# RNIB Scotland response to the Scottish Parliament Call for Views on Post-legislative scrutiny of the Social Care (Self-directed Support) (Scotland) Act 2013

### Introduction

The 2023 version of the RNIB Sight Loss Data Tool states that the number of people estimated to be living with sight loss in Scotland is 183,000. This is projected to rise to 214,000 people by 2032.[[1]](#footnote-1)

With rates of sight loss expected to increase and an ageing population, it becomes even more pressing for the Scottish Government and local authorities to ensure self-directed support (SDS) is set up to enhance the life opportunities and independence of blind and partially sighted people.

We welcome the post legislative scrutiny of the Social Care (Self-directed Support) (Scotland) Act 2013. This comes at a crucial time as new arrangements for community health and social care are being discussed as part of the proposed National Care Service.

This call for views asks one main question. Our response combines feedback from blind and partially sighted people on their experiences of self-directed support, as well as other information obtained from internal and external reports.

### RNIB Scotland response to "Please tell us what you, or the person you represent, think about the implementation of self-directed support to date."

Our response highlights key themes on the implementation of self-directed support (SDS):

1. Research findings on SDS
2. Transparency of process and eligibility criteria (including budgets and financial constraints; and long waits)
3. The importance of accessible information
4. Available data
5. Awareness of visual impairment amongst social care practitioners
6. Role of visual rehabilitation
7. Eyecare support pathway

### Research findings on SDS

Findings from the "My Support My Choice" joint research project [[2]](#footnote-2), published in 2020, highlighted key issues which blind and partially sighted people face in relation to SDS. This study was conducted before the COVID-19 pandemic by Self-Directed Support Scotland (SDSS) and The Alliance.

Whilst some people's experiences of support changed because of the COVID-19 pandemic, many of the themes highlighted by the report are still relevant today. For example, simply finding out about SDS remains a barrier for many blind and partially sighted people. Often this can come down to the provision of accessible information, but also depends on the workforce having the appropriate level of training and awareness of visual impairments.

Eye Clinic Liaison Officers (ECLOs) are well informed and skilled in providing holistic information and advice to people with sight loss, which includes making referrals onto other support services where required.

This helps overcome the multitude of barriers which blind and partially sighted people often face when attempting to navigate complex health, social care, and welfare systems. However, they are not funded in every health board area across Scotland so provision of this type of support remains patchy.

### Transparency of process and eligibility criteria

##### Eligibility criteria

Blind and partially sighted people also highlighted changes to eligibility criteria as another barrier to accessing SDS. One person was informed by their social worker at their last review that the criteria had changed, and their support package would now be reduced.

However, after receiving advice from a local independent information and support provider they were able to assert their needs and get the hours reinstated. Reflecting on their fluctuating experience of SDS, they said that the support independent organisations provide is vital to enable blind and partially sighted people to pursue their options under SDS.

Many spoke about having to fit within narrow criteria used in social care assessments, which can limit the prospect of using SDS creatively. This approach tends to focus on hours of personal care support required as opposed to a person's outcomes.

One person said this does not consider the full experience of blind and partially sighted people:

"There is a lack of consideration in terms of how a person manages a task when living with a visual impairment, and background factors. For example, I can hang my clothes up and put them on, but I can't see if they have stains on them. I don't need a person to physically help me with dressing, but I do need someone to make sure I am wearing clean clothes, and to work my washing machine. These tasks can be discounted when it comes to assessing the level of assistance required."

The same person also spoke about lack of consideration to the consequences should she not receive practical assistance with certain elements of daily living and personal care. For example, living with a visual impairment means a person may be unable to notice hazards or things which could present a risk to their health and safety at home. This could result in a potentially unhealthy or at worst, dangerous living situation. SDS reviewers may overlook aspects of everyday living such as whether someone with sight loss would know if food was safe to eat or whether it had gone off or was mouldy.

