1. Are you generally in favour of the Bill and its provisions?

Yes – We think that having a Self Directed Support Bill is a good step forward

2. What are your views on the principles proposed?

We think that these are good principles. They will be an important starting point for the development of self directed support in practice.

We do think that there should be a fourth principle that can strengthen the first three. “Openness and transparency” about the process should be added as a fourth principle so that collaboration and informed choice can take place.

For Self Directed Support to be truly collaborative, individuals taking part in it need to know information on the same levels as the other parties to the process.

A key part of the transparency that should be at the heart of the Self Directed Support are decisions over the use of resources. The use of a Resource Allocation System (RAS) is now common to give individuals an indication of what resources they will be able to use to meet their needs.

Local Authorities have become aware that R (Savva) v Royal Borough of Kensington & Chelsea made clear that the figure generated by the RAS should only be used as a starting point, which could be – and should be - altered to meet the appellant’s assessed needs.

However without openness and transparency over how this altering is done and how the individual can “collaborate” and be “involved” in the altering then “informed choice” will be severely limited.

We know of local authorities who use a RAS to deliver individual indicative budgets but have opaque systems for the subsequent adjustment of the budgets to meet actual needs. No one knows how much discretion in altering the budgets different social work officers have. No one knows how much power Resource Screening Groups have to increase or decrease indicative budgets. No one knows how Risk Enablement Panels arrive at their final decisions. Each such obscure decision undermines people’s faith in the process.

By adding such a fourth principle, we can expect people to have much more confidence with the process of Self Directed support

The second point we would like to make here is that for people to have confidence in these principles, it is important to know how the Scottish
government is going to keep an eye made sure that the principle parties stuck to them.

- Would they form part of the Single Outcome Agreement?
- Are they going to be measured some way?
- Would the Care Inspectorate (SWIA) use them in their inspection of local authorities?
- Is there going to be special reporting on this matter to the Scottish Government?
- Are they just decoration that was hung around the Bill to make it look more interesting?

3. What are your views on the four options for self-directed support proposed in the Bill?

We like the four options that are on offer for self directed support. Too often people are offered a council arranged service on a take it or leave it basis. It is really important that the council will now have a duty to offer all the 4 options.

It will be important to make sure people have all the options explained to them at the start so that they know what they can do.

To make this a real choice it will be important that the people had the help to make a choice. Many adults with learning disabilities need special types of support that can help them make real choices. We talk more about this in another answer.

We have found that there is already a lot of confusion over the different terms. Many professionals we have spoken to find the terms used to describe the four options easy to confuse with other terms. Many people with learning disabilities who we have spoken to have just got used to the phrase “direct payments” and don’t see the difference. As a result it will be important to stick to consistent language in the use of such terms.

4. Do you have any comment on the proposal that the self-directed support options should be made available to children and their families, together with the proposal that the degree of control a child may have over the process should vary with age?

These seem fine to us.

5. Are you satisfied with the provisions relating to the provision of information and advice, together with those concerning the support that should be offered to those who may have difficulty in making an informed decision?

We think the provision of good information is crucial to the success of the Self Directed Support process.
There need to be more consistency in providing information. We have members all over Scotland and they have reported that there is too much variation between local authorities. Already different forms of assessment, budgets, levels of payment, views on capacity and so on are in effect in different areas.

This position is likely to get worse as much of the emerging structure of the Self Directed Support will be unique to each of the 32 local authorities, if there is no change in current practice.

General Information should go back to the basic principles in the Bill as a good starting point and it is important that any information produced really takes on the principles of collaboration and informed choice.

Our members felt accessibility in information was important. Making sure that information is produced in Easy Read is important for everyone. Language should be simplified and the design features take into account the needs of those who find it hard to read written text for a variety of reasons. But Easy Read should also be tested for comprehension as some recent Easy Read documents meet the letter of making it simpler but then fail to cover the important points.

Good information may be enough for some active people but for some people with learning disabilities a more active form of support brokerage should be considered.

