Social Care (Self-directed Support) (Scotland) Bill

Scottish Council on Deafness

The Scottish Council on Deafness represents over seventy organisations working with and on behalf of Deaf Sign Language users, Deafblind, Deafened (Acquired Profound Hearing Loss) and Hard of Hearing people in Scotland; and individuals who have an interest in deaf issues or are deaf themselves.

Our membership provides an effective working partnership between the Voluntary Sector, Social Work and Education Departments, NHS Trusts, Health Boards and the Government.

Background to Contribution

One in five of the population in Scotland has a hearing loss. This means there are over one million people in Scotland with a hearing loss, from the profoundly deaf to those who are hard of hearing. They have different communication needs.

There are approximately 6,000 deaf people whose first or preferred language is British Sign Language (BSL).

Many deaf people who need and use social care and health services will apply for and receive SDS. Many of our member organisations provide the specialist support that deaf people require as the majority of local authorities have “mainstreamed” social work services for the deaf – see SCoD’s Social Work Skill Audit – http://www.scod.org.uk/Research-i-46.html.

Contribution

SCoD is generally in favour of the proposed Bill, but there needs to be more information on how the Principles will be monitored and what will be put in place for the occasions where they are not adhered to.

SCoD is particularly concerned about the need to respect and provide communication support for Deaf, Deafblind and Deafened people as well as deaf people with minimal language skills; for example, Deaf people who have a Learning Disability or severe and enduring mental health issue or physical disability such as paralysis and aphasia from a stroke/brain haemorrhage and cannot use standard British Sign Language.

The general principles, as outlined in para. 7 of the Policy Memorandum, focus on the 3 issues of “involvement”, “informed choice” and “collaboration”. In each of these areas, the reality of experience of deaf people is that none of these principles is being properly applied by the appropriate authority. For example, in some local authorities deaf people are not able to access independent advocacy in order to be fully involved in the process of accessing SDS; in others, the local authority is not involving the deaf person in the process and is not providing the deaf person with all the information they need.
in an appropriate accessible format so that they can make an informed choice. In fact, if the deaf person has additional and often complex needs, they are given so little information that the whole process of applying for and managing SDS becomes a danger to their mental health as the deaf person struggles to understand what it means to have to manage their own budget.

In terms of “involvement”, the majority of care managers/social workers with responsibility for overseeing the care arrangements for deaf people have little or no skills in communicating with deaf people and many are not even ‘deaf aware’. See SCoD’s Social Work Skill Audit - http://www.scod.org.uk/Research-i-46.html.

Under the previous system of Regional Local Government, all the Scottish Councils had a recognised service for deaf people, which employed staff with an acceptable level of communication skills. Today, the majority of Councils have no specialist services and no staff with adequate communication skills. It is these staff members who are carrying out the SDS assessments and making recommendations for support. What this means in practice is that many deaf people with complex support needs are being told that they should be able to access support from mainstream services that are cheaper than specialist deaf services, but are not appropriate to the deaf person’s needs and staff in mainstream services cannot communicate directly with the deaf person so support packages break down, leaving already vulnerable people even more vulnerable.

There is also a problem with BSL/English interpreters have had no training in working with deaf people with minimal language skills, so that the provision of such interpreters for deaf people with additional and often complex support needs is not always an appropriate solution. All these issues taken together lead to a reality in which the notion in which the principle of “involvement” for deaf people with other communication skills is merely tokenistic. For example, one of our members Hayfield Support Services with Deaf People have already had examples of care managers using BSL/English interpreters when meeting with their deaf service users about SDS assessments and funding, and then later finding out that the service user has no understanding of what had taken place.

Informed choice

Such choices can only be made when an individual has the knowledge and understanding themselves, or has the support and advice of an independent advocate. Many Deaf and Deafblind people have little literacy skills and may also have few numeracy skills. There are Deaf people with additional and complex needs who have no reading or writing skills and are completely innumerate, and who have little grasp of their first language – BSL. These deaf people have little understanding of how the benefits system works and how their existing care packages are funded. It is unlikely that they could fully grasp the issues involved with the change to SDS or what choices they might have to make. At the same time, they are hampered by the fact that there are NO independent advocates with skills for communicating directly with deaf people in Scotland, and so they cannot
access help or advice from this source. In many circumstances, care managers wish to involve carers in the decision-making process even when the deaf person does not want this.

