



**The Health and  
Social Care  
Alliance  
Scotland  
(the ALLIANCE)**



**Response to National Care Service  
(Scotland) Bill (Stage 2) Call for  
Views**

**13 September 2024**

## Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to comment on the Scottish Government's draft Stage 2 amendments to the Bill.

### 1. What is your view of the proposed National Care Service strategy (see proposed new sections 1A to 1E)?

Strongly support

Tend to support

**Partly support and partly oppose**

Tend to oppose

Strongly oppose

Undecided / no opinion

Although not specifically referred to in the question, we have also included views on the amendments to the National Care Service (NCS) principles in this answer, as they are contained in the proposed new sections referred to.

On a more general note, the ALLIANCE believes that consideration must be given to how all relevant bodies who will be subject to the principles, including social care providers, will be adequately funded to deliver them in practice.

### **National Care Service principles (section 1, new sections 1A and 1B)**

#### **Financial stability (amended 1 (1) (b))**

The ALLIANCE recommends that the principle that “the services provided by the National Care Service must be financially stable in order to give people long-term security” section 1 (1) (b)) should be expanded to require investment to be made sufficiently available as to deliver on the principles.

#### **Rehabilitation (amended 1 (1) (c) (i))**



The ALLIANCE welcomes that one of the Scottish Government’s proposed amendments would add rehabilitation to the Principles (amended 1 (1) (c) (i)), however, we recommend that the Bill could further benefit from a definition of community rehabilitation (including prehabilitation) being added, based on the Community Rehabilitation Best Practice Standards.<sup>1</sup> Similarly, a definition of Community Health in the Bill may be beneficial.

### **End of life (amended 1 (1) (c) (iii))**

ALLIANCE members raised concern with the principles set out in the Bill as introduced, as their wording would appear to exclude any recognition of the ongoing needs people have when their health is in irreversible decline, or they are approaching the end of life. Although the Scottish Government has attempted to address this through the proposed inclusion of “ongoing, increasing or increasingly complex” in amended 1 (1) (c) (iii), this does not adequately address the issues raised, which were specifically about ensuring it is clear that the NCS will care for people until the end of life.

The Scottish Partnership for Palliative Care has proposed wording which would better ensure this is recognised in the principles, without being drawn into a list of specific services, which the ALLIANCE would recommend as an alternative:

“Services provided by the National Care Service will include care and support for people whose health is in irreversible decline through illness or old age and for whom the end of life is approaching.”

### **Additional principles (amended 1 (1) (d) (ii), (e) (iii) and (ea))**

Proposed Scottish Government amendments would add three additional principles to require services provided by the National Care Service to be designed so that they are experienced by those people and carers as integrated (new section 1 (d) (ii)); that opportunities are taken to otherwise give better and further effect to these principles (new section 1 (e) (iii)), and



services provided by the National Care Service are to protect and improve the safety of the persons to whom the services are provided (new section 1 (e) (ea)).

The ALLIANCE support these additional principles, and particularly welcomes the commitment to services being experienced as integrated by people and unpaid carers.

### **Trauma informed practice (amended 1 (1) (e) (zi))**

The ALLIANCE has called for NCS services to be trauma informed, so we support the expansion of the principle around continuous improvement, as proposed by new section 1 (e) (zi), to ‘take account of whole life experiences, including psychological trauma’.

### **Inclusive communications (amended 1 (1) (f))**

The proposed changes to the inclusive communications principle (amended 1 (1) (f)) are an improvement on the wording in the Bill as introduced, and more in line with the social model of disability. The ALLIANCE recommends that “and met” is added to the wording of the principle after the word “recognised”, to strengthen the practical effect of the principle. This would make the principle appear as follows:

“the National Care Service workforce is to communicate with people in an inclusive way, which means ensuring that the diverse communication needs of individuals (in relation to speech, language or otherwise) are recognised **and met**, in particular so that individuals can receive information and express themselves in ways that best meet their individual needs,”

### **Defining human rights (amended 1 (2))**

The ALLIANCE welcomes the addition of a definition of human rights, including the rights contained in any international convention, treaty or



other international instrument ratified by the UK. We had previously recommended the Bill be amended to require Scottish Ministers to have regard to international human rights instruments in developing the Charter, in particular the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Rights of Persons with Disabilities (CRPD). We would also agree that other instruments, such as the European Convention on Human Rights (ECHR) and the UN Convention on the Rights of the Child (UNCRC) are relevant to social care and the National Care Service.

The proposed definition should future proof the legislation to be able to include any developments in this respect. For example, there are ongoing deliberations at the UN about an international convention on the rights of older people, which if agreed and ratified by the UK would be highly pertinent to NCS services.

### **Application of the NCS principles, standards and outcomes (new schedule 2B)**

Paragraph 2 of new schedule 2B replaces references to the integration planning principles and the integration delivery principles in statute with references to the National Care Service principles and the National Care Service strategy.

The ALLIANCE tentatively supports this change, though we recommend further consideration is given to ensure that nothing important is lost from the removal of the integration planning and delivery principles.

### **Effect of the principles**

The ALLIANCE is concerned that amendments as a consequence of the shared accountability agreement may mean that the practical effect of the principles is weakened. In the Bill as introduced, Scottish Ministers would have responsibility for community health and social care, and everything they do in discharging this duty would have to reflect the principles. For this



reason, in response to our queries, Scottish Government advised that it was not necessary to specify in the Bill that the Charter must reflect human rights, or be available in accessible formats, as the Charter would be covered by the duty to reflect the principles.

