The Health and Social Care Alliance Scotland (the ALLIANCE)

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

Report from the wider findings from the engagement 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

Table of Contents

Introduction

This report sets out the wider findings of 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. The findings in relation to this research aim have been captured in a separate report.

This is the second of two reports on the findings from these focus groups. In addition to sharing what improvement would look like, people shared rich information throughout these focus group conversations about their current experiences with services and their delivery. These wider findings are presented here according to the SLIF outcome that they are relevant to, and the report has been shared with relevant policy teams across the Scottish Government.

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 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.

Each focus group concentrated on a different outcome in the SLIF. They explored what matters to people accessing care and support and/or providing unpaid care, as well as people who work in adult social care support and community health. As stated above, the wider findings about people's current experiences of using adult social care support and community health services have been captured in this report and are set out below under the relevant SLIF outcome.

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.'

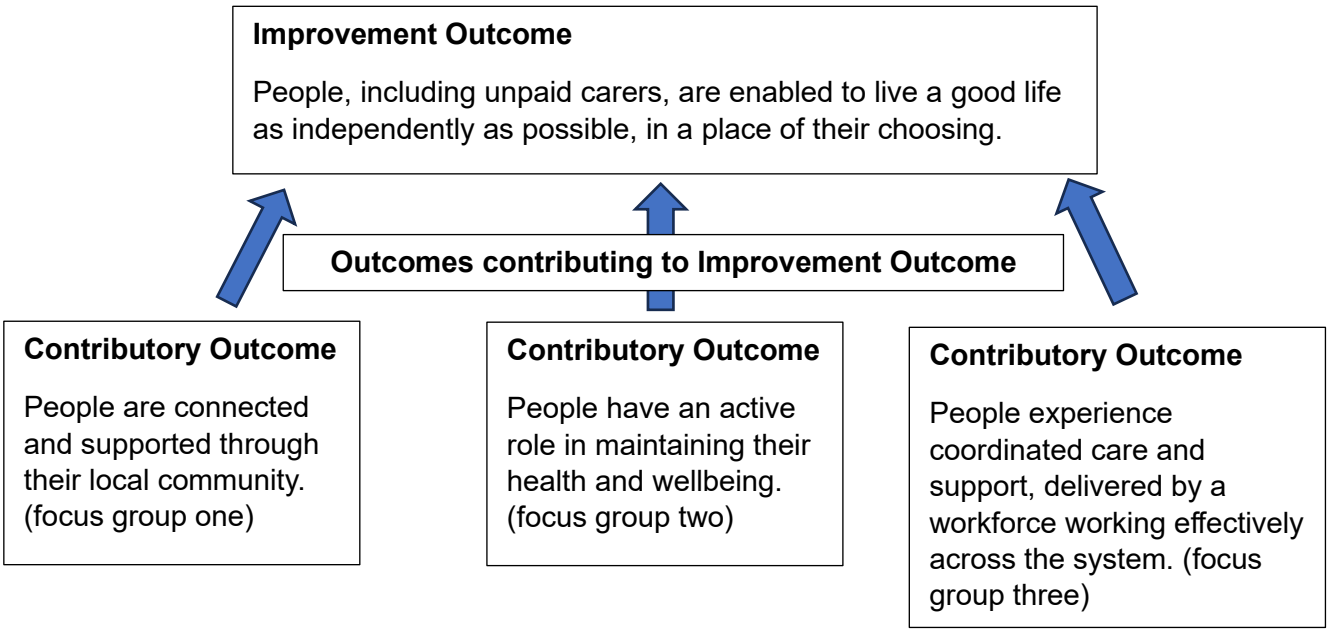
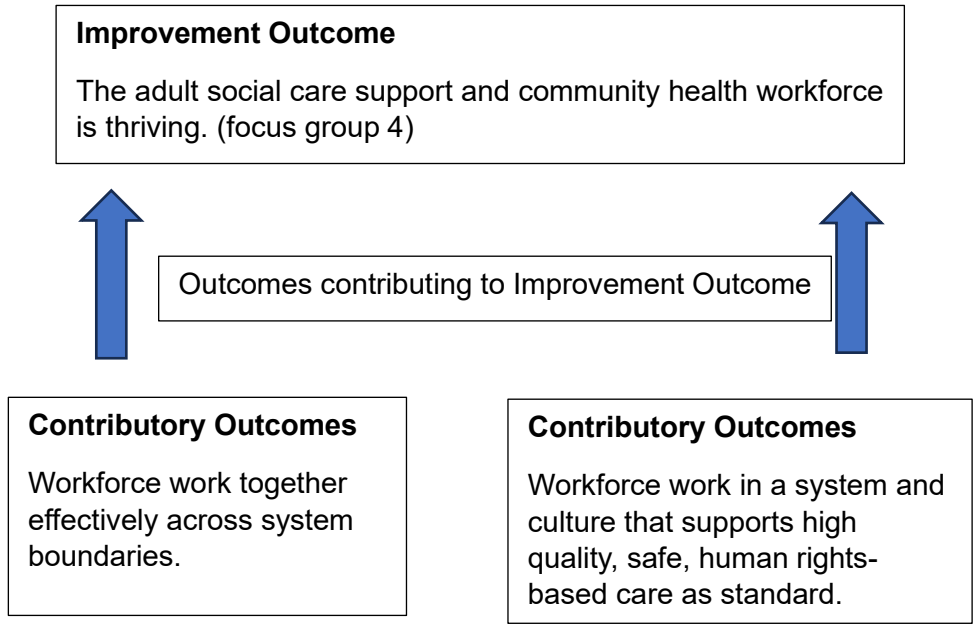


