The Health and Social Care Alliance Scotland (the ALLIANCE)

Adult social care support and community health: What it means to me

Engagement report for the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health

October 2024

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Introduction

This report sets out the findings from a series of focus group conversations with people who have lived and living experience of using or working in social care support and community health services.

These conversations were facilitated by the Health and Social Care ALLIANCE (the ALLIANCE), and aimed to inform the development of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health (SLIF). The focus groups explored what improvement in social care support and community health would look and feel like to people.

This report is the first of three from these focus group conversations.

Throughout the conversations, people also shared rich information about their current experiences with services and their delivery. This detail is captured in a second report and has been shared with relevant policy teams across the Scottish Government.

The third report provides the Literature Review conducted by the ALLIANCE, of existing evidence to understand what improvement to care and support services would look like to people with lived and living experience and how it would benefit people's lives. This was used to inform the development of the focus group conversations.

Background

The SLIF has been developed by the Scottish Learning and Improvement Framework Steering Group, which is co-chaired by the Scottish Government, COSLA and SOLACE, and includes representation across Social Care, Social Work and Community Health, including regulators, providers, Health and Social Care Partnerships (HSCPs) and Improvement Bodies.

It sets out the vision and priorities for improvement across Adult Social Care Support, Social Work and Community Health. It aims to provide a new approach to improvement and to track improvement by the outcomes that matter to people. It will support a move away from a

predominant focus on scrutiny and measuring performance to an approach which builds learning, improvement and quality management into the system.

The SLIF is currently a strategic document and this work facilitated by the ALLIANCE is supporting work to translate the SLIF into clear, tangible, and deliverable actions.

The ALLIANCE is supporting the translation of the SLIF by undertaking research and engaging with people to help understand what people feel progress towards achieving “good” community health and social care support means to them.

The ALLIANCE has a strong history of facilitating dialogue and discussion and extensive experience of employing different approaches to engage with a wide cross-sector of people, including citizens, community and third sector representatives. This has given the people of Scotland the opportunity to inform policy and service design. One of our three core aims is to ensure the voices, expertise and rights of disabled people, people with long term conditions and unpaid carers drive policy and sit at the heart of design, delivery and improvement of support and services.

Methodology

In September 2024, the ALLIANCE facilitated four focus groups with people with lived and living experience to inform the development of the SLIF.

Four focus group sessions were held. A total of 17 individuals with lived and living experience of accessing health and social care support took part in the discussions across the first three sessions, which were attended by 14, 10 and 6 people respectively (some participants attended more than one session). The final focus group was held with members of the workforce and was attended by 17 people.

The ALLIANCE promoted the opportunity to participate in these focus groups via our membership and wider networks, as well as on our website and social media accounts. Each participant self-identified as having experience of accessing health and social care support for a disability or long-term condition. The workforce focus group was targeted at people who have experience of providing care and support and community health services. As this engagement was not targeted at specific communities with protected characteristics (such as race, ethnicity, gender, sexuality or religion), the ALLIANCE did not collect this information.

The focus groups explored what outcomes matter to people accessing care and support and/or providing unpaid care, and people who work in adult social care and community health. This included thinking about how people would know improvements were happening.

As described above, the first three focus groups included people with lived and living experience of using social care support and community health services.

These groups looked at the main improvement outcome “People including unpaid carers, are enabled to live a good life as independently as possible in a place of their choosing”.

Each focus group explored a separate contributory outcome that feeds into the main improvement outcome. Figure 1 on the next page provides a full list of the contributory outcomes discussed.

The fourth focus group met with people with lived and living experience of working in social care support and community health services. This session focused on the second main improvement outcome that ‘The adult social care support and community health workforce is thriving’, and its contributory outcomes. Figure 2 on the next page provides a full list of the contributory outcomes discussed.

Scottish Learning and Improvement Framework: Outcomes

The figures below give an overview of the main improvement outcomes and contributory outcomes in the SLIF. More detailed information on the SLIF outcomes can be found at https://www.gov.scot/publications/draft-scottish-learning-improvement-framework-adult-social-care-support-community-health/.

Figure 1. Contributory outcomes for the main improvement outcome 'People, including unpaid carers, are enabled to live a good life as independently as possible, in a place of their choosing.'

