

Scottish Council on Deafness

The Scottish Council on Deafness represents 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.

General Comments

When SCoD met with Angela Bonomy and John Paterson in 2012, we suggested that if there had to be a single joint sensory impairment strategy, then that strategy should have three distinctive strands to it – deafness/hearing loss, sight loss and the third – deafblindness; not the three main groupings that are stated in point 2.2. on page 3 of the paper. The reason for this is that whenever a joint sensory impairment strategy has been mentioned at SCoD meetings, deaf people told us that this would take their lives back about 20 years to a time when their needs

“were lumped in with people who can’t see. Like we all have the same needs and the same lives.” Deafened man, Fife

“Has the government not learned anything? My needs are different to someone who cannot see, just as their needs are different to mine. I cannot hear but I can see fine. I don’t even need glasses to read. So why are we all being considered as though we are one group of people with the same needs?” Deafened man, Blairgowrie

“One stop shops for deaf people and blind people. Why? Do we all have the same needs? I need an interpreter to help me when I go to my son’s school, or to the bank, or to the hospital. Does a person who cannot see need an interpreter? I imagine that person would need a stick or a dog or someone to help them get to the school, or to the bank, or to the hospital, but when they get there, they can speak and hear what is said to them. I can’t. So my needs are completely different to theirs. Why are we all put in one group? Nobody asked me and others I have been in touch with if we wanted ‘one stop shops’. It is something else that was done to us, not with us.” Deaf woman, Paisley

“The government can’t even get it right when ‘consulting’ with us. This paper was produced in English, but where was the BSL version? We went to a consultation event and couldn’t ask questions or give our point of view because that is the first time we had any information that we could understand. This is not a joint sensory impairment strategy for us, Deaf BSL users; it is only for the government and organisations.” Deaf woman, Glasgow

Our members, including associate members who are themselves mainly deaf, have told us that any deaf strategy needs to be broader than health and/or social care services as these limited strategies have not worked in the past. Deaf people need the same access to life in Scotland as their hearing peers and so want a broad strategy that covers access and accessibility.

Who is the strategy framework aimed at?

The consultation document has not been written in plain English. It appears confused as to who it is aimed at – voluntary sector organisations, deaf people, people with a sight loss, their carers and families, public agencies?

Sensory Impairment

The majority of deaf people who SCoD comes in contact with do not recognise the term “sensory impairment”. One deaf man (Inverness) said “would I have a sensory impairment if I couldn’t smell, taste or feel. I can’t hear so why don’t people use loss of hearing or deaf. Why not call it what it is so that everyone understands what you’re saying?” Using the term “sensory impairment” suggests that the medical model of disability is being used, rather than the social model. Other strategies have moved away from using the term “impairment” as it is a medical term -

“More generally, we recognise that there is a need to be sensitive about the use of words like ‘disorder’ or ‘impairment’. These are clinical terms that are understood in those settings and included in sections of that nature. However, we know that many individuals on the autism spectrum do not accept those terms, preferring to stress that they have a different way of being in, perceiving and engaging with the world and those with whom they share it.” The Scottish Strategy for Autism
<http://www.scotland.gov.uk/Publications/2011/11/01120340/2>

Point of clarification

Point 4.6 “At the time of writing, the proposed British Sign Language (Scotland) Bill...through the Equalities Third Sector and Communities Directorate within the Scottish Government.”

This point seems to imply that the Scottish Government is responsible for the proposed Bill when in fact it is the Cross Party Group on Deafness and MSP Mark Griffin who are taking this development forward.

Deaf BSL users

There is no acknowledgement of the fact that Deaf BSL users do not think of themselves as being disabled, but as a linguistic minority with their own history, language and community. Nowhere in law is this recognised and therefore the only legislation that Deaf BSL users have been able to use to access goods and services in their own language is disability law – the Disability Discrimination Act 1995 and 2005 and the Equality Act 2010 (protected characteristic – disability). Even if the British Sign Language (Scotland) Bill becomes law, it will take many years before access to goods and services will be on a par with Deaf BSL users’ hearing peers.

Person – centred?

Deaf people themselves appear to be the least important people in this strategy (along with people with a sight loss and those who are Deafblind). Even strategic frameworks should have the person at the centre of the framework and show how the person will be included in what will be taken forward. This strategic framework does not do this. It appears to solely be organisation-based. Diagnosis seems to be the most important factor with support for those people who already know what is wrong with them taking a very distant second place.

