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

Consultation response: A National Care Service for Scotland

2 November 2021

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# Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to share our views with the Scottish Government on the proposed National Care Service for Scotland.[[1]](#endnote-2) 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.[[2]](#endnote-3)

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 consultation response draws on this rich and substantial evidence base. Most recently, 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*,[[3]](#endnote-4) and extensive engagement to directly inform the Independent Review of Adult Social Care.[[4]](#endnote-5) *My Support My Choice* is the most recent and comprehensive reflection of people’s experiences of accessing SDS and social care in Scotland prior to COVID-19. Our response is also informed by a National Care Service consultation event with Scottish Government held on 7 October and supplementary data from our members.[[5]](#endnote-6)

# Section 1 – Improvement

Question 1. What would be the benefits of the National Care Service taking responsibility for improvement across community health and care services? (Please tick all that apply)

* Better co-ordination of work across different improvement organisations
* Effective sharing of learning across Scotland Intelligence from regulatory work fed back into a cycle of continuous improvement
* Intelligence from regulatory work fed back into a cycle of continuous improvement
* More consistent outcomes for people accessing care and support across Scotland
* **Other – please explain below**

ALLIANCE response:

* **Disabled people, people living with long term conditions, and unpaid carers must be enabled to be the commissioners of their own support and care.**
* **Social care and support should be available when people require it, with equitable access across Scotland.**
* **Services need to be made easier for people to access.**
* **The successful implementation of SDS should be at the heart of the National Care Service.**
* **The National Care Service should embed human rights based approaches throughout, from design to implementation and improvement.**

At present, Self-directed Support (SDS) is Scotland’s approach to social care, designed to enable people to make “an informed choice on how their Individual Budget is used to meet the outcomes they have agreed.”[[6]](#endnote-7) SDS is underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion. The national SDS strategy notes that, “The process for deciding on support through SDS is through co-production […] support that is designed and delivered in equal partnership between people and professionals.”[[7]](#endnote-8)

The goal of this legislation was to shift the balance of power from people who provide services towards those who access them. In this way, people were to become pro-active agents instead of passive recipients of care. Social care should ensure every person in Scotland can reach their full potential – yet there are still significant irregularities in its delivery, with individuals unable to access an effective, integrated system. The successful implementation of SDS should be at the heart of the National Care Service.

A recurring theme the ALLIANCE hears is that the social care system is currently not working as it should for many people and third sector organisations across Scotland. We would welcome concrete action to ensure better co-ordination of work across different improvement organisations, effective sharing of learning across Scotland, that intelligence from regulatory work is fed back into a cycle of continuous improvement, and more consistent outcomes for people accessing care and support across Scotland.

Participants in *My Support My Choice* and the Independent Review of Adult Social Care engagement events stated that access to services must be made significantly easier to navigate. To achieve this change, there needs to be a focus on human rights and personal outcomes, and a transformation of commissioning and procurement processes. Scotland needs an approach that allows for people to choose and have access to the best support for them. Disabled people, people living with long term conditions, and unpaid carers need to be enabled to be the commissioners of their own support, to manage their own care, and for the systems to trust people – financially, in terms of risk assessment, and in decision making.

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. Any programme of improvement needs to consider the support and resources required to enable 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.

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, but also to become much more proactive in providing preventative and early intervention provision.

The ALLIANCE welcomes the Scottish Government’s commitment to ensure that human rights are “at the heart” of the social care system. Human rights offer a way to improve community health and social care for people. To achieve this, it is imperative that rights are referenced and embedded throughout policy, and that all proposed changes take an explicitly human rights based approach, including improvement.

This can be done, for example, by using practical tools like the five-point PANEL Principles to assess work and identify priorities for improvement against “participation”, “accountability”, “non-discrimination and equality”, “empowerment”, and “legality”.[[8]](#endnote-9)

The rights based “AAAQ” framework can also be functionally adapted to design and measure social care systems and services against indicators of whether they are “available”, “accessible”, “acceptable” and of good “quality”.[[9]](#endnote-10) The United Nations and World Health Organisation have identified indicators and created toolkits that can be used to measure progress and improvement against specific human rights – like the right to health – and whole treaties, like the UN Convention on the Rights of Disabled People (CRPD).[[10]](#endnote-11)

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).[[11]](#endnote-12) 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,[[12]](#endnote-13) which is found in the International Covenant on Economic, Social and Cultural Rights (ICESCR). 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 ICESCR, International Convention on the Elimination of All Forms of Racial Discrimination (CERD), 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”.

Question 2. Are there any risks from the National Care Service taking responsibility for improvement across community health and care services?

ALLIANCE response:

* **The implementation of the National Care Service should not compromise local service delivery and existing good practice.**
* **The National Care Service should focus on improving the experiences of (and outcomes for) disabled people, people living with long term conditions, and unpaid carers.**
* **Changes should be clearly communicated to people who access and provide social care and support, to avoid people losing access to essential care and support during any transitions.**
* **Existing fragmentation between public services could be exacerbated; concerted efforts are needed to avoid silo working and improve communication across the public sector.**

While the National Care Service offers opportunities to respond to many of the existing problems within Scotland’s community health and social care services, there are also a range of potential risks. Firstly, 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 eligibility criteria, it needs to do so without compromising locally effective services and individual expertise (including lived experience).

Furthermore, radical overhaul of current service provision and delivery runs the risk of focusing attention on system change rather than on the experiences of (and outcomes for) people accessing services and unpaid carers. This concern echoes some views expressed about the integration of health and social care.[[13]](#endnote-14) There is also a risk that existing fragmentation and disconnect between existing services areas (e.g. social security, housing, healthcare, social care) is continued and exacerbated in the creation of the National Care Service, with public sector employees and systems operating in silos – while disabled people, people living with long term conditions, and unpaid carers are required to code switch between different policy areas, often with different requirements and expectations.

Finally, any changes should be clearly communicated to all people who need to access services, to ensure that they are not discriminated against, understand and are involved in the process. Accessible formats that meet people’s rights and requirements should be used to avoid them losing access to essential care and support during any transitions. For example, the ALLIANCE recognises that one in six of the Scottish population have significant hearing loss, and this is due to increase by 50% in the next 20 years. Over 180,000 people in Scotland have significant sight loss and this is due to double by 2031. A conservative estimate by Deafblind Scotland reports 5,000 people living with deafblindness – and this figure does not include children born with congenital deafblindness.[[14]](#endnote-15) Accessible information and skilled communication partners are central to ensuring that people’s rights are enshrined and upheld.

**To counter these risks, the ALLIANCE recommends that the National Care Service should:**

* **Explicitly integrate equality and human rights 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.[[15]](#endnote-16)
* **Adopt human rights budgeting** to embed fairness, transparency and people’s participation in financial decision making, resource allocation and spend, monitoring and accountability.[[16]](#endnote-17)
* **Empower rights holders (people who access social care, unpaid carers, social care workers) to know, understand and claim their rights, and support duty bearers (e.g., public bodies, service providers, improvement and scrutiny agencies) to know, understand and fulfil their human rights obligations**, for example through the prism of the five-point PANEL principles.[[17]](#endnote-18)
* **Ensure that co-production is embedded throughout the design, development and delivery of the National Care Service** – not merely in consultation, but as an integral part of the process.
* **Use accessible information and inclusive communication** to work with people with lived experience in the design of policy and public services, including formats such as Community Languages,[[18]](#endnote-19) BSL, Braille, Moon, Easy Read, clear and large print, and paper formats. This would also include best practice in terms of budgetary and time management to ensure that accessible information and inclusive communication options are produced in good time, rather than retrospectively.
* **Support and work directly with third and independent health and social care organisations as equal and valued partners**, resourced by additional, sustainable, ongoing and secure funding.
* **Focus on interconnected design and communication across service areas** when developing the National Care Service.

# Section 2 – Access to care and support

Question 3. If you or someone you know needed to access care and support, how likely would you be to use the following routes if they were available?

1. Speaking to my GP or another health professional.
2. Speaking to someone at a voluntary sector organisation, for example my local carer centre, befriending service or another organisation.
3. Speaking to someone at another public sector organisation, e.g. Social Security Scotland
4. Going along to a drop-in service in a building in my local community, for example a community centre or cafe, either with or without an appointment.
5. Through a contact centre run by my local authority, either in person or over the phone.
6. Contacting my local authority by email or through their website.
7. Using a website or online form that can be used by anyone in Scotland.
8. Through a national helpline that I can contact 7 days a week.
9. **Other – Please explain what option you would add.**

ALLIANCE response:

* **People should be able to access high-quality information about social care and support from a wide range of routes.**
* **The National Care Service should acknowledge and sustainably fund the valuable work of the third sector, from independent advocacy to Community Links Practitioners.**
* **Not all population groups receive the same quality of information about social care; targeted work is needed to ensure equitable access.**

The ALLIANCE would recommend access to care and support – and information about them – is made available through all the routes referred to in Question 3. Although most people in Scotland may (try to) access social care at some point in their lives – or know someone who does – it remains little known and misunderstood. Widening and increasing national and cross-sectoral knowledge will not only improve people’s access to support and care, it will also help achieve the cultural shift so it is seen as an investment in people, society and economy and an essential part of Scotland’s public services alongside health and education.

In *My Support My Choice*, 43% of survey respondents first heard about Self-directed Support (SDS) from social work professionals, 17% from friends and family members, and only 6% from NHS health staff.[[19]](#endnote-20) Interviewees and survey respondents who received information and signposting from health staff spoke positively about the usefulness of this support, and the ALLIANCE recommends widening the pool of professionals who are informed about SDS and can encourage people to access it. Making more use of educational professionals, hospital staff, GPs and other community health practitioners would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations.

These research findings were echoed by participants in the ALLIANCE Independent Review of Adult Social Care engagement activity, who also highlighted the role of wider community involvement in social care (e.g. housing organisations). The report from these engagement events summarised the situation as follows:

“There are a lot of players involved in social care, and participants emphasised the need for improved integration of wider community support, including housing, leisure, employability and transport. Whilst there has been an attempt to integrate health and social care over the last seven years, there was felt to be a need to get the two working closer and better together and to connect to ‘an informed hub’ of multi-agencies.

“Participants were of the view that Integration Authorities have yet to include housing organisations and the third sector as equal partners, limiting the potential they could achieve if they worked collaboratively as equals. It was highlighted that integration needs to be visible at delivery level. In the engagement sessions, it was felt that it would be pivotal to the transformational change needed if the NHS, local authorities and health and social care partnerships agree on a data set they can share with multiple agencies, and for the individual to own and hold this information. This would encourage empowerment and community engagement.”[[20]](#endnote-21)

One participant with lived experience of social care support provided the following comment:

“Third sector support services act independently from health, and independent of those delivering social care services – why do we need three different guidelines or ‘red tape’ when each service sector is meant to be working in partnership?”[[21]](#endnote-22)

While the proposal to widen the ways in which people access support is welcome, further detail is needed on how this cross-sector collaboration will work in practice. It is important that any approach prioritises the gaps in existing systems, particularly for people who are currently less likely to be access social care (but who still need support).

For example, we know from *My Support My Choice* that women generally received less information about SDS options and budgets than men and were less content with the quality of information that they received.[[22]](#endnote-23) Similarly, Black and ethnic minority respondents reported greater difficulties in accessing suitable services, and the need for more support (including having information available in community languages and a range of accessible formats) for specific communities.[[23]](#endnote-24) It is important for the design of the National Care Service to address what motivates people to utilise certain services, e.g. community-based services might be preferred by some people over health care services if there is a lack of trust for institutions.

Regarding community-based services and support, the ALLIANCE suggests that services such as ALISS (A Local Information System for Scotland) could also be embedded in the strategy for how people access support and resources. ALISS helps people in Scotland find and share information about services, groups, activities and resources that help them live well. We believe that people should be able to easily access information about what is available in their community. Organisations and local groups can share information about what they offer, and people – including health and social care professionals and the general public – can find information about what is available near them.[[24]](#endnote-25)

The ALLIANCE also suggests that the proposed National Care Service needs to acknowledge the vital role played by Community Links Practitioners in supporting people and signposting people to support and resources (also referred to as social prescribing) and commit to further expansion. The ALLIANCE employs 55Community Links Practitioners, who are based within 63 GP surgeries across Glasgow and West Dunbartonshire. The Links Worker Programme[[25]](#endnote-26) aims to mitigate the impact of the social determinants of health for people that live in areas of high socio-economic deprivation (the most deprived 15% of areas, as measured by the Scottish Index of Multiple Deprivation (SIMD)).

Our Community Links Practitioners work to no exclusion criteria and have no maximum number of contacts with a person – meaning they will share the person’s journey for as long as it takes to facilitate their access to more specific or longer-term support. This flexibility affords this model of Links Working the opportunity to support those often furthest away from participation in their communities to full engagement. We know from speaking to our Community Links Practitioners that many people seek information about accessing social care and SDS from Community Links Practitioners, with whom they often have well-established and trusting relationships; acknowledging this expertise and communication pathways in any planning would be advantageous to people accessing support and health and social care staff alike.

Scotland has diverse communities that all need to be able to access local and national support services and resources, without discrimination. Once again those engaging with us via the Independent Review of Adult Social Care engagement events identified improving communication to be a priority, both in terms of language requirements and of people’s ability to access online resources. Participants also noted that third sector organisations are meeting this need via community-based projects that tirelessly deliver high quality, evidence-based work to support diverse communities, often within a challenging funding environment.

Question 4. How can we better co-ordinate care and support (indicate order of preference)?

* Have a lead professional to coordinate care and support for each individual. The lead professional would co-ordinate all the professionals involved in the adult’s care and support.
* Have a professional as a clear single point of contact for adults accessing care and support services. The single point of contact would be responsible for communicating with the adult receiving care and support on behalf of all the professionals involved in their care, but would not have as significant a role in coordinating their care and support.
* Have community or voluntary sector organisations, based locally, which act as a single point of contact. These organisations would advocate on behalf of the adult accessing care and support and communicate with the professionals involved in their care on their behalf when needed.

ALLIANCE response:

* **People need to be able to build up trusting relationships with social work professionals, via regular and consistent support from a designated person.**
* **The National Care Service should acknowledge and sustainably fund the vital role of independent advice and support organisations and independent advocacy.**

Rather than indicate an order of preference for the three options provided, the ALLIANCE would like to use this opportunity to address the broader question of how to improve the co-ordination of care and support. Respondents to *My Support My Choice* outlined the importance of consistent support from social work professionals. Participants stated that having a regular, consistent social worker gave people time to build up trust and awareness of people’s needs and individual situations. Social workers being able to take time to get to know people also facilitated flexibility of support arrangements. People also reported that it could be difficult and time consuming to build trust. One interviewee summarised their experience of struggling to trust their social worker as follows:

“She was actually really good, the social worker assistant; she was trying to understand what you were saying […]. But it was really difficult for me to open up completely because it’s a stranger. You’re thinking, this is your life and its things you could do 15 years ago you couldn’t do now and […] it’s kind of difficult to say to somebody. […] So, I was very distrusting, that [my SDS package] had been up to 15 hours, because there was nothing in writing.”[[26]](#endnote-27)

Several participants experienced challenges with communication and consistency when they had a change of social worker without being notified. One interviewee confided that this has negatively coloured their reactions to engaging with social work. Another person reflected that their relationship with their current social worker “improved over time”. They stated that “relationships are very important, and communication makes such a big difference. There has to be continuity with social workers.”

People also reflected on the role of local independent advice and support organisations. When asked whether access to independent information and support made SDS easier for them, people responded in a positive fashion. 223 people “strongly agreed” or “agreed” with that statement (71%), and 26 people (8%) “disagreed” or “strongly disagreed” with that description of independent support and advice organisations. A further 65 people (21%) said that they were unsure.[[27]](#endnote-28)

Separately, respondents also highlighted the value of independent advocacy. 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.”[[28]](#endnote-29)

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.

As detailed in our response to question 3, the ALLIANCE also suggests that the proposed National Care Service needs to acknowledge the vital role played by Community Links Practitioners in supporting people and signposting people to support and resources (also referred to as social prescribing) and commit to further expansion.[[29]](#endnote-30) We know from speaking to Community Links Practitioners employed by the ALLIANCE that many people seek information about accessing social care and SDS from Community Links Practitioners, with whom they often have well-established and trusting relationships; acknowledging this expertise and communication pathways in any planning would be advantageous to people accessing support and health and social care staff alike.

Overall, respondents to *My Support My Choice* highlighted the importance of consistent, co-ordinated communication and of having a single trusted point of contact within social work. Separately, they also 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.

Question 5. How should support planning take place in the National Care Service? For each of the elements below, please select to what extent you agree or disagree with each option:

Although the proposed answers to Question 5 are worded from the point of view of someone who accesses – or is seeking to access – social care services, the ALLIANCE has answered these questions using evidence gathered *My Support My Choice: People’s Experiences of Self-directed Support and Social Care in Scotland* and our extensive engagement activity for the Independent Review of Adult Social Care.[[30]](#endnote-31)

1. How you tell people about your support needs

Support planning should include the opportunity for me and/or my family and unpaid carers to contribute.

**ALLIANCE response: strongly agree.** Moreover, support planning should not merely offer the “opportunity” for people to “contribute” but should be expressly designed to prioritise and implement the choices of people accessing services, their families, and unpaid carers. As outlined earlier in our response, Self-directed Support (SDS) is underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion. The national SDS strategy notes that, “The process for deciding on support through SDS is through co-production […] support that is designed and delivered in equal partnership between people and professionals.”[[31]](#endnote-32) Any revised system of support planning should deliver these commitments on meaningful choice, co-production and equal partnership – beginning with conversations about support planning that are led by disabled people, people living with long term conditions, and unpaid carers, supported by social work professionals. These conversations should also include discussion about how much (if any) unpaid care people are willing and able to give, and/or receive.

If I want to, I should be able to get support from a voluntary sector organisation or an organisation in my community, to help me set out what I want as part of my support planning.

**ALLIANCE response: strongly agree.** People accessing services should be able to choose to be supported by a voluntary sector organisation or organisation in their community, properly resourced via sustainable commissioning processes. Furthermore, participants in both *My Support My Choice* and our Independent Review of Adult Social Care engagement events outlined the usefulness of independent advocacy and of independent advice and support organisations, and of the third sector more broadly.

When asked whether access to independent information and support made SDS easier for them, people responded in a positive fashion. 71% of respondents “strongly agreed” or “agreed” with that statement, 8% “disagreed” or “strongly disagreed” with that description of independent support and advice organisations. A further 21% said that they were unsure.[[32]](#endnote-33)

We also asked people about their experiences of independent advocacy – as distinct from independent support and advice. Respondents highlighted the usefulness of independent advocacy – 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.

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.

1. What a support plan should focus on

Decisions about the support I get should be based on the judgement of the professional working with me, taking into account my views.

**ALLIANCE response: disagree.** Social work professionals play an important and valuable role in supporting people to access support. However, support planning should not merely “tak[e] into account” the views of disabled people and people living with long term conditions but should be expressly designed to prioritise and implement the choices of people accessing services, their families, and unpaid carers.

As outlined earlier in our response, Self-directed Support (SDS) is underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion. The national SDS strategy notes that, “The process for deciding on support through SDS is through co-production […] support that is designed and delivered in equal partnership between people and professionals.”[[33]](#endnote-34)

Any revised system of support planning should deliver these commitments on meaningful choice, co-production and equal partnership – beginning with conversations about support planning that are led by disabled people, people living with long term conditions, and unpaid carers, supported by social work professionals.

Decisions about the support I get should be focused on the tasks I need to carry out each day to be able to take care of myself and live a full life.

**ALLIANCE response: disagree.** However well-intentioned, any approach that focuses on “the tasks I need to carry out each day” is likely in practice to default to a deficits approach and a medical model, rather than a human rights or social model; detailing what people cannot do, and the minimum required to “take care of myself” rather than anything more aspirational or individualised.

For example, any task-based assessment would be less likely to prioritise the right to family life than something that focused on outcomes, set by the person accessing services, and informed by their own choices and priorities. While the reference to “liv[ing] a full life” is welcome, any definitions of what a “full life” entails should rest with individual disabled people, people living with long term conditions, and unpaid carers.

Furthermore, greater clarity is needed on who is making “decisions about the support I get”, what information is used in that decision, and who has access to and sets the decision-making criteria. Clear processes of accountability to the person to whom data pertains is also essential to meet the requirements of PANEL principles.[[34]](#endnote-35)

In *My Support My Choice*, research participants commented on the importance of transparency in a variety of ways, centred around the need for clear information about what to expect from the process of accessing support, and how to challenge decisions. Some people spoke warmly of their social workers and the transparency of process, saying “there was no problem”, they had copies of all agreements and paperwork, and that when they queried sections of the plan their social worker “was quite happy to agree to some changes”.

However, many people require greater transparency about how care decisions are made and by whom, alongside inclusive communication and easy access to information. People reported difficulty obtaining paperwork and documentation concerning their care arrangements, even after repeated requests to social work departments, and difficulty obtaining information about how to lodge formal complaints. Several people reported that health and social care professionals stigmatised people with lived experience of mental health problems and disregarded their preferences around social care arrangements.

Another person recommended asking an independent person to attend meetings with health and social care professionals to ensure transparency of practice:

Respondent: There are other resources involved because people […] can’t just write their own notes when you’ve not got anybody attending. It’s difficult.

Interviewer: Would you recommend as a service user to have someone present?

Respondent: Yes. Because your notes and [social work’s] notes are completely different, […] and you are not allowed to have copies.”[[35]](#endnote-36)

People were not always provided with a clear calculation and breakdown of how SDS budgets are assessed and decided on, based on information from needs assessments/ reviews. One interviewee stated:

“Apparently it goes to a board or something to decide what support you get. I asked for a copy and was never given a copy of how they worked it out or anything. I was just told [we would] get three hours support, enough to get three hours of somebody coming a week. But I wasn’t told how they worked that out, how they came about that figure, anything. I got a report about it, but they didn’t say how they then took that report to be quantifiable as anything. […] It just was somebody on high has decided.”[[36]](#endnote-37)

Any revised system of decisions about support should deliver on the commitments in the SDS legislation on meaningful choice, co-production, and equal partnership, and ensure transparency of process in how decisions are made.

