Social Care (Self-directed Support) Scotland Bill

Independent Living in Scotland

**Recommendation 1:** in addition to LA’s ‘promoting’ SDS, at section 17, the Bill should place a duty on them to identify potential SDS users and monitor and record how they do this.

**Recommendation 2:** regulations underpinning specific circumstances around delivery of each option, are drawn broadly enough to ensure they enable the widening and simplification of access intended.

**Recommendation 3:** to help facilitate this, the regulations should be coproduced with disabled people, their organisations, other user led groups and carers.

**Recommendation 4:** the duty to “give effect to” the option chosen be aligned in the Bill to the timescales within the National Eligibility Framework.

**Recommendation 5:** the principles and framework supporting the options in the Bill, are underpinned by a comprehensive system of support for disabled people and other service users.

**Recommendation 6:** an amended set of principles, underpinned by a “statement of intent” that recognises the role of SDS in promoting and preserving human rights and independent living, should be developed to include: Freedom, choice, dignity, control, better outcomes for individuals, mutuality, equality & portability.

**Recommendation 7:** any involvement in SDS, from assessment to provision, is underpinned by a legislative right to support and advocacy for it.

**Recommendation 8:** that the Bill be clearer and stronger on the role of advocacy, peer support and support organisations; especially Disabled People’s Organisations, including on where they sit in terms of the overall framework for SDS and on the LA’s duties to engage them. Specifically, we would like to see the addition of duties on LA’s to refer people to such support organisations at sections 2(3), 5 and 8 of the Bill.

**Recommendation 9:** gateways to accessing support from the LA and therefore SDS, are considered within the Bill.

**Recommendation 10:** charging for community care services is a significant barrier to independent living and so it should be free at point of delivery.

**Recommendation 11:** provisions to charge carers be removed. Instead the Bill should be seen as an opportunity to address some of the issues in relation to the powers on LA’s to charge, under section 87 of the 1968 act.

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1 “It’s our world too”; ILiS, 2010
Recommendation 12: a Commission on the Funding of Social Care in Scotland be set up

Recommendation 13: that the disabled person or other SDS user receive SDS directly to meet the needs that arise from the informal carer’s role

1. Independent living in Scotland

The Independent Living in Scotland project

1.1. The Independent Living in Scotland project (www.ilis.co.uk) is funded by the Scottish Government, hosted by Inclusion Scotland and steered by a group of disabled people. It is part of the wider Scottish Government initiative on independent living. The Scottish Government’s commitment to independent living is set out in the “Vision for Independent Living” (http://www.ilis.co.uk/independent-living/a-vision-for-independent-living-in-scotland/). It aims to support disabled people in Scotland to have their voices heard and to build the disabled people’s Independent Living Movement (ILM)².

Independent living

1.2. 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”. With such support, disabled people can exercise their rights and duties of citizenship via their full and equal participation in the civic and economic life of Scotland – thereby changing the public misperception of them as being a drain on society’s resources rather than an active contributor.

1.3. The principles of independent living, freedom, choice, dignity and control, do not only relate to specific services and provisions for disabled people, but to the whole of disabled people’s interactions with society; its organisations, facilities and structures; and every aspect of their quality and equality of life³: These principles are underpinned by the following basic rights.

- Full access to our environment
- Fully accessible transport
- Technical aids and equipment
- Accessible and adapted housing
- Personal assistance
- Inclusive education and training

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² http://www.ilis.co.uk/
• An income, including income within the state-benefit system for those unable to work
• Equal opportunities for employment
• Accessible and readily available information
• Advocacy and working towards self-advocacy
• Counselling, including peer counselling
• Accessible and inclusive healthcare provision
• Communication and appropriate support for communication
• Civic participation

1.4. For some disabled people SDS is an essential link in the chain of rights needed to ensure they are free to live their life in the way they choose, to be in control of it and to do this with dignity.

2. The Bill

2.1. A drive to entrench disabled people and other community care users as people with equal rights and as equal citizens in the delivery of social care, is not only morally, but legally and financially just. We therefore support the intention and aims of the Bill. Furthermore, in line with the principles of independent living, we further support the intentions of the Bill to provide people with choice and control over their support and to increase uptake of DP’s as one mechanism of doing this.