Others spoke about the preventative role having the right support package in place can help with:

"If I got a package together, I could get extra support to give me a bit freer time to myself. … that's the trouble with self-directed support, it was all meant to be positive, but it ended up becoming just a risk adverse process whereby people were prioritised if there was a high risk of falls or stumbles, that kind of thing at home, rather than identifying what was important to them."

Some people found the entire process undermined their independence. For example, being seen as too self-reliant isn't a good thing. This quote exemplifies this:

"I was told I wasn't disabled enough" … she continued … "I was told oh, you are able to lift your leg into the bath. I'm quite good at lifting my leg into the bath, but it's my balance makes the risk of falling higher for me. … the person assessing me couldn't understand that."

Others spoke of lack of consistency of staff and not being able to speak to the same social worker when making SDS enquiries. One person stated:

"I was speaking to various people when I got through (to the social work department) and then nobody seemed to know who was meant to be doing it. … I was told you need to wait in the queue for a social worker to sign it off. … I got fed up waiting."

##### Budgets/Financial pressures

Blind and partially sighted people highlighted common themes of budgets and financial pressures as barriers to achieving the level of independence they require through SDS. Travel costs, for example, particularly for those living in rural areas, may make it more difficult to access support and services. More acknowledgement and accommodation of travel costs in their SDS budgets would help. Many claimants would also welcome assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain travel pass.

Additional costs are not considered when budgets are allocated for support. For example, someone may require a carer or Personal Assistant (PA) to attend activities or appointments with them, but companion/support costs are not always covered.

There is a need for social care professionals to consider the impact on people's mental and physical health when changing packages and eligibility criteria. Reductions in SDS budgets and tightened eligibility criteria can pose serious risks to blind and partially sighted people on low incomes who access or are trying to access social care. It can lead to people having to manage without support or making unacceptable demands on family and friends to assume roles as unpaid carers.

##### Long waits

Long waits emerged as a common theme during discussions with those we spoke to in relation to this call for views.

Some reported waiting longer than six months for a needs assessment or review following a request; others had waited longer. One individual reported waiting for two years to get a care plan signed off. When she contacted her local authority, she was told that her support plan is waiting to be signed off by a social worker. However, she still does not have any information about the plan and what it contains.

We spoke to a person who stated their social care needs went unmet during ongoing lockdowns of the COVID-19 pandemic as resources were targeted elsewhere.

There is still a lack of clarity about whether support will be reinstated as this quote demonstrates:

"My support virtually vanished overnight when the first lockdown of the coronavirus pandemic started. I contacted the support provider but was unable to pursue this any further. There were confusing messages about whether support could be provided because it was classed as 'social support', and everything had closed down. I didn't know if I had time allocated to me and if I could use it for anything else."

Many also spoke of the barriers to accessing information in the right format (see more below).

### The importance of accessible information:

Having the right information prior to any conversations or assessments is crucial for blind and partially sighted people. It enables them to prepare any information required or questions beforehand.

Not receiving information in a timely, accessible manner can lead to significant challenges particularly when it comes to considering options available under SDS.

One person said that she could not access information on SDS from the local authority website as it was only available in PDF format and her screen reader was unable to read it out. When she contacted the telephone number to request an accessible format the person copied and pasted the text from the PDF into a Word document, but it wasn't formatted correctly so was still inaccessible to her.

The lack of accessible information has led to frustration:

"The whole process was a bit flawed in my respect because I feel I wasn't given the proper information in the first instance to deal with my own support."

The findings from the My Support, My Choice (MSMC) report also found that blind and partially sighted people were less satisfied with the information they received about SDS compared to other research respondents overall.

For some blind and partially sighted people, information is best provided face-to-face. More than one conversation may be needed, and people should have access to independent advocacy and support during meetings if they want. Social work professionals should proactively follow up with people after assessments and reviews to address any outstanding concerns.

The benefits of having early, high-quality, and accessible information cannot be understated, including reduced demands on staff time because applicants are better prepared for discussions and assessments.

