



## **Scottish Parliament Health and Sport Committee: Social Care Inquiry**

### **Written Evidence**

#### **Deafblind Scotland**

Deafblind Scotland's vision is a society in which deafblind people have the permanent support and recognition necessary to be equal citizens. Deafblind Scotland enables deafblind people to take their rightful place in their local communities and ensures their voices are heard at local and national government levels. Our objectives are:-

- To help deafblind people in Scotland live as rightful members of their communities and to encourage and support, contact and friendship between deafblind people and sighted hearing people
- To liaise with health and social service providers to make appropriate support available for deafblind people in Scotland
- To provide and encourage the provision of facilities for the support, education and personal development of deafblind people in Scotland
- To develop and maintain appropriate accommodation for the benefit and use of deafblind people
- To raise awareness within the public of the needs and contributions that Deafblind people can make to enable them to take up their role as participating citizens

We are a national charity and Scotland's principal authority on meeting the complex needs of individuals living with deafblindness. Through our services Deafblind people are enabled to have an independent life, possible through provision of specialist communication support access and advice; guidance in navigating self-directed support; information/formatting services; welfare rights advice and support; accredited training; health, wellbeing and skills development activities and a specialist guide/communicator service. DbS membership can be the crucial factor in determining whether a deafblind person is able to maintain an independent lifestyle. We work with members to build awareness of issues related to living with deafblindness. Members deliver deafblind awareness sessions with public bodies, employers, schools and community groups and we support deafblind people to contribute to our accredited training and employ deafblind/Deaf staff to run our SQA

and Signature accredited Guide/Communicator, BSL, tactile BSL training and Deaf people to work as Guide/Communicators.

### **Q1: How should the public be involved in planning their own and their community's social care services?**

It is Deafblind Scotland's understanding that there has been much work undertaken and clear policy and legislation available to guide the processes for engaging with the public. Generally, and at a community planning prioritisation level, we are aware that this work to achieve meaningful involvement of social care service users and where appropriate their carers has not been central to the process to date. It is our view that overall, engagement work is sporadic and not of a sustained nature. There has also not been the necessary consistent investment in supporting people to engage with the planning process, although we do appreciate that this position is improving, however much more needs to be done to ensure engagement is equitable. This is particularly so with regard to groups that have the least voice and are less readily able to advocate on behalf of their needs. For engagement to be meaningful for people with dual sensory impairment there would need to be determined commitment and associated resource to enable them to participate at any level of community planning of social care services.

People who are deafblind have substantial visual and hearing loss which causes extreme difficulty with communication, information and mobility. As a result deafblind people are amongst the least visible in society and many face multiple intersecting layers of discrimination through often being older, living with another long term condition or disability or being from an ethnic minority backgrounds where there is an elevated rate of visual impairment.

Sense's report highlighted the grave health inequalities and barriers faced by deafblind people on accessing health and social care. The report indicated that inaccessible information and lack of communication support are the key barriers currently preventing deafblind people from accessing these services. One in two (56 per cent) deafblind people have left a GP appointment having not understood what had been discussed. We believe this also to be the experience of deafblind people accessing social care support.

Although estimates on numbers of deafblind people are hard to determine accurate, in part due to framing of previous census questions and lack of research into the issue but also within Scotland, deafblindness is not a specific diagnosis and visual impairment and hearing loss or D/deafness are diagnosed separately through different clinical processes. However, based on global research it can be estimated that there is somewhere between 20,000 and 31,000 people in Scotland who face significant challenges with hearing and sight loss such as is described above. This is therefore a group that requires a voice, however to achieve this there is a need for investment in accessible community planning processes but also Guide Communication Support to enable people to access pre-engagement information, travel safely to and from participation opportunities and to be able to communicate through the assistance of a communication specialist when in meetings or other such planning sessions.

Currently not only are we not seeing this happen at a community planning level but neither is this happening at an individual care planning level. Despite the intent behind the Health and Social Care Standards, many of our service users are experiencing less of a say in their individual care outcomes than before. For example, within Self-directed Support assessments, although members are being asked for their views when decisions are being made we are finding that many members are having their hours reduced. This has meant that for many they are finding that they do have Guide Communication support to attend to necessary daily living tasks such as shopping or hospital appointments but not with regard to remaining socially connected. In this regard the intention behind SDS is failing as in many cases we are finding social work staff undertaking assessments who have little or no understanding of the impact of a dual sensory impairment and the profound isolation resulting from this. Workforce competencies around SDS assessments but in particular the needs of those with disabilities requires to be strengthened and individuals fully involved in planning their own support throughout the entire process and consulted at every stage to allow choice and control over the care they receive and ensuring what is important to each person is what is taken into account during assessment. In our experience it is vital that information provided is easily accessible and in their preferred format to ensure understanding and allowing them to make informed decisions regarding their support. Adequate time to prepare and book specialist communication support before assessment has also been an issue and recent recommendation about a case that went to the Ombudsman regarding a deafblind person's self-directed support decision found that best practice should be to give people with these significant disabilities 6 weeks prior notice of assessment visits. Although helpful this is currently only advice.