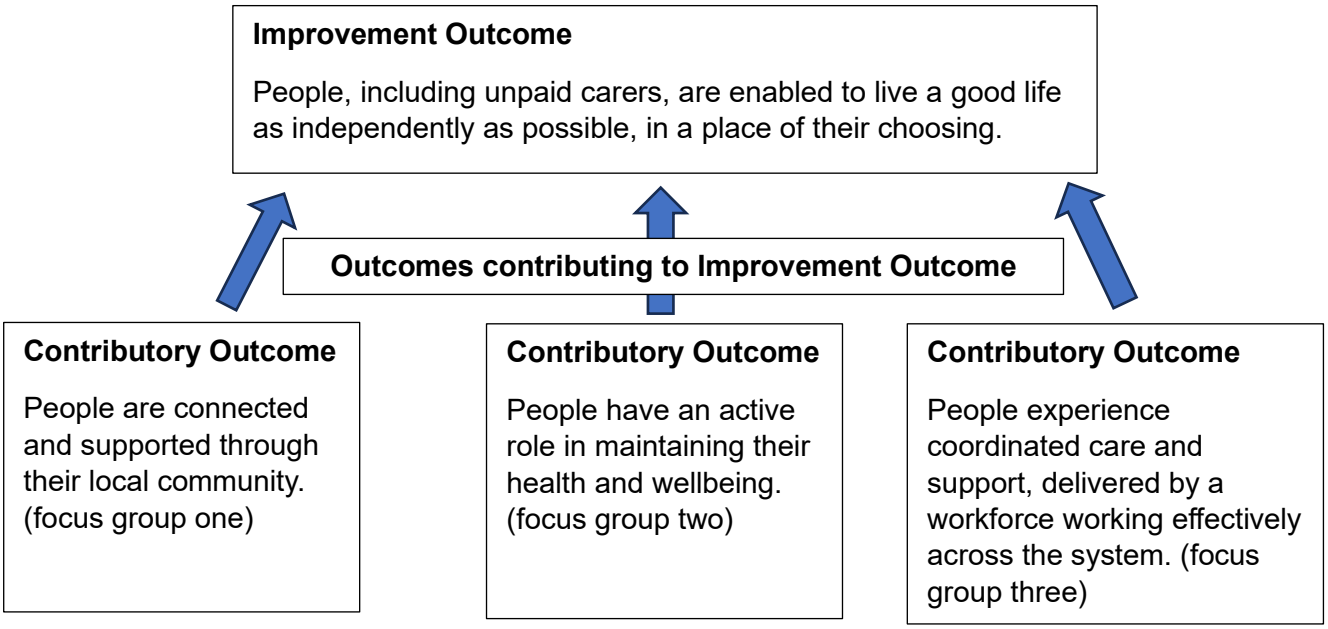
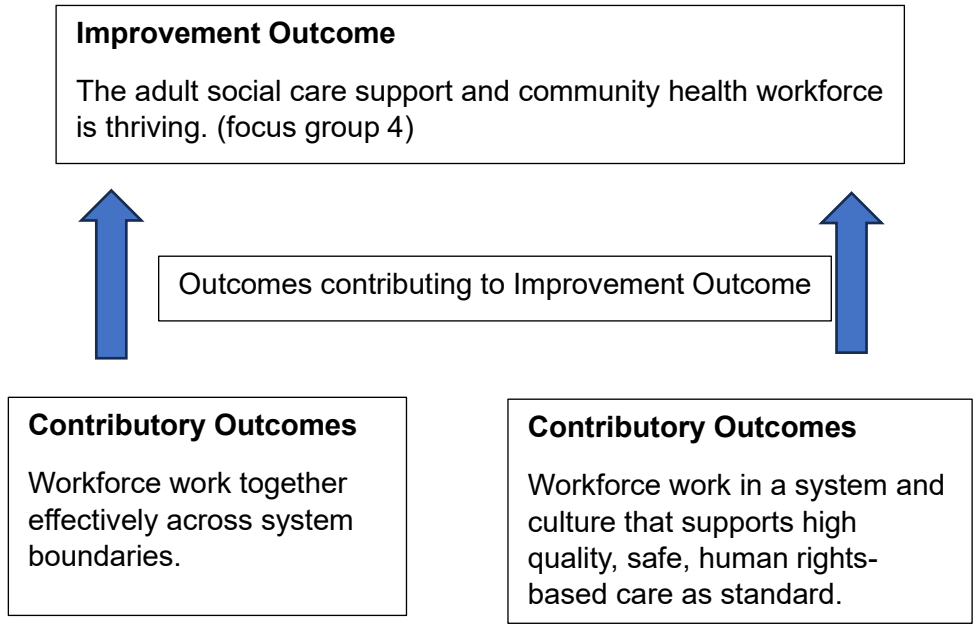


Figure 2. Contributory outcomes for the main improvement outcome 'The adult social care support and community health workforce is thriving.'