Decisions about the support I get should be focused on the outcomes I want to achieve to live a full life.

**ALLIANCE response: agree**. An approach that focuses on outcomes has the potential to align with a human rights model of disability, prioritising people’s access to their rights and requirements (e.g. the right to family life). Furthermore, any system focused on outcomes should be set by the person accessing services and informed by their own choices and priorities. While the reference to “liv[ing] a full life” is welcome, any definitions of what a “full life” entails should rest with individual disabled people, people living with long term conditions, and unpaid carers.

It is worth noting that task- and outcomes-based approaches are not necessarily mutually exclusive; but the priority of any agreed system should be ensuring that people realise their rights. This could include the right to independent living, privacy and family life, and access to food. Across *My Support My Choice*, participants discussed how important flexibility and meaningful choice were to them and their families.

1. Whether the support planning process should be different, depending on the level of support you need

N/A

I should get a light-touch conversation if I need a little bit of support; or a more detailed conversation with a qualified social worker if my support needs are more complex.

N/A

If I need a little bit of support, a light-touch conversation could be done by someone in the community such as a support worker or someone from a voluntary sector organisation.

N/A

However much support I need, the conversation should be the same.

N/A

**Light touch and/or more detailed support planning should take place in another way – please say how below:**

ALLIANCE response:

* **People’s first conversation about support planning should be detailed, unhurried, and involve a professional who is knowledgeable about social care and support, with the ability to signpost people to a range of local services.**
* **Everyone should be able to choose between any of the four SDS options, wherever they live in Scotland.**

A number of relevant recommendations have been made in *My Support My Choice*,[[37]](#endnote-38) which explored people’s experiences of SDS/social care assessments and reviews in detail. The first time anyone has a conversation about support planning and the associated processes, they should have the time and facilities to have an in-depth conversation with someone who is fully aware of the support available to them in their area, and who can assist them in considering all areas of a potential support arrangement (including detailed discussion of all four SDS options).

Subsequent, follow-up conversations about support could be more light touch, if the individual accessing support does not feel that they need a more in-depth discussion. That light touch conversation could be with a social work professional or someone from a voluntary organisation (or equivalent), if said organisation is given sustainable funding. However, the person accessing support should be able to request a fuller conversation at any point if they feel that a conversation has not met their rights or requirements, or that their questions have not been answered.

People accessing services should be able to choose to be supported by a voluntary sector organisation or organisation in their community, properly resourced via sustainable commissioning processes. Respondents to *My Support My Choice* highlighted the usefulness of independent advocacy – 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. 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.

Participants in both *My Support My Choice* and our Independent Review of Adult Social Care engagement events also outlined the usefulness of independent advice and support organisations. People should be able to request that an independent advocate or person from an independent advice and support organisation attend any meetings to discuss support planning, if they so desire. Conversations should be arranged to take place at a time and place of the person’s choosing, with adequate notice given, and fully accessible information should be made readily available – again, with suitable notice.

Support planning should not merely offer the “opportunity” for people to “contribute” but should be expressly designed to prioritise and implement the choices of people accessing services, their families, and unpaid carers. As outlined earlier in our response, SDS is underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion. The national SDS strategy notes that, “The process for deciding on support through SDS is through co-production […] support that is designed and delivered in equal partnership between people and professionals.”[[38]](#endnote-39) Any revised system of support planning should deliver these commitments on meaningful choice, co-production and equal partnership – beginning with conversations about support planning that are led by disabled people, people living with long term conditions, and unpaid carers, supported by social work professionals.

Regarding planning access to community-based services and support, the ALLIANCE suggests that services such as ALISS (A Local Information System for Scotland) could also be embedded in the strategy for how people access support and resources. ALISS helps people in Scotland find and share information about services, groups, activities and resources that help them live well. Organisations and local groups can share information about what they offer, and people – including health and social care professionals and the general public – can find information about what is available near them.[[39]](#endnote-40)

As outlined in the ALLIANCE responses to questions 5a and 5b, greater clarity and/in order to ensure accountability is needed on who is making “decisions about the support I get”, what information is used in that decision, and who has access to and sets the decision-making criteria.

Many people require greater transparency about how care decisions are made and by whom, alongside inclusive communication and easy access to information. People reported difficulty obtaining paperwork and documentation concerning their care arrangements, even after repeated requests to social work departments, and difficulty obtaining information about how to lodge formal complaints. For example, several people reported that health and social care professionals stigmatised people with lived experience of mental health problems and disregarded their preferences around social care arrangements.

Consideration of the needs of people nearing end of life should also be included in any process for conversations around support planning as part of anticipatory care planning. People living with a terminal condition and/or nearing end of life who are accessing palliative care should still have choice and control over their care and support, and their input – and that of their families and friends – should be a key part of decision making. This is particularly important given that most people who are resident in care homes are in the last 18 months of their life, and over 30,000 frail older people receive care at home every week in Scotland (in addition to other people receiving end of life care at home from other population groups).[[40]](#endnote-41) Marie Curie research has projected that by 2040, there will be over 60,000 people dying with palliative care needs – 10,000 more than currently – and two thirds of deaths will be in community settings, i.e. in people’s own homes, care homes and hospices.[[41]](#endnote-42)

This support planning should include having chaplains, social workers, and mental health professionals (if appropriate) join palliative care teams in home settings – if that is where people wish to die. Furthermore, people nearing end of life should have access to support lines 24/7, across Scotland. This prioritisation of palliative and end of life care in planning processes would provide people and their families with appropriate care and support, but also to ensure that people at end of life do not enter hospital settings if it is possible for people to die at home and that is their wish (though access to such services should not preclude hospital access when that is where people wish to die). The National Care Service must facilitate a collaborative approach between all those providing social care, to fully support people’s choices about their care and support – with the third sector involved in strategic conversations about local population needs from the outset, as well as in operational conversations about care delivery.

Participants in the ALLIANCE engagement activity for the Independent Review of Adult Social Care reflected on the importance of support planning. People stated that the purpose of a support plan is to identify the outcomes which are important to an individual and provide the support necessary to make these achievable. Participants stressed the importance of creating a valuable support plan; it needs to be robust, person centred and completed independently of the companies providing the care – without this foundation, care and support will consequently be delivered inadequately.

Discussions about support planning are complex and will vary from person to person (and across different points in that person’s self management of their condition). People may want decisions about care/support to be made by professionals in some instances but not others; it is important to have a system that is sufficiently flexible to allow variation, led by the service user and their family’s preferences at any one point in time. We also support the principles into practice framework development by the Scottish Transitions Forum and partners, and the importance of a support plan that evolves with a person across their life. We suggest that this work and learning should be used in any support planning strategy within the proposed National Care Service.[[42]](#endnote-43)

To achieve this, it is imperative that rights are referenced and embedded throughout policy, and that all proposed changes take an explicitly human rights based approach, including improvement. This can be done, for example, by using practical tools like the five-point PANEL Principles, and the rights based “AAAQ” framework.[[43]](#endnote-44)

As discussed in our response to question 1, 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 the human rights based approach. The impact of changes to support planning should therefore also be planned and measured in alignment with equality, including use of Equality and Human Rights Impact Assessments, as a practical tool to inform policy. Furthermore, if Equality and Human Rights Impact Assessments are to be used effectively, it is important that the Scottish Government commits 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.

Across *My Support My Choice*, participants discussed how important flexibility and meaningful choice were to them and their families. Any revised system of support planning or light-touch decisions about support should deliver on commitments in the SDS legislation, and as part of human rights based approaches more broadly, on meaningful choice, co-production and equal partnership.

Question 6. The Getting It Right For Everyone National Practice model would use the same language across all services and professionals to describe and assess your strengths and needs. Do you agree or disagree with this approach?

ALLIANCE response: agree.

Please say why.

ALLIANCE response: at present, people report that the variety of language used across the social care sector is complex and frequently confusing.[[44]](#endnote-45) Greater streamlining of language would reduce that confusion for people, especially people transitioning from children and young people’s services to adult social care, and for people moving from one local authority to another.

The consultation document indicates that “GIRFE will provide a model that uses the same language to describe and assess an adult’s strengths and requirements, and with common practice tools across professional groups.” As previously indicated at question 1, the Scottish Government has committed to ensuring that human rights are “at the heart” of the social care system. To achieve this, it is imperative that rights are referenced and embedded throughout policy, and that all proposed changes take an explicitly human rights based approach, including GIRFE.

Human rights offer a common language that would work across and unify all parts of the new social care system, ensuring a joined-up approach between and across improvement, the National Care Service, Community Health and Social Care Boards, commissioning, regulation, and valuing the workforce. It is important that any language chosen for the proposed GIRFE national practice model is co-produced with disabled people, people living with long term conditions, unpaid carers, and the third sector. It should be equally accessible to people accessing services and health and social care professionals, and comprehensible to workers across sectors.

Question 7. The Getting It Right for Everyone National Practice model would be a single planning process involving everyone who is involved with your care and support, with a single plan that involves me in agreeing the support I require. This would be supported by an integrated social care and health record, so that my information moves through care and support services with me. Do you agree or disagree with this approach?

ALLIANCE response: agree.

Please say why.

ALLIANCE response:

* **Support planning should be led by people accessing services.**
* **People’s health and social care records should be shared across connected sectors, following appropriate consent and safeguarding processes.**
* **People should be controllers of and have access to their own health and social care records.**
* **We recommend a “digital choice” approach – where people can make an informed choice between digital or non-digital health and social care services.**
* **Data processing should not replace opportunities for people to share their experiences with people involved in their care.**
* **People who access and provide social care and support should be educated in data collection and digital health and social care, to ensure meaningful consent and understanding, and maximise opportunities to engage with digital technology while still ensuring people’s safety and privacy and preserved.**

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. Furthermore, we suggest that the above GIRFE proposal should be reframed, so that there is a single planning process that is led by the people accessing services, rather than merely involving them in decisions about support.

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.[[45]](#endnote-46) 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.

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.[[46]](#endnote-47)

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.”[[47]](#endnote-48)

*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.[[48]](#endnote-49)

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).[[49]](#endnote-50) 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.

Question 8. Do you agree or disagree that a National Practice Model for adults would improve outcomes?

ALLIANCE response: yes – it could improve outcomes for people.

Please say why.

ALLIANCE response:

* **The proposed National Practice Model should focus on ensuring that people who access social care are at the forefront of decision-making processes.**
* **Data collection on people’s outcomes should use mixed method approaches to survey people’s experiences, and be co-produced with disabled people, people living with long term conditions, and unpaid carers.**
* **Legislation should confirm a commitment to the social and human rights model of disability, and explicit recognition of people’s rights.**

The ALLIANCE welcomes the descriptions of the GIRFE National Practice Model for adults that prioritise providing “an easier way to access help and support when it is needed” and valuing the expertise of people accessing services and their families and unpaid carers in “seeking to achieve the best outcomes for them”. The proposed system should focus on ensuring that disabled people, people living with long term conditions, and unpaid carers are at the forefront of identifying what they require and their chosen outcomes, with social work professionals supporting their decisions (rather than practicing substitute decision making).

To achieve this, it is imperative that rights are referenced and embedded throughout National Practice Model, and that all proposed changes take an explicitly human rights based approach, including GIRFE. Any approach that focuses on improving outcomes has the potential to align with a human rights model of disability, prioritising people’s access to their rights and requirements (e.g. the right to family life). Any system focused on outcomes should be set by the person accessing services and informed by their own choices and priorities, and include their experiences at the heart of assessing whether outcomes have improved following the introduction of a National Practice Model.

With regard to assessing improvements in people’s outcomes, any data collection to evidence this 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, and draw upon existing expertise within the third sector (e.g. Penumbra’s personal outcomes software). 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 would help to ensure that appropriate weight and priority is given to people’s experiences alongside nationwide statistics.

The next chapter of the consultation document notes the welcome provisions in the Carers Act that recognise and give effect to unpaid carers’ rights. In a subsequent chapter on data, a question is posed as to whether legislation should be used to require relevant parties to provide data meet common data standards and definitions for that data collection. The ALLIANCE would strongly encourage the Scottish Government to also take the opportunity of new legislation to reiterate its commitment to the social and human rights model of disability and explicitly recognise people’s rights. This would support a National Care Service that provides “consistency, equity and fairness”, and help improve upon existing SDS and carer law and policy to give greater effect to the rights of people who access social care and how these – and people’s personal outcomes – are measured.

For example, consideration could be given to recognising (amongst others) a right to person centred social care (that would include available, accessible, acceptable, co-ordinated and good quality services); a right to timely and accessible information about care and support; a right to a single, strengths-based planning process; and a right to be freely and meaningfully involved in active decision making about care and support. While current measures provide for some of these, there is inconsistency in their implementation and ongoing issues with accountability if requirements are not met. This has a direct impact on people’s experiences and lives, as well as their trust and confidence in the social care system. The solution to these issues could be provided by recognising and giving effect to people’s rights in law and taking a human rights based approach in its implementation.

# Section 3 – Rights to breaks from caring

Question 9a. For each of the below, please choose which factor you consider is more important in establishing a right to breaks from caring. (Please select one option from each line. Where you see both factors as equally important, please select ‘no preference’.)

Question 9a. Standardised support packages versus personalised support

ALLIANCE response:

* **All unpaid carers should have access to short breaks, which should accommodate both personalised support and access for everyone.**
* **Accessing short breaks should be simple, transparent, and equitable. It should not be linked to Carer’s Allowance.**
* **People should be able to choose how they wish to spend and access their budget for short breaks, and not required to choose from a set list of providers.**
* **Any system of short breaks must work for both adult and young carers, and be co-produced with them.**

The ALLIANCE believes that both personalised support and standardised levels are equally important. On the one hand, 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. Furthermore, any assessment process should not be linked to Carer’s Allowance.

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

Flexible, regular access to short breaks for all unpaid carers should be strongly encouraged because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers. However, people also highlighted that provision needs to accommodate and be appropriate to people with complex support requirements – it must be both sufficient and flexible enough to enable breaks that are fit for purpose. As such, people should have the choice about how to access and pay for short breaks – either receiving money directly from local authorities/HSCPs (or Community Health and Social Care Boards), or by having an agreed amount of time for short breaks, where the funding is sent directly to the provider of their choice (or a combination thereof).

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.[[50]](#endnote-51)

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.

It is also important to note that the above proposals require unpaid carers to undergo some form of assessment prior to accessing short breaks. According to both the National Carer Organisations and respondents to *My Support My Choice*, not all unpaid carers have access to a support plan – although the Carers (Scotland) Act 2016 entitles all carers to an assessment (now referred to as a Carers Support Plan). As such, it is important to ensure that any system for short breaks reliant on a support plan also responds to the current implementation gap around carer support plans (and communication thereof), so people are not left outside the system without support or access to short breaks.

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.

Question 9a. A right for all carers versus thresholds for accessing support

The ALLIANCE believes that all unpaid carers should have the right to access short breaks, with appropriate and tailored support for the people for whom they care during that time. 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. 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.

Questions 9a. Transparency and certainty versus responsiveness and flexibility

The ALLIANCE believes that “certainty about engagement” and “flexibility and responsiveness” are equally important in organising any system for short breaks. All unpaid carers should have the right to access short breaks, with appropriate and tailored support for the people for whom they care during that time. 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.

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). Any proposed system should ensure that all unpaid carers should be able to be certain of their access to regular short breaks; and these breaks should be fit for purpose, with individualised provision for each person.

Questions 9a. Preventative support versus acute need

The ALLIANCE believes that providing preventative support and meeting acute need are equally important in organising any system for short breaks. All unpaid carers should have the right to access short breaks, with appropriate and tailored support for the people for whom they care during that time. Preventative support would potentially be provided by ensuring that every unpaid care had access to short breaks on a regular basis.

However, there should still be sufficient flexibility available to support people in acute need when required – which does not happen for many people at present. In the ALLIANCE’s role administering the Self Management Fund for Scotland, many carer organisations have highlighted to us the unmet need for self management support for unpaid carers. The ALLIANCE believes that the provision of long-term preventative support needs to recognise the importance of self management support for unpaid carers.

9b. Of the three groups, which would be your preferred approach? (Please select one option.)

* Group A – Standard entitlements
* Group B – Personalised entitlements
* **Group C – Hybrid approaches**

Please say why.

ALLIANCE response:

* **All unpaid carers should have access to short breaks.**
* **Accessing short breaks should be simple, transparent, and equitable. It should not be linked to Carer’s Allowance.**
* **People should be able to choose how they wish to spend and access their budget for short breaks, and not required to choose from a set list of providers.**
* **Short break facilities must be able to accommodate and be appropriate for people with complex support requirements.**
* **Any system of short breaks must work for both adult and young carers, and be co-produced with them.**

The ALLIANCE supports hybrid approaches to access to short breaks. The importance of using SDS for short breaks was also mentioned by several people in *My Support My Choice* as an important chance for people to relax and recuperate. One interviewee explained that short breaks enabled long distance visits to the SDS users’ relatives without needing to stay at their houses, allowing the SDS user to both see their family and have privacy and support for their personal care.

Another person described their experience as follows:

“It’s been fantastic for us, with [Name’s] respite, because we started to use [respite venue]. […] We were just supposed to send [Name] for like Friday to Tuesday but they have [a camp] that runs for 10-11 days, and they have it for adults and they have it for children, so we have used that. […] As far as we’re concerned, [Name’s] away on holiday, rock clambering, away having a great time. […] That was amazing.”[[51]](#endnote-52)

However, many people also spoke about problems accessing short breaks, even when it was included in their personal outcomes plan, and the subsequent difficulties that could cause. One person stated that problems over accessing short breaks had had serious consequences for their relationship with and trust in their social worker. They summarised their experience as follows:

“The last [assessment] meeting I had, I left in tears as they threatened to cut my hours if I continued to ask about respite. It’s the first time I’ve ever felt ashamed/apologetic/a burden to have a disability. They hadn’t read my file so had no idea what [name of condition] was, made assumptions that I could do more for myself, and couldn’t understand why I needed someone with me when I go outside.”[[52]](#endnote-53)

People also reported that some local authorities specified designated centres for the provision of short breaks, rather than allowing people to choose which arrangements suited them best and refused to fund short breaks outwith those providers. This caused problems in terms of respecting people’s choices, but also prompted longer waiting lists for spaces at those designated centres – particularly around typical holiday periods.

Respondents highlighted the need for people to be able to use their short break budgets flexibly, as long as they could demonstrate that activities met their personal outcomes and were within budget. Flexible, regular access to short breaks for all unpaid carers should be strongly encouraged because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers.

However, people also highlighted that provision needs to accommodate and be appropriate to people with complex support requirements – it must be both sufficient and flexible enough to enable breaks that are fit for purpose. As such, people should have the choice about how to access and pay for short breaks – either receiving money directly from local authorities/HSCPs (or Community Health and Social Care Boards), or by having an agreed amount of time for short breaks, where the funding is sent directly to the provider of their choice (or a combination thereof).

Within the Independent Review of Adult Social Care engagement activity, there was a strong and consistent message that there is a failure to support unpaid carers. This was particularly the case on the topic of short breaks which are intended to give an unpaid carer a break from their caring responsibilities. Furthermore, in the ALLIANCE’s role administering the Self Management Fund for Scotland, many carer organisations have highlighted to us the unmet need for self management support for unpaid carers.

The ALLIANCE believes that the provision of long-term preventative support needs to recognise the importance of self management support for unpaid carers. The ALLIANCE heard 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. 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.

It is also important to note that the above proposals require unpaid carers to undergo some form of assessment prior to accessing short breaks. According to both the National Care Organisations and respondents to *My Support My Choice*, not all unpaid carers have access to a support plan – although the Carers (Scotland) Act 2016 entitles all carers to an assessment (now referred to as a Carers Support Plan). As such, it is important to ensure that any system for short breaks reliant on a support plan also responds to the current implementation gap around carer support plans (and communication thereof), so people are not left outside the system without support or short breaks.

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. Any proposed changes must be co-produced with disabled people, people living with long term conditions, and unpaid carers. The commitment made in the 2021 report of the Social Justice and Fairness Commission that “unpaid carers should be formally recognised and treated as equal partners in the decision-making process”[[53]](#endnote-54) should be sustained throughout the development of the National Care Service. The process of accessing short breaks should be simple, transparent, and equitable. Any assessment process should not be linked to Carer’s Allowance.

# Section 4 – Using data to support care

Question 10. To what extent do you agree or disagree with the following statements?

Although some of the proposed answers to Question 10 are asked from the point of view of someone who accessed – or is seeking to access – social care support, the ALLIANCE has answered these questions using evidence gathered from *My Support My Choice: People’s Experiences of Self-directed Support and Social Care in Scotland*, our extensive engagement activity for the Independent Review of Adult Social Care, and our work developing human rights principles for digital health and social care.[[54]](#endnote-55)

Question 10a. There should be a nationally-consistent, integrated and accessible electronic social care and health record.

ALLIANCE response: Strongly agree.

Question 10b. Information about your health and care needs should be shared across the services that support you.

ALLIANCE response: Strongly agree.

Question 11. Should legislation be used to require all care services and other relevant parties to provide data as specified by a National Care Service, and include the requirement to meet common data standards and definitions for that data collection?

ALLIANCE response: Yes

Please say why.