RNIB Scotland's research report, "Communication Failure"[[3]](#footnote-3), published in 2020, found significant shortcomings when it came to blind and partially sighted people being able to access health information in an accessible format. Within the social care system there is also a need to recognise the fundamental role accessible information plays in enabling blind and partially sighted people to exercise genuine choice and control over their care and treatment needs.

### Available Data

There are concerning gaps in SDS data gathering and analysis. The data classifies people with sensory impairments alongside people with physical disabilities which may not give a consistent picture of the actual numbers of people with sight loss using different options under self-directed support.[[4]](#footnote-4)

Another factor worth considering is that currently there is no national dataset available of people living in Scotland who are registered as Severely Sight Impaired (SSI) or Sight Impaired (SI). The Scottish Government last published national statistics on people certified as Visually Impaired (CVI) across Scotland as long ago as 2011, the figures relating to 2010.[[5]](#footnote-5) Having an up-to-date record of everyone registered in Scotland as SSI or SI could help target resources more effectively and also help to report on numbers who may be using the options under SDS.

### Awareness of visual impairment amongst social care practitioners

Blind and partially sighted people have told us that social care/work practitioners do not have enough awareness of how a visual impairment can impact on a person in daily life. This quote highlights why this is important:

"They're probably over-worked as well, but yet again they need to still treat people with respect and understand that it's important to ask us how our impairment impacts on us, rather than deciding what we need."

It was noted that assessments need to consider wider factors, instead of highlighting what a person cannot do.

"We should be more enabled to do things, yet the system is set up to make you highlight the negatives about yourself and doesn't recognise that barriers are often encountered because of the attitudes of other people or environments which aren't inclusive."

There should be more focus on tasks a person wants to do and building support around this.

This highlights the benefits of good conversations and consistent relationships with social workers, including direct and varied lines of prompt communication. It is important that social workers have a good breadth and depth of knowledge about SDS and local services, can demonstrate good listening skills and empathy with blind and partially sighted people, including taking time to listen and become familiar with their needs.

Others noted that maintaining independence is a key factor in enabling them to enjoy everyday life. However, there is sometimes a concern that if a person is seen as too independent, they will not qualify for support.

Others spoke of lack of flexibility in using direct payments. For example, one person spoke of the importance of respite for her and her Guide Dog. A PA could allow her Guide Dog to have breaks as well as the opportunity to rest and run free. This is crucial for the ongoing welfare of the Guide Dog and their owners, see quote on this issue here:

"They didn't seem to understand that sometimes I need to be away from my Guide Dog. They don't understand it's not fair for her to be with me 24/7 and she needs time off for her own welfare – she needs someone to take her out for a free run for an afternoon, but I don't have someone to do that."

### 6. Role of visual rehabilitation:

Sight loss or a deterioration in a person's sight can be an overwhelming and challenging time. Everyday activities can seem like daunting obstacles to overcome. Making a cup of tea; shopping; crossing a road safely; reading post; how to cook; how to continue working, all of these and many other everyday activities can feel insurmountable.

Visual rehabilitation plays a key role for blind and partially sighted people, yet its provision is patchy across Scotland.

There is also a lack of awareness of the role of visual rehabilitation within the social care system. People need to receive the right support at the right time. Early support means that people can learn and develop the right skills to ensure that they are able to continue with the work, activities and the way of life that is crucial for them.

Some spoke of the inter-connectedness between visual rehabilitation services, within self-directed support and how it can enhance independence.

For example, a person spoke of their experience of having a Personal Assistant (PA) to be able to assist her participate in activities related to her social and professional life. She can use a long cane for navigation when out. However, having a PA enhances her independence as she has the right level of knowledge and skills to provide the appropriate support she needs. It means she can participate actively in employment, training, and other social opportunities and gives her the freedom to be able to choose what activities to participate in.

Accessing social care, including visual rehabilitation, can build confidence and enable independence, as well as avoid health costs further down the line.

The positive impact this has cannot be underestimated. RNIB Scotland regularly hears from people who report feelings of isolation, frustration, depression, and fear over their future. Visual rehabilitation and self-directed support can open opportunities for blind and partially sighted people ensuring their ongoing needs are met and their right to Independent Living is fully realised.