Findings

Focus group 1: People are connected and supported through their local community.

1.1. People are able to participate in community, employment and education, if they wish to do so.

We heard that disabled people and people who receive support often do not feel included as part of their communities. Participants repeatedly described wanting care and support that enables them to feel “normal”, like anyone else in their communities. Participants shared personal experiences of the negative attitudes they had experienced within the community, and explained how barriers they experienced to getting around and accessing spaces could make them feel excluded and lead to them feeling isolated.

Participants described what they felt would be the possible impacts of feeling able to participate in their communities, employment and education, these included;

- Lessened stress and anxiety, and increased confidence, from being supported and believed.
- Feeling valued and deserving of support.
- Not feeling judged and stigmatised by others in their communities and by people working in health and care.
- Engaging more in activities, learning new skills and connecting with other people.
- Feeling like an equally valued member of the community, participating in local politics and having their voices heard.

1.2. People experience quality, reliable, safe and consistent care and support that is right for them, through their life course.

Participants found it challenging to envision what the achievement of this outcome might look like for them. One person said:

> *“I don’t know what it would look like because I have never received it.”*

Participants shared experiences of what life had been like when they felt they had received insufficient care and support. These included feeling alone and experiencing poor mental health.

Nevertheless, through exploring these experiences, we identified characteristics of reliable, good quality and safe care, listed below;

- Trusting relationships with people providing support.
- Accessing care locally.
- Responsive and holistic care planning with access to preventative support.
- Being supported at home (or in a homely setting).
- Having control over information and care records, and your privacy respected.

We heard that receiving quality, reliable, safe and consistent care and support would help people to feel supported and believed, safe and secure, valued, and it would support them to build confidence and gain a sense of control over their life.

Understanding progress

Participants suggested how their lives might be different and how they would know progress was being made:

> *"I wouldn't feel worthless, like no one cares."*
>
> *"More people would feel involved and valued."*
>
> *"there would be more people able to remain in work (either paid work or voluntary work), because if you don't receive care that is needed then you are more likely to have to reduce hours or have to leave employment or voluntary work."*
>
> *"Feedback such as the feedback collected for Primary Care from the GP will improve. The stories that are shared on Care Opinion [1] will be more positive than current levels. The NHS & Community*

[1] The Care Opinion website allows people to share their experiences of health and social care services: About Care Opinion | Care Opinion

Care feedback of services from service users will improve. There will be less poor experiences reported in the media."

1.3. People experience flexible, responsive care and support to meet their needs, provided through quality relationships.

Flexible responsive care and support

When asked how their lives might improve in the achievement of this outcome, participants said:

"Your life would feel normal and natural every day."

"Flexible care should equate to care that is tailored for each individual and their circumstances."

"Being able to choose when you need the care, not having that decided for you. Additionally, consistency with the people providing care so there would be a relationship and someone who knows what is required. Having a budget so that you are in control of when/who/how."

Local availability of services was seen as relevant to the flexibility of care:

"People [who] don't have services close at hand have to spend their own money to travel great distances to get their care."

Self-directed Support was highlighted as important to enabling flexible care, because it "is a bit more in the person's control."

Relationships with carers

The role of trusting relationships was repeatedly emphasised. It was felt that reliable, safe care is trauma-informed and recognises the impact of people's past experiences. Participants highlighted that it takes time to build trust. It was particularly important that they could trust those involved in their care to keep their information confidential, be discrete and respect their privacy.