One other problem with information is that even the best information on available resources cannot make up for the lack of resources. We note that Centres For Independent Living are looking at how they can support people with learning disabilities and that some of the other “funded” projects will be doing the same. But there will be gaps both geographically and organisationally in the type and range of support on offer to people with learning disabilities and “information” cannot substitute for that.

There is a need to recognise the importance of independent advocacy given that many existing user of services will be in existing relationships with service providers. This makes it hard for people to consider alternative care options if it means changing of what they have at present. Having an independent advocate can support people having a real choice.

We think it is a weakness in the bill that it does not place a duty on local authorities to ensure that there is adequate resources provided to ensure that the three (four?) principles of the Bill are implemented in their area and then good information provided on these resources.

On the second part of this question, we do have some concerns over the question of support for people with learning disabilities within the Self Directed Support process.
At our consultation meeting we heard worries about who might support people who didn’t have family around to help. There were some suggestions that they might find that they ended up having a guardian.

We know that there is a real problem with this issue. Many people with learning disabilities in Glasgow have been put in guardianship as part of the SDS process.

The Office of the Public Guardian reports an increase of 67% in the numbers of guardianship orders in the year up to end of December 2011 in the Glasgow City Council area.

<table>
<thead>
<tr>
<th>Glasgow City</th>
<th>Financial</th>
<th>Welfare</th>
<th>Both</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>35</td>
<td>113</td>
<td>83</td>
<td>231</td>
</tr>
<tr>
<td>2009</td>
<td>24</td>
<td>113</td>
<td>78</td>
<td>215</td>
</tr>
<tr>
<td>2010</td>
<td>25</td>
<td>135</td>
<td>101</td>
<td>261</td>
</tr>
<tr>
<td>2011</td>
<td>38</td>
<td>148</td>
<td>201</td>
<td>387</td>
</tr>
</tbody>
</table>

The all Scotland increase has been of the order of 7% for each of the last 5 years. The table below shows that most of the applications for guardianship were not by the local authority but by private individual.

<table>
<thead>
<tr>
<th>For the year to Dec 31st 2011</th>
<th>Private guardianships granted 2010-11</th>
<th>Local authority guardianships granted 2010-11</th>
<th>All applications granted 2010-11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasgow City (learning disability only)</td>
<td>135</td>
<td>14</td>
<td>149</td>
</tr>
</tbody>
</table>

From families we have spoken to, we believe the rise in private individual applications can be linked to family members taking out guardianship to ensure they have a right to participate in the assessment and support plan processes of Glasgow’s Personalisation programme. Often this has been done at the suggestion of local authority staff.

Already we know of two cases where individuals are being supported to challenge their families taking guardianship out on their behalf. Many people with learning disabilities don’t like to challenge their families, so we have no real idea that all the guardianships that have been granted are benign.

The bill only proposes help for people in the choice of options and in the assessment process. It doesn’t offer support in the long term process of managing the budget and care. This means that there will some help for the start of the process but people might still end up in guardianship.

We think that for most people this will be a formal process but it is a worrying side effect of a process that is meant to empower people to take more control over their own lives.
We have heard that even where local authorities supported people to take up Direct Payment already there were problems with local authorities making sure people got the right help to manage these. Many people with learning disabilities who did have capacity to make a number of decisions over their own lives were being refused a Direct Payment unless there was a guardianship order in place.

As a result we are disappointed that the earlier proposal to allow a “suitable person” to be nominated and approved for the sole purpose of managing the Self Directed Support option was not progressed. We hope that the original proposal can be revisited as part of this consultation.

6. Are you satisfied that the method for modernising direct payments in the Bill will result in the change that the Government seeks?

We think it is right that local authorities should be empowered to allow the employment of close family members where this is the supported person’s and carer’s informed choice and where it is appropriate to do so.

But we are not sure about whether this will lead to real change. Much of the research and results from practical experience such as the test site work indicates that local authority internal barriers provide most of the difficulties in developing self directed support.

