambitious; aiming for “improvement” sets a relatively low bar. Instead, we recommend that the legislation be amended to specifically commit to the realisation of rights and independent living for everyone in Scotland, with social care being free and available at point of need. A key part of this work should be ensuring that disabled people, people living with long term conditions, and unpaid carers are involved in decision making at all levels, including resource allocation – enabling meaningful participation and accountability, in line with human rights based principles.

## Establishment and abolition of care boards (Sections 4 and 5 / Schedules 1 and 2)

Question: Sections 4 and 5 make provision for the establishment and abolition of care boards and for financial assistance for boards. As set out in the Policy Memorandum, the Bill “makes provision for the Scottish Ministers to establish and fund these boards, called “care boards” in the Bill, to plan and deliver NCS service locally, replacing current Integration Authorities”. The Policy Memorandum continues: “There is also provision for “special care boards” to deliver national functions if needed”.

Connected to Section 4 and annexed to the Bill, Schedule 1 sets out detailed provisions related to the constitution and operation of care boards while Schedule 2 makes consequential amendments to public authorities legislation.

In providing comments on these sections of the Bill, please consider:

- Whether you support the establishment of care boards as set out in these sections of the Bill and provisions on financial assistance for boards?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

As outlined earlier in this response, the ALLIANCE recommends that Section 4(3)(a) (Establishment and abolition of care boards) should be amended to ensure meaningful input from people with lived experience. Care boards should be required to have multiple lived experience representatives, representing disabled people, people living with long term conditions, and unpaid carers to be considered quorate. Boards should ensure full voting rights for representatives who access services and unpaid carers, and their attendance (properly reimbursed for their time) should be a pre-requisite for quorate meetings and decision-making. Leaving these items as optional possibilities for care boards is not a meaningful commitment to participation and empowerment, or human rights based approaches.

Furthermore, representation and involvement of people with lived experience should cascade throughout the decision making process, beyond care board meetings. Such action would be in keeping with the recommendations of the Independent Review of Adult Social Care, and the responses to the 2021 consultation on the National Care Service. The analysis report on the latter summarised the issue as follows:

“The importance of including people with lived experience in design, implementation and day-to-day decision-making was emphasised throughout

the engagement events. This should include involvement at the earliest stages and the participation of people with lived experience should be facilitated and be meaningful (i.e. with voting rights etc)."<sup>51</sup>

Given that the analysis of the 2021 consultation on the National Care Service proposals indicated strong support for all Board members (including third sector and lived experience representatives) to have voting rights, it is disappointing that the Bill has not made a stronger commitment to this action. The consultation analysis report offered the following summation:

“There was a view that their involvement should be meaningful and that these members should not be included in a tokenistic way. In line with this, there was a strong majority in support of the proposal that all Board members should have voting rights with 90% of individuals and 86% of organisations that answered this question in agreement.”<sup>52</sup>

It is also important that secondary legislation outlines requirements for care boards to operate in a way that is suitable for lived experience representatives. This detail should include (but not be restricted to): fair remuneration with consistent rates of pay for representatives across Scotland; support to access meetings and associated papers; accessible communications; ensuring that meeting timings suit the requirements of lived experience representatives, rather than assuming that patterns that work for health and social care staff are suitable.

## **Strategic planning and ethical commissioning (Chapter 2)**

Question: This Chapter of the Bill requires care boards to have a strategic plan setting out their vision, objectives and budgets for their care board area and incorporating an ethical commissioning strategy. Scottish Ministers must also have a strategic plan and an ethical commissioning strategy for any services provided at the national level.

The Policy Memorandum states that ethical commissioning strategies should set out “arrangements for providing services and how those arrangements have been designed to ensure they best reflect the NCS principles”.

In providing comments on this chapter of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this chapter of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

The ALLIANCE welcomes the commitment to ethical provisioning within the Bill. However, Section 10 (Meaning of ethical commissioning strategy) should be strengthened, with primary legislation providing a clear definition of ethical commissioning and the principles of ethical commissioning, to aid in consistent implementation. This section is also an opportunity to strengthen the Bill’s commitment to fair work and human rights budgeting.

In order to achieve effective change to commissioning and procurement processes within the National Care Service, it is essential that choice, co-production, and human rights approaches should be embedded into any proposed systems from the outset, in order to ensure that social care staff are treated and valued appropriately. Furthermore, it is important to draw on the learning from other areas of public services (e.g. social security) and establish key values for the National Care Service, that value and prioritise lived experience and ensure fair and transparent commissioning processes. By doing so, there is the potential to create a common culture and shared principles amongst all stakeholders.

To achieve this, it is imperative that rights are referenced and embedded throughout the development of the National Care Service, and that all proposed changes take an explicitly human rights based approach, to ensure better outcomes for people. This can be done, for example, by using practical tools like the five-point PANEL Principles.<sup>53</sup> This should include taking human rights based approaches to how the proposed Structure of Standards and Processes will be designed, inspected, and upheld. Accountability is a key part of PANEL principles; and clear communication on monitoring of implementation at a local level is essential if the proposed Standards are to improve staff conditions and experiences.