Figure 2. Contributory outcomes for the main improvement outcome 'The adult social care support and community health workforce is thriving.'



Findings

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.

Participants described wanting care and support that enables them to feel "normal," like anyone else in their communities to support them to participate in the community, employment and education.

Participants shared their current experiences and told us that people who are disabled or living with a long term condition can often not feel included as part of their communities because of a range of barriers such as inaccessible spaces and some experiences of negative attitudes in communities.

One participant said that for disabled people, this means that:

> *"Their whole world has shrunk."*

When asked to reflect on what could improve to help them feel more connected and supported in their local communities, participants told us:

> *"More opportunities/awareness for volunteering locally can bring people together and often results in ongoing support and friendships. There may well be opportunities but if so, I am not aware. A local newsletter (online with little cost) to inform people of supports/ volunteering/ classes/ groups etc would be good."*

> *"Would be very satisfying to be able to help people within the community and likewise, be helped with certain things."*

During this session, participants reflected on their experiences of participating in their communities and accessing support during the COVID pandemic, highlighting the availability of online supports and activities, as well as changes in community attitudes such as increased "neighbourliness":

> *"A whole new world opened up to me."*

"The pandemic showed it was possible to meet the needs of housebound people."

It was felt that third sector organisations had been good at continuing to make online and hybrid events available, but concerns were raised that other sectors had withdrawn these online supports:

"Online access [has been] such a lifeline for me…"

Access to services

Access to services was an issue raised by participants in relation to being able to participate in community, employment and training. Participants highlighted certain structural barriers to accessing the care and support they need and felt that those providing support need to have the right tools and support to deliver high-quality care and support:

"I feel people do care – the service is inadequate and not set up in a way which allows people to be responsive."

"Well paid care jobs in local communities… for everybody to care and offer a service to support those in need."

We heard about the importance of having community-based activities that are accessible, local, available to access online and cater to a range of ages, groups and abilities. This includes variety in the timings of the activities; one participant was unable to attend their local community council events because they only took place in the evenings and did not include an option to participate online. In addition to feeling excluded, this meant they were unable to raise their concerns or have them addressed in this public forum.

