Health and Social Care Alliance Scotland (the ALLIANCE)

Independent Review of Adult Social Care in Scotland – Engagement Activity

September to November 2020

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Social Care
Review
People at the centre

Executive Summary

The First Minister announced there would be an Independent Review of Adult Social Care in Scotland on 1 September 2020, appointing Derek Feeley, as Chair supported by a small advisory panel.

From late September to mid November 2020, the Health and Social Care Alliance Scotland (the ALLIANCE) sought views from across the country to help shape and inform the Independent Review of Adult Social Care in Scotland.

A series of digital engagements with individuals with experience of social care support and organisations representing the interests of people who receive, or commission for themselves, social care and support.

In addition, an email address and online survey was set up for individuals, families and carers to respond to and a facilitation pack was distributed which supported organisations to host local or targeted events during the consultation period to access the views of individuals, families and carers.

Analysis of contributions showed that there were some examples of good quality and effective support operating at a local level however, there are high levels of frustration around the existing structure and design of social care services. Eligibility criteria, workforce development, the value of unpaid carers and the implementation gap between policy and practice were amongst many of the key themes that people told us needed the review panels attention, to improve service provision.

The third sector's contributions to providing social care support was identified across our engagement activity as one of the biggest strengths of the social care system, with self management principles providing the foundation to high quality, long term, asset based support. There was a general consensus from the engagement activities for Scottish Government to increase resources and support for the third sector to ensure quality local delivery of services and support, which is encompassing the principles of choice and control and which meets people's needs.

It was strongly felt that communication and equality need to be explicitly addressed in the recommendations of the Social Care Advisory Panel.

The engagement activity was broad and diverse and raised an array of key themes. These themes are captured and reported in this document, sharing the views and learning of individuals and organisations across Scotland.

The ALLIANCE would like to thank all those who took the time to share their experiences, views and hopes for the adult social care system in Scotland. This document aims to summarise those views and consider recommendations to support the Independent Review of Adult Social Care Scotland.

