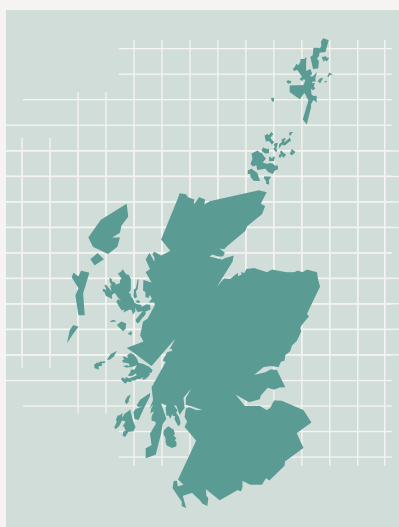
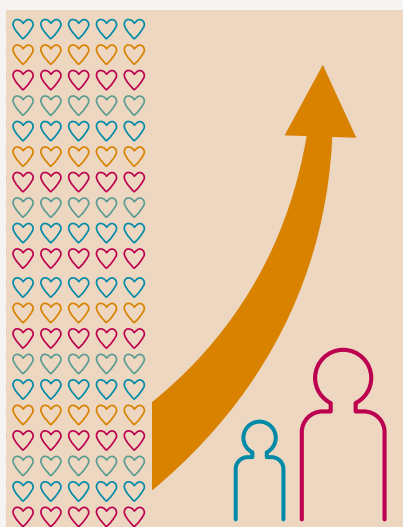


Health and Social Care Alliance Scotland (the ALLIANCE)

Challenge and Change:

the Future of Social Care in Scotland



May 2022

Contents

Foreword **1**

Sara Redmond, Chief Officer, Health and Social Care Alliance Scotland (the ALLIANCE)

“Pieces of the puzzle”: data and unpaid carers **3**

Claire Cairns, Director, Coalition of Carers in Scotland

The National Care Service: the rights of children and young people **5**

Snow (Tuisku) Curtis Kolu, Policy Officer, Includem

The proposed National Care Service needs to take care with data **9**

Layla Robinson, Partnership and Engagement Manager, Advanced Care Research Centre at University of Edinburgh

Proposed National Care Service is failing the most vulnerable who are from ethnic minority communities **12**

Rohini Sharma Joshi OBE, RSJ Equality Consultancy

Social care data: the gap between word and deed **15**

Alex Stobart, Director Scotland, Mydex

Considering mental health within the National Care Service **18**

Craig Smith, Senior Policy and Research Officer, Scottish Association for Mental Health (SAMH)

Young Carers and the National Care Service	20
<hr/>	
Paul Traynor, Head of External Affairs (Scotland), Carers Trust	
Adopting a different approach: on not eating the elephant	23
<hr/>	
Karen Hedge, Deputy CEO, Scottish Care	
Crisis point for social care, and the need for change	26
<hr/>	
Antony Clark, Interim Director of Performance Audit and Best Value, Audit Scotland	
About the ALLIANCE	28
<hr/>	
References	29

Foreword



Sara Redmond

Chief Officer

Health and Social Care Alliance
Scotland (the ALLIANCE)

On 9 August 2021 the Scottish Government launched their consultation on proposals for a National Care Service for Scotland.¹ As the contributors to this anthology show, the challenges for those delivering and accessing social care have been long standing – and further exacerbated by the COVID-19 pandemic. Change is urgently needed.

The ALLIANCE recognises the need for action, within a sector straining under the pressures of the last several years; not merely systems restructuring, but meaningful change that improves people’s lives. To do this, Scotland must keep the vision of social care and the expertise of lived experience at the heart of the future being set out, enabling local solutions to ensure choice, control, dignity, and freedom. As Craig Smith states in his chapter, we must, “ensure that the National Care Service is genuinely built on a foundation of lived experience involvement with the promotion of independent living at its heart.”

Embedding lived experience in the proposed National Care Service involves more than consultation. A range of contributors in this anthology discuss the importance of good data, and the need for Scotland to ask the right questions to track whether any new system is providing meaningful improvements in people’s lives. How do we measure what will really indicate whether we have transformed the system away from crisis response, and whether people have meaningful choice and control over their care and support?

What measures are put in place to deliver and monitor improved transparency and accountability, and to address known data gaps? As Rohini Sharma Joshi OBE outlines

in her chapter, the current system does not work for everyone. She writes that, “for Scotland’s ethnic minority older people, social care services have long been confusing, challenging and sometimes even downright inaccessible. Their specific care needs remain not fully understood, which often results in them being overlooked.” We must scrutinise whether the proposed system addresses existing inequalities, and whether it creates any new cliff edges – such as gaps between early years/education services and social care if social care for children and young people is included within the National Care Service.

Throughout all of this, money is the elephant in the room. We must ensure that there is adequate resourcing for the realisation of rights, and to enable early intervention in providing care and support in ways which enable people to live well. Whilst ethical commissioning and a greater focus on collaboration rather than competition is welcome, we also need to remember that procurement is not the only funding route through which investment into preventative sources of support will be secured. For many smaller, community-led organisations, we need to ensure that there is sufficient investment in their core costs to enable them to be community anchors.

The National Care Service offers both risk and opportunities. To mitigate the former, and take full advantage of the latter, we must prioritise the expertise of people with lived experience of social care, improve our data collection and analysis, and reform current funding models. At every stage, those designing, developing, and delivering the proposed new system should consider: how will this improve the lives of people accessing – or trying to access – and delivering social care?

We cannot miss this opportunity, and we don’t have the time to wait.



“Pieces of the puzzle”: data and unpaid carers

Claire Cairns, Director, Coalition of Carers in Scotland

For the last four years, ever since the Carers Act became law, I have been seeking an answer to the relatively simple question “What has the Carers Act money been spent on”? But, despite direct questions and some Freedom of Information (FOI) requests, I have yet to receive a full and consistent answer from local authorities, nor to the wider question “How much is each local authority spending on carer support?”

I know from colleagues that my experience is not untypical and they have also met a blank wall when they are looking for answers on how government commitments have translated into reality at a local level.

So why isn't this information available at our fingertips, included in annual reports and transparent within accounts? Is it that social care is so complex, data will only ever provide an out of focus, blurry picture of what is really happening? Or is it obfuscation? An implicit agreement between government and local authorities, not wishing to draw attention to how money is moved from pot to pot, like the old cups game, nobody knows where it has ended up.

