Social Care (Self-Directed Support) (Scotland) Bill

Inclusion Scotland

1. Views on the Bill as a whole

Inclusion Scotland welcomes the opportunity to give evidence to the Health and Sports Committee and we submit the following comments and recommendations on behalf of our members, who have been consulted on the draft Social Care (Scotland) SDS bill (2011). We have worked in co-operation with Independent Living in Scotland (ILiS) Project¹ and its other steering group members to flag up our key issues with the bill. Our DPO members have been working hard to identify disabled people’s views on SDS, and some of our members have had opportunities to attend meetings and share these.² We have also identified those expressed in others’ consultations and in research.³

Recommendations are highlighted in bold.

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

1.1 Inclusion Scotland is generally in favour of the Bill and its provisions. The bill is necessary to achieve choice and control for disabled people within legislation, and we therefore support its intention and aims.

1.2 The Government needs to fully engage with: Local Authorities via COSLA, disabled people and their organisations, local voluntary organisations, people already using DP’s, advocacy organisations, and the independent living movement; to ensure the provisions of the bill are fully understood by all and that publications and guidance to support people can be co-produced with the people that will benefit from them. This would resolve the current experience of SDS being ‘publicised insufficiently’ (p. 6, Manthorpe et al. 2011⁴).

1.3 There should be further allowance throughout for independent advocacy, in addition to advice and information, as this is an essential requirement for the majority of disabled people making life changing decisions. The inclusion of independent advocacy will safeguard the disabled person from abuse, financial or otherwise, or biased decision making,⁵ as informal and formal

¹ Inclusion Scotland has membership of the Independent Living in Scotland (ILiS) Project steering group, and are now hosting the ILiS project.
² Inclusion Scotland listened to some of the concerns of members of Glasgow Disability Alliance at the organisation’s “Self-Directed Support: The Road to Discovery” information and engagement event for + 350 of GDA’s members, held in Glasgow in April 2012.
³ For example, Rummery, Kirstein, and David Bell, Alison Bowes, Alison Dawso and Elizabeth Roberts 2012 ‘Counting the Cost of Choice and Control Evidence for the costs of self-directed support in Scotland’ University of Stirling, for the Scottish Government, SRR Findings No. 110/2012 http://www.scotland.gov.uk/Resource/0038/00388620.pdf
⁵ Please see also the Scottish Independent Advocacy Alliance submission to this evidence collection, and go here http://www.siaa.org.uk/ for further information.
carers alike may have vested interests in the option/s chosen by the individual.

2. General principles underlying the Bill

What are your views on the principles proposed?

2.1 We welcome the principles underlying the bill set out in Section 1, as they clarify for disabled people and professionals alike their expectations in terms of assessment and provision of SDS.

2.2 In order to encompass an independent and human rights based agenda, we **recommend that the Scottish Government incorporate the independent living principles** proposed in the ILiS project evidence submission, those of: *freedom, choice, dignity, control, improving outcomes for individuals, mutuality, equality, portability, and accountability*, in order to achieve the highest possible standards of support for disabled people to live independently and within their community.\(^6\)

2.3 We support the widening access to SDS that the bill provides as this is a measure that may improve implementation of the culture change that is required to make independent living a reality, ensure flexibility and choice; and ultimately ensure the success of SDS. In order to gauge the success of this aim, we therefore support the ILiS **recommendation that ‘in addition to LA’s ‘promoting’ SDS, at section 17, the Bill places a duty on them to identify potential SDS users, and also to monitor and record how they do this, and how many people this ‘attracts’’.**\(^7\)

2.4 If SDS is to be used to allow someone to become an employer, then it should resource and empower them to meet their responsibilities as an employer, both during the time when their personal and social needs are being met and directly thereafter. This has also been recommended within the Scottish Government’s commissioned study into the barriers and facilitators of SDS (Manthorpe, et al. 2011\(^8\)) which examined the experiences of SDS users in 3 LA pilot rollouts.

2.5 **There should therefore be provision within the bill for allocation of resources to individuals to cover incidental and consequential costs in use of DP’s: for example, training, sickness, holiday and redundancy payment for support staff.** This will ensure that disabled people are not left with inadequate hours or quality of support because they are covering these additional costs that they would not incur if they chose another option,\(^9\) and nor will the family of a person be left to cover these extra costs after the death of the person in receipt of the direct payments, as can currently be the experience.\(^10\)

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\(^6\) ILiS Project [http://www.ilis.co.uk/independent-living/](http://www.ilis.co.uk/independent-living/)

\(^7\) Point 2.3, p. 3 of ILiS’ submission to the same inquiry, April 2012.