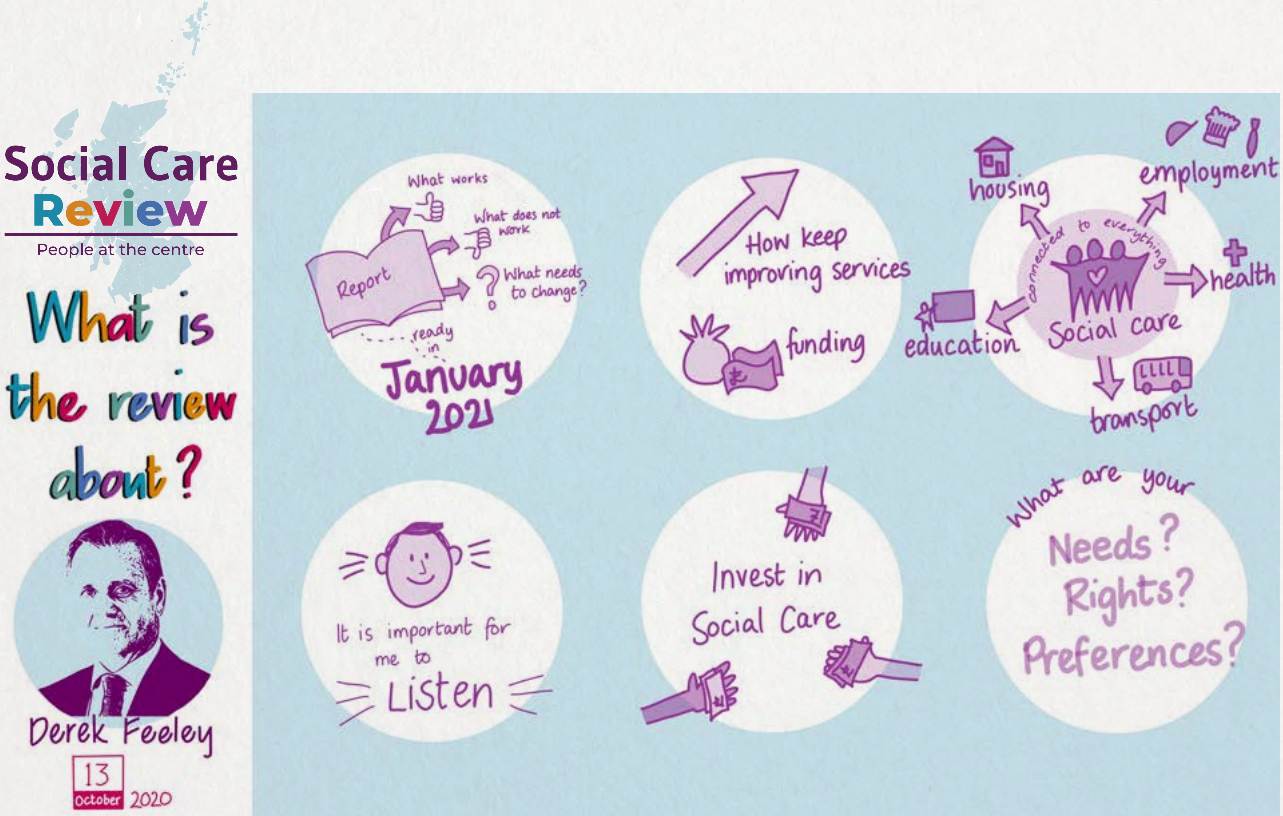
Contents

Background

The First Minister announced there would be an Independent Review of Adult Social Care in Scotland on 1 September 2020. The review aims to recommend improvements to adult social care in Scotland, in terms of the outcomes achieved by the people, their carers and families who use social care services, and the people who work in adult social care.

From late September to mid November 2020, the Health and Social Care Alliance Scotland (the ALLIANCE) sought views from across the country to help shape and inform the Independent Review of Adult Social Care in Scotland.

The ALLIANCE designed and led on the **People at the Centre (Social Care Review) Engagement Programme**, using a person centred focus, to capture insights from organisations, key stakeholders and people who access social care support. The ALLIANCE utilised the strength of its membership to engage with organisations with first-hand knowledge and experience of adult social care, and to access people with lived experience to ensure people were at the heart of this review engagement process.



The programme aims:

- Listen to the voices of people and organisations across Scotland on the needs, rights and preferences of people who use services, their families and their carers.
- Design and deliver an inclusive and diverse programme of engagement and communication activity that ensured people were supported to participate and their voices were heard.
- Capture learning and feedback on current experiences from people, unpaid carers and third and public sector organisations – particularly focused around identified care groups.

Programme activity was delivered in three ways:

1. A series of digital engagement events with groups of organisations representing the interests of people who receive, or commission for themselves, social care and support.
2. An ‘open call’ for individuals, families and carers to comment on their experiences of accessing social care and support and what they would like to change or improve through a telephone conversation, online survey or completing a downloadable paper form
3. A facilitation pack for organisations to use for local or targeted events during the consultation period to access the views of individuals, clients, service users and carers.

Over 300 participants were engaged with over 14 online events hosted by the ALLIANCE including many people who live with a long term condition, disabled people, unpaid carers and third sector organisations. The engagement events were themed to reflect the diversity of adult social care and to welcome and enhance the voices of lived experience. Short reports from all the events are available on the ALLIANCE website.

Introduction

What we heard was significant

A frequently repeated theme was that the social care system is currently not working for many people and families across Scotland.

Social care, as a working definition, exists to ensure every person in Scotland has the ability to reach their full potential, yet there are still irregularities in its delivery with individuals not experiencing a combined and integrated system.

Accessing social care support can feel exceedingly difficult and over-complicated, with many gatekeepers. To access support there are huge amounts of paperwork, asking people to justify why they are applying for help. Social care provision needs to be changed to a human rights based approach. Once we embed this terminology and culture, there would be a collective vision based upon what people need and have a right to access rather than experiencing system imposed limitations. It was strongly felt that access to services must be made significantly easier and the system should be simpler to navigate.

In order to achieve this, there needs to be a focus on personal outcomes and a transforming of the commissioning processes. We need an approach that allows mixed services- taking the best support elements from statutory and third sector organisations and allowing people to choose. Individuals 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 rather than being system driven.

Social care should be seen as an investment of citizenship. We have an opportunity to embed citizen involvement and co-production in re-designing services and adopting an approach that commits to continuous improvement. We need to have support services which are readily available when a person needs to access them, but also to become much more proactive in providing preventative and early intervention provision.