Participants shared that participation in their community could also be impacted through both social connections and the physical built environment.

Social connections

Social connections were identified by participants as important to support participation in their communities. Some participants felt their sense of belonging had been impacted by their experience of negative attitudes, biases and tensions within their community.

Participants felt it would make a difference if other members of their communities were more informed about living with a disability and about invisible disabilities such as chronic pain and other long term conditions. They spoke about their experiences of feeling judged and the perception that they were not trying hard enough to "overcome" their conditions:

> *"I get stigmatised because I am young and living with chronic pain."*

One participant spoke about internalised ableism – the feeling/belief that they are responsible for their disability/condition: "it's my fault." They wanted the people they interact with to be aware of systemic issues, like ableism, so that they don't reinforce negative self-thoughts. This would help them to feel supported and believed.

Feelings of being judged, dismissed, not listened to and experiencing internalised stigma are common experiences raised in ALLIANCE engagement more broadly. These experiences can not only negatively impact a person's wellbeing but can also act as a barrier to participation in community, employment and education.

Physical/built environment

Participants discussed access to community spaces as important to enabling participation, social connections and sense of belonging. Being able to access all spaces was important, especially those spaces where support is provided:

> *"To feel well, safe and secure and bright in your spirit, your surroundings need to be nice."*

We heard several examples of people not being able to access healthcare facilities and other services because they were lacking

inclusive adaptations. This can prevent people from being able to participate in their communities, as well as accessing the support they need. Reflecting on these challenges, participants said it was:

> *"easy to see why people become more isolated and are afraid to come out [and] become more socially introverted because services aren't thinking about who they are catering for."*

Participants stated that they had experienced a lack of reliable and accessible public transport which also created a barrier to participation as people were unable to get around their communities independently. Although outside the remit of health and social care support services, this issue is frequently raised by people the ALLIANCE has engaged with when discussing participation in communities.

In general, participants valued having access to nature and town/village centres that are easy to get around and that have all the things they need available locally. They felt that communities should be designed to be inclusive places where "everybody is welcome." This meant having more accessible, informal community spaces and a focus on relationships and connections.

Additionally, several participants called for greater recognition of the validity and value of online communities, especially for neurodivergent people:

> *"Thinking of the communities I actually have, they are all online. Autistic people around the world – writers, poets. I wish that people would see online communities as part of community. If you live in an area where people don't share your values, it would make a difference if they were recognised."*

> *"Online communities should be valued the same as other communities such as geographical community."*

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

Participants shared their experiences of receiving care and support. Some participants highlighted experiences of feeling dismissed and not feeling as if they were treated always with respect by those providing support.

Several participants felt that consistency and reliability of support was an issue for them with insufficient support in their community. This meant they were facing challenges caring for other disabled members of their household as well as themselves.

Being able to access care and support locally, and the availability of specialist adult social care support in Scotland, were also important to participants. Some people raised concerns about being unable to access the preventative care and support they needed for their conditions because of a lack of access to services locally, including dentistry.

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

People shared their experiences of receiving flexible responsive care and support, and highlighted that Self-Directed Support, although not perfect, was a more enabling approach for flexible care and support because it “is a bit more in the person’s control.”

Third sector and community based organisations were also highly valued by participants who access and provide services for their ability to respond to local need quickly and flexibly.

Participants spoke about the impact of instances where they did not have access to flexible care and support. One participant shared an experience of not being able to visit friends and family because of fears of disrupting their care and support.

We heard that people would be less likely to disengage from services that they experienced as flexible and responsive – with the caveat that they felt that services which were not flexible enough to meet their needs and preferences risk “disengaging from people”.

