

R N I B

Scotland

See differently

**Royal National Institute of Blind People
(RNIB) Scotland Response to the Scottish
Government National Care Service
consultation**

Introduction

The Royal National Institute of Blind People (RNIB) Scotland is the country's leading charity working with blind and partially sighted people. We support children and adults with sight loss and help them to live full and independent lives, campaigning for their rights.

In 2010, the date of the most recent figures published by the Scottish Government, the number of people registered as blind or partially sighted in Scotland was reported to be 34,492.¹ Research suggests that around 10 per cent of eligible people do not register making the true figure closer to 40,000.

Around 178,000 people live with a significant degree of sight loss in Scotland, around 4,300 of which are children and young people.

This number could eventually double unless we act to prevent avoidable sight loss. The rise of sight threatening conditions such as diabetes and an aging population will increase the number of people affected by sight loss unless action is taken.

RNIB Scotland welcomes the opportunity to respond to this consultation as we want to see blind and partially sighted people receive timely social care services that is delivered by qualified staff, is of a high consistent standard and is sustainable, well-resourced, and respected. These services should successfully enable independence and wellbeing.

RNIB Scotland considers it vital that the National Care Service consultation puts people with sight loss at the heart of decision making, leading to timely treatment and support.

¹ A National Statistics Publication for Scotland: Registered Blind and Partially Sighted Persons, Scotland 2010, Scottish Government, 2010.

The consultation poses a selection of questions; to highlight key points relating to sight loss we have replied to Questions 1, 2, 3, 9, 11, 14, 16, 35, 53, 64, 68, 73 and 91. The replies are based on previous RNIB/RNIB Scotland surveys, public consultation responses, literature review and specific consultation for this response.

In addition, an important aspect of this consultation process was to ensure that we gathered lived and living experience directly from blind and partially sighted people, to convey strong evidence of how health and social care is impacting on their lives. Anonymised quotes are presented throughout this document, including three case studies (from pages 21 to 23).

RNIB Scotland responses

Key points

To see positive change for blind and partially sighted people within social care, there needs to be:

- Services which are equitably provided no matter where people live in Scotland and which are delivered to a good and consistent standard.
- A care service that considers the whole person - holistic and human rights based.
- A health and social care workforce which is provided with compulsory training to enable them to assist and guide blind and partially sighted people in an appropriate manner, which is person-centred.
- Accessible information for blind and partially sighted people about their rights and services they are entitled to, including access to support/ knowledge for self-management.

Question 1: What would be the benefits of the National Care Service taking responsibility for improvement across community health and care services?

Currently, people with sight loss are not able to consistently access the social care support they need, at the time they need, to maintain their independence. Services are inconsistent between local authorities due to poor processes, differing priorities and resources, lack of guidance or lack of regulation.

There is therefore a need for a consistent service approach throughout Scotland rather than a postcode lottery with varying degrees of support, and different waiting times.

One respondent gave us their opinion about the new proposals:

“In principle, a National Care Service is a good idea. Connections mean that whenever people come into the system, it has a coordinated approach. I say this in theory, as it is great to come from a centralised point - but it can be dangerous, as the personal side of care can potentially not be as specific. With people not being held accountable - there needs to be a balance.”

A lack of consistency can lead to frustration across the health and social care sector, with some individuals feeling “bothersome” in consequence.

Evidence suggests that people with sight loss are left feeling confused about what is available to them. This is also in part due to a lack of accessible information, as a respondent shared with us:

“There is a lack of accessible information which is leading to [my friend] having the fear of asking for help... and being supported to be independent. Ensure that people who have these challenges shouldn't feel ashamed... and bothersome.”

Individuals may also be reluctant to seek assistance from social care, for fear of being put into a care home, rather than the focus being on supporting independence. Blind and partially sighted people have also shared with us that having a support worker can be seen as a failing, as one respondent said:

“I sometimes feel quite alone because I feel like I am one of few visually impaired people who uses a support worker, as it is seen as a failing. So, to meet other people that use this service is incredibly important and to also learn the pitfalls and positives of this kind of system.”

