Adult social care reform for Scotland – discussion paper

Purpose

1. To seek your views and input on working with Scottish Government and COSLA to develop a national programme to support adult social care reform.

Rationale

2. Scottish Government and COSLA recognise the significant challenges within adult social care in Scotland. The projected growth in demand requires a move to different models of care over and above increases in funding. This change must be holistic. It relates not only to the type of care and support that is delivered, and how and where, but also to the way in which care is assessed, organised and planned. The integration of health and social care – and the greater opportunities for multi-disciplinary working it enables – is one approach to addressing this fundamental change in the needs and expectations of our population. It is an historic shift that continues to require effort, energy, and change to realise in practice.

3. Within the new landscape of integration, Health and Social Care Partnerships' local strategic commissioning plans signify a step towards a new future for adult social care. Progress is being made by local areas in adapting the care landscape so that it is fit to respond to the current and future needs of their populations; in reshaping the nature and support of the workforce; and in working with communities to develop local capacity and resilience.

4. However, there continue to be challenges. While local redesign, innovation and collaboration are working towards reform, Scottish Government and COSLA recognise that there is a particular role for national support in ensuring the right conditions are in place for Partnerships to develop and deliver their plans, and realistically be able to make policy a reality.

5. Scottish Government and COSLA recognise the opportunity for national input to support and bring momentum to the reform agenda, and ensure that collectively, local reforms lead to a consistent outcome – namely realisation of our vision for health and social care. A national programme to support local reform has the potential to serve as a platform for Partnerships, providers, supported people, Scottish Government, COSLA, and other stakeholders to work together to provide shared leadership for this agenda. The Scottish Government's commitment to developing a national programme with partners was recently formalised by the First Minister in the 2018-19 Programme for Government[1], which was published on Tuesday 4 September.

6. The national programme of support will be developed with due regard to the wider policy landscape – not least the ongoing efforts nationally and locally to embed self-directed support; work identified through the National Health and Social Care

[1] Document available at: https://beta.gov.scot/publications/delivering-today-investing-tomorrow-governments-programme-scotland-2018-19/. Relevant section on social care which mentions this commitment is on page 69.

Workforce Plan; the mainstreaming of the new Health and Social Care Standards; the review of integration; activity arising from the recently published Digital Health and Care Strategy; the Technology Enabled Care programme; the transformation of primary care; the Scottish Access Collaborative programme; Scotland's public health priorities; developments in housing and housing services; and others.

7. Scottish Government has also been working with Inclusion Scotland to establish the 'People-led Policy Group', a new engagement framework through which policy makers will access the views of people who have lived experience of adult social care when developing policy. The core group of around 15-20 people, supported by a wider policy panel of around 50 people, will be actively involved in the creation, testing, and early development of policy, and will complement existing local engagement methods such as Our Voice. It is likely to launch end October/early November. All members will be users of adult social care support, including carers, and will have experience of different kinds of social care for different purposes, and from a spread of areas across Scotland. The group is in development and many of you have been working with Inclusion Scotland to design the process for recruiting to it.

Developing a national programme of support

8. We want to work with you to identify where and how national input could best support local reform efforts. An initial step will be to form the principles, values and priorities for the national programme.

9. The Scottish Government recently carried out a period of research and engagement with stakeholders (listed at Annex 2) to gather views on the challenges within the current system and suggestions regarding national support of reform. Many of you were involved in this, and your expertise, experiences, and suggestions underpin the proposed direction of travel for the national programme. The findings of this work are summarised at Annex 1 and include the outcome of a substantial project to refine and develop our understanding of what needs to change in order for self-directed support to be fully embedded (the 'change map'). We would value the opportunity to reflect on these findings with you: specifically, whether you recognise your input if you were involved in the engagement; whether they are an accurate reflection overall of what you face in your work; and how they could best be used to inform:

a) the national programme of support for local reform
b) a refreshed Implementation Plan for self-directed support 2019-2021

10. Alongside our work with you we are engaging with Chief Officers, Chief Finance Officers, and Chief Social Work Officers, and other stakeholders including Local Authorities and NHS Boards; and will work closely with the People-led Policy Group. We aim to collectively build consensus on: the key areas for change, how this change will be achieved, who needs to be involved, and the collective leadership and ownership of the reform programme.

Key opportunities for a national programme

11. We are clear that the priorities and shape of the national programme must be developed in collaboration with the social services sector, the People-led Policy Group, Chief Officers, Chief Finance Officers, Chief Social Work Officers, and other stakeholders including further supported people. However, our initial stakeholder engagement has highlighted some potential areas where the programme could bolster local activity. These are expanded here:

Awareness and value of social care

a) It is widely recognised that there is a need to raise the profile of social care in Scotland and increase awareness of its value for individuals and society. The programme is an opportunity to raise this awareness collectively, at a national level. Recent research suggests that social services and social workers are held in higher esteem by the public than was previously thought[2]. The most recent Health and Care Experience Survey (2017/18) found that 80% of people who received help and support from formal services rated the overall help, care or support services as excellent or good. There is, however, further work to be done to strengthen our understanding of perceptions around social care and social work – specifically, how social care is understood and valued in our society, the expectations of what statutory care services are there to provide, and the role of preventative and wider support in the community. This part of the programme would align with and build on the wider ongoing and developing efforts to attract and retain the best people to the social care profession.