In the Reshaping Care for Older People: A Programme for Change 2011 – 2021 it states

“Our existing approach can sometimes shoehorn people into services we currently have rather than working with them to design the services that will truly help them. It will be achieved by nurturing the principles of co-production, participation, empowerment, and enablement.

4.6 Co-production transforms the relationship between those who provide services and those who receive them.” <http://www.scotland.gov.uk/Resource/0039/00398295.pdf>

The See Hear paper does not appear to follow the principles of co-production, participation and empowerment, but does seem that deaf people will be “looked after” by organisations and agencies.

Deaf people with complex needs

Although people with a learning disability have been mentioned briefly in terms of the incidence of hearing and sight loss, there is no mention of the needs of deaf people with a learning disability or deaf people with complex needs.

Many deaf people with complex needs are supported by Hayfield Support Services with Deaf People or by Sense Scotland. These two organisations provide specialist support services which are expensive. In areas of Scotland where there are few deaf services, deaf people with complex support needs are all too often let down by mainstream services and become more and more isolated and vulnerable.

The case studies below show the level of specialist support some deaf people need and why:

Mr A is a profoundly deaf man who has been diagnosed as being autistic and has severe learning difficulties, communication problems and often exhibits challenging behaviour. He has a high degree of dependency, is unable to get about outside on his own and cannot read or write. He attended a school for deaf children as a boarder but made little or no academic progress. On finishing school, his mother found it increasingly difficult to cope with him at home. Communication between mother and Mr A was very limited. Mr A was placed in full-time residential care in Glasgow by his local social work department. He went home occasionally during his first year in residential care. Following a home visit, Mr A was able to sign to staff that his mother had hit him. This was fully investigated by social workers and police, but there was insufficient evidence to bring charges. Legal action was taken to obtain a Welfare Guardianship Order, which is still in place. Mr A has fairly regular contact with his mother and with grandparents but this is supervised. Mr A has a fascination with children and toddlers, and unfortunately this often manifests itself in unprovoked attacks on them where he will slap or push the child. This is the main reason why he must always be closely monitored and supervised when outside. Mr A is making slow but noticeable progress with his communication and with learning simple, practical skills. He is able to take part in a range of activities, including short, basic college courses - arts & crafts, cooking and baking - with support. However he will need much close care and support for the foreseeable future. Without the level of support given to Mr A, there would be a strong possibility that he would end up in some form of long-term hospital care setting, where he would have restricted personal and social development due to his limited communication skills.

Ms B is Deaf who had an oral education but who now uses BSL. She was brought up in a one parent family with 2 younger siblings. After leaving school she had a couple of periods of employment, and her life was fairly settled for some years. As the only Deaf person in the family, she started showing signs of frustration and aggression at home, and her mother helped her to move to her own rented accommodation, in order to get her out of the family home. She became very isolated and withdrawn and started drinking heavily. Several years ago, she suffered a severe mental health crisis, which resulted in her being hospitalised in a mainstream psychiatric hospital for over a year. She was eventually diagnosed as having paranoid schizophrenia. On being discharged from hospital, there was concern about how she would cope on her own, and arrangements were made for her to go into residential care. She now lives in a

specialist supported accommodation unit after working with staff to develop her daily living skills. She continues to have access to 24-hour care and support, through day support services and on-site care staff at her supported accommodation. Most of the time, Ms B is a pleasant, thoughtful and helpful woman, who has many practical and social skills. However, she still occasionally has bouts of drinking which result in a complete change in personality and behaviour – she can become very threatening and argumentative, and has also had episodes of violent behaviour which have resulted in police involvement and court appearances. Without the support Ms B receives, she would quickly revert to her previous negative, isolated lifestyle, which could lead to further mental health crises and/or court appearances. Mainstream services are unable to offer the necessary support that Ms B needs to remain as independent as she is.

Ms C is Deaf, has a Learning Disability and has cerebral palsy which is getting worse. She can follow BSL fairly well, but finds it increasingly difficult to express herself in sign language because of the effects of the cerebral palsy on her hands and her constant jerks and tremors. It has got to the point that it is now mainly care staff who work with her regularly and who know her really well who can follow her attempts to sign. As her condition has worsened it has limited some of the practical skills that she used to have, so that her level of dependency is slowly increasing. Most of the time Ms C is a cheerful and affable person, but occasionally she can get agitated and frustrated. Without specialist support, Ms C would not have any real quality of life.

