Recommendation 1: in addition to LAs ‘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

Recommendation 2: that Scottish Government and local Authorities fully recognise and fund the statutory obligations placed upon SDS recipients as employers

Recommendation 3: 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 4: to help facilitate this, the regulations should be coproduced with disabled people, their organisations, other user led groups and carers

Recommendation 5: the duty to “give effect to” the option chosen be aligned in the Bill to the timescales within the National Eligibility Framework

Recommendation 6: 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 7: an amended set of principles, underpinned by a “statement of intent” are developed, the principles include: Freedom, choice, dignity, control, better outcomes for individuals, mutuality, equality & portability

Recommendation 8: any involvement in SDS, from assessment to provision, is underpinned by a legislative right to support and advocacy for it

Recommendation 9: that the Bill be clearer and stronger on the role of advocacy, peer support and support organisations; especially Disabled People’s Organisations¹, including on where they sit in terms of the overall framework for SDS and on the LAs duties to engage them. Specifically, we would like to see the addition of duties on LAs to refer people to such support organisations at sections 2(3), 5 and 8 of the Bill

Recommendation 10: gateways to accessing support from the LA and therefore SDS, are considered within the Bill

Recommendation 11: charging for community care services is a significant barrier to independent living and that it should be free at point of delivery

¹ “It’s our world too”; ILiS, 2010
Recommendation 12: provisions to charge carers be removed and instead use the Bill as an opportunity to address some of the issues in relation to the powers on LAs to charge, under section 87 of the 1968 act

Recommendation 13: a Commission on the Funding of Social Care in Scotland be set up

Recommendation 14: that the disabled person or other SDS user receive SDS directly to meet the needs that arise from the informal carer’s role.

Scottish Personal Assistant Employers Network (SPAEN)

1.1. SPAEN is uniquely placed amongst user lead membership organisations in having a Scotland wide remit. SPAEN is able to take a Scotland wide view in addressing issues that affect the needs and requirements of persons who are substantially or permanently physically, mentally or sensory impaired or others in need of community care services and also those individuals who wish to become personal assistant employers or manage their self directed support. SPAEN promotes the Social Model of Disability and the aims of the Independent Living Movement through the provision of high quality services and a range of advocacy services, monitoring and disseminating of information on local and national developments.

SPAEN was established and constituted as a registered charity in March 2000 and SPAEN’s objectives over the last ten years have been and continue to be the provision of high quality services to enable individuals to improve their conditions of life, encouraging them to live fulfilling and independent lives by facilitating their active participation in and full integration into the community. To achieve these objectives SPAEN provides a comprehensive service of high quality advice; assistance; guidance; support and training and in addition it supports those who require help to make appropriate, sound and suitable decisions in managing their self directed support packages and in safe recruitment.

Our Vision is of an inclusive society in which disabled people and other Community Care Service Users are fully integrated by leading full and independent lives.

Our Method is that of promoting mutual support among those who are striving to lead full and independent lives by taking control of the management of everyday affairs.

Our Impact will be to reduce the social exclusion of disabled people; as well as the social cost of this exclusion.
1.2. SPAEN welcomes the Scottish Government’s proposal for a Self-Directed Support (Scotland) Bill and sees it as another opportunity to further the implementation of self directed support in Scotland. Our response deals with the issues we feel are most appropriate to our organisation. SPAEN broadly mirrors the views of our sister organisation ILiS in general adding our own additional comments. Whilst the Bill recognises the obligations upon the Local Authority it fails to fully appreciate the similar obligations placed upon the recipient once they become an employer in their own right. These statutory obligations include such matters as redundancy, TUPE, Family Friendly rights and discrimination duties. These matters are dealt with more fully in section 3.

Independent living

1.3. 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.

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 life: 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
- 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

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.

2.2 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.

2.3 We also support the aim of the Bill in widening access to SDS overall. However, would recommend that in addition to LAs ‘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

2.4 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.

2.5 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 LAs 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

2.6 The principles are a crucial and welcome addition to the Bill. The nature of SDS is such that few circumstances around it 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.

2.7 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.

2.8 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 1.3 & 1.4 above).

2.7 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. 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 UNCRPD. One of their recommendations to do this, is to ensure that upcoming legislation on social care has independent living as an outcome of it.

2.8 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 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”

3 JCHR; “Implementation of the right of disabled people to independent living: 23 annual report 2010/12”; 2012
2.9 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:

2.10 Freedom: users of SDS are free to live their life in the way that they choose and SDS aims to support this to happen.

2.11 Choice: users of SDS can choose how to live their life, what they do with it and who they involve in it and SDS aims to support this to happen.

2.12 Dignity: everyone is entitled to dignity in their own life and others respect this dignity.

2.13 Control: people can and should control their own lives, including what they do, who with, and when they do it and SDS aims to support this.

