Health and Sport Committee

Public Bodies (Joint Working) (Scotland) Bill

Lothian Centre for Inclusive Living

Members of the Health and Sport Committee, Richard Lyle MSP, Aileen McLeod MSP and Nanette Milne MSP attended an event organised by the Lothian Centre for Independent Living (LCiL) on Monday 30 September 2013. This was arranged in conjunction with Inclusion Scotland, the Independent Living in Scotland Project (ILiS), Self-Directed Support Scotland (SDSS), and members of the Independent Living Movement.

LCiL organised this event to provide the Committee with the opportunity to hear directly from a cross-section of disabled people and disabled people's organisations (DPOs) their views of the Public Bodies (Joint Working) (Scotland) Bill, which the Committee was considering at stage one.

Participants were divided into small discussion groups, with one Member allocated to each group.

Central to the overall theme of the event was the document 'It's our world too: 5 Asks for a better Public Bodies (Joint Working) (Scotland) Bill'. This document consisted of evidence pulled together from disabled people at a series of workshops organised by ILiS. In summary, the '5 asks' (www.ilis.co.uk) are:

- 1. Independent living, equality and human rights should be explicit in the principles and outcomes of health and social care integration.
- 2. Disabled people must be considered as full and equal stakeholders and co-producers in health and social care integration.
- 3. Disabled people, other users of the integrated systems and the wider third sector should be involved in leading on the principles of an integrated system and on how money within it is spent.
- 4. Social Care (Self Directed Support) (Scotland) Act 2013 and Public Bodies (Joint Working (Scotland) Bill 2013 must work together to promote seamless care provision
- 5. The integration agenda should not further entrench health inequalities.

The overriding theme that emerged from each of the discussion groups was that the principles of independent living and human rights should lie at the heart of the Bill.

On the Bill itself, points raised by participants included:

- there is a need to formally link the Bill to the Self-Directed Support Act: "SDS and health and social care integration should work together".
- It "should be about supporting people to participate in society and lead an ordinary life".

• The issue of 'portability of care' was raised for people who had moved from one part of the country to another.

Comments against the intentions of the Bill included:

- "health and social care integration as perceived will make things worse"; and
- one participant was concerned that "there'll be less money, less care, less resources".
- Other concerns in relation to integration included a silo-working mentality; and
- the fact that Health Boards covered several local authority areas.

Regarding the involvement of disabled people and DPOs, participants were clear that disabled people should "have a seat at the table" right from the start and that DPOs should also be involved to represent disabled people at all levels in the integration process. Participants wanted to see proactive support offered by the new integrated boards; that is to say disabled people shouldn't need to request services when they are already known to health and social care providers.

Participants stressed the important role of GPs, who in some cases, may be the sole source of support for disabled people.

Some issues of oversight were raised:

- some participants felt that the Ombudsman lacked independence the 'community health council' model was suggested as an alternative as this is a panel of people who use the system and so understand it by direct experience.
- It was felt that an independent monitoring system would oversee a fairer distribution of services to disabled people; and the Bill should contain provision for an independent review body to consider complaints (as current systems for handling complaints weren't felt adequate).

Participants raised other points in relation to current systems that they hoped the legislation would address, including:

- the time taken by social work services to put provisions in place, which can lead to 'bed-blocking';
- a concern that the current system lacks a continuity of care, so for example, disabled people are repeatedly asked to explain their circumstances to different people.
- There was also concern raised of a lack of awareness-raising about disability and long term chronic conditions in BME communities.

Finally, there was some concern about the integration of budgets between health and social care systems, particularly where the first is predominantly free at the point of use and the other has charges associated with it.