\(^8\) Ibid, ‘Facilitation’, point 5.4, available here: [http://www.scotland.gov.uk/Publications/2011/03/30091835/5](http://www.scotland.gov.uk/Publications/2011/03/30091835/5)


\(^10\) Communication from an IS member to whom this has recently happened.
2.6 Timely implementation, at the same time conducted with attention to detail, and in co-production with disabled people and their advocates, will ensure people are not left waiting to receive the kind of support they want or need.

2.7 This has not been the experience for some who have been through this process in LA’s where SDS has already been rolled out to service users:

‘Glasgow City Council rushed through their charging policy, they didn’t give people enough notice of this or information about what was happening. I had two weeks’ notice of this change, it was a real bolt from the blue. This made me upset and stressed because I had already made plans about how I could spend my money. These plans were for a couple of months in the future and included visiting my family in London and going on holiday. I am now in debt and will be for the next few months’

Having to pay charges means I have less money to do things in the community. This is going to leave people stuck at home more than they are used to and will not be good for their health’ (Idem Lewis).11

2.8 Currently some people in receipt of SDS in parts of Scotland are unhappy with the experience because during or after transition to SDS, the amount of money the person receives has been cut. This leads some to think that SDS is merely a ticket to less support. **We hope the Government and CoSLA will find a way to safeguard against such consequences, to ensure that people are able to access the support they choose, with the appropriate amount of resources allocated to do so. This needs to be included in the bill.**

3. Options for self-directed support

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

3.1 We welcome the four options for self-directed support proposed.

3.2 In order to ensure successful delivery of these options, we recommend that the regulations underpinning specific circumstances around delivery of each are broad enough to ensure they enable widening and simplification of access to and flexibility of use of the options. And therefore we further recommend that these are coproduced with disabled people, their organisations and their carers throughout Scotland.12

3.3 Clarity is also needed around flexibility of reviewing options, so that people are aware that they can change their chosen option if and when they wish to.

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11 People First member, Glasgow.
12 IS members can help facilitate this. IS are already working with ILiS and other steering group members to gather evidence from disabled people, and we are planning future information and engagement events in alliance with our partner and member organisations. We further draw the Committee’s attention to Glasgow Disability Alliance’s SDS Road to discovery workshop report when it is published, here: [http://www.gdaonline.co.uk/index.php](http://www.gdaonline.co.uk/index.php).
3.4 Statutory guidance explaining the options and how they might be used, and guidance on all the bill’s principles and provisions, should be: easy to follow, in accessible formats, co-produced with disabled people, and readily available in all local authority areas following publication of the bill.

3.5 Proposed timescales should be publicised which show when the options will be presented to disabled people and to their carers, so that no matter in which LA they live in, they will have the options offered by a certain date, assurances for a smooth transition to receipt of their choices, and will not face a possible ‘postcode lottery’ of delays.

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?

4.1 We agree that the SDS options should be made available to children and their families in order to enable families the same flexibility, choice and control regarding support for disabled children as disabled adults.

4.2 In addition to the degree of control accounting for age, which we agree with, we think the maturity of the child should also be accounted for. Most children will be able to understand and express their choice, and this should also be reflected in the bill.

4.3 Should the child lack capacity to make a decision, it might be that a family member, guardian or carer needs to make a decision on their behalf in the best interests of the child.13

4.4 As with disabled adults, it is important that there is a role for independent advocacy both for disabled children and their parents and carers. Clear guidance and communication support should be made available for all children in order that they can have support to express their opinions. The services of a local independent advocate should be offered to a child so they may benefit from experienced and unbiased advice and information.

4.5 This will also aid in identifying fully the additional mix of care and support that may suit the child and its family best, providing authorities and others involved with truly person-centred and co-produced information.

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?

5.1 No. We would like to see more provision throughout the bill for support and advocacy for anyone who needs it. We think that the provision of this should be a default position and there should be a duty on LA’s, at appropriate sections within the Bill, to refer people to such support.

13 We would refer the Committee to the Children’s organisations’ evidence regarding regulations in additional existing legislation that might apply within this bill.
5.2 This should apply not just to making the decision, but also when managing the option chosen, which may cause significant challenges for the individual. For many, the extent of impairment may have little impact on capacity to manage the implications of a choice. For example, someone who has always led a relatively independent life with a support package and who may have a high level of capacity for decision making may still have no experience whatsoever in being an employer, nor knowledge of the risks and opportunities that this may present. For this reason, the link between advocacy and support and capacity is arbitrary and support should be offered on the basis outlined above (5.1).

