

CONSULTATION QUESTIONS

Progress and Challenges

Q.1 Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carer?

Yes No

Please provide any comments, evidence and/or examples here

See Q3

Q. 2 Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of *The same as you?*

Please provide any comments and/or examples here

Development of Local Area Coordinator roles; although inconsistent application of this across local authority areas.

Reduced reliance on traditional forms of day care towards more inclusive options (Although less progress for people with more complex support needs)

Closure of learning disability hospitals

Increase in person centred support plans

More people connecting with their local communities (although still much to do here)

Improved access and understanding within some health services, for example having learning disability 'champions' and Hospital Passports.

Q. 3 Can you give examples of issues in current work and/or policies that still need to be addressed?

Please provide any comments and/or examples here

(please see also Graphic Facilitation Notes from National Involvement Network meeting 14/9/12)

Choice and Control

A recent evaluation (2012) of the 'Charter for Involvement' carried out by members of the National Involvement Network (NIN) supports the priority theme (p61) to 'ensure the meaningful engagement of people with learning disabilities and family carer in service design and delivery'. Their Evaluation shows that nearly all of the 12 CEO's of voluntary organisations and the 46 people who get support that we spoke to think that people who get support should be involved 'a lot' in how organisations are planned and run.

We also learned that support organisations are at very different stages of involvement. Many provider organisations tell us that they want to improve involvement but need help to do this.

Although we hear a lot about 'co-production', the tremendous capacity of people with learning disabilities to positively shape how services will be planned and organised has not yet been fully realised. We have learned that getting involvement right takes significant time, commitment and investment. **We believe that future policy should give more detail about what engagement and involvement should look like.**

The SAY Consultation report (p27) focuses on involvement in personal life / person centred plans. We wholly support that people should be at the heart of any plans about their lives. **We think that future policy should be clearer about how these should be made and look, for example they should be made in a way that the person can understand, for example using pictures, audio and DVDs.**

It is particularly concerning that the Consultation Report (p22) found that 'about one third of the respondents were able to name at least one close friend.' This suggests that two thirds of people with learning disabilities are not able to name a close friend. **We think that including support to find and maintain friendships in peoples personal life / person centred plans is one way to help improve this.**

We also think future priorities should include people having opportunities and structures in place for people to be more involved in how their support organisation is planned and run, for example being involved with management boards and committees, writing key policies and in evaluating their support. We think that the 'Charter for Involvement' is a good model for this as it has been proven to make a real difference.

We have found that the meaningful engagement of people who get support in local authority planning processes is often at a less well-advanced stage than in voluntary provider organisations. This has sometimes led to big

decisions being made, such as day centre closures, without proper involvement and consultation with the people who will be affected.

We think that future policy should put a greater emphasis on evidencing meaningful engagement within local authority planning and decision-making processes. People who do get involved often tell us they are just beginning to understand how the council works when everything is re-organised, or key individuals leave, and they feel that they have to start at the beginning again. There are already good guidelines available to help improve this, such as the National Standards For Community Engagement, written by Communities Scotland. The Principles and Standards of Citizen Leadership also offer good principles and guidance.

Involvement should be with Community Planning as well as planning for learning disability services and we very much support the future priority to (p61) to "Fully involve...in the development and implementation of self-directed support."

Lack of suitable transport options to access activities and opportunities is regularly raised as a key issue, particularly by those who live in rural areas. This was identified as recommendation 18 in the SAY. **We believe that peoples experience of public transport provision should be evaluated and dialogue established with relevant Scottish Government departments to develop strategies to improve this.**

We are also conscious that there has been an increase in numbers of reported incidents of Disability Hate Crime (In Scotland in 2011-12, 68 charges were reported with an aggravation of prejudice relating to disability, 20 more than were reported in 2010-11). Further to this, many people with learning disabilities report that bullying affects their lives. **Future policy should seek to promote work with self advocates, the police, young people and other community members as appropriate to engage in discussions as to appropriate action to tackle bullying and hate crime at local level.**

We welcome the priority theme and action (p63) to 'Monitor the impact of welfare benefit changes.' Benefit changes could lead to increased poverty for many people with learning disabilities that undermine Scottish Government aspirations for people to have increased independence, choice and control. The Scottish Government should seek to ensure that changes to Welfare Benefits work to the advantage of people with learning disabilities, to ensure an adequate income to lead a 'good life' rather than that people are left disadvantaged or indeed in poverty.

We believe that future policy should also include a commitment to providing benefit advice and information. It should also include support for people with learning disabilities and their carers to manage their finances.

Self-Directed Support (SDS)

We appreciate why this does not feature greatly in the Consultation Report. ARC Scotland facilitates forums for provider organisations across Scotland

that are attended by over 200 senior staff from a wide range of organisations. SDS is the single biggest issue that they raise with us.

Provider organisations tell us that they have very mixed feelings about SDS. On one hand they are optimistic that it will help them to achieve their organisational mission and values. On the other hand they are concerned that it will increase the vulnerability of the people they support and create significant organisational challenges in their organisation. Many organisations have little or no experience of the practical application of SDS, so these views are largely based on perceptions rather than direct experience.

Providers tell us that what they most want is practical examples of SDS working in practice, dialogue with their local authority about their plans to roll out SDS locally and opportunities to work collectively and share learning with other organisations.