2.2. We also support the aim of the Bill in widening access to SDS overall. However, would recommend that, in addition to LA’s ‘promoting’ SDS, at section 17, the Bill places a duty on them to identify potential SDS users and monitor and record how they do this and how many people it ‘attracts’.

Provisions in the Bill

2.3. We welcome the suite of options for support offered in the Bill. However, we are clear that the strength of their success lies in the proposed regulations on conditions of their payment, who can access them and in what circumstances. For this reason, we recommend that the regulations underpinning specifics circumstances around delivery of each option, are drawn broadly enough to ensure they enable the widening and simplification of access intended. We further recommend to help facilitate this, that they be coproduced with disabled people, their organisations, other user led groups and carers.

2.4. We also welcome the duty to give effect at section 9, to the choice of options at section 3. However, we note that currently, many LA’s operate waiting lists for provision such as Direct Payments. In order to meet current eligibility criteria timescales, people are often offered traditional forms of support, until Direct Payments ‘become available’. To this end, we continue to recommend that the duty to “give effect
to” the option chosen be aligned in the Bill to the timescales within the National Eligibility Framework.

Principles of the Bill

2.5. The principles are a crucial and welcome addition to the Bill. The nature of SDS is such that few circumstances around its delivery will be the same. For this reason, principles underpinning decisions around it are essential to set out the ways in which professionals and individuals should operate, within the levels of discretion needed.

2.6. We welcome a focus on involvement, assistance and collaboration and particularly that these principles extend to assessment and provision, we recommend that the principles and framework supporting the options in the Bill, are underpinned by a comprehensive system of support for disabled people and other service users, we will return to this in the next section.

2.7. Whilst we welcome the existing principles, we still feel they are too focussed on process and imply that SDS is an end itself. This does not account for the wider independent living context in which SDS plays a part (section 1 above).

2.8. The SDS Bill offers a once in a lifetime opportunity not only to ensure disabled people and other community care users have the principles of choice and control over their community care enshrined in law, but so too for Scotland to lead the way and set down in domestic law, the intention to support independent living and disabled people’s right to participate in society and live an ordinary life.

2.9. The Joint Committee on Human Rights report, published in March 2012, recognised that the current framework of legislation supporting independent living was insufficient to protect the rights to it, set out in the UNCRPD4. One of their recommendations to do this, is to ensure that upcoming legislation on social care has independent living as an outcome of it.

2.10. To support this and seize the opportunity the Bill presents for Scotland, we continue to believe in and recommend an amended set of principles, underpinned by a “statement of intent” could address this. We suggest the following text for the statement of intent could sit under an amended version of the current preamble to the Bill so that it would read:

“An Act of the Scottish Parliament to enable local authorities to provide support to disabled people, other community care users and carers; to make provision about the way in which social care

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4 JCHR; “Implementation of the right of disabled people to independent living: 23 annual report 2010/12”; 2012
services are provided by local authorities; and for connected purposes.

SDS is one type of provision society makes, among several, which underpins disabled people’s right to independent living. Together with the other rights of independent living, it is intended that SDS, through this Bill, will empower those using self-directed support, to lead independent lives, to have the same freedom, choice, dignity and control as other citizens at home, at work, and in the community, so that they may participate in society and live an ordinary life”

2.11. Underpinning this and in keeping with a human rights based approach to policy making and service delivery, we recommend an amended set of principles, that include: Freedom, choice, dignity, control, better outcomes for individuals, mutuality, equality' portability and accountability. Detailed descriptions of these principles can be found in our submission to the Scottish Government’s proposal on a SDS Bill, in July 2010, at sections 5.7 – 5.15.

2.12. It is our belief that without such principles, not only are we missing an opportunity on which to build on the rights of disabled people and other service users, but that the basic underlying intentions of SDS; control and choice, citizenship, equality; cannot be truly realised.

