

Adult Health and Social Care Consultation response

September 2012

Self Directed Support Scotland (SDSS) is a national membership organisation which actively promotes Independent Living by supporting, working with and championing the aims of Self Directed Support disabled people's organisations.

This submission has been drawn up using the experiences of disabled people across member organisations and service users at consultation events held in Glasgow and Edinburgh. SDSS member organisations represent over 3000 disabled people across Scotland.

SDSS has also developed a joint response to this consultation with other disabled people's organisations; Inclusion Scotland, GDA, GCiL, LCiL, Independent Living in Scotland Project, and SDEF.

- SDSS welcome the Health and Social Care Integration (HSCI) programme. HSCI will potentially deliver:
 - **Better care pathways.** Service users will no longer have to apply to different organisations for the same social care. Continuity as well as quality is critical to the experience of health and social care services and avoids repeating the use of different assessments and workers.
 - **Individual outcomes.** Currently, most of what is delivered is based on service outcomes. SDSS recognises the value in this, in terms of setting standards at a wider level; service users also want to be able to determine outcomes based on their own circumstances. Service users should be involved in deciding what care and support is most appropriate for their needs, and be given choices and options, rather than being told *'this is what you'll get'*.
 - **Accountability.** SDSS believe there should be clear mechanisms in place to hold services to account so service users know who is responsible for delivering packages of care and support. This will prevent people falling through the gaps, particularly during transitions between services (e.g. from child to adult services, as well as adult to older people's services).
 - **Efficient use of resources.** SDSS welcome moves to remove organisational boundaries which limit the provision of resources. Agencies typically have dictated how and when support can be provided which limits service user's

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choice and control and can act as a barrier to taking up basic rights as an active and equal participant in society.

- **Shifting investment from acute services to prevention.** Investment in preventative services is crucial to enable all people to live independently in their communities and prevent unnecessary hospital admissions. Voluntary sector agencies can respond flexibly and adapt their response according to individual needs at a local level. They also bridge some of the gaps that currently exist between health and social care services. Their role should be recognised and enhanced through integration.
- SDSS also fully endorse, as partners in developing, two key collective responses:

Independent Living in Scotland (ILiS) - the 5 asks document

Long Term Conditions Alliance Scotland (LTCAS – Shared statement from 3rd sector organisations).

- SDSS believe that independent living principles, outcomes, human rights and citizenship should be central to the integration agenda. The independent living philosophy provides a robust underpinning framework on which to build policy, values and practices. During a period of change, the philosophy can support organisations to consult on sustainable strategies and services aimed at all citizens in society.
- SDSS urge the Scottish Government to remain fully aware of local consultation and implementation processes across Scotland. This is particularly important in respect of decision making processes and governance structures which may serve to exclude the involvement of disabled people, and others who are at risk of being side-lined.
- The whole integration philosophy should involve a co-production between organisations, disabled people, people with long term conditions and older people. Disabled people must be considered, respected and supported as key stakeholders and co-producers in the development and delivery of integrated health and social care and they are ready, willing and able to do this.

Partnership arrangements must be truly representative and able to distinguish between the unique contributions of service users, carers and third sector. Preventative investment to support disabled peoples' views being heard early on will save resources in the long term and avoid unnecessary spend on inappropriate resources.

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- It is important that disabled people, other users of the integrated systems, and the wider Third sector, are involved in leading, not just on the principles of an integrated system, but on how money within it is spent. Systems developed to control, assess for, distribute and determine eligibility for health and social care services must be developed in conjunction with service users involved at every level and be based on the principles of independent living.
- Access to services and eligibility criteria should be led by individual needs and requirements, rather than focussing on a medicalised approach to services.
- The portability of care packages through local authority and health board areas needs to be factored into the HSCI agenda. Currently if service users move home to another local authority, they need to seek reassessment for the same social care services. This acts as a barrier to service users and should be addressed as part of the integration agenda.
- SDSS believe the HSCI should include considerations on genuinely enabling people to have a say and shape the system through:
 - Developing collective support as part of a process that enables disabled people to have a representative and informed voice. They should be involved in decision making at a planning and commissioning level to represent the experience and views of service users.
 - Supporting independent and user-led organisations that offer impartial advice, information and support. SDSS members, including Ayrshire Independent Living Network, Glasgow Centre for Inclusive Living, and Lothian Centre for Inclusive Living, have well established and trusted methods of engagement with disabled people on an on-going basis, therefore their role must be recognised and utilised to inform and engage disabled people on developments.
 - A progressive consultative mechanism which is evaluated so that service users are confident that they can achieve their individual outcomes and move beyond the concept of just 'being cared for'. Disabled people should be involved in determining how success will be measured for them, so that the right questions are asked instead of using scales and other methods which are often informed by medical models.

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- An emphasis on the social model of disability being central to the development services so that change is influenced by equality of opportunity and inclusion rather than by power and cultural interest. SDSS is apprehensive that the integration agenda could serve to maintain and enhance the role of clinicians in decisions made about service user's care and support.
- SDSS believe that Self Directed Support (SDS) must be integrated closer into the HSCI agenda. The SDS Bill should be extended to include health funded support in the community for individuals when they 'exit' hospital based services. The Scottish Government's SDS Strategy makes it clear that service users and professionals should be seen as equal partners and this must be reflected in the integration agenda, to ensure progress on SDS continues.