Although estimates of deafblindness place it at higher levels than many other disabilities that are more commonly understood the numbers of people requiring high levels of support hours are small and it should therefore be possible to ensure that some of the most vulnerable people in our society, many of whom have multiple disabilities, are able to have some quality of life through social care support. Many recent decisions taken following SDS assessments have left people in great distress. A number of composite case studies can be provided on request. These would be composite because many of our service users are anxious or fearful about challenging SDS decisions in case they lose more or all of their support hours. On reading this response it is important to not underestimate the level of vulnerability encountered by deafblind people and the lack of recourse that many feel they have when faced with decisions which negatively impact on their already daily challenging lives.

**Q2: How should Integration Joint Boards commission and procure social care to ensure it is person centred?**

At an individual level each persons' needs will be different depending on what is important to that individual. We have had a service user tell us one thing really important to them is having a home cooked dinner. It is vital that each person's human rights are respected in order that they feel improvement to their life. In our

experience deafblindness can cause individuals to feel extremely lonely and isolated and for them the most important outcome is to have opportunities for interactions with others and a sense of social connectedness and belonging. However service need is currently being assessed based only on 'Substantial and Critical' needs which does little to promote this basic human right. The right to 'participate in essential economic, social, cultural and leisure activities'.

At a community wide level there should be the full involvement of local communities and third sector providers, who best understand the needs of groups who often face the greatest challenges. Many, but not all providers have in place involvement mechanisms to engage with people who use their services, including often representation at a governance level. Using this grassroots knowledge voluntary organisations can make a great contribution to helping the public sector plan and deliver efficient and effective services. Often voluntary organisations provide services that act preventatively and support people to stay at home and within their own families and communities rather than requiring more specialist services. However, the tendering processes used in procurement of services themselves can often lead to competition within the sector and indeed create a conflict of interest in gaining an impartial sector view. Unfairly these procurement processes also only apply to the independent/voluntary providers and not to the statutory sector and due to tendering on many and often small contracts it places a significant administrative burden on a sector that often only receives resources for direct services. Some key issues include: the balance of focus on cost versus quality of services, the need for training and specialist knowledge to respond in a competitive way to tenders which as a result can favour larger organisations that can afford to employ staff with specialist tendering skills and very often tenders have specifications that have not been built around either the needs of the community or indeed informed by the feasibility of the practical implementation of the tasks set out. One factor that has changed over time is the move towards re-tendering of services, which may enable commissioners to make financial savings but do little to create a stable and experienced third sector workforce. This is also not in line with the principles of SDS as can be seen with the current framework arrangements, whereby if an organisation is not successful then they cannot be selected for some (or in some cases most) of the options within SDS. This does not align well with placing choice and control with the service user.

Working together with the third sector at a community level to commission services that the public themselves and evidence indicates are most meaningful in supporting people is critical. More selective, flexible and sustainable funding processes in line with commissioning priorities rather than tenders should be possible as is permitted within the Procurement Reform (Scotland) Act 2014. CCPS have responded to this and other opportunities to present alternatives and we would support the call for options such as Alliance Contracting built on trusted relationships to be applied in social care settings. Reliance on costs/efficiency as the key measure will not provide the outcomes necessary to address our current social care crisis as many of the positive outcomes that the often preventative approaches achieved by voluntary sector services will be spread across a range of sectors and further downstream from the input of support. It could be useful to consider historical commissioning and contracting patterns of practice such as those seen at the outset of Care in the Community, whereby many of new innovative services grew up from long term

relationships and joint planning between commissioners, the third sector and those with a lived experience. It was not a perfect process but one with intention to produce community led and outcome focused results based on the local knowledge of the key challenges and priorities for improvement.

Voluntary organisations can support the public sector throughout the commissioning cycle from providing insights and gathering evidence on community needs through to supporting and mobilising service users including those most seldom heard to engage with planning processes and within evaluation of services. Involving people with a lived experience of using services can in itself provide a therapeutic benefit in building skills and confidence as well as providing people with a socially valuable role.

The role of the Care Inspectorate needs to be reconsidered to enable them to look at how the Health and Social Care standards are being implemented not only within services and individual care but within commissioning practice which holds the key to unlocking the quality of those services.