Collaboration

There has been little in the way of support or advice from many of the local authorities that our members work with – contact seems to be limited to repeated demands for more information and for cuts in fees. Two of our members, Hayfield Support Services with Deaf People and Deafblind Scotland met with staff from the Scottish Government SDS Bill team to raise the issues with them, but this meeting did not provide any solutions for supporting their service users in having a “good” SDS experience.

In terms of authorities ‘collaborating’ with deaf individuals, experience to date has been that authorities give limited time to meetings or appointments when, in fact, all deaf people should be given more time so that they can ask questions while there is communication support present. Communication support for deaf people is booked for a minimum two hour period no matter how short the appointment might be. If the deaf person has complex needs including complex communication support needs then a longer appointment will allow the person's communication support worker to help the person understand what is being asked of them.

There have also been occasions when interpreters or communication support workers are not available and care managers have used family members to assist with communication without seeking the deaf person’s permission or irrespective of how capable the family member is at communicating with them. There may also be a conflict of interest if the family member is also one of the care givers.

There are also problems with local authorities not collaborating with our member organisations’ care staff who have the best overall view of an individual’s needs and abilities having the necessary skills to work with and communicate with the individual on a one-to-one basis and who might have been working with the deaf person for a long time. Where this is the case, “collaboration” is tokenistic, without any real commitment to ensure the best outcomes for the deaf people involved.

Information and advice

These issues have already been addressed above, but it is important to stress the fact again that deaf people in general, and deaf people with minimal language skills in particular are not having their rights protected and their needs met by the present way that SDS is being introduced. Although SCoD produced an accessible DVD on SDS for deaf people, many mainstream care managers are unaware of this resource. It would also appear that the Scottish Government are also unaware that this resource exists as a consortium bid was put in by four deaf organisations and one of the outcomes was to produce accessible information about SDS for deaf people.
Safeguards for people who access SDS

The Scottish Government should look at what safeguards can be put in place to ensure that deaf people and deaf people with complex needs have the same equality of access to SDS as their hearing peers, otherwise the proposed Bill will not effect the changes the government seeks to Direct Payments.

In fact, early indications show that local authorities are taking a very restrictive, non-specialist view of service provision, which could limit and possibly endanger the future of specialist deaf services in Scotland. This in turn would lead to deaf people receiving inappropriate, inaccessible care packages or having to be placed in hospital/mainstream care settings at considerably more cost to the Government. For deaf people with complex needs there is only one organisation that provides the specialist care and support services that these people need and that is Hayfield Support Services with Deaf People. Hayfield is a unique service for deaf people with complex needs in Scotland, whose future can only be assured by a formal recognition of the need for appropriate funding.

Care services need good communication that is appropriate

All care and support services in Scotland should be based on good and appropriate communication. Where there is a barrier to such communication, such as deafness, there must be recognition that accessible and appropriate support needs to be available to safeguard the needs and aspirations of the deaf individuals involved; and where the deaf person has additional complex needs, there needs to be specialist deaf support services to meet the needs of these people. Once these specialist support services are no longer there, there is no getting back the expertise and experience that they provided.

Example of specialist deaf support service for deaf people with complex needs

Hayfield Support Services with Deaf People works with deaf people with multiple, complex needs. All staff receive training in a range of communication and care issues, and as such they are a unique resource in Scotland. Hayfield staff are not registered interpreters, but through their day-to-day contact with the people they work with they have learned the most appropriate ways of communicating with each individual, whether it is through the use of idiosyncratic signs (which would not been known to BSL/English interpreters), mime, and/or pictorial and graphic mediums.

Finally

SCoD is disappointed that, due to a lack of understanding of the needs of deaf people with complex needs, the assessment process has led to these people being slotted into the category of “physical disability”, irrespective of what their complex needs are and what effect they have on the deaf person’s life and care needs.
Instead of trying to ensure that the deaf person can make an informed choice about how they would like to live and who can support them, it would appear that by labelling these deaf people as being "physically disabled" they can be mainstreamed into cheaper support services. This is not equity and parity with their hearing peers, rather this is discrimination based on cost of service. Is this what the Scottish Government wants for some of its most vulnerable citizens?

Deaf people in Scotland have physical and mental illnesses that are the same as those of their hearing peers, but have the additional disability of not being able to hear in a hearing world. If the person then has additional communication support needs, surely in this day and age, it is appropriate for these to be met by people who have the expertise and knowledge that has been gained over the course of many years of working with and supporting deaf people rather than by people who may be excellent carers but have no knowledge of how to communicate with deaf people.

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