

A public consultation on draft regulations and statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013



RESPONDENT INFORMATION FORM

Please Note this form **must** be returned with your response to ensure that we handle your response appropriately

1. Name/Organisation

Organisation Name

Scottish Council on Deafness

Title Mr Ms Mrs Miss Dr Please tick as appropriate

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3. Permissions - I am responding as...

Individual

Group/Organisation

Please tick as appropriate

(a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

Please tick as appropriate

Yes No

(b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

(c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

Are you content for your **response** to be made available?

Please tick ONE of the following boxes

Yes, make my response, name and address all available

or

Yes, make my response available, but not my name and address

or

Yes, make my response and name available, but not my address

Please tick as appropriate

Yes No

(d) We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate

Yes

No

4. Additional information – I am responding as:

Please tick as appropriate

1. Member of the public	<input type="checkbox"/>
2. Individual health/social care professional	<input type="checkbox"/>
3. Central government	<input type="checkbox"/>
4. Local authority	<input type="checkbox"/>
5. Community Health Partnership	<input type="checkbox"/>
6. Health Board	<input type="checkbox"/>
7. Support & information or advocacy organisation	<input type="checkbox"/>
8. Voluntary sector organisation	<input checked="" type="checkbox"/>
9. Private Sector organisation (e.g. private social care and support provider)	<input type="checkbox"/>
10. Professional or regulatory body	<input type="checkbox"/>
11. Academic institution	<input type="checkbox"/>
12. Other – please specify	Member organisation

Consultation Questionnaire

The Scottish Council on Deafness

The Scottish Council on Deafness represents organisations and agencies working with and on behalf of Deaf Sign Language users, Deafblind, Deafened (Acquired Hearing Loss) and Hard of Hearing people in Scotland; and individuals who have an Interest in deaf issues or are deaf themselves. Throughout the response, the term “deaf” is used to describe Deaf BSL users, Deafblind, Deafened and Hard of Hearing people, unless specified. “BSL” is British Sign Language.

General comment

The guidance is clear and in the main, easy to understand. See comment for **Question 13: Do you have any further general comments on the guidance?** on appropriate professional registered language/communication support.

Section 2 : Values and Principles

Question 1a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 1c: Do you have any further comments on this section of the guidance?

The guidance should be written using the Principles of Inclusive Communication as written by ILiS Working Group in 2010.

Page 7 of 79: “The professional -They may arrange for some additional assistance so that the supported person can play a full part in the assessment or support planning process. They may give voice to a supported person’s wishes.”

The word “may” is rather ambiguous and suggests that there are times when the supported person will not be included.

Nowhere is there any mention of independent advocacy for the “supported person” and their carer.

Page 8 of 79: “The finance manager or finance official - Finance managers and officials play an important role in determining and administering the level of spend assigned to services. As such, they should ensure that the right processes and systems are in place, and that they support the collective objectives for care and

support in their local area.”

It is important that the finance managers/officials receive equality, diversity and disability awareness training so that they understand the impact of their decisions on the supported person. They should also receive deaf awareness training as part of the more general disability awareness training.

Section 3: Values and Principles

Question 2a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 2c: Do you have any further comments on this section of the guidance?

Independent advocacy for the “supported person” and their carer should be included here. There needs to be more detail about “what it means in practice”.

For example, “The professional should involve the supported person in a genuine and active way in deciding their outcomes and in planning and delivering their support” by providing appropriate professional registered language/communication support if the person has a language/communication support need; or by referring to an independent advocacy organisation if the person needs this additional support to make their own, informed decisions.

Section 4: Eligibility and Assessment

Question 3a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 3c: Do you have any further comments on this section of the guidance?

Page 17 of 79: “29. A good assessment rests on critical thinking and constructive challenge. It rests on the professional’s ability to be open and honest with the person. It requires good judgement, awareness and significant “people” skills. The professional should be skilled in conversation and able to strike the right balance between advising the individual and supporting them to play an active part in the assessment process.”

A good assessment can only happen for a deaf person if the appropriate professional registered language/communication support is in place. But it might also mean knowing when the person’s communication support needs need to be met by a specialist care worker, for example, if the person is deaf and has

additional complex needs. It may be that the person also needs an independent advocate to provide additional support.