Self-directed support

b) We recognise Audit Scotland's conclusion that self-directed support is not yet fully embedded as Scotland's approach to social care. We would welcome a discussion with you on the intention and practical realities of self-directed support; on how we work together to share and develop agreed best practice; and on how both the reform programme and a refreshed Implementation Plan developed with your engagement could support that aim.

Articulation of our vision and ambition for adult social care

c) Reform must be underpinned by a shared and widely recognised understanding of adult social care within the context of integration, and interpretation of what that means in practice. Stakeholders have been clear that this shared vision and purpose is necessary if policies such as self-directed support and integration are to have their full effect and bring about coordinated, systemic, and sustainable change for adult social care. Though these policies go some way in setting that vision, further reflection is needed on the systemic changes and collaboration required to realise it. The national programme is an opportunity to develop a national vision for social care that is rooted in practice, and the necessary levers and support to realise it. This will also help strengthen the representation of the ambition for social care in national planning.

The provider landscape

d) Currently, 80% of social care in Scotland is delivered by the private and voluntary sectors. How services and support are planned, designed, developed, and

[2] McCulloch, T., Webb, S. and Clarke, D. (2017) *What the public think about Scottish social services and why.* Available from: http://www.socialworkscotland.org/What-we-do/Publications/

delivered is key to reform. The national programme would be a vehicle for developing collective leadership of this agenda with these sectors. This would include learning from organisations that are changing to meet the new landscape and needs of our population, sharing good practice, supporting these efforts to be maximised throughout the sectors, and developing collective, pragmatic responses to the shared challenges across the system.

Cost of care and how care is paid for

e) A national programme would create a platform for an honest discussion about the cost of social care, the value we place on social care as a society, and models of how care is paid for. This could involve exploring the balance of financial risk between the individual, local government, and national government; and how to address the challenge of prioritising preventative approaches within the reality of demand for care now and in the future.

Barriers to current reforms

f) Feedback from Partnerships and wider stakeholders is that they frequently encounter barriers that delay or unnecessarily complicate their current reform efforts. The national programme would be a route to identifying these barriers, and making or supporting the changes that need to happen at local and/or national level to address them. This would offer a space to identify and develop necessary changes or developments to national policy to facilitate local improvement.

Strong and collective leadership

g) Leadership of social care reform must be far-ranging. There is a need for parties from different parts of the sector – including Scottish Government and COSLA – to come together to consider the changes that still need to be made, their respective contributions to those changes, and to take decisions collectively that will enable those changes to happen. A key focus of the national programme would be on creating the right environment for collective decision-making.

Conclusion and next steps

12. **We are seeking your:**

a) views on whether the material presented at Annex 1 resonates with your experience and understanding of the current system, its challenges, and where the national programme could bring additional value to support local reforms. If not, then your views on what is missing;

b) initial views on a shared vision/common outcomes for adult social care and how it/they will be realised;

c) views on potential short, medium, and long term priorities for the national programme, taking into consideration the suggestions presented throughout this paper and the material at Annex 1;

d) views on any pitfalls that the national programme should avoid;

e) views on what you would wish to see in the refreshed Implementation Plan for self-directed support 2019-2021. (e.g. what barriers or enablers could be addressed at national level to support what you are doing locally? Are you undertaking work around the indicators in the change map that you would like to publicise, and that others could learn from?);

f) suggestions on how best to work with you – collectively and individually – on progressing the national programme.

13. **Included at Annex 3 is a pro forma for recording your views**. We would be grateful for return of your completed copy to Andrew.Scott3@gov.scot by **5pm on Thursday 27 September 2018**.

Jamie MacDougall
Deputy Director, Care Support and Rights
Scottish Government

John Wood
Chief Officer for Health and Social Care
COSLA

ANNEX 1

Summary of findings of research and engagement on the shape of a national programme to support adult social care reform

1. Scottish Government has recently carried out a period of research and engagement into:

a) the understanding, perceptions, and experiences of the current adult social care system in Scotland – both for those seeking or using support, and those involved in its direction, management and delivery; and
b) what adult social care should look like in the future, and what has to change to enable that.