Key Themes:

Structure of Services

Participants told us the current care system is designed around fixed time, task-based performance. Care staff workplans are focused on delivering specific tasks within set time allocations; this is the complete opposite to person centred care. In order to transition towards a person centred support service, changes need to happen in the way Scotland commissions support services. This must be led by establishing a social contract and an overhaul on how people are assessed, with a focus on holistic needs and framed by a human rights based approach.

Participants felt that at present the care system is driven by outputs rather than outcomes. For an improved social care system, there needs to be a shift to personal outcomes- the focus needs to be on the individual and not on the service.

The focus on eligibility by commissioners was described as obstructive, with a lack of value placed in early intervention services. Equally, third sector services are scrutinised for proof of value and evidence-based results, a need which doesn't appear to be replicated for statutory services. The culture that underpin the commissioning process is not supportive of the services that people need.

Commissioning of Services

In the view of participants, 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.

Design of Services

> **'Service design and delivery can only improve if people with lived experience are involved in the process. It is impossible to address inequality, if the people who experience it are not in the room.'**
>
> [Engagement event attendee, third sector organisation]

A strong priority identified was for services to be redesigned to work more seamlessly together. Opportunities to be more efficient need to be taken and it is no longer acceptable to continue doing the same thing and expecting different results. People with lived experience of accessing social care services and support need to be heavily involved with the service design process. When seeking to engage with people and their carers who use services, there is value assigned to community engagement support.

The disparity in investment between hospital services and social care was frequently raised with a sense that 'massive amounts' have been spent on acute services and hospitals, 'a reasonable amount on social care and rehabilitation in the middle, and tiny amount on prevention and early intervention'. Participants felt, if this was reversed, with the majority of spend placed on the early intervention agenda, it would result in savings in the future.

Related to the above, participants were concerned that the term social care can have a negative connotation, of a service provided to those in a crisis situation and of a support service to prevent or delay a situation deteriorating further. In the view of participants, this is not helpful, as people are looking for constructive yet optimistic support, achieving goals and outcomes they could never have previously achieved – 'aiming high and striving for new life experiences and adventures.'

Social Care should be a springboard not a safety net.

Social care was described as very different in its delivery from health, with the need expressed for an effective way of the services to work together in a more integrated way, with individual's needs at the forefront. In the view of participants, there is a compromise between standardising and customising services to meet the need of the individual, and social care needs to be able to deliver on both.