I know I am slightly oversimplifying matters; data is notoriously difficult to capture in a meaningful and consistent way and so often it is collected without a clear purpose in mind. For example, we collect how many carers have received an Adult Carer Support Plan, but does this really have value without knowing if they got the support they needed in the end and if it made a difference to their lives? Yet it is of course challenging to extrapolate such meaning, using the blunt tool of databases and large data sets.

A strong message from Derek Feeley's Independent Review of Adult Social Care was the importance of recording what support people asked for but didn't receive – the old “unmet needs” question.² If captured, this would be the richest data set available for planning future social care services and if we are serious as a country in our ambition to expand and improve social care, then this must surely be a data must.

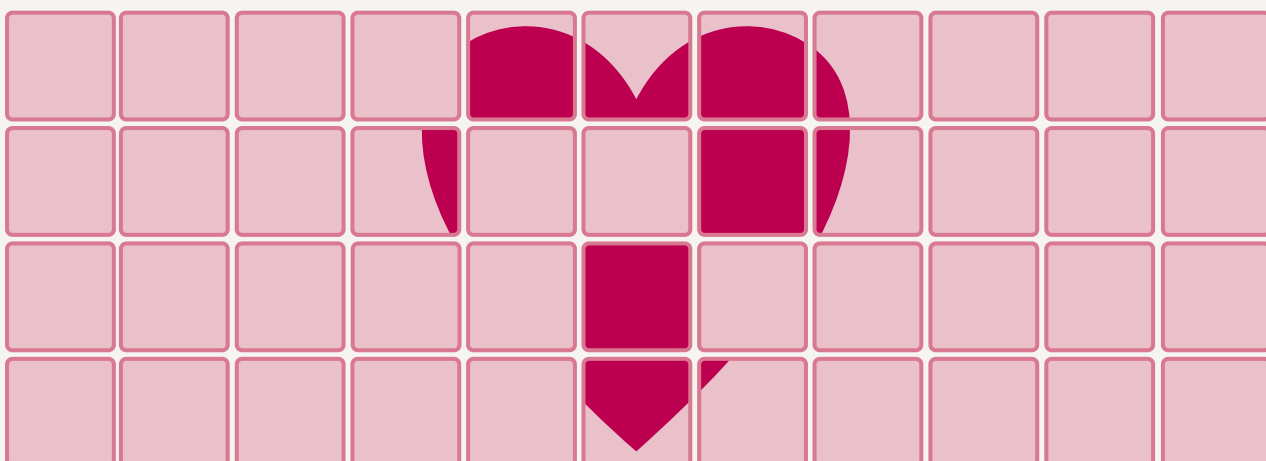
It would tell us what people asked for when they didn't meet eligibility criteria because they weren't (yet) in crisis, and isn't this the definition of preventative support? It would also tell us what people said they needed that wasn't available to them, pointing out current gaps in services, as well as what we need more of. So often presumptions are made about this, yet having worked in the carers' movement for over 25 years, I can say that each caring relationship is like a fingerprint, unique in its own pattern with its own distinct requirements.

So will the role of a National Care Service overseeing data collection lead to improvements in our evidence base around social care? Improvements in our understanding of the outcomes for people who use social care and unpaid carers? And ultimately improvements in people's ability to live their lives the way they choose?

I suppose it's too early to tell, without knowing more about the scope and functions of the National Care Service. But if we are to learn from our current failings, I would say the National Care Service needs to deliver the following three things:

- 1.** We need more consistency and transparency around data. So often data that is meticulously collected locally, can't be benchmarked nationally due to variations. This will require investment in accessible electronic systems, as well as a common approach on how data is collected. We also need more transparency around the simple questions, such as what is being spent on what?
- 2.** A lot of effort is put into collecting data for no reason. We need to only collect data on things that matter, that has purpose. We also shouldn't underestimate the richness and importance of qualitative data. Let's agree to never use the phrase "It's only anecdotal" again. People's lived experience illuminates and provides meaning to data and stats.
- 3.** While national oversight is welcomed, this information sits locally in our communities and we mustn't forget that. We must also strike a tricky balance between involving the smaller community-led organisations who are often overlooked when it comes to data, but who provide an essential service, while at the same time not overburdening them with too many demands for collecting, collating and reporting. We don't want frontline workers to have to

My final thought is that while data is an important tool in reforming social care, it can mislead as well as inform. If you are missing too many pieces of the puzzle, you aren't seeing the real image.



The National Care Service: the rights of children and young people

Snow (Tuisku) Curtis Kolu, Policy Officer, Includem

There are many unknowns around the inclusion of children's services within the scope of the National Care Service (NCS), including its links to existing programmes for transformation and how meaningful participation of children, young people and families in decision making has or will be ensured. As their inclusion is a central tenant to Getting it Right for Every Child (GIRFEC) and a human rights-based approach, their voices are critical at all levels.

Without a human rights-based approach, the new service may simply resume, or potentially exacerbate, the existing challenges as set out by the Independent Care Review – echoed by the findings of Includem's recent Voices report.³

Based on these findings, Includem have highlighted four key areas that must be considered if the NCS is to work for children, young people and family services.

1. Poverty: mitigating the wider economic and social factors impacting wellbeing

A rights respecting approach requires consideration of the economic and social factors that impede access to human rights and widens the poverty related wellbeing gap. Low wages, inadequate social security, cuts to support and inequalities result in a postcode lottery for local services and safety. It is critical to address the pressures experienced by families in poverty and its impacts on their physical and mental health.

Voices report:

“ I sometimes struggle but I just get on with it...My kids would never go without, I would, but not them. Sometimes I only eat one meal a day.

2. Trust: relationship-based practice and whole family support

The NCS must be built to respond to the needs of those it seeks to support, rather than the requirements of a system or institutions. This requires flexibility and responsiveness based on individual and family needs and local factors. As a result of experiences of stigma and shame, rebuilding trust through relationship-based practice is crucial. In recognition of the importance of family wellbeing to the lives of children and young people, whole family support must be at the heart of the new service.

Clear communication is essential, including the need to rethink recording, ensuring it serves to help support families and takes a genuine approach to iterative informed consent, rather than creating a culture of suspicion.

Voices report:

“ I don't feel comfortable speaking to social work, I don't have a relationship with them.



3. Complexity: a responsive and holistic approach

From a wide range of daily struggles with poverty, experiences of domestic abuse, neurodiversity, mental health, substance misuse and more, children, young people and families face multiple inter-related challenges. There are considerable gaps and complexity in services, particularly in early intervention and limits to support between social work and CAMHS, with families reaching crisis point before being able to access help.