ALLIANCE response:

* **We recommend that legislation should include a duty on local and national public bodies to carry out systematic and robust data gathering on people who access social care (following principles of consent and choice).**
* **Data collection should use mixed method approaches to survey people’s experiences, and be co-produced with disabled people, people living with long term conditions, and unpaid carers.**
* **Analysis of results should be published in accessible and publicly available format on at least an annual basis, and include intersectional analysis on how social care is working for different groups of people across Scotland.**
* **People should be controllers of and have access to their own health and social care records, which should be able to be shared across relevant health and social care services if they grant permission.**
* **Data sharing should include third sector organisations providing services to people, as well as health and social care staff working for public bodies (where appropriate).**
* **We recommend a “digital choice” approach – where people can make an informed choice between digital or non-digital health and social care services.**
* **Data processing should not replace opportunities for people to share their experiences with people involved in their care.**
* **People who access and provide social care and support should be educated in data collection and digital health and social care, to ensure meaningful consent and understanding, and maximise opportunities to engage with digital technology while still ensuring people’s safety and privacy and preserved.**

*My Support My Choice* demonstrated that there are concerning gaps in national and regional data gathering and analysis around social care.[[55]](#endnote-56) 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.

To avoid gaps and improve analysis, we recommend 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) should be included in legislation, in line with the principles of consent, choice and ownership described in our response to question 7.[[56]](#endnote-57)

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) care experienced people, survivors of trauma and/or abuse, and victims of crime. This data should be published regularly and made available to the public (after following standard research ethics around anonymity for respondents).

It is important that this collection of data on people’s experiences of social care is both regular and 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.

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 would help to ensure that appropriate weight and priority is given to people’s experiences alongside nationwide statistics. Such 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.

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. 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 proposed 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 support wider public health.

With regard to data sharing, many research participants in *My Support My Choice* reported a lack of communication between different service providers (especially between health, housing, and social care sectors). This disconnect meant they were required to revisit trauma and recount their experiences unnecessarily – and “you get sick of telling your story all the time.” Some people also stated that they were not routinely provided with paperwork about their care and support arrangements, even when they requested these material (e.g. copies of budgets, personal outcome plans).

In addition, many ALLIANCE members who work with children and families as they transition into adult services describe a similar disconnect and lack of joined up support planning and communication taking place. We support the principles into practice framework development by the Scottish Transitions Forum and partners, and suggest that this work and learning should be used in any transitions strategy within the proposed National Care Service.[[57]](#endnote-58)

A nationally-consistent, integrated and accessible electronic social care and health record could help alleviate some of these problems. 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.

Within the Independent Review of Adult Social Care engagement activity, many organisations told us that technology is also readily available to support data sharing, and to support the creation of a single support plan for individuals. People are also using digital technology as a tool to aid self management and keep people better connected and reduce isolation. Participants also stated that there should be formalised data sharing, with “every person having one single data record/care plan”.[[58]](#endnote-59)

Data sharing should also not be restricted to health and social care staff working directly for Community Health and Social Care Boards or local authorities. It is important that third sector organisations providing services to people should have access to data where it is appropriate and the assessment of appropriate access should be in dialogue with and led by the person accessing support. For example, third sector organisations providing shopping for people should have access to information on their allergies, dietary requirements, food preferences, and any factors that affect their food preparation habits.

In addition to our wider calls for the collection of disaggregated data in social care, we also suggest that if staff are trained in identifying people experiencing malnutrition, then data should be collected on people identified as at risk of malnourishment, or who are malnourished. Such actions would enable targeted work to improve the health and wellbeing of the individuals in question, as well as enabling wider attention to be paid to the importance of food within health and social care policy – particularly as current research indicates that particular population groups are at higher risk of preventable malnutrition (e.g. older people living alone with low incomes).[[59]](#endnote-60)

These actions would also be in keeping with wider Scottish Government commitments to ensure that “by 2025, Scotland will be a Good Food Nation where people from every walk of life take pride and pleasure in, and benefit from, the food they produce, buy, cook, serve and eat each day”.[[60]](#endnote-61)

As detailed in our response to question 7 above, the ALLIANCE recommends that any legislation used to require all care services and relevant parties provide data to the National Care Service should comply with the following human rights principles in digital health and social care:

* **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.[[61]](#endnote-62)

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.”[[62]](#endnote-63)

We recommend that legislation should be developed in line with the 9 Core Principles for good practice in data collection and digital systems for healthcare, from the *My World, My Health* project.[[63]](#endnote-64)

Question 12. Are there alternative approaches that would address current gaps in social care data and information, and ensure a consistent approach for the flow of data and information across the National Care Service?

One of the current gaps in social care information is the difficulty many people have in accessing their own records. It is vitally important that people who use social care services have access to and control of their data, including access to any electronic social care and health record. People should not have to resort to Freedom of Information requests or court action to acquire information about their SDS/social care. Information should be easily accessible by the individuals to whom it pertains, and/or their Guardians.

Furthermore, any electronic portal should be available in a range of accessible and tailored formats (e.g. hard copy and digital; large print; Braille; Easy Read; BSL). 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.

While the ALLIANCE welcomes efforts to respond to the known issues around data sharing and data gaps in health and social care, we espouse a “digital choice” approach; people should have control over their data, and the method by which it is communicated to them. A “digital choice” approach to data records would mitigate digital exclusion and promote and protect the rights of people accessing services. By embedding choice and a human rights based approach into digital health and care service records – and focusing on outcomes, rather than delivery method – people should have parity between digital and non-digital health and care services.

As outlined in our responses to questions 7 and 11, the ALLIANCE suggests that any data collection systems for the National Care Service should comply with the principles of consent, choice and ownership described in *Human Rights Principles in Digital Health and Social Care* and the *My World, My Health* project.[[64]](#endnote-65)

# Section 5 – Complaints and putting things rights

Question 13. What elements would be most important in a new system for complaints about social care services? (Please select **3 options**)

* Charter of rights and responsibilities, so people know what they can expect
* Single point of access for feedback and complaints about all parts of the system
* Clear information about advocacy services and the right to a voice
* Consistent model for handling complaints for all bodies
* Addressing complaints initially with the body the complaint is about
* Clear information about next steps if a complainant is not happy with the initial response
* **Other – please explain**

ALLIANCE response:

* **Everyone should have access to an easy to access, transparent, and fair complaints system within the National Care Service.**
* **The National Care Service should acknowledge and sustainably fund the vital role of independent advocacy, and health and social care staff should be trained to signpost people towards independent advocacy.**
* **Any complaints system should follow human rights based approaches, and be co-produced with disabled people, people living with long term conditions, and unpaid carers.**

The ALLIANCE has not selected the three “most important elements” for a system of complaints, as all of the above options are equally important; as such, we have instead selected “other”. A properly functioning, accessible and robust complaints system is one important practical application of the human rights based approach principle of accountability, and it is not desirable at this early stage of system design to create an artificial hierarchy of its separate components.

According to *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. 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.

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.[[65]](#endnote-66)

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.[[66]](#endnote-67)

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).[[67]](#endnote-68)

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.[[68]](#endnote-69) 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.

One respondent 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.”[[69]](#endnote-70)

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.

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.

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 National Care Service offers an opportunity to create a mechanism for review, with the power to overturn decisions by the proposed Community Health and Social Care Boards (or equivalent body), and provide clear redress for people who require it.

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.

Question 14. Should a model of complaints handling be underpinned by a commissioner for community health and care?

There is a clear need for independent scrutiny and accountability of the National Care Service complaints system, which could be fulfilled by a commissioner for community health and social care.

Please say why.

Respondents to *My Support My Choice* and our engagement activities to inform the Independent Review of Adult Social Care were clear that individuals who access services and unpaid carers need to be enabled to be the commissioners of their own support, to manage their own care, and for the systems to trust people who access services. They highlighted the need for greater accountability and transparency of complaints systems, including escalation procedures when people are dissatisfied with responses or faced with long waiting times for responses to challenges or complaints (in some cases in *My Support My Choice* over a year).[[70]](#endnote-71)

Question 15. Should a National Care Service use a measure of experience of those receiving care and support, their families and carers as a key outcome measure?

ALLIANCE response: Yes

Please say why.

At present, data collection in social care does not include any measures of outcomes as experienced and assessed by service users and their families and unpaid carers. This results in a disjoint between a model of social care that is in principle outcomes focused, but in practice social care is frequently assessed in terms of costs and set tasks. Including the experience of those who access care and support as a key measure would go some way to countering that problem and prioritise the importance and expertise of people with lived experience. An approach that focuses on personal outcomes has the potential to align with a human rights model of disability, prioritising people’s access to their rights and requirements (e.g. the right to family life). Any system focused on outcomes should be set by the person accessing services and informed by their own choices and priorities. This should also include input from people access end of life or palliative care, their families, friends, and unpaid carers.

It is important that this collection of data on people’s experiences of social care is both regular and 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.

 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 and 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 appropriate and sustainably resourced to carry out this data collection and analysis at national and local levels.

# Section 6 – Residential care charges

Question 16. Most people have to pay for the costs of where they live such as mortgage payments or rent, property maintenance, food and utility bills. To ensure fairness between those who live in residential care and those who do not, should self-funding care home residents have to contribute towards accommodation-based costs such as (please tick all that apply):

N/A

Question 17. Free personal and nursing care payment for self-funders are paid directly to the care provider on their behalf. What would be the impact of increasing personal and nursing care payments to National Care Home Contract rates on:

* Self-funders
* Care home operators
* Local authorities
* Other

N/A

Question 18. Should we consider revising the current means testing arrangements?

ALLIANCE response: Yes

If yes, what potential alternatives or changes should be considered?

ALLIANCE response:

* **Social care and support should be free at the point of delivery.**
* **Everyone should be able to access the social care and support they require.**
* **The National Care Service should follow a human rights budgeting approach.**

Social care and support should be free at the point of delivery. Access to many of the accommodation-based costs listed above are human rights (e.g. the right to food). The redesign and implementation of any new systems within the National Care Service should begin with PANEL principles and human rights, and then consider costings via a human rights budgeting approach.[[71]](#endnote-72) To present access to free at point of delivery residential care and care at home as in binary opposition is a comparative approach that does not prioritise human rights.

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. While not a specific question in this consultation, we reiterate our position that non-residential care charges increase financial pressures on people who access care, and potentially causes people to forego essential services.[[72]](#footnote-2)

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. In the long term, Scotland should be working 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 recommend this take place in the next Budget round.

# Section 7 – National Care Service

Question 19. Do you agree that Scottish Ministers should be accountable for the delivery of social care, through a National Care Service?

ALLIANCE response: 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[[73]](#endnote-73) 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.

Please give details

ALLIANCE response: **regardless of who is ultimately made accountable for the delivery of social care through the National Care Service, it is imperative that the following key priorities are enacted to establish a system of effective accountability in social care:**

* **Transparency**
* **Accessibility**
* **Consistency**
* **Human rights based approach[[74]](#endnote-74)**

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.[[75]](#endnote-75) 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.

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.”[[76]](#endnote-76) 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).”[[77]](#endnote-77)

Question 20. Are there any other services or functions the National Care Service should be responsible for, in addition to those set out in the chapter?

ALLIANCE response:

* **Inclusive and accessible communication should be embedded across all parts and stages of social care, as a key responsibility of the National Care Service.**
* **Health and social care staff, and decision-makers in public bodies, need better training and awareness of the requirements of people with sensory loss.**
* **The National Care Service should ensure that everyone accessing social care has access to culturally appropriate choices of food, at times that suit them and their family.**
* **The National Care Service should acknowledge and value the role of allied health professionals in service planning and implementation.**
* **The National Care Service must consider climate change within wider long-term planning – e.g. investing in clinically and environmentally safe PPE, and developing sustainable and accessible travel for people who access and deliver health and social care services.**

The ALLIANCE supports wider calls from Food Train, the Scottish Food Coalition, Nourish Scotland, and Common Weal (amongst others) that everyone should have access to high quality food, as a human right. We suggest that it is essential that people’s equitable access to food is considered as part of the design and implementation of the National Care Service. Such actions would be in keeping with wider Scottish Government commitments to ensure that “by 2025, Scotland will be a Good Food Nation where people from every walk of life take pride and pleasure in, and benefit from, the food they produce, buy, cook, serve and eat each day”.[[78]](#endnote-78)

Everyone, including people who use social care, should have access to culturally appropriate choices of food, at times that suit them and their families. We know from *My Support My Choice* that at present many people using social care experience limited choice when it comes to food. Many people (particularly those accessing Self-directed Support via Option 3) reported being served food at atypical and inconvenient times, that could vary each day (e.g. breakfast at 9am, lunch at 11am). One person outlined that they were offered a range of dietary choices by their care provider each week – but that none of them were geared to food commonly eaten by people from their ethnic community:

“In the afternoon, I get afternoon tea, the service they have, to give you sandwich or soup or whatever it is. There’s a lot of options, and they ask me, ‘what do you want?’ I give them a week before what I would want that particular day. […] But the point is that if you look at the things that they have written down, the food is not ethnic minority at all. Nothing to do with ethnic minority. The potatoes and veg that you get is all mashed up. Chips are also all mashed up! So, it’s very difficult.”[[79]](#endnote-79)

Other people highlighted the need to include preparation time for hot food for people, and the importance of the social element of eating with people (including support with eating if required). Many people will have a paid carer provide support with food, but said support is often restricted to a very limited time period and food that is quick to prepare and eat. One person summarised the situation as follows:

“The only person they see all day! And […] they come, open the fridge, they make them a sandwich – and they hate eating cold food!”[[80]](#endnote-80)

Within our *My Support My Choice* thematic report on the experiences of people with sensory loss, people also highlighted the importance of proper support with shopping for food. However, while some people with sensory loss have that support included in their social care arrangements, this is not true across all parts of Scotland.

One blind participant was told that they could not have help with shopping, because that was outwith the purview of Self-directed Support, and that they should order food online instead – even though their screen reader struggled with online grocery ordering. They also found shopping stressful if reliant on assistance from shop workers who they did not know and who were not fully trained in how to assist blind and partially sighted people. In practice, they use their Personal Assistant (PA) hours for social engagement, in part, to shop; but this is not officially acknowledged in their outcomes plan.[[81]](#endnote-81)

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. Existing material includes Food Train’s “Raising the Issue of Malnutrition Toolkit”.[[82]](#endnote-82) 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 following the reduction of the Universal Credit £20 uplift in 2021.

Such actions would be in keeping with recommendations in the Good Food Nation consultation (and elsewhere) that the Scottish Government needs to ensure policy coherence across the varied actions being taken forward across this parliamentary term. The *Good Food National proposals for legislation* documentation summarises the situation as follows:

“[C]onsultation respondents noted that food impacts across a wide range of policy sectors and on all aspects of life and identified a need to ensure that the ethos of Good Food Nation is embedded across all sectors and all public authorities, for example, by linking into poverty initiatives. […] There was also reference from a few organisations that the introduction of Good Food Nation implies a fundamental shift in how Scotland governs the food system and a need for policy coherence to achieve Good Food Nation status.”[[83]](#endnote-83)

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. For example, many people who lip read now have reduced access to communication due to the wide-spread use of face coverings, and limited use of transparent masks. Many staff are not aware that they can and should remove face coverings in order to communicate with people with sensory loss; this should be included in any mandatory training programmes.

In addition to these physical problems with access, many people with sensory loss report that they have limited access to key communication and public health messaging – which became particularly acute during the pandemic. It is essential that all communication is fully accessible for people with sensory loss, and that those accessible formats are released promptly.

The ALLIANCE recommends the use of systems such as Contact Scotland (which has seen a marked increase in use during the pandemic);[[84]](#endnote-84) 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 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.

ALLIANCE members also highlighted the role of allied health professionals (AHPs) for people accessing social care, and the need for their important work to be acknowledged and planned for within the National Care Service. 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.”[[85]](#endnote-85)

In line with partnership work on climate change between the ALLIANCE’s Health and Social Care Academy and Scottish Care, we propose that the National Care Service should commit to and fund a model of sustainable social care, including appropriate data collection on targets within social care. Karen Hedge, National Director at Scottish Care, reflected on the need to consider sustainability within social care, stating that:

“For too long social care has been missing from the climate change debate. Currently, there is no disaggregation of health and care data on CO2 emissions which means that we can neither identify nor benchmark the extent to which there is impact. However, given the essential role that social care plays in infection prevention control, it can be assumed that there is a resulting and significant contribution in the form of single-use plastics, PPE and chemical use. In addition, a key purpose of social care is in supporting people to have choice and control in their lives. This requires a sector who is skilled to provide support to individuals who choose to prioritise a sustainable lifestyle.”[[86]](#endnote-86)

Our 2020 provocation paper called for three key actions in health and social care that respond to the dual concerns raised by climate change and the impact of COVID-19:

* Create a £25 million social care climate change innovation fund.
* Invest in clinically and environmentally safe PPE.
* Develop sustainable and accessible travel for people who access and deliver health and care services.[[87]](#endnote-87)

Ambitious and considered planning for sustainable social care is in keeping with the Scottish Government’s welcome commitments for Scotland to become a net-zero nation by 2045.[[88]](#endnote-88) Action in this area would be in keeping with human rights based approaches; recognising that climate change is one of the greatest threats to human rights, and the need to guarantee a human rights based approach for individuals who work in and access social care and support in a changing climate.

Finally, 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. Services like Contact Scotland BSL are invaluable to people with sensory loss 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.

Any additional services, functions and/or responsibilities of the National Care Service should be clearly laid out and co-produced with disabled people, people with long term conditions, and unpaid carers. To achieve this, it is imperative that rights are referenced and embedded throughout policy, and that all proposed changes take an explicitly human rights based approach using PANEL Principles to assess work and identify priorities for improvement.[[89]](#endnote-89)

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). 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.

Question 21. Are there any services or functions listed in the chapter that the National Care Service should not be responsible for?

ALLIANCE response: The third sector provides a range of valuable and essential support services to people across the health and social care landscape. Any proposed National Care Service should acknowledge and include the work of the third sector and providers – but independent organisations should remain autonomous, to maximise the choice available to disabled people, people living with long term conditions, and unpaid carers.

Participants in our Independent Review of Adult Social Care engagement activity noted that third sector organisations are meeting this need via community-based projects that tirelessly deliver high quality, evidence-based work to support diverse communities, often within a challenging funding environment. One participant with lived experience of social care support provided the following challenge to current systems:

“Third sector support services act independently from health, and independent of those delivering social care services – why do we need three different guidelines or ‘red tape’ when each service sector is meant to be working in partnership?”[[90]](#endnote-90)

Partnership working and co-production – with both people with lived experience and the third sector that delivers much of the tailored support to people – is key to the successful development of the proposed new systems.

Similarly, the usefulness of independent advocacy and independent advice and support organisations has been highlighted throughout this consultation response, as one of the key recommendations coming out of *My Support My Choice*.[[91]](#endnote-91) It is imperative that independent advocacy and advice organisations remain both independent and sustainably funded to be able to continue their vital work.

# Section 8 – Scope of the National Care Service

Question 22. Should the National Care Service include both adults and children’s social work and social care services? Please say why.

ALLIANCE response:

**If the National Care Service includes both children’s and adult’s services, it is key that the following principles are upheld:**

* **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.**
* **An equitable and person-centred approach to service delivery should be adopted throughout.**

The ALLIANCE’s Independent Review of Adult Social Care engagement activity indicated that merging children’s and adults’ 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.[[92]](#endnote-92)

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 social security and education – the latter of which is currently delegated to local authorities. In this case, the role of local authorities in decision-making about children’s services 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.”[[93]](#endnote-93)

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. Special attention should be paid to how budgeting decisions will be managed by the National Care Service – including a human rights based approach, and work on a caring economy.

Question 23a. Do you think that locating children’s social work and social care services within the National Care Service will reduce complexity for children and their families in accessing services for disabled children? Please say why.

ALLIANCE response:

* **Further clarity is needed on how the National Care Service will reduce complexity for children and their families who access services.**
* **Reducing complexity in accessing care must not result in reduced capacity for social care services to deal with people with complex requirements and should preserve existing good practice.**
* **The National Care Service must ensure that any new systems are co-produced with disabled children and young people, young people living with long term conditions, and their families and unpaid carers.**

Proposals to reduce bureaucratic complexity for people accessing services are welcome, and a single point of continued access to social care, via the proposed National Care Service, offers the possibility of a simpler process for children with disabilities and their families. However, further clarity is needed on how the National Care Service plans to do this, including for disabled children and their families. Our members have raised concerns about the potential risks in how eligibility criteria and assessments might be carried out under the proposed National Care Service – particularly given known issues around changing levels of support when people transition between children and young people’s services and adult services. In *My Support My Choice*, parents whose now-adult children use SDS reported widespread difficulties with transitioning from children’s social services to adult social services.[[94]](#endnote-94)

Many reported a break in service provision over several months, and a negative impact on family life and their adult children’s independence and opportunities.Furthermore, many parent/Guardian carers we heard from stated that there was an explicit or implicit assumption from social work professionals that they would provide unpaid care indefinitely – even in instances where their adult child stated that they wished to be supported to live independently in their own home.[[95]](#endnote-95)

Any proposed merger of children and adult’s services into the National Care Service must ensure pro-active attention is paid to the needs of each group, including embedding co-production in design and assessment of progress. Such approaches would be in line with the statement in *The Promise* that “we need to ensure that people are not only consulted about decisions that impact them – they must be empowered to shape those decisions.”[[96]](#endnote-96)

Respondents to both *My Support My Choice* and our Independent Review of Adult Social Care engagement activity spoke of problems with the complexities of accessing social care in Scotland, and navigating the bureaucratic process. Proposals to reduce that administrative load – for staff and service users alike – are welcome. However, it is also crucial that reduced complexity in accessing care will not result in reduced capacity for social care services to deal with people with complex requirements.

