

Annex G Consultation Questionnaire

About SCLD

SCLD is a Centre for Excellence funded by the Scottish Government, which is made up of 12 partner organisations whose mission is to work in partnership with people with learning disabilities, people on the autism spectrum and family carers to challenge discrimination and to develop and share good practice. SCLD's goal is an inclusive Scotland where everyone is valued and respected for who they are and what they contribute as equal citizens.

SCLD's partnership organisations include 12 third sector organisations and universities: Association for Real Change (ARC), British Institute for Learning Disabilities (BILD), Badaguish Outdoor Centre, Capability Scotland, Central Advocacy Partners, Down's Syndrome Scotland, ENABLE Scotland, Key, PAMIS and the Universities of Dundee, Glasgow and St Andrews.

We work in collaboration with our Partners and other organisations to improve the lives of people with learning disabilities, people on the autism spectrum and their families.

You can find out about our work at www.sclد.org.uk

SCLD's strategic priorities are to:

- Promote equality for people with learning disabilities, people on the autism spectrum and their families through influencing and evaluating policy and practice at a national and local level.
- Promote policies and practices to enable and empower people with learning disabilities and people on the autism spectrum.
- Help to build more inclusive communities by improving access to information and support.

Key points

- SCLD welcomes the Scottish Government's intentions to create closer working relationships between health and social care. Research evidence from 'The same as you?' evaluation has shown that people with learning disabilities and their families often struggle to attain the kind of 'seamless' service which is the aspiration of these proposals. People with learning disabilities and family carers can find it difficult to negotiate complex systems of health and social care.
- SCLD is of the view that proposals to integrate health and social care services must be underpinned by a broad and comprehensive understanding of human rights and equality.
- SCLD is not of the view that focusing initially on older people's services is a practical and helpful approach, given that the proposals will demand systemic changes that will affect all users of health and social care services. A more wide-ranging consideration of the diverse needs and equality characteristics of the people who use health and social care services is required.
- SCLD is concerned that there is relatively little clarity as to the 'fit' between proposals to integrate health and social care services and other key policies, for example self-directed support.
- SCLD is concerned that the proposals for representation of people who use services and carers within the new Health and Social Care Partnerships are limited. SCLD strongly recommends that the participation of people who use services and family carers must be reflective of a diverse range of experiences and capabilities. SCLD has substantial experience of working with people with learning disabilities to facilitate their meaningful engagement with complex areas of policy and practice. Our experience of working in this way shows that with the right kind of support and adequate resource policy and practice can be enhanced. Therefore, SCLD is of the view that there needs to be a more systemic and comprehensive approach to building the capacity of public sector bodies, and to the development of policy that supports people who use services appropriately to enable their contribution.

- SCLD also seeks reassurances that whichever model is chosen, **all** people who use services are able to access the support and services they need and that there will not be a competition for resources between different groups. The progress which has been made for people with learning disabilities over the last decade and more in terms of living meaningful lives in the community must not be lost because of administrative and funding changes.

The case for change

Question 1: Is the proposal to focus initially, after legislation is enacted, on improving outcomes for older people, and then to extend our focus to improving integration of all areas of adult health and social care, practical and helpful?

Yes No

SCLD welcomes the Scottish Government's intention to create closer working relationships between health and social care. Research evidence from 'The same as you?' evaluation has shown that people with learning disabilities and their families often struggle to attain the kind of 'seamless' service which is the aspiration of these proposals (see <http://www.sclد.org.uk/training-consultancy/research/say-evaluation/same-you-research-team-reports>). People with learning disabilities and family carers can find it difficult to negotiate complex systems of health and social care.

However, despite welcoming the intentions of the proposals set out in the consultation paper, SCLD is not of the view that the proposal to focus initially on older people's services is practical and helpful for a number of reasons:

- This approach will not facilitate the kind of systemic change which the Christie Commission set out as desirable for public services.

- There are significant differences between the services which disabled people and older people access which would invalidate this approach. Disabled people, including people with learning disabilities, may require support from health and social care services throughout the whole course of their lives and not just with the advent of ageing. This means that the requirements which disabled people have of services over the course of their lives and the outcomes they wish to achieve may differ significantly from those of older people. Any integrated systems set up to support older people may not be appropriate for disabled people, including people with learning disabilities. The integration proposals do not provide any indication of how integration will be rolled out to other groups. As stated above people with learning disabilities will interact differently with Local Authority (LA) and NHS support services – it is essential that the integration plans are developed to reflect the needs of all groups of people who use LA and NHS services.
- Many of the drivers for the integration of health and social care of older peoples' services apply to disabled peoples' services. Disabled people have fought for the availability of appropriate services in their homes and their communities rather than in acute or institutional settings.
- People who use services have multiple identities and do not fall into neat categories; this will make identifying budgets and providing services across the integrated/non-integrated divide very challenging.
- The implementation of the policy for older people alone will create silos of knowledge which will not necessarily be available to services for other groups of people who use services.
- There is a lack of clarity as to how the integration of health and social care services for older people would impact upon services for the remaining groups- what would be the working arrangements for these services?