The close integration and links between health, education, social care, family support and youth justice are key for effective prevention and early intervention. Particularly for targeted support for children that are care experienced or deemed 'at risk', we must consider the risks and disruption that excluding services from the NCS may cause. For example, its proposed scope excludes early years and education services – fundamental to children's wellbeing and continuity of preventative and early intervention.

The creation of a NCS needs to ensure it addresses rather than reinforces existing gaps and disconnect in service provisions – with a holistic approach across support services that are simple and easy to navigate and access. These must be responsive and in place before families hit crisis point. This could include access to early intervention based on self-reporting, investment in a wider range of community-based support, and family advocates with skills in preventative approaches in situations of complex needs.



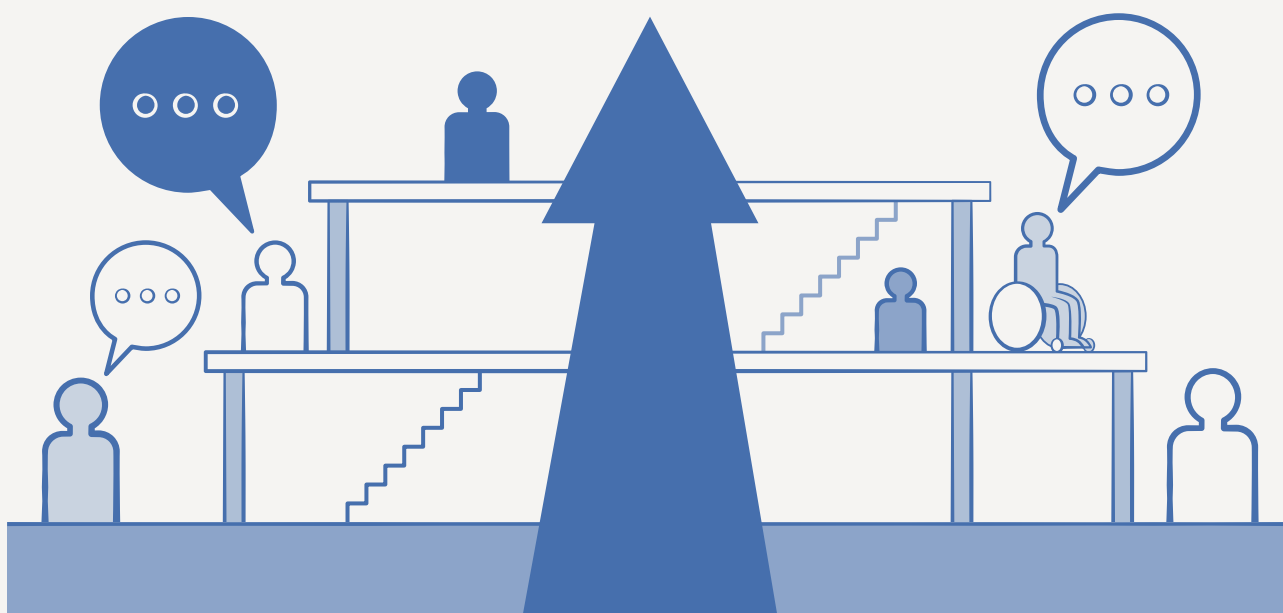
4. Investment: parity of esteem and improvement

While the potential for additional resources in the implementation of the NCS is welcome, there are real concerns on how this will be allocated.

Services provided to children and young people, while interconnected, are distinct from adult services. Due to the scale of acute issues also experienced in adult services and Scotland's aging population, there is real concern that the integration of children's services risks a lack of parity in funding. The significance of our earliest experiences in life to our wellbeing, health and ability to thrive cannot be underestimated, and children's services need to be given equal status with adult services – particularly as preventative and early intervention can avoid more costly interventions down the line.

Rather than the development of new organisational structures, investment should be driven by and focused on improvement to required support services. To embed real cultural change, investment into children's services needs to encourage innovation and partnership working across different organisations, rather than competition. The NCS could strengthen a coherent approach in improvement and design and seek to ringfence resources to guide complex change and innovation. Additionally, structural change will not be effective without change to workforce conditions, giving them the time and space to provide proper support in this highly valuable and skilled work.

For children, young people and family services to truly benefit from the NCS, it must #KeepThePromise and have lived experience at its heart. We recognise and welcome the ambition for change to a sector that has struggled with challenging resourcing conditions for some time. However, the voices of children, young people and families and their needs cannot be the afterthought of a service designed for and by adults.



The proposed National Care Service needs to take care with data

Layla Robinson, Partnership and Engagement Manager,
Advanced Care Research Centre at University of Edinburgh

What is data?

Data is a collection of information about a thing, a person, anything really. Sports statistics? Data. The application form you just submitted? Data. Hospital records? Data. In this context, we are talking about data as it sits with regards to a person's health and care – any long term conditions, age, where they live, family, accidents or incidents and so on and so forth.



Why is data important?

Health and care data allows us to see what has happened to people, for example have they had falls, what medication they are on, and therefore what may happen to them in the future to provide a means of predicting future care needs.

What's missing?

Typically, care home residents and those receiving care at home are poorly represented in routine data, as shown in our recent briefing on social care data.⁴ This data gap reflects the wider marginalisation of the social care sector and the people who need social care. People in receipt of adult social care are among our most vulnerable citizens, but we cannot systematically improve their care without understanding their needs and patterns of care.

We need better social care data that can be linked to health and other data to improve our understanding of the needs of some of our most vulnerable citizens. Better data and understanding are critical, but have to be used effectively to improve the quality, safety and experience of care in later life.

Data is not a panacea, but good data and improved understanding are key building blocks in making social care better, and a necessity for health and social care integration.

Collecting data from multiple sources can create a comprehensive picture of the needs of each person, illustrating what support (mental, physical, social, adaptations) they need now, or in the future, leading to an improvement in their quality of life.

Although there are many things we can do now to make better use of existing data, closing the social care data gap requires system-wide change:

- **Reliable identification of care home residents and those in receipt of publicly funded social care at home (including short-stay residents and short-term recipients)**
- **Use of a shared unique identifier to link data from different sources**
- **Access to individual-level, anonymised data to inform policy and planning and for research, including integration of information governance to enable rapid, secure access to legitimate users**
- **Investment in capacity for large-scale, anonymised linked data analysis of social care data, including support for collaborative working to develop meta-data**
- **Development and integration of a core national dataset for care homes and care-at-home to support integrated care delivery, service planning, commissioning, policy and research**

Currently, the only reliable way to know who is a care home resident is to ask the care home. We would never attempt to measure who was admitted to hospital by looking at GP or ambulance records; hospitals record who is admitted.