Care workers and unpaid carers are the backbone of Scotland’s social care system – it could not exist without them. However, there are ongoing and long-established issues with workforce recruitment, retention, training and quality (as discussed in *My Support My Choice*).<sup>54</sup> As outlined by Engender in their 2020 response to the

*Commission on Social Justice and Fairness: Reform of Social Care*, social care in Scotland is gendered in three ways:

- Women are the majority of service users; 75% of social care clients are aged 65 or more, of whom 67% are women. Women are also more likely to be disabled or have long-term health conditions than men.
- Women are the vast majority of social care workers, accounting for 85% of employees across the sector, and up to 96-100% in particular subsectors.<sup>55</sup>
- Women are the majority of unpaid carers. Women are particularly overrepresented amongst carers on low incomes who are also in paid work, have multiple or 'sandwich' caring roles, and/or care for over 35 hours per week.<sup>56</sup>

Despite the competencies, expertise and dedication required of its workforce, social care is often referred to as an undervalued and underpaid job, with low pay and poor terms and conditions. As Lindsey Millen, Policy and Development Manager at Close the Gap summarised for the ALLIANCE in *Future of Social Care: an anthology* (2021):

“This undervaluation is sustained by gender stereotypes and assumptions about women’s and men’s capabilities and interests. There’s a widespread assumption that caring and other unpaid work done in the home is better suited to women because historically it has been their role. This drives the undervaluation of this work when it’s done in the labour market, with jobs such as cleaning, catering, childcare and social care paid at, or close to, the minimum wage as a result. Additionally, the stereotype that women are intrinsically more caring is used to justify the low pay of care work in the labour market, with perceived job satisfaction a substitute for fair pay.<sup>57</sup> This undervaluation of women’s work underpins occupational segregation, the gender pay gap and women’s poverty.”<sup>58</sup>

Without systematic and wide-spread change to value care work, and response to the intersectional inequalities in the current system, it is not likely to prompt substantive change.

The Fair Work Convention reports that fair work is not being consistently delivered in Scotland’s social care sector and that this is often driven by funding and commissioning systems.<sup>59</sup> There are ongoing concerns about the differential pay and conditions for third and independent sector workers compared to those employed by local authorities. Research for the Scottish Government and COSLA notes that “the main reason why people leave the workforce is for better terms and conditions, particularly pay levels and another driver is to do a less demanding job for similar or better rates of pay.”<sup>60</sup> The Fair Work Convention have highlighted that failure to address these issues will have broader consequences, for example low pay will

significantly contribute to inequality in women's working conditions and Scotland's gender pay gap.

During our Independent Review of Adult Social Care engagement activity, ALLIANCE members recognised that people receiving care and workers providing care have rights, and those rights do not have to be in conflict. Ensuring paid carers receive a good wage for every hour worked remains the right thing to do. To achieve the best quality care, we must prioritise paying social care staff better and must avoid rolling back to the institutionalised settings of the past to meet the financial challenges of today. While the mention of fair work in the Bill is welcome, further detail is needed. In particular, if social care work is to be properly valued, there must be plans to acknowledge and encourage career development and specialisation, with associated training and funding. For example, Guide Communicators and BSL interpreters train for several years to reach the levels of competency required to support people who are Deaf or deafblind, yet there is no competency framework to acknowledge that specialism within care work.

At the core of issues related to fair work are the rights of people who access support and services and unpaid carers, as well as the rights of people who provide them. Efforts to improve the value and status of care work are welcome; equally, any work in this area should be designed and developed with co-production at its heart from the outset, with full engagement from and with disabled people, people living with long term conditions, and unpaid carers, and with social care workers. Valuing care, partnership working and co-production – with people with lived experience and social care staff – are key to the success of the National Care Service.

### **National Care Service Charter (Sections 11 and 12)**

Question: Sections 11 and 12 of the Bill make provision for the Scottish Ministers to prepare and publish a National Care Service charter, to be co-designed with those with lived or living experience and reviewed on a five-yearly basis.

According to the Policy Memorandum, the Charter “will set out what people can expect from the NCS and provide a clear pathway to recourse should the rights in the Charter not be met”.

The first and subsequent versions of the charter must be subject to public consultation and a copy must be laid before the Scottish Parliament

In providing comments on these sections of the Bill, please consider:

- Whether you agree with provisions to create a National Care Service charter?
- Whether there is anything important missing from these provisions?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

There is much material in the proposed Charter that is welcome, including the commitment to co-produce it with people with lived experience. It is essential that this process is transparent to the public, and that the contributing group is representative and supported to participate. However, as with the principles in Section 1, there is nothing in the legislation to indicate consequences if the material set out in the Charter is not fulfilled. If we are to see meaningful implementation of the Principles and Charter, and of human rights based approaches to the National Care Service more broadly, the accountability processes must be clear, with effective redress available if systems fail.

Data collection and publication, as previously discussed in this response, is one pillar of work to ensure progress and action. An independent body, who would be responsible for scrutiny and the identification of areas where people's rights are not being realised is another key action to ensure public accountability. The National Care Service should draw on learning from the Scottish Mental Health Law Review and the Social Security Act in developing these sections of the Bill and associated proposals.

## Independent advocacy (Section 13)

Question: Section 13 of the Bill gives Scottish Ministers powers to make provision via secondary legislation for independent advocacy services in connection with services provided by the National Care Service.

The Policy Memorandum highlights the emphasis placed by the Independent Review of Adult Social Care on the importance of access to independent advocacy and brokerage services, including peer services, “in empowering people accessing support and unpaid carers” and ensuring “that their voices are heard”.

It goes on to state the Scottish Government’s intention to “develop and implement a coherent, consolidated and consistent approach to independent advocacy services across the range of NCS services” and to do this through co-design with people with lived or living experience of accessing services.

In providing comments on this section of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this section of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this section of the Bill?
- Whether an alternative approach would be preferable?

As mentioned earlier in this response, the ALLIANCE welcomes the mention of independent advocacy in Section 13. However, we suggest this this section should be further strengthened at this stage of proceedings to provide more detail. It is essential that a definition of independent advocacy is provided within primary legislation, to enable consistent implementation of these important services (and particularly to ensure that services are fully independent). We recommend that the legislation should use the definition of independent advocacy as offered by the Scottish Independent Advocacy Alliance (SIAA). 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.<sup>61</sup>

There should also be a legislative duty 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.

