The Scottish Consortium for Learning Disability (SCLD) is a Centre for Excellence that is made up of 12 partner organisations that have joined together, with funding from The Scottish Government, to help people make the changes set out in ‘The same as you?’ ‘The same as you?’ provides a national policy framework for supporting and transforming services for people with learning disabilities and their families in order that people are enabled to lead full lives in their communities. 2010 marks its tenth anniversary. SCLD’s partner organisations are ARC, BILD, Badaguish Outdoor Centre, Capability Scotland, Central Advocacy Partners, Down’s Syndrome Scotland, ENABLE Scotland, KEY Community Supports, PAMIS, University of Dundee, University of Glasgow and the University of St Andrews.

1. SCLD strongly endorses the Social Care (Self-directed Support) (Scotland) Bill. We believe that the Bill can help to deliver greater choice and control to people with learning disabilities and/or on the autism spectrum. We would like a more explicit recognition of the fact that the purpose of self-directed support is to enable people to achieve the aims of independent living and identify and move towards the outcomes which matter most to them.

2. SCLD generally supports the principles in section 1 of the Bill. However, with respect to Principle 2, we think the concept of ‘reasonable requirement’ for assistance may not go far enough towards ensuring that people with learning disabilities are provided with the information and support they need to enable them to express views and make an informed choice. The recent evaluation of ‘The same as you?’ found that there is still low awareness of self-directed support and a significant unmet information need in this area. We would urge local authorities to work together with people with learning disabilities to ensure that their information and processes are enabling people to engage with self-directed support.

3. SCLD supports the availability of different options for different people in order to maximise choice and control. However, it is our view that all people who use services, whatever the option they choose, should be advised of the monetary resource which has been defined for them to meet agreed outcomes.

4. SCLD welcomes the proposal that the self-directed support options should be made available to children and their families and also that the degree of control a child may have over the process should vary with age. However, we would suggest that a person-centred approach would allow for discretion, so that, for example, a child under the age of 12 who had formed a
view of the way they wish to receive their support should be allowed to express this.

5. SCLD welcomes the Bill’s focus on timely, accessible information and support in relation to self-directed support. We would stress that people with learning disabilities must be involved in producing and evaluating information and guidance on self-directed support for this to be meaningful. Furthermore, it will not be sufficient for local authorities merely to make sure that people with learning disabilities receive accessible information. To be enabling, accessible information is a tool to be used alongside skilled information support workers. We would welcome some more detailed acknowledgement of the types of information which local authorities are expected to provide under Section 8, for example, easy read information, plain English information, large print information etc. We would also highlight that one individual may have multiple information needs – for example easy read information in another language.

In addition, the policy memorandum refers in paragraph 31 to people with ‘severe learning difficulties.’ We would advise that even people with capacity and with relatively low support needs may need quite a considerable amount of support to understand the options available to them and to make an informed choice. Furthermore, even people who do lack capacity may not wholly lack capacity and may be able to engage with some aspects of their support planning.

6. No response

7. SCLD supports the idea that local authorities should be able to release support to carers following a carers’ assessment. In recent research evaluating ‘The same as you?’ we found that carers’ assessments rarely led to offers of additional support and this would offer the potential to change this. However, we do not believe that additional support for carers should in any way affect or detract from the support which the disabled person chooses.

8. No response

9. No response

10. SCLD acknowledges that many of the principles and goals of the Bill are underpinned by human rights, particularly the focus on greater choice and control, participation and inclusion. However, SCLD is not satisfied with the assessment which has taken place in regard to the effect of the Bill on human rights. Human rights essentially describe the relationship between an individual and the state. They set the expectations both of what the state
must refrain from doing as well as what it must actively set out to do in order to respect, protect, fulfil and promote human rights. Given that social care is still an arena in which individuals may be heavily dependent on services provided by the state, any change to the mechanism by which individuals receive state funded support must inherently give rise to human rights issues. We are particularly concerned that the fact that self-directed support effectively places a distance between the individual and the state could lead to public authorities effectively abnegating their responsibility to the protection and promotion of human rights. We would suggest that human rights based outcomes should play a part in the commissioning and monitoring of an individual’s care package to ensure this does not happen.

We acknowledge paragraph 52’s assertion that local authority intervention into an adult’s life could have impacts on their article 8 right to protection of private and family life. However, it should also be noted that if an authority were to fail to undertake intervention into an adult’s life, this could also be an interference with a person’s human rights. Authorities have both positive obligations to undertake activity to protect rights (e.g. organising and holding elections or taking steps to protect life, for example through policing) as well as obligations to refrain from proscribed activities (e.g. torture). Failing to provide appropriate care and support could interfere with article 3 rights and, as the JCHR has recently highlighted, UNCRPD Article 19 right to independent living.

11. No response.

Scottish Consortium for Learning Disability
24 April 2012