What should the National Care Service do about this?

Improved data collection would help the National Care Service, the people being cared for, and carers. The absolute minimum data needed simply includes who is a care home resident, whether they are a permanent or temporary resident. Importantly, the burden of data collection on care homes has to be minimised, and all data collection has to provide value to the care home itself.



Proposed National Care Service is failing the most vulnerable who are from ethnic minority communities

Rohini Sharma Joshi OBE, RSJ Equality Consultancy

The launch of the new National Care Service provides an important opportunity to address the care needs of Scotland's ethnic minority older people. However, there is a danger that, like health and care services before it, the new organisation is falling into the same trap of too much talk and not enough action.

For Scotland's ethnic minority older people, social care services have long been confusing, challenging and sometimes even downright inaccessible. Their specific care needs remain not fully understood, which often results in them being overlooked. And this is a particularly sad state of affairs, as this first generation of ethnic minority older people have worked hard all their lives. They have raised their children without support, equipping them to live a better life and often depriving themselves of respite and relaxation in order to give their families the very best.

These were typically self-reliant entrepreneurs, working very long hours, seven days a week. They didn't think to ask for support, and indeed few would have known that support may have been available. And now, in their older age, when they have very real and pressing care needs, they can't, as tradition would have had it in the past, turn to their children. Their second-generation grown-up children are busy working and raising their own families.

We have in Scotland, a generation of ethnic minority older people that are disenfranchised from the care they deserve and are entitled to because of challenging language and cultural barriers.

There was hope, with the overwhelming evidence of the disproportionate impact of COVID-19 on ethnic minority people, that any new approaches and services would be sensitive and go the extra mile to deliver on the recommendations made by various advisory groups set up to deliver equality.



The new National Care Service promises to be “more integrated” and “transparent”, phrases which have been wheeled out to introduce new services for decades. But they remain empty words without considering new approaches, and more importantly, new actions to meet these needs.

For example, the new National Care Service again promises to support unpaid carers. However, it is evident that ethnic minority carers do not understand the term. They continue to struggle with the demands made on them as carers because they don’t think they have a choice. Many of these carers are physically and mentally exhausted. They desperately need access to information on how they can be helped and access to a service which understands and meets their cultural needs.

The recent Race Equality Framework in Scotland 2030 acknowledges that the health and care services was found to be less effective for people of specific ethnicities and highlighted a need to ensure social care services were provided appropriately, especially for older people in minority ethnic communities. It recognised the importance of being listened to and treated equally and fairly with respect for dignity and human rights as part of a person-centred approach. To support this goal, several programmes of work are being undertaken in Scotland to improve the currently patchy evidence base on ethnic health and care inequalities.

Stakeholders who took part in the development process for the Framework felt that the Scottish health care system needs to build more specialism around these issues and that health services in general need to be more responsive to the circumstances and needs of minority ethnic people. Taking account of the particular needs of different service-users in regard to their particular characteristics and circumstances was identified by the Scottish Government as part of the key principles underpinning health and social care integration in Scotland.

Another research initiative by Scottish Care, the Scottish Care Cameo series of articles, included a piece of research entitled *Keeping Body and Soul Together: reviewing the physical, emotional and spiritual needs of ethnic minority older people in Scotland*. This paper highlighted the care needs of this group of older people and stressed the importance of devising practical solutions to the barriers to services, rather than producing strategies and policies which have no meaning and don’t deliver effectively for ethnic minority communities in Scotland.

It is therefore disheartening that the National Care Service's commitment to equality is that "it will consider the impact on equality groups". The Race Equality Framework project and Scottish Care has already quite clearly done the research, talked to stakeholders and made recommendations.

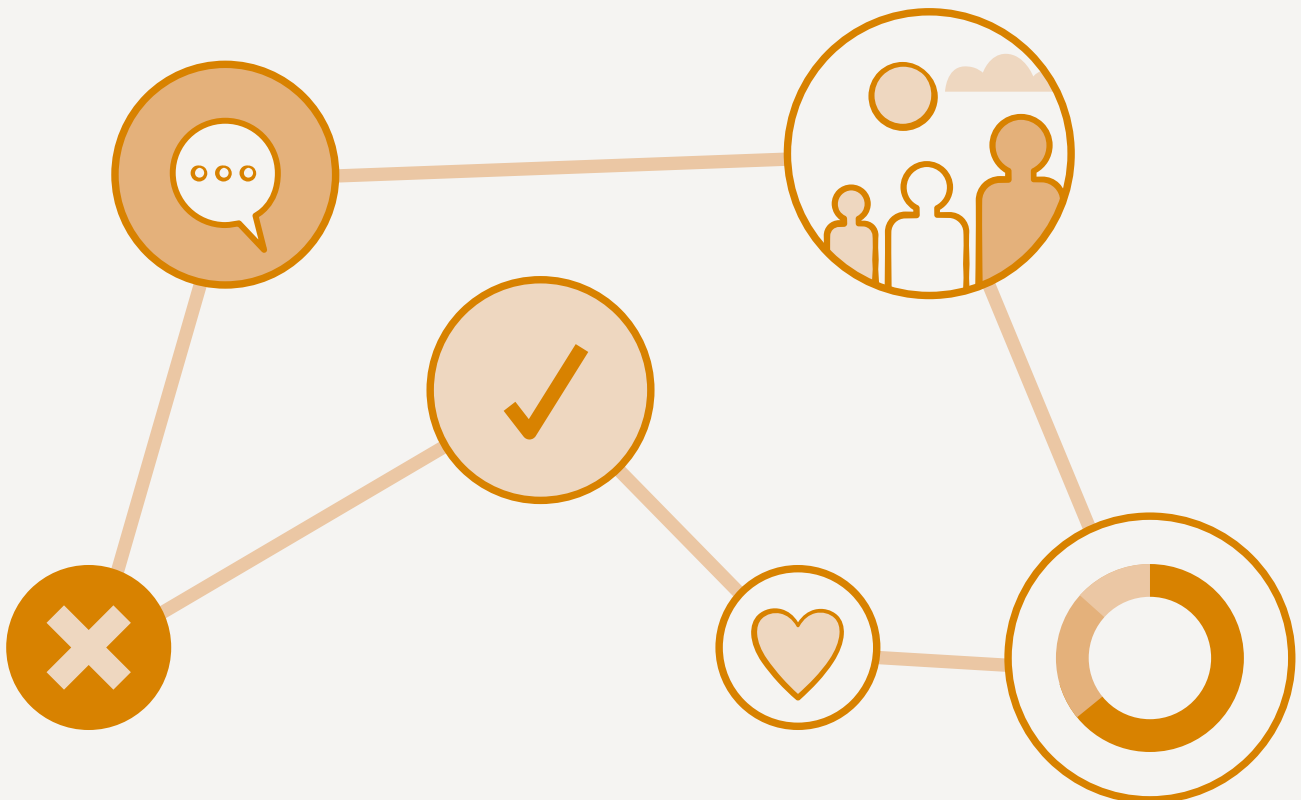
If the new care service is still to "consider" then the question has to be asked "is there a commitment to deliver?"

