Social Care (Self-directive Support) (Scotland) Bill
Sense Scotland

Introduction
Sense Scotland is a leader in the field of communication and innovative support services for people who are marginalised because of challenging behaviour, health care issues and the complexity of their support needs. The organisation offers a range of services for children, young people and adults whose complex support needs are caused by deafblindness or sensory impairment, physical, learning or communication difficulties. Our services are designed to provide continuity across age groups and we work closely with families and colleagues from health, education, social work and housing. This breadth and depth of approach to service delivery helps us take a wider perspective on the direction and implementation of new policies.

Views on the Bill as a whole

1. Are you generally in favour of the Bill and its provisions?
We generally welcome the Bill, as long as, together with regulations, it will support people to have greater opportunity to lead the lives they wish.

General principles underlying the Bill

2. What are your views on the principles proposed?
We agree with the principles, as far as they go, but believe that they need to be strengthened to go beyond ‘collaboration’ - to imposing a duty to act on needs identified by the person or their representative. Without a commitment that people will get comprehensive, good quality support, which will enable them to make comparable choices to non-disabled people, the Bill may be implemented in a way that simply calculates the cost of support, not the impact the support has on people’s lives.

We believe that the current widespread use of eligibility criteria in determining who receives support, acts against the positive intentions of the Bill and, on a wider note, against agendas relating to prevention and equality. This issue becomes even more pronounced when considered in relation to adult carers. Please refer also to our response to question 7.

We believe that the principles, as long as they are the right ones, will support people in holding their local authorities to account, but that they need to be backed up by regulation, or by stronger duties within the Bill.
Options for self-directed support

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

We believe that these are reasonable options to offer – our concern relates more to how people can be supported to manage a direct payment (see question 6), and that by addressing this issue, more people could be supported to take the direct payment option, and develop capacity in this area.

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?

In principle, this seems correct. However, ‘maturity’ is also mentioned, and it will be very important that people who have complex communication support needs are not automatically deemed to lack the maturity required to make decisions or manage a budget.

Whatever the age or maturity of the child, it will be essential that their communication support needs are fully taken into account in determining what kind of support they will receive.

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?

See our comment above relating to assumptions which link communication ability to decision making.

We welcome the provision for support for the person to gain information, and make decisions about self-directed support, but it must be recognised that this support will often come from third sector organisations, and there is a cost involved. Sense Scotland frequently offers free advice and guidance to people needing support, their families, and other professionals. However, given the likely increase in demand with the hoped-for increase in uptake of self-directed support arrangements, this will not be sustainable in the long term, and our resources will be stretched. In order that people with communication support needs receive adequate assistance, the cost of this support should be built in to the process, and local authorities should be obliged to meet it. Without strong regulation relating to this, many people will have their communication support needs ignored.

It will be important that the information and advice given is timely – people with communication support needs often receive no specialist input prior to making major decisions, and on a much more general level, we know that many families do not receive their financial assessments and information
about charging early enough to take it into account in trying to plan their support arrangements. This is key, as it is one of the greatest causes of anxiety, and anxiety can prevent clear thinking about support.

Direct payments

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

We are disappointed that the option of empowering local authorities to pay direct payments to people who are not currently able to assist with the management of finances has not been taken. This could be implemented by introducing the notion of a ‘trusted’ person, who could be agreed by, and accountable to, the supported person (if possible) and the Local Authority in relation to the specific task of managing a person’s individual budget. If this is not to be included in primary legislation, we would hope that regulations relating to 13 (2) (g) would be put in place at the earliest opportunity, to deal with this issue.

We are also disappointed that direct payments for people in residential care have been put aside to be dealt with in regulations, and feel that this omission from primary legislation results in compromising the values which have led to the Bill.

Adult carers

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

We welcome the inclusion of consideration of adult carers. Support for them can provide them with the energy and space to offer more empowering support to their relatives. It must be recognised however that the reality for carers is that the current duty which exists elsewhere - to offer a carer’s assessment - is frequently ignored. We can cite a meeting we held with 13 parents in 2011, where only one had been offered an assessment, and the local authority would not provide that person with a written record of it, as a line manager would not ‘sign it off’. Another, more recent example, repeated with another parent, relates to a statement by a social worker that they should give up work to care for their child. Work can be essential to sustain a carer’s role in the long term, providing them with a life outside caring. Current experience indicates that this section will need to have strong regulations, review arrangements and enforcement behind it, to give it any relevance within the Bill.

Individuals’ responsibilities and risk enablement

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?

Yes.
**Financial Memorandum**

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

If self-directed support is to achieve the aim of improving outcomes for people, enabling them to feel more in control of their support, then good planning is essential prior to arrangements being put in place. This will require advice and guidance which can be very time consuming if offered adequately to people with communication support needs. This is an issue which is already often ignored, and will continue to be ignored with self-directed support, if financial support is not available to ensure the involvement of specialist workers.

Self-directed support brings higher transaction costs for providers, and these are not short-term, but continue throughout the period of service provision. Sense Scotland is a reasonably large organisation and is experienced in dealing with a range of support arrangements. With the growth in self-directed support, these costs will increase significantly for us, and could be impossible to sustain for a smaller provider, without assistance.

**Effects on equal opportunities, human rights, island communities and sustainable development**

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 agree that the Bill, if properly implemented, will increase human rights. However, experience to date is that the language of self-directed support is being used in some areas, with the prime intention of allocating resources, not improving outcomes. Strong audit of the implementation of the Bill will be required to ensure that what may be described as self-directed support does not result in more restricted lives.

**Other matters**

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

No.

Sense Scotland
23 April 2012