For example, much of the hold up in giving people direct payments is a concern by local authority staff that money may be diverted elsewhere or spent inappropriately. While there is evidence that only relatively small amounts go missing and there are much larger forms of waste in local authority spending, such attitudes are hard to overcome.

We suspect that similar problems may apply to the future employment of relatives. Even when the Scottish Government has empowered people to employ family members, local authority staff may be reluctant to grant approval for fear of misuse. As a result the Scottish Government’s plans for change may be hard to deliver.

7. Do you have any views on the provisions relating to adult carers?

Yes – we are very concerned that the current proposals will not see a material change for carers. There already exists opportunities for local authorities to carry out assessments on carers and to identify the needs that they have. This power has existed for some considerable time.

The provisions relating to adult carers seem to add little to the existing legislative position. Giving local authorities the power to meet the needs of carers assessed as part of the process of supporting the vulnerable adult is unlikely to lead to any automatic increase in resources going to meet carers needs directly or indirectly.
Many stories exist about the problems that carers face. For example, the last Cross Party Group for Carers heard from one family carer who had received her first Carers Assessment three years earlier. She had not received any services in her own right in this time.

Even the Financial Memorandum to the Bill expects little real change as a result of this proposal “It is reasonable to conclude that the volume of carer’s assessments in Scotland is not significantly lower than in England and would not be expected to rise substantially in response to the Bill.” (p28)

Our members have reported how life is very hard for carers and it took time to get an assessment and then not getting a real choice about the support. When they didn’t accept the first offer they were made, they might be told they were off the books. This is because local authorities have no obligation to provide services. As a result, they view the refusal as in indication that the carer is not really in need.

If the principle of collaboration is to be meaningful for carers, then the position of carers needs to improve by providing a legal duty on local authorities to meet their needs.

8. Do you agree with the approach taken by the Scottish Government not to place restrictions on who may be employed by an individual through the proposals in the Bill?

We think that there is merit in individuals being able to choose to employ family members to support themselves. For many people, family members are their chosen carers and the quality of support offered could be far better than that offered by a dispassionate or casual member of staff.

We know there are problems with the management of such relationships and it can be hard to exercise control of your own support when it gets confused with family relationships. This, of itself, is no reason to prevent such arrangements but it does require further thought on how this can be managed.

Monitoring through Adult Care and Support arrangement, or through a Care Manager or through a specialised financial and management support agency or the provision of independent advocacy are all possibilities. The arrangements for the monitoring of family members to provide support should be considered whenever permission is given for this arrangement.

We do think that there is the question of training is a key issue in who is employed. There is no nationally recognised qualification for personal assistants and no legal requirement for the personal assistants to be trained. Even where a personal assistant or a support worker is hired from and agency they are likely to be supplied with only basic on-the-job training in health and safety, food hygiene, moving and handling and so on.

For the “early adopters” who are motivated to make this process work this may be fine, because they have the capacity to direct and train support staff in
detail on the job. But for many others who arrive as Self Directed Support as the mainstream option or for those people with profound learning disabilities who do not have the capacity to direct their own staff, there is a high degree of vulnerability. Such individuals may not alert or be able to alert staff to inappropriate activities that they are inadvertently or otherwise carrying out that put people at risk.

The consequence of this can be fatal as recent cases may indicate.

Even where staff are formally trained in nursing or other tasks, this cannot be taken to assume that they individual knowledge of a person’s needs and the chosen balance between risk and safety.

For the management of risk for people with profound disabilities needs far more consideration than has been given to date. It cannot be assumed that these people’s needs are the same at that of other people with disabilities. The questions of capacity and communication make understanding their needs and their opportunities to challenge good and bad practice by support staff much more challenging than has been considered to date.

