Discussion between carers 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 carers, and should not be taken as being a verbatim note of the discussion.

General
- Principles and possibilities of SDS are huge
- Social workers are the professionals so they know best about what to offer, and even well informed individuals can easily fall into that thinking. SDS provides opportunity to “turn that on its head”
- Using direct payments enables services to be tailored to what is required but for carers it can be time consuming in additional to normal caring role
- SDS Bill has potential to build on what already exists, however, some concern that SDS may turn out be same as current practice, as changes in social work practice which are required may not occur.

Barriers to accessing SDS
- Lack of information on how to access SDS:
  - Including need for assessment and information on rights as soon as someone who requires community care is discharged from hospital
  - Need for health coordinator who liaises with carers centres on a person’s discharge from hospital
- Lack of training on how to use SDS:
  - Service users, carers and social workers have lack of knowledge and understanding of rights and entitlements to SDS
- Difficulties in accessing appropriate care – including sourcing carers who meet service users requirements including cultural needs or preference for male carers

Assessment process
- Self-Assessment Qualification (SAQ) for service users was felt to be inappropriate and not fit for purpose
- Assessment process for those needing community care services could be more robust – particular in Glasgow when people were reassessed
- Concern that social workers did not have knowledge and training required to undertake assessments – due to lack of knowledge of options available they can tend to rely on CareFirst package (as don’t have to think about cost etc.)
- Service users and carers not provided with sufficient information
• Carers organisations had begun providing advice as a result – example given of one occasion where a social worker had thanked carers organisation for being present to advise not only the carers, but the social worker as well

• Need to ensure same provision available to people across Scotland - variation between and within local authority areas of the use of SAQ

• Time it took for assessments was generally thought to be too long

• Questions and implications of the answers of SAQ not always clear to person completing it

• Not always appropriate support when SAQ was being completed

• Examples given of where process had not worked well:
  o Service user was asked if they could take their own medication, they ticked “yes” but in reality they were handed their medication to take, they did not physically prepare the medicine themselves. The answer they gave meant that they were assessed as being able to undertake the whole process. Therefore effecting the result of the assessment and possibly the resources provided.
  o An individual saying they were fine, when they were just coping with existing services, which resulted in less services being offered after the assessment

**Budget**

• Concern that SDS is a way of cutting budgets through the backdoor with personal budgets being cut following reassessment of needs

• More could be done with the budget to make services more personalised but only if it is based on the sum of resources dedicated to previous service provision

• Money is only part of the issue, it is about how resources are used, making sure they achieve quality of care provision

• More transparency needed about budgets and what can and can’t be done in the climate of budget cuts

• Advice and information was recognised as important, but needs to be clear that time and resources needed around advice should not eat into budgets/resources available for support

• Having an equivalent budget, such as through a Direct Payment, and, for example, using that to employ PAs did make a difference:
  o You were able to better respond to an individual’s needs and wishes – ultimately improving their quality of life
  o These options could be more response than, for example, a day centre
• Call for relaxation on exemptions so that family members could be PAs, particularly in circumstances where the individual service user had profound and complex needs

• Unfair that family carers don’t have access to financial support when they provide care

• Carer can take on a number of roles, none of which are recognised or supported - one carer delivered care directly for her son and also managed the team of PAs he used.

• Sometimes carers in this situation felt that PAs provided through agencies could not be flexible enough

• Concern about PAs being employed on a self-employed basis

Choice
• Choice an attractive aim of SDS process

• New assessment process could be a ‘Hobson’s choice’ – without a carer you got a higher budget than if you stayed at home

• Unpaid carers were being expected to pick up the shortfall in budget – carers giving thought to whether they should continue in role

• Concern that costs were being distributed from existing service users to new demand

Supporting carers
• Not everyone had been offered a carers assessment under current legislation – some told no point doing one because no services would be provided as a result

• Where there was a lack of assessment of carers needs and provision of support this could impact on their quality of life – example given of carer not being provided with training on how to correctly lift the person they were caring for resulting in physical injury

• Carers Assessment should be conducted at same time as service user is assessed

• Criticism that Carers Assessment where done were not:
  o Done enough
  o Not done well
  o Not reviewed

• Call for SDS Bill to include a duty to provide services following an assessment, rather than a discretionary power – concern that when unmet need identified it wasn’t then provided

• Carers could receive a direct payment in their own right under the Bill:
o Why does this require a separate budget? As this is an additional mechanism that they did not want to deal with

o Others wanted a separate budget and did not like the fact that it was linked to the service user budget

- Respite care in Glasgow comes out of the service users budget
- Inflexibility in respite care – service user had respite arranged but the service user was unwell when the time came for them to go to respite. It was not possible to rearrange it, respite lost and the budget along with it

Training
- Training significant issue – need to ensure that everyone knows that SDS is not just about filling in a form, that it offers a different way of deciding on care options – starting with social workers
- Training required for carers needed before SDS is implemented, then support required for them going through the process of care planning – including where required how to use individual budgets and knowledge of employment law.
- Training programmes have been developed and are used by carers. SPAEN – provide information on employee rights, tax etc.

Guardianship
- Carers often not aware that they need guardianship of person they are caring for before they can access SDS payments.

- Guardianship process can be lengthy

Other issues
- Need for independent advocacy
- Lack of forward planning when service user moves from children to adult services