Self Directed Support Scotland

1. SDSS – who we are, and our aims and objectives

Self Directed Support Scotland (SDSS) provides a forum for Self Directed Support Organisations throughout Scotland to work together to promote better outcomes for people receiving or considering Direct Payments. As a membership organisation, SDSS has a wealth of experience and knowledge of Personalisation, Self Directed Support (SDS) and its attendant tools, such as Direct Payments, to call upon.

Self Directed Support Scotland actively promotes Independent Living for disabled people by supporting, working with and championing the aims of Self Directed Support Organisations, which themselves support disabled people to access and benefit from Self Directed Support. Self Directed Support Organisations (or Disabled People Led Support Organization) are organisations which are managed and controlled by disabled people.

**Self Directed Support Scotland’s objectives are to:**

- Promote the social model of disability and philosophy of the Independent Living Movement throughout Scotland;
- Research best practice and identify examples of good practice in Self Directed Support and to report on these to member organisations and others;
- Provide a national campaigning voice for member organisations;
- Provide support to existing and evolving member organisations;
- Provide a forum for member organisations to work together and share ideas, experiences and information;
- Provide training for member organisations, staff and others.

1.2 Summary profile of a Disabled People Led Support Organization

- A Disabled People Led Support Organization have a majority of disabled people and or people with long term conditions on their board or management committee, and has a clear accountability process to members and/or service users.
- These organisations share and adhere to common standards
  - Work within the Social Model of Disability
  - Promote Independent Living
  - Promote people’s Human Rights and other legal rights
- Be shaped and driven by the initiative and demand of the organisation’s service users
- Be Peer Support based
- Cover all local disabled people, carers, and other who use support either directly or by establishing links with other local organisations or networks
- Be non-discriminatory and recognize and work with diversity in terms of race, religion and belief, gender, sexual orientation, disability and age
- Recognise that carers have their own needs and requirements as carers
- Engage the organisation’s service users in decision-making processes at every level of their organization

The role of a Disabled People Led Support Organization is to support people who wish to access SDS and or Direct Payments recipients through providing a range of services including:

- Advice and /or advocacy
- Support in using individual budgets or other forms of SDS
- Support in recruiting and employing Personal Assistants
- Support with or offer Payroll service
- Provide independent information about SDS and Direct Payments
- Offer peer support
- Offer training
- Assist with assessment
- May provide Disability Equality Training

Disabled People Led Support Organization do not employ or manage PAs on behalf of people awarded Direct Payments. However, if a Direct Payment recipient requires additional support to manage their finances, the organization may be able to provide this.

2. SDSS position on The Bill and recommendation

2.1 SDSS welcomes the legislative initiative in that it clarifies the rules, rights and obligations on direct payments and brings them up-to-date with current practice, while reinforcing the personalised person centred approach to engagement with individuals that is important to delivering cultural change.
2.2 Our response fully endorses the response sent to the Committee by Independent Living in Scotland (ILiS) and all of the points made in their response are points that we would make also. In addition to it and in order to improve the Bill, we would like to offer recommendations on two particular aspects that at present limit the Bill’s scope and chance of delivering positive changes for disabled people (across all impairments), people with long term conditions and older people. These views relate to the Committee’s questions 2 and 5.

2.2.1 Response to question 2: The overarching aim of the Bill should be to enable independent living for people in receipt of SDS

2.2.1.1 SDSS welcomes the move to address outdated aspects of community care and move it into the 21st century, using SDS as a much more effective means for people to buy better and more flexible support. We believe, however, that the Bill as currently worded cannot ensure the radical changes in social care that are required to address the needs of Scottish disabled people, people with long term conditions and older people, so that they are equal citizens in the community. The reason for this is that the vision and values at the origin of direct payments, which are central to (although not unique within) this Bill, and were set out by disabled people themselves, have been lost, depriving the Bill itself of a vision and ambitious aims.

2.2.1.2 Independent Living should be the overarching aim of the legislation (and of the SDS Strategy for Scotland) so that it can further enable the implementation of positive changes in society towards the rights of disabled people. SDS should be a method of accessing Independent Living, whereby "...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".

2.2.1.3 It is our understanding, however, that the keenly anticipated current bill misses the unique opportunity to place SDS as a key tool of societal change and fails to enable an effective response to the Joint Committee on Human Rights report, published in March 2012, which recognised that the current framework of legislation supporting independent living was insufficient to protect the rights to it, set out in the UNCRPD. Undermining its own strength, the Bill ignores one of their recommendations to do this by ensuring that upcoming legislation on social care has independent living as an outcome.