SCLD would also seek reassurances that whichever model

is chosen, **all** people who use services are able to access the support and services they need and that there will not be a competition for resources between different groups. The progress which has been made for people with learning disabilities over the last decade and more in terms of living meaningful lives in the community must not be lost because of administrative and funding changes.

Outline of proposed reforms

Question 2: Is our proposed framework for integration comprehensive? Is there anything missing that you would want to see added to it, or anything you would suggest should be removed?

Yes No

There is a lack of clarity as to how the proposals to integrate health and social care will 'dovetail' effectively with other key policy changes, in particular, the introduction of self-directed support. For example, it is not clear whether under the new proposals, people will be able to direct support in both a health and a social care context. There needs to be a more detailed outline within the proposals to explain how integration will develop alongside self-directed support policy and legislation. For example how will integrated health and social care budgets affect resources available for peoples' individual budgets?

National outcomes for adult health and social care

Question 3: This proposal will establish in law a requirement for statutory partners – Health Boards and Local Authorities – to deliver, and to be held jointly and equally accountable for, nationally agreed outcomes for adult health and social care. This is a significant departure from the current, separate performance management mechanisms that apply to Health Boards and Local Authorities. Does this approach provide a sufficiently strong mechanism to achieve the extent of change that is required?

Yes No

SCLD believes that it is essential that the national outcomes reflect the desired outcomes for all people who use services and carers. As indicated in our response to question 1. SCLD wishes to highlight the importance of independent living for disabled people, including people with learning disabilities. SCLD's view is that it is essential that the national outcomes framework is not based on outcomes developed primarily for older people but is developed in a way that is inclusive of all relevant groups, including those with lifelong needs. The User and Carer Forum which was established to contribute to the Changing Lives review of Social Work Services (2008) found that the outcomes identified for older people did not fully represent their aspirations. The recent evaluation of 'The same as you?' evidences the outcomes desired by people with learning disabilities and their families. Respondents identified that they wanted access to more homes and opportunities to live independently, improved support, more job opportunities, more accessible public spaces and transport, more chances to learn, more facilities and things to do during the day, good health care and improved awareness about people with learning disabilities (Curtice and Trew, 2012) (http://www.sclد.org.uk/sites/default/files/the_same_as_you_evaluation_final_report_010612_0.pdf)

Question 4: Do you agree that nationally agreed outcomes for adult health and social care should be included within all local Single Outcome Agreements?

Yes No

Comments

Governance and joint accountability

Question 5: Will joint accountability to Ministers and Local Authority Leaders provide the right balance of local democratic accountability and accountability to central government, for health and social care

services?

Yes No

SCLD is of the view that if this system of accountability is properly implemented, it should provide the right balance.

Question 6: Should there be scope to establish a Health and Social Care Partnership that covers more than one Local Authority?

Yes No

Comments

Question 7: Are the proposed Committee arrangements appropriate to ensure governance of the Health and Social Care Partnership?

Yes No

The proposed committee arrangements for non-voting members do not go far enough. As stated in our earlier answers SCLD believes that for integration of health and social care to deliver improved outcomes for all people who use health and social care services there needs to a systematic and well-resourced approach to supporting meaningful engagement of a diverse range of groups. In particular we are concerned that people with learning disabilities will not be effectively supported to engage with the implementation of this policy.

Question 8: Are the performance management arrangements described above sufficiently robust to provide public confidence that effective action will be taken if local services are failing to deliver appropriately?

Yes No

SCLD would like to see a more detailed discussion of how the performance management proposals will engage people who

use services and carers.

Question 9: Should Health Boards and Local Authorities be free to choose whether to include the budgets for other CHP functions – apart from adult health and social care – within the scope of the Health and Social Care Partnership?

Yes No

Comments

Integrated budgets and resourcing

Question 10: Do you think the models described above can successfully deliver our objective to use money to best effect for the patient or service user, whether they need “health” or “social care” support?

Yes No

Comments

Question 11: Do you have experience of the ease or difficulty of making flexible use of resources across the health and social care system that you would like to share?

Yes No

Some people with learning disabilities who have complex health needs and attend day provision find difficulty in accessing flexible health and social care resources with the result that management of health procedures takes priority and their needs for engagement and activity are unmet.

There are difficulties in accessing flexible health and care resources to enable people with learning disabilities with

complex needs to leave long-stay/NHS accommodation for supported living in the community.

Some people with learning disabilities are living inappropriately in older people care homes and lack of flexibility in accessing health and care resources can be a contributory factor.

These are examples of how within a user group some people can be particularly disadvantaged by the lack of flexible resource use.

Question 12: If Ministers provide direction on the minimum categories of spend that must be included in the integrated budget, will that provide sufficient impetus and sufficient local discretion to achieve the objectives we have set out?

Yes No

Comments

Jointly Accountable Officer

Question 13: Do you think that the proposals described here for the financial authority of the Jointly Accountable Officer will be sufficient to enable the shift in investment that is required to achieve the shift in the balance of care?