9. Do you have any views on the assumptions and calculations contained in the Financial Memorandum?

We are concerned about the comments in the Financial Memorandum on page 17 about the Alzheimer’s Scotland Direct Payment project from 6 people in Ayrshire. This is such a small number as to be statistically insignificant but more importantly it is not controlled by any comparison to alternative forms of non-Direct Payment provision other than residential care.

Such stories, and they are nothing more than this, have been common throughout the development of self directed support and have helped to contribute to an attitude that SDS can be linked to cost cutting without any adverse side effects. A number of local authorities are already building in percentage reductions in the care budgets to be met by the introduction of SDS e.g. Glasgow 20%, North Ayrshire 10%.

Such stories, instead of supporting a move to Self Directed Support, actually undermine it as many individuals become wary that SDS will see their care budgets cuts.

We also have concerns over the Transformation costs allocation of funding for local authorities. £24 million is to be granted over 3 years, peaking in year 2 and then declining. The evidence from the test sites project run by the Scottish Government was of a much slower scale development over the 2-3 years that it ran for.

Only a small number of people in each local authority, in the order of 50-100 were enabled to take up Self Directed Support options despite funding of ½ million per year being made available to each local authority. The amount
proposed is less than this if the £24 million is split evenly between local authorities.

As a result we believe the expectations of this policy and bill need to be clearly stated as significantly less than full scale transformation or the amount of funding made available to support the change process needs to be increased.

We think it is a mistake for the Financial Memorandum not to look at what will happen with the Independent Living Fund. The existence of the ILF has been important in supporting the move towards SDS. For individuals managing this contribution to their care has helped them become more confident in managing the local authority contribution in Direct Payments. 

The ILF is closed for new applications but the latest statement on the Independent Living Fund has guaranteed a degree of security to it for the remainder of this session of the Westminster parliament. That is expected to be 2015. In Scotland in 2009 ILF spent £60 million.

A long term proposal to transfer the ILF funds to local authorities may be put out for consultation shortly. This will be aimed at the English proportion of the fund but will have implications for Scotland. For Scotland the fund is likely to be transferred to the Scottish Government to manage, who would then be able to decide the appropriate placing within a Scottish context. They may be able to choose to transfer it to local authorities or not.

We have a number of real concerns over such a transfer to local authorities

- The value of additional funding may be lost amongst the much bigger pot of social care spending
- There is no statutory right to “independent living” so the money will be directed towards basic care needs.
- There may be reductions in the level of support enjoyed by recipients as there will no longer be a necessity for a minimum care package to be in place for ILF eligibility.
- The ILF money may eventually be lost entirely to the social care budget as it may not be ringfenced.

Our view is that the Independent Living Fund should continue to exist as a ringfenced fund managed by the Scottish Government and use its resources to complement local authority spending on social care services. The ILF is a relatively small contribution to social care. In 2009 local authorities spent £840 million on social care for people with learning or physical disabilities – 14 times as much as the £60 million contributed by the ILF.

Its funds would be better used to support people who already received a social work service but were in need of further support to improve their quality of life. Funds could be allocated following assessment by ILF assessors to meet quality of life outcomes, perhaps guided by the Talking Points model.
This would mean that where people were having their basic needs met by the local authority, they could apply to get additional help from the Independent Living Fund to

- Live safely and securely in their own home
- Have meaningful things to do in their lives
- Make, keep and sustain friendships
- Keep in good health and well being.

Applications to the new ILF could and should also be available to those who fall out with the eligibility criteria for social care services i.e. their needs are classed as less than critical or substantial. Such people at moderate “risk” can also have a high level of needs but because their families are coping at home, the local authority does not see them as a priority. They often only need a small input of care to prevent their needs rising and failure to get this may see themselves presenting to the social work departments again with a greater level of needs. The ILF could provide a small degree of funding to these people on the same basis of outcomes in order to help them live sustainable independent lives.

In a sense this would return the Independent Living Fund to a clear purpose a fund to provide more flexibility and money for the individual in organising their support to live independently in the community.

Nonetheless these changes to the ILF impact on the future of the Self Directed Support Bill and need to be taken into account.