For example, engagement activity carried out by the ALLIANCE to inform the Independent Review of Adult Social Care highlighted that, “often people doing the assessments do not understand the functional difficulties of people with sensory impairments.”[[97]](#endnote-97) Others comments on lack of knowledge or training on how to communicate with people with learning disabilities.[[98]](#endnote-98) Similar concerns were raised in *My Support My Choice* – for more extensive discussion, see our thematic reports on the experiences of people with learning disabilities and blind and partially sighted people.[[99]](#endnote-99)

This is a particularly important point to consider if the proposed changes of the National Care Service are to adequately support the requirements of disabled children and young people who will access services. The ability to respond flexibly to individual and complex rights and requirements should be retained, and the centrality of involving a skilled and knowledgeable workforce in this process cannot be overlooked.

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 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 GIRFE 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 the 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.

Finally, 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].”[[100]](#endnote-100)

Questions 23b. Do you think that locating children’s social work and social care services within the National Care Service will reduce complexity for transitions to adulthood? Please say why.

ALLIANCE response:

* **Any redesigned system must improve people’s experiences of transitioning between children and young people’s services and adult social care.**
* **Changes to the delivery and organisation and children and young people’s services should preserve existing good practice.**
* **Clarity is needed on the interactions between the National Care Service, the NHS, and education services, with an agreed and unified common language.**
* **The National Care Service must ensure that children and young people have equitable access to services.**

Respondents to both *My Support My Choice* and our Independent Review of Adult Social Care engagement events spoke of problems with the complexities of accessing social care in Scotland, and navigating the bureaucratic process. Proposals to reduce that administrative load – for staff and service users alike – are welcome and a single point of continued access to social care, via the proposed National Care Service, offers the possibility of a process that does not require a transition – with all its known problems – at age 18 from one part of social care services to another. A key recommendation of the Independent Review of Adult Social Care in relation to transitions is that “social work and social care support should be made more cohesive across age and professional groupings, [and] should enable transitions between children’s services and adult services.”[[101]](#endnote-101)

*My Support My Choice* also offered the following summary: “Work is still required to improve systems for transition between children’s and adult services so they work well for people who use SDS/social care, their families and unpaid carers.”[[102]](#endnote-102) Further clarity is needed on how the National Care Service proposes to implement these changes, and it is crucial that reduced complexity in accessing care will not result in reduced capacity for social care services to deal with complex cases.

Our Independent Review of Adult Social Care engagement events also highlighted some key gaps in relation to transitions from children’s to adult services that could be addressed with the creation of a National Care Service. The National Care Service proposes changes to how eligibility criteria and assessments will be established and carried out. In our Independent Review of Adult Social Care engagement activity, a gap was identified in how assessments are currently carried out for some disabled people and people living with long term conditions, for example people with sensory loss. One participant stated that, “often people doing the assessments do not understand the functional difficulties of people with sensory impairments.”[[103]](#endnote-103)

Similar concerns were raised in *My Support My Choice* – for more extensive discussion, see our thematic report on blind and partially sighted people.[[104]](#endnote-104) This is a particularly important point to consider if the proposed changes of the National Care Service are to adequately support the rights and requirements of disabled children and young people who will access services as adults, with an opportunity to establish continuity of care and support. 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.”

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. To this end, special attention should be paid to how budgeting decisions will be managed by the National Care Service – including human rights budgeting approaches, and work on a caring economy.

People also emphasised the need for an integrated and unified approach to transitions planning across health and social care, and in particular involving an integrated and unified approach to data sharing across health and social care, with less paperwork and bureaucracy, which can be overwhelming and confusing both for people accessing services and those who care for or support them. Integrating data management and sharing in transition to adult services was identified in both *My Support My Choice* and our Independent Review of Adult Social Care engagement activity as a way to address gaps and difficulties in transitions to adult services, and which has also been highlighted as a priority area in the National Care Service consultation. The recently refreshed guidance on information sharing developed as part of GIRFEC and in collaboration with stakeholders could be a useful starting point as well as ensuring connectedness with the impending Transitions Strategy due to be developed this Programme for Government.

However, a “digital first” approach will not be appropriate for everyone, and this needs careful consideration when thinking of a centralised approach to data management and sharing generally, as well as in the context of transitions. The ALLIANCE recommends a “digital choice” approach; people should have control over their data, and the method by which it is communicated to them. A “digital choice” approach to data records would mitigate digital exclusion and promote and protect the rights of people accessing services. By embedding choice and human rights approaches into digital health and care service records people should have parity between digital and non-digital health and care services.

Furthermore, clarity on the interactions between the National Care Service, NHS and education is needed, 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 GIRFEC, can reduce complexity if implemented adequately across sectors. Members have expressed that, because GIRFEC already provides a unified language and approach, a structural change may not be the solution to address current systemic issues. As such, a proper scoping of the gaps that currently exist in this approach is also needed to understand how the introduction of a GIRFE approach with the National Care Service would work effectively in practice.

Equitable access to social care needs to be guaranteed, particularly for those people who have complex requirements. Furthermore, a robust mechanism needs to be put in place to ensure that children and young people have an equal footing at the point of access to services, regardless of circumstances.

Questions 23c. Do you think that locating children’s social work and social care services within the National Care Service will reduce complexity for children with family members needing support? Please say why.

ALLIANCE response:

* **Further clarity is needed on how the National Care Service will reduce complexity for children and young people with family members needing support.**
* **The National Care Service should ensure that young carers have easy access to regular, suitable short breaks, in any combined system for social care.**
* **The National Care Service must ensure that any new systems are co-produced with people accessing services and their families, including young carers.**

Respondents to both *My Support My Choice* and our Independent Review of Adult Social Care engagement events spoke of problems with the complexities of accessing social care in Scotland, and navigating the bureaucratic process. Proposals to reduce that administrative load – for staff and service users alike – are welcome and a single point of continued access to social care, via the proposed National Care Service, offers the possibility of a simpler process for children with family members who require support. However, further clarity is needed on how the National Care Service plans to do this in practice. A clear outline of how rights to short breaks will be established generally throughout the National Care Service and especially for young carers, is needed.

In the ALLIANCE’s “Response to Scottish Government consultation on Young Carers Grant regulations” (2018), a key recommendation was that a flexible, easy and accessible application process needs to be in place to ensure that young carers’ can access support and breaks from caring.[[105]](#endnote-105) This could be challenging if the National Care Service integrates children‘s and adults‘ services, and simultaneously proposes a standard approach to support packages for carers, which may be less flexible to individual or complex requirements.

It is important to ensure 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. 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.

People also reported that some local authorities specified designated centres for the provision of short breaks, rather than allowing people to choose which arrangements suited them best and refused to fund short breaks outwith those providers. This caused problems in terms of respecting people’s choices, but also prompted longer waiting lists for spaces at those designated centres – particularly around typical holiday periods.

Respondents highlighted the need for people to be able to use their short break budgets flexibly, as long as they could demonstrate that activities met their personal outcomes and were within budget. Flexible, regular access to short breaks for all unpaid carers should be strongly encouraged because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers. However, people also highlighted that provision needs to accommodate and be appropriate to people with complex support requirements – it must be both sufficient and flexible enough to enable breaks that are fit for purpose.

During our Independent Review of Adult Social Care engagement activities, we heard that the experiences of people accessing care during short breaks can often be inadequate, with some individuals being allocated a place in a care home which was inappropriate for their requirements or age. With limited choice and lack of appropriate solutions, often unpaid carers did not feel able to take up opportunities for short breaks (as suitable care was not available).

Some people we spoke to felt that care homes operate as a business so do not have beds readily available for short stays as it doesn’t make “business sense” if the aim is to maximise capital. 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.

Furthermore, children and young people with caring responsibilities may have different understandings of their roles compared to those of adult carers. During an event held by the ALLIANCE in support of the Young Carers Grant consultation response, participants expressed that:

"It may be difficult for any young carer to quantify the number of hours of care that they provide – as they may be in a routine and no longer perceive some of their tasks as caring. They believed that caring hours should include replacement parental duties which should be provided by the cared-for person. For example, a young carer taking on parental responsibilities for a younger sibling – who doesn’t have a disability – because their parent is their cared-for person and is unable to provide this support for their younger sibling. [...] criteria should [...] reflect this.”[[106]](#endnote-106)

Consideration needs to be given to how access to rights to breaks from caring may impact children’s and young people’s access to other social care support. Consideration also needs to be given to how different policy domains may interact with each other, for example provisions through education. Equitable access to social care, for both young carers and any family members needing support, must be ensured from the first point of access.

Question 24. Do you think that locating children’s social work services within the National Care Service will improve alignment with community child health services including primary care, and paediatric health services? Please say why.

ALLIANCE response: **if children’s services are included within the National Care Service to improve alignment with community child health services, primary care, and paediatric health services, a clear outline of how this would be implemented is needed. The following considerations should be prioritised within any restructuring:**

* **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.**
* **An equitable and person-centred approach to service delivery should be adopted throughout.**

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.”

Proposals to improve communication and data sharing between the NHS, social care, and people who access services are welcome. In particular, we strongly support plans to develop a unified, integrated and consistent approach to data management and sharing. However, it is essential that this process follows a person centred and human rights based approach, with clarity about how people who access services can access and control their data, and have oversight of how it is stored, handled, and viewed by others. The system should take into account the requirements of children, young people, and their families or carers.

We also recognise the existing knowledge gap about Self-directed Support among primary care staff, and propose that work to improve integrated data sharing should also include efforts to improve understanding about SDS among the workforce in the health care sector. As outlined in *My Support My Choice*:

“It would […] be helpful to widen the pool of professionals who are informed about SDS and can encourage people to access it. Making more use of educational professionals, hospital staff, GPs and other community health practitioners would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations.”[[107]](#endnote-107)

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. To this end, special attention should be paid to how budgeting decisions will be managed by the National Care Service – including human rights budgeting approaches, and work on a caring economy.

Question 25. Do you think there are any risks in including children’s services in the National Care Service?

ALLIANCE response: yes

If yes, please give examples.

ALLIANCE response:

* **The implementation of the National Care Service should not prevent the delivery of the outcomes set out in GIRFEC, The Promise, UNCRC incorporation, and a range of other connected commitments to improve children’s services.**
* **Communication about the National Care Service must be accessible for children and young people and their families.**
* **Children and young people’s services should be sustainably and appropriately resourced, as a key investment within the National Care Service, and to ensure that highly specialised work is not lost – e.g. children’s palliative care.**
* **Health and social care professionals must be trained to support children and young people’s requirements, and be aware of intersectional policies that affect them (e.g. housing, education, etc.).**
* **Any system change must be co-produced with disabled children and young people, young people living with long term conditions, and their families and unpaid carers (including young carers).**

The ALLIANCE has identified several potential risks associated to including children’s services in the proposed National Care Service. First, concerns have been raised by our members about how the inclusion of children’s services in the National Care Service would work to implement and reconcile several overlapping policy areas and existing initiatives pertaining to children’s services. It is imperative that the National Care Service delivers the outcomes set out by:

* Getting It Right For Every Child (GIRFEC)
* The Promise
* UNCRC incorporation
* The National Guidance for Child Protection
* The Child Poverty (Scotland) Act 2017
* The Bairns’ Hoose (Scottish Barnhaus) Report
* Support for Learning: All our Children and All their Potential
* Children and Young People’s Mental Health and Wellbeing Programme Board
* Part 13 of the Children (Scotland) Act 2020 and the Looked After Children (Scotland) Amendment Regulations 2021 protecting sibling relationships for children in care

There is significant concern about the risk of losing existing good practice in relation to children’s services, and that a structural change is unlikely to fix current systemic issues in children’s services. We know that the introduction of a unified, common language to communicate across children’s social services, such as GIRFEC, can reduce complexity if implemented adequately across sectors.

Members have expressed concern that, because GIRFEC already provides a unified language and approach, a structural change may not be the solution to address current systemic issues. As such, a proper scoping of the gaps that currently exist in this approach is also needed to understand how the introduction of a GIRFE approach with the National Care Service would work effectively in practice – and that attention to children and young people’s experiences needs to be a key part of any change, lest their rights and requirements be neglected in favour of the adult majority of the people accessing social care. ALLIANCE members also expressed concern that existing expertise and good practice among highly specialised work in children’s palliative care could be adversely affected by the proposed changes, especially with regard to appropriate and sustained resources.

It is currently unclear whether the pressing and ongoing issues of resourcing and finance in the sector will match policy changes brought about by the introduction of the National Care Service. The potential benefits of the unifying approach proposed by the National Care Service would only come into effect if budgets are levelled up rather than levelled down; there is significant concern from our members that budgets currently set aside for the provision of children’s services could be redirected or absorbed into other areas of social care provision once the National Care Service is implemented. For example, there are concerns that the recently announced £500 million Whole Family Wellbeing Fund could be diverted, reducing the support available for children and young people.

Similarly, it is currently unclear whether additional resource and investment to train and grow the social care workforce will be prioritised with the introduction of the National Care Service. This is particularly important when thinking about how to adequately support the rights and requirements of disabled children and young people, children and young people living with long term conditions, and young carers. Our members noted that proper resourcing and financing of the workforce contributes to adequate provision for people who access services, and allows professionals to forge meaningful relationships with the people who they support. The importance of trusting and sustained relationships with social work professionals was also captured in *My Support My Choice*:

“People highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS.”[[108]](#endnote-108)

Another key risk associated with the inclusion of children’s services in the National Care Service is that the requirements and/or experiences that specifically affect children can be easily overlooked when merging policy domains. There is a risk that children’s status and rights as outlined by the UNCRC will not be adequately considered when the National Care Service comes into effect. It is imperative that the commitments laid out in *The Promise* with regards to children’s status and rights are fully embedded in the National Care Service*:*

“Scotland must recognise children’s status as human beings with a distinct set of rights. Children are not passive recipients of care. The system must revolve around the rights of the child so their health, education and right to play (for example) are never compromised by contact with the ‘care system’. The system must uphold their rights at every turn.”[[109]](#endnote-109)

This particular concern has been discussed by ALLIANCE members as an issue of power; close attention must be paid to whose voice is most likely to be heard and prioritised if children’s services are included in the National Care Service, particularly in the case of disabled children and young people, children and young people living with long term conditions, children in care, and young carers. As stated in *The Promise,* “Scotland must make particular effort to understand and act upon quieter voices, including infants and nonverbal children and those with learning disabilities.”[[110]](#endnote-110) The ALLIANCE’s Getting to Know GIRFEC programme was established because many disabled children and young people and their families as well as the organisations who support them were unaware of the GIRFEC approach and their entitlements under such an approach. During the pandemic we heard that the needs and experiences of disabled children and young people have not been listened to; their perspectives and experiences must be at the forefront of change and system design and implementation going forward.

It is imperative that this commitment is not lost if children’s services become part of the National Care Service. This a particularly important consideration when thinking about equitable access to services; there is a risk in assuming that people who use services have equal footing at point of access. Without adequate measures and the support of a knowledgeable and expert workforce, equity of access cannot be guaranteed for younger children, disabled children and young people, those living with long term conditions, children in care, and young carers.

Indeed, not all professionals will be adequately trained to support children and young people’s requirements, or be aware of the other intersecting policy domains that affect children and young people’s lives e.g. education, housing, or migration policy (if supporting asylum seeking children and young people).[[111]](#endnote-111) This is also especially important considering that current criteria and assessments to access adult services are more rigid than those in place to access children’s services; there is concern among our members that these processes will be made more complex for children if the National Care Service is introduced.

In line with the GIRFEC approach, people emphasised that eligibility criteria and assessment processes need to be requirements based and preventative – moving away from a crisis-led provision of social care to an early intervention approach that can help address what a child requires before reaching a crisis point.

A final risk in including children’s services in the National Care Service is that children and families have not been given an opportunity to feed into what is outlined in the National Care Service consultation document, or to meaningfully engage with the consultation process to the same degree as found in the Independent Review of Adult Social Care for adult social care. This reduced focus could result in a system that is not fit for purpose, designed to provide services based on how the public sector is organised rather than designed in line with children and young people’s rights, requirements and experiences.

As such, 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
* 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.

# Section 10 – Healthcare

Question 26. Do you agree that the National Care Service and at a local level, Community Health and Social Care Boards should commission, procure and manage community health care services which are currently delegated to Integration Joint Boards and provided through Health Boards?

ALLIANCE response: there is a clear need for a coherent, transparent and fair approach to the commissioning and procurement of community health and social care services, which could be fulfilled and managed by the proposed Community Health and Social Care Boards. Irrespective of who takes over management of commissioning and procurement, the priority of any reform in this area should be improving the outcomes of people who access services.

Please say why.

ALLIANCE response:

* **Commissioning and procurement models should follow person centred and human rights based approaches, including human rights budgeting.**
* **Any revised system of commissioning, procurement and management should value and work in partnership with the third sector.**
* **Public authorities must move away from price-based competition and competitive tendering, or there will be a detrimental impact on the sustainability of providers, and the quality of support and choice for individuals accessing social care.**

The ALLIANCE welcomes proposals to make the commissioning and procurement of community health services more robust and integrated with social care services. In particular, we strongly support plans to develop a unified, integrated and consistent approach to service provision, provided this is done following a person centred and human rights based approach throughout. This should be achieved regardless of whether the commissioning, procurement, and management of services sits within the remit of the National Care Service.

Whether or not the commissioning, procurement, and management of health services sits within the remit of the National Care Service, it is imperative that health inequalities are responded to, and that existing problems are not perpetuated. The system as is stands is not equitable or available to all. Equity of access to services, from the point of access, needs to be ensured for all; this can only be achieved if a knowledgeable and skilled workforce is available to support people who access services, and by taking a preventative approach that is not crisis-led.

We also advocate that any revised system of commissioning, procurement and management should value and work in partnership with the third sector. In many instances, third sector organisations are delivering important community-led health and social care initiatives – such as those invested in by the Self Management Fund for Scotland. These preventative and early intervention approaches are often not currently included within the delegated budget directed by Integration Authorities. Yet they contribute to personal outcomes of people and are delivering Scottish Government's vision for better population health. If considering community health care services, it is imperative that Community Health and Social Care Boards map and accommodate the full range of support and services that are available and needed when developing a strategic commissioning plan.

This is particularly important as this group of organisations have typically not benefited as intended from integration – it is vital that they, and the people they support, are properly included in the National Care Service. We support calls from many of our members, including the Coalition of Care and Support Providers in Scotland (CCPS), that unless public authorities move away from price-based competition and competitive tendering, there will be an ongoing detrimental impact on the sustainability of providers, and the quality of support and choice for individuals accessing social care.

Finally, as outlined in *My Support My Choice*, “professionals should fully incorporate equality assessments into their processes for service users and families,”[[112]](#endnote-112) with human rights, intersectionality, and conscious and unconscious bias training provided to staff across health and social care. In addition to this, proposals to streamline the commissioning, procurement, and management of services via the National Care Service need to make clear what additional resource and financing will be made available to the health and social care sector and draw on human rights based approaches. Special attention should be paid to how budgeting decisions will be managed by the National Care Service, including human rights budgeting approaches and work on a caring economy, to adequately support the workforce.

Question 27. If the National Care Service and Community Health and Social Care Boards take responsibility for planning, commissioning and procurement of community health services, how could they support better integration with hospital-based care services?

ALLIANCE response:

* **Human rights training should be mandatory for all staff engaged in health and social care work – from management level to public-facing roles – and commissioning and procurement system should embed human rights based approaches throughout.**
* **Disabled people, people living with long term conditions, and unpaid carers should be able to be commissioners of their own support and manage their own care.**
* **Any revised system of commissioning, procurement and planning should value and work in partnership with the third sector, including sustainably resourcing third sector organisations to carry out their vital work.**

The ALLIANCE welcomes proposals to streamline people’s experiences of using (and transitioning between) hospital-based care services and care at home. This is line with what participants in *My Support My Choice* and Independent Review of Adult Social Care engagement events reported, stating that access to services must be made significantly simpler to navigate.[[113]](#endnote-113) To achieve this change, there needs to be a focus on human rights and personal outcomes, and a transformation of commissioning and procurement processes – including training in human rights based approaches and ethical commissioning for staff across all levels of the commissioning, tendering and procurement process.

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 this 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.”[[114]](#endnote-114)

Yet, when used properly, equalities impact assessments are useful tools to address health inequalities and ensure policies are tailors 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.

Regardless of which body ultimately takes responsibility for planning, commissioning, and procurement of community health services, it is imperative that disabled people, people living with long term conditions, and unpaid carers are also the commissioners of their own support, to manage their own care. Systems need to trust people – financially, in terms of risk assessment, and in decision making.

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.[[115]](#endnote-115)

It is imperative that third sector involvement and expertise is also at the forefront of planning, commissioning, and procurement of community health services. People accessing services should be able to choose to be supported by a voluntary sector organisation or organisation in their community, properly resourced via sustainable commissioning processes, with independent advocacy and independent advice and support organisations available to assist people who access services. Members who provided insights to inform the *Framework for Integrated Health and Services* emphasised that “commissioning and procurement processes and the resulting investment into the third sector” are central to ensuring adequate integration of health and social care services across sectors.[[116]](#endnote-116) The report concluded that:

“The third sector will be able to strengthen its contribution to health and social care integration through joint bids and innovative partnerships […] for this to be successful, it would need to be supported by the redevelopment of the commissioning and funding procedures which initially created this competitive climate.”[[117]](#endnote-117)

Question 28. What would be the benefits of Community Health and Social Care Boards managing GPs’ contractual arrangements? (Please tick all that apply)

* Better integration of health and social care
* Better outcomes for people using health and care services
* Clearer leadership and accountability arrangements
* Improved multidisciplinary team working
* Improved professional and clinical care governance arrangements
* Other (please explain below)

N/A

Question 29. What would be the risks of Community Health and Social Care Boards managing GPs’ contractual arrangements? (Please tick all that apply)

* Fragmentation of health services
* Poorer outcomes for people using health and care services
* Unclear leadership and accountability arrangements
* Poorer professional and clinical care governance arrangements
* Other (please explain below)

N/A

Question 30. Are there any other ways of managing community health services that would provide better integration with social care?