However, in the context of the shared responsibility agreement, the proposed amendments make it less clear who the duty bearers are that will be responsible for giving effect to the principles in everything they do, and how widely the principles apply.

From reading the Explanatory Notes, they describe the revised effect of the principles as follows:

“Section 1 defines the National Care Service principles, which are then referred to in:

- section 1D, which requires the Scottish Ministers to have regard to them in devising the National Care Service strategy,
- section 12E and paragraph 9 of schedule 2C which, respectively, require the National Care Service Board to fulfil its general purpose in the way that seems to it most consistent with the principles and then to account, each year in its annual report, for how the ways in which it has fulfilled its functions have been consistent with the principles,
- the National Health Service (Scotland) Act 1978, the Public Services Reform (Scotland) Act 2010 and the Public Bodies (Joint Working) (Scotland) Act 2014 (all as modified by schedule 2B of the Bill), in each of which the National Care Service principles replace a reference to the integration planning principles or the integration delivery principles (the effect of these changes are further explained in paragraphs 94 to 98 of these Notes).”



It is important that the principles are considered in all aspects of planning, commissioning, procuring, delivering, and monitoring services and support within the scope of the NCS, both nationally and locally. Therefore, clarity is needed as to what impact these changes will have on the practical effect of the principles, and which actors have a duty to give them practical effect to drive the system change that is needed. If the effect is to weaken the practical effect of the principles, then further amendments to the Bill to place duties on Scottish Ministers, local authorities or the NCS boards would be necessary.

### **National Care Service strategy (new sections 1C, 1D and 1E)**

The ALLIANCE has consistently recommended that care boards should be required to co-produce their strategic plans with people with lived experience and unpaid carers. Although the new section 1D would require Scottish Ministers to consult ‘the public in Scotland’ generally and the NCS Board, NCS local boards, local authorities and health boards specifically, there is no specific requirement to consult, or co-produce, people with lived experience or unpaid carers in national planning.

The ALLIANCE recommends the list in new section 1D (2) is expanded to create a specific requirement to co-produce with people to whom the NCS provides services, family members and carers, and the workforce. In addition, as detailed in our response to question 2, we recommend that there should be a specific requirement to co-produce third sector organisations involved in delivering NCS services.

We strongly recommend that the strategy, principles and other aspects of the National Care Service are co-produced<sup>2</sup> with the groups above in practice, rather than merely consulted on. We would recommend the Bill being amended to require co-production if it possible to do so.

## **2. What is your view of the proposal to create a National Care Service Board, and the provisions about the role and functions**



**of the Board (see in particular new Chapter 1B of Part 1, and new schedule 2C)?**

Strongly support

Tend to support

**Partly support and partly oppose**

Tend to oppose

Strongly oppose

Undecided / no opinion

The ALLIANCE welcomes the proposed creation of a National Care Service Board. This presents the opportunity to improve accountability, consistency and the sharing of good practice, compared with current arrangements.

We welcome the commitment to give all members of the Board, including lived experience members, full voting rights. Although it is not the only barrier to full participation by service user<sup>3</sup> and unpaid carer members of Integration Joint Boards (IJBs), not having voting rights contributes to them not being fully included as equal and valued members.

Although the Scottish Government plans to co-design additional membership categories, the ALLIANCE recommends membership should be set out in primary legislation. We recommend membership of the NCS Board and local boards, with full voting rights, is given to the categories set out in Integration Joint Boards regulations<sup>4</sup>, which requires an IJB to appoint at least one member in respect of the following groups:

- (a) staff of the constituent authorities engaged in the provision of services provided under integration functions;
- (b) third sector bodies carrying out activities related to health or social care in the area of the local authority;
- (c) service users residing in the area of the local authority; and
- (d) persons providing unpaid care in the area of the local authority.<sup>5</sup>





Although the proposed amendments require NCS Board members to be appointed to represent staff, service users, and unpaid carers, third sector representatives are notably absent. It is not made clear why this is the case, especially if the other groups above are proposed to be represented on it.

The ALLIANCE recommends that the third sector should be represented, with full voting rights, on both the NCS Board and local boards. The third and independent sector provides 78% of social care services<sup>6</sup> and consequently is a major stakeholder who should be included, as well as playing a considerable role in informing and influencing policy and practice improvements. The third sector also delivers and provides an invaluable perspective and expertise in community led health approaches, community capacity building and a range of activity addressing the social determinants of health and prevention work.

We welcome the Scottish Government's recognition that people with lived experience may require support to meaningfully participate in decision making and agree that this should be co-designed. While this does not necessarily require to be detailed in primary legislation, we do believe that consideration should be given to including a provision that adequate resources are to be provided to facilitate this participation. The ALLIANCE has extensive experience of supporting people with lived experience to meaningfully participate in decision making, including on IJBs, and would be able to inform this activity, as detailed in our response to question 3.

A significant part of whether the National Care Service can address long standing issues in social care rests on the National Care Service Board and its membership. However, discussions at the Expert Legislative Advisory Group demonstrate that many different stakeholders want a seat at this table. Given this, greater consideration needs to be given to how decisions will be made, issues identified, agendas set, and budgets decided, and how effective the accountability mechanisms are to enable robust scrutiny, as in itself, adding lived experience members will not necessarily lead to different decisions being made without further changes to governance.



We also recommend strengthening the requirement that the NCS Board’s corporate plan must set out how the Board intends to meaningfully involve people with lived experience, unpaid carers and the workforce (new section 12I (2) (b)), to ensure it is co-produced with them.