2. A wide range of stakeholders were involved (full list at Annex 2), including:

- supported people
- support/representative organisations, including carers organisations
- social work staff
- professional bodies
- care providers
- Care Inspectorate
- Local Authorities and Health and Social Care Partnerships
- policy teams across related areas of Scottish Government

3. The feedback and insights gathered during that work were collated, and are presented here as:

- stakeholders' views of the areas that, collectively, represent the root and locus of the key issues and opportunities within the current **adult social care system**, and where there is a need to consider how the national programme could help reform the system. This was with a view to both alleviating issues and capitalising on opportunities, to create a system that can deliver the right care and support for people, is sustainable for the future, and interacts in the right way with communities, healthcare, housing services, and wider public services (**Section A overleaf**); and
- initial areas of exploration, to improve our understanding of the national picture of these key issues and opportunities within the current system, and inform decisions on priorities for the programme (**Section B overleaf**).

4. **At Section C overleaf** is the 'change map' that is the result of substantial work to refine and develop our understanding of what needs to change in order for self-directed support to be fully embedded.

A. Stakeholders' views of the areas that, collectively, represent the root and locus of the key issues and opportunities within the current adult social care system

Assessment and support planning	Commissioning and procurement and new models of care	The cost of care, and how care is paid for
Care homes	Decision-making and authority in the system	Supporting independent living
Workforce recruitment and retention[3]	Portability of care	Transparent and impactful investment
Digital and technology[4]	Community resilience	Unpaid caring
The provider landscape	Data on social care and how it is used	Local and national leadership
Intermediate care	Interface with primary and acute care	Multi-disciplinary working/seamless services for those who use them
Risk	Social isolation and loneliness	Inspection and regulation

[3] Activity on workforce recruitment and retention is being taken forward under the National Workforce Plan Part 2. There will be a role for the wider reform activity to inform, support, and contribute to this work.

[4] The Digital Health and Care Strategy and the established Technology Enabled Care (TEC) programme will be key vehicles through which to address the issues and opportunities of digital and technology in reform of adult social care.

B. Initial suggested areas of exploration to improve our understanding of the national picture of the key issues and opportunities within the current system (in Section A), and inform decisions on priorities for the programme

(1) (i) Understand what kind of data are collected in the different models for social care assessments across Scotland. (ii) Understand how the review and evaluation of assessment processes feeds into improvement initiatives. (iii) Understand what kind of data are collected when reviewing whether a care package is supporting someone in the right way, and to what extent these data are linked with data on assessments to inform process improvement.

(2) Research existing best practice models in assessment and resource allocation, and together with partners explore the potential for shared expectations and support for the adoption of best practice.

(3) Understand what data are available on the agility of the current system[5], and what they tell us about how system agility impacts on people's experience and outcomes and the distribution of resources within the system.

(4) Quantify the social and economic impact of current provision on prevention, independent living and community participation.

(5) Evaluate the impact of the extension of free personal care as it is implemented for all adults, including costs.

(6) Map the distribution of autonomy and authority within social care, and look at the different models for this existing across Scotland – including consideration of how risk at the front line is connected with corporate risk management structures.

(7) (i) Understand the current capacity for, and extent of, re-ablement and preventative and low-level interventions across Scotland, and the impact of this on people's outcomes, on independent living, and on the demand for care long term. (ii) Explore with partners examples of where and how re-ablement, and preventative and low-level interventions have been maximised.

(8) (i) Explore whether charging and/or charging practice influences individual and system behaviours, choices, and outcomes, and if so, how this manifests across Scotland. (ii) Understand the impact of variation in charging practice across Scotland on portability of care and the decisions people make about care.

(9) Understand the current and potential role, capacity, and visibility of community and community supports in social care.