ALLIANCE response:

* **A human rights and person centred approach should be at the forefront of any service redesign, including human rights based budgeting and work on a caring economy.**
* **The National Care Service should be co-produced with disabled people, people living with long term conditions, and unpaid carers throughout, from design to implementation and improvement.**
* **The National Care Service should draw upon existing knowledge and expertise in the third sector on ways to manage and integrate community health and social care services (e.g. expertise and good practice within palliative and end of life care).**
* **The National Care Service should acknowledge the role of Community Links Practitioners in supporting people to access integrated health and social care and commit to further expansion across Scotland.**
* **Educational professionals, hospital staff, GPs and other community health practitioners should all attend mandatory training about social care, to better signpost people to care and support (including in the third sector).**

The ALLIANCE welcomes the need to focus on ensuring better integrated working between community health and social care services and support. The success of this will be dependent on a sustained focus on creating the right culture and ways of working between sectors and partners. A human rights, person centred approach should be at the forefront of any service redesign efforts looking to better integrate community health and social care services. As outlined in *My Support My Choice*, “professionals should fully incorporate equality assessments into their processes for service users and families,”[[118]](#endnote-118) with human rights, intersectionality, and conscious and unconscious bias training provided to staff across health and social care. Proposals to implement the National Care Service need to clearly outline what additional resource and financing will be made available to the health and social care sector to support this approach. Further, special attention should be paid to how budgeting decisions will be managed by the National Care Service – including human rights budgeting approaches, and work on a caring economy in order to adequately support the workforce.

It is imperative that the fundamental principles of co-production, choice, and control, and the human rights principles of equality, non-discrimination, participation and inclusion are embedded into systems from the outset. The national SDS strategy notes that, “The process for deciding on support through SDS is through co-production […] support that is designed and delivered in equal partnership between people and professionals.”[[119]](#endnote-119) The National Care Service should deliver these commitments on meaningful choice, co-production and equal partnership – beginning with conversations about support planning that are led by disabled people, people living with long term conditions, and unpaid carers, supported by social work professionals.

To achieve this, it is vital that rights are referenced and embedded throughout policy, and that all proposed changes take an explicitly human rights based approach, including improvement. This can be done, for example, by using practical tools like the five-point PANEL Principles to assess work and identify priorities for improvement against “participation”, “accountability”, “non-discrimination and equality”, “empowerment”, and “legality”.[[120]](#endnote-120) The United Nations and World Health Organisation have identified indicators and created toolkits that can be used to measure progress and improvement against specific human rights – like the right to health – and whole treaties, like the UN Convention on the Rights of Disabled People.

Also at the forefront of our recommendations to provide better integration of community health and social care services is the importance of drawing on available third sector expertise when developing policy and practice guidance. This was articulated in our *Framework for Integrated Health and Services* report as a need for Scottish Government to have a clear understanding of the third sector’s role in health and social care integration, which should be reflected and promoted in its strategy and policy. Participants highlighted that:

“An important element of this development is the continued representation and promotion of the third sector as an equal partner at a national level […] Some delegates highlighted instances of Third Sector Interfaces enabling representation of the sector by developing local forums for organisations to inform and escalate issues to the third sector representative, a practice which with support could be adopted across Integration Authorities.”[[121]](#endnote-121)

The crucial role played by independent advocacy and independent advice and support organisations in ensuring that social care is delivered effectively and justly has been emphasised throughout this consultation response. Based on views gathered in *My Support My Choice*, it is clear that people value and benefit from the work of independent advocacy and independent advice and support organisations, and these services play an important role in SDS particularly and social care generally.

As well as ensuring that these services continue to be sufficiently and sustainably 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. 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. It is imperative that independent advocacy and advice organisations remain independent. Local peer support networks should also be encouraged and supported.

Regarding community-based services and support, the ALLIANCE suggests that services such as ALISS (A Local Information System for Scotland) could also be embedded in the strategy for how people access support and resources. ALISS helps people in Scotland find and share information about services, groups, activities and resources that help them live well. We believe that people should be able to easily access information about what is available in their community. Organisations and local groups can share information about what they offer, and people – including health and social care professionals and the general public – can find information about what is available near them.[[122]](#endnote-122)

As stated in our answers to questions 3 and 4, The ALLIANCE also suggests that the proposed National Care Service needs to acknowledge the vital role played by Community Links Practitioners in supporting people and signposting people to support and resources (also referred to as social prescribing) and commits to further expansion. We know from speaking to the Community Links Practitioners employed by the ALLIANCE that many people seek information about accessing social care and SDS from Community Links Practitioners, with whom they often have well-established and trusting relationships; acknowledging this expertise and communication pathways in any planning would be advantageous to people accessing support and health and social care staff alike.

In addition to action on services explicitly concerned with health and social care support, it is also important to consider the role of services providing people with access to food and support with shopping. Everyone, including people who use social care, should have access to culturally appropriate choices of food, at times that suit them and their families. This means that Self-directed Support calculations should include meal preparation time and support with eating, if appropriate and desired by people – not just the provision of microwave meals that limit people’s choices. Furthermore, it is important to acknowledge the importance of community elements of food – such as local lunch clubs – in combating malnutrition and loneliness. Several respondents to *My Support My Choice* indicated that the “social” element of their Self-directed Support was integral to allowing them to engage with their local communities, and offered attendance at local lunch clubs as a key example. People also reflected on the significant negative impact of reduction to packages, especially cuts to support for social engagement – with ensuing increases in loneliness and isolation. We suggest that people’s right to participate in community life should be considered when making decisions about people’s care and support.

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. Existing material includes Food Train’s “Raising the Issue of Malnutrition Toolkit”.[[123]](#endnote-123) 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 following the reduction of the Universal Credit £20 uplift in 2021.

In addition to the above examples, ALLIANCE members also highlighted examples of good practice in community health and social care work in palliative and end of life care (although there is not yet equitable access to projects such as the Marie Curie Fast Track system), or similar projects to promote wrap-around care and support at home for people nearing end of life.[[124]](#endnote-124) The expertise of the third sector, community and volunteer organisations in support people nearing end of life and their families is significant, and should be properly acknowledged, valued, and sustainable resourced by the proposed National Care Service. This is particularly important given that most people who are resident in care homes are in the last 18 months of their life, and over 30,000 frail older people receive care at home every week in Scotland (in addition to other people receiving end of life care at home from other population groups).[[125]](#endnote-125) 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 and advice/support around death, dying and bereavement, hospices should be engaged as key partners in strategic commissioning processes.

One of the potential benefits of an integrated approach in providing community health and social care services is the cascading of knowledge about social care into the health care sector, including across specialist services. ALLIANCE members providing evidence to support the *My Support My Choice* report highlighted that it is imperative that primary care staff are aware and knowledgeable about the important role that social care plays in supporting people’s health and wellbeing. The report concluded on this subject as follows:

“Making more use of educational professionals, hospital staff, GPs and other community health practitioners would be particularly valuable, as well as building on the existing expertise of social workers, independent advice and support organisations.”[[126]](#endnote-126)

# Section 11 – Social work and social care

Question 31. What do you see as the main benefits in having social work planning, assessment, commissioning and accountability located within the National Care Service? (Please tick all that apply)

N/A

Question 32. Do you see any risks in having social work planning, assessment, commissioning and accountability located within the National Care Service?

N/A

# Section 12 – Nursing

Question 33. Should Executive Directors of Nursing have a leadership role for assuring that the safety and quality of care provided in social care is consistent and to the appropriate standard? Please select one.

ALLIANCE response: leadership within the health and social care sector also emerged as a prominent theme during the ALLIANCE’s National Care Service consultation event.[[127]](#endnote-127) Participants voiced a need for change to take place at a leadership level. They stressed that for this to happen social care expertise and mechanisms should be prioritised, rather than replicating the systems that are in place within the NHS. This change was about questioning the hierarchical structure and power dynamics that are more common in a medical setting, and about giving the same value to social care that is afforded to health care.

Furthermore, merging health and social care organisational structures was perceived as a risk by some, with concerns raised about the potential loss of existing good practice in the social care sector that could happen with the introduction of the National Care Service. As one participant said, “We need to exercise caution around using health structures to address social care issues – there is much within social care in terms of approaches and how we work that we need to be careful not to lose.” Others emphasised that, with the implementation of the National Care Service, capacity building at a community level needs to go hand in hand with any considerations about reforming leadership in health and social care. This echoes some of the findings from the ALLIANCE’s Implementing the Framework for Community Health and Integrated Services report, in which diversity at leadership level was also identified as a key enabler of successful health and social care integration.[[128]](#endnote-128)

Question 34. Should the National Care Service be responsible for overseeing and ensuring consistency of access to education and professional development of social care nursing staff, standards of care and governance of nursing? Please select one.

N/A

Question 35. If Community Health and Social Care Boards are created to include community health care, should Executive Nurse Directors have a role within the Community Health and Social Care Boards with accountability to the National Care Service for health and social care nursing?

N/A

# Section 13 – Justice Social Work

Question 36. Do you think justice social work services should become part of the National Care Service (along with social work more broadly)?

Please say why

N/A

Question 37. If yes, should this happen at the same time as all other social work services or should justice social work be incorporated into the National Care Service at a later stage?

N/A

Question 38. What opportunities and benefits do you think could come from justice social work being part of the National Care Service (Tick all that apply)

N/A

Question 39. What risks or challenges do you think could come from justice social work being part of the National Care Service (Tick all that apply)

N/A

Question 40. Do you think any of the following alternative reforms should be explored to improve the delivery of community justice services in Scotland? (Tick all that apply)

N/A

Questions 41. Should community justice partnerships be aligned under Community Health and Social Care Boards (as reformed by the National Care Service) on a consistent basis?

Please say why

N/A

# Section 14 – Prisons

Question 42. Do you think that giving the National Care Service responsibility for social care services in prisons would improve outcomes for people in custody and those being released? Please say why.

ALLIANCE response:

* **If the National Care Service takes responsibility for social care services in prisons, it should ensure that choice, co-production, and human rights approaches to social care support are embedded into systems from the outset, in order to ensure equitable access to social care.**

Irrespective of whether the National Care Service or another body has responsibility for providing social care services in prison, there is a clear need to improve outcomes for disabled people and people living with long term conditions who are in custody or being released from prison. The system at present is frequently disjointed and does not fully support people.

The goal of the SDS legislation was to shift the balance of power from people who provide services towards those who access them. In this way, people were to become pro-active agents instead of passive recipients of care. Social care should ensure every person in Scotland can reach their full potential – including people who have lived experience of prison.

Within *My Support My Choice*, we heard from several people who had lived experience of prison. People highlighted the difficulties they had experienced in accessing social care support, and in disconnect between support in prison and after release. They also reported widespread stigma amongst health and social care staff. They suggested that there was a need for more training and empathy for health and social care professionals about people’s human rights. Across the people we heard from there was widespread support for the need for more training in supported decision making and person centred care in order to improve people’s outcomes.[[129]](#endnote-129)

Contributors to our Independent Review of Adult Social Care engagement events also highlighted that social care needs are often unrecognised within prison populations and the wider criminal justice system. The submissions identified limited support being available for people living with long term conditions who found themselves within the criminal justice system, with no recognition of an individuals’ right to reasonable adjustment within the prison population. The submissions also highlighted data sharing and access to information to be a problem for this group of people.[[130]](#endnote-130)

If the National Care Service takes responsibility for social care services in prisons, it should ensure that choice, co-production, and human rights approaches to social care support are embedded into systems from the outset, in order to ensure equitable access to social care. Prioritising these approaches within any system redesign should ensure that people have better experiences and outcomes. Staff working within the criminal justice and prison systems should also be trained in human rights, accessibility, and the importance of supported decision making for disabled people and people living with long term conditions.

Question 43. Do you think that access to care and support in prisons should focus on an outcomes-based model as we propose for people in the community, while taking account of the complexities of providing support in prison?

ALLIANCE response: yes

Please say why.

ALLIANCE response:

* **An outcomes based model has to potential to improve people’s experience of and access to care and support in prisons.**
* **Any system redesign should prioritise human rights and person centred care.**
* **Staff working within the criminal justice and prison systems should be trained in human rights, accessibility, and the importance of supported decision making for disabled people and people living with long term conditions.**

SDS and social care are underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion. The goal of the SDS legislation was to shift the balance of power from people who provide services towards those who access them. In this way, people were to become pro-active agents instead of passive recipients of care. Social care should ensure every person in Scotland can reach their full potential – including people who have lived experience of prison.

Within *My Support My Choice*, we heard from several people who had lived experience of prison. People highlighted the difficulties they had experienced in accessing social care support, and in disconnect between support in prison and after release. They also reported widespread stigma amongst health and social care staff. They suggested that there was a need for more training and empathy for health and social care professionals about people’s human rights. Across the people we heard from there was widespread support for the need for more training in supported decision making and person centred care in order to improve people’s outcomes.[[131]](#endnote-131)

Contributors to our Independent Review of Adult Social Care engagement events also highlighted that social care needs are often unrecognised within prison populations and the wider criminal justice system. The submissions identified limited support being available for people living with long term conditions who found themselves within the criminal justice system, with no recognition of an individuals’ right to reasonable adjustment within the prison population. The submissions also highlighted that data sharing and access to information was a problem for this group of people.[[132]](#endnote-132)

An approach that focuses on outcomes has the potential to align with a human rights model of disability, prioritising people’s access to their rights and requirements. Furthermore, any system focused on outcomes should be set by the person accessing services, and informed by their own choices and priorities. While providing support is prison is complex, systems should still acknowledge people’s expertise and knowledge of their own access requirements, and enable choice as to their preferred support and requirements, with continuity of social care support provision planned between prison and release. Across *My Support My Choice* and our Independent Review of Adult Social Care engagement activity, participants discussed how important meaningful choice was to them and their families.

If the National Care Service takes responsibility for social care services in prisons, it should ensure that choice, co-production, and human rights approaches to social care support are embedded into systems from the outset, in order to ensure equitable access to social care. Staff working within the criminal justice and prison systems should also be trained in human rights, accessibility, and the importance of supported decision making for disabled people and people living with long term conditions.

# Section 15 – Alcohol and drug services

Question 44. What are the benefits of planning services through Alcohol and Drug Partnerships? (Tick all that apply)

* Better co-ordination of Alcohol and Drug services
* Stronger leadership of Alcohol and Drug services
* Better outcomes for service users
* More efficient use of resources
* **Other opportunities or benefits - please explain**

ALLIANCE response:

* **The ALLIANCE welcome the proposed “no wrong door” approach, and the potential for a simplified process for accessing care and support.**
* **Choice, co-production, and human rights approaches should be embedded into systems, in order to ensure equitable access to social care.**
* **Health and social care staff, and people working in Alcohol and Drug Partnerships, need more training in supported (rather than substitute) decision making and in trauma informed and human rights based approaches.**
* **There should be close integrated working and appropriate and prompt data sharing between Alcohol and Drug Services and Partnerships, the National Care Service, the NHS, and other related services. This should include people having access to and control of their data.**

The ALLIANCE has selected “other” in our response to this question, as there is not sufficient evidence available to demonstrate that continuing to plan services through Alcohol and Drug Partnerships will provide better co-ordination of services, stronger leadership, better outcomes for people, and more efficient uses of resources. However, there are potential benefits if any system redesign and planning process focuses on co-production and human rights based approaches. Social care should ensure every person in Scotland can reach their full potential – including people who have lived experience of addiction.

Within *My Support My Choice*, we heard from several people who had lived experience of addiction. People highlighted the difficulties they had experienced in accessing social care support, and in disconnect between support and information sharing across adult social care and alcohol and drugs services. They also reported stigma amongst health and social care professionals about alcohol and drug use. They suggested that there was a need for more training and empathy for health and social care professionals about people’s human rights.

Across the people we heard from there was widespread support for the need for more training in supported decision making and person centred care in order to improve people’s outcomes.[[133]](#endnote-133) Given these concerns, we welcome the proposed “no-wrong-door” approach to seeking access for support for drug and alcohol problems, improved connectivity between mental health and alcohol and drug services, and commitment to a trauma-informed workforce.

If services continue to be planned through Alcohol and Drugs Partnerships, then choice, co-production, and human rights approaches should be embedded into systems, in order to ensure equitable access to social care. Prioritising these approaches within any system redesign should ensure that people have better experiences and outcomes. Staff working within all connected systems should also be trained in human rights, trauma-informed practice, accessibility, and the importance of supported decision making for disabled people and people living with long term conditions.

Any proposed system should ensure that there is close integrated working and appropriate and prompt data sharing between Alcohol and Drug Services and Partnerships, the National Care Service, the NHS, and other related services. Relevant partner groups should also ensure clear communication and information sharing with health, social care and housing professionals and teams working in homelessness, including in the third sector, given known overlap with those services for people who have lived experience of addiction. Respondents to *My Support My Choice* who had experienced homelessness reported very poor implementation of SDS – particularly when they accessed social care support via addiction or housing services rather than mental health support.

Most people only received information about the different options after decisions about their care had already been made. In most cases the service users did not have any input into decisions about their care and support. Existing problems with transparency, choice, communication between services, and stigma towards people with lived experience of addiction must be clearly addressed in any revised system.

Question 45. What are the drawbacks of Alcohol and Drug Partnerships? (Tick all that apply)

* Confused leadership and accountability
* Poor outcomes for service users
* Less efficient use of resources
* **Other drawbacks - please explain**

ALLIANCE response:

* **People have reported widespread stigma among health and social care professionals towards people with lived experience of addiction or of gambling. Continuing to provide support via Alcohol and Drugs Partnerships could perpetuate existing problems.**
* **The current system for accessing support is fragmented, with areas where there is no clear governance and accountability for the provision of support and treatment to people (e.g. gambling harm).**
* **People experiencing homelessness reported very limited access to social care and SDS, with little or no choice or control.**
* **The current system lacks transparency and accessibility for many people.**

Within *My Support My Choice*, we heard from several people who had lived experience of addiction. People highlighted the difficulties they had experienced in accessing social care support, and in disconnect between support and information sharing across adult social care and alcohol and drugs services. They also reported stigma amongst health and social care professionals about alcohol and drug use. They suggested that there was a need for more training and empathy for health and social care professionals about people’s human rights. Across the people we heard from there was widespread support for the need for more training in supported decision making and person centred care in order to improve people’s outcomes.[[134]](#endnote-134) There is a risk that continuing to provide services via Alcohol and Drug Partnerships will simply perpetuate existing disparities and problems.

We have heard from ALLIANCE members that the current system is fragmented when organisations try to develop recovery models and approaches for people who have lived experience of addiction and seek investment for such models. In addition, the Scotland Reducing Gambling Harms Programme,[[135]](#endnote-135) which has been established to ensure the voices of lived experience inform actions to reduce gambling harms in Scotland, has highlighted that the current model creates gaps for people seeking recovery from gambling harms. At present, there is no clear governance and accountability for the support and treatment that people with lived experience of gambling harm require.

Respondents to *My Support My Choice* who had experienced homelessness (many of whom had also experienced addition) reported very poor implementation of SDS – particularly when they accessed social care support via addiction or housing services rather than mental health support. Most people only received information about the different options available to them after decisions about their care had already been made. In most cases the service users did not have any input into decisions about their care and support.

Existing problems with transparency, choice, communication between services, and stigma towards people with lived experience of addiction must be clearly addressed in any revised system, or there is a risk that stigma and inequitable access to health and social care are continued within the National Care Service and Alcohol and Drug Partnerships. Choice, co-production, and human rights approaches should be embedded into any proposed systems from the outset, in order to ensure equitable access to social care. Prioritising these approaches within any system redesign should ensure that people have better experiences and outcomes. Staff working within all connected systems should also be trained in human rights, accessibility, and the importance of supported decision making for disabled people and people living with long term conditions.

Question 46. Should the responsibilities of Alcohol and Drug Partnerships be integrated into the work of Community Health and Social Care Boards?

ALLIANCE response: there is a clear need for a transparent and simple process for people to access social care – whether via specialist teams in addiction services, or wider contact with social work. Whether or not the responsibilities of Alcohol and Drug Partnerships are integrated into the work of Community Health and Social Care Boards, the access to social care for people with lived experience of addition must improve. The ALLIANCE believes that the key driver for whether social care service delivery and responsibility should be reorganised is whether it will be underpinned by human rights and person centre principles and guarantee and deliver the best possible outcomes for people.

Please say why.

ALLIANCE response: whether or not the responsibilities of Alcohol and Drug Partnerships are integrated into the work of Community Health and Social Care Boards, existing problems with transparency, choice, communication between services, and stigma towards people with lived experience of addiction must be clearly addressed in any revised system. Choice, co-production, and human rights approaches should be embedded into any proposed systems from the outset, in order to ensure equitable access to social care.

Furthermore, the responsible body should ensure that the proposed system should include robust and independent oversight to ensure effective safeguards against arbitrary decisions and strong accountability mechanisms to provide redress for people if things go wrong (including access to independent advocacy and independent advice and support). To achieve this, it is imperative that rights are referenced and embedded throughout the development of the National Care Service in terms of how it engages with Alcohol and Drugs Partnerships or integrates these responsibilities into Community Health and Social Care Boards, and that all proposed changes take an explicitly human rights based approach, including improvement. This can be done, for example, by using practical tools like the five-point PANEL Principles.[[136]](#endnote-136)

Question 47. Are there other ways that Alcohol and Drug services could be managed to provide better outcomes for people?

ALLIANCE response: choice, co-production, and human rights approaches should be embedded into any proposed systems from the outset, in order to ensure equitable access to social care. To achieve this, it is imperative that rights are referenced and embedded throughout the development of the National Care Service in terms of how it engages with Alcohol and Drugs Partnerships or integrates these responsibilities into Community Health and Social Care Boards, 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.[[137]](#endnote-137)

In addition to a human rights based approach, it is important that the proposed Alcohol and Drugs Services acknowledge and draw on both third sector expertise, and lived experience – including embedding meaningful co-production in the design and development of services.