2.2.1.4 We believe that given the current commitment of the Scottish Government to independent living, supported it as it appears by other political
parties, the Scottish Parliament should be given the opportunity to vote on an ambitious piece of legislation that would visibly and practically reflect support for this commitment.

2.2.1.5 To this end we support the proposal of the Independent Living in Scotland (ILiS) recommendation of an amended set of principles, which would be underpinned by a “statement of intent”. The statement would read as follows:

“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”

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

- **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.

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

- **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.

- **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.

- **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.
• **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.

• **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.

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

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.

2.2.2 **Response to question 5:** The Bill should place a clear duty on local authorities to signpost and provide free access to peer support, advocacy, and disabled peoples support organisations, in order to obtain and use independent information.

2.2.2.1 The lack of a more detailed legal framework around support and information, and the confusion between the two, constitute a great risk to the successful outcome of the Bill. As currently introduced, the Bill fails to ensure that the main players in SDS are accountable for the delivery of the subsequent national SDS Strategy. In relation to information and support the Bill lacks clarity on what constitutes independent and adequate information (Section 5 (3) and (4)). Very importantly, by not stipulating that local authorities, or the Scottish Government, have a duty to signpost and provide free access to peer support, advocacy, and disabled peoples support organisations, in order to obtain and use independent information (Section 8 (2) and (3)), it leaves future SDS recipients at risk of not realising what their choices are, making misinformed choices or not fully grasping the full scope of, and opportunities within the four options. Most importantly it may also leave them without the necessary support to manage a SDS package successfully.

2.2.2.2 If true to its purpose such a duty would also lead to the duty of ensuring that resources are available, either from local authorities or Scottish Government, for independent and disabled people organisations to provide adequate independent information and support in all areas of Scotland.
2.2.2.3 Based on more than 20 years’ experience, including witnessing how the legislation on direct payment did not result in ALL eligible people effectively being offered this particular option, a duty to signpost or refer people to independent organisations led by disabled people, people with long term conditions and older people, would ensure that they are ALL informed about ALL options as well as ALL support available to manage them.

2.2.2.4 Although the SDS strategy may address the training needs of the workforce in relation to knowledge and use of SDS, local authorities themselves recognise that they will not be able to mainstream the knowledge of SDS in just a few years and that it will take much longer to bring the cultural shift underpinning long-term change. Disabled peoples organisations were at the forefront of direct payments and the idea of more flexible solutions, working with local authorities to develop sustainable solutions for individuals. **They are therefore the best placed to lead on providing information on, and support with SDS, for the benefit of individuals and statutory agencies.**

2.2.2.5 SDSS know of a number of people currently in receipt of a direct payment who say the reason for their choice is that they do not wish to receive a ‘service’ as such but prefer to have their support as a mean to use mainstream services, be more included in the wider community and/or live a more independent life. Historically this option has been conceded to people who knew that it could be ‘allowed’, in many cases had the capacity to argue for it, were generally more confident or had the support of a disabled people led support organisation to explore the option without prejudice to choose it and support if desired along the way. **By placing a statutory duty to signpost or refer to disabled people’s support organisations the Bill will ensure that this option is not just for those who are deemed to have greater capacity.**

2.2.2.6 At present people in receipt of a direct payment do not have to use any of their monies to access information or support to manage their package. If this changes and Support Organisations have to sell their services such as information and support directly to people this would completely change the nature of the relationship with disabled people, people with long term conditions and older people, by becoming merely another service provider as well as impacting on the ability of those organisations to remain inclusive and led by the people they serve. **It is therefore crucial that these organisations remain directly funded by statutory agencies.**

2.2.2.7 For individuals, free and open access to independent organisations means that they are not limited by their funding to obtain information from a particular type of direct care provider or on a particular option.
2.2.2.8 Based on our long and current experience we know that quite a number of people who have the capacity to choose a particular option, e.g. a direct payment, are not necessarily able to manage it without support. The knowledge of flexible and free access to support at any time (including crisis time) from professionals, and organisations they know and which have an intrinsic knowledge of their situation because they are led and staffed by their peers, is an essential part of a successful and positive experience of SDS/Direct Payment.

2.2.2.9 A duty to signpost or refer to peer support, advocacy services and disabled peoples support organisations, given the intrinsic inclusive nature of these organisations, would ensure that local people would have the opportunity, through these organisations, to engage with the national SDS project, co-produce development and solutions with other stakeholders and be fully involved in the future shape of health and social care. It would also provide the strategic network of people and their organisations to progress aspects of the strategy and measure and evaluate its impact over the years.

Self Directed Support Scotland
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