One participant spoke about the importance of feeling understood and not being judged, particularly in relation to "invisible disabilities", and the

key role that carers can play in supporting an individual to feel confident, safe and secure:

> *"When you're not understood by the services you're engaging with it can reinforce ideas that it's all in your head. For a carer to have an understanding of variable conditions is helpful – just because someone can get to the door to meet you last time doesn't mean that they're able to do that today. […] What that good relationship could look like is not having to feel like defending yourself, not having a constant low level of confidence – you're always waiting for someone to put you down, to question how disabled you really are. To be listened to, to be understood, treated with compassion."*

Participants described what could help enable positive relationships:

> *"I would like to hire someone of my own choosing."*

> *"Connecting with people and asking 'what do you need', 'what would you like me to do?' Giving people a choice and a voice instead of thinking you know better about what they need."*

Participants shared that a good relationship with their carer would be empowering:

> *"Life would be good for both carer and me! Being upbeat, friendly, optimistic together would make for a good team. In fact, feeling that it is team work as opposed being 'cared for' would be ideal. If there was something the cared for person could provide and be made to feel useful would be so empowering."*

> *"With my carer I was able to go for a walk with my dog, get my prescription, get my driving license. She helped me build my confidence…having someone there to support [me] and encourage independence was really helpful."*

Participants also shared what they felt was needed to enable someone to experience flexible, responsive care and support to meet their needs, A lot of this focused on skills and training for people who provide care and support:

> *"As a neurodivergent person, what would make a massive difference would be: training by actually neurodivergent people to all care staff - the stigma and myths attached to my neurotypes create so much additional trauma that then I don't have anyone to help me deal with."*

Across all three outcomes discussed, participants made clear that it was important to them that people with lived experience are meaningfully and continually involved in ongoing work about health and social care improvement:

> *"I think in response to how would we know if there is better care - the most obvious is to ask. Doing this as action research, making improvements and then going back to service users to ask again, that's the way to capture views, and needs that perhaps change, too."*

Focus group 2: People have an active role in maintaining their health and wellbeing.

2.1. People's rights are respected, protected and upheld.

Participants also described what it means to them to have their rights respected, protected and upheld when receiving care and support. Participants described rights-respecting care and support as being **person-led**, driven by individuals' needs and **personal outcomes**, rather than budgets and targets, and not limited by strict eligibility criteria:

> *"Let me be the judge of what is fair to me."*

This extended beyond care and support services, reflecting the themes discussed in the first focus group (People are connected and supported through their local community):

> *"You'd have equity… If you could get out and about more because people upheld and protected your rights you'd feel a more valued member of society."*

It was also acknowledged that rights respecting care would have a positive impact beyond the individual as there would be less stress on family members and carers.

Participants also highlighted that a better awareness of rights among people seeking support, as well as people providing care and support, would be key to rights being respected, protected and upheld.

Participants said they felt that being able to trust that their rights would be respected, protected and upheld would give them confidence in accessing care and support. This included feeling safer when accessing services and asking for help:

> *"I would get what I needed out of services rather than [being] apprehensive to discuss things."*

Person-led[2] care, improved complaints processes, and access to local advocacy services were felt to be important to ensuring rights are respected, protected and upheld.

Participants stated that complaints processes that are easy to understand and access are important to them having confidence that their rights will be upheld:

> *"We need in every service someone on duty who can respond to your issue immediately. Someone taking responsibility for that. People don't want to complain they just want the issue dealt with."*

The ability to access free, local advocacy was highlighted as important:

> *"You don't want to repeat your story…it's distressing. It's difficult enough to ask for help. What could improve is a one stop shop –*

[2] This review uses the term person-led care to denote care where the person is at the centre of the care plan. This describes an approach to care and support that is characterised by respectful and compassionate interactions that focus on the wellbeing outcomes that matter most to the person.

you tell your story to one person and they advocate on your behalf."

2.2. People are actively involved in their care decisions, or the care decisions of people they care for.

Participants said that having an active role in their care decisions, or the care decisions of the person they care for, would give them more control over their own lives and the freedom to live as they choose:

> *"Quite simply, live the life we want to, not just survive or exist."*

Being meaningfully involved in care decisions would mean having more agency and power to shape their support so that it is right for them. Participants said that having more say and control would reassure them that they would receive the care they needed.

We heard that it is important to use the framing of person-led health, to focus on the individual as the primary decision maker in choices about their care.