Respondents to *My Support My Choice* highlighted the usefulness and importance of independent advocacy services, and of independent advice and support. One interviewee said that a local independent advice and support organisation was the key to “unlocking Self-directed Support [...] and I can’t thank them enough for that.” People recommended getting in touch with independent advocacy and independent support and advice organisations as early as possible.<sup>62</sup>

We analysed *My Support My Choice* responses using the Scottish Index of Multiple Deprivation (SIMD), where areas 1 and 2 represent the most deprived 40% of areas in the country, and areas 4 and 5 are the least deprived areas. Deprivation in areas can relate to people having a low income but it can also mean fewer available resources or opportunities. SIMD looks at the extent to which an area is deprived across seven domains: income, employment, education, health, access to services, crime and housing.<sup>63</sup>

It is evident that people living in the most deprived areas of Scotland were more likely to find that access to independent advocacy made SDS easier for them than people in more affluent areas. 58% of people living in SIMD quintiles 1 and 2 (the most deprived 40% of areas) strongly agreed or agreed that access to independent advocacy made SDS easier for them, in comparison to 45% of people in SIMD quintiles 4 and 5 (the least deprived 40% of areas). However, it is worth noting that this variance was not due to a substantially larger number of people in quintiles 4 and 5 reporting that independent advocacy was not useful, but because more people in affluent areas were unsure whether or not independent advocacy would be helpful (44% selecting “don’t know” from quintiles 4 and 5, compared to 36% of people from quintiles 1 and 2).<sup>64</sup>

While most people find access to independent advocacy makes SDS easier for them, we found that older people are less likely to know about these services and find them useful. 55% of people who were 40 or younger agreed or strongly agreed that access to independent advocacy made SDS easier for them, and 54% of people aged 41-64 reported the same. In contrast, only 46% of people who were 65 or older agreed or strongly agreed with that statement, and while only 9% disagreed or strongly disagreed, 45% of that age group stated that they “didn’t know” and were generally less likely to have accessed those services.<sup>65</sup> As such, any complaints system should ensure that targeted work takes place to guarantee that specific population groups with lower engagement with independent advocacy (e.g. older people) are informed of the role of independent advocacy and how to access these services in the event of a complaint.

When good relationships were established, collaboration led to effective support planning and implementation of SDS options. One interviewee described the positive outcome of a meeting between their social worker, the interviewee, and an independent advocate, despite initial apprehension from the social worker:

“But I still felt that they were ticking boxes along the line of, “well for my job I’ve got to cover this, this, this and this.” Which [...] that’s what she’s employed to do as such, but it does come over as a different kind of experience. But we did have a meeting here with social work and [...] advocacy when we were getting more into the detail of things. So, [the social worker] was open and she did come to that and [...] it was a good meeting. I think she was apprehensive when she arrived but at the end she actually did say, ‘this has turned out to be a really good meeting’, because it gave her a better idea of what we wanted.”<sup>66</sup>

This positive account of the involvement of independent advocates in the development of support plans is an excellent example of all parties benefiting from their involvement, with productive outcomes for the person in need of support and social work professionals alike.

One respondent to *My Support My Choice* stated that advocacy and peer support is “critical” for Black and minority ethnic people accessing social care. They stated that:

“I’ve just helped somebody who’d had their funding removed because of the social worker’s report [...] you need somebody there. [...] The matter ended up at the tribunal, and the tribunal decision was [...] to negate the social worker’s report, because the social worker’s report meant that the funding was stopped. And therefore, it is critical that you have some sort of advocacy in order to ensure that the social worker’s decision[s] are valid.”<sup>67</sup>

Survey respondents and focus group participants noted that confidentiality and time to build up trust was important to the success of independent advocacy. Several people highlighted that they had benefited from the involvement of independent advocacy services during their assessments and reviews. Various forms of advocacy were mentioned, including local user-led service organisations, independent advocacy, solicitors, national legal aid organisations and carers’ centres.

Social work professionals should also have a duty to pro-actively and regularly inform people who use social care, their families and unpaid carers about how they can challenge decisions, and access independent advocacy and support, complaints procedures and the independent oversight of the Scottish Public Services Ombudsman (SPSO) (and other independent oversight mechanisms). People should always have access to independent advocacy and support, including translators, for complaints and associated meetings, if they desire.

People clearly value and benefit from independent advocacy and support, and these services play an important role in SDS and social care. As well as ensuring that these services continue to be sufficiently resourced to carry out their vital work, we

recommend that local authority and health and social care partnership staff be given more training and information about local independent support and advocacy organisations, so they can more routinely refer people to these resources as part of assessment processes and recognise the value these independent services can bring to their own work. Focused efforts are required to ensure older people, Black and minority ethnic people, and people from all socioeconomic backgrounds are aware of – and can access – independent advocacy and support services. Local peer support networks should also be encouraged and supported. The National Care Service should ensure that responsibility for training on these fronts is clearly outlined.

Overall, respondents to *My Support My Choice* spoke about the positive impact of both independent advocacy and independent advice and support organisations – and gave useful examples of best practice, with social work and the third sector working collaboratively, and achieving outcomes that met the rights and requirements of people accessing support. Plans to revise the co-ordination of care and support should ensure clear communication pathways for people accessing support. They should also respect, involve and sustainably fund the vital role of both independent advocacy and independent advice and support organisations.

Increased and sustainable funding for, and access to, independent advocacy – and investment in other forms of supported decision-making – would also help protect people’s right to active participation in decisions that affect them.