The proposed amendments allowing additional functions to be conferred on the National Care Service Board by regulations (new section 26B) leave a lot to be decided by secondary legislation. Consideration should be given to including additional functions in primary legislation, or – if this is not possible – that any regulations are subject to robust scrutiny.

### **3. What is your view of the proposal to establish National Care Service local boards and to remove other integration models (see in particular Chapter 1A of Part 1, and new schedules 2A and 2B)?**

Strongly support

Tend to support

**Partly support and partly oppose**

Tend to oppose

Strongly oppose

Undecided / no opinion

As detailed above, the ALLIANCE recommends that the third sector should be represented with full voting rights on both the NCS Board and local boards. Similarly to the proposal for the national NCS Board, there is no clear rationale given for third sector representatives not to be given voting rights, while others are.

We welcome the Scottish Government’s commitment in the Expert Legislative Advisory Group papers to ensuring appropriate support is provided to enable lived experience representatives on IJBs to carry out their roles and agree with suggested list of actions it has proposed. The ALLIANCE is gathering evidence from the IJB Lived Experience



Representatives Network, which we host, and has recently published ‘More Than Equal’, a joint report with the Coalition of Carers in Scotland making recommendations for how service user and unpaid carer representatives can be supported to play a meaningful role in decision making<sup>7</sup>.

The ALLIANCE disagrees with the proposal in new section 12B to rename integration authorities to NCS local boards (e.g. Orkney National Care Service local board). We believe this risks confusion because the body would then be described as a ‘national local’ board. Renaming also risks overlooking the integration agenda – which is still a work in progress – and the role of health in integration.

We favour integration authorities and Integration Joint Boards retaining their current names. If a change is felt necessary, for instance due to feedback expressed at the Expert Legislative Advisory Group that it is not clear from the name what an Integration Joint Board does, then ‘Community Health and Social Care Board’ (as proposed in the original NCS public consultation) might be an alternative that avoids the issues above.

The local boards’ governance processes and the way they function in practice also need to enable lived experience involvement, regardless of what name is used. For example, consideration needs to be given to how meeting agendas are set and who informs and sets them. It also needs to be clearly articulated how decisions are made, and appropriate training and support must be provided to ensure that a culture of collective leadership is fostered.

The proposed Bill requires local boards to consult ‘users of the service provided’ in creating local strategic plans, but not unpaid carers or third sector organisations. The ALLIANCE recommends that the Bill is amended to require co-production of local strategic plans with people who access services, unpaid carers and third sector organisations.



In principle, the ALLIANCE supports the provision to remove alternative integration models under the Public Bodies (Joint Working) Act (new section 12B (a) (ii)), as having one model improves national consistency and would improve understanding of integration. However, we recommend further consultation is carried out with public authorities, people with lived experience and third sector organisations in Highland, which is the only area to use the alternative lead agency model to ensure this does not lead to poorer outcomes for people as a result of the change.

#### **4. What is your view of the proposed new provisions on monitoring and improvement (see new sections 12K and 12L) and on commissioning (see new section 12M)?**

##### **Monitoring and improvement**

Strongly support

Tend to support

Partly support and partly oppose

**Tend to oppose**

Strongly oppose

Undecided / no opinion

We are concerned that the proposed role of the National Care Service Board appears to be only to have a focus on oversight of IJBs/local boards, rather than a focus on national consistency, improvement support, monitoring progress and setting national standards. While ensuring scrutiny happens is important, it should also be recognised that some of the issues currently faced relate to systemic matters, statutory responsibilities and national targets set, such as the Local Delivery Plan Standards.

If there is no recognition that the national picture needs to change to support the IJBs/local boards then change may not happen. We recommend the National Care Service Board's role should include supporting the sharing of learning, good practice, and ideas across the country, monitoring progress and systemic issues including through



identifying data gaps and trends, identifying where there is a need for – and undertaking – strategic commissioning of national services, as well as having an oversight function. Without these additional duties, as proposed, its main function could be seen as merely ‘marking the homework’ of local integration authorities/NCS local boards.

In addition, consideration should be given to how to resolve national issues which make local implementation difficult, such as budget allocations, directions and policy siloes. Consideration also needs to be given to ensuring that integration of health and social care continues at pace and scale. This includes, for example, aligning Health Board, local authority, and IJB budget timelines. The ongoing siloed approach to these continues to act as a barrier to a joined up approach.

In addition, there is no mention in the Bill of monitoring unmet need, nor is it clear if the NCS strategy will include ensuring that there is a review of models of care and market facilitation so that people’s needs are met in line with their will and preferences. The ALLIANCE recommend the Bill is amended to add monitoring unmet need to the function of the NCS Board.

### **Commissioning**

Strongly support

Tend to support

Partly support and partly oppose

**Tend to oppose**

Strongly oppose

Undecided / no opinion

The ALLIANCE is concerned at the removal of ethical commissioning requirements from the Bill (removal of sections 6 (3)(c), 7(2)(f) and 10). Introducing ethical commissioning is a vital component of implementing the recommendations of the Independent Review of Adult Social Care, and removing the requirement represents a step backwards.



We understand the Scottish Government intends to introduce guidance and practice improvements related to ethical commissioning. However, the ALLIANCE recommends that primary legislation include a requirement that strategic plans must set out plans for ethical commissioning strategy for the delivery of services.