My concern is that the National Care Service is signalling a reluctance to deal with inequalities head on. Its commitment is lacking robustness and its actions lack a determination to forge forwards. Instead, its emphasis seems to be more on learning and understanding, which whilst it buys time for service providers, it means nothing if it doesn't deliver changes for those who need it most.

If the already overwhelming evidence from years of research and consultation is not to be considered, those affected, many of whom are weary of giving their opinions to researchers, may not only lose the will to participate, but will find that any changes will be too slow and too late!

It is crucial for Scotland's ethnic minority older people that there is a real will for tangible change, that actions and measures are taken that will make a real change to people's lives.

The time for talking, researching and listening with no real action is over. It's time to stop kicking the can down the road, perhaps because of a fear of getting it wrong. It's time for Scotland's ethnic minority older people to enjoy the support to which they are entitled in their own age. They have earned it.



Social care data: the gap between word and deed

Alex Stobart, Director Scotland, Mydex

When it comes to “building back better” from COVID-19 and making real advances in the provision of health and social care, Scotland has a problem. For the last few years, it has said all the right things. But it isn’t doing them.

The Scottish Government’s Covid Recovery Strategy says it wants to tackle inequality and disadvantage, build “firm foundations” for “more resilient communities, businesses, economy and society, make progress towards a wellbeing economy and accelerate inclusive person-centred public services”. Its proposal for a National Care Service says it wants to redesign “the system around the individual”.⁵

But detailed, practical initiatives to make these happen are not forthcoming.

As one participant pointed out to a stakeholder recovery roundtable chaired by John Swinney MSP in May 2021:

“ One of the big challenges is to close the gap between policy and practice. There is no shortage of aspirational policy, but have we taken the opportunity to consolidate some of these excellent ideas? Are we driven by existing boundaries of service delivery rather than concentrating on what individuals need? There are opportunities to find efficiencies by having a person-centred approach.⁶

One reason for lack of progress may be the nature of the political process. Politicians get many of their “wins” from announcements that get favourable coverage; actual implementation involves blood, sweat and tears that’s easier left to others.

But there are bigger barriers too. As the roundtable participant noted, it’s hard to join dots across and outside silos rather than within them – and if we really want NHS and care services in Scotland to build inclusive person centred services we need person centred data infrastructure that enables this rather than blocking it.

Take health and social care. It is extremely data dependent. We need data to diagnose problems, to build treatments and programmes, and to organise their efficient delivery through care pathways and referrals. Day in, day out front-line service providers wrestle with data logistics challenges: getting the right (reliable, accurate) data to the right people at the right time. Without this, things can grind to a halt. Time and precious resources are diverted to filling the data gap and mistakes are made, resulting in even more wasted time and resources.

And that’s just looking at it from service providers’ point of view. Patients and their friends, families and carers are also managing lots of data about conditions and treatments, care plans, appointments and general life management as they deal with their situation.

But the data systems we currently use are anything but inclusive or person-centric. Quite the opposite. They are organisation centric, focused internally on the needs of the organisation (or parts of it), organised in silos, with one part not talking to another.

This is a by-product of data management’s history. The way data is collected and used in our society and economy today was never designed to address the issues we now face. Its organisation-centric nature reflects its origins in helping multiple separate organisations achieve their goals, not to create system-wide efficiencies or be inclusive of individuals (never mind person-centred and human rights based).

This is the bigger, deeper challenge we now face: building enabling infrastructure that’s fit for a new set of purposes. The Scottish Government’s March 2021 paper An Ethical Digital Nation says:

“ We must design and deliver products and services that use data and digital technologies in transparent, honest and inclusive ways and build trust by ensuring that we protect personal privacy and empower people to be informed users and to control their personal information.⁷

What it now needs to do is use a new layer of infrastructure that enables this: that is person-centric by design because it makes individuals the point where data is aggregated about them; that empowers them to share this data with service providers as and when needed; that keeps them in control of the sharing of this data at all times.

The principles behind this approach are long-established. When citizens pass their driving tests, the DVLA provides them with a driving licence that enables them to instantly verify the fact that they are entitled to drive. They can carry this information around with them and present it to whoever needs it, whenever they need it. With it, they can also prove other things about themselves such as their name, date of birth, address.

In a digital age, why shouldn't citizens be able to do the same with their health and care information such as their CHI number, blood type, diagnosis, referrals – any and all information that is relevant to their health and care? They should be able to take this information with them from service provider to service provider in a secure, digital form, sharing it as and when needs be, including with friends, family and their own personal carers.

The Scottish Government has accepted the principles behind this approach with its embrace of the Scottish Attribute Provider Service (SAPS) that would allow citizens to do the same with data needed to access and use public services. Now all the Scottish Government has to do is turn words into deeds. The Scottish Approach to Service Design provides a clear pathway for achieving this.



Considering mental health within the National Care Service

Craig Smith, Senior Policy and Research Officer, Scottish Association for Mental Health (SAMH)

The National Care Service has the potential to embed a truly human rights based approach to the organisation and delivery of social and community health care. But to achieve this it must empower people – including people living with mental health problems – to be full partners in decisions about their care.

Unsurprisingly much of the political debate on the National Care Service has focused on structure and political accountability. These discussions include where responsibility for social care will sit, and how the national service will be structured locally. Important as this is, we urgently need to ensure attention is shifted to the much-needed culture change in social and health care design, procurement and delivery. This to ensure that the National Care Service is genuinely built on a foundation of lived experience involvement with the promotion of independent living at its heart. This will require genuine co-production with people who will be supported by the NCS and recognition of the third sector as equal partners in social care design and delivery.

So how do the current Scottish Governments proposals stack up?