One participant with lived experience of social care support who participated in the ALLIANCE Independent Review of Adult Social Care engagement activity provided the following challenge to current systems:

“Third sector support services act independently from health, and independent of those delivering social care services – why do we need three different guidelines or ‘red tape’ when each service sector is meant to be working in partnership?”[[138]](#endnote-138)

Partnership working and co-production – with both people with lived experience and the third sector that delivers much of the tailored support to people – are key to the successful development of the proposed new systems.

Question 48. Could residential rehabilitation services be better delivered through national commissioning?

ALLIANCE response: there is not sufficient evidence to indicate whether rehabilitation services would be better delivered via national commissioning. However, there is substantial evidence available on the need for fairer commissioning models, and the ALLIANCE is strongly in favour of reform to current commissioning processes across health and social care more broadly.

Please say why.

ALLIANCE response:

* **Any proposals to move residential rehabilitation services to a national commissioning model should be co-produced with disabled people, people living with long term conditions, and unpaid carers.**
* **The National Care Service should acknowledge the vital role of the third sector in health and social care. This means developing sustainable funding and flexible approaches to commissioning with the third sector, focused on equalities, human rights and personal outcomes.**
* **Communities should be more involved in the commissioning of services.**

Any proposals to move residential rehabilitation services to a national commissioning model should prioritise co-production with disabled people, people living with long term conditions, and unpaid carers in the design of new systems and continue to take a local perspective on the pathways leading people into as well as pathways once they have accessed residential rehabilitation services. Furthermore, it should draw on the existing body of expertise and recommendations on commissioning and procurement models more broadly. Crucially, if the National Care Service does move rehabilitation services to operate within a national commissioning model, measures should be put in place so that existing good practice is not lost or diluted in the process.

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.[[139]](#endnote-139)

Sustainable funding and flexible approaches to commissioning, focused on equalities, human rights and personal outcomes – and designed to encourage innovative practice – are essential to both the successful design and implementation of the National Care Service, and to the continued survival of third sector social care organisations and the vital services they provide.

In the 2019 the Coalition of Care and Support Providers in Scotland (CCPS) published their Business Resilience Survey, where just under 50% of respondents (third sector providers) stated that they had abstained or withdrawn from a procurement process in the 12 months preceding the survey.[[140]](#endnote-140) Respondents reported that “financial sustainability of services was a primary consideration […] when considering whether to bid for a service”, especially when competing against private companies for contracts. More broadly, CCPS warned that for two years running an increasing number of providers “required additional funding to be sustainable […] using reserves and cross-subsidising to fund service deficits and maintain services.”

They concluded the report as follows:

“Providers are well aware of the financial difficulties that Local Authorities and Integrated Joint Boards (IJBs) face. However, it is not sustainable to continue to expect social care providers to pick up this cost for unsustainably funded services. […] The recent Accounts Commission report that local authorities and IJBs are facing similar challenges with their own funding suggests that this situation is unlikely to improve without intervention.” [[141]](#endnote-141)

At our 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. It was described that by involving communities more in the commissioning of services and support that it would be possible to make better use of the range of resources available to support a person to live their life.

It was shared that participants felt that the role of the third sector is one of the biggest strengths of our social care system – its ethos of person centred support provides 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 current commissioning processes were overhauled.

Participants felt that 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.[[142]](#endnote-142) People also commented that specialist support, including in support for people with alcohol and drug problems, is readily available via the third sector, but participants felt it needs to be better recognised and valued by the public sector.

The ALLIANCE proposes that any new commissioning process should embed human rights PANEL principles[[143]](#endnote-143) throughout the design of the commissioning and procurement process. It should also ensure that co-production is embedded throughout any commissioning and procurement models (during design, implementation, and review). Partnership working and co-production – with both people with lived experience and the third sector that delivers much of the tailored support to people – are key to the successful development of the proposed new systems.

Question 49. What other specialist alcohol and drug services should/could be delivered through national commissioning?

N/A

Question 50. Are there other ways that alcohol and drug services could be planned and delivered to ensure that the rights of people with problematic substance use (alcohol or drugs) to access treatment, care and support are effectively implemented in services?

N/A

# Section 16 – Mental health services

Question 51. What elements of mental health care should be delivered from within a National Care Service? (Tick all that apply)

* Primary mental health services
* Child and Adolescent Mental Health Services
* Community mental health teams
* Crisis services
* Mental health officers
* Mental health link workers
* **Other – please explain**

ALLIANCE response:

* **Service provision for mental health needs to be broad, ranging from preventative and recovery services to critical support to enable people to live independently and well.**
* **Eligibility criteria and long waiting lists are significant barriers to people being able to access mental health support at the right time; these issues need to be addressed within any service redesign in the National Care Service.**
* **Third sector organisations should be valued and sustainably funded, as the principal providers of support for individuals with mental health conditions.**
* **Health and social care staff should be trained in supported (not substitute) decisions making, mental health awareness training, and in trauma informed and human rights based approaches.**
* **Any revised system to provide mental health services within the National Care Service should be co-produced with people with lived experience of mental health problems and their families.**

Mental health service provision was raised as a concern across our Independent Review of Adult Social Care engagement activity. It is widely recognised that people with lived experience of mental health problems in Scotland do not enjoy their human rights as fully as they could, and that barriers also exist for unpaid carers – for example due to concerns about patient confidentiality. Responses to our Independent Review of Adult Social Care engagement activity stated that service provision for mental health needs to be broad, ranging from preventative and recovery services to critical support which people need to live independently and well, as part of the community.

People identified eligibility criteria as the main barrier to accessing mental health support – both within health and social care – meaning people are unable to access the most appropriate support at the right time to allow them to live their lives well. Waiting lists for “mild to moderate” mental health support are long, and people described a system that is failing to keep people well and prevent their health deteriorating to a point where they then meet the “at risk” criteria.

Third sector organisations identified themselves during discussions as the principal lead in providing support for individuals with mental health conditions, despite it being a statutory requirement for local authorities. They emphasised the importance of self management centred support, holistic services and the contribution of lived experience in both service design and delivery.

We also know from *My Support My Choice* that many people with lived experience of mental health problems do not have equitable access to social care.[[144]](#endnote-144) It is important that any redesign of services within the National Care Service ensures that these existing gaps in provision are met, and that people with mental health problems have the same access to social care and support as those accessing services for other reasons. This is particularly important when it comes to aspects of choice and control over support, as people with mental health problems were less likely to have been offered information about all four options of SDS than respondents to *My Support My Choice* more broadly.[[145]](#endnote-145)

Of the people with lived experience of mental health problems who spoke to the *My Support My Choice* research team in interviews and focus groups, several felt that they had been offered limited or no choice over how their SDS was arranged, without all four SDS options being offered. One person summarised the experience of people with mental health problems accessing social care, that “we are not able to make choices and decisions; it’s the ones above us.”[[146]](#endnote-146)

Work by the ALLIANCE on *The Independent Inquiry into Mental Health Services in Tayside* (2018), based on the views of over 200 people with lived experience of mental ill health, had the following concrete recommendations to improve people’s experiences:

* There needs to be investment in preventative, community assets […] that could reduce reliance on formal services.
* Staff employed by statutory agencies should receive mental health awareness training.
* Each area […] should have a crisis intervention centre that is open out of hours. The centre would be staffed predominantly by volunteers and those who have experience with mental ill health.
	+ Such a centre should capture, rather than replace, the current on the ground resources […]
	+ This includes Breathing Space, the Samaritans, Spiritual Care and other third sector organisations.
	+ There needs to be greater collaboration between these groups to offer a more consistent and joined up approach to people […]
* While respecting confidentiality, the role of family carers should be seen as a valued part of the assessment process with the promotion of advance statements and other tools to assist with anticipatory care planning.
	+ People should be informed about Advance Statements by clinicians and supported to develop one by someone who has been through the process or a local advocacy group.
* The assessment process needs to be reviewed with a view to expanding the information available and examining risk assessment tools.
* Digital person held records should be explored as a way to support joining up services and give a better picture of an individual.
* Processes around access and referrals need to be person led rather than service led. In order to support this there should be:
	+ Routine care planning and medication reviews.
	+ Link workers attached to GP practices to connect services.[[147]](#endnote-147)

The priority throughout the process of service redesign should be on improving the quality, equitability, and access to services for people with mental health problems including services and support with a focus on prevention, early intervention, and recovery. Co-production with people with lived experience of mental ill health and their families should be at the forefront of this process, and embedded throughout, from design to implementation and review. Throughout all of this, the National Care Service should value and support the work of the third sector in supporting people with mental health problems.

Question 52. How should we ensure that whatever mental health care elements are in a National Care Service link effectively to other services, e.g. NHS services?

ALLIANCE response:

* **The National Care Service should value and draw upon the expertise of third sector organisations specialising in support people with mental health problems, in designing service connectivity (including data sharing agreements).**
* **National Care Service legislation and mental health law should comply with the UNCRPD, focusing on people’s “will and preference” rather than substitute decision-making.**
* **The National Care Service should acknowledge the role played by Community Links Practitioners in supporting people and signposting them to services and commit to expanding the programme further across Scotland.**

Any work to link National Care Service mental health services to other services (e.g. NHS) needs to prioritise human rights and equalities concerns, and accommodate the role and significance of the third sector in service delivery. The ALLIANCE response to the Scottish Mental Health Law Review phase 1 consultation (May 2020) provided key recommendations on interlinked services for mental health, based on people’s lived experience, including:

* “Mental health engages a wide array of human rights, which are indivisible, interdependent and interrelated, however the Act does not protect these rights as well as it could. The ALLIANCE believes equalities and human rights should be incorporated into mental health law and mainstreamed within practice. This includes robust oversight to ensure effective safeguards against arbitrary decisions and strong accountability mechanisms to provide redress for people if things go wrong.”[[148]](#endnote-148)
* “The ALLIANCE believes that mental health law would better maximise participation in decision-making if it complied with the UNCRPD, with greater regard given to a person’s ‘will and preference’ rather than substitute decision-making. In the meantime, further work is needed to boost the number of good quality advance statements and ensure compliance with them. Increased 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.”[[149]](#endnote-149)

One participant with lived experience of social care support who participated in the ALLIANCE Independent Review of Adult Social Care engagement activity provided the following challenge to current systems:

“Third sector support services act independently from health, and independent of those delivering social care services – why do we need three different guidelines or ‘red tape’ when each service sector is meant to be working in partnership?”[[150]](#endnote-150)

In line with our answers to questions 3, 5, and 26, regarding community-based services and support for mental health, the ALLIANCE suggests that services such as ALISS (A Local Information System for Scotland) could also be embedded in the strategy for how people access support and resources. ALISS helps people in Scotland find and share information about services, groups, activities and resources that help them live well. We believe that people should be able to easily access information about what is available in their community. Organisations and local groups can share information about what they offer, and people – including health and social care professionals and the general public – can find information about what is available near them.[[151]](#endnote-151)

The ALLIANCE also suggests that the proposed National Care Service needs to acknowledge the vital role played by Community Links Practitioners in supporting people and signposting people to support and resources (also referred to as social prescribing) and commits to further expansion. We know from speaking to the Community Links Practitioners employed by the ALLIANCE that many people seek information about accessing social care and SDS from Community Links Practitioners, with whom they often have well-established and trusting relationships; acknowledging this expertise and communication pathways in any planning would be advantageous to people accessing support and health and social care staff alike.

Partnership working and co-production – with both people with lived experience and the third sector that delivers much of the tailored support to people – are key to the successful development of the proposed new systems. During service and system design, the focus should remain on the outcomes for people accessing services and streamlining their access to appropriate care and support (specifically people with lived experience of mental health problems).

# Section 17 – National Social Work Agency

Question 53. What benefits do you think there would be in establishing a National Social Work Agency? (Tick all that apply)

N/A

Question 54. Do you think there would be any risks in establishing a National Social Work Agency?

N/A

Question 55. Do you think a National Social Work Agency should be part of the National Care Service?

N/A

Question 56. Which of the following do you think that a National Social Work Agency should have a role in leading on? (Tick all that apply)

N/A

# Section 18 – Reformed IJBs: Community Health and Social Care Boards

**Governance model**

Question 57. “One model of integration… should be used throughout the country.” (Independent Review of Adult Social Care, p43). Do you agree that the Community Health and Social Care Boards should be the sole model for local delivery of community health and social care in Scotland?

ALLIANCE response: there is a clear need for a single, transparent and accessible model of integrated health and social care across Scotland, as demonstrated and recommended in the Independent Review of Adult Social Care (and wider feedback from ALLIANCE members). This could be fulfilled by Community Health and Social Care Boards – but it is essential than any change is focused on action for people accessing services, rather than on high-level system redesign without improvement on the ground.

Please say why.

ALLIANCE response:

* **There should be a single, transparent and accessible model of integrated health and social care across Scotland. Everyone should have equitable access to social care, including all four options of SDS.**
* **If the proposed Community Health and Social Care Boards are created, they must embed co-production and human rights based approaches from the outset.**
* **Community Health and Social Care Boards should have 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.**
* **The third sector and housing services must be viewed as equal partners within the proposed Community Health and Social Care Boards.**
* **The National Care Service should take careful note of the failings of integration in creating Community Health and Social Care Boards, and prioritise people’s expertise and outcomes over organisational power sharing agreements.**

The Independent Review of Adult Social Care highlighted the variety of care across Scotland, and the need for greater consistency of service provision. The Care Inspectorate’s 2019 thematic review of SDS also found that there is inconsistent availability of all four SDS options around the country and some people do not have access to all four options (a finding echoed in *My Support My Choice*).[[152]](#endnote-152) *My Support My Choice* also found that people experienced problems with retaining their care and support when they moved across different local authority boundaries; having one equitable model of integration and access to social care, overseen by Community Health and Social Care Boards, could assist in combatting this “postcode lottery” of service provision. However, it is essential that Community Health and Social Care Boards are formed with co-production at their heart from the outset, with full engagement from and with disabled people, people living with long term conditions, and unpaid carers, with representatives with lived experience having full voting rights on all Community Health and Social Care Boards, and their attendance (properly reimbursed) a pre-requisite for quorate meetings and decision-making.

At present, the health and social care sectors are frequently fragmented, with mixed communication across, and even within, organisational boundaries, and a lack of integrated working across the whole system of health and social care (as detailed in *Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future*).[[153]](#endnote-153) This report outlined a pressing need for local mechanisms for people to access support, that are firmly linked nationally into the NHS and proposed National Care Service. At our Independent Review of Adult Social Care engagement events, people acknowledged that there are a range of different parties involved in social care, and participants emphasised the need for improved integration of wider community support, including housing, leisure, employability and transport. Whilst there has been an attempt to integrate health and social care over the last seven years, there was felt to be a need to get the two working closer and better together and to connect to “an informed hub” of multi agencies.

Participants were of the view that Integration Authorities have yet to include housing organisations and the third sector as equal partners, limiting the potential they could achieve if they worked collaboratively as equals. It was highlighted that integration needs to be visible at delivery level. In the engagement sessions, it was felt that it would be pivotal to the transformational change needed if the NHS, local authorities and health and social care partnerships agree on a data set they can share with multiple agencies, and for the individual to own and hold this information. This would encourage empowerment and community engagement.

One attendee with lived experience summarised their perspective as follows, and highlighted the need to learn from the problems with integration:

“Third sector support services act independently from health, and independent of those delivering social care services – why do we need three different guidelines or ‘red tape’ when each service sector is meant to be working in partnership?”[[154]](#endnote-154)

These concerns about integration, and the learning it offers for the creation of the National Care Service, are not new. In 2018, the ALLIANCE published *We Need To Talk About Integration*, an anthology of people from the third and independent sector, people with lived experience, and individuals from the public sector and academia reflecting on integration (and its successes and failures).[[155]](#endnote-155) Annie Gunner Logan, Director of CCPS, summarised her chapter as follows:

“What needs to happen next? Here’s some thoughts. The integration project needs to stop bulldozing Self-directed Support, and instead be guided by it. Commissioning and procurement need to change out of all recognition, if providers are to be enabled to deliver transformation and innovation. And we need to face up to the fact that marrying a multi-provider price-competitive market (social care) with a top-down directly-funded public delivery system (the NHS) has thrown up all kinds of barriers to the potential of our sector to deliver truly integrated services.”[[156]](#endnote-156)

The creation of the proposed Community Health and Social Care Boards should take careful note of the failings of integration and prioritise people’s expertise and outcomes over service redesign and organisational power sharing agreements.

Question 58. Do you agree that the Community Health and Social Care Boards should be aligned with local authority boundaries unless agreed otherwise at local level?

As with our previous responses to questions in this section, the ALLIANCE recommends that any change is focused on action for people accessing services, rather than on high-level system redesign without improvement on the ground.

The ALLIANCE proposes that any process should explicitly embed human rights based approaches throughout (e.g. using PANEL principles)[[157]](#endnote-157) and ensure meaningful co-production with disabled people, people living with long term conditions, and unpaid carers throughout design, implementation, and review. Partnership working and co-production – with both people with lived experience and the third sector – are key to the successful development of the proposed new systems. Finally, if the Community Health and Social Care Boards take responsibility for implementing much of the proposed National Care Service, measures should be put in place so that existing good practice is not lost or diluted in the process.

Question 59. What (if any) alternative alignments could improve things for service users?

In line with our responses to the previous questions in this section, the ALLIANCE recommends that any change is focused on action for people accessing services, rather than on high-level system redesign without improvement on the ground.

The ALLIANCE proposes that any process should explicitly embed human rights based approaches throughout (e.g. using PANEL principles)[[158]](#endnote-158) and ensure meaningful co-production with disabled people, people living with long term conditions, and unpaid carers throughout design, implementation, and review. Partnership working and co-production – with both people with lived experience and the third sector – are key to the successful development of the proposed new systems. Finally, if the Community Health and Social Care Boards take responsibility for implementing much of the proposed National Care Service, measures should be put in place so that existing good practice is not lost or diluted in the process.

Question 60. Would the change to Community Health and Social Care Boards have any impact on the work of Adult Protection Committees?

The ALLIANCE suggests that any shift to Community Health and Social Care Boards should ensure that case reviews (including significant case reviews) under the current remit of the Adult Support and Protection (Scotland) Act 2007 follow a consistent process for complaints and case reviews under wider system reform for social care and prioritise people’s human rights.

**Membership of Community Health and Social Care Boards**

Question 61. The Community Health and Social Care Boards will have members that will represent the local population, including people with lived and living experience and carers, and will include professional group representatives as well as local elected members. Who else should be represented on the Community Health and Social Care Boards?

ALLIANCE response: It is essential that Community Health and Social Care Boards are formed with co-production at their heart from the outset, with full engagement from and with a wide range of disabled people, people living with long term conditions, and unpaid carers, with their attendance (properly reimbursed and remunerated) a pre-requisite for quorate meetings and decision-making. In order to ensure as much diversity as possible, there should be multiple lived experience members in each Community Health and Social Care Board, to enable representation from a range of age groups, genders, disabilities and long term conditions, along with other protected characteristics.

It is also the position of the ALLIANCE that strong engagement infrastructure needs to be invested in to enable the involvement of the local population in a way that meets their needs and preferences for engaging with this local decision-making body for health and social care. The ALLIANCE delivers a range of engagement programmes and is increasingly learning that a “one size fits all” approach will not suffice to ensure that we are hearing from, listening to and acting upon the needs, interests and priorities of people with lived and living experience. Such approaches are also in line with the “planning with people” guidance issued by Scottish Government and COSLA in March 2021.[[159]](#endnote-159)

Question 62. “Every member of the Integration Joint Board should have a vote” (Independent Review of Adult Social Care, p52). Should all Community Health and Social Care Boards members have voting rights?

ALLIANCE response: yes. It is essential that disabled people, people living with long term conditions, and unpaid carers who are members of Boards have full voting rights.

Question 63. Are there other changes that should be made to the membership of Community Health and Social Care Boards to improve the experience of service users?

ALLIANCE response: members with lived and living experience and unpaid carers should have full voting rights and be fully renumerated and reimbursed for their time – both in terms of preparation and attendance at meetings (including travel time), as well as their expenses paid. Eilidh Brown, Partnership Development Lead at TSI Moray summarised the situation as follows:

“When public sector partners do not fully commit to this type of mutual process, or recede from this because the shift in power feels uncomfortable, relationships become strained, and trust tarnished. Yet, we know that there is a willingness to work together in a different way, if decision making were re-structured to become fairer, more inclusive and more fully embracing of the subsidiarity principle. […] This mutual approach must be a pre-requisite for the establishment of a national care service that can embrace rather than detract from the principle of subsidiarity, keeping decision making as close to the ground as possible, by resourcing and supporting the development and delivery of care from the bottom up, where people with lived experience are not just heard but supported to be central to service design and active participants in financial decision-making processes.”[[160]](#endnote-160)

As outlined in our response to the previous question, the ALLIANCE believes that strong engagement infrastructure needs to be invested in to enable the involvement of the local population in a way that meets their needs and preferences for engaging with this local decision-making body for health and social care. The ALLIANCE delivers a range of engagement programmes and is increasingly learning that a “one size fits all” approach will not suffice to ensure that we are hearing from, listening to and acting upon the needs, interests and priorities of people with lived and living experience. There is also a pressing need to acknowledge and sustainably fund the range of third sector organisations that are well placed to support people to contribute to Community Health and Social Care Boards (or any other organisational structure).

The membership of Community Health and Social Care Boards should be made public, and people should be able to email or write to the Clerk of each Board to request that correspondence be forwarded to specific members, to enable members to represent people’s concerns and opinions to the Board. Processes for communication should be transparent and available in a variety of accessible formats.