The ALLIANCE also strongly recommends that the Bill is amended to add a definition of ethical commissioning, which was not contained in the Bill as introduced. At present there are a wide variety of interpretations of what “ethical commissioning” entails. A clear and commonly understood definition is required. If it is not provided in primary legislation, Scotland is likely to see inconsistent delivery of ethical commissioning – leading to the perpetuation of ongoing problems with varied delivery of services across different care boards and areas.

Ethical commissioning strategies should be human rights based and demonstrate the following, in line with the Independent Review of Adult Social Care recommendation 34<sup>8</sup>:

- Fair Work practices which encourage the development of a quality, sustainable, and appropriately valued work force;
- Climate and circular economy considerations to support a just transition to net zero;
- Financial transparency and commercial viability of any outsourced services;
- Full involvement of people with living experiences throughout, putting the person at the centre of making the choice;
- Shared accountability between all partners and stakeholders involved in delivery of services;



- The prioritisation of people’s outcomes over cost-based analyses;
- Collaborative tendering, with approaches agreed by all strategic planning partners.

With the removal of the references to ethical commissioning, new section 12M would be the lone reference to commissioning in the Bill. This would merely allow the NCS Board to commission goods and services.

### **Procurement (section 41 and new sections 41A and 41B)**

Although not specifically referred to in the consultation question, the ALLIANCE has views on the related area of procurement, contained in new sections 41A and 41B, together with section 41 which the Scottish Government has consulted stakeholders about.

The ALLIANCE is broadly content with the principle of proposed new section 41A, which requires procurement strategies to be informed by NCS local boards’ strategic plans. As detailed above however, we would recommend a definition of ethical commissioning and procurement is added to the Bill to ensure that it is complied with in practice.

In relation to section 41, the Scottish Government has made a number of suggestions for modification to the system of reserved contracts, intended to make it easier for IJBs/NCS local boards to reserve contracts for delivering social care services for the third sector. The ALLIANCE welcomes this in principle.

The Scottish Government consulted members of the Expert Legislative Advisory Group on a number of potential further changes to the Bill in this area, which are not contained in the draft amendments.

The ALLIANCE is broadly content with the Scottish Government’s proposed revised definition of third sector organisations for these purposes, which we consider would cover our relevant third sector members:



- organisations (other than public bodies like local councils) that exist wholly or mainly to provide benefits for society or the environment
- all the money they generate is reinvested in that social purpose or in the beneficiary community and no dividends are provided to independent shareholders

We would also agree with the Scottish Government's proposal that the clause on limiting contract years should be removed.

We also suggest that consideration is given to how the reserved procurement process will be reviewed to enable transparency, for instance by requiring the local procurement strategy to set out why the reserved process has been utilised, or why it has not. This could be enabled through the procurement strategy and annual reports which need to be published to enable transparency.

In principle, we would agree with a provision suggested by the Scottish Government to give the Minister the power to change the light touch regime threshold for community health and social care services. We would suggest that any limitations to this power are also set out (e.g. whether the level must be based on particular factors, or whether the increase would be unlimited).

We would also suggest that there could be a role for the National Care Service Board in advising the Minister on when to use their power to increase the threshold.

The ALLIANCE also recommends that a requirement is placed on the National Care Service Board to review and monitor the execution of local procurement strategies to ensure that they are delivering on the NCS strategy and local NCB strategies, given the number of problems that





currently arise in practice for providers related to commissioning and procurement.

**5. What is your view of the proposed new provisions to designate a National Chief Social Work Adviser and for the creation of a National Social Work Agency (see new section 26A)?**

Strongly support

Tend to support

Partly support and partly oppose

Tend to oppose

Strongly oppose

**Undecided / no opinion**

**6. What is your view of the proposed amendments to the Public Bodies (Joint Working) (Scotland) Act 2014, as set out in the marked up version of the Act?**

Strongly support

Tend to support

**Partly support and partly oppose**

Tend to oppose

Strongly oppose

Undecided / no opinion

Although some of the proposed changes to the Public Bodies (Joint Working) Act are welcome, on the whole, the Act will not be considerably strengthened by the proposed amendments.

Paragraph 1 of schedule 2B would enable Scottish Ministers to add to the range of functions capable of being delegated through an integration scheme, for example by adding children's services. This could lead to controversy in practice if this is done without proper consultation and has the potential for unintended negative outcomes.



As further detailed in our response to question 1, there is a lack of clarity as to what extent local boards will be required to ensure the NCS principles are complied with. The amendments would only require local boards to 'have regard' to the NCS principles. This is not the same level of responsibility as the duty to comply and does not strengthen existing duties. Furthermore, the current requirement to 'comply' with the integration delivery principles is amended by the Bill to requiring local boards to 'reflect' the NCS principles, which appears to weaken current requirements. With weak duties placed on NCS local boards it is unclear to what extent the NCS principles can be realised in practice.

Paragraph 3 of the Bill's schedule 2B, which extends the required content of strategic plans to include an assessment of the needs of the population of the local authority area (or areas) for which the board has responsibility, should be strengthened to ensure that a meaningful assessment takes place in practice. As detailed in our response to question 4, we recommend that monitoring unmet need is added to the function of the NCS Board, and which would further support this proposed requirement.

Our views on other proposed changes to the Act, such as renaming Integration Joint Boards, are detailed under other questions in this response.