Page 18 of 79: “Collaboration

The professional must collaborate with a supported person in relation to the assessment. They should work with the person and towards a shared goal, in this case the identification, development and subsequent delivery of the supported person’s outcomes. They should facilitate the active contribution of the person as a partner in working towards a shared goal.

Involvement

The supported person (adult, child or carer) must have as much involvement as they wish to have in the assessment.

Informed Choice

The supported person must be provided with any assistance that is reasonably required to enable them to express their views about the assessment.”

The professional needs to know when to bring in appropriate professional registered language/communication support for a deaf person and also when to allow a specialist care worker to help the person communicate their thoughts, needs and wishes.

The carer may also require appropriate professional registered language/communication support to make their views known.

Page 20 of 79: “Implementing an outcomes approach is not straightforward. The demands placed on the professional may lead to a tick box approach to assessment. In contrast, skilled and flexible communication is required to fully engage individuals in defining what is important to them in life.”

The professional needs to know when and how to bring in appropriate professional registered language/communication support for deaf people and their carers. Otherwise these principles cannot be applied to deaf people.

Page 21 of 79: Self assessment – this needs to be taken into consideration when a deaf person with complex needs wants to remain with a specialist support provider – for example Hayfield Support Services with Deaf People or Sense Scotland. This type of specialist support is not cheap, but may be the most necessary support services for the deaf person so that they can reach their full potential.

Section 5: Support Planning

This section of the guidance covered:

- general guidance on support planning
- risk
- resources
- the choices that must be made available to the supported person and
- information and support

**Question 4a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 4c: Do you have any further comments on this section of the guidance?

Page 23 of 79: “The support planning process - the act of considering the outcomes and pulling together a plan - can make a significant difference to the person’s life. In light of this the support plan should be developed in a collaborative way. A good support plan will demonstrate a link between the individual’s eligible needs, their outcomes and the support required to meet those needs and outcomes. It will be written in language that the supported person understands. It will be presented in a way that is engaging and helpful to the supported person as they embark on their pathway through support. It may include pictures alongside text.”

It may be that the person’s support plan has to be produced in other formats than “written”, for example if the person is a Deaf or Deafblind BSL user, then the most appropriate format would be on DVD in British Sign Language. Or the person may want it in Moon. The person should be asked what language or format they want the plan in.

Page 24 of 79: “46. The two parties should take a proportionate approach, spending appropriate time on those risks that carry the greater potential impact or likelihood. The professional should seek to enable positive, informed and proportionate risk taking. They should consider the risks of not acting as well as the risks of choosing a particular support option. They should also review and monitor the person’s risks and they should encourage the supported person to undertake this task alongside other important individuals in the person’s support plan.”

One of the potential risks that should be looked at is moving the deaf person from a specialist support service where staff and others can communicate directly with them to mainstream services, including non specialist deaf services and hearing services, where the staff and other service users struggle to communicate directly with the person. Will this lead to the person realising their full potential or will it isolate them and lead the person to lose any skills they already have.

Page 25 of 79: “47. The “resource question” should not be about financial resource – money – alone. The professional should consider all of the possible resources available.”

Specialist support services for deaf people with additional complex needs does not come cheap and if these services are the ones that the deaf person wishes to have support them, then the cost should be looked at in terms of the person’s fulfilment

as an active citizen in Scotland who is part of civic life rather than as a “burden to the state because of the cost of care and support”. Some people require more than mainstream services and so should be able to access them at the cost they are. And these services should be valued for what they offer, not simply required to cut their costs so that their services can be provided “on the cheap”. That is also doing a disservice to the people who rely on these support organisations.

Pages 25 and 26 of 79: “50. The important point to bear in mind is that while systems and tools can be useful aids, they are no substitute for the skilled judgement of a social work or health professional. The authority must ensure that the approach taken to the allocation of resources is both fair and transparent. They should take steps to involve user and carer groups in the development of any methodology used to define or determine budgets for individuals.”

If the social work or health professional is not fully deaf aware, then they should have a duty to involve the people and professionals who best know the deaf person being assessed. Steps need to be taken to involve deaf users and carers groups in the development of the methodology as hearing people do not, in the main, have much knowledge of the needs of deaf people especially when it comes to specialised support – for Deaf BSL users, Deafblind people and for deaf people with additional complex needs.

Page 28 of 79: “54. All of the choices must be described to the supported person. A key challenge for the professional will be how to relate the options to the supported person and how to make them “come alive” to the supported person.”

