Discussion between service users and MSPs from Health and Sport Committee

The following notes outline the broad themes and views that were discussed in the three discussion groups with service users, and should not be taken as being a verbatim note of the discussion.

General

- The introduction of the Social Care (Self-directed Support) (Scotland) Bill was generally welcomed.
- SDS offers more control, more choice and more flexibility
- All 4 SDS options in Bill are required as people need different types of support at different times
- The Bill has the potential to support independent living by making explicit the link between SDS and wider independent living more generally
- But, how will it be implemented? Will local authority social work staff be adequately trained?
- Scottish local authorities have been slow to offer direct payments and other forms of SDS, even when service users have made direct requests, due to:
  - Fear of change and aversion to risk
  - Concerns about negative media publicity if a direct payment is used for certain social activities e.g. attendance at football matches, or respite care to stay with relative abroad
- But there are many positive examples which demonstrate that SDS can and does work and enhances service users’ level of choice and control
- Successful implementation of SDS can reduce the need for social care interventions and can generate savings for the NHS too. It can also lead to better outcomes in terms of independent living, whereby people can contribute to society, have support to access learning and get a job and play key roles in their communities.
  - Consider the Christie Commission case study on preventative spending

SDS and independent living

- SDS can reinforce the objectives of the disabled people’s independent living movement
  - Independent living means “disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”.
  - Supporting independent living is a positive approach for everyone in society but there is limited understanding among the general public about what it means in practice
The Bill should state that SDS is intended to support independent living

- Direct link with human rights – not strong enough in Bill at present
  - SDS can provide people with the support they need to participate as full and equal members of society

**Barriers to accessing SDS**

- Information – people need to know about SDS before they can decide whether to access it. Part of this information should come from existing services users – considering a model of peer support
- Social work budgets – resource allocation systems, eligibility criteria, charging for social care generally and restrictions on funding
  - People were concerned that RAS’s reduced accountability of the LA to meet assessed need
  - Further concern that the SDS may not be cost neutral but it will deliver better outcomes for the individual and thus value for money
  - Concerns that in fiscal squeezing, social care must not be cut as disabled people will be consigned into poverty though lack of opportunities to participate
  - Charging is a huge barrier, particularly when a large proportion of disabled people currently live in poverty
  - There is a need for minimum entitlements in terms of what people can expect, and that these should apply nationally, to help mitigate against issues associated with portability of care
  - Strong feeling from disabled people that there needs to be a Commission on the Funding of Social Care in Scotland to address the wider issues of eligibility/charging/resource allocation

- Assessment process for SDS
- Cultural change – required from social work managers, staff and service users
- Training – social workers require more training to understand the principles of SDS and on the options available
- Peer support – service users need support mechanisms to help during transition

**Theory and practice of SDS**

- Concern about potential difference between what is written in legislation and guidance and what happens in practice:
  - The legislation and guidance on Direct Payments was excellent, but this was not necessarily what happened in practice.
  - What would be different with SDS Bill and associated guidance?

**Portability**
• Need for service users to be able to move to another area and be sure they will get equivalent levels of support. The package of support should move with them – a basic human right. More evidence of what is happening in practice is required.

Qualification for SDS

• Concerns raised about assessment process for SDS and that individuals who do not have critical needs, but lower level needs may not be able to access SDS.

Budgets

• To give people real choice and control means appropriate funding.
• Concerns raised about whether a person’s SDS package would be taken into account under the new welfare arrangements.
• There are more restrictions on how an individual can spend SDS money than other types of public money individuals receive -such as child benefit.
• Many local authorities charge for various social services. Suggestion that if charge is taken from an individual service user’s budget this could lead to a decrease in funding. This would affect the ability of the individual to achieve the level of service they need and therefore their quality of life.
• General consensus that charging for social care is a barrier to accessing it.

Health care

• Health services still can promote a very medicalised form of care, removed from independent living.
• Lack of awareness of SDS amongst healthcare professionals – role for GPs to promote it.
• Concerns about integration of health and social care and the effect it would have on independent living.
• Request to committee to consider how SDS and the integration of health and social care will work together.

Monitoring and evaluation

• Monitoring, evaluation and quality assurance of the implementation of the Bill is vital.
  o Monitoring must be meaningful – not just numbers of people receiving direct payments.
  o Need for local authorities to learn from each other about their experiences.
• Should be a user-led review of legislation once it comes into force to monitor the experience of service users.

Support for service users - Independent advocacy

• There is no mention in the Bill of independent advocacy.
• This is a fundamental requirement to allow all service users to have their voices heard and to support people to make decisions around SDS e.g. both processes and potential outcomes of it – without this, choice will be meaningless

• A right for service users to access independent advocacy must be included in the Bill

• Independent advocacy particularly important for those with a learning disability, as they may not feel comfortable in challenging the views of professionals or families

• Lack of availability of independent advocacy in rural areas

• Positive experiences of people using their local SDS unit for advice. Need for joint working between the unit, service user groups and carers.

• Suggested that potential for SDS unit, social work department or support work and PA advice to be biased as they will be keen for the service user to stay with them or their service

• Advice also available from voluntary organisations, such as centres for inclusive living. Some of these services may be provided under contract from a local authority. No suggestion they would not provide good advice, however it was felt perception also mattered

Black and Minority Ethnic community

• The BME community face potential barriers to access SDS including language and cultural issues

Rural areas

• Service users in remote rural areas may have little or no choice of providers

Experience from Glasgow

• Social work budgets cuts in Glasgow have resulted in restrictions to the potential of SDS
  
  o Success is dependent on the level of funding available
  
  o Some personal budgets have been cut by between 50-70 percent
  
  o Argument has been that re-assessment process is about “equity” and meeting current demand – but this has occurred within a fixed budget
    ▪ Acceptance that it is a political decision about whether to move money from other priorities

• Concerns raised that:
  
  o Social workers did not understand the context
  
  o Self-Assessment Questionnaire was not appropriate
  
  o Possible misinformation about what SDS can be used for – some options could not be funded from the individual budgets provided
  
  o Process was rushed for those with learning disabilities
• An appeal procedure was put in place – but shouldn’t care needs assessments be accurate in the first place?

**Direct payments**

• Direct payments should be sufficient to allow a service user to select an agency of choice to deliver care – not merely the lowest level of service

• If employing a Personal Assistant, the budget must be sufficient to meet statutory obligations as an employer e.g. 5.6 weeks annual leave (or the equivalent statutory minimum); appropriate training

**Other matters**

• A social care commission should be created in order to monitor services, portability, charging systems, eligibility.

• A commission to look at funding including eligibility, charging and budgets.

• Software should be developed to facilitate self-assessment

**In conclusion**

• “Grab this and go with it. Yes, there are barriers, but they can be broken down.”