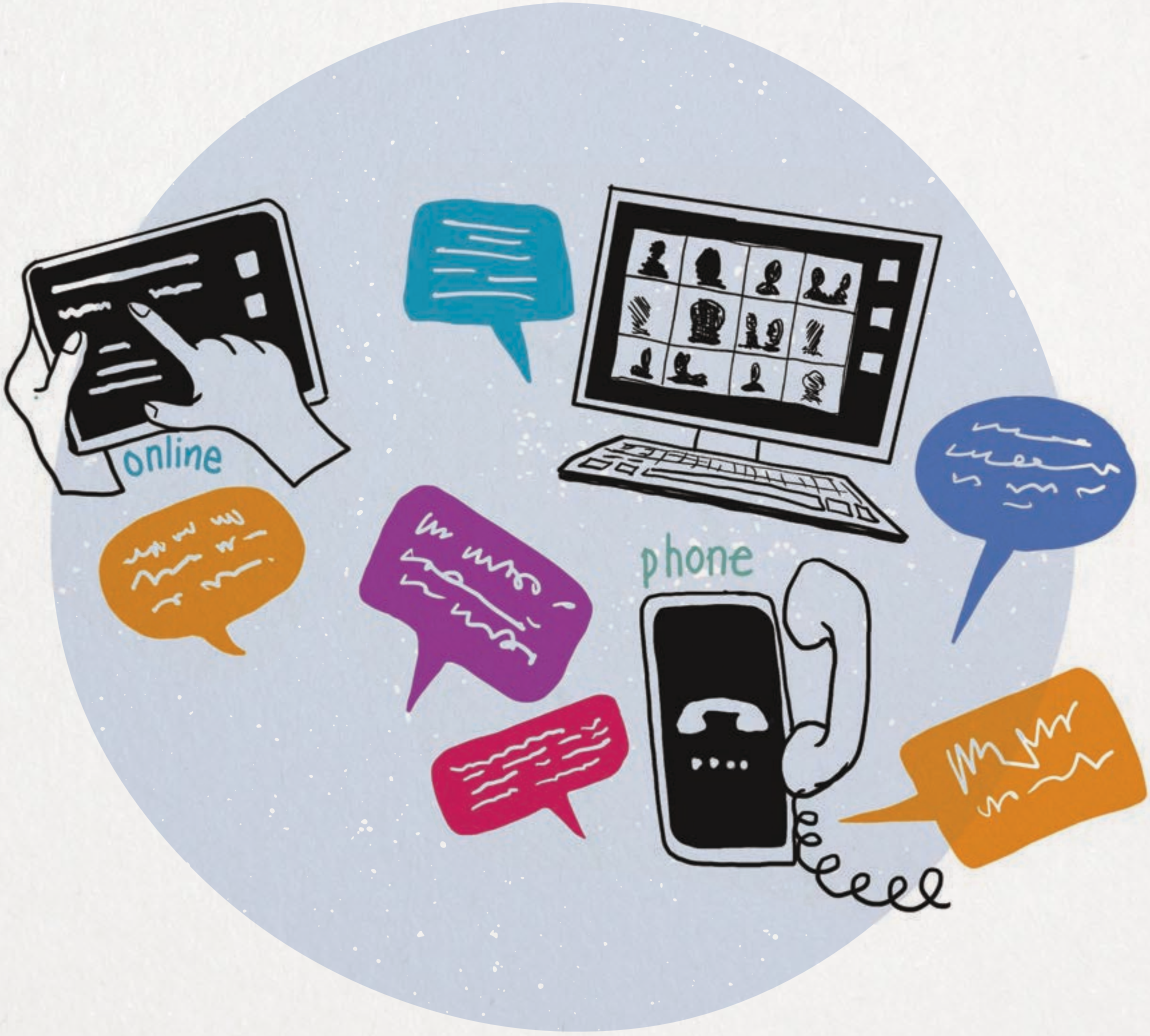
Individuals value relationships and feeling connected to their communities, this need is often addressed by the support of local third sector projects, such as befriending, walking groups and activity based interactions.

Technology

Technology was a significant theme across our engagement activity with a consensus that a cultural and attitudinal shift towards technology is needed. Technology is an integral part in delivering care and allowing people to live independently in their own communities. It promotes independence and offers individuals control over aspects of their lives, in turn offering the unpaid carer small periods of relief.

Housing services have worked in small groups to coproduce a support system which is shaped by the people who access the support. Technology has supported service innovations, with 24/7 digital support services. Social landlords, many of whom have accelerated their digital service offering and capacity, can act as facilitators for the individual and for health services.

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 reducing isolation.



Eligibility Criteria

Participants spoke of a disparity of access to social care between local authority areas, caused by each area being responsible for setting their own criteria. Participants were concerned that eligibility criteria is being utilised as a resource management tool by local authorities, with social care increasingly acting as another emergency service with no preventative output. The eligibility criteria for accessing social care support in many Integration Authorities were described as being set at 'crisis and emergency'. Preventative work is 'scarcely mentioned', ultimately meaning there is a failure to support people to live well and independently, preventing their situation deteriorating to a point where they then meet the 'at risk' criteria.

The level of care and support received by individuals and their families is determined by the local authority, often allocating individuals with standard care packages. Participants noted that the quality of care individuals receive depends on where they live. Participants believed there is need for transformational change in behaviour and culture to ensure it is no longer acceptable for services to be a 'postcode lottery'. Additionally, participants felt support needs to be accessible earlier, promoting outcome focused support.

Participants believed that there needs to be a range of services which are available when they are needed. There are simple aids and devices which can ease the effects of living with long term conditions, however, participants reported that people often are not aware of them or that they can self refer for support. Signposting 'can be poor', and this lack of information sharing in some cases can prevent the individual from achieving the support they need.

Accessing social care is difficult with lots of barriers.