Experiences of relationships with carers

When asked about experiences of carers providing flexible responsive care and support, participants shared the positive impact that good relationships have in their life. One participant recounted a positive and enabling relationship with their carer. Their experience illustrates the difference that good quality care and support can make to a person's life, and echoes the qualities of person-led[1] care and support such as trusting relationships that help empower people to achieve personal outcomes:

> *"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."*

There were also some negative experiences shared that people told us had left them feeling wary, distrustful and anxious. Participants stressed that carers should receive training to enable them to be trauma-informed and recognise that it takes time and effort to build trust, particularly with people who have had negative past experiences. Listening and acting on what people say they need was seen as vital, especially for those who have had traumatic experiences:

> *"How can I have trust in anyone because of my traumatic experience? Having a bad experience means you might be scared that anyone can hurt you."*

Their responses emphasised the important role that carers and people providing support play in helping people to access spaces in the community, build confidence, skills, social connections and independence.

[1] 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.

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."*

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

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

The SLIF will also support the system to demonstrate its contribution to the human rights PANEL Principles.[2] This includes that have the right to live as independently as possible, to be actively involved in decisions about their care and support, to participate in their community, employment or education (Participation); people have the right not to be discriminated against and to be treated equally (Non-discrimination and Equality); and to be valued and respected (Empowerment). Rights awareness is an important facet of the PANEL Principle 'Empowerment' and is included in a separate section below.

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:

> *"Working to targets and outcomes – they're not actually dealing with what you need. So it puts people off asking, leading to more stress and not getting the help they need. If people were asked at the first stages it would be easier."*

[2] SHRC, A human rights based approach: an introduction.

Participants shared experiences of times that they felt their rights had not been respected:

> *"For someone with a chronic condition that varies a lot, flexibility is needed. It would mean your needs are actually being met at the time needed, not what I am experiencing which is the way we structure our services doesn't meet you, so you don't get anything."*

One participant described an experience where they had made a complaint and advocated for their rights, which had not resulted in accessibility adaptations to the facility, this caused a feeling of exclusion and a declining trust that services would uphold their rights:

> *" […] When you don't have the proper backing for your rights to be protected, respected and upheld, this is what happens. No one is protecting us. […]*

Participants told us how feeling that their rights were respected, protected and upheld would help them feel safer when accessing services and feel able to ask for help, while also not worry that they may have to "prepare to fight" or to repeat their stories:

> *"It is traumatising to have to keep repeating your story. We need to tell our story to one person and for them to then advocate for you and then to arrange to organise the NHS and Social care that is needed. People need to feel listened too and some empathy."*

Participants described how speaking up and advocating for themselves or someone they care for had damaged relationships and resulted in them feeling stigmatized or seen as "difficult" by some services. They felt it was very important to them to be able to trust that their rights would be respected, protected and upheld when advocating for themselves:

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

Some people also suggested that experiencing their rights being respected and upheld would result in them having more confidence that

their personal information would be treated respectfully and confidentially. Confidentiality was raised by some participants as a concern for people living in smaller communities with close-knit populations.

Experience of rights awareness

Raising awareness of rights generally and among people providing care and support was seen as important to improving people's current experiences. People told us that they felt rights can be confusing and overwhelming, and participants thought it would be helpful if they could be provided with information about the most relevant rights in different circumstances:

> *"One of the biggest problems is that people don't know what their rights are."*

Staff sometimes not being aware of people's rights was mentioned as an additional barrier:

> *"Sometimes the services and carers don't know our rights either which can cause significant issues"*

> *"None of us know where to go. Nobody is pointing us. There should be some way of being pointed in the right direction."*

It was suggested that people providing care and support should ask people if they know their rights and provide them with information relevant to their circumstances, for example a leaflet that describes their rights and entitlements. They also felt that there should be more rights-based training for people working in health and social care support.

Local health and wellbeing hubs were proposed by participants that are accessible to all that can provide information about rights, help and support, and the importance was stressed of having mandatory guidance and policies in place to protect and uphold rights:

"Advisory guidance doesn't mean it has to be followed so how does one get their rights upheld? How are staff supposed to know how to treat different people in the absence of guidance?"