3. Support, assistance and information

3.1. SDS is not only a relatively new concept to professionals and disabled people and other users alike, but has the potential to change a person’s life for the better. However, as with anything new, people often need support to make decisions on it and for various reasons, including their well documented discrimination and oppression⁵, disabled people, sometimes need targeted support to do this. This support is not just with decisions relating to the mechanisms of SDS, but so too on the decisions associated with the potential life change SDS carries with it. The statistic that; by age 26, young disabled people are more than three times as likely as other young people to agree with the statement “whatever I do has no real effect on what happens to me” reflects the frustrated aspiration experienced by disabled people and the challenge in raising the consciousness of disabled people.

3.2. For this reason, we welcome the focus on support and information at sections 5 and 8. However, we feel, specifically since choice is the

default option, that in order to ensure the potential of SDS is fully realised for the individual and so too society at large, any involvement in SDS, from assessment to provision, must be underpinned by a legislative right to support and advocacy for it. The provisions currently offer support with decisions on SDS at various sections, however, these are offered mainly on the basis of individual capacity (section 5(1b)), are open to discretion on the grounds of what one person deems ‘reasonable’ (section 2(3)) and are not underpinned by a duty to signpost to advocacy and support at key points in the framework.

3.3. Specifically, section 2(3), recognises that people may need assistance with decisions. However, the assistance provided is only to be what is “reasonably required”. In light of the complex issues outlined above in terms of frustrated aspiration, coupled with the dominant assumption that someone with capacity is unlikely to need support, the term ‘reasonably’ in this context is problematic.

3.4. Furthermore, the link between the need for support and capacity issues means that generic support to manage SDS is not in the Bill. We would argue that depending on the SDS option chosen and degree of control that it demands, an individual may need support to manage and may initially appear unable to do so. It should not be assumed that because someone does not appear to know about or manage provision under a particular option e.g. how to be an employer, that they cannot manage that option. The role of generic support and training is crucial here. If support were by default, as suggested above, people could access it to varying degrees.

3.5. In practise, as well as having implications for the decision making process as outlined above, the Bill also leave unclear, similar provisions for Guardians, those with Power of Attorney or parents (sections 5(2a & b) & 7 in the Bill); all of whom may also need support to make informed choice around such fundamental life changing options.

3.6. To address these issues, we continue to recommend that the Bill be clearer and stronger on the role of advocacy, peer support and support organisations; especially Disabled People’s Organisations⁶, including on where they sit in terms of the overall framework for SDS and on the LA’s duties to engage them. Specifically, we would like to see the addition of duties on LA’s to refer people to such support organisations at sections 2(3), 5 and 8 of the Bill.

3.7. We feel this will ensure a clear legislative link between how the principles of the Bill are supported in practice. It will also ensure that

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⁶ “It’s our world too”; ILiS, 2010
the ability to make informed choice and to manage its provision is
underpinned by a secured framework of support to do so.

4. Gateways to and charging for provision

4.1 Whilst we recognise that SDS is a mechanism of support rather than a
fundamental change in provision duties of LA’s, we believe that to
monopolise on the potential it offers for equality and human rights, the
gateways to accessing support from the LA and therefore SDS,
must be considered within the Bill. Without this focus, SDS will
remain an unmet aspiration, accessed by the few.

4.2 Rising eligibility criteria is seeing many disabled people excluded from
access to social work services. This not only creates critical demand in
the system at a later stage but, prevents many disabled people and
users of community care from accessing SDS and so too in many
cases, as the JCHR report highlights with some concern, enjoyment of
their basic human rights. Addressing this then, is not only needed to
ensure Scotland gets the most out of SDS, but also for compliance with
the UK’s human rights obligations under the UNCRPD.

4.3 In addition, disabled people are faced with impossible choices between
paying for essential costs such as food and heating, or paying
community care charges. The result is hardship and in some cases a
decision to stop paying for all or part of the community care, thus
effectively surrendering it. People are left with unmet needs that
threaten their enjoyment of human rights and inevitably their access to
SDS

4.4 Disabled people have said of community care charges: “What you’re
buying with your charge is a human right, and I don’t believe that
anyone in our society should have to pay for a human right. No-
one else pays to go to the toilet or to get out of bed in the
morning.” Recent published opinion has referred to community care
charges as a ‘tax on disability’; a ‘tax on economic and social
opportunity’; a ‘tax on participation and citizenship’ and a
‘financial penalty directly related to impairment and the need to
use services’; therefore institutional discrimination of the highest
order.