Social Care Assessment

Access to social care support was described as 'becoming notoriously difficult', with the third sector supporting increased numbers of people, who have been assessed as not eligible for care, and therefore unable to access support. Social care assessments were described by participants as being completed based upon a medical model, with little or no account given to holistic and social needs. The assessor's knowledge of complex conditions and sensory impairments often appears inadequate for the task involved, pointing to a staff training need.

Participants were of the view that the social care assessment process needs to be reviewed and simplified, as it is currently too long and complex. During assessment discussions, participants strongly felt the conversation needs to be around needs and rights rather than about money. In the experience of participants, often people doing the assessments do not understand the functional difficulties of people with complex needs, neurological conditions and sensory impairments, meaning third sector support organisations spend a lot of time fighting for people's rights to get Self Directed Support (SDS) and other benefits or attending appeals [See page 13 for further information about SDS]. Statutory services need to work closer with the third sector and a wider pool of support which already exists in the individual's life.

Participants recommended that the assessment process should be a collaborative engagement process with the person's needs at the centre - 'it should feel nurturing and supportive, rather than a battlefield' as one participant put it. This is pertinent for individuals and families who are transitioning from a care package in children services to under resourced support in adult social care.

The assessment process should be a collaborative engagement process with the persons needs at the centre, it should feel nurturing and supportive, rather than a battlefield.

Workforce Development

How the social care workforce is valued and supported will be significant in improving and implementing change in the social care system. Participants 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.

Workforce Wages

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 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?’**
>
> [Engagement event attendee, third sector organisation]

Workforce Training

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.

Workforce Development

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.

> **‘The good carers that came in were worth their weight in gold and should be rewarded or acknowledged for this.’**
>
> [Open call response, unpaid carer]

Workforce- Unpaid Carers

The care system relies heavily upon unpaid carers, who often have to leave employment to meet the demand of their caring responsibilities. Despite the considerable number of hours and commitment to the caring role there are little provision for training and support. Participants recommended that the role of unpaid carers should be developed, to build on their expertise and acknowledge their role as a valued part of the social care workforce.

Integration in Practice

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.

> **‘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?’**
>
> [Engagement event attendee, lived experience]

Implementation Gap

It was acknowledged that Scotland has been world leading in producing high quality policy, including the Charter of Rights for People with Dementia, the Social Care (Self Directed Support) (Scotland) Act 2013 and The Carers (Scotland) Act. Self Directed Support (SDS) was described as a perfect example of where the intent behind the legislation is unarguable and, if correctly implemented, Scotland would be benchmarked as a country which provides quality support for those that need it and for every citizen to thrive. However, the challenge is to turn policy into practice which participants felt had been lacking and expressed hope that the Independent Review could help address.

It was noted that at present there are a huge number of different standards in social care, and yet their importance is minimal if the message does not reach those delivering the service on the ground. Participants expressed a desire for person centred standards, based on what matters to people. The group recognised there are great examples of forward thinking within Health and Social Care Partnerships- now there is a much-needed focus on closing the current implementation gap.

> **‘Scotland’s Health Improvement, Efficiency, Access and Treatment (HEAT) Standard from 2013 is that everyone newly diagnosed with dementia is entitled to be offered, at minimum a years’ worth of post diagnostic support. Seven years later, the group identified that only 42% of people who are entitled to this have been offered this support.’**
>
> [Engagement event attendee, third sector organisation]

Unpaid Carers

Participants were of the clear view that without the thousands of unpaid carers across Scotland the social care system could not cope or work. In return, it was felt important that unpaid carers are valued and have easy access to support and know what is available and how to apply. There was felt to be a need for more transparent and visible help, with access to a whole range of services that unpaid carers need not only to help them in their supporting role but also to live a fulfilling life themselves.

The ALLIANCE engagement sessions heard repeatedly from unpaid carers that carers assessments are not being undertaken, that carers feel undervalued and their human rights are being ignored. Unpaid carers are 'relentlessly' providing care, night and day, with many reported to be paying for provision themselves in order to get a break from their caring responsibilities. Information regarding access to some social care support or financial support was described as often not forthcoming. When unpaid carers are dealing with caring 24/7 it is very difficult for them to have any energy left to 'fight' for social care support. Participants believed there should be an emphasis on carers being allowed and supported to live well instead of just surviving on a day-to-day basis.