## **7. What is your view of the Scottish Government's proposed approach to addressing the areas of further work outlined in the Minister's covering letter?**

### **Direct funding**

Strongly support

**Tend to support**

Partly support and partly oppose

Tend to oppose

Strongly oppose

Undecided / no opinion



In principle, introducing the power for Scottish Ministers to directly fund reformed integration authorities for specific purposes could be positive, and facilitate greater national consistency and support a rights based service, whilst we note the Minister's comments in her letter about the complexity of achieving this.

However, the Bill does not contain enough detail about the need to ensure that the National Care Service is sufficiently funded to progressively realise the rights it is there to deliver. We recommend including a requirement on Scottish Ministers to ensure that adequate funding is made available to deliver on delegated functions.

### **Inclusion of children's services**

Strongly support

Tend to support

Partly support and partly oppose

Tend to oppose

Strongly oppose

**Undecided / no opinion**

The section of the Bill requiring consultation before bringing children's services into National Care Service would be removed by amendments. The Scottish Government has explained that this is due to the changes to previous plans, retaining Integration Joint Boards rather than creating new Care Boards, and as such children's services will automatically become part of the NCS, as they are covered by IJBs in some parts of the country.

Despite this, the ALLIANCE believes that the Scottish Government should continue to develop a strong evidence base, and carry out detailed consultation and co-production, including with children and young people, before making any decisions as to whether children's services are brought into the NCS infrastructure.



ALLIANCE members have highlighted some advantages of bringing children’s services into the NCS, including that it is an opportunity to address some existing issues with transitions to adult services. However, our members have also highlighted a number of risks, including how services delivered via the NCS 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.

### **Inclusion of Justice Social Work**

Strongly support

Tend to support

Partly support and partly oppose

Tend to oppose

Strongly oppose

**Undecided / no opinion**

### **Anne’s Law**

Strongly support

**Tend to support**

Partly support and partly oppose

Tend to oppose

Strongly oppose

Undecided / no opinion

The ALLIANCE supports the introduction of Anne’s Law. We note that the Scottish Government is exploring whether it would be possible to deliver Anne’s Law more quickly through an alternative route and would support this if it were possible.

The National Care Service Bill was intended to be a convenient legislative vehicle to deliver Anne’s Law, and it is not connected to NCS services. We therefore fully understand campaigners’ frustration that the delays to the



Bill have delayed Anne’s Law. We also note that this is equally the case for the provisions in the Bill related to rights to breaks for carers, as detailed in our response to question 9.

The ALLIANCE also recommends extending visiting rights to settings with shared living facilities other than care homes, such as hospitals. During the COVID-19 lockdown, our members raised issues about the impact of the limitation of visitation rights for people in accommodation other than care homes.

### **8. What is your view of the initial draft of the National Care Service Charter?**

Strongly support

Tend to support

**Partly support and partly oppose**

Tend to oppose

Strongly oppose

Undecided / no opinion

#### **Content of draft Charter**

Although we are encouraged by some amendments to the Charter, we believe that because it was drafted before the law has been passed, rather than after, then the Charter may not reflect what is in the law.

Due to the ‘placeholder’ content, the ALLIANCE is not able to provide the Committee with a fully informed view of the ‘Scotland’s National Care Service (NCS)’ sub-section of the Charter. However, we would make the general point that as this sub-section is part of the Charter’s ‘Introduction’ that a comprehensive overview of the NCS and what services it will provide is included.

Within the ‘How to use this charter’ sub-section, it states that people can get more detailed information on their rights within the “Legal Underpinning



of the NCS charter document [insert link once available]”. As we cannot access the legal underpinning document it is not possible to give an informed opinion about whether all relevant rights are encompassed by the NCS Charter and Bill.

Within the ‘Who this charter is for’ sub-section, we are encouraged to see that the amended Charter states that it is for anybody who is accessing or waiting to access NCS support including children and young people transitioning to adult services, carers and anybody with a personal interest in the wellbeing of someone using the NCS. As children and young people have been referenced, the Charter and its legal underpinnings should reflect holistic family support principles and GIRFEC.

Within the same sub-section, it states the people can “read a child-friendly version[s] of the Charter [insert links when available]”. Additionally, due to the ‘placeholder’ content, the ALLIANCE is unable to provide the Committee with a fully informed view of “information on how to access different accessible formats of the Charter” or assess the accessibility of these versions. We suggest that this information and the different accessible formats be included within the Charter and made publicly available.

The section on ‘Your rights’, the ALLIANCE believes the Charter should include a right to coordinated and joined up care and support. People have consistently spoken about the negative consequences of having to repeat their experiences via multiple organisations and services, which risk retraumatisation and/or disengagement.

To enable everyone to understand and easily access the services and information they are given people must be able to proactively ask and receive accessible communication in a wide range of alternative formats. We therefore welcome this referenced within the ‘Your Rights’ section, however we believe the Charter should clearly state that the NCS follows the Principles for Inclusive Communication and the ‘AAAQPA’ key



elements of the right to health, which are availability, accessibility, acceptability, quality, participation and accountability<sup>9</sup>.

The ALLIANCE believes that the Charter needs to better articulate people's rights to communication, independent advocacy and supported decision making. Although these are referenced, they are not framed – as they should be – as human rights under binding international human rights treaties. To ensure that people's rights are put at the very centre of NCS policy and practice, any implementation of the Charter should follow the PANEL principles to enable people to take a human rights based approach when delivering services.

In the 'Equality, dignity and respect' section, we are encouraged to see an acknowledgement of protected characteristics and the right not to be discriminated against. However, the Charter does not make specific mention – as it should – of the Equality Act. It also fails to reflect the fact that equality and non-discrimination are fundamental human rights principles that apply to everyone<sup>10</sup>.