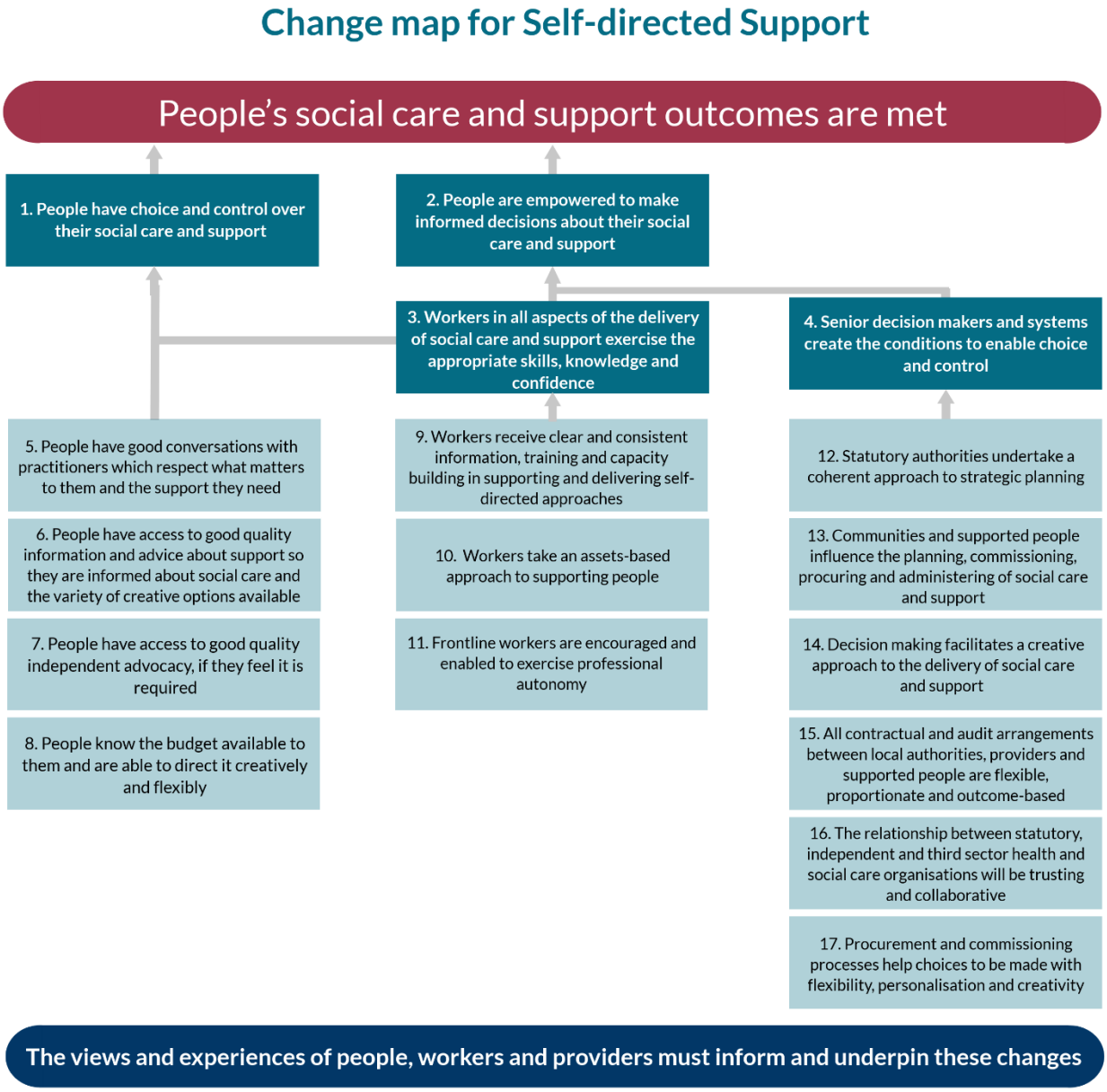
(10) Understand how Partnerships' current work on the sustainability of the care home market and redesigning care homes for the future can be supported and further developed.

[5] For example, end-to-end times from first contact to delivery of support, the speed of individual processes therein, and the nature and outcomes of review arrangements.

(11) (i) Understand the impact of commissioning and procurement practices, and their variation across Scotland, on the landscape of care provision and experiences of self-directed support. (ii) Identify existing good practice and (iii) explore how best to promote and support the adoption of best practice in commissioning and procurement.

(12) Understand the impact of definitions of care services in the Public Services Reform (Scotland) Act 2010 in the implementation of new models of care.

C. Change map for self-directed support



ANNEX 2

People, organisations and events involved in the engagement

Interviews or workshops were held with the following:

- Active and Independent Living Improvement Programme (AILIP)
- Age Scotland
- Alzheimer Scotland
- ARC Scotland (Chairs of providers forums)
- Chief Officers (individual basis)
- Coalition of Care and Support Providers in Scotland (CCPS)
- Coalition of Carers in Scotland (COCIS)
- Co-operatives UK
- Cornerstone
- COSLA
- ENABLE Scotland
- Glasgow Disability Alliance
- Healthcare Improvement Scotland
- iHub
- In Control Scotland
- Inclusion Scotland
- Marie Curie
- Minority Ethnic Carers of Older People Project (MECOPP)
- Royal College of Nursing
- SAMH
- Scotland Excel
- Scottish Care
- Scottish Enterprise
- Scottish Government Chief Social Work Adviser
- Scottish Government policy teams, including data, statistics and outcomes; housing; digital; technology-enabled care; analytical services; social isolation and loneliness; public health; primary care; Our Voice; fair work; social security, and others.
- Scottish Older Person's Alliance (SOPA)
- Scottish Social Services Council (SSSC)

- Social workers (individual basis)
- Social Work Scotland (SWS)
- The Scottish Commission for Learning Disabilities (SCLD)

These interviews and workshops were complemented with informal engagement and evidence-gathering at a range of events, including **among others**:

- 'Building the SDS change' conference
- 2017 Digital Health and Social Care conference
- 'Community Led Support in Scotland – 1 year on' (sharing of the learning from the first year of Community Led Support in Scotland and other connected programmes)
- 'Personalisation in the age of austerity' – Social Work Scotland seminar
- 'Embedding dignity and respect in social security systems' – Equality and Human Rights Commission seminar

ANNEX 3

Adult social care reform for Scotland – discussion paper

RESPONSE FORM

Are you responding as an individual or an organisation?