It was recognised that there are many people and families who are playing a supporting role for an individual but would not recognise themselves as an unpaid carer. People in this situation are not actively seeking the support and help which may be available to them. For some people from ethnic minority communities there can be stigma associated to asking for carers support which means families do not access this aid. Equally, we heard that unpaid carers from ethnic minority communities take on more caring responsibilities when the system fails to provide appropriate paid carers in keeping with the individual's cultural needs.

> **' As an ageing person myself the stories that Carers share with me in my role as a carers representative have filled me with apprehension and concern for my own future.'**
>
> [Engagement event attendee, carers representative]

Respite

Across our engagement approaches, 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 respite which is intended to give an unpaid carer a break from their caring responsibilities. The ALLIANCE heard the experiences of the person in need of care during this time can often be inadequate, with some individuals being allocated a place in a care home, which is inappropriate for their needs or age. With limited choice and lack of appropriate solutions, often the carer doesn't feel able to take their respite opportunity and will forsake taking a break.

Some people we spoke to felt care homes are operating as a business so do not have beds readily available for respite or 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 person presents challenging behaviour, this increases the barriers to accessing respite support. Paid carers are no longer 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.

Self Directed Support

A decade since Self Directed Support was introduced as the 'great vision' of Scotland, it was perceived to be one of the most influential changes to social care support and yet participants felt there was still a struggle to implement such changes across Scotland. Whilst participants described many examples of organisations delivering great practice, there were concerns raised that social work staff are 'operating under outdated learning'. Participants felt that staff and organisations are not being trained efficiently and are underequipped, making it impossible for them to support individuals and families to achieve the best solutions.

Delivery was described as differing greatly across local authority areas. In some areas SDS is being permitted to be used flexibly whereas in others this did not appear to be the case. There appears to be inequality in admission to the system and it was described as 'far from self directed' when others get to decide on what support will look like and cost.

Participants stressed a need to improve regulation, ensuring human rights are the foundation to SDS. For those accessing the service, there was felt to be a need to ensure that the individuals feel empowered and lead on decision making, increasing knowledge of what individuals are entitled to, and amplifying their voices is key to improved service delivery. People's right to SDS should not be dependent on their level of advocacy, access should be guaranteed.

National Care Structure

There needs to be a shared vision of social care founded upon rights that allows people to live rich and fulfilling lives. Those who attended our engagement events felt there isn't a need to replicate the National Health Service for social care support as local service provision and flexibility are key components to achieving such a concept.

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.

- National Standard- 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
- National Learning System- focus on national and local learning, having national impact, with a human rights and vision at the centre
- Formalised data sharing- every person having one single data record/ care plan
- A national structure, providing career structure across integrated partnerships (including the third sector) would provide good foundations, with operations running locally, providing specialist support

Responses to the ALLIANCE 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.

Communication and Communication Support

Communication support is right at the heart of what makes life meaningful, catalysing good mental health and social inclusion. People living with sensory impairments felt this is a notion which can often be lost when it comes to support packages. They told us that people are often having to choose between accessing personal care and communication support- which is unmerited as one is 'care' and one is 'social'. Emotional and social support ought to be valued on par with care needs.

Consensus from our engagement events is there needs to be truly inclusive communication no matter what the person's communication needs are, and this should be provided and not supplemented by an individual's care package. Many professionals don't understand the full impact of sensory loss and communication needs, which can mean they fail to understand the person. Social care must support individuals with communication needs to have a voice and have equal access to person centred care.

Participants also stressed that inclusive communication needs to be explicit, and that good practice should be embedded in mainstream practice. People need to feel that communication is valued, and their needs are respected.

> **'Telephone contact is not an option for us. My father doesn't have a mobile phone because of arthritis he cannot manage the buttons so relies on email for communication. We are told over and over that email is not secure so social services won't use that form of communication. And yet that is what he uses to communicate with his GP.'**
>
> [Open call response, family member/lived experience]

Self Management

People living with long term health conditions, disabled people and third sector organisations who attended our engagement events, both agreed that there are excellent examples of quality services currently being provided by the third sector, promoting self management principles and placing the lived experience of people at the centre. They felt it is essential for the review of social care to recognise the importance of self management supporting services, with an emphasis on peer support and social prescribing. It was suggested peer support could be a paraprofessional role, utilising the wealth of knowledge that comes from lived experience and the insight that can be gained from someone who has had similar experiences.