These choices must be described in such a way as the supported person will understand – so the professional may need to bring in appropriate professional registered language/communication support or a specialist case worker to help in this task.

Pages 31 and 32 of 79: “72. The professional should explain the options in a clear and accessible way. They should tailor any communication to the communication needs of the individual. They must provide the individual with an explanation of the “nature and effect” of the options available to them under the law.”

The professional must bring in appropriate professional registered language/communication support if the person and/or their carer asks for or needs this, and where the deaf person has complex needs, their specialist care worker so that the options can be explained in a way that the deaf person understands.

Section 6 : Monitoring and Review

**Question 5a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 5c: Do you have any further comments on this section of the guidance?

Reviews need to be accessible to the supported person and their carer so appropriate professional registered language/communication support will need to be provided by the professional for any requested or statutory reviews.

Section 7 : Facilitating genuine choice for individuals

Question 6a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 6c: Do you have any further comments on this section of the guidance?

Genuine informed choice for deaf people can only take place if their assessment process is fully accessible to them and their carers. This should not merely be implied, but should be stated that this is a necessary part of the assessment, choice and review process and that it has to be made available when asked or when the professional thinks it appropriate. If the person has additional complex needs it may be necessary to include their specialist care worker in the process to help facilitate communication.

Section 8 : The role of the NHS professional

Question 7a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 7c: Do you have any further comments on this section of the guidance?

Page 45 of 79: “91. The professionals involved in jointly funded packages of support should put in place the appropriate joint arrangements for the on-going monitoring and review of the supported person’s needs.”

A professional should take responsibility of ensuring that appropriate professional registered language/communication support is booked for the supported deaf person and their carer.

Section 9.1 : Children and Families

**Question 8a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 8c: Do you have any further comments on this section of the guidance?

Again, appropriate professional registered language/communication support may have to be provided for the child and/or the family. This needs to be stated.

Section 9.2 : Supported decision-making and circles of support

**Question 9a: Was this section of the guidance clear and easy to understand?
(please tick)**

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 9c: Do you have any further comments on this section of the guidance?

Page 52 of 79: “Assistance with understanding and/or making decisions”

If the supported person is deaf with additional complex needs then it may be appropriate to involve the people that know this person best and that could be from a specialist deaf organisation where the staff have the necessary skills to interpret exactly what the supported person wants.

Where the person is a Deaf BSL user or Deafened or Deafblind, then it is important that appropriate professional registered language/communication support is put in place and that the professionals do not make judgements about the deaf person's capacity to make their own choices and decisions based on their own (the professional's) lack of communication skills.

“107. The professional must then take “reasonable steps” to enable the supported person to make the relevant decisions. They should exercise judgement in deciding whether the supported person requires such assistance. However, where they decide that additional assistance is required they must take reasonable steps to identify a person or persons who can provide some extra assistance to the supported person.”

If the supported person is deaf, “reasonable steps” should not include booking appropriate professional registered language/communication support; this should be a necessary part of the assessment if the professional does not have the necessary communication skills to communicate directly with the supported person and/or their family/carer. For example, the professional should have a minimum of Level 3 BSL to communicate directly with and carry out a full assessment with a Deaf BSL user.

Page 53 of 79: “108. Where a supported decision-making arrangement or a “circle of support” is being considered the agreement of the supported person is paramount. The supported person must be invited to agree to any arrangement whereby another individual or group of individuals are being invited to provide them with assistance. The supported person’s agreement must be secured before the individual(s) can provide any assistance.”

If the professional does not have the necessary communication skills to communicate directly with the supported person, then appropriate professional registered language/communication support needs to be in place to ensure the supported deaf person is agreeing to a “circle of support” being involved.

Even where the language/communication support professional knows the supported deaf person, the professional carrying out the assessment needs to be aware that they are there only to provide language/communication support and should not be asked for information concerning the person being assessed. This is a training issue – working with language/communication support professionals – that all professionals carrying out SDS assessments should have.

Page 53 of 79: “111. As stated, assistance to make decisions and assistance to communicate decisions are two distinct forms of assistance, and they are treated as such on the face of the 2013 Act. The supported person may require some additional support from, for example, an interpreter or a speech and language therapist, or from a family member or friend. If so, the professional must take reasonable steps to identify other people who can help the supported person to communicate their decisions. The professional should take steps to get the supported person’s agreement before they arrange any assistance for the supported person.”