There is much to welcome in the Government's proposals. In particular, we at SAMH warmly welcome the proposed "Getting It Right For Everyone" (GIRFE) approach to support planning. The focus on personalised support built around desired outcomes for people receiving care is the right one. We hope this approach will lead to people having much more genuine choice and control over decisions about their care – something we know can positively improve people's mental health. While in a health care context, our research on the experience of treatment for depression, *Decisions Were Made About Me Not With Me*, found that research participants who were happier with their level of involvement in decision making about their treatment and support were more likely to be satisfied with their treatment.⁸ We are pleased that proposals on support planning will be aimed at greater coordination of care, and portability of care plans. This should make a real difference where someone is supported by various organisations, or moving to a new area, reducing the stress of people having to retell their story.

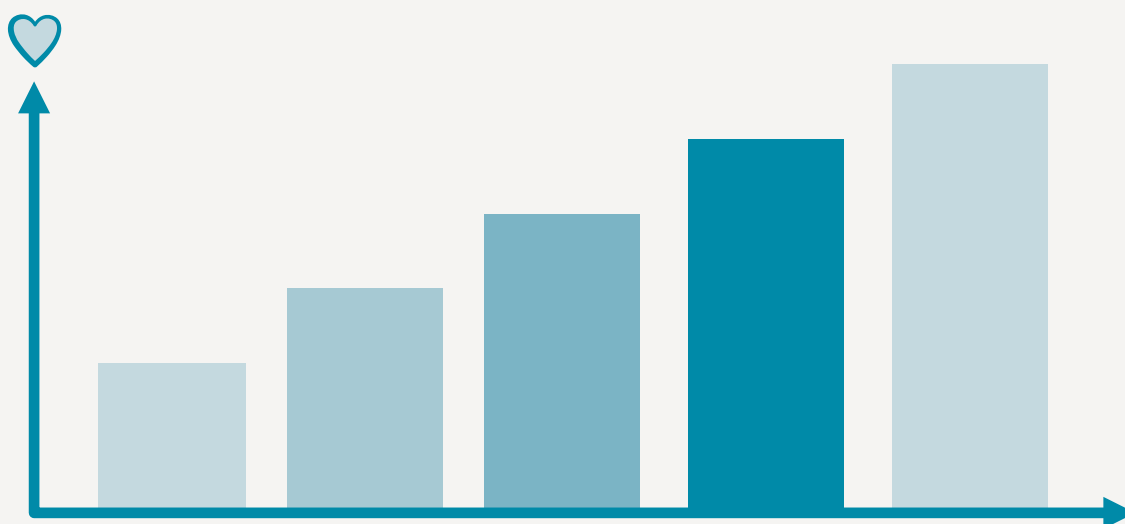
But making this approach a reality requires adequate staffing and resourcing of social care and community services, not just legislative action. As the development of the NCS moves forward we urgently need to see more details about how it will be adequately funded, both in the short and long term – something that to date has been missing.

Despite welcome proposals such as the GIRFE approach we are concerned that in some areas the plans don't go far enough or have too little detail. We warmly welcomed the Independent Review of Adult Social Care, which provided the framework for the proposed reforms; but as they stand, these proposals don't fully implement the recommendations of the review. For example, we welcome a commitment to "human rights based", "ethical commissioning" of services.⁹ Yet there is little in the detail of the Scottish Government's proposals that gives us confidence that services won't – as is too often the case today – still be designed and commissioned around local budgetary constraints.

As the independent review set out, to ensure person centred and human rights based services, we need a fundamental break with the current model of competition. Cost-driven procurement processes must change to a culture of collaboration. It is crucial that the power imbalance between people receiving care, social care providers and commissioning bodies is addressed.

For example, to ensure genuine compliance with the UN Convention on the Rights of Persons with Disabilities and a human rights approach more generally, it is crucial that the model of commissioning and procurement adopted by the National Care Service, particularly at a local level, moves away from a reliance on generic frameworks for adult social care. Access to specialist, personalised services built around someone's individual needs is critical to promoting recovery and independent living. While the emphasis on national minimum quality standards and an outcomes-focused approach to care in the Government's proposals on commissioning are welcome they do not give us confidence that a framework approach will end. It is essential that people with mental health problems can access specialist mental health social care support, delivered by practitioners with specialist training in mental health. Our experience with social care services commissioned through local generic frameworks has too often resulted in people with mental health problems not being supported by practitioners and services that can cater to their needs.

As the development of the National Care Service moves into the next stages, SAMH will continue to champion the importance of lived experience involvement and the specific needs of people living with mental health problems. This is a once in a generation opportunity to radically improve social care in Scotland, and it must be grasped.



Young Carers and the National Care Service

Paul Traynor, Head of External Affairs (Scotland), Carers Trust

Young Carers Action Day is an annual campaign day organised by Carers Trust. Now in its seventh year, it raises awareness of young carers and the immense contribution they make to their families and local communities through caring for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

This year's theme is Taking Action on Isolation. During the pandemic, when many services were reduced or not available, many young carers spent more time caring at home and were unable to get a break. Young carers have told us they have felt increasingly isolated from friends as a result.

Carers Trust undertook a survey at the start of this year to hear directly from young carers about their experiences. A total of 571 young carers took part across the UK, with 170 respondents based in Scotland. Our survey paints a bleak picture about the lack of support for young carers who all too often face the complexities of juggling their caring role with education.¹⁰

The survey found that:

- **1 in 5 young carers were unable to take any break from their caring role.**
- **Over half of young carers were feeling less connected to others.**
- **1 in 3 young carers didn't feel included with their friends.**
- **31% of young carers felt they don't get enough rest or time for themselves.**
- **A third of young carers felt lonely.**
- **42% of young carers "always" or "usually" feel stressed.**

This sense of anxiety in a context of loneliness and isolation is reinforced in many of the comments left by young carers in the survey:

“ I'm more stressed and anxious and I just feel like I need a break.

“ My mental health is awful, and I really struggle to take time for myself at home. The only time I have away from my family is at school, but I don't even like going to school because I get so nervous for everything and I'm always so exhausted.

“ I never got a break in almost two years, I worked hard to keep mum out of hospital as I was scared what would happen if she went in. I never get any thanks or praise for what I do...

In response to these findings, Carers Trust Scotland are calling for young carers to have a right to access the regular breaks they need to support positive wellbeing, reduce social isolation, and live a fulfilled life alongside caring.

We know that breaks can be very beneficial for young carers, giving them time to recharge and do things they enjoy. Young carers are, and must be seen as, children and young people first and foremost and their rights must be upheld. Short breaks provide a much-needed release from the physical and emotional demands of the caring situation and help promote positive health and wellbeing.

According to Scottish Government data, as few as 3% of unpaid carers of all ages currently receive statutory support for breaks from caring. Across Scotland, there appears to be significant variation in the availability of breaks, and young carers' experiences will be different due to a variety of factors, including where they live.