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7 JCHR; “Implementation of the right of disabled people to independent living: 23 annual
report 2010/12”; 2012
8 Elder Woodward; “The Ethics of Charging”, 2011
9 Learning Disability Alliance Scotland; “Alliance News, Making Sure Your Voices are Heard:
The Hidden Tax on Care”, 2011
10 Clark, L (2006) “A comparative study on the effects of community care charging policies for
personal assistance users”, MA dissertation, University of Leeds
(http://www.leeds.ac.uk/disability-studies/archiveuk/Clark,%20Laurence/A%20comparative%20study%20on%20the%20effects
%20of%20community%20care%20charging.pdf)
4.5 When the extra costs of being disabled are taken into account, 47.5% of households including a disabled person live in poverty\textsuperscript{11}: 50% of disabled people of working age are in work, compared with 80% of non disabled people of working age\textsuperscript{12}: and of the £18bn in benefit cuts proposed as part of Welfare Reform, a disproportionate amount will fall on disabled people\textsuperscript{13}. Disabled people therefore already live in poverty. They face a double disadvantage when it comes to public cuts; once in their pocket and again in their services. They are also disproportionately affected by them\textsuperscript{14}. Disabled people cannot afford to bridge the gap between demand for public sector resources and supply of them.

4.6 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 is, put simply, 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.

4.7 At a CoSLA Community Care Charging Listening Event (August 2011), Mike Brown, Convenor of the Association of Directors of Social Work’s Resources Standing Committee, presented a handout which showed that local authority income from charges for social care services in the fiscal year 2009-10 was £228m. Of this, £225m came from charges for community care. Income for ‘non residential services’ amounted to £42.6m; only 3% of the £3.6b gross expenditure on social care in Scotland\textsuperscript{15}. Yet, as Laurence Clark points out\textsuperscript{16}, for the individual disabled person, community care charges can amount to over 70% of their weekly income. In addition, as the Audit Commission in England reported in 2000 that between 20-40% of income from charges is spent

\textsuperscript{11}“Destination Unknown”; Demos report, 2010
\textsuperscript{12}Office for National Statistics - Labour Force Survey, Jan - March 2009
\textsuperscript{13}Inclusion Scotland; “Know the Score: Welfare Reform Briefing”, 2010
\textsuperscript{14}“Know the Score on Welfare Reform”; Inclusion Scotland, 2010
\textsuperscript{15}Brown, Mike, (2011) “Context for charging – Financial Challenges”, CoSLA Community Care Charging Listening Event (ADSW Resources Committee)
on administration costs\textsuperscript{17}. These figures alone indicate that charging for community care is not only inefficient and insignificant for society at large, but it is incongruent to any sense of social justice.

4.8 Community care is essential for the equal enjoyment of human rights of disabled people (The British Institute of Human rights have produced a guide that outlines the role of community in securing these rights\textsuperscript{18}) 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.

4.9 In light of the figures involved and of the impact on human rights, it is the view of ILIS, and many disabled people and Disabled People’s Organizations, 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.

4.10 We also believe, for the reasons outlined above and since carers are considered partners in care, it is fundamentally wrong to charge them for services, as proposed in section 16 of the current of the Bill. We recommend that provisions to charge carers be removed and instead used as an opportunity to address some of the issues outlined above, particularly in relation to the powers on LA’s to charge, under section 87 of the 1968 act.

4.11 We recognise however, that without a fundamental reassessment of how we spend our money, there are significant fiscal challenges for funding social care. For this reason, we continue to recommend a Commission on the Funding of Social Care in Scotland, to facilitate widely informed local and national budgetary decisions on the funding of community care in the future. We believe that the introduction of this Bill, coming from intentions of a human rights based approach, is an excellent time to set Scotland ahead of the international game in terms of its recognition of the value of social care and to set up such a commission.

5. Carers

5.1 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 believe that, in every possible circumstance, the LA should be obliged to offer support to the service user.


\textsuperscript{18} British Institute of Human Rights; “Your Human rights: A Guide for Disabled People”, 2006
5.2 However, 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 formally considered not to have capacity). We continue to believe this is a much more empowering method of supporting informal carers.

5.3 We believe that 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.

Independent Living in Scotland Project
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