Participants reflected on what the impact might be for them if they were more actively involved in decisions about their care, or the person they cared for:

> *"there would be less errors made, less incorrect assumptions made by people who don't understand my conditions or how it affects my life. They wouldn't make decisions that restrict my life."*

> *"How it would look differently is if they invited you and included you… to feed into the meeting and that would feed into your care plan and any decisions they make about your care."*

> *"You would have to be valued, be a part of something. Any meeting about you or a loved one you should get reports for each one. I've been told that [multidisciplinary team] meetings don't involve me…why am I not involved in something that directly affects my life?"*

Meaningful co-production and acting on the voice of people with lived and living experience were particularly important, with one participant suggesting that equal participation should be enshrined in law:

> *"I think the voice of lived experience is central… you have to have people who are the voices of lived experience being part of decision making. That's paramount to things changing."*

Participants highlighted the following aspects of inclusion which would improve their experience of being involved in their care decisions:

- Being able to feed into their own care plans and have control over care packages.
- Being meaningfully listened to and having needs acted on.
- More funding for Self-directed Support (SDS), and being supported in the time period between choosing SDS option one and putting that support in place.
- More resources given to communities, and less resource diverted to administration and duplication of services.
- The ability for disabled people to represent themselves.

Focus group 3: People experience coordinated care and support, delivered by a workforce working effectively together across the system.

3.1. People's journeys are integrated with smooth pathways.

Participants in this session felt that receiving well-coordinated care and support would mean that they could enjoy life more and not feel like they have to "accept the bare minimum." Integrated care was regarded as foundational, i.e. "hav[ing] the basics in life", that allow one to "enjoy life and live it to the best of your ability."

Participants felt that well-coordinated support would help them to feel safe, and that they would not experience the anxiety and stress caused by navigating the system. It was suggested that well-coordinated care means receiving the right care, when it is needed; not reaching a crisis

point before needs are met. They felt that joined-up services would minimize or avoid disruptions to care, make services easier to navigate, and help them feel confident that all their needs would be met:

> *"I have no clue where to go for information or who to ask. A one-stop information point – somewhere you can ring with a 'no stupid questions' attitude, to ask about services and not be laughed at or told 'that's not our remit.'"*

Being able to navigate more easily between services was particularly important to unpaid carers:

> *"Joining up [services] and sharing information is absolutely fundamental to the changes that need to be made."*

Participants felt that well-coordinated care would support them to be seen as a whole person and have their needs met holistically, rather than "split up." In this way, care coordination was linked to the person-led care themes and whole-person approaches discussed in sections 1 and 2:

> *"How can they see the whole person when your care is split up? For care to be person-centred you have to see the entirety of the person."*

> *"Because you have a voice, they feel like you don't need support. But everybody's needs are different. I didn't ask to be born with a learning disability. I cannot change who I am and they have to listen to what I want."*

> *"If your care isn't connected you really can't talk about your future needs."*

Participants felt that it would be beneficial if people providing help and support received training about how to "think outside the box." This meant being able to think and act outside of their immediate role to see the person they support in the whole and recognise if they may be experiencing other challenges, which would support a more preventative approach.

3.2. Leadership and workforce are able to consider future needs in care planning.

One facet of well-coordinated care described by participants was being able to anticipate and accommodate future/changing needs. The ability of those providing care and support to consider future needs in care planning was important, and participants reiterated the desire for more say and control in their care planning. This was also discussed in the focus group with people who work in adult social care support and community health services (People have an active role in maintaining their health and wellbeing).

Participants felt that trusting that support would be available to meet future/changing needs was linked to a sense of comfort and reassurance. Again, the absence of anxiety and worries was a significant impact envisioned by participants if leadership and workforce were able to consider future needs in care planning.

Participants further felt that considering future needs in care planning would improve access to respite and temporary care provision if something unexpected happened. Participants also felt assurance that their needs would be met in a timely manner – that support would be there when needed – and not reaching a crisis point before needs are met would be important to improve outcomes:

> *"Approaching end of life care, the reassurance that care will be appropriate would be welcoming and less frightening. As a family we are scared about what is in front of us."*

Focus group 4: The workforce work effectively together across the system.

This session brought together people who work in adult social care support and community health services.