### Complaints (Sections 14 and 15)

Question: Sections 14 and 15 of the Bill make provision for a **complaints service** and for the handling of complaints.

The Policy Memorandum sets out the Scottish Government’s intention to “co-design to develop and strengthen the complaints system with those with lived experience”. The Scottish Government’s own consultation sought views on potential measures to underpin these complaints and redress processes, including the possible development of a model for the role of National Care Service Commissioner.

In providing comments on these sections of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

The ALLIANCE welcomes efforts to improve the complaints system within social care. A properly functioning, accessible and robust complaints system is one important practical application of the human rights based approach principle of accountability.

Through research in *My Support My Choice*, many people require greater transparency about how care decisions are made and by whom, alongside inclusive communication and easy access to information. They also highlighted the need for disabled people, people living with long term conditions, and unpaid carers to be involved in decision making at all levels. People reported difficulty obtaining paperwork and documentation concerning their care arrangements, even after repeated requests to social work departments, and in obtaining information about how to lodge formal complaints. People's access to information and documentation about their care arrangements and decisions is important in enabling them to complain and challenge decisions, and must be prioritised as part of any new system.

Any complaints system should also be accessible to the families and friends of people who accessed or wished to access services and have since died. Complaints should not be disregarded, or investigation cease because a complainant has died. This is particularly important for people accessing social care as part of end of life or palliative care; a complaints system must be accessible to everyone, including people at end of life and their families and friends.

We suggest that further detail is needed on the clause pertaining to who handles complaints. It is important that any system ensures that the person handling a complaint is independent from the persons and duty bearers involved – and that independence should be clearly outlined in legislation. Furthermore, it is also vital that any complaints system has the facility for people working within social care and social work to raise concerns about practice, to an independent party.

This section of legislation should also include a commitment to embedding feedback loops within the complaints system. A system which states publicly what actions have been taken in response to complaints, and details how systems have been improved and progress has and will be evaluated (while still following appropriate ethics principles in anonymising people who raise complaints), would ensure greater transparency and accountability. Such an approach would be in line with PANEL principles.<sup>68</sup> The National Care Service should also draw on learning from what does and does not work within existing complaint structures, in health and social care, mental health, and social security. It should aim to build a complaints system that enables reflective learning for social care and social work staff, where complaints can be seen as an opportunity for growth and improvement – as well as providing redress to people who have had poor experiences of services.

The ALLIANCE supports calls from the Scottish Human Rights Commission, the Equalities and Human Rights Commission, and the Independent Review of Adult Social Care for a robust complaints system to enable individuals to challenge decisions about their care and support. The need for such a system is illustrated by the suspension of complaints procedures during COVID-19 in some local authorities. Although the local authorities in question updated their online guidance following investigation from the Scottish Human Rights Commission and the Scottish Public Service Ombudsman, the lack of knowledge about the duties of public bodies strengthens the argument in favour of a robust, national complaints system – and for wider training in human right based approaches (where accountability and transparency are key elements).

By embedding choice, co-production, and a human rights based approach into systems from the outset, people should have better experiences and outcomes. Such approaches would also ensure that robust accountability processes are in place, and clearly communicated to people accessing services, offering prompt redress for people if things go wrong.

#### **Ministers' powers to intervene (Chapter 4)**

Question: Sections 16 to 22 of the Bill establish powers for Ministers to intervene with respect to care boards and contractors, for instance in case of an emergency or of service failure.

In providing comments on this chapter of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this chapter of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

The ALLIANCE cautiously welcomes the proposals for Ministers to intervene in the case of emergency or of service failure. Such provisions should be centred around ensuring that people who access services continue to have their requirements met, even during a period of transition or crisis, and that their will and preference are respected. We suggest that it is important for legislation to indicate a clear definition of “emergency” to ensure that the process for intervention is fully transparent and Minister can be held publicly accountable for the implementation of this Section.

We also suggest that Section 18 (Transfer of care board’s functions in an emergency) requires further detail to ensure that human rights based approaches are followed in the event of an emergency. While contingency planning should be

included in legislation, we suggest it is important that this section outline that Ministers should have a duty to refer to the principles set out in Section 1:1 even in the event of emergency transfer of functions – particularly regarding the expertise of lived experience representatives from care boards.

We know from evidence provided to the COVID-19 Inquiry that a number of practical problems were caused by early decisions being made without input from disabled people, people living with long term conditions, and unpaid carers. It is 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.

### **Connected functions (research, training, other activities and compulsory purchase (Chapter 5))**

Question: Chapter 5 of the Bill establishes certain functions connected to the provision of care, including enabling Scottish Ministers and care boards to:

- conduct, assist in conducting or give financial assistance in relation to research;
- to provide training or to provide financial support to undertake training;
- to provide financial assistance to undertake other activities connected to the services provided to individuals by the National Care Service;
- and to compulsorily purchase land required to exercise a relevant function.

In providing comments on this chapter of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this chapter of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

As outlined earlier in this response, there is no concrete commitment within the Bill to collecting a national dataset on people's experiences accessing social care (with intersectional analysis). Disaggregated data gathering and intersectional analysis is essential to develop fully realised policies and practices that prioritise equal access to SDS and social care for everyone, following human rights principles of equality, non-discrimination, participation and accountability. It should also be made clear who is responsible for national analysis and the publication of said data, and the frequency of reporting.

Similarly, the section on “Training” empowers Ministers and care boards to provide people with relevant training, yet no further detail is provided on what should be “core” training which should be available to people across Scotland (and resourced accordingly). We suggest that this section should be expanded to include a commitment to the sustained provision of training for all duty bearers and people who access services. Without investment to build capacity amongst the workforce, effectively implementation of human rights based approaches is unlikely to be realised in practice.