2.14 Better outcomes for individuals: rules and processes, including assessments and eligibility criteria, work for the individual and their best interests. The outcomes for disabled people and other users of SDS, in terms of better health and well being, should be at the centre of both the legislation and the way that it is implemented.

2.15 Mutuality: SDS is a tool provided to support users to participate in their own life, in their local community and this includes in decisions on their care and support. It is provided alongside the tools needed to make decisions on the way people obtain their care and support and the type that they select. Disabled people and other users of SDS must be equal partners in care.

2.16 Equality: SDS is one tool among many to ensure the equality of disabled people and other users of it, within our society. SDS enables disabled people’s participation in wider society and their empowerment to take charge of their own lives. SDS is empowering in its design and delivery and plays a key role in the overall empowerment of disabled people and other users.

2.17 Portability: Disabled people and other users of SDS have clear entitlements to SDS, regardless of where they live. Disabled people, and other users of SDS, know that they can move freely, for whatever reason, across Scotland and that their support package can come with them.

2.18 Accountability: Service users, providers, assessors and professionals must all be accountable to the principles within the Bill.

2.19 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 oppression\(^4\), 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 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 practice, 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 Organisations⁵, including on where they sit in terms of the overall framework for SDS and on the LAs duties to engage them. Specifically, we would like to see the addition of duties on LAs 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 with regards to Employment Law in particular e.g. Redundancy, TUPE, Family Friendly rights and discrimination duties as per our comment in 1.2. We recommend the following:

- Compulsory training on the basic employer’s statutory obligations for staff commissioning and administering the support package.

- A basic employer’s statutory obligations module within the vocational qualifications and becomes part of a LA SWD induction programme and continuous skills development within specific area teams.

- That finance teams have employers statutory obligations included in any induction programmes. Equip the finance teams with the information required to sufficiently fund a support package enabling the obligations under the Employment Rights Act, amongst others, to be fulfilled on matters such as redundancy, sleepovers/National Minimum Wage, false self employment and mispayments.

- To help encourage and evidence the support provided by the Local Authorities monitoring of the service users agreement to manage and direct the support package details of the specific employer obligation requirements should be issued. This provides the SDS recipient with the information they have been assessed as knowing and provides the Local Authorities with security in the knowledge that the individual has the information required. The Bill needs to be more prescriptive in section 8 so that when it is enacted it makes clear the duties and

⁵ “It’s our world too”; ILiS, 2010
obligations, of a Local Authority, as at present it is open to interpretation which leads to a postcode lottery of information provision.

- Compulsory training on the basic employer’s statutory obligations as a prerequisite in supporting those wishing to become a PA employer. Specific specialised training is available to service users/or those assisting them who decide to employ, with a monitoring system in place to ensure that this is attended. Therefore, shows an understanding/willingness to comply with the contractual obligations they will have with the Local Authority: signing to agree to be a good and competent employer and meet all their employer obligations.

- By inputting the above stages in place the recipient will be assured that the appropriate safe guards are in place both at Social Work and Finance Department level permitting the recipient to undertake their duties and obligations in statute as an employer.

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 LAs, 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 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, their basic human rights. Addressing this then, is not only needed to ensure we get 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 accesss to SDS

4.4 Disabled people have said of community care charges:

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6 JCHR; “Implementation of the right of disabled people to independent living: 23 annual report 2010/12”; 2012
“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.”

4.5 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.

4.6 When the extra costs of being disabled are taken into account, 47.5% of households including a disabled person live in poverty: 50% of disabled people of working age are in work, compared with 80% of non-disabled people of working age: and of the £18bn in benefit cuts proposed as part of Welfare Reform, a disproportionate amount will fall on disabled people. 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. Disabled people cannot afford to bridge the gap between demand for public sector resources and supply of them.

4.7 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

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7 Elder Woodward; “The Ethics of Charging”, 2011
8 Learning Disability Alliance Scotland; “Alliance News, Making Sure Your Voices are Heard: The Hidden Tax on Care”, 2011
10 “Destination Unknown”; Demos report, 2010
12 Inclusion Scotland; “Know the Score: Welfare Reform Briefing”, 2010
13 “Know the Score on Welfare Reform”; Inclusion Scotland, 2010
the support they need to enjoy their rights and freedoms under all such regulations and conventions

4.8 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. Yet, as Laurence Clark points out, 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 on administration costs. These figures alone indicate that charging for community care is not only inefficient and insignificant, but it is incongruent to any sense of social justice.

4.9 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) 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.

4.10 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.

4.11 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 onLAs to charge, under section 87 of the 1968 act.

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4.12 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, where possible, the LA should seek to offer support to the service user.

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 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.

Scottish Personal Assistant Employers Network
24 April 2012