The professional should have to provide the evidence of how they have got the supported deaf person’s agreement for booking appropriate professional registered language/communication support. If the professional does not have the communication skills necessary to communicate directly with the deaf person, how will they know that the person has understood and has agreed? For example, will the professional have the necessary information in BSL on DVD that they can play to a Deaf BSL user?

Page 54 of 79: “The professional should ensure that the proxy is:

- fully involved in the assessment;
- supported to collaborate with the professional, and;
- supported to make informed choices about the supported person’s support.”

The professional may have to provide appropriate professional registered language/communication support for the proxy who may also be a Deaf BSL user, Deafblind, Deafened or Hard of Hearing.

“113. The professional may have doubts or questions about a supported person’s capacity.”

This should never be based solely on the professional’s lack of communication

skills. For example, if the professional has no BSL skills, then the supported person’s capacity cannot be based on the fact that they do not understand spoken English. SCoD has anecdotal evidence that this has happened on occasion in other circumstances – the Deaf person has had no spoken English and as their first language is BSL, have not understood what is being said to them by lip reading; and have not understood a leaflet in written English. The professional has then decided that the person does not have capacity to make their own decisions. When a BSL/English Interpreter has been provided, the Deaf person has been found to have full understanding of the assessment process and what is expected of them. This is a training issue for all assessment professionals.

Section 9.3: Carers

Question 10a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 10c: Do you have any further comments on this section of the guidance?

Page 56 of 79: “115. A good quality carer’s assessment rests on a problem-solving conversation between the professional and the carer and a strong focus on personal outcomes.”

The professional should, when planning the carer’s assessment, find out if the carer needs appropriate professional registered language/communication support as the carer could be a Deaf BSL user, Deafblind, Deafened or Hard of Hearing. The assessment will not be of good quality if the professional cannot communicate directly with a deaf carer.

Page 57 of 79: “117. Support to a carer can mean a wide variety of things. It can mean access to universal services available in the community, referral to a known source of information and advice (for example, to a condition-specific organisation or to a carers centre) or the provision of further information in the form of booklets, websites, advice or guidance on coping with their caring role.”

The professional should be aware of specialist carers’ support – for example, if the carer is deaf, then are there any deaf organisations in the area that provide carer support. The professional will also have to “weed out” any support that is telephone based and does not provide an email or SMS contact. Information in the form of booklets, etc should also be accessible for Deaf BSL users and Deafblind carers.

“118. It can also mean arranging some form of “funded” services or support. Funded support to the carer can be of significant benefit to the carer and to the supported person.”

Does this mean that the local authority would provide funding for appropriate

professional registered language/communication support for deaf carers where the mainstream organisation/service providing the support does not have funds to provide communication support? It could be that the carer does not want to go to a deaf organisation for support as very often these organisations provide all kinds of services and the carer does not necessarily want other people in the Deaf Community, for example, knowing everything about them and their family/life. Deaf carers should have the choice of getting support from mainstream services with communication support or from the local deaf organisation.

Section 9.4: Direct payments

Question 11a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 11c: Do you have any further comments on this section of the guidance?

Page 62 of 79: “128. Of the four options available under the 2013 Act, the direct payment, if constructed and developed on a sound basis, carries the greatest level of flexibility. Professionals should make this point clear to individuals. Similarly, the organisation as a whole should seek to convey this point in the promotional literature.”

Any promotional literature should be available on alternative formats and languages, including on DVD in BSL. The supported person and/or their carer should be able to access information that they can understand before and at their assessment so that they can make informed choices. It should not be the case that information is available; for example, in English, Easy Read, a number of spoken languages, but a Deaf BSL user who is being assessed needs to wait until the information is translated into BSL which can take a long time. We understand that the professional with appropriate professional registered language/communication support will explain options to the supported Deaf/Deafblind person, but if the supported person who is not Deaf and receives information they understand to take away with them, then in the interests of equality and parity, so should the Deaf/Deafblind person.

Section 9.5: Wider legal duties and strategic responsibilities

Question 12a: Was this section of the guidance clear and easy to understand? (please tick)

Yes	No
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 12c: Do you have any further comments on this section of the guidance?