Without this support people can lose confidence, independence, and become more socially isolated and lonely. This can lead to increasing problems with mental health as well as a reduction in physical activity.

Mental wellbeing is often a factor reported to RNIB services, people that are unable to access rehabilitation face losing access to the things that once brought them joy, things like exercise, days out with family/friends, or watching a football match.

Local health and social care services must be able to refer and/ or signpost to third sector advice line support, self-directed support, and peer support groups as part of a wider approach to enable blind and partially sighted people to live well.

### 7. Eyecare support pathway

Such a wider approach is backed up by RNIB's eyecare support pathway which has been developed in partnership with NHS, social care and the third sector.[[6]](#footnote-6) The pathway outlines four key stages so that people with sight loss get the right support at the right time from initial diagnosis to ongoing support, these include:

* Having my initial appointment
* Having my diagnosis confirmed
* Support after my diagnosis
* Living well with my condition

The eyecare pathway resource provides guidance for those providing services as well as for people living with an eye condition at various stages of their eye care journey.

Findings from the "My Support My Choice" research suggests that some blind and partially sighted people are not able to use SDS as flexibly as they should, which can negatively impact on quality of life and enjoyment of their right to independent living and equal participation in society.

This flexibility could be in how people are empowered and supported to use their SDS, but also relates to people's ability to have ongoing conversations with social work professionals, and adjust systems accordingly on a regular basis:

"When you just find out you're partially sighted, it's all new and you're not really prepared to ask the right questions and you don't really know what to do. As it gets worse, you don't really hear from anyone; there's no follow up."

This can lead to future problems further down the line. Lack of follow up leaves many people in limbo, uncertain what support they may be able to access, whilst as many sight loss services are stretched beyond their capacity, there can be long waiting times to access any kind of specialist support.

The eyecare support pathway could be used to ensure that people know what to expect and can be used by service providers to measure whether they are delivering the support people with sight loss need. Such models could also be applied to self-directed support and to the integration of health and social care.

The eyecare support pathway is about enabling a person to live confidently with their sight loss condition and make sure they can access information, and support they need throughout life. It also embeds the rights of individuals to actively participate and take control of their support. This is fully compatible with the four fundamental principles of SDS of participation and dignity, involvement, informed choice, and collaboration.

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1. See [RNIB Sight Loss Data Tool - statistics on sight loss | RNIB | RNIB](https://www.rnib.org.uk/professionals/health-social-care-education-professionals/knowledge-and-research-hub/sight-loss-data-tool/) [↑](#footnote-ref-1)
2. My Support My Choice: Blind and Partially Sighted People's Experiences of Self-directed Support and Social Care Thematic Report, December 2020 available as a PDF from: <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/12/ALLIANCE-SDSS-MSMC-Blind-and-Partially-Sighted-Report-Dec-2020.pdf>

 [↑](#footnote-ref-2)
3. 'Communication Failure? Review of the accessibility of health information for blind and partially sighted people in Scotland' (RNIB Scotland, 2020): <https://media.rnib.org.uk/documents/Communication_Failure.pdf> [↑](#footnote-ref-3)
4. <https://publichealthscotland.scot/publications/insights-in-social-care-statistics-for-scotland/insights-in-social-care-statistics-for-scotland-support-provided-or-funded-by-health-and-social-care-partnerships-in-scotland-202122/self-directed-support/> [↑](#footnote-ref-4)
5. A National Statistics Publication for Scotland: Registered Blind and Partially Sighted Persons, Scotland 2010, Scottish Government, 2010 at <https://www.gov.scot/publications/registered-blind-partially-sighted-persons-scotland-2010/> [↑](#footnote-ref-5)
6. RNIB Eye Care Support Pathway report can be downloaded as a PDF from: <https://www.rnib.org.uk/documents/2078/APDF-IN230702_Eye_Care_Support_Pathway_Report.pdf> [↑](#footnote-ref-6)