☐ Individual

☒ Organisation

Full name or organisation's name:

Health and Social Care Alliance Scotland (the ALLIANCE)

Phone number: 0141 404 0231

Email: lucy.mulvagh@alliance-scotland.org.uk; andrew.strong@alliance-scotland.org.uk; colin.young@alliance-scotland.org.uk

QUESTIONS

Question 1

Is there a key issue or opportunity in the current adult social care system that is not included in Annex 1 and that you believe should be added? If so, please give details here.

The ALLIANCE's 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.

We welcome the opportunity to respond to the consultation by the Scottish Government and COSLA on a national programme to support adult social care reform.

The ALLIANCE believes that a strong equalities and human rights based framework must be embedded within the adult social care system to ensure more consistent positive practice – and therefore outcomes – to which individuals are entitled.

Human rights provides a common language and unifying philosophy with which to address the areas identified at A and B in Annex 1, and human rights principles underpin and are mainstreamed throughout the SDS Change Map at C.

We believe the adult social care system in Scotland should be founded upon the rights based PANEL Principles (Participation, Accountability, Non-discrimination and Equality, Empowerment, and Legality). These offer a way to put human rights into practice, including in the design, delivery, and assessment of care and support. As well as the free, equal, meaningful and active participation by people in decisions that affect them, accountability and legality are key parts of a human rights based approach which should not be avoided or ignored.

Employing an equalities and rights based approach to social care helps to clarify expectations of fair, consistent and respectful experiences, and of redress when standards fall below this. It offers a coherent values based system to reform social care in order to "*empower the citizens of Scotland and unlock them from the failings of past systems, rather than locking them into a new system that lacks a clear vision*"[6]. Rights based approaches like Care About Rights[7] need to become the norm, allowing for a shift in the balance of power from practitioners to people who access support and services. Ensuring people have choice and control over their services and support is central to a rights based approach.

The ALLIANCE also shares the view of ENABLE Scotland that, to date, the benefits of the extremely positive introduction of the Scottish Living Wage have only really been felt by social care practitioners who work daytime hours. We believe that this must be extended to pay all frontline staff the higher Scottish Living Wage for every hour of work.

Paying the living wage would benefit employers in the longer term by reducing expenditure on recruiting and training new members of staff, and most importantly would ultimately benefit people who access support and services by enabling them to enjoy increased quality and continuity of care from a skilled and valued workforce.

Within this dynamic, it is important to acknowledge the increasing downward pressure being placed on funding for local authority commissioned social care services provided by the Third and Independent sectors.

This has resulted in increasing inequity between people working in local authority social care and people employed by Third/Independent sector providers commissioned by the local authority, who are often paid much less with poorer terms and conditions. In some instances, this has led to Independent/Third sector providers pulling out of providing social care as they can't provide a quality service

6 https://www.centreforwelfarereform.org/uploads/attachment/332/personalisation-and-human-rights.pdf

7 http://scottishhumanrights.com/careaboutrights

for as little as they are being asked to. In these cases, the services are brought back in-house and paid for at a much higher rate by the local authority.

We believe that addressing issues like this in the national programme to support reform – as well as the wider goals of the Fair Work Framework[8] – ensures that a rights based approach extends to all stakeholders involved in adult social care.

In terms of the initial suggested areas for exploration at Annex 1 (B), we note that there is already a substantial body of evidence available to help improve our understanding (e.g. Audit Scotland reports[9]). To the list provided at (B) we would add:

- Explore the role that alternative forms of fiscal planning and management, e.g. human rights budgeting, could play in supporting the reform process[10]. Human rights can support difficult decision-making and ensure decisions about value for money and efficient use of resources are made on an equal basis. The rights based approach also provides a framework for balancing competing rights, interests and risks on a transparent and equitable basis.

- Explore the weight given to qualitative evidence – including the views of people who access and provide social care – compared to quantitative data and redress any imbalance.

- Identify how funding is specifically allocated towards prevention and early intervention in social care (compared to e.g. critical intervention).

- Explore how to increase and enhance the role of the Third and Independent sectors in strategic decision-making and strategic commissioning.

Question 2
In your view, what should the shared vision/common outcomes for adult social care be?

Social care is a means to an end – it is supposed to help people live independently and participate equally in society. We believe that rather than create a new shared vision/common outcomes, we can look to the wider policy landscape within which the proposed national programme sits. As well as the work described at paragraph

[8] http://www.fairworkconvention.scot/framework/FairWorkConventionFrameworkFull.pdf
[9] http://www.audit-scotland.gov.uk/reports/e-hubs/transforming-health-and-social-care-in-scotland
[10] http://www.scottishhumanrights.com/economic-social-cultural-rights/human-rights-budgeting/

6, the current review of health and social care integration[11], and the previous review into targets[12], should be taken into account.