Comments

The Guidance document as a whole

Question 13: Do you have any further general comments on the guidance?

The guidance should include a statement on why professionals need to assess the person's communication support needs as soon as possible and access appropriate professional registered language/communication support. As noted in several sections above, if the supported person and their carer are to be able to fully participate in their assessment and make informed choices about care and support packages, then they must have the means in place to do this. If the professional does not have the necessary communication skills do carry out the assessment(s), then appropriate professional registered language/communication support will need to be in place from the start.

"111. As stated, assistance to make decisions and assistance to communicate decisions are two distinct forms of assistance, and they are treated as such on the face of the 2013 Act. The supported person may require some additional support from, for example, an interpreter or a speech and language therapist, or from a family member or friend."

To mention assistance to make decisions and assistance to communicate decisions this far on in the guidance is too late. If the deaf person needs assistance from a BSL/English Interpreter, a Guide/Communicator, an Electronic Notetaker or a Lip Speaker from the start, and this is not in place, none of the recorded information in the assessment can be taken as true and any decisions made by the supported deaf person cannot be taken as being informed.

The costs and benefits arising from this guidance

Question 14: Do you have any comments on the financial costs or benefits of the requirements set out in the guidance?

Can you identify any financial costs or benefits to individuals, local authorities, health boards, providers or any other person or organisation affected by the guidance. In considering the costs and benefits you may wish to consult the Business Regulatory Impact Assessment published for the Social Care (Self-directed Support) (Scotland) Act available at the following hyperlink:

<http://www.scotland.gov.uk/Publications/2012/03/5525>

We plan to update the BRIA in light of the comments and information from this consultation.

Comments

The equality and human rights impacts of the guidance

Question 15 (a): Do you have any views on the impact of the guidance on any or all of the following equality categories:

- i) age;**
- ii) disability**
- iii) gender;**
- iv) lesbian, gay, bisexual and transgender;**
- v) race, and;**
- vi) religion and belief**

Without a statement on the use of appropriate professional registered language/communication support for assessment for supported people and their carers who are deaf, the guidance could have a negative impact on the lives of Deaf BSL users, Deafblind people, people who are Deafened (have an Acquired Profound Hearing Loss) and people who are Hard of Hearing; and Deaf people with additional complex needs – SCoD has produced a Position Statement on the needs of deaf people with additional complex needs. The Scottish Council on Deafness has anecdotal evidence of assessments carried out with deaf people where the professional carrying out the assessment is sure that they have enough communication skills that they do not need to book communication support. When the deaf person has challenged decisions that have been made at the assessment or shortly after and based on the assessment, it has been found that what they meant has been wrongly recorded or completely misunderstood and that they have not understood everything said to them.

Question 15 (b): Do you have any views on the impact of the guidance on human rights?

For more information about human rights please see the Scottish Human Rights Commission's website at:

<http://www.scottishhumanrights.com/abouthumanrights/whatarehumanrights>

Comments

Draft Regulations

Question 1: What are your views on Part 2 of the draft Regulations (calculation, payment and termination of direct payments)?

Comments

Question 2: What are your views on Part 3 of the draft Regulations (appropriate/inappropriate circumstances for the employment of close relatives)?

If a person is Deaf or Deafblind, then it might be that the only people in their area who have the necessary skills to communicate directly with them are close relatives. Should these relatives be "banned" from taking payment simply because they are relatives? As long as the relatives are not in an abusive relationship with

the supported person (and this should be checked independently) then there should be no reason for not paying them for their care.

Question 3: What are your views on Regulation 11 which deems individuals who are placed under a variety of criminal justice orders to be ineligible to receive direct payments?

For example, is it appropriate to impose the exclusions listed in Regulation 11? Are there any persons not listed in regulation 11 to whom it would be inappropriate to offer the option of a direct payment?

Comments

Question 4: What are your views on restricting access to direct payments for those who are homeless, those who are fleeing domestic abuse or those who require support in relation to drug or alcohol addiction?

This should be dealt with on a one to one basis as people will have different coping mechanisms and ways of managing their lives. For example, someone who is disabled and homeless could be staying with friends and family on a rotating basis and be in the position to manage their own support needs in a perfectly “acceptable” way. Or a homeless person with an addiction who is in the preparatory stages of moving into their own tenancy with support from an organisation could be managing their own SDS as part of their resettlement package. One person who is fleeing domestic abuse and is living with friends or in a shelter could manage their own SDS, but another who has taken their children may not as they have too many other things to think about.