A proposed "right to a break" for unpaid carers was consulted on during the National Care Service consultation and this was welcomed by most young carers we consulted with. It is vital that this right is introduced, and that young carers do not become forgotten in the planning and implementation.

From our discussions with young carers, the hybrid model was the preferred option. This approach would achieve the best outcomes for young carers by combining a guarantee of preventative support through a non-assessed minimum entitlement, alongside a right to additional support for those with higher levels of assessed need.

The process for young carers accessing short breaks should be simple and fair. There must be flexibility on how short break budgets are used to meet the diverse needs of young carers. Considered planning is essential to ensure young carers do not become an after-thought of short break provision, recognising that their needs and requirements may be different from adult carers.

We believe that young carers having a right to the breaks they need is a progressive step to taking action on isolation.



Adopting a different approach: on not eating the elephant

Karen Hedge, Deputy CEO, Scottish Care

Don't eat the elephant... yet.

The African proverb "there is only one way to eat an elephant: a bite at a time" could be applied to the creation of a National Care Service, but I warn that if we go down that route alone, we will fail.

Sure, the elephant metaphor is great for goal setting – breaking things down into to small measurable tasks sounds sensible, and I have used it many times to great success, from planning and executing a house move to making it round IKEA with small children (and getting everything on the shopping list, without buying any more tea lights, injury, or destruction...).

But the issue with the NCS, unlike the poor elephant, is that social care is very much alive and must remain so, or there will be catastrophic failure to the people and the wider systems it supports – think NHS. It doesn't matter which bit of the elephant you start on or how you progress – it's not going to affect any other part. Social care is entirely different and the failure to embrace its dynamism, difference, inter-connectedness, and hyper-localism is what has prevented lasting systemic change to date.

Social care is comprised of a rich myriad of organisations who aim to deliver services which the people who rely on them for independence want. Despite this laudable aim, they sometimes fail at the point of delivery because competition driven systems and processes prevent them from doing so. A prime example of this is thinking about care delivery in 15-minute increments rather than intent, and the difference it is making. Oftentimes public sector procurement activity is confused with commissioning, which is much wider and of which procurement is only a small part – from the Independent Review of Adult Social Care (IRASC):



“ In Scotland, we used the term strategic commissioning to mean medium to long term planning that determines the choice of services and supports to meet individuals' needs, rights and preferences to live independently or as independently as possible.¹¹

The great contradiction being that it is working together which maximises resource and potential. As such, the IRASC calls for collaborative and ethical commissioning in the NCS. Now this should not be surprising news – commissioning and procurement have required overhaul for many, many years now. It has been going on so long some have suggested it is a wicked problem, but quite to the contrary, there are many papers explaining how we should commission and there are plenty of documented small-scale successes. So, instead of thinking that this legacy will be hard to overcome we need to take advantage of all that evidence and ask the question, “How do we make it work this time?”.

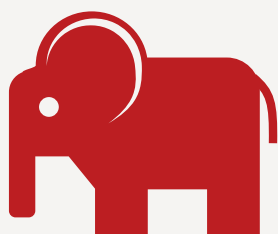
Well, and here is the crux, people think the next question is “How do we create an NCS which has collaborative and ethical commissioning?” Instead, the question we should really be asking is “How do we use collaborative and ethical commissioning to create the NCS?”.

Turns out in one mighty metaphor combo, that all this time we have been looking through the wrong lens whilst eating our elephants.

Ethical and collaborative commissioning must be embedded in the approach from the onset. And to overcome the implementation gap, we must embrace and adopt some fundamental principles towards this new commissioning approach as those outlined in Scottish Care's “Time for Change”, a Framework towards the NCS.¹² Everything in this framework supports a commissioning approach which considers the uniqueness and diversity of social care as an advantage, understands the need for local solutions for local interests, and takes seriously the need to work collaboratively with all stakeholders in the system having equal status, including those with lived experience and those deliver care and support. It also recommends that we “put the foot down”. This one needs no explanation; simply put, time is short.

Laying the groundwork for the NCS will not be easy. While we have design methodologies that will take us towards a flourishing NCS, it is the initial steps taken which will be the marker of things to come. To fully embrace ethical commissioning, an approach based upon collaboration and grounded in human rights, there needs to be a shared ethos and framework underpinning that design process, with a mutual regard for expertise and desire to effect positive change.

While the NCS will offer national structures of governance and accountability, it must also be fluid and agile, creating the conditions for diversity and localism, led by and for people not systems. We need to recognise and value our social care ecosystem and its potential as outlined in Scottish Care's paper “What if and Why Not?:



“ When we look to the future of social care and the role of social care in this integrated partnership, we need to understand the layers of complexity, contextual nuances and the relationships that exist within its own individual ecosystem. By starting at the point of people and communities, we can begin to understand the needs and aspirations for health, social care and wellbeing, and work together with people, communities and partners to identify the preferable and most appropriate ways to support these. We must shift beyond the mindset of existing systems and services to embrace individual and community capacities, and collaborative opportunities to enable innovative support mechanisms. If we wish to achieve a transformational vision for health and social care in Scotland, we need to reimagine the whole system and go through a careful process of understanding the contributions, capacities, and potential of every element. Further, this needs to happen at a societal level involving individuals, communities, partners at every step of the journey.¹³

This time it's not about reinventing the wheel. It's about adopting a different approach.

Oh, and recognising that eating the elephant is the very last part of the process.*

*No elephants were harmed in the writing of this Opinion.

Crisis point for social care, and the need for change

Antony Clark, Interim Director of Performance Audit and Best Value, Audit Scotland

This gives me a chance to say more about the messages we laid out in the recent Social Care briefing that Audit Scotland prepared on behalf of the Auditor General for Scotland and the Accounts Commission.¹⁴ This was an especially important piece of work for us which drew on the significant body of evidence from our previous reports relevant to social care, including health and social care integration and self-directed support. Find out more on our health and social care web hub.¹⁵

We felt now was a critical moment to re-emphasise the challenges long experienced by both those delivering and receiving social care. These challenges, many of which are longstanding, have been deepened and exacerbated by COVID-19.

In our briefing we stated that some social care services are at near crisis point, that urgent action was needed now, before a National Care Service (NCS) was established. Services aren't consistently meeting individual needs and too many people who need care, who have been assessed as needing care, simply aren't getting the help they need to live the life they determine. Those messages won't come as a surprise to any ALLIANCE members. And they aren't new messages either.