Participants stressed that long term investment is needed into these types of preventative support services. Short term funding continues to be an issue and prevents long term planning and capacity to build on its successes across Scotland.

Support Plan

The importance of an effective Support Plan was a theme raised by participants at most of our engagement events. Its purpose 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.

Those who attended the events, described how an individual's Support Plan should be like a passport, a document allowing you to travel down all eventualities in life. It needs to be one single plan, incorporating all factors of life, being flexible and being reviewed regularly. A quality support plan is also helpful when communicating with housing, educators and employers. The notion that an individual should own more than one, would suggest their creation is for service providers and not the individual, which should not be the case.

A care plan should be a digital passport. One single care plan which could be used across agencies (care, health, housing, employment, education), help support their life journeys and live a fulfilled life.

Transitions

The ALLIANCE hosted a themed engagement event around transitions. During this session it became clear from the discussion how broad and extensive transitions in social care can be. Its significance is beyond an individual's move from children to adult services but should also be inclusive of transition from carer to carer, sighted to non-sighted services and adults into older adult services. The group agreed many of these transitions are predictable and should be planned for in partnership with the person experiencing the transition.

The group identified transitions to be about making sense of the new system an individual must engage with and making sure that systems are designed to work around the person and not the services is a necessary principle. Individuals who are experiencing the transition are still the same person, so it is important that services are being developed to match the person's needs as they grow older or their needs change. The group agreed there is a need for improved communication and embedding of person centred approaches into support plans, ensuring both the individual and the support plan successfully transfer into the next chapter of people's lives.

Participants shared their experiences of successful transitions and affirmed supported transitions are often achieved when the role of 'navigator' is someone who has nothing to do with the funding of care, allowing the process to be based on needs rather than funding allocation. Transition support should be applied to the same aspired standards of SDS, ensuring people have as much choice and control as possible.

Charging for Social Care Services

During our 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 huge, 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.

Care homes were also a point of discussion at our engagement events which raised questions around the privatisation of social care support, particularly around care homes. There was agreement at the events that there needed to be transparency with care home provision. A substantial amount of public money invests in their services and with that there needs to be an agreed expectation of return.

Mental Health

Mental health service provision was raised as a concern across our engagement methods. Responses stated service provision for mental health needs to be broad, ranging from preventative and recovery services to support and keep people well, to critical support which people need to live independently and well, as part of the community.

Respondents identified eligibility criteria as the main barrier to accessing mental health support, 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 were described as long. The experiences 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 principle lead in providing support for individuals with mental health conditions, despite it being a statutory requirement for local authorities. As stated above, they emphasised the importance of self management centred support, holistic services and the contribution of lived experience in both service design and delivery is priceless.

Housing

Housing is a human right that affords people dignity and without a right to housing other basic human rights will be compromised. Services delivered by housing providers go far beyond an individual's right to a home. Social landlords employ a huge number of care staff, with care support being a principle responsibility delivered by housing services.

Housing Associations have a lot to offer in terms of service design and development for integrated health and social care, however housing providers expressed concerns about an absence of an agreed shared vision. Providers communicated that by placing housing at the heart of service integration, using a place-based approach, individuals and the wider environment would be better connected with service outputs designed for the whole community.

The participants identified current infrastructure to be unsupportive in helping people to stay in their home and the need to achieve a single, unified approach to local commissioning with a united, harmonised legal infrastructure.

There are also some barriers around the way people experiencing homelessness are supported by the current system. It was stressed that both responsive and preventative approaches are under resourced and sub-standard. Homelessness affects many people who have complex and multiple care needs, and who must be supported effectively. Participants articulated a desire for a hub approach, enabling multiple needs to be dealt with through a partnership approach.

Equalities

When considering improvement and change to the social care system, the people we engaged with stated that the Scottish Government needs to be specific about mainstreaming equality. It is not enough to provide recommendations and state 'equalities will be addressed throughout'.

Gender Equality

It was articulated that care is an infrastructure, which enables people to live dignified lives and it continues to be undervalued, because it is gendered. Women are the vast majority of unpaid carers; it is mostly women who work in the care sector and the majority of those who access care are women. The ALLIANCE was told that tackling this under valuing of social care cannot be addressed without acknowledging care and women are deeply interlinked, and the fundamental place of care in our society is essential for gender equality.