Whilst we recognise it is not pragmatic to list every population group who may experience inequality and discrimination in relation to the NCS, the ALLIANCE recommends that the Charter explicitly acknowledges other population groups whose rights could be most at risk. This would, for example, include people who are homeless, those who are care experienced, migrants, refugees and people seeking asylum, and people with lived experience of substance use.

The ALLIANCE is also concerned about certain wording in the draft Charter in relation to rights. For example in the 'Involvement, Participation and Choice' sub-section there is a sentence stating that 'You have the rights to... be as involved **as possible** in planning and decisions about your support and how it is delivered'. Any limitations to the right to participate in decision making should be clearly explained.



We welcome the inclusion of a dedicated sub-section on ‘Independent advocacy’, a definition of independent advocacy and its different types and the distinction made from advice. However, due to the ‘placeholder’ content, the ALLIANCE is not able to provide the Committee with a fully informed view on the ‘Independent advocacy’ sub-section. We would suggest that this sub-section should clearly refer to the right to independent advocacy. Any services that will be providing independent advocacy for people accessing the NCS, and how people will access such support should be illustrated.

The ALLIANCE is concerned about wording in the ‘Information’ subsection, where it states ‘If your support has to change for any reason you can **expect** us to give you information about that change’. This contradicts the right to participation; people should have a right to participate in decisions about service alterations. In order to make an informed choice, people need accessible information about why a change is being proposed, what alternative options are available, and be fully involved as an equal decision maker in planning for this provision.

In relation to supported decision making, provisions in the Charter should be designed to give full effect to this right by following UN guidance<sup>11</sup>. The ALLIANCE believes the Charter wording should be amended to include reference to a person’s ‘will and preference’ as well as their ‘views’. An important distinction needs to be made between forms of supported decision making that enable a person to make decisions themselves (or that decisions are taken based on their will and preference), and forms of substitute decision making that are made by others based on the ‘best interests’ of the person. The latter would include powers of attorney and guardianship.<sup>12</sup>

Within the subsection ‘The NCS information and advice services’, there is ‘placeholder’ content which means that the ALLIANCE is not able to provide the Committee with a fully informed view of the sub-section of the Charter. We would make the general point that any new NCS information and advice services should be co-produced with relevant stakeholders





including people who access the NCS, unpaid carers, and independent advocacy, advice and legal services. Any information and advice provided must be accessible, tailored to the individual's needs, and provided proactively.

In relation to the 'Your rights over the information we hold about you' sub-section, we are encouraged that people's right to easily access their personal information held by the NCS under the GDPR is reflected. However, due to the 'placeholder' content, we are unable to comment further on any details of how to request such access.

Unfortunately, due to the 'placeholder' content, the ALLIANCE is not able to provide the Committee with a fully informed view on the 'Upholding your rights' sub-section of the Charter. However, we would make the general point that this section should explicitly refer to the right to remedy and redress. Any new feedback, complaints and redress system/service should be co-produced with relevant stakeholders, including people who access the NCS, unpaid carers, and independent advocacy, advice and legal services.

### **Amendments related to Charter (sections 12 (4A) and 12A)**

The ALLIANCE is content with proposed amendments which would allow Scottish Ministers to delegate future work and changes to the Charter to the National Care Service Board (new section 12 (4A)), provided it does not remove the requirement to consult or co-produce with people with lived experience.

The ALLIANCE welcomes the proposed amendment to consult with unpaid carers and family members, as well as people who access NCS services and those who provide them (new section 12 (1) (i), which we had previously recommended. As detailed elsewhere in this response however, we believe that this should be a requirement to co-produce with them.



We also welcome the proposed amendment to add a duty to the NCS Board to promote the Charter (new section 12A), which the ALLIANCE has also previously recommended. Inclusive communication is vital to this, and we would seek clarification, as detailed in our response to question 1, that the inclusive communication duty in the NCS principles would also extend to the promotion of the Charter.

To ensure monitoring that the Charter is implemented in practice, the ALLIANCE recommends that the Bill is amended to require the NCS Board to publish annual reports detailing how the Charter has been implemented in that year.

### **9. Do you have any other comments on the Scottish Government's proposed draft Stage 2 amendments to the National Care Service Bill?**

#### **General comments**

The ALLIANCE welcomes the Committee giving people and organisations an opportunity to comment on the Scottish Government's draft Stage 2 amendments through the Call for Views. Although this is unusual and represents a departure from usual Parliamentary procedure, it is appropriate due to the significant changes since the Bill was introduced.

We are also extremely grateful to the Committee for agreeing to extend the deadline in response to a joint request from several organisations and individuals, including the ALLIANCE. This will allow a number of our members to respond to the Call for Views who would otherwise have been unable to, and for representative organisations to be able to consult their members on responses.

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>13</sup> and extensive engagement for the Independent Review of Adult Social Care.<sup>14</sup> We have engaged heavily with the development of the National Care Service since it was proposed, including detailed responses to the Scottish Government's 2021 consultation<sup>15</sup>, and the Committee's 2022 Call for Views on the Bill as introduced<sup>16</sup>.

The ALLIANCE has participated in a large number of Scottish Government National Care Service stakeholder groups and co-design workshops, have encouraged our members to do so, and have facilitated lived experience engagement in these processes.

We support the principle of the creation of a National Care Service. The NCS offers an opportunity to improve people's experiences of rights based, person centred social care – if designed and implemented in a way that responds to the concerns and experiences of people accessing social care and the workforce, and the recommendations in the Independent Review of Adult Social Care.