**Community Health and Social Care Boards as employers**

Question 64. Should Community Health and Social Care Boards employ Chief Officers and their strategic planning staff directly?

ALLIANCE response: research carried out by the ALLIANCE into integration highlighted that many health and social care staff reported “challenges in establishing and agreeing arrangements for decision-making and accountability”. They stated that:

“Even where new committee structures had been established and strategic plans had been agreed, there continued to be tensions, most often between HSCPs and NHS boards, about (i) which aspects of health and social care should be under the direction / authority of the partnership(s) and which were the responsibility of the board; (ii) how resources should be allocated; and (iii) which corporate entity was responsible for managing certain resources. In some areas, it was reported that attempts made to resolve these serious fundamental questions had resulted in conflict and damaged relationships. One interviewee [a senior manager] commented that this issue was the number one challenge for integration in her area: ‘I think the challenge around integration is related to decision making and authority, and who has the right to make decisions. So in the absence of a clarity around decision making and authority comes a bit of confusion and apathy which delays change.’”[[161]](#endnote-161)

There is a potential disjoint between Chief Officers being both employed by and directing organisations, which contributed in part to the confusion detailed above regarding integration. Any new system design in the National Care Service should draw on learning from integration, including with regard to direct employment of staff.

Question 65. Are there any other staff the Community Health and Social Care Boards should employ directly? Please explain your reasons.

N/A

# Section 19 – Commissioning of services

Question 66. Do you agree that the National Care Service should be responsible for the development of a Structure of Standards and Processes? If no, who should be responsible for this?

ALLIANCE response: the National Care Service could be responsible for the development of a Structure of Standards and Processes. If they do take responsibility for this work, they should ensure that lived experience is at the forefront of the development and implementation of such material.

Question 67. Do you think this Structure of Standards and Processes will help to provide services that support people to meet their individual outcomes?

**Yes.** The Structure of Standards and Processes has the potential to help to provide services that support people to meet their individual outcomes. However, in order to achieve this, it is essential that choice, co-production, and human rights approaches are embedded into any proposed systems from the outset, in order to ensure that disabled people, people living with long term conditions, and unpaid carers lead on choices pertaining to their care and support.

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.[[162]](#endnote-162) This should include taking human rights based approached 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 people’s experiences of social care and support.

Finally, partnership working and co-production with people with lived experience are key to the successful development of the proposed new Structure of Standards and Processes and enabling people to meet their individual outcomes.

Question 68. Do you think this Structure of Standards and Processes will contribute to better outcomes for social care staff?

ALLIANCE response:

* **Choice, co-production, and human rights approaches should be embedded into any proposed systems from the outset.**
* **There is an urgent need to address established issues with social care workforce recruitment, retention, training and quality, and to acknowledge and respond to how care work is gendered and undervalued.**
* **Ensuring paid carers receive a good wage for every hour worked is the right thing to do. To achieve the best quality care, we must prioritise paying social care staff better, and giving them appropriate access to training and professional development.**

**Yes.** The Structure of Standards and Processes has the potential to contribute to better outcomes for social care staff. However, in order to achieve this, 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.[[163]](#endnote-163) This should include taking human rights based approached 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.

With regard to wider issues in the social care workforce, 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*).[[164]](#endnote-164) 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.[[165]](#endnote-165)
* 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.[[166]](#endnote-166)

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.[[167]](#endnote-167) This undervaluation of women’s work underpins occupational segregation, the gender pay gap and women’s poverty.”[[168]](#endnote-168)

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.[[169]](#endnote-169) 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.”[[170]](#endnote-170) 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 – and this action must be a key part of any work to develop a Structure of Standards and Processes.

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 successful development of the proposed new Structure of Standards and Processes.

Question 69. Would you remove or include anything else in the Structure of Standards and Processes?

ALLIANCE response:

* **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.**
* **Sustainable funding and flexible approaches to commissioning, focused on equalities, human rights and personal outcomes – and designed to encourage innovative practice – are essential to the successful design and implementation of the National Care Service.**
* **The Structure of Standards and Processes should include person centred standards, and agreement on eligibility criteria (to end inequalities across local authorities), and a national structure to enable partnership working across Scotland (including the third sector). They should also embed human rights PANEL principles throughout.**

As discussed in our response to question 48, 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.[[171]](#endnote-171)

In the 2019 Coalition of Care and Support Providers in Scotland (CCPS) Business Resilience Survey, just under 50% of respondents (third sector providers) stated that they had abstained or withdrawn from a procurement process in the 12 months preceding the survey.[[172]](#endnote-172) Respondents reported that “financial sustainability of services was a primary consideration […] when considering whether to bid for a service”, especially when competing against private companies for contracts. More broadly, CCPS warned that for two years running an increasing number of providers “required additional funding to be sustainable […] using reserves and cross-subsidising to fund service deficits and maintain services.”

They concluded the report as follows:

“Providers are well aware of the financial difficulties that Local Authorities and Integrated Joint Boards (IJBs) face. However, it is not sustainable to continue to expect social care providers to pick up this cost for unsustainably funded services. […] The recent Accounts Commission report that local authorities and IJBs are facing similar challenges with their own funding suggests that this situation is unlikely to improve without intervention.” [[173]](#endnote-173)

Sustainable funding and flexible approaches to commissioning, focused on equalities, human rights and personal outcomes – and designed to encourage innovative practice – are essential to the successful design and implementation of the National Care Service.

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 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,[[174]](#endnote-174) 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.”[[175]](#endnote-175)

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.”[[176]](#endnote-176)

At our 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. It was described that by involving communities more in the commissioning of services and support that it would be possible to make better use of the range of resources available to support a person to live their life.

It was shared that participants felt that the role of the third sector is one of the biggest strengths of our social care system – its ethos of person centred support provides 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.

Participants felt that 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.[[177]](#endnote-177)

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, commissioning and procurement models should consider the significant role played by the third sector in palliative and end of life care.[[178]](#endnote-178) 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 and advice/support around death, dying and bereavement, hospices should be engaged as key partners in strategic commissioning processes.

We also heard from participants in our Independent Review of Adult Social Care engagement events about the structure of the National Care Service. Participants stated that there needs to be a shared vision of social care founded upon rights that allows people to live rich and fulfilling lives. At a national level, those who engaged with the ALLIANCE felt it could be helpful to have a common purpose, with aligned principles and values, detailed as follows:

* National Standards – person centred standards, based on what matters to people, limited in number.
* National Agreement on eligibility criteria, to end the discrepancies in delivery across local authorities.
* A national structure, providing career structure across integrated partnerships (including the third sector) would provide good foundations, with operations running locally, providing specialist support

Respondents also emphasised that a balance must be found between local service delivery and national standards, with reliable application of those national standards right across the country. Participants emphasised that a lot of care is best delivered locally, by local third sector organisations and the diversity of social care provision is a strength. For this to be achieved there needs to be increased resources and accurate support for the third sector to ensure a quality local delivery service, which provides people with options for care and support which meet their needs. Specialist support is readily available via the third sector, but participants felt it needs to be better recognised and valued by the public sector.

We also support calls from the Coalition of Care Providers in Scotland to provide more detailed statutory guidance for the reform of procurement and competitive tendering of health and social care contracts. These reforms should ensure that procurement and tendering processes are based on quality, collaboration, and co-production with people accessing and providing social care and support, and focused on the rights and requirement of disabled people, people living with long term conditions, and unpaid carers. The Independent Review of Adult Social Care recommended that:

“A shift from competitive to collaborative commissioning must take place and alternatives to competitive tendering developed and implemented at pace across Scotland. Commissioning and procurement decisions must focus on the person's needs, not solely be driven by budget limitations.”[[179]](#endnote-179)

In order to delivery on outcomes and improvement for both people accessing and delivering social care support, the National Care Service must ensure that commissioning and procurement models are redesigned, following human rights based approaches and meaningful co-production.

**The ALLIANCE proposes to add the following items to the Structure of Standards and Processes, which will:**

* **Embed human rights PANEL principles throughout the design of the commissioning, tendering, and procurement process.**
* **Ensure that co-production is embedded throughout the commissioning, tendering, and procurement models developed and used in the National Care Service (during design, implementation, and review).**

Within commissioning, tendering and procurement processes, the National Care Service should commit to giving explicit priority to employers who evidence compliance with the following actions:

* Pay all employees and contractors at least the real Living Wage, as set by the Living Wage Foundation,[[180]](#endnote-180) and cover travel costs connected with work, including paid travel time. This is particularly important for people providing care at home to several people a day across different locations.
* Recognise and offer increased pay to people with specialist skills within social care work – e.g. Deafblind guide communicators, people with advanced paediatric first aid qualifications, and those with other specialised knowledge and training.[[181]](#endnote-181)
* Do not use zero-hour contracts (or equivalent).
* Support workers to make autonomous judgements if people’s care and support requirements (e.g. care at home) need to take longer than originally scheduled.
* Support flexible and part-time working requests.
* Support employees and contractors who request caring leave.
* Provide employees and contractors with appropriate training and development opportunities (where people are paid during their attendance at any training etc.).

**Market research and analysis**

Question 70. Do you agree that the National Care Service should be responsible for market research and analysis?

ALLIANCE response: the National Care Service could be responsible for marketing research and analysis. If they do take responsibility for this work, they should ensure that lived experience is at the forefront of the development and implementation of research processes. In particular, they should focus on data collection and analysis of measurable outcomes for people accessing services, using co-produced research design and mixed methods.

If no, who should be responsible for this?

* Community Health and Social Care Boards
* Care Inspectorate
* Scottish Social Services Council
* NHS National Procurement
* Scotland Excel
* No one
* Other – please comment

ALLIANCE response: whoever takes responsibility for market research and analysis should prioritise improvements to create a fairer, more transparent commissioning and procurement process, which is co-produced with people who access and provide care and support, and acknowledges both people as commissioners of their own care, and the role of the third sector.

**National commissioning and procurement services**

Question 71. Do you agree that there will be direct benefits for people in moving the complex and specialist services as set out to national contracts managed by the National Care Service?

ALLIANCE response: there is insufficient evidence available as to whether people will directly benefit from moving complex and specialist services to the management of the National Care Service. However, there is a clear need to provide appropriately tailored and funded support to people with complex requirements, and a management model that prioritises their rights could improve the quality of life, choice, and control for people accessing complex or specialist services.

If no, who should be responsible for this?

* Community Health and Social Care Boards
* NHS National Procurement
* Scotland Excel

ALLIANCE response: the proposed move to have complex and specialist services set out in national contracts managed by the National Care Service has the potential to improve people’s experiences of social care; but it also carries risks. Firstly, while a coherent national approach to complex and specialist services may assist with some of the problems around commissioning of services, the provision of consistent good quality care across the country, and varying application of eligibility criteria, it needs to do so without compromising locally effective services and individual expertise (including lived experience and that of third sector providers). Furthermore, radical overhaul of current service provision and delivery runs the risk of focusing attention on system change rather than on the experiences of (and outcomes for) people accessing services and unpaid carers. This concern echoes some views expressed about the integration of health and social care.[[182]](#endnote-182)

**To counter these risks, the ALLIANCE recommends that the National Care Service should:**

* **Explicitly integrate equality and human rights 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.[[183]](#endnote-183)**
* **Adopt human rights budgeting to embed fairness, transparency and people’s participation in financial decision making, resource allocation and spend, monitoring and accountability.[[184]](#endnote-184)**
* **Empower rights holders (people who access social care, unpaid carers, social care workers) to know, understand and claim their rights, and support duty bearers (e.g., public bodies, service providers, improvement and scrutiny agencies) to know, understand and fulfil their human rights obligations, for example through the prism of the five-point PANEL principles.[[185]](#endnote-185)**
* **Ensure that co-production is embedded throughout the design, development and delivery of the National Care Service – not merely in consultation, but as an integral part of the process.**
* **Use accessible and inclusive communication to work with people with lived experience in the design of policy and public services, including formats such as Community Languages,[[186]](#endnote-186) BSL, Braille, Moon, Easy Read, clear and large print, and paper formats.**
* **Support and work directly with third and independent health and social care organisations as equal and valued partners, resourced by additional, sustainable, ongoing and secure funding.**

At our Independent Review of Adult Social Care engagement events, participants stated that the third sector is one of the biggest strengths of our social care system – its ethos of person centred support provides 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 – including that of complex and specialist settings.

Participants felt that 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. People also commented that specialist support is readily available via the third sector, but participants felt it needs to be better recognised and valued by the public sector.

As discussed in our answers to questions earlier in this consultation, the ALLIANCE also suggests that the proposed National Care Service needs to acknowledge the vital role played by Community Links Practitioners in supporting people and signposting people to support and resources (also referred to as social prescribing) and commits to further expansion. We know from speaking to the Community Links Practitioners employed by the ALLIANCE that many people seek information about accessing social care and SDS from Community Links Practitioners, with whom they often have well-established and trusting relationships; acknowledging this expertise and communication pathways in any planning would be advantageous to people accessing support and health and social care staff alike.

Partnership working and co-production – with both people with lived experience and the third sector that delivers much of the tailored support to people – are key to the successful development of the proposed new systems.

# Section 20 – Core principles for regulation and scrutiny

We propose the following core principles. We have numbered these to make it easier when answering the questions, but they are all equally important.

1. Scrutiny and assurance should support human rights-based care, focus on outcomes for people, and the positive impact community health and social care services are making to their lives, including the relationships staff have with them.
2. Activity should be targeted, proportionate, intelligence-led, and risk-based. This approach will allow the regulator to choose different types of scrutiny, assurance, or quality improvement intervention relative to the individual service and how it is performing.
3. The NCS should generally seek to review, update, and improve standards and practices as an organisation and across the care sector on a regular and ongoing basis (this is a separate role and process from any improvements which those who have responsibility for delivering social care services (or overseeing those) may be required to make arising from enforcement or other action by the regulator).
4. There should be a strong link between the regulation of the workforce and their professional standards and the inspection and scrutiny of the services they work in.
5. Overall national scrutiny should involve the regulator working collaboratively, where possible, with other professions and agencies and continue to be informed by lessons learnt and good practice arising from the experience of the pandemic.
6. Regulation is fundamental to ensure a qualified and skilled social care workforce which enables employers to deliver high quality, responsive care and support.
7. Regulation is a key element in ensuring the safety of vulnerable people, ensuring high standards for practice, conduct, training and education across the workforce.
8. Scrutiny and assurance should aim to reduce inequalities with an emphasis on people, prevention, partnership and performance.
9. Where possible, regulators should involve people in the development and delivery of scrutiny approaches and amplify the voice of people experiencing care.
10. Where appropriate, scrutiny and assurance should take account of legislative requirements, Scottish Government policy, national standards, and codes of practice.

Question 72. Is there anything you would add to these core principles?

The ALLIANCE welcomes the statements in the core principles that the National Care Service will “support human rights-based care” in National Care Service regulation, reducing inequality, and the “development and delivery of scrutiny approaches”. However, we suggest that the core principles could go further in their commitments, as follows:

* Scrutiny and assurance should not only support but practice and embed human rights throughout system delivery. It should also include the use of trauma informed approaches to care and support. (Principle 1)
* Interventions by the regulator, especially around risk, should explicitly include the voices and opinions of people accessing services and unpaid carers in the decision-making process. (Principle 2)
* Any reviews and updates to National Care Service organisational standards and practices should be co-produced with disabled people, people living with long term conditions, and unpaid carers, and changes clearly communicated to people who access services, alongside published Equality and Human Rights Impact Assessments (EQHRIAs) for any changes. (Principle 3)
* Development of national scrutiny should also involve disabled people, people living with long term conditions and unpaid carers as well as social care professionals and agencies when reflecting on examples of good practice and lessons learned. (Principle 5)
* In addition to “aim[ing] to reduce inequalities”, the regulator should work closely with data collection teams to analyse areas where people are not receiving equitable access to or quality of social care and develop regularly reviewed targets for improving those people’s experiences. (Principle 8)
* Rather than stating that regulators should “involve people in the development and delivery of scrutiny approaches and amplify the voice of people experiencing care”, “where possible”, there should be a commitment to embedding co-production throughout the process (not just involvement), with meaningful integration of lived experience in design and decision making throughout the process. (Principle 9)
* Finally, we suggest that all communication from the regulators should use accessible and inclusive communication to work with people with lived experience in the design of policy and public services, including formats such as Community Languages,[[187]](#endnote-187) BSL, Braille, Moon, Easy Read, clear and large print, and paper formats.

Question 73. Are there any principles you would remove?

ALLIANCE response: no.

Question 74. Are there any other changes you would make to these principles?

The ALLIANCE welcomes the statements in the core principles that the National Care Service will “support human rights-based care” in National Care Service regulation, reducing inequality, and the “development and delivery of scrutiny approaches”. However, we suggest that the core principles could go further in their commitments, as detailed in our answer to Question 72.

We also support proposals from our members, including Close the Gap, for a wider use of gender sensitive evaluation of social care work. Any evaluation system must take active steps to address in-built bias (including gender bias but engaging with intersectional biases across other protected characteristics as well). This would be in line with calls within the Independent Review of Adult Social Care to:

“Conduct a national job evaluation exercise for work in social care, to establish a fair and equitable assessment of terms and conditions for different roles. This should take account of skills, qualifications, responsibilities and contribution.”[[188]](#endnote-188)

The ALLIANCE also agrees with calls that employees should meet gender competent minimum standards of employment, as part of wider issues to address the undervaluing of social care and the gendered nature of the workforce.[[189]](#endnote-189) These minimum standards should also be embedded into the commissioning, tendering and procurement processes of the National Care Service.

# Section 21 – Strengthening regulation and scrutiny of care services

Question 75. Do you agree with the proposals outlined above for additional powers for the regulator in respect of condition notices, improvement notices and cancellation of social care services?

N/A

Please say why.

N/A

Question 76. Are there any additional enforcement powers that the regulator requires to effectively enforce standards in social care?

The ALLIANCE suggests that in order to effectively enforce standards in social care, the regulator not only needs the legal power to do so, but a firm and sustained commitment from Scottish Government to supporting them in their decisions – including in instances where services provided by the National Care Service, under the direct auspices of Ministers, are criticised. As such, the regulatory body must be able to operate independently of the Government, to enable constructive criticism. It could also be useful to provide a range of publicly available examples of regulatory intervention for service providers and users, drawn from within and outwith Scotland.

# Section 22 – Market oversight function

Question 77. Do you agree that the regulator should develop a market oversight function?

N/A

Question 78. Should a market oversight function apply only to large providers of care, or to all?

N/A

Question 79. Should social care service providers have a legal duty to provide certain information to the regulator to support the market oversight function?

N/A

Question 80. If the regulator were to have a market oversight function, should it have formal enforcement powers associated with this?

N/A

Question 81. Should the regulator be empowered to inspect providers of social care as a whole, as well as specific social care services?

N/A

# Section 23 – Enhancing powers for regulating care workers and professional standards

Question 82. Would the regulator’s role be improved by strengthening the codes of practice to compel employers to adhere to the codes of practice, and to implement sanctions resulting from fitness to practise hearings?

The regulator, the Scottish Social Services Council (SSSC), should be able to enforce adherence to their codes of practice and set timescales on reasonable periods for qualifications and registration for care staff. SSSC should also have the power to compel or support employers to ensure that sanctions are enacted within specific timescales. However, it is key that the codes of practice are co-produced with service users as well as staff, and meaningfully accommodate the experiences and priorities of disabled people, people living with long term conditions, and unpaid carers.

Furthermore, it is key that valuing the social care workforce is at the heart of any regulatory change. How the social care workforce is valued and supported will be significant in improving and implementing change in the social care system. Participants in our Independent Review of Adult Social Care engagement events noted that the staff turnover in the care system is in excess of 30% which makes it hard to retain skills and relationships within social care support. Participants were of the view that it will be hard to achieve a human rights based approach until the social care workforce is valued, trained and paid appropriately.

Question 83. Do you agree that stakeholders should legally be required to provide information to the regulator to support their fitness to practise investigations?

ALLIANCE response:

* **The National Care Service should address known data gaps in national and regional data collection and analysis around social care**, to improve people’s experiences – including providing information to the regulator during fitness to practice investigations.
* **Data analysis should be published regularly and made available to the public** (after following standard research ethics around anonymity for respondents).
* **Data sharing should follow human rights principles** in digital health and social care (including digital choice approaches, and ensuring people have access to and control of their data).

**Yes*.*** *My Support My Choice* demonstrated that there are concerning gaps in national and regional data gathering and analysis around social care. 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.[[190]](#endnote-190)

To avoid gaps and improve analysis, we recommend 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 Scottish Index of Multiple Deprivation (SIMD) classification. Non-protected characteristic data should be gathered 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 consequently have least access to services are protected.

For example, this may include (but is not restricted to) care experienced people, survivors of trauma and/or abuse, and victims of crime. This data should be published regularly and made available to the public (after following standard research ethics around anonymity for respondents). Stakeholders should have a legal duty to provide information to the regulator to support their fitness to practise investigations.

However, it is equally important that service users’ personal information is only shared with their consent and/or that of their Guardians, and that the use and retention of that information, as well as who will access it and for what purposes, is clearly conveyed to the individuals in question. 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.

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. As discussed in our responses to questions 7, 11 and 12, we suggest that any requirements for stakeholders to provide data to the regulator should comply with the principles.[[191]](#endnote-191)

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.”[[192]](#endnote-192)

*My World, My Health* drew nine core principles from the engagement work across the project, which we suggest should 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.[[193]](#endnote-193)

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).[[194]](#endnote-194) A 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.

Question 84. How could regulatory bodies work better together to share information and work jointly to raise standards in services and the workforce?

ALLIANCE response: the Care Inspectorate and the Scottish Social Services Council (SSSC) should pro-actively work to draw on each other’s expertise to develop better standards for staff and service users alike. Public Health Scotland and groups responsible for data collection in the National Care Service should also work closely with regulatory bodies to highlight areas of concern and/or improvement within existing and emerging datasets. 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.