The diversity of the workforce was also discussed, and participants explained that equalities need to be addressed around the gender pay gap, which includes care staff. We need a diverse workforce and leadership to implement change.

Race Equality

Conversations also took place about the extent to which the social care system met the needs of all of Scottish society. It was strongly expressed that the way social care is delivered is not a one size fits all approach and there must be consideration for how we communicate and offer support to BAME people and communities. It was shared with us that for some people from ethnic minority communities there can be stigma associated with asking for carers support which means families do not access this help.

Scotland has diverse communities which need to be able to access local and national support services and resources. Once again those engaging with us identified improving communication to be a priority, both in terms of language needs and of people's ability to access online resources. Participants also expressed that small third sector organisations are delivering on this need with community projects which are carrying out quality evidence-based work supporting diverse communities and are working tirelessly with little funding.

The broader context around which the social care system operates was also referred to during engagement events

Nutrition

Our engagement sessions noted that food is not prioritised within social care services, yet one in ten older people in Scotland are malnourished. The group believed food is central to who we are as individuals and provokes dignity and choice so must be acknowledged and valued, with the importance of grassroots projects being recognised for their value in addressing malnourishment but as well as reducing social isolation.

Transport

In our engagement discussions, transport was raised as an issue for many people, with accessibility and mobility in accessing and delivering care support a key consideration. Travelling time and costs can be a barrier to accessing services. Often specialist support is not available locally and considerable travel is needed, eliminating it as a viable option.

Employability

Accessing employment was identified as a huge barrier for disabled people and people living with long term conditions. It was expressed that disclosing their disability during the application process has adversely impacted the success of the submission, with many employers failing to even acknowledge the application. These experiences highlight the huge amount of work that has still to be done in terms of society embracing disabilities. Employers need to think differently and more positively about disabled people and long term conditions, as both potential recruits and valuable colleagues, focusing on ability and skills. Stigma continues to be a problem within employment and further education, where people have experienced feeling ignored, disrespected and unappreciated by fellow students.

Responses from our open call also raised local issues for communities around the funding for learning centres and supported employment. Submissions highlighted these serviced taught people life skills, helping individuals to build their confidence and independence, but this support had sadly ceased, meaning the stepping stones are not in place for people to move towards paid employment, the right to work is a human right.

Social Needs

There was agreement across the engagement activities that social care is meant to enable people to live fulfilled lives, offering support which fits around the person, not the person fitting around support. Social care should not be '9 to 5', because social lives are not. People rely on support to successfully enjoy a social life. Individuals who access social care support spoke of their enjoyment being spoilt by their nights coming to an end prematurely due to staff changeovers. Evenings are coming to an end at 10pm which does not reflect the lives of other adults in society, therefore infringing on their human rights. There is an emphasis on the 'care' but not the 'social' element.

Social Security System

Those with lived experience shared with the ALLIANCE the view that health and social care services need to work closer with the social security system. They explained how unpaid carers can be forced to give up their paid employment to take on this role, often this is before an age where they would be entitled to state pension. It was shared that Carers Allowance is insufficient, especially when you must pay for day services which offer any respite. Further, Carers Allowance stops if the person in receipt of care is in a care home or is in hospital.

Palliative Care

Our engagement activity identified that effective conversations are paramount planning for palliative care, focused around what matters to the individual and how formal and informal forms of support can input to achieving their personal aims. Participants identified that when most people are approaching the end of their lives, their needs will change, and this can often occur rapidly. Service providers need to be proactive and skilled to react to this, being prepared to offer quality care. SDS was identified by participants to be too slow and administrative to meet the speed of these changes and the needs of people in this position, so must be improved to encompass a variety of circumstances.

Criminal Justice System

Responses from our open call 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.

The ALLIANCE would like to thank all those who took the time to share their experiences, views and hopes for the adult social care system in Scotland. This document aims to summarise those views and consider recommendations to support the Independent Review of Adult Social Care Scotland.

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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 nearly 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 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.

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Visuals supplied by Laura Brodrick, Think Big Picture www.thinkbigpicture.co.uk

Social Care
Review
People at the centre

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