However, we believe that the Bill as introduced requires substantial amendments at Stage 2 if it is to deliver improvements to the rights based, person centred social care that people need.

As detailed in this response, whilst a number of the Scottish Government's amendments are welcome, they would not fully deliver these improvements. We are concerned that three years on from the original Scottish Government consultation, and more than two years since the Bill was introduced, a considerable amount of detail of how the NCS would operate in practice remains unclear. Our members have consistently reported difficulty in engaging with the Bill, due to this lack of detail and clarity.



The ALLIANCE participated in the Scottish Government's Expert Legislative Advisory Group which provided comment ahead of the publication of the draft Stage 2 amendments. However, we would want to take the opportunity to make it clear that our participation should not be taken as an indication that we are necessarily supportive of all the Scottish Government amendments or have co-designed them. We did not have sight of the text of the amendments prior to them being shared with the Committee, and this response should be taken as the ALLIANCE's views on them.

### **Independent advocacy (section 13)**

The ALLIANCE recommends that the existing section 13 of the Bill is further amended to include a definition of independent advocacy. This is important to ensure that the independent advocacy provided is genuinely independent. We recommend that the legislation should use the definition of independent advocacy in line with that offered by the Scottish Independent Advocacy Alliance (SIAA) and agreed by their membership of independent advocacy organisations and groups. This states that independent advocacy should:

- Have structural, financial and psychological independence from others
- Provide no other services, has no other interests, ties or links other than the delivery, promotion, support and defence of independent advocacy<sup>17</sup>.

In addition, the ALLIANCE supports the recommendations made by SIAA that further amendments should provide a right of access to independent advocacy in connection with the services that the National Care Service provides; and a duty placed on Scottish Ministers to secure the availability of independent advocacy services to people using NCS.

### **Transfer of National Care Service local boards' functions (sections 18 and 19)**



Section 18 and Section 19 are understandable contingency measures to include within the Bill to ensure that the NCS Board is accountable for the delivery of the National Care Service. While it is to be hoped that neither Section is required in practice, it is reasonable to outline in primary legislation measures to enable direct Ministerial input in instances where radical intervention is required.

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

Furthermore, we suggest that Sections 18 and 19 of the Bill require further detail to ensure that human rights based approaches are followed in the event of an emergency or service failure. The Bill should state explicitly that the NCS Board should have a duty to refer to the principles set out in Section 1 of the Bill, and the Charter, in the event of transfer of care board’s functions due to emergency or service failure – particularly regarding the expertise of lived experience representatives from care boards.

We know from evidence provided to the COVID-19 Inquiry that a wide range of practical problems and inequalities in the pandemic response were caused by early decisions being made without input from disabled people, people living with long term conditions, and unpaid carers. As such, it is particularly important that the National Care Service learns from that experience and embeds safeguards to ensure that experts by experience



are included in decision making processes in emergency as well as everyday scenarios. If the NCS intends to be a rights based organisation, then this is the rights based way to approach emergency measures.

### **Data collection and intersectional analysis (section 23)**

The ALLIANCE recommends an amendment is made after section 23 to include a duty to carry out national data collection and intersectional analysis of people's access to and experience of social care services, and to ensure that information is used within strategic planning.

While sections 23 (Research) and 36 (Care records) contain much welcome content, there is no commitment within the Bill to collect or analyse a national dataset on people's experiences of social care, nor to including that information within national or local strategic planning.

At present, data collection on social care is variable across each local authority and Health and Social Care Partnership. This causes substantial difficulties for analysts looking to collect and analyse social care data – and, in turn, for Ministers, local authority, and health and social care staff to effectively plan and deliver high quality social care, based on people's requirements and experiences. Without measures in place in primary legislation to ensure good data collection and intersectional analysis, the National Care Service will struggle to evidence and respond to people's needs across Scotland.

This challenge is particularly acute given the problems highlighted in the Independent Review of Adult Social Care and in *My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland*, which demonstrated that some groups of people receive poorer access to social care, compounding existing health inequalities (including people with learning disabilities, people from Black and ethnic minority communities, people with lived experience of mental health problems, disabled women, and people with sensory loss.)<sup>i</sup> These data gaps have continued to be a



barrier for making improvements to the implementation of Self-directed Support.

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

### **Complaints service (section 14)**

Although the ALLIANCE agrees with the requirement on Scottish Ministers to provide a complaints service for the National Care Service, this section should be strengthened by also including that it will outline what remedies are available if the complaint is upheld; and to ensure a robust complaints monitoring system to identify any systemic issues which are obstacles to the NCS principles being realised.

### **Care records (section 36)**

The ALLIANCE notes the amendments related to section 36 (Care records), which partly address concerns that we and our members raised about the original wording creating unintended barriers to implementing an integrated Health and Care Record. However, we would recommend a further amendment to ensure that citizens, unpaid carers or third and independent sector social care providers are not inadvertently excluded from data sharing arrangements.

### **Right to breaks for carers (section 38)**

The ALLIANCE supports the creation of a right to breaks for unpaid carers. However, unpaid carers have raised concerns that without sufficient



funding being provided, there is a risk that carers will not be able to access this right in practice.

To address this, the Bill should place a duty on Scottish Ministers to ensure there is adequate investment made available to local authorities so that this duty can be met.