Scottish Council on Deafness Position Statement

Deaf People with Complex Needs

Deaf people often have other conditions, illnesses and disabilities in the same way that members of the hearing population do. Deaf people are also susceptible to the same illnesses and diseases as the rest of the population, but depending on their level of hearing loss, these illness and diseases can have a consequence for the way that the deaf person communicates with others and their understanding of what others are trying to say to them.

These illnesses and conditions include:

Mental Health Problems

Epilepsy

Learning Disabilities

Behavioural Problems

Learning Deficits (eg through poor schooling)

Social/Emotional Disorders

Autism

Sexual Disinhibition

Growth Disorders

Dementia

Brittle Bone Syndrome

Diabetes

Blindness

Limb Amputation

Cerebral Palsy

Severe Eczema /Undiagnosed Skin Conditions

These illnesses and conditions can lead to poor communication skills; a lack of independent living skills; a lack of social skills; severe problems with literacy and numeracy; and a potential danger to self and others.

There are Deaf people who have limited communication skills due to the fact that they have had an additional disability since birth or a very young age. These people need specialist support to help them in their daily lives and people who know how to communicate with them and who can provide a continuity of care.

Communication issues

Some Deaf people with complex needs have personal signs, for example those used in their families. These will be specific to the person themselves and may not be recognisable British Sign Language (BSL) signs. The majority of Deaf people with complex needs will not benefit from the support of registered BSL/English interpreters as they cannot follow what is being signed to them in BSL; they prefer to work with support staff from specialist deaf services who know their personal communication abilities and needs.

There are very few mainstream social workers/care managers and other medical/social care professionals who have any BSL skills, and even less who have experience of working directly with deaf people with complex communication needs.

Very few registered BSL/English interpreters have training in working with Deaf people with minimal language skills.

There is a severe lack of accessible and appropriate care services for deaf people in the community, for example Care at Home and Housing Support services. This is especially true for deaf people with complex needs. Therefore there is a need for specific, specialised care provision to be made available so that deaf people with complex needs can have any chance of accessing an equitable service with other deaf people and with their hearing peers.

Retention of staff for continuity of care for deaf people with complex needs

In order to meet the minimal Care Standards, all care staff have to have access to the appropriate levels of SVQ training.

All care staff working with Deaf people with complex needs should be trained to a minimum of BSL Level 2 – with ongoing further training when available and appropriate.

Organisations providing services to deaf people with complex needs must also ensure that care staff have access to additional training in order to provide appropriate care in other specialised fields, such as autism awareness, mental health, managing challenging behaviours, first aid, monitoring and dispensing medication. Staff training should also involve establishing links with agencies which work in other specialised fields, which can also benefit from the sharing of knowledge and experience.

The more specialised this training is means it has to be provided “in-house” as there are few specialist organisations who work with deaf people with complex needs in Scotland.

Lack of equality for deaf people with complex needs

Over the past 20 years, specialist social work departments for deaf people in general and for deaf people with complex needs in particular have closed and the services they provided have been “mainstreamed”; there have also been cuts made to other specialist support services. Many deaf people with additional complex needs are being let down by mainstream services and their health, safety and wellbeing is being put at risk.

There has never been a recognised career structure for social workers or other care professionals working with deaf people. This has meant that while other areas of social work/social care have provided pathways for staff to become senior managers and planners, the ‘voice’ of deaf people has never been represented at the forums which make decisions about future policy and funding.

Recent changes in the funding of care and support services have failed to take into account the specific requirements of making appropriate provision for the future care of deaf people with complex needs and there is a real danger that the few existing specialised services may be lost, because they are being compared solely with other, non-specialist services rather than being judged in terms of the work that they actually do.

The Scottish Council on Deafness recommends that:

1. Equality Impact Assessments should be carried out to ensure that the needs of deaf people with complex needs are included in all services.
2. The Scottish Government in partnership with local authorities, health boards and specialist deaf organisations look at the needs of deaf people with complex needs in Scotland and make recommendations on what services have to be available to ensure that these people live healthy, safe and satisfying lives.
3. When local authorities are setting rates for the personalisation agenda and self-directed support, they must take into account the cost of specialist services for deaf people with complex needs and ensure the necessary financial support is in place.
4. All public bodies involved in the procurement of services for deaf people with complex needs involve the deaf people in the planning and tendering processes. If renewing contracts, service user feedback will be sought before a contract is renewed.