During the progress of the Public Bodies (Joint Working) (Scotland) Act 2014, the ALLIANCE repeatedly called for a set of guiding, human rights based principles on the face of the legislation, and that the new Health and Social Care Partnerships (HSCPs) should be under a duty to have due regard to human rights. Whilst this was not adopted, the subsequent Act included a principle underpinning both planning and delivery of health and social care services that the "rights of service users" should be respected.

This is echoed by the new Health and Social Care Standards, which seek to provide better outcomes for everyone and to ensure that individuals are treated with respect and dignity and that the basic human rights to which we are all entitled are upheld.

Self-directed Support (SDS) is intended to be embedded as the mainstream approach to social care in Scotland. As such, it should be a key driver for the shared vision/common outcomes for adult social care. The national SDS strategy is underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion.

How should the vision/outcomes be developed?

- Fully engage and involve people who access support and services and unpaid carers from the beginning. A co-production approach must be embedded at all stages – in wider system and service-specific design, processes for delivery, and monitoring improvement.

How will the vision/outcomes be realised?

- Empower individuals and communities to be contributing, active citizens, especially in areas of high deprivation. This demands longer term investment in local communities and groups to ensure people are supported to live well outside of hospital, e.g. using technology to support and enable self management, and easy access to information and tools to improve health and care literacy. It's crucial to help people and staff to know how, where and when to ask for support.

11 http://www.parliament.scot/S5_HealthandSportCommittee/Inquiries/20180622_Cab_Sec_and_COSLA.pdf

12 https://beta.gov.scot/publications/review-targets-indicators-health-social-care-scotland/

- Invest in approaches which place a value on reciprocity and strong community connections between all formal and informal sources of support. This will encourage joint working, pooling of local assets, opportunities to form relationships, appropriate data sharing and two-way signposting systems. Making better and more coherent use of existing tools like A Local Information System for Scotland (ALISS), Community Link Practitioners, shared training and greater integration of Third Sector and public services (e.g. police, libraries, schools, adult literacy organisations, health and social care).

- Gaun Yersel' – The Self Management Strategy for Long Term Conditions in Scotland[13] describes a shift away from the medical model to a person centred (not 'patient-centred') view. Going further and adopting an approach based on the human rights model of disability[14] would encourage a trust and belief in individuals' capacity to improve and manage their own health and indicate a move from a hierarchal "them and us" culture to one which is more holistic and person centred.

- Development of an integrated and simple feedback and improvement framework (not just a 'complaints system') that speeds up the process and taps into the person's experience, by asking them to contribute their ideas for improvement. This will introduce a positive aspect to a usually negative process and represents true co production. (The Scottish Public Service Ombudsman recently described people who pursue complaints as "marathon runners").

- Utilise local, national and worldwide networks to learn from and share good practice of innovative and sustainable services and systems.

How would success be measured?

Robust data should be collected directly from people who access support and services about their experiences, the outcomes they have achieved and what could have been improved upon.

Question 3
What should the priorities for the national programme be in the short, medium and long term, taking into consideration the suggestions presented throughout this paper and the material at Annex 1?

Short term priorities:

[13] http://www.scotland.gov.uk/Resource/0042/00422988.pdf
[14] https://www.researchgate.net/publication/283713863_A_human_rights_model_of_disability

- Explore the interaction between adult social care and the social security system.
- Implement living wage commitment for all staff working in adult social care (including overnight shifts).
- Develop strategies to support the adult social care sector through the projected workforce issues created by Brexit over the coming years.
- Incorporate the recommendations from the recent Paper for Ministerial Strategic Group for Health and Community Care[15].

Medium term priorities:

- Coordinate open, frank and wide-ranging national and local discussions between people who access support and services, commissioners and providers about the future of adult social care and how to deliver it.

Long term priorities:

- Create a common rights based framework for funding and delivering health and social care which recognises the autonomy of individuals and prioritises their contribution to and status in our society.

Question 4
What potential pitfalls do you see arising in the development and implementation of the national programme?

In adult social care, there is a stark gap between progressive legal and policy language on the one hand and people's experiences of implementation on the other (the 'implementation gap'). Inclusion Scotland has identified an "unacceptable contrast between the positive rhetoric of the National Strategy on Self-directed Support and experience on the ground"[16]. The ALLIANCE's research on people's experiences of SDS supports this[17].

While we still need evidence of what works – and doesn't – for people, there is a danger that overly focusing on further reflection and policy development will be at the expense of going ahead with practical action based on our substantial knowledge to date.

15 https://www.alliance-scotland.org.uk/wp-content/uploads/2018/03/Health-and-Community-Care-MSG-Third-and-Independent-Sector-Engagement-with-Health-and-Social-Care-Integration-Report-1.pdf
16 http://inclusionscotland.org/wp-content/uploads/2016/01/Inclusion-Scotland-UNCRDP-DDP-2016-2020-response-1.pdf
17 https://www.alliance-scotland.org.uk/blog/resources/personal-experiences-of-sds-reports/

Other potential pitfalls we have identified include:

- Lack of long-term, sustainable investment in groups and organisations that strive to support people to live well, and by doing so contribute to measures to prevent and self manage long term conditions. Non-NHS formal and informal organisations are hindered by short-term funding and lack of security which impacts badly on local people and staff and stalls efforts to connect communities. Too often, people are prevented from accessing valuable support when high performing local groups lose their funding.