In line with our response to the previous question, the ALLIANCE suggests that regulatory bodies should comply with the human rights principles for digital health and social care, as outlined in our partnership work with VOX and Scottish Care.[[195]](#endnote-195) We also recommend that the third sector should be recognised and included in data sharing to raise standards, support the workforce, and improve outcomes of disabled people, people living with long term conditions, and unpaid carers.

Question 85. What other groups of care workers should be considered to register with the regulator to widen the public protection of vulnerable groups?

ALLIANCE response: health care assistants and people working in day centres should be required to register with the regulator. Personal assistants (PAs) should be able to register with the regulator, but any changes to the regulation of care workers must be carefully developed and co-produced.

In *My Support My Choice*, participants reflected on the value of good PAs, and some reflected on their interactions with SSSC. One person stated that:

“What would help is if there would be genuinely self-employed care workers and personal assistants […] real, genuine, actual, somebody like yourself, setting up, and genuinely actually responding to local need and offering the services that there are gaps for. There are several barriers to this. One, HMRC does not recognise – I was told, none of these people can be SSSC registered, SSSC and HMRC won’t let them.”[[196]](#endnote-196)

Two other interviewees stated that they were not interested in formal registration but on whether someone was a good fit:

“I’m not really interested in someone with […] an impressive CV. I’m more interested in someone I can meet, get along with, trust. And that might be someone who’s never had a job, but if I feel I can trust them, if I feel they’re going to be reliable then I’m more interested in that person than someone who just went and done a degree.”

“We are not looking for someone who has 20 certificates saying, ‘I am a carer’. We are looking for someone who would be able to care […] in a way that is appropriate. Our personal assistant didn’t have any care qualification, but that wasn’t an issue for us. People find it really hard to find appropriate care. Sometimes they have to look at it realistically of what they want, and you have to look at what the [SDS user] needs.”[[197]](#endnote-197)

Other respondents highlighted that trust and having people from similar communities, who spoke the same language as the person receiving care, were key to successful PA relationships, rather than additional regulation. Respondents also spoke extensively about difficulties in recruiting PAs and care staff more broadly (with 55% of survey respondents stating that they agreed or strongly agreed with the statement “lack of a regular personal assistant (PA) makes SDS difficult for me”); any changes to the regulation of care workers must be carefully developed and co-produced with disabled people, people living with long term conditions, unpaid carers, and care workers, to ensure that additional paperwork and bureaucratic process do not cause further loss of workers in the sector and reduce the standard of living for people accessing services and their staff.

# Section 24 – Valuing people who work in social care (Fair work)

Question 86. Do you think a ‘Fair Work Accreditation Scheme” would encourage providers to improve social care workforce terms and conditions?

ALLIANCE response: yes, if implemented properly with a focus on human rights approaches, and co-produced with people accessing and providing social care and support.

Please say why.

ALLIANCE response:

* **A “Fair Work Accreditation Scheme” may combat some of the problems around the undervaluing of care work; however, it cannot enact substantive change without other actions to address intersectional inequalities.**
* **Commissioning, tendering and procurement processes should prioritise bids that comply with Fair Work principles and gender competent minimum standards.**
* **The National Care Service should address in-built bias (including gender bias, given workforce demographics) with an intersectional evaluation of social care work, to establish fair and equitable assessment of terms and conditions.**
* **Any work in this area should be co-produced with disabled people, people living with long term conditions, unpaid carers, and social care workers.**

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*).[[198]](#endnote-198) With 85% of the workforce identifying as female, and the majority of unpaid carers also women, issues related to social care are highly gendered.[[199]](#endnote-199) 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.

A “Fair Work Accreditation Scheme” may combat some of the problems around care work. However, as discussed in our answer to question 68, without systematic and wide-spread change to the perceived value of care work, and responses 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.[[200]](#endnote-200) 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.”[[201]](#endnote-201) 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.

**The ALLIANCE recommends action on the following priority areas in order to deliver fairer work in health and social care:**

* **Scottish Government, local authorities, HSCPs, and the proposed Community Health and Social Care Boards should give priority in commissioning and procurement to employers who pay all employees and contractors at least the real Living Wage, as set by the Living Wage Foundation,[[202]](#endnote-202) and cover travel costs connected with work, including paid travel time.**
* **Scottish Government, local authorities, HSCPs, and the proposed Community Health and Social Care Boards should give priority in commissioning to employers who do not use zero-hour contracts (or equivalent).**
* **Recognise and offer increased pay to people with specialist skills within social care work – e.g. Deafblind guide communicators, people with advanced paediatric first aid qualifications, and those with other specialised knowledge and training.[[203]](#endnote-203)**
* **Support workers to make autonomous judgements if people’s care and support requirements (e.g. care at home) need to take longer than originally scheduled.**
* **Support flexible and part-time working requests.**
* **Support employees and contractors who request caring leave.**
* **Implement redundancy protection for unpaid carers who have taken caring leave.**
* **Implement redundancy protection for new parents (including people who have taken adoption leave).**
* **Embed human rights PANEL principles throughout the design of the commissioning and procurement processes (both in health and social care and more broadly).**
* **Ensure that co-production is embedded throughout commissioning and procurement models (during design, implementation, and review) – again, both in health and social care and across other sectors.**
* **Provide employees and contractors with appropriate training and development opportunities (where people are paid during their attendance at any training etc.).**

The ALLIANCE also supports proposals from our members, including Close the Gap, for a wider use of gender sensitive evaluation of social care work. Any evaluation system must take active steps to address in-built bias (including gender bias but engaging with intersectional biases across other protected characteristics as well). This would be in line with calls within the Independent Review of Adult Social Care to:

“Conduct a national job evaluation exercise for work in social care, to establish a fair and equitable assessment of terms and conditions for different roles. This should take account of skills, qualifications, responsibilities and contribution.”[[204]](#endnote-204)

The ALLIANCE also agrees with calls that employees should meet gender competent minimum standards of employment, as part of wider issues to address the undervaluing of social care and the gendered nature of the workforce.[[205]](#endnote-205) These minimum standards should also be embedded into the commissioning, tendering and procurement processes of the National Care Service.

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.

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.

Question 87. What do you think would make social care workers feel more valued in their role? (Please rank as many as you want of the following in order of importance, e.g. 1, 2, 3…)

* Improved pay
* Improved terms and conditions, including issues such as improvements to sick pay, annual leave, maternity/paternity pay, pensions, and development/learning time
* Removal of zero hour contracts where these are not desired
* More publicity/visibility about the value social care workers add to society
* Effective voice/collective bargaining
* Better access to training and development opportunities
* Increased awareness of, and opportunity to, complete formal accreditation and qualifications
* Clearer information on options for career progression
* Consistent job roles and expectations
* Progression linked to training and development
* Better access to information about matters that affect the workforce or people who access support
* Minimum entry qualifications
* Registration of the personal assistant workforce
* **Other (please say below what these could be)**

Please explain suggestions for the “Other” option in the below box.

ALLIANCE response:

**The ALLIANCE supports calls from our members, including Close the Gap and Engender, to consider the gendered nature of the social care workforce when designing training and development.[[206]](#endnote-206) This should include (although not be restricted to) the following:**

* **Employees should be paid the normal hourly rate or the Real Living Wage to attend training (whichever is higher).**
* **Providers should meet the costs of mandatory training requirements, including those for employee SSSC registration. Costs for PA training should be included within SDS budgets.**
* **Training and development opportunities should be accessible within working hours and on a flexible and part-time basis to enable people with caring responsibilities to participate.**
* **Employees should not be expected to attend training and development in their own time**.

The ALLIANCE has not ranked the suggested actions from the question in order of importance, as priorities will differ for people across the sector depending on their circumstances. A properly robust and fair work environment, that values carers and care work, must accommodate the preferences and expertise of people accessing and providing social care and support. It is not desirable at this early stage of system design to create an artificial hierarchy of its separate components.

Alongside other changes, it is important to acknowledge and respond to the gendered nature of care work when discussing action around improving the status of care work. Women make up the majority of care recipients across Scotland, they fill an estimated 85% of social care jobs,[[207]](#endnote-207) and there are 1.1 million unpaid carers in Scotland, of whom 61% are women.[[208]](#endnote-208)

In *We Need to Talk About Integration*, Emma Ritch, Executive Director of Engender, summarised the need to better consider women’s lives and rights. Her comments in that anthology refer to integration, but are equally relevant to care work more broadly:

“To succeed for women, integration boards need to have gender-competent governance that is not undermined by conflicts of interest. Strategic plans need to explicitly include equality outcomes for women, including care workers, health workers, and carers, and enable action that will realise them. Locality and workforce planning must engage with the question of gender equality, including occupational segregation and women’s propensity to engage in unpaid care. Failing to count can mean failing to plan for or manage, and we are concerned both at the lack of gender-disaggregation in the core suite of indicators, and in the content of the indicator around unpaid care. We have greater ambitions for carers than that they ‘feel supported to continue in their caring role’.”[[209]](#endnote-209)

Without direct action to address the employment conditions within social care, we are unlikely to see a meaningful reduction in the gender pay gap or improved public perception of the valuation of social care and its importance as a sector.

Elsewhere in this response we have discussed the importance of food for people accessing social care and their families. It is also vital that food is considered within wider discussions around workforce and Fair Work in social care. At present, many care staff are operating under extreme time pressures – in addition to having limited time to provide support for people accessing social care, many care workers do not have dedicated time set aside for them to access food in between traveling from one location to another. It is important that staff access to food and rest is considered in work planning and the valuing of care staff.

The above suggestions for improving the value of care work need to ensure that co-production with care workers is embedded throughout the models developed and used in the National Care Service (during design, implementation, and review). Wider systems change should also include greater use (and public acknowledgement) of Equality Impact Assessments and the role these play in social care decision making. 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 Equality and Human Rights Impact Assessments (EQHRIAs).

Question 88. How could additional responsibility at senior/managerial levels be better recognised? (Please rank the following in order of importance, e.g. 1, 2, 3…):

* Improved pay
* Improved terms and conditions
* Improving access to training and development opportunities to support people in this role (for example time, to complete these)
* Increasing awareness of, and opportunity to complete formal accreditation and qualifications to support people in this role
* Other (please explain)

Please explain suggestions for the “Other” option in the below box.

N/A

Question 89. Should the National Care Service establish a national forum with workforce representation, employers, Community Health and Social Care Boards to advise it on workforce priorities, terms and conditions and collective bargaining?

Please say why or offer alternative suggestions.

N/A

# Section 26 – Workforce planning

Question 87. What do you think would make it easier to plan for workforce across the social care sector? (Please tick all that apply)

N/A

# Section 27 – Training and development

Question 91. Do you agree that the National Care Service should set training and development requirements for the social care workforce?

ALLIANCE response: yes – in consultation and co-production with people accessing and providing social care and support.

Please say why.

ALLIANCE response:

* **Care workers should have access to a range of training and continued professional development opportunities (including personal assistants).**
* **Training and development should be included in SDS budgets, and all care workers and employees should be paid in full for time spend attending training sessions.**
* **Health and social care staff should attend mandatory training in person centred approaches, and awareness training for a range of more specific considerations (e.g. communication with people with sensory loss, identifying people experiencing or at risk of malnutrition, religiously and culturally appropriate food preparation).**
* **All health and social care staff should attend training in human rights based approaches – including people who are not in public-facing roles, but are involved in social care decision-making.**

Many respondents to *My Support My Choice* indicated that they would welcome more support to arrange care worker recruitment, training and continued professional development. It is also evident that some people would welcome improved access to suitably trained and high calibre care workers. An important care consideration for research participants was personal assistants who were qualified to carry out the specific specialised personal care they need, with appropriate medical training. Some people reported that it was not clear whether PA training costs should come out of their SDS budgets.[[210]](#endnote-210)

One interviewee discussed how some agency staff lack training in how to respect disabled people’s individual capabilities. They recounted how one support worker had little training on how to support people with physical disabilities or visual impairments, and that this led to points of conflict about the interviewee’s independence and choices on a day-to-day basis. The interviewee felt that the care worker would have benefited from more training in how to respect the people they supported and their autonomy and decision making capabilities.

Several Black and minority ethnic respondents highlighted problems with the cultural awareness of social workers and carers. People’s concerns included service users and carers not sharing a common language, organising effective diversity and awareness training for staff, and the practicalities of understanding and accommodating culturally or religiously appropriate food preparation.

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. Existing material includes Food Train’s “Raising the Issue of Malnutrition Toolkit”.[[211]](#endnote-211) 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 following the reduction of the Universal Credit £20 uplift in 2021.

One person reflected that “if there are specifics […] which we know [are culturally specific], then in fact what we’ve got to say that within social work training for their degrees […] that these are aspects that need to be considered on the course” – and that this awareness needed to be extended to care workers more generally. This statement was met with broad agreement from other focus group participants, who also concluded that it was important that social care workers should “learn to ask”, in order to constantly improve their awareness of people’s cultural contexts, as “they have to learn from their experiences.”

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. For example, many people who lip read, use BSL or Makaton now have reduced access to communication due to the wide-spread use of face coverings, and limited use of transparent masks. Many staff are not aware that they can and should remove face coverings in order to communicate with people with sensory loss; this should be included in any mandatory training programmes. Furthermore, people with sight loss, or deafblindness, can be further disadvantaged due to pandemic-related environmental changes, such as the alterations to the location of bus stops, widening of pavements, and increased street furniture. This will require sighted guide support to refamiliarise the route with the individual.

In addition to the training examples listed above, 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 this 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.”[[212]](#endnote-212)

Yet, when used properly, equalities impact assessments are useful tools to address health inequalities and ensure policies are tailors 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.

The ALLIANCE also supports calls from our members, including Close the Gap and Engender, to consider the gendered nature of the social care workforce when designing training and development.[[213]](#endnote-213) This should include (although not be restricted to) the following:

* Employees should be paid the normal hourly rate or the Real Living Wage to attend training (whichever is higher).
* Providers should meet the costs of mandatory training requirements, including those for employee SSSC registration. Costs for PA training should be included within SDS budgets.
* Training and development opportunities should be accessible within working hours and on a flexible and part-time basis to enable people with caring responsibilities to participate.
* Employees should not be expected to attend training and development in their own time.

The ALLIANCE Independent Review of Adult Social Care engagement events report states that staff delivering assessments need to possess a wide knowledge of long term conditions, with additional training and knowledge in understanding how complex needs, neurological conditions and communication impacts on the care of an individual.

During the engagement sessions it was noted that if someone is new to the care sector it is difficult apply the theory they have learned into the practical implications of the service environment. To address this need, some organisations have opted to prioritise work-based shadowing with online learning support.

Participants remarked that while the social care workforce is expected to act with dignity and empathy, as well as with some technical expertise and skill, this is not rewarded in the level of wage. Participants stressed that the sector needs to be better rewarded and supported in order to reduce the high staff turnover rate, noting that 20% of the workforce is experiencing in work poverty. One participant summarised the situation as follows:

“One of our staff has decided to work for the NHS as a cleaner for £13 an hour, rather than the £9 we pay to work with most complex needs in the communities. How do we value this workforce when you have disparity of pay like that?”[[214]](#endnote-214)

It was pointed out by participants that care support staff are working tirelessly, within rigid timeframes and exhaustive workloads. Carers have very limited time to spend with people, and there is little acknowledgement given to how they can practically travel across communities to people’s homes and spend quality time with people in the time allocated. Participants stressed the need to create a better working environment for staff, allowing time for reflection of practice and space to link with other staff to communicate stresses and concerns. It was suggested that district nurses would be a welcomed addition to social care support, working alongside carers, to help embed integration, offering a joined-up workforce.

Respondents to the Independent Review of Adult Social Care engagement events agreed that there should be a national learning system, with a focus on national and local learning. Such a system would have national impact, with a human rights and vision at the centre. Any set training and development requirements as part of this system should be carefully developed and co-produced with disabled people, people living with long term conditions, unpaid carers, and care workers, to ensure that additional paperwork and bureaucratic process do not cause further loss of workers in the sector and reduce the standard of living for people accessing services and their staff. Furthermore, any training programmes for care workers should also be accessible to Personal Assistants and unpaid carers, either with the costs included in the relevant SDS budgets or free of charge to attend.

Question 92. Do you agree that the National Care Service should be able to provide and/or secure the provision of training and development for the social care workforce?

ALLIANCE response: yes

# Section 28 – Personal Assistants

Question 93. Do you agree that all personal assistants should be required to register centrally moving forward?

ALLIANCE response: no.

Please say why.

ALLIANCE response: personal assistants (PAs) should be able to register with the regulator, but any changes to the regulation of care workers (including compulsory registration of PAs) must be carefully developed and co-produced with disabled people, people living with long term conditions, unpaid carers, and personal assistants. Donald Mcleod, Chief Executive of Self Directed Support Scotland, reflected on the treatment of the PA workforce throughout the pandemic – and the delays to the £500 thank you payment issues to health and social care staff experiences by PAs. Expressing caution about the risk of a compulsory registration process leading to the “assimilation” of the unique role of PAs within the wider social care workforce, he stated that:

“Surely we can be flexible in considering voluntary recognition and support as an option to ensure that PAs have equity in terms of recognition as well as terms and conditions, valuing lived experience and ensuring that any changes have the full support of the independent living movement, if PAs are to have a legitimate place within a National Care Service.”[[215]](#endnote-215)

In *My Support My Choice*, participants reflected on the value of good PAs, and some reflected on their interactions with SSSC. One person stated that:

“What would help is if there would be genuinely self-employed care workers and personal assistants […] real, genuine, actual, somebody like yourself, setting up, and genuinely actually responding to local need and offering the services that there are gaps for. There are several barriers to this. One, HMRC does not recognise – I was told, none of these people can be SSSC registered, SSSC and HMRC won’t let them.”[[216]](#endnote-216)

Two other interviewees stated that they were not interested in formal registration but on whether someone was a good fit:

“I’m not really interested in someone with […] an impressive CV. I’m more interested in someone I can meet, get along with, trust. And that might be someone who’s never had a job, but if I feel I can trust them, if I feel they’re going to be reliable then I’m more interested in that person than someone who just went and done a degree.”

“We are not looking for someone who has 20 certificates saying, ‘I am a carer’. We are looking for someone who would be able to care […] in a way that is appropriate. Our personal assistant didn’t have any care qualification, but that wasn’t an issue for us. People find it really hard to find appropriate care. Sometimes they have to look at it realistically of what they want, and you have to look at what the [SDS user] needs.”

Other respondents highlighted that trust and having people from similar communities, who spoke the same language as the person receiving care, were key to successful PA relationships, rather than additional regulation. Respondents also spoke extensively about difficulties in recruiting PAs and care staff more broadly (with 55% of survey respondents stating that they agreed or strongly agreed with the statement “lack of a regular personal assistant (PA) makes SDS difficult for me”); any changes to the regulation of care workers must be carefully developed and co-produced to ensure that additional paperwork and bureaucratic process do not cause further loss of workers in the sector and reduce the standard of living of people accessing services and their staff. Furthermore, any training programmes for care workers should also be accessible to Personal Assistants and unpaid carers, either with the costs included in the relevant SDS budgets or free of charge to attend.

Question 94. What types of additional support might be helpful to personal assistants and people considering employing personal assistants? (Please tick all that apply)

* National minimum employment standards for the personal assistant employer
* Promotion of the profession of social care personal assistants
* Regional Networks of banks matching personal assistants and available work.
* Career progression pathway for personal assistants
* Recognition of the personal assistant profession as part of the social care workforce and for their voice to be part of any eventual national forum to advise the National Care Service on workforce priorities
* A free national self-directed support advice helpline
* The provision of resilient payroll services to support the personal assistant’s employer as part of their Self-directed Support Option 1 package
* **Other (please explain)**

ALLIANCE response: recognising care work as an essential part of the caring economy and enabling people who access Universal Credit or other state entitlements to take on part-time care work as PAs without being required to hit a specific hours per week threshold or lose access to key entitlements. One interviewee in *My Support My Choice* reflected on their initial difficulties with recruitment – and particularly the overlap between care work and state entitlements for some workers. They recounted how rules on working hours could compound recruitment difficulties – for example, if someone had an SDS package for 15 or 16 hours a week, and this clashed with the Universal Credit working requirements, preventing otherwise good PA candidates from taking up post.[[217]](#endnote-217)

People should also be able to employ family members (who are not Guardians) as PAs if they wish – rather than only with permission from the local authority/HSCP on a case-by-case basis. Some of our members commented positively on being able to employ family members as PAs as a result of the changes to guidance during COVID-19 pandemic and wish to see such guidance made permanent.

Question 95. Should personal assistants be able to access a range of training and development opportunities of which a minimum level would be mandatory?

ALLIANCE response: respondents to *My Support My Choice* outlined that many people would welcome assistance in arranging training and development opportunities for PAs. It is important that any training and development opportunities developed through the National Care Service for care workers are accessible to PAs, to ensure that the workforce has appropriate opportunities for continued professional development, and that people have the appropriate skills to carry out their vital roles in providing people with care and support.

However, any move to set a mandatory minimum level should only come after careful consultation with both the workforce and disabled people, people living with long term conditions, and unpaid carers. Respondents to *My Support My Choice* indicated that they did not wish to see an increase in administrative labour around accessing social care, and many people who responded to *My Support My Choice* and our Independent Review of Adult Social Care engagement events raised concerns about problems with recruitment and retention of care staff.[[218]](#endnote-218) Any measures to set minimum levels of training for the PA workforce should ensure that they do not exacerbate existing problems with and for the workforce and people who access services. Furthermore, any training programmes for care workers should also be accessible to Personal Assistants and unpaid carers, either with the costs included in the relevant SDS budgets or free of charge to attend.

# 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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