In addition to human rights training, we also suggest that there should be a concerted roll out of training to reduce stigma. Through the ALLIANCE’s “Reducing Stigma, Emphasising Humanity” series, organisations and people with lived experience have told us that stigma can act as a key barrier to people accessing the mental health treatment and support they need, and can be perpetuated by staff, wider society and self-stigma.<sup>69</sup>

Research has shown that people report positive experiences of mental health care and support when professionals take time to listen, respond in a flexible and person centred way, and can demonstrate skills, expertise and legal knowledge to challenge stigma and discrimination.<sup>70</sup> This was echoed in the findings of the Independent Inquiry into Mental Health Services in Tayside, which reported that trust and respectful relationships are essential for the delivery of good mental health services.<sup>71</sup> During the ALLIANCE’s ‘Reducing Stigma, Emphasising Humanity’ event series, participants also referred to experiences of internalised stigma and suggested that this was often reinforced by a lack of appropriate resources or support mechanisms, and a lack of understanding from healthcare professionals.

In our response to the Scottish Mental Health Law Review, the ALLIANCE strongly welcomed the Review’s proposal to recommend a positive duty on the Scottish Government to address stigma and discrimination against people with mental health conditions. We also made the following recommendations, which should be included in planning for the National Care Service:

- **Adopt the measures outlined in Article 8 of the UNCRPD to increase awareness of the rights and dignity of people with lived experience,**<sup>72</sup> including through publicity campaigns, education and training programmes. Awareness raising campaigns should be co-produced with people with lived experience at local and national levels. The World Health Organisation’s QualityRights Tool Kit also provides training and practical tools to help countries review and improve services, with direct reference to the UNCRPD, and could be used to ensure rights based law is reflected in rights based practice.<sup>73</sup>

- **Develop training, education, understanding and awareness of mental health conditions and the different types of associated stigma and discrimination**, including self-stigma, stigma by association, structural stigma and prejudice.<sup>74</sup> This should include information for family members, the general public, as well as people working with and delivering care and support to people with mental health conditions.
- **Invest in good quality, accessible and inclusive resources to support individuals who experience stigma**, including self-stigma and stigma by association.
- **Adopt learning from the Scottish Mental Illness Stigma Survey**, coordinated by the Mental Health Foundation, See Me and Glasgow Caledonian University, and exploring people's experiences of mental health stigma and discrimination to create real change in Scotland.<sup>75</sup>
- **Place greater emphasis on supporting the workforce to be trauma informed.** Awareness of trauma and the barriers that those affected by trauma can experience when accessing care, support and treatment can help to reduce stigma and encourage the workforce to engage with people in a person centred way and in accordance with individual needs and circumstances. Developing trauma enhanced practice will require time and investment. Existing tools, such as the National Trauma Training Programme,<sup>76</sup> should be implemented as mandatory training for workforces engaging with people with mental health conditions. This will enable staff to plan and deliver services safely and effectively to people affected by trauma.

The above actions may also require the creation of a new body to oversee training and evaluation, or the empowerment of an existing body to take responsibility for that remit. In either case, appropriate resourcing should be provided to ensure effective implementation.

The ALLIANCE also supports calls from Food Train, the Scottish Food Coalition, Nourish Scotland, and Common Weal (among others) that health and social care staff should be trained in identifying people experiencing or at risk of malnutrition, and providing assistance to improve their access to high quality food. We suggest that the National Care Service should embed training on malnutrition and preventative action therein as a compulsory element of any training programmes and CPD schemes for health and social care workers, along with associated action when people are identified as experiencing or at risk of malnutrition. Existing material includes Food Train's "Raising the Issue of Malnutrition Toolkit" and the "REHIS Eating Well for Older People" training course.<sup>77</sup> We recommend that the National Care Service draws upon existing expertise in this area from within the third sector –

particularly given the sharp increase in food poverty and use of food banks during COVID-19 and the sharp rise in the cost of living in 2022.

The ALLIANCE also heard from members who have experienced sensory loss that there is a pressing need for health and social care staff, and wider networks of decision-makers in public bodies (e.g. local authorities and health and social care partnerships) to have better training and awareness of the access needs of people with sensory loss. These access requirements have, for many people with sensory loss, been compounded by the COVID-19 pandemic.

More widely, the ALLIANCE proposes that human rights training to be mandatory for all staff engaged in health and social care work – from management level down to public-facing roles. Without properly developed training, delivered by properly resourced and sustainably funded organisations, the National Care Service will not be able to meaningfully follow through on its stated commitment to prioritising human rights. We support calls from the Scottish Human Rights Commission and the Equalities and Human Rights Commission to ensure human rights training for staff within the sector – with specific, useful examples related to their individual roles.

In their response to the 2021 National Care Service for Scotland consultation, the Equalities and Human Rights Commission discusses the treatment of equalities impact assessments as a key example:

“The current approach to equality impact assessments is a good illustration of this lack of understanding and awareness in practice. Often equality impact assessments (EIA) are, at best, used to check if a policy may result in unlawful discrimination. At their worst, they are a form-filling, ‘tick-box’ exercise carried out at the end of policy development or decision-making processes. The information in them is often limited and of poor quality and so decision-makers are unable to use them to make informed decisions. In practice, they rarely produce high quality decision-making or effective governance.”<sup>78</sup>

Yet, when used properly, equality impact assessments are useful tools to address health inequalities and ensure policies are tailored to the rights and requirements of individual population groups. Widespread and well-designed training in human rights based approaches can make a key difference to the effective use and implementation of such tools, and to people’s experiences of social care and support.