- The pace and scale of change is not fast enough, with too much focus on improvements within the current system instead of radically re-thinking what it means to live well in a future Scotland. It is clear that we need a paradigm shift rather than continuing to do the same with dwindling resources. Taking an equalities and human rights based approach can help us realise transformational change as opposed to small scale changes to existing models.

- Greater care should be taken to ensure people are not admitted to places of care sooner than is needed, an example of not adopting a rights based, person centred approach.

- Further uncertainty is looming due to Brexit and its implications, particularly for the social care workforce if no deal is secured in relation to freedom of movement. In some areas, social care is dependent on EU migration for recruitment, particularly for specialist posts. Reducing the pool of available workers could lead to further pressure in meeting demand and possible increases in agency costs.

Question 5
What would you wish to see in the refreshed Implementation Plan for self-directed support 2019-2021? (e.g. what barriers or enablers could be addressed at national level to support what you are doing locally?)

The ALLIANCE wants to see SDS being consistently implemented according to its underlying rights-based values and principles, to achieve transformational change in social care culture and services, and help improve people's lives. We therefore welcome the proposal by the Scottish Government and COSLA to develop a focused and systematic response at the national level and provide leadership and guidance for local developments. We recommend full, meaningful and active involvement by the Third and Independent Sectors, people accessing services, unpaid carers and other relevant stakeholders in the development and oversight of the Implementation Plan to help achieve this aim.

The ALLIANCE is troubled by our research findings[18] that people do not think their SDS package is sufficient to meet their daily social care requirements. We therefore welcome suggestions for a national conversation on the future of social care and SDS, which could acknowledge the issues with funding, commissioning, procurement and service delivery. Open and honest discussions around Scotland involving a representative mix of all relevant stakeholders could help increase everyone's understanding of the barriers and enablers facing different groups involved in social care. We also support the view of SAMH that in addition to discussion on SDS we also need to ensure that the staff responsible for implementing it are properly trained and understand what they can and can't do, that packages are properly funded and that unnecessary restrictions are not placed on what people can do with their budgets.

We believe that Health and Social Care Partnerships could instigate greater collaboration between health services (e.g. community practitioners, GPs and hospital settings) and social care colleagues to promote integrated and preventative approaches through SDS. The Implementation Plan can help share good practice.

To address low uptake and poor understanding of SDS, we recommend a targeted campaign co-designed by the Scottish Government, COSLA, local authorities, HSCPs, social workers, the Third and Independent sectors, people who access services, unpaid carers/family/friends and other relevant stakeholders. We support the view of SAMH that raising awareness and understanding of SDS should be targeted at people who use services and the general public, although the priority is those who currently use services.

To gain a fuller picture of SDS, we recommend robust qualitative research is regularly undertaken and shared on people's personal experiences and their perceptions of the impact it is having on their lives.

Most people that took part in the ALLIANCE's research would appear to find out about SDS through personal interaction. We therefore recommend that the NHS, HSCPs and social work departments prioritise direct discussions about SDS with people who access services during contact about care and support. Particular attention must be given to this in mental health settings. We also recommend that HSCPs and others could make SDS information and support more readily available and accessible in health settings like GP practices and hospitals, and through Allied Health Professionals.

Local authorities should ensure there are regular review processes for everyone accessing social care (including those already in receipt of SDS), to ensure people

[18] https://www.alliance-scotland.org.uk/blog/resources/personal-experiences-of-sds-reports/

are encouraged to fully explore all four options to best establish the most appropriate arrangement that meets their outcomes. People's experiences, conditions and outcomes can all change over time, and the processes and systems that support them should reflect this.

Practitioners should be mindful of the impact an individual's protected characteristics (e.g. gender, age, ethnicity, sexual orientation) and intersectionality – as well as their social care requirements – may have on their opportunities to make decisions around SDS. Ensuring there is free and easy access to independent advocacy and independent advice will help strengthen people's empowerment and supported decision-making.

We also strongly recommend further national and regional investigation into the causes and consequences of the different SDS options chosen and who makes the choice, depending for example on a person's protected characteristics as well as the personal outcomes they seek to achieve.

To support ongoing improvement to SDS we recommend creating (a) a proactive feedback loop whereby decision-makers and delivery bodies regularly seek people's views and report back on what's been done (or not) and why; and (b) a national independent 'whistle-blowing' mechanism for those delivering and accessing SDS to raise concerns.