What do specialist support services mean for deaf people with complex needs in Scotland?

Mabel

Mabel is a 50 year old woman who has been in specialist deaf residential care in Glasgow for almost 20 years. Before this, she lived with her mother who had found it increasingly difficult to manage Mabel's increasingly strange behaviour. Her mother had been advised to place Mabel in a local residential care home. This was not accessible to Mabel and could not fully support her.

Mabel has been profoundly deaf since birth, and was also diagnosed with having quite severe learning difficulties at an early age. Mabel lives in a signing environment in Hayfield, but her BSL skills and vocabulary are very limited. It is extremely difficult to have any sort of conversation with Mabel, as she tends to focus on a repetitive stream of names and common items.

A number of years ago she was assessed as having mental health problems, and has since undergone several periods of in-patient care both in mainstream and specialist psychiatric hospitals. However, because of her communication problems it has so far been impossible to give her condition a formal diagnosis, though it is possible that she may have a schizophrenic illness. She has been prescribed various anti-psychotic drugs over the years.

She has no recognisable friendships with other service users, but will approach staff on a regular basis and share with them. However, there have also been a number of incidents when she has become aggressive with staff and has even assaulted people at times. Because of the complexity of Mabel's multiple conditions, the main aim of the specialist deaf care service is to provide her with a secure, caring environment, where it is possible to avoid situations which may trigger her aggression, to monitor her mental health and support her in contacts with other care agencies. It is presently felt to be unlikely that Mabel will ever be able to live independently.

Hamish

Hamish is a 50 year old man who returned to live in specialist residential deaf care two years ago, having previously undergone a period of independent living training with the organisation 20 years ago, before returning to his home area where he had his own tenancy. Although on the face of it, Hamish appears to be quite an able person, he has difficulty with general health issues and a lack of insight into how his lifestyle has affected not only his physical well-being but also his life in general.

While living on his own, he developed diabetes, due largely to poor diet, and his condition deteriorated to the extent that he ended up having one of his legs amputated. At this point, he could no longer continue to maintain his independence and had to return to a care setting. Despite what has happened to him, he refuses to accept any of the advice that is offered to him from medical and care staff, and he continues to have a diet and life-style that could have very serious implications for his life. Even with continuing monitoring, support and encouragement, including ensuring that he takes his self-administered insulin injections, he has recently lost a toe from his remaining foot.

Although Hamish has the practical skills for independent living, he does not have an understanding of his health issues and has no insight as to what the safe management of his diabetes means to his being able to live a healthy, active life and that is stopping him returning to living on his own as to do so would endanger his life.

Alexander

Alexander is a 45 year old man who has lived in specialist deaf residential care for 20 years. As a child, he had attended a residential school for deaf children and was then placed in a long-stay psychiatric hospital, where he had no access to sign language.

When he first moved into the specialist residential care, he had very limited communication skills and practically no social skills or independent living skills. He also suffers from severe eczema and another as yet undiagnosed skin conditions over large areas of his head, hands and body, which requires the application of creams and lotions several times a day.

Although advancement with Alexander has been very slow, because of the extent of the depths of his problems and the fact that he started from a situation in which even the most basic of recognised communication was initially beyond him, he has made

great personal progress and has now achieved a situation of semi-independent living, though he will need continuing monitoring and support to help him with his physical health issues, to help him to maintain his social networks and his self-confidence, and to continue to improve his communication skills.

These three people all receive support from a deaf organisation that specialises in working with deaf people with complex needs. The organisation stimulates independent living by helping individual deaf people with complex needs to fulfil their personal potential and to become more active and self-reliant.

All three have had support/care from mainstream organisations or agencies, but have only existed until receiving specialist support from people who can help deaf people communicate their wishes and wants; even though they are not living “independently”, they are independent in what they are achieving in their lives.

For more information about specialist support services for deaf people with complex needs, contact:

Hayfield Support Services with Deaf People – Voice & Text Telephone: 0141 429 0335; General Email: mail@hayfield.org.uk.

Sense Scotland – Voice Telephone: 0)141 429 0294; General Email: info@sensescotland.org.uk