10. Are you satisfied in the assessments that have taken place in regard to these matters and in the conclusions reached by the Scottish Government?

We have some concerns over the evidence used in the Equality Impact Assessment to look at the impact of the policy on people with disability generally and in particular people with learning disability.

The IBSEN report and the Scottish Government 2008 review of Direct Payments are early works looking at the introduction of new systems. Many of the points in the reports were qualified and cannot be taken as a clear indication of what might happen in the future. They are clear stories about what has happened in the past and as far as we are aware no one has questioned the validity of what they found.

Two main types of problems have been noted with this type of review. First most of the individuals looked at in the studies were “early adopters”. Individuals highly motivated to take more control over their own lives or who were seeking to find a new system to resolve problems that had emerged in their lives. This motivation leads “early adopters” to be more active in the management of their own care and support and will lead to these enjoying an enhanced lifestyle with better outcomes. The experience of “early adopters”
cannot be assumed to be continued in the mainstreaming of Self Directed Support.

Secondly many of the early pilot projects looked at in IBSEN and even the Scottish Government’s test sites enjoyed an initial funding boost to support the projects. This brought in extra staff to manage budgets, allowed for additional project support in person centred planning and more time generally to be spend preparing and supporting the individuals taking part. Given that we are in a time of restricted resources, there will not be such additional funding for the mainstreaming of Self Directed Support.

This does not mean that the conclusion reached in the Equality Impact Assessment is necessarily wrong but it is too early to be sure. Some of the evidence that is emerging from the implementation of Self Directed Support in Glasgow is that some of tools that are being used to assess needs and allocate resource are not properly tuned to the needs of people with more profound disabilities leading to a large number of appeals. Some of those whose appeals are unsuccessful or are not supported to appeal may be having to manage with inadequate resources to meet their needs.

This may arise because of the wrong processes or poorly applied processes. No research has been carried out on such causes but it is also possible that the problem occurs because the local authority believed that as Self Directed Support was more “equal” and “fairer” there would be no equality issues to concern it.

We think that the needs of people with more profound disabilities is poorly understood in the context of self directed support. Even when family carers are closely involved in planning the care of the individual, they will rarely be present when support is actually being delivered. As we indicated above, training may not be adequate but even where it is, there is a question over the “capacity for good judgement” in support staff.

Where Self Directed support is linked to reduction in spending, casual staff, staff on zero hour contracts may be asked to step in at the last minute to provide support for people whose needs they do not fully understand. The safe use of hoists and changing facilities, gastronomy feeding or even the safe use of wheelchairs may be unfamiliar to such staff and real dangers to people may emerge.

Equality Impacts Assessments need to look at what the likely outcomes of such legislation might be and how such risks should be handled. It may mean statutory duties placed on local authorities to have Risk Enablement Panels, it may mean a further role for Adult Protection Committees. These are issues that need to be considered seriously.

We think that this matter requires continuous examination. An equality impact assessment is a continuous process and not a single action. It is important that the Scottish Government continues to review the equality impacts of this policy. We believe this will involve ensuring that local authorities and health
boards monitor the impacts of the implementation of the policy on the ground and feed these back to the Scottish Government.

We think that advice issued by the Department of Health and ADASS in England to local councils on their duties to carry out EIAs as they implement the national policy is worth bearing in mind.

Advice on local equalities impact assessments

- Councils should make sure that they have carried out an overall equalities impact assessment relating to social care transformation, which includes in its scope the introduction of self-directed support. This will therefore include resource allocation.

- Councils should consider how they will monitor the impact of the policy on all six equalities groups. This is likely to include collecting data on uptake of self-directed support and outcomes for the six groups.

- Councils should consider the advice in the equalities section of this common resource allocation framework, in particular the need to apply the same approach to identifying needs to all groups.


11. Do you have any comments on any other provisions contained in the Bill that you wish to raise with the Committee?

No.

Learning Disability Alliance Scotland
24 April 2012