We know that many people have to make some financial contribution towards the cost of their social care and that several local authorities have increased charges for non-residential social care services as part of their regular income. Already struggling with cuts to social security, this can push people even further into poverty. Some people are discouraged from applying for social care in the first place because of charges. This further increases the risk of harm, deterioration and potential crisis. We would encourage exploration of this issue in the Implementation Plan. For example, the cost of support required by each individual could be calculated after the health and social care needs that meet their outcomes have been identified. We support SAMH calls in the short term for legal guidance on income thresholds and charging rates; a top limit on charges; free care for those on compulsory treatment and no requirement for providers to collect charges; and in the long term for charges to be abolished as part of a wider review of charges and commissioning[19].

The ALLIANCE believes that both health and social care services should be portable and that anyone accessing social or ongoing health care should be able to freely move and settle at will with the same access to quality services and support.

[19] https://www.samh.org.uk/documents/SAMHs_Views_Social_Care_Charging.pdf

Question 6

Are you undertaking any specific work around the indicators in the change map for self-directed support (at Annex 1) that you would like to publicise and that others could learn from?

The ALLIANCE has previously undertaken research into people's personal experiences of SDS[20]. We carried out this research to gain a better understanding of the personal experiences of SDS among people who access social care and support across Scotland and help contribute to the growing body of qualitative evidence on SDS. By increasing awareness and understanding of these experiences, we aim to help inform and improve SDS practice at local and national levels. The ALLIANCE, along with SDSS, are repeating this research project for 2018/19.

Question 7

Within your wider work on health and social care integration, does your organisation have established mechanisms for adult social care improvement that the national programme should engage with? (Or if you are an individual, are you involved with anything of that sort?)

The ALLIANCE has over 2,500 members, bringing together a large network of national and local Third and Independent Sector organisations, Associates in the statutory and private sectors, NHS Boards, HSCPs and individuals who access services and support, as well as unpaid carers. There are many benefits to collaborating with this dynamic, cross-sector community that are working to improve the lives of people who access health and social care services in Scotland (www.alliance-scotland.org.uk). There are several specific ALLIANCE programmes and that can also support and engage with the national programme:

The ALLIANCE's SDS programme can support dialogue and test activity on how SDS can work effectively as part of an integrated approach to health and social care (www.alliance-scotland.org.uk/health-and-social-care-support-and-services/self-directed-support).

A Local Information System for Scotland (ALISS) helps people find and share information about local services and resources that support health and wellbeing (www.aliss.org). Our wider Digital Health and Care team (www.alliance-scotland.org.uk/digital/digital-health-and-care/) help increase citizen participation and bring the voice of lived experience to digital health and care initiatives.

[20] https://www.alliance-scotland.org.uk/blog/resources/personal-experiences-of-sds-reports/

House of Care works to make care and support planning conversations routine for people with long term conditions and support self management (www.alliance-scotland.org.uk/health-and-social-care-support-and-services/house-of-care/).

The ALLIANCE's Integration Support team increases the Third Sector's capacity to contribute to health and social care integration – particularly within strategic decision making processes – and supports HSCP capacity to work effectively with the Third Sector (www.alliance-scotland.org.uk/health-and-social-care-support-and-services/integration-support/).

The Self Management Network Scotland (SMNS), which is hosted by the ALLIANCE, has over 600 members who work together to share knowledge, learn and change the delivery of health and social care (www.alliance-scotland.org.uk/self-management-and-co-production-hub/self-management-network).

The ALLIANCE's Health and Social Care Academy (the Academy) is a cross-sectoral platform for transformational change in health and social care using the voice of lived experience (www.alliance-scotland.org.uk/people-and-networks/health-and-social-care-academy).

Our Links Worker Programme makes links between people and their communities through GP practices (www.alliance-scotland.org.uk/in-the-community/national-link-programme).

All the ALLIANCE's programmes work with a wide range of partners and stakeholders at a national and local level to collaborate in health and social care.

How can the national programme enable partners across local and national levels to work together to establish collective leadership for the programme?

- It is essential that all stakeholders are committed to the practical realisation of the shared vision. Ensuring robust mechanisms to monitor practical action towards achieving the shared outcomes, and accountability for deviation, could reassure everyone involved.

- The Social Security Experience Panels are one approach to facilitate meaningful inclusion of people with lived experience in better understanding and improving upon current systems[21].

[21] beta.gov.scot/policies/social-security/engagement-on-social-security/

- The recently established National Suicide Prevention Leadership Group provides one model of a mixed membership body charged with overseeing delivery of the new national policy[22].

- Free, meaningful and active engagement by Third and Independent sector representatives, people who access social care services, and unpaid carers requires resources and support. We recommend a co-design approach be taken to ensure that the collective leadership makes the best use of skills, experience and capacities of everyone involved to jointly create effective solutions to the complex challenges.

Additional comments

Please email your response to Andrew.Scott3@gov.scot by 5pm on Thursday 27 September 2018.

[22] news.gov.scot/news/suicide-prevention-plan