Yes No

Comments

Question 14: Have we described an appropriate level of seniority for the Jointly Accountable Officer?

Yes No

Comments

Professionally led locality planning and commissioning of services

Question 15: Should the Scottish Government direct how locality planning is taken forward or leave this to local determination?

Yes No

Scottish Government input into locality planning would be welcome, but this might be most appropriately achieved through the use of guidance.

Question 16: It is proposed that a duty should be placed upon Health and Social Care Partnerships to consult local professionals, including GPs, on how best to put in place local arrangements for planning service provision, and then implement, review and maintain such arrangements. Is this duty strong enough?

Yes No

Much will depend on the wording of the duty. SCLD would welcome multi-disciplinary expertise at a local level. However, we would caution against privileging a medical model view of the needs of disabled people, including people with learning disabilities.

We would also suggest that people who use services have much expertise to offer service planning and it is therefore critical that they are supported appropriately to contribute their views on an equal standing with people from professional backgrounds.

Good practice in making such support effective was developed by the Changing Lives User and Carer Forum which brought together people with a range of experiences of health and social care services e.g. 'Principles and Standards of Citizen Leadership (Scottish Government with SCLD, 2008) and

resources such as 'Supporting You to Support Us' (<http://www.seld.org.uk/seld-projects/citizen-leadership/supporting-you-support-us>). The citizen leadership standards have recently been matched to the leadership capabilities in the Continuous Learning Framework, so that they can be applied to workforce development (<http://www.sssc.uk.com/clf/special-access/landing-page.html>).

Question 17: What practical steps/changes would help to enable clinicians and social care professionals to get involved with and drive planning at local level?

Health and social care policy in Scotland emphasises the central role that people who use services should have in service planning and delivery. There is a general agreement that services should be built around people and communities.

This driver is not adequately addressed within the integration proposals. We would recommend that this could be facilitated by:

1. Workforce development and training that focuses on developing the skills of the LA and NHS staff to ensure that the people who they support can contribute their views and experiences.
2. Proposals to engage with communities to contribute to planning local health and social care services.

Question 18: Should locality planning be organised around clusters of GP practices? If not, how do you think this could be better organised?

Yes No

Whilst we agree it is important to have a strong input in planning at a local level it is also important to ensure that services meet the needs of all people in a local area. For example patients

with learning disabilities can be unequally distributed between GP practices. Thus it is important that there are mechanisms within the planning proposals to enable aggregated data relating to different groups to ensure their needs are factored into local delivery plans.

Question 19: How much responsibility and decision making should be devolved from Health and Social Care Partnerships to locality planning groups?

Comments

Question 20: Should localities be organised around a given size of local population – e.g., of between 15,000 – 25,000 people, or some other range? If so, what size would you suggest?

Yes No

Do you have any further comments regarding the consultation proposals?

Outcomes

SCLD is of the view that nationally agreed outcomes for health and social care must be co-produced with people who use services, including people with learning disabilities. Nationally agreed outcomes must be based explicitly upon human rights and the principles which underpin these. Public sector organisations are likely to need support and capacity building in relation to both these drivers.

In the proposed list of outcomes, the understanding of independent living is limited and there is room for further development; independent living is underpinned by freedom, choice, dignity and control. While questions of safety and risk

are important issues

Transitions from Children's to Adult Services

This consultation, in partnership with the Children and Young People's Bill Consultation will create two very distinct systems for children's and adult services. SCLD would recommend that some resource is used in examining the impact that this will have on transitions for young disabled people from children's to adult services. This is already a very difficult time for young people with learning disabilities and family carers and the creation of two distinctive systems may make this even harder.

Do you have any comments regarding the partial EQIA? (see Annex D)

SCLD recognises that the EQIA as it stands is only a partial one. We appreciate that this has been based on responses received at a workshop event and that the full EQIA has still to be undertaken. However, we are somewhat disappointed at the lack of evidence, depth and complexity of the EQIA and would advocate that there needs to be a much more robust process to undertake a comprehensive EQIA.

In particular, the considerations of the impacts of the proposals on human rights are limited, both in terms of the rights considered – Articles 3 and 5, 6, 9, 11 and 14 are notably absent – the depth of consideration and the people who hold these rights and the organisations responsible for protecting them, notably the status of Health and Social Care Partnerships in this regard. It is critical to consider both the ways in which public authorities can 'refrain from' interfering with human rights as well as the ways in which they must actively put policies/services etc into place in order to protect human rights. Scotland's obligations under international human rights law must also be included here, for example in the binding, hard-law obligations contained within the articles of the United Nations Convention on the Rights of

Persons with Disabilities.

Will Health and Social Care Partnerships be required to undertake EQIAs?

SCLD would welcome the opportunity to discuss further how the proposed changes may impact (negatively or positively) upon people with learning disabilities and their families.

Do you have any comments regarding the partial BRIA? (see Annex E)

Comments