Further, while a coherent national approach may assist with problems around commissioning of services, the provision of consistent good quality care across the country, and varying application of the national eligibility criteria, it needs to do so without compromising locally effective services and individual expertise (including

lived experience). Equality and human rights need to be integrated across all parts of the social care system, including legislation; fiscal, inspection, regulation and commissioning frameworks; employment and workforce development; service design and delivery; monitoring and evaluation. This should include a focus on a caring economy.<sup>79</sup>

### **Inclusion of children's services and justice services (Section 30)**

Question: Chapter 6 also makes provision for the inclusion of **children's services and justice services** within the scope of the National Care Service at some point in the future, subject to a public consultation on the proposed inclusion of these services. It is proposed that any such inclusion of these services within the scope of the National Care Service would be achieved via secondary legislation.

In providing comments on this section of the Bill, please consider:

- Whether you agree with proposals to include children's services and justice services within the scope of the National Care Service, either now or in the future?
- Whether there is anything important missing from this section of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this section of the Bill?
- Whether an alternative approach would be preferable?

The ALLIANCE understands that Scottish Government is undertaking a programme of research and consultation to inform the decisions outlined in Section 30 (Consultation before bringing children's and justice services into the NCS). It is essential that the Scottish Government ensures that these plans are clearly communicated to the public, with transparency and accountability, and that all plans are properly co-produced with people who access services and their families.

The ALLIANCE's Independent Review of Adult Social Care engagement activity indicated that merging children's and adult social services could offer an opportunity to deal with some of the existing issues in transitions. This is also in line with recommendations put forward by *The Promise*, which highlights the need for integration and improved interaction between services and sectors, as children transition into adult services – with calls for professionals to be supported to maintain relationships with children and young people throughout transition periods and beyond.<sup>80</sup>

Nonetheless, a strong evidence base is still needed to understand what the additional benefits of merging these two service domains would be, the potential risks, and how this would work in a Scottish context. Clarity is particularly needed on

how services delivered via the National Care Service would interact with other policy domains and funding models that have an impact on children's lives, in particular health services, social security and education – the former of which is the responsibility of the NHS, and the latter of which is currently delegated to local authorities.<sup>81</sup> In this case, the role of local authorities and current providers of services in decision-making about children's services and justice social work within the proposed National Care Service needs to be made clear.

Such an approach would help to ensure that the commitment in *The Promise* to person centred change is upheld:

“Scotland must implement the rights of the child in a way that does not reinforce a focus on policy, process and procedure but supports the ability of children and those around them to connect and develop relationships and cultures that uphold their rights as a matter of course.”<sup>82</sup>

Furthermore, clarity is needed on the interactions between the National Care Service, NHS and education policy, particularly the latter which is currently under the remit of local authorities. We know that the introduction of a unified, common language to communicate across children's social services, such as Getting It Right For Every Child (GIRFEC), can reduce complexity if implemented adequately across sectors. However, a proper scoping of the gaps that currently exist in this approach is also needed to understand how the introduction of a Getting It Right For Everyone (GIRFE) approach with the National Care Service would work effectively in practice. The ALLIANCE's Getting to Know GIRFEC programme has highlighted a range of gaps in the implementation of GIRFEC, and a lack of awareness among many families of the core principle of the approach; this would be useful material to draw on while designing and implementing the proposed Getting It Right For Everyone system.

Crucially, if the National Care Service does merge children's and adult services, measures should be put in place so that existing good practice in children's social services is not lost or diluted in the process. Particular care should be taken not to lose existing expertise and good practice among highly specialised work in children's palliative care. To this end, special attention should be paid to how budgeting decisions will be managed by the National Care Service, and to ensure that children and young people's voices are fully represented in any co-production work embedded in the design and development of the National Care Service. These calculations should be transparent and readily available and accessible to the public, including children and young people.

Equitable access to social care needs to be ensured for all those accessing services. Whilst the proposed pyramid of services outlined by the National Care Service includes access to targeted services, it is crucial that everyone who requires targeted

and/or specialised services from the point of access can do so. This, again, can only be ensured by having a properly trained and specialised workforce that can recognise the requirements of disabled children and young people, including prevention and early intervention. This workforce includes the use of independent advocates specialising in supporting children and young people – as outlined in *The Promise*:

“Advocates must be skilled and knowledgeable about the rights and entitlements of children. There must be specialist advocates available to support disabled [children].”<sup>83</sup>

The ALLIANCE suggests that it is imperative that the following actions are carried out if children’s services are to be included in the National Care Service:

- A Children’s Rights and Wellbeing Impact Assessment of the National Care Service consultation should be completed.
- Children’s and young people’s voices should be heard, and inform how services should be delivered throughout the design, implementation and improvement of the National Care Service.
- All communication should be accessible to ensure that children and young people accessing services and their families can be involved meaningfully in planning and making decisions about their care arrangements, including those with sensory loss and multiple and complex needs.
- An equitable and person-centred approach to service delivery should be adopted throughout.
- Budgets and social care support must be flexible enough to ensure children and families get the support they need in a timely way.

The above considerations would also respond to one of the main findings from an ALLIANCE-funded project into disabled children, young people and unpaid carers’ experiences of accessing health and social care services during the COVID-19 pandemic. That research project found that young people are often not aware of the social care and social security entitlements they are accessing or can access:

“The theme of social care, state entitlements and supports emerged as a distant and unfamiliar one for the children and young people interviewed. When asked about what social care services, benefits and supports they received from the Government (such as payments, access to day centres, clubs, transport assistance), the majority said they did not know this information.”<sup>84</sup>

The Bill and associated work should be explicit in acknowledging how information sharing, transitions, and the management of children and young people’s and justice

social work will be carried out during any transition period. It should also indicate how information sharing, resources, and staff management will be arranged in the event that children's services and justice social work are included within the National Care Service, or remain outwith that structure, without reducing the quality of support available to people.