**Q3: Looking ahead, what are the essential elements in an ideal model of social care (e.g. workforce, technology, housing etc)?**

- Recruitment and retention of a skilled workforce – raising the profile of pursuing a career in social care as a profession with a clear career pathway rather than a manual low skilled low paid job. Within our work at Deafblind Scotland our main workforce are Guide/Communicators, these are individuals that are trained to be the eyes and the ears of a deafblind person. To undertake this role they are trained as Guide Communicators within our Signature accredited training and thereafter go on to train in BSL 1 - 3, with many training to a higher communication standard such as BSL level 6, Tactile BSL and Deafblind Manual. Pay is also an issue, there is high expectations and responsibilities placed on a social care worker with SSSC professional registration, continuous personal development, adhering to policies and procedures with Adult Support and Protection, Child Support and Protection, Health and Safety, Manual Handling, Risk Assessment, Administering medication. Salary scales do not accurately reflect the requirements and commitment of the role or additional skills worker require to carry out in their job as mentioned above. Current hourly rates paid by most local authorities do not support the third sector to pay staff adequately and these differ from the higher rates paid to statutory sector staff who undertake the same or similar roles. These rates also do not take into account administration costs, assessments, progress/outcome reviews or engagement processes. Within Deafblind Scotland, many service users are very isolated and often a Guide Communicator and Deafblind Scotland administration staff are their only contact with the outside world. As a result, our organisation carries high administration and office support costs to ensure that a person can always reach someone if they need reassurance. This is a frequent daily need for some of our members using some assistive technology,

contactScotland or have enough hearing to use a telephone to make contact. Parity of pay between sectors but also full cost recovery for valued third sector organisations would be a clear way to resolve these issues.

- Early Intervention and Prevention– our experience of working with people living with dual sensory impairment has shown us that it is vital to make connections with people as early as possible particularly when they start to experience a loss of their second sense. For example, someone born Deaf who communicates using British Sign Language who starts to lose their sight perhaps due to Usher Syndrome will require to learn new or adapt their communication skills (Tactile BSL, Deafblind Manual). For many of our members both sensory impairments are acquired later in life which makes learning new skills to remain independent even more difficult. Early intervention is vital to ensuring individuals can continue to engage and remain part of society before their loss of sight and hearing makes it much harder to learn alternative communication. This would be true for individuals with many other conditions where early intervention and prevention can ensure they maintain the best quality of life possible. Investment in this area is crucial going forward to ensure social services can respond to demand placed on more specialist parts of the system and minimise reliance on these from individuals who have been enabled to remain independent for longer.
- Strengths focused and aspirational – services need to have ambitions for individuals to enable them to feel that it is possible to retain or rebuild skills and independence whether following an illness or when living with a disability/sensory impairment or to have enough aspiration to try a new opportunities or challenge and make new social connections that will enhance their quality of life. Where this is not possible, and people are living with a deteriorating and/or significantly life limiting condition, then they need to feel that any independence in actions or choice will be maximised as long as is realistic and even then some new experiences may be possible.
- Person, family and community centred (a whole system approach) – there already is much in place to support a person-centred approach but it is also critical to understand the individual within the socio-ecological context in which they live. Some may be part of a family which will have dynamic relationships that can fluctuate and impact positively or negatively on an individual's ability to manage, recover or grow in independence. Equally neighbourhoods, communities of choice as well as geography all matter alongside wider structural issues that can help or hinder a person's ability to thrive e.g. poverty, lack of access to opportunities such as employment, education or good quality housing.
- Rights based Accountability structures – ensuring that those that can be held to account for service planning and commissioning priorities as well as individual care focused decision making and those that hold them to account (e.g. Care Inspectorate) are focused on the human rights of the individual seeking care and support. Much legislation is in place to support this but as discussed above this is not the consistent practice. The Care Inspectorate needs to have powers they can easily and fully enact to allow them to

challenge and support improvement of social care commissioning that is based on priorities of commissioners rather than those that use services.