Provider organisations will have a central role in progressing the SDS agenda and improving choice, independence and control for people with learning disabilities. **Along with engaging with people who get support in the development of SDS, local authorities should also engage with providers in their area so they can contribute to the process and are given an opportunity to consult with the people they support and make necessary operational changes.** This is already happening in some areas, such as the Scottish Borders, Fife and Aberdeenshire.

Provider organisations tell us that they want opportunities to work collectively in local authority areas to improve their capacity to support people to live independently. For example, provider organisations capacity to support people to find and sustain paid employment is under-developed and under-resourced.

Providers who attend our forums have expressed concern about the potential risks to people with learning disabilities who are supported by unregulated and untrained personal assistants. This a particular concern for people with complex support needs.

Further to this, there is concern that established provider organisations who are required to comply with regulatory requirements face unfair competition from unregulated personal assistants. This could lead to a lowering of standards of care and support that may have a direct effect on people's quality of life.

Most of the people with learning disabilities that we speak to know very little about SDS. **Future priorities should therefore include supporting people who are in receipt of SDS to tell their stories in creative ways in order to help inform other people who get support about the choices and opportunities available to them.**

The strategic role required from Community Planning Departments in delivering the growth of self-directed support will be important to its success. If this does not happen as hoped for it may leave many people with learning disabilities isolated from their communities. This would

particularly disadvantage people who live in rural areas.

Future priorities should include ensuring that Social Work SDS leads link with Community Planning departments. Community planning could help support the growth of new community resources in response to the gaps in terms of what people need to improve their life chances.

Future priorities should also include supporting people with learning disabilities to engage with and influence local community planning processes (see 'Choice and Control' above).

Good Practice – Organisations

Q. 4 Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?

Please provide any comments and/or examples here

ARC Scotland supports and facilitates:

The National Involvement Network to publish and promote the Charter For Involvement. A recent evaluation shows that this has helped improve involvement for at least 1,750 people who get support.

The Scottish Transitions Forum that brings together over 170 people from diverse backgrounds. All are committed to improving choice, independence and control for young people with additional support needs who are in transition.

Forums for Provider organisations in 5 local authority areas that are attended by over 200 senior staff. These provide links between providers and local authority representatives and a forum to work collectively to improve their capacity to support people to live the life of their choosing.

Self-advocate groups for people with learning disabilities that have engaged with the concept of 'Citizen leadership' to make a real difference. This includes helping to build peoples confidence and capacity to influence change. We have supported self advocates to actively engaging with and influence; Access Panels, Community Councils, Local Authority Learning Disability planning processes, SDS planning processes and Local Authority tendering processes.

Good Practice - Individuals

Q.5 What have you done, as an individual, to make positive changes within your local area?

Please provide any comments and/or examples here

Future Priorities - Healthcare

Q.6 What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?

Please provide any comments and/or examples here

Improved access and understanding within some health services, for example having learning disability 'champions' and Health Passports.

Double appointments, particularly with GP's but also if required in hospital to enable people to have sufficient time to communicate directly with health staff, rather than communication going via family or support staff.

Training for staff within health care settings about how to work with and understand the needs of people with learning disabilities.

Ensuring all information about health care issues is fully accessible.

Future Priorities - Education

Q.7 What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?

Please provide any comments and/or examples here

(See response from ARC Scotland- Scottish Transitions Forum)

Future Priorities – Independent Living

Q.8 What still needs to be done to ensure that people with learning disabilities are able to live independently?

Please provide any comments and/or examples here

Improved guidance and support for provider organisations to meaningfully involve the people they support in how their services are planned and run

Greater clarity about how personal life plans / person-centred plans should be made and look, they should be made in a way that the person can understand, for example using pictures, audio and DVDs. They should also include support to find and maintain friendships and relationships.

A greater emphasis on evidencing meaningful involvement and engagement within local authority planning processes, and genuine co production at all levels including Nationally.

Resources made available to provider organisations and local authorities to improve involvement and engagement with people who use services.

A commitment to providing welfare benefit advice and information and support for people with learning disabilities and their carers to manage their finances.

Promote work with self advocates, the police, young people and other community members as appropriate to engage in discussions as to

appropriate action to tackle bullying and hate crime at local level.

Peoples experience of public transport provision should be evaluated and dialogue established with relevant Scottish Government departments to progress strategies to improve this.

Opportunities for people who are in receipt of SDS to tell their stories in creative ways in order to help inform other people who get support about the choices and opportunities available to them

Ensuring that Social Work SDS leads link with local authority Community Planning departments to inform service and community development and ensure that roll-out of SDS features in local plans.

Support for people with learning disabilities to engage with and influence local Community Planning processes.

Provider organisations should be encouraged and supported to work collectively in local authority areas to share good practice and improve their capacity to support people to live independently, including finding paid employment.

Future Priorities – Employment

Q.9 What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?

Please provide any comments and/or examples here

Greater investment (including staff training and resources) to increase the capacity of service provider organisations, including day care services to support people to find and sustain employment

Future Priorities

**Q.10 What other future priorities do we need to focus on?
(Please list these in order of importance with the most important first)**

Please provide any comments and/or examples here

Engagement of local authority SDS leads with local provider organisations. so they have an opportunity to influence the process and time to consult with the people they support and make necessary operational changes.

Clarity from SSC and others about the regulation of Personal Assistants to ensure that people, particularly those with more complex support needs, do not become more vulnerable as a result of SDS.

Clearer role for SCLD in identifying action plan setting out the steps to be taken –and by whom – for identifying key challenges, co-ordinating strategies to address these and measuring outcomes.