2.2. People are actively included in their care and support decisions, or those of the people they care for.

People felt their current care and support arrangements often felt restrictive; examples included not having control over choices such as when to get up in the morning or go to bed at night.

Some participants shared experiences in which they had felt assessments or decisions had been made without their knowledge, which negatively affected trusting relationships.

Participants said that workforce challenges, particularly the lack of carers available in their areas, were a barrier to being able to have a more active role in maintaining their own health and wellbeing, and having control over their care and support. It was felt that carers, both paid and unpaid, needed to be better supported:

"Carers in Scotland are not looked after properly – if they gave up the whole system would fall apart."

Meaningful involvement in decision making at local and national level

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

"Unless you're a carer or someone who requires support, it's hard to comprehend. You have to be part of something to understand what it feels like. 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 expressed frustration around not always feeling heard. They perceived a power imbalance between decision makers and people with lived and living experience, and worried that their views could be easily dismissed.

Participants said it was important for the overall vision for health and social care support to be based on listening to and involving people with lived and living experience, but there was a general perception that at times improvements were not always being implemented.

Participants felt that some existing high-level policies would enable them to have a more active role in their health and wellbeing or for someone they care for if implemented. They expressed frustration about repeatedly being consulted on similar issues and felt action needed to be taken:

> *"decisions are not filtering into actions that I experience."*

They stressed the importance of transparency, including publishing minutes of all meetings and the results of any actions taken.

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

People told us that when/if they receive good, coordinated care and support, they felt “safer”, “heard”, and “understood” but they also expressed that their experiences had led them to feel that it was unlikely for this to happen consistently.

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

On discussing experiences during COVID specifically, one participant described. Participants felt that well-coordinated care and support would also help them to be seen as a whole person and have their needs met holistically, rather than “split up.” In this way, care and support coordination was linked to the person-led care themes and whole-person approaches mentioned in sections 1 and 2. They suggested that in a more joined-up system, healthcare professionals and those providing support would have a better understanding of individuals’ conditions and circumstances, which would improve the care and support they receive and promote more preventative approaches.

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.

Integration of a range of services was a focus of the discussion, for example, the ability to access appropriate housing. Participants also highlighted the importance of feeling understood when accessing support and having a range of options to suit their needs:

> *“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.”*

These views related to the workforce perspectives (4. 'The workforce work effectively together across the system') – namely, that those working in adult social care support and community health want to be able to communicate and coordinate better across services in order to meet individuals' holistic needs.

We heard that systems can be difficult to navigate, and people wanted easier access to information about where to go for help and support. One participant talked about getting different, sometimes conflicting advice from different services and being unsure of who to listen to.

> *"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."*

Navigating between different services is also challenging for unpaid carers and takes a lot of additional time and effort. One person said, "joining up [services] and sharing information is absolutely fundamental to the changes that need to be made." They cited the 'hub and spoke' model used at the Beatson Cancer Centre as an example of "fantastic care" because it treats their brother's needs holistically, as opposed to in a siloed way.

> *"I found during COVID that people were just looking to keep passing you on to another service. They would briefly listen to your story then give you another number to pass you on to another service but no-one would take responsibility. It felt just like a tick-box exercise to say they gave you another phone number to call, but it happened service after service so people then just give-up."*

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

The ability of those providing care and support to consider future needs in care and support planning was deemed as important by the participants. One participant said their life has improved by having the support they need now in place, but they were worried about whether

council budgets would impact their care and support, and whether there would be cuts to their home support in the future.

Participants were aware of funding challenges facing the sector, citing the impact of short-term, unreliable funding on the sustainability of services they rely on. This view was shared by the workforce representatives we engaged with, who felt more integration between statutory and third sector/community organisations was needed.

4. The adult social care support and community health workforce is thriving

4.1 The workforce work effectively together across system boundaries

During the session with representatives working in community health and adult social care support, participants shared their experiences of working effectively together across the system.