- A flexible and innovative range of third sector providers – to ensure that services are person-centred, services need to be able to respond to a very diverse range of needs. To achieve this they need to have the resources to implement change such as upskilling and training staff when needs change. In current procurement arrangements there is little room to cost for training and development of staff. Often those smaller, very grassroots and agile organisations can struggle to thrive under current procurement arrangements. This means that bigger organisations who may have systems and structures in place that can make them less flexible/adaptable and more difficult to change workforce direction can be unintentionally favoured. As before competitive tendering and the hourly rates can add to this challenge with bigger organisations being more able to absorb on-costs. This risks building a homogeneous social care sector which inherently undermines any possibility of creating a person, family and community centred model.
- A range of service modalities – Innovation poses its own challenges so care always needs to be taken to ensure that ‘new wheels’ are not constantly being invented but that well tried and tested approaches are supported. However, where there remains unmet need innovation has an important role. Smaller more agile organisations are often best placed to pilot test a new idea but support is often needed to turn round evidence quickly and to invest thereafter where this is shown to work. Unfortunately again and paradoxically within current tendering processes some solid service methods and approaches experience disinvestment whereas real grassroots innovation is stifled. Importantly learning from what works needs to be shared and guidance provided on evidence informed approaches. Decisions on support offered by social care services should not be left entirely to local commissioners without support who may have varied expertise in the area, particularly where there is some specialist knowledge required. Training, guidance and support is needed to enable local commissioners to make evidence informed decisions. There is increased understanding of the value of digital technology in offering health and social care support, however this needs further investment and well tested approaches strengthened and made more readily available. This is vital in reaching those higher numbers of people who cannot leave their own home due to mobility, disability or rurality. Where this shouldn’t be instead of access to human facing support, it can be used to reassure, prompt or offer additional support to people. In Deafblind Scotland our office support staff offer a life line to people who have no other way of undertaking tasks such as booking health appointment for themselves, a visit to the vet for guide dogs or arranging for house repairs.
- Longer term funding – the move over the years to shorter term tendering has not only stifled innovation by making it difficult for smaller organisations to thrive but recruiting and retaining high quality staff becomes extremely challenging. It is often not understood by providers that as a contract comes to a close and where there is no guarantee of continued funding then the

workforce may have to be put on notice of redundancy if no alternative work is available within an organisation. In these instances all too often staff members make the decision to move to more stable jobs within the statutory sector.

Overall, as a country we need to build up a social care sector that is valued in its own right and the specialism it brings is understood. How we pay, train and support the workforce says a lot about the value placed on them. Retention of Guide Communicators is a significant problem within DbS, a challenge that we meet by going the extra mile in public fundraising to prop up our commissioned services. As is well rehearsed the public are becoming less inclined towards or able to afford charitable giving leaving charities with even greater challenges ahead. Even despite efforts to fund training and more competitive rates of pay that recognise the high level of specialism within Guide Communication, we still find that many staff members once trained can find much better terms and conditions working within other sectors.

#### **Q4: What needs to happen to ensure the equitable provision of social care across the country?**

There are already national standards and national agreed outcomes in place to support equality of approach across the country. However, the reality is that there are great variances with how assessments are carried out and how Self-Directed Support is implemented in each local authority. This brings about anomalies in the packages of support approved depending on where the person lives, resulting in a postcode lottery. There requires improvement with continuity of standards across all areas to ensure equity of provision of care. Some local authorities are very good at prioritising and implementing legislation e.g. BSL Act and others are less rigorous which we have found to create inconsistency for individuals causing distress, frustration and anger amongst those that use services. Improvement on this would see a human rights based approach being adopted across all local authorities supported by adequate funding to meet individuals important needs. Consistent set of standards on the application and decisions around eligibility for SDS would be greatly welcomed.

One key challenge is in involving national third sector organisations which has been identified as being an issue by Audit Scotland. National services may not have the capacity to engage with every local authority but there needs to be a process of drawing down this experience where there are real areas of specialism. A failure to do this will result in those seldom heard voices who may only exist in small numbers in each locality being missed. This is the case for deafblind people as although the prevalence is higher than is often quoted overall (5,000 is estimate most often used), those with the highest level of need and poorest quality of life are only represented in small numbers in each local authority. However, arguably these are the individuals with the highest level of need. There needs to be a process to look at equitable commissioning that has standards set and has accountable lines at a national level bringing together local authorities to agree these; ensuring that those who face the greatest social and health inequalities are given a greater level of priority as recommended in the Christie report around addressing inequalities and Marmot's

work on universally proportionate approaches<sup>12</sup> Both of which still hold many of the answers on how to address inequalities.

The return of some core grant funding to support the growth and to sustain a healthy social care sector is essential to ensure that Scotland has good quality best available evidence informed services, available right across the country and not the current lottery of provision. The loss of core grants over the years has meant that many good quality third sector providers have been unable to continue. There is already in place standards and Inspection arrangements to monitor the quality of these providers and alongside the implementation and compliance of these the additional requirements placed on such organisations by SSSC have meant that third sector providers have higher levels of accountability than ever before and than many of their public sector counterparts but very little practical support in return. To create an even adequate social care system requires some investment in service and practice development. However to create an equitable service across the country will also need arrangements in place to support a jointly bought into approach to addressing inequalities – across sectors and across localities.

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<sup>1</sup> <https://www2.gov.scot/Resource/Doc/352649/0118638.pdf>

<sup>1</sup> <http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review>