5.3 This is a particular concern as the experience of implementation of a choice will vary considerably from person to person due to the individualistic nature of the policy and of needs and ambitions of the disabled person. The challenges that it presents will be equally varied.

5.4 The importance of such advocacy and assistance in choice and control over SDS was highlighted by Idem Lewis, a service user in Glasgow who is a member of People First Scotland:

'It is really important that people get the right independent support when planning their SDS. Asking someone what support they want is very difficult to answer, when they have always been told what support will and will not do. There needs to be time spent preparing, thinking it through, before people will be able to make informed choices. This independent support should be on-going'.

Without the support I got from People First, which really allowed me to calm down when I was really upset, I worry that I could have become unwell. I worry about how other people will cope in similar circumstances if they can’t access good advocacy and independent support'.

6. Direct payments

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

6.1 Inclusion Scotland hope that the bill and its provisions secure a culture change where SDS is offered widely and provides the choice, control, freedom and dignity that we seek as disabled people. For this reason, the regulations and guidance within the bill need to aim to do this. There are several areas that should be addressed within the bill before we believe it can realistically achieve this:

6.2 The aims of the bill should be to achieve equality of access, as mentioned above, and therefore should address the rising eligibility criteria for social care, with its regional variations – and which restricts access to social service care for many disabled people - need to be addressed so that more people are eligible for SDS at the point of need rather than at the point of crisis.

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14 For more information on People First Scotland, please visit http://www.uoa7.net/peoplefirst/
6.3 Care charges, which we see as a tax on disability, limit options that disabled people have as they find that much of their income is spent on personal care. By reducing their incomes and limiting options, care charging may limit the potential that this bill has for increasing the choice, control, freedom and dignity that we wish to see happening with implementation.

6.4 The following points are contained within the ILiS submission, and we fully promote them:

- ‘Article 14 of the European Convention on Human Rights states that, “The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination”. Article 19 of the UNCRPD highlights that in order to ensure disabled people equally enjoy the rights laid out in the ECHR; states must ensure that “disabled people have a right to live in the community; with the support they need and can make choices like other people do”. One of the things states must do, put simply, is to make sure that disabled people get the help they need to live in the community. Paying for equal enjoyment of human rights in this way is specifically unique to the experience of disabled people who use community care; there is no other sector in society which is charged to enjoy human rights. We therefore believe that any such charge discriminates against disabled people in their access to the support they need to enjoy their rights and freedoms under all such regulations and conventions.

- …‘Community care is essential for the equal enjoyment of human rights of disabled people … and so systematic barriers to accessing it have implications for enjoyment of them. As the policy memorandum points out, SDS advances human rights in terms of delivery of care, however, if barriers to accessing it, such as charging for it, are not addressed, it can never achieve this aspiration.

- It is therefore our view that ‘charging for community care services is a significant barrier to independent living and that it should be free at point of delivery, as health services are’ (pp. 8-9, ILiS submission).

6.5 We therefore recommend that these concerns are reflected in provision of health and social care that is offered through the regulations in this bill, with a clear commitment and plan to achieve this. This means the Government, CoSLA, LA’s and regional health services should work together to ensure a realistic vision of this is included in it.

7. Adult carers

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

7.1 Inclusion Scotland also supports the following recommendations made by ILiS\textsuperscript{16} in this same evidence collection. That:

- ‘Starting from the premise that unpaid carers can benefit indirectly when the person they care for has greater choice and control over their support, we

\textsuperscript{16}Points 5.1-5.3, p. 10.
believe that, where possible, the LA should seek to offer support to the service user.

- ‘Where informal care is the express choice of the disabled person or other SDS users, we recommend that the disabled person or other SDS user receive SDS directly to meet the needs that arise from the informal carer’s role (other than in cases where the individual is considered not to have capacity). We continue to believe this is a much more empowering method of supporting informal carers.

- ‘...Any move to offer support to unpaid carers directly must be supported by a separate system of assessment and a ring fenced budget for this provision, so that provision of support to a user doesn’t impact on the funding available to the carer and vice versa’.

8. Inclusion Scotland wish to thank the Scottish Parliament’s Health and Sports Committee for inviting comments on the SDS bill, and we look forward to assisting the Scottish Government and CoSLA in further co-producing their approach to providing genuine choice, control, freedom and dignity to disabled people and their carers in Scotland.

Inclusion Scotland
24 April 2012