This should also include a duty for monitoring and oversight to ensure this right is fulfilled in practice. This may be a duty that would be appropriate to be placed on the Scottish Ministers, or the National Care Service Board, although our understanding is that the inclusion of the right to breaks in the Bill is as a convenient legislative vehicle, rather than being part of the NCS infrastructure.

### **Purpose statement**

We believe that the Bill needs a purpose statement included at the outset that defines the purpose of social care. This would include the provisions that it should be universally provided, is intended to enable people's human rights, and will work towards removing eligibility criteria.

As suggested by Food Train, this could be based on the definition of the National Care Service set out in the report of the Independent Review of Adult Social Care:

“Everyone in Scotland will get the social care support they need to live their lives as they choose and to be active citizens. We will all work together to promote and ensure human rights, wellbeing, independent living and equity.”<sup>18</sup>

### **About the ALLIANCE**

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing





together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

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

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

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

#### We aim to:

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



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<sup>1</sup> Community Rehabilitation Best Practice Standards Scotland, Chartered Society of Physiotherapy on behalf of the Right to Rehab Coalition, March 2024. Available at [https://www.csp.org.uk/system/files/publication\\_files/002028\\_Rehab%20on%20Track\\_Community%20Standards\\_Scotland%20version.pdf](https://www.csp.org.uk/system/files/publication_files/002028_Rehab%20on%20Track_Community%20Standards_Scotland%20version.pdf)

<sup>2</sup> 'CoProWeekScot 2021 – Talking co-production in Scottish Government', Scottish Government, 23 November 2021. Available at <https://blogs.gov.scot/participation/2021/11/23/talking-co-production-in-scottish-government/>

<sup>3</sup> We have used the term 'service user' in this section for consistency with the IJB membership regulations below.

<sup>4</sup> The Public Bodies (Joint Working) (Integration Joint Boards) (Scotland) Order 2014. Available at <https://www.legislation.gov.uk/ssi/2014/285/article/3/made>

<sup>5</sup> As above.

<sup>6</sup> National Care Service – adult social care workforce: evidence, Scottish Government, 21 June 2022. Available at <https://www.gov.scot/publications/national-care-serviceadult-social-care-workforce-scotland/pages/3/>

<sup>7</sup> 'More Than Equal – Valuing and supporting the expert contribution of people with lived experience, the ALLIANCE and Coalition of Carers in Scotland (April 2024). Available at <https://www.alliance-scotland.org.uk/wp-content/uploads/2024/05/More-Than-Equal-Report-2024-WEB.pdf>

<sup>8</sup> Scottish Government, *Independent Review of Adult Social Care in Scotland* (2021), p. 78, available at: <https://www.gov.scot/binaries/content/documents/govscot/publications/independent-report/2021/02/independent-review-adult-social-care-scotland/documents/independent->



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<sup>9</sup> Scottish Government, *Principles of Inclusive Communication: An information and self-assessment tool for public authorities*, (2011) available at: [Principles of Inclusive Communication: An information and self-assessment tool for public authorities - gov.scot \(www.gov.scot\)](https://www.gov.scot/binaries/content/documents/govscot/publications/inclusive-communication/documents/inclusive-communication/govscot%3Adocument/inclusive-communication.pdf); United Nations Office of the High Commissioner for Human Rights, *OHCHR and the right to health*, available at: [OHCHR and the right to health | OHCHR](https://www.ohchr.org/en/press-releases/2019/04/ohchr-and-the-right-to-health).

<sup>10</sup> United Nations Office of the High Commissioner for Human Rights, *What are human rights?*, available at: [What are human rights? | OHCHR](https://www.ohchr.org/en/press-releases/2019/04/ohchr-and-the-right-to-health).

<sup>11</sup> From provisions to practice: implementing the Convention – Legal capacity and supported decision-making, United Nations Department of Economic and Social Affairs. Available at <https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-six-from-provisions-to-practice-implementing-the-convention-5.html>

<sup>12</sup> Adults with Incapacity Amendment Act: consultation, Scottish Government, 25 July 2024. Available at <https://www.gov.scot/publications/adults-incapacity-amendment-act-consultation/>

<sup>13</sup> The ALLIANCE and Self Directed Support Scotland, *My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland* (October 2020), available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/10/ALLIANCE-SDSS-MSMC-National-Report-Oct-2020.pdf>.

<sup>14</sup> The ALLIANCE, *Independent Review of Adult Social Care in Scotland – Engagement Activity* (Sept – Nov 2020), available at: [https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/SCR\\_report\\_WEB-compressed.pdf](https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/SCR_report_WEB-compressed.pdf).

<sup>15</sup> The ALLIANCE calls for National Care Service to be “investment of citizenship”, 2 November 2021. Available at <https://www.alliance-scotland.org.uk/blog/news/the-alliance-calls-for-national-care-service-to-be-investment-of-citizenship/>

<sup>16</sup> ALLIANCE response to the National Care Service (Scotland) Bill, 2 September 2022. Available at <https://www.alliance-scotland.org.uk/blog/news/alliance-response-to-the-national-care-service-scotland-bill/>

<sup>17</sup> Scottish Independent Advocacy Alliance, “What is independent advocacy?”. Available at: <https://www.siaa.org.uk/what-is-independent-advocacy/>.

<sup>18</sup> p. 18, Independent Review of Adult Social Care, 2021. Available at <https://www.gov.scot/binaries/content/documents/govscot/publications/independent-report/2021/02/independent-review-adult-social-care-scotland/documents/independent-review-adult-care-scotland/independent-review-adult-care-scotland/govscot%3Adocument/independent-review-adult-care-scotland.pdf>