Increasing confusion?

Too often there is confusion about what is accessible for deaf people – how often are they offered accessible documents in Braille, audio, large print? By putting together a framework for people with a hearing loss and/or a sight loss, this simply compounds the misconceptions in the general public and services, including the Scottish Government, rather than helping to get rid of them.

Monitoring and evaluation

The paper does not seem to follow other recent government strategies which are clear that service delivery should be carried out as a result of co-production and that monitoring and evaluation should be part of the co-production process.

The Dementia Strategy is very clear that people with dementia and their carers would be involved in the implementation and monitoring of the work to deliver the strategy

“The work to deliver the Strategy will be overseen by a Dementia Strategy Implementation and Monitoring Group involving all the key partners responsible for taking forward the changes, as well as people with dementia and the people who care for them. This Group will publish an Annual Report in June 2011 and June 2012.” Page 8-9, Executive Overview, Scotland’s National Dementia Strategy
<http://www.scotland.gov.uk/Resource/Doc/324377/0104420.pdf>

Deaf people and people with a sight loss deserve no less consideration than people with dementia, therefore any implementation and monitoring group must include Deaf BSL users, Deafblind people, Deafened people and Hard of Hearing people, their families and carers.

One Stop Shops

The biggest criticism that deaf people who have contacted SCoD about the One Stop Shops in their area is that they feel that they have not been consulted on whether or not this is what they want. Rather they have been informed that this is the way forward for deaf services and then asked what they think about it. Deaf people want services designed with them not despite them.

Another criticism is that if the service is provided by a One Stop Shop then the sight loss service should be in the same place as the one for hearing loss, not in two separate locations where the person has to travel between. This appears to be the case in at least one area of Scotland and deaf people feel they are no longer receiving a good service because of this.

The final criticism is that too often good quality, local services are being ignored in the tendering process as they are either unaware of the tender or do not have the resources to match fund as some of the national organisations can. Deaf people have told SCoD that they want deaf services run by local organisations that involve them.

What now?

Before the strategic framework is finalised, SCoD would like to see an audit carried out, not on the current spend on sensory impairment, but against the 2004 Community Care Services for Adults with a Sensory Impairment: An Action Plan. The recommendations being made in this framework appear to mirror those that were set in 2004:

Recommendation 1

The Scottish Executive should consult on the best methods of collecting information to assist service planning and delivery, for all those with a sensory impairment, including consideration of the registration process.

Recommendation 2

The Scottish Executive should consider how local partnerships can ensure that the ability to capture sensory impairment and needs arising from this in the Single Shared Assessment process for older people is incorporated into SSA for other care groups.

Recommendation 3

The Scottish Executive should develop an information strategy for people with a sensory impairment by reviewing existing information standards in conjunction with the Scottish Accessible Information Forum and other appropriate organisations to assess what is and should be available.

Recommendation 4

It is recommended that every social work or social care facility should have staff who are able to meet the basic communication needs of a person with a sensory impairment by April 2006.

Recommendation 5

It is proposed that a short-life working group be set up to consider how best to review, commission and disseminate research findings on meeting the needs of people with a sensory impairment, the underlying purpose being to identify what needs to change in community care services for people with a sensory impairment so that present inconsistencies and specialist needs are addressed.

Recommendation 6

It is proposed that a short life working group be set up to produce common sensory impairment service standards, to be completed for implementation by September 2005.

Recommendation 7

A national training strategy which strikes a balance between generic and specialist needs should be devised that places the needs of users and carers at its heart and is based on existing good practice standards. As a first step, the Scottish Executive should carry out an exercise to map all the information that is currently available, clarify the numbers involved and assess the usefulness of training programme content.

SCoD would also like to see the “Scottish Best Practice Standards: Social Work Services for Deaf, deafened, hard of hearing and deafblind people” http://www.scod.org.uk/Other_publications-i-135.html brought up to date, promoted and used by staff from the statutory or independent sector who commission, manage or provide social care services.

SCoD would like to see co-production being used to create a strategic framework for deaf people, people with a sight loss and Deafblind people that fully reflects what the people themselves want as well as what services and the Scottish Government can provide. The framework should be aspirational, imaginative and looking to a future where deaf people, people with a sight loss and Deafblind people are fully active in all aspects of life in Scotland.