4.2 Workforce work in a system and culture that supports high quality, safe, human rights-based care as standard.

Participants reflected on what would make them feel supported to deliver high-quality, safe and human rights-based care:

- Good support and supervision, and effective and engaging management.
- Opportunities to shadow others.
- Good terms, conditions and pay to support people to stay in their roles.
- Training that is appropriate for roles and supports development, as well as more in-person training that brings staff together.
- Being listened to and having their views acted on.
- Greater focus on prevention and early intervention, moving away from strict eligibility criteria, and feeling able to meet people's care and support needs in the community at an earlier stage.

Participants further shared their thoughts illustrating their experiences related to the above points:

> *"Support for your own wellbeing – it's about supervision, checking in on wellbeing. That has to be at the forefront and meaningful not just a token gesture. Hearing what people need and putting measures in place to create a better environment to work in."*

> *"I think the other thing about the quality of care and making us feel like we're doing a good job – half the time we spend is being advocates for people and it's so disheartening when you can't get support for them because the funding isn't there and other barriers. If it wasn't a constant battle and still not getting the outcome that you want."*

> *"Effective lines of communication, if these were in place things would work better and less would be missed."*

Lastly, we heard about the difference this would make in their lives and jobs:

- Feeling more valued as an individual.

- Having positive relationships with colleagues, experiencing less stress at work, and improving staff retention.
- Enabled to be more creative in how they support people.
- Building more trusted relationships with the people they support.

Improved pay, terms and conditions were seen as a necessary baseline to enable other improvements:

> *"[That's] why colleagues are leaving and all the experience that is lost with them – terms and conditions, which are related to short term funding. Lack of stability in their personal lives*."

4.1 Workforce work effectively together across system boundaries

Participants shared their views about what working in an environment that enables people to work more effectively with others across the system could look like.

Participants felt that there were areas where people were working well together already, but that they experienced there is less integration between strategic and grassroots level services, and made a number of suggestions for how to improve integrated ways of working:

- Staff from across teams and services have an understanding of what each other's roles are, and this could be supported by opportunities to come together and learn from each other. This could include spaces and places to network and the opportunity to shadow each other.
- Being able to meet people's needs more holistically through better information sharing and linking up information.
- More equitable funding and commissioning processes for third sector supports focusing on sustainability, continuity and prevention.
- Growing the Community Links Programme to reduce pressures on GP practices and get more people involved in community services.
- Clearer signposting and access to up-to-date information on what services and supports are available in their areas, as people often don't know how to access services or what is available to them.

- Effective communication between services, with more time for staff to feedback and communicate effectively with the people they work with.
- More effective and efficient systems to improve time-efficiency. This could include removing some of the red tape/bureaucracy.

Conclusion

The conversations with people with lived and living experience of using or working in adult social support and community health services have been undertaken to inform the development of the SLIF and ensure that the SLIF framework tracks improvement by what matters most to people.

Throughout the conversations, participants explained that to them, the purpose of high-quality, reliable, rights-respecting, integrated care and support is to enable people to live as independently as possible, to be empowered and in control of their lives. This was often referred to as wanting to feel “normal” – to be treated with dignity and respect, and not made to feel different because of their disabilities or conditions. Being “normal” was about the ability to make choices about your life and pursue your own goals.

In terms of the positive difference that they envisioned high-quality, reliable, flexible, person-led care could make in their lives, participants spoke about building confidence, being empowered to make choices about how they live, having control over their care and support, feeling an equal part of society and having good, trusting relationships with carers that enable them to feel safe, secure and listened to.

This aligns with the experiences voiced by the workforce, who further added how working effectively together in a supportive system and culture would help them to feel more valued as individuals, have more positive relationships with colleagues and the people they support, be more creative in how they support people, and reduce stress at work.

There is a body of work ongoing to support improvement across the social care support and community health system, the SLIF will support the tracking of improvement as a result of this body of work by the

outcomes that matter to people with lived and living experience or using or working in in social care support and community health services. To ensure ongoing opportunity for people to self-define the outcomes that matter to them it will be important to continue to meaningfully involve people with lived and living experience in the development and future reviews of the SLIF.

Contact

Justine Duncan, Director of Communication and Engagement
E: Justine.Duncan@alliance-scotland.org.uk

Kerry Ritchie, Programme Manager
E: Kerry.Ritchie@alliance-scotland.org.uk

Charlotte O'Brien, Policy Officer
E: Charlotte.Obrien@alliance-scotland.org.uk

T: 0141 404 0231
W: http://www.alliance-scotland.org.uk/

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 3,600 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.