Significant efforts will also be required to ensure that people's access to care and support is not adversely affected by the proposed implementation of major changes to adult social care, and a delayed or separate delivery of children and young people's and justice social work. In particular, the ALLIANCE and our members are concerned about transitions, which are already a known challenge for people accessing and delivering services, and the potential loss of good practice if staff are redeployed to adult social care during the implementation of the National Care Service.

Irrespective of whether or not children and young people's services are included within the National Care Service, it would be useful for primary legislation to provide a clear definition of a "child" or "young person". We also support calls from our members that the National Care Service should be compatible with and supportive of *The Promise* – in particular, that care experienced young people should be supported until they are 25 years old, and the importance of ensuring that systems are designed to enable flexible and well-supported transitions from children to adult's services.

Finally, while a decision on the inclusion of children and young people's services within the National Care Service has yet to be made, the ALLIANCE suggests that children and young people and their families should be included within each area of co-design, including (but not restricted to) the development of care records. A system designed with universal access in mind from the outset is likely to be suitable for people of all ages; a system designed for adults, that is retrospectively adapted for children, is likely to be less successful, and unfairly disadvantage children and young people and their families. Examples of good practice in this area include PAMIS's digital passports.<sup>85</sup>

## Health and social care information (Part 2)

Question: Part 2 of the Bill gives the Scottish Ministers powers to establish a **scheme for care records to be shared** between the proposed National Care Service and the National Health Service. It also makes provision for Scottish Ministers to produce an information standard which will set out how certain information is to be processed.

In providing comments on this part of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this part of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this part of the Bill?
- Whether an alternative approach would be preferable?

The third and independent sectors should be explicitly considered as key partners throughout the legislation, and named in both the explanatory policy memoranda and regulation regarding Section 36 of the Bill (Care records). Examples of this include naming the third and independent sectors as “community planning partners” (Section 8) and stating explicitly that they should be included in the list of groups who can have access to people’s care records (with permission and as appropriate).

One of the weaknesses of the current system is that health and social care records are not shared across connected 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 single planning process with integrated 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. If people accessing social care are to be able to access and manage their care records then funding should also be dedicated to ensuring equitable access and appropriate training where required. Similarly, full training should also be provided for all staff who are required to access care records.

In *My Support My Choice*, several participants highlighted problems with transparency, and specifically record keeping – including interviewees who experienced a breach of General Data Protection Regulations (GDPR) during their interactions with social work.<sup>86</sup> Safeguards should be put in place in any integrated record keeping system to ensure that they are only used to aid in the provision of care and support – not to check whether people are being truthful about the health of family members, or persons unconnected to the matter under discussion. People should have control of and access to their data in any new system. It is also important that systems for record keeping and data sharing should include varied levels of access to people’s health and social care data – and that the criteria for what data is available to whom is co-produced with disabled people, people living with long term conditions, unpaid carers, and health and social care professionals.

The ALLIANCE recommends that the National Care Service should draw upon the learning and proposals in the Mental Health Law Review – in particular, that legislators and duty bearers should ensure that care records and assessments are undertaken and recorded in line with people’s human rights.<sup>87</sup>

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 the following key principles:

- **People at the centre.** People should have access to inclusive and flexible digital services that meet their needs, rights, preferences and choices, with support if appropriate. Digital services should be focused on the best outcomes for the person, not the needs of the service or the health and social care system.
- **Digital where it is best suited.** People should be involved in deciding how, where and when digital is used in health and social care, and co-create rights based digital services to ensure they are appropriate and effective. Digital services are not always appropriate and should not automatically be the default health and social care service.
- **Digital as a choice.** People should be able to make an informed choice between using digital or non-digital health and social care services – and to switch between them at any time – without compromising the quality of care they experience. People should be fully involved in decisions made about their care. This should include information about any digital options being considered, and the non-digital alternatives.
- **Digital inclusion, not just widening access.** People should have access to free training and support to develop the skills, confidence and digital literacy they require to make a meaningful choice whether to access digital health and social care services. Digital services should be accessible, trustworthy and inclusive.
- **Access and control of digital data.** People should have access to data held about them by health and social care services and have control over this data and how it is used. People should give free, prior and informed consent to the use and sharing of their data, particularly outside health and social care. If consent is given, sharing should allow people to avoid ‘re-telling their story’, be straightforward for all involved, and maintain the highest possible security before, during and after sharing.<sup>88</sup>

In addition to this work, the ALLIANCE also heard from 125 people representing a range of stakeholders and members of the public in our *My World, My Health* project (in partnership with Digital Health and Care Innovation Centre), exploring how people

living in Scotland felt about data use in public health services. One of the key conclusions was as follows:

“An overwhelming majority of our participants stated that the individual whose data is collected, processed, and shared should be in control of how this is done. It was also argued that there needs to be rigour in the use of data, in line with the individual’s consent. Furthermore, the purpose of the data processing should be for the benefit of the individual or wider society. There should be no adverse effects to individuals whether they opted-in or -out of sharing data.”<sup>89</sup>

*My World, My Health* drew nine core principles from the engagement work across the project, which we suggest should usefully inform the development of digital systems in the National Care Service:

- **GDPR.** Data should only be collected, processed and shared in line with the GDPR key principles of: Lawfulness, fairness and transparency; Purpose limitation; Data minimization; Accuracy; Storage limitation; Integrity and confidentiality; Accountability. GDPR adherence should constitute the bare minimum standard for the development of any future data systems.
- **Consent.** Individuals should be empowered to make informed decisions about any uses of their personal data. Consent should be given freely, without any pressure, repercussions, or fear of discrimination. When developing consent processes, we must ensure that we are taking into consideration cultural and contextual factors and that people are at the centre.
- **Purpose.** In addition to the GDPR principle of purpose limitation, the purpose for any type of data processing must be clear, transparent and for the benefit of either the data subject or wider society. Personal data should not be collected, used and shared for commercial gains unless informed consent for this specific purpose has been granted.
- **Lived experience.** Data processing should not replace opportunities for people to share their own stories and experiences with those involved in their care. Data might be used to complement and provide evidence in support of one's narrative but should not replace it fully.
- **Choice.** Care must be taken to ensure that if individuals do not want to opt-in to data-enabled processes there are no negative consequences to them because of this. Quality of care and service provision should be agnostic of people’s data related attitudes, skills, or confidence.
- **Ownership.** Data subjects should have the right to own and control their own data unless they take an informed decision to pass this responsibility to someone else. Owning their information, individuals can amend it, grant and remove access permissions as necessary. This can help build one-source of truth whilst also empowering individuals to control their own information.

- **Trustworthiness.** Consideration needs to be given to whether data is accurate. Do people have the devices, skills or connection required to gather it? If the data effects any benefits or sanctions, will the quality of self-reporting be influenced? We must also ensure that any data which will affect decisions is validated and interpreted without biases or prejudices.
- **Education.** Data education is needed for members of the public, professionals and support workers to ensure that
  - those whose data is collected, processed, and shared fully understand what they are consenting to and are empowered to make decisions with regards to their own information.
  - those using data understand its potential uses and can maximise on the opportunities provided, while ensuring the safety and privacy of those they are supporting.
- **Safeguarding.** Data must not be used to stigmatise or discriminate against individuals unfairly. We must ensure that decision making processes, whether automated or made by individuals, do not have inherent biases that could be detrimental to individuals' wellbeing. Steps must also be taken to ensure data is not misinterpreted or used for malicious purposes.<sup>90</sup>

The above principles should be carefully applied to both children and young people and to adults, when designing care records and information sharing systems. Secondary legislation should be clear in outlining how transitions from children and young people to adult social care work with regards to citizen access to and control of care records, as well as offering clarity in respecting will and preference in instances where the person accessing care has a Guardian.

For example, a care record system that fully follows a human rights based approach would allow a change of information controller from a child's parent/carer to an adolescent at appropriate age and stage (with access and graduated control throughout the transition process). Respecting the rights of children to access, understand, and (eventually) control their care records and information sharing therein would be compliant with the human rights based principles of the United Nations Convention on the Rights of the Child (UNCRC), in particular Article 12 (respect for children's views): "Every child has the right to express their views on matters that affect them, and for these views to be taken into consideration."<sup>91</sup>

Finally, the ALLIANCE is a member of the Professional Records Standards Body (PRSB) advisory board. The PRSB has developed a suite of standards that are potentially usable across Scotland (and the UK).<sup>92</sup> We support the development of data standards orientated to a Scottish context. Data standards can and should promote clear and communication across systems, and assist in data collection.

## Right to breaks for carers (Sections 38 and 39)

Question: Sections 36 and 37 of the Bill propose amendments to the Carers (Scotland) Act 2016 and consequent changes to the Social Care (Self-directed Support) (Scotland) Act 2013, principally with a view to establishing a **right to breaks for carers**.

In providing comments on these sections of the Bill, please consider:

- Whether you agree with the proposed amendments to the Carers (Scotland) Act 2016?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

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.

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).

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

suit 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.<sup>93</sup>

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 to take people, leaving psychiatric or dementia units in hospitals as the only option available. The system as is 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.

### **Implementation of Anne's Law (Section 40)**

Question: Section 40 of the Bill proposes amendments to the Public Services Reform (Scotland) Act 2010 with a view to supporting implementation of "Anne's Law" related to visits to or by care home residents.

In providing comments on this section of the Bill, please consider:

- Whether you agree with the proposed amendments to the Public Services Reform (Scotland) Act 2010?
- Whether there is anything important missing from this section of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this section of the Bill?
- Whether an alternative approach would be preferable?

The ALLIANCE supports Anne's Law and a human rights based approach to care, including learning from the pandemic about people's experiences of restrictions to care home visits. We strongly recommend that learning from the COVID-19 pandemic should be carried throughout all National Care Service work, with particular attention to examples where people's human rights were breached, to ensure such is not repeated in the future. We also suggest that this section of the Bill should make explicit reference to Article 26 of the UNCRPD (habilitation and rehabilitation).

### **Reserved right to participate in certain contracts (Section 41)**

Question: Section 41 of the Bill proposes amendments to the Public Contracts (Scotland) Regulations 2015 to allow the right to bid for **contracts for certain services to be reserved to certain types of organisation**.

In providing comments on this section of the Bill, please consider:

- Whether you agree with the proposed amendments to the Public Contracts (Scotland) Regulations 2015?
- Whether there is anything important missing from this section of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this section of the Bill?
- Whether an alternative approach would be preferable?

It is essential that this section of the Bill ensures that the third and independent sectors can bid for contracts, and that the commissioning and procurement processes embed fair work principles and the sustainable delivery of high quality services, focused on people's outcomes. We also suggest that this section should include a duty to evaluate workforce provision, with a view to effective recruitment and retention of staff and service providers across Scotland.

## About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay 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 better cross-sector understanding and partnership.

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**End of document.**