Participants highlighted some examples of what worked well, such as the agility of the third sector and GIRFEC and rights education in schools. Multidisciplinary teams were also raised as an example of good practice, but it was felt that they sometimes didn't include key professionals close to the individual and unpaid carers.

However, participants felt there was less integration between strategic and grassroots levels. They shared their experiences on collaboration between services overall:

> *"[when] carers of young people don't have access to adult services, they fall through the gap."*
>
> *"data sharing can be a challenge in our work. For example, when doing risk assessments around health it can be difficult to get information from [other parts of the system] that can complement our support package for an individual."*
>
> *"there is too much form filling and people are having to tell their stories over and over."*

Participants reported some challenges relating to funding. Participants emphasised the loss that is felt by individuals, communities and statutory services when vital third sector supports are unable to renew their funding. It was suggested that changes to commissioning routes and processes were necessary to address these challenges:

> *"HSCP are picking up the challenges that our colleagues in the third sector are experiencing because of the lack of grant funding and the implications on ourselves with health and social care, because we became so reliant on that sector and the community is so reliant on that sector… We always hear about the NHS and the need for prevention, but a lot of that preventative support is being done by the third sector… We need to make it [funding] more equitable and fair for all."*

We heard that the third sector's ability to be highly creative, agile and responsive to community and individual needs was highly valued by statutory services.

Participants shared the Growing the Community Links Programme as a good example of integration between statutory and third sector support that could reduce pressures on GP services and get people involved in more community services:

> *"It would be beneficial if there were more [Community Link Practitioners] here."*

Having forums and meetings that bring people together so that they can raise awareness of each other's services within localities was highlighted as helpful, however it was reported to be challenging to gain a full picture of all the services that are available. Participants said they would find a means of staying on top of the service and support landscape in their areas helpful.

One participant highlighted a positive example, where a QR code was used that enabled people to access an up-to-date directory of organisations in the area:

"Spaces and places to come together to get to know each other and other services. Somewhere we can network and find out what everyone does"

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

Participants spoke about feeling a loss of professional relationships, extra work and confusion caused by high staff turnover and service changes among organisations in their areas, and linked this to short-term funding and other funding challenges.

Much like the focus groups with people with lived and living experience of using services, participants with lived experience of working in social care support or community health services shared their concern that policies existed to support improved conditions and ways of working, but there were challenges to them being implemented and sometimes this did not happen. They also expressed concern that if there were budget cuts they could impact the most vulnerable and disadvantaged:

"One of the challenges that we're facing at the moment is the fact that we have all these great policies, documents about how we should be operating but when you're actually working with people you're hearing these stories… it's almost like we have the things already in place… but we're not following through on any of them. It's the implementation and the monitoring and the asking people."

Conclusion

This report captures the wider information gathered during the focus groups that related to people's experiences of using or working in services and their delivery. It has been shared with wider policy teams across the Scottish Government.

During the focus groups, participants reported feeling as though the current system at times could not meet their needs and uphold their rights, and that this could lead to a feeling of stigmatisation, dismissal and feeling ignored. These experiences could then contribute to poor mental health, difficulty managing conditions, stress, anxiety and fears

about the future, as well as negative impacts on family members and unpaid carers.

What mattered most to participants is having flexibility, choice and control. Participants' reflections on services during COVID-19 offer insight into the positive difference that changes to care and support can make in people's lives. Though challenges existed during this period, and experiences were not universally positive across Scotland, participants also described that "a whole new world opened up to me" and "the pandemic showed it was possible to meet the needs of housebound people."

This aligns with the experience of the workforce, whose views captured in the main report relayed how working effectively together in a supportive system and culture would help them 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, and the findings from this report have been shared with relevant policy teams in Scottish Government working in these areas. This improvement work includes the Scottish Learning and Improvement Framework, which 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.

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.