In a 2016 report we emphasised the challenging task councils face responding to financial pressures and managing the market for social care provision.¹⁶ And our briefing highlighted that, six years on, difficulties around commissioning services continue. It's clear that current commissioning and procurement procedures have led to competition between providers at the expense of collaboration and quality.

Back in 2016, The Fair Work Convention resulted in a greater understanding of how the commissioning system led to wider structural problems. The impact has been maximising employer flexibility, perhaps at the expense of employees – zero-hours, low hour and sessional contracts. We urge the Scottish Government to look again at the system changes needed, and not delay. Doing so is not simply a nice to have – it is crucial as the sustainability of the social care market is key to maintaining Scotland's capacity to address individual care needs.

We know that social care services, when they work well, make a fundamental difference to people's quality of life. There has been excellent work by the ALLIANCE in ensuring the voices of people receiving social care support are amplified. The establishment of the Social Care Covenant Group is also greatly welcomed.

Our social care briefing asks the Scottish Government to embed the voice of people who have accessed care in its planning, to ensure there is a deeper understanding of what a preventative and human rights-based approach to social care looks like.

But for that to happen a more strategic approach to investing in social care is required. This involves developing an understanding of the longer-term costs, identifying double-running costs while setting up new services, whilst moving much more resource and pivoting the focus into preventative services.

Our social care services are often intimate and personal. Giving staff the time, place, and space to deliver more than just a basic service puts humanity, value and meaning into this vital role. We've heard from people who think staff do not have the time to do anything but provide basic care, that because of this they are unable to deliver compassionate and dignified support. To do otherwise requires a fundamental and systemic change. For staff to feel valued and engaged in their work, they need adequate pay. But more than that, they need to come home after what can be emotionally and physically demanding work, feeling they've done their job well, with the time to make and develop connections with the people for whom they provide care.

Our briefing urges the Scottish Government, along with its partners, to take action to address these challenges now. Waiting for the establishment of a NCS to address some challenges is no longer a viable option. A clear plan is needed now to address the significant challenges facing social care in Scotland – doing so doesn't require legislation. The Scottish Government needs to take action now, with clear timescales, removing any uncertainty about the future direction of social care, building on lessons learned from previous reform.



About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

References

- 1 Scottish Government, "A National Care Service for Scotland" (2 Nov 2021). Available at: <https://consult.gov.scot/health-and-social-care/a-national-care-service-for-scotland/>
- 2 Scottish Government, *Independent Review of Adult Social Care in Scotland* (Feb 2021). Available at: <https://www.gov.scot/publications/independent-review-adult-social-care-scotland/>
- 3 includem, *Voices: Families' Experiences of Poverty and Services* (Nov 2021). Available at: <https://includem.org/wp-content/uploads/2021/11/Voices-Families-Experiences-of-Poverty-Services-Digital-Edition.pdf>
- 4 Bruce Guthrie, "Navigating blindfold in a blizzard: the invisibility of social care in routine data" (2021). Available at: https://www.ed.ac.uk/files/atoms/files/acrc_briefing_1_social_care_data.pdf
- 5 Scottish Government, *Covid Recovery Strategy: for a fairer future* (Oct 2021). Available at: <https://www.gov.scot/publications/covid-recovery-strategy-fairer-future/documents/>
- 6 Scottish Government, "Coronavirus (COVID-19) Stakeholder Recovery Roundtable minutes: May 2021" (25 May 2021). Available at: <https://www.gov.scot/publications/coronavirus-covid-19-stakeholder-recovery-roundtable-minutes-may-2021/>
- 7 Scottish Government, *A Changing Nation: How Scotland will Thrive in a Digital World* (May 2021). Available at: <https://www.gov.scot/publications/a-changing-nation-how-scotland-will-thrive-in-a-digital-world/documents/>
- 8 SAMH, "Decisions were made about me not with me." *A SAMH Research Report: Treatment and Support for Depression* (2020). Available at: https://www.samh.org.uk/documents/Decisions_were_made_about_me.pdf
- 9 Scottish Government, *Independent Review of Adult Social Care in Scotland* (Feb 2021). Available at: <https://www.gov.scot/publications/independent-review-adult-social-care-scotland/>
- 10 Carers Trust, "Our survey on the impact of Coronavirus on young carers and young adult carers in Scotland" (2022). Available at: <https://carers.org/young-carer-and-young-adult-carer-coronavirus-research/our-survey-on-the-impact-of-coronavirus-on-young-carers-and-young-adult-carers-in-scotland>
- 11 Scottish Government, *Independent Review of Adult Social Care in Scotland* (Feb 2021). Available at: <https://www.gov.scot/publications/independent-review-adult-social-care-scotland/>
- 12 Scottish Care, *Time for Change: Conceptualising a National Care Framework* (July 2021). Available at: <https://scottishcare.org/wp-content/uploads/2021/07/Time-for-Change-Final-Version1.pdf>
- 13 Scottish Care, "What is and why not?" *Making the Future of Social Care a Reality* (Nov 2020). Available at: <https://scottishcare.org/wp-content/uploads/2020/11/SC-What-If-and-Why-Not-Making-the-Future-of-Social-Care-a-Reality-Nov-20.pdf>
- 14 Audit Scotland, *Social Care Briefing* (Jan 2022). Available at: <https://www.audit-scotland.gov.uk/publications/social-care-briefing>
- 15 Audit Scotland, "Transforming health and social care in Scotland". Available at: <https://www.audit-scotland.gov.uk/reports/e-hubs/transforming-health-and-social-care-in-scotland>
- 16 Audit Scotland, *Social work in Scotland* (Sept 2016). Available at: <https://www.audit-scotland.gov.uk/publications/social-work-in-scotland>



Contact:

Hannah Tweed, Senior Policy Officer

E: hannah.tweed@alliance-scotland.org.uk

Rob Gowans, Policy and Public Affairs Manager

E: rob.gowans@alliance-scotland.org.uk

 0141 404 0231  info@alliance-scotland.org.uk  @ALLIANCEscot  ALLIANCEscot

 [alliance.scot](https://www.instagram.com/alliance.scot)  [alliancescotland](https://www.linkedin.com/company/alliancescotland)  [alliancescotland](https://www.youtube.com/channel/UCvD11111111111111111111)  ALLIANCE Live

www.alliance-scotland.org.uk

Health and Social Care Alliance Scotland (the ALLIANCE)

Venlaw Building, 349 Bath Street, Glasgow G2 4AA

The ALLIANCE is supported by a grant from the Scottish Government. The ALLIANCE is a company registered by guarantee. Registered in Scotland No.307731. Charity number SC037475. VAT No. 397 6230 60.

End of document.