Social care support should be a way of enabling a person's life, not hindering it. More transparency and education are needed to give people the confidence to seek the support they need to build their quality of life.

Health and social care should be accessible to all, no matter where they live, with more consideration made about what information is available. If there was more consistency, then people would know what to expect

from a national service, including their rights to access or retain support when needed. This is conveyed in an example given by one of our respondents who is blind:

“... When my husband passed away who had a visual impairment, my support package was almost cut in half and then I had to fight [for it to be retained] when I moved area as my requirements were still there.”

A centralised system could defer care packages to different localities, with pathways of care retained no matter where a person lives/moves to. National funding could also assist with this, so that local areas are provided the equivalent amount of financial support dependent on population size, to provide support for those who need it. This could also include a central complaints system, which ensures accountability.

Question 2: Are there any risks from the National Care Service taking responsibility for improvement across community health and care services?

A nationally integrated health and social care service should have a coordinated approach, meaning that when a blind or partially sighted people comes into the system, it is centrally logged and centrally managed. However, the right balance needs to be struck, and a national service should not be a one-size-fits-all approach - it needs to be equitable and person-centred.

We want to ensure that the public service “pyramid” on page 20 of the consultation, shows a link between local societies and third sector services. For example, our Eye Clinic Liaison Officers (ECLOs) provide emotional and practical support to patients from the point of diagnosis of an eye health condition. This service is provided throughout the patient’s journey and is critical to their mental health and wellbeing. An integrated service is essential to ensuring that patients do not fall through the gaps.

In addition, as one respondent shares:

“I have a query about the one size fits all approach, so when you apply it to the rural areas it’s difficult. If you start in the rural areas and make it fit cities, rather than the other way round, this would be better.”

Local considerations and/or adaptations should always be considered when establishing the National Care Service.

The third sector should be an essential component of the National Care Service - working collaboratively to support individuals who require care.

National and local societies provide a range of services and support that greatly impact positively on an individual's health and wellbeing - the coronavirus pandemic is a clear example of how the third sector demonstrated initiative and drive to continue service provision when other services had to be paused or cancelled. There needs to be inclusion of this sector at board level, as well as being seen and acknowledged as an established route of care between primary and secondary care.

Question 3: If you or someone you know needed to access care and support, how likely would you be to use the following routes if they were available?

GP or another health professional

GPs are more than just a first point of call for health concerns, they are a community-based service with access to local Links Workers and other support networks within the locality. As shared with us:

“... [GPs] not just a “one stop shop” of just going to see a GP, it could be that you meet other people within that system... It's not just about seeing them anymore.”

Understanding a person's needs is essential and GPs who have long-standing relationships with their patients, have built good foundations of trust. People with sight loss value the interpersonal skills that their local GP demonstrates, who not only understands their healthcare needs, but also their accessibility needs. This was clearly demonstrated during the pandemic, with most blind and partially sighted people requesting to see their GP to have the COVID-19 vaccine administered. However, the pandemic has caused additional strain on community-based services, as explained by one of our respondents:

“The GP service is under stress - I'm diabetic, so I'm aware that my eye conditions are multiple - and I know that people are under strain, but people work in silos and don't look at the whole person, the whole condition - it's all separate. It's an inability to do things - it's an investment not a drain.”

Communication can easily breakdown when there is a lack of sensory impairment awareness and understanding from health and social care

staff, with simple adaptations such as sighted guiding, causing great barriers to better person-centred care.

Accessible buildings give blind and partially sighted people the confidence to attend a GP and hospital appointment independently. Further assistance such as clear audio announcements at reception is required when entering an unknown building to ensure that patients access the required department. In some cases, people with sight loss have not been greeted appropriately by healthcare staff leading to individuals being confused and frustrated. One respondent told us:

“Even when greeted at the eye clinic or hospital, there is no right guidance.”

Unless health and social care staff have good communication skills, it can be virtually impossible for people with sight loss to follow what is happening in their appointment. One respondent suggested:

“Training for health service staff about disability support.”

In addition, accessible information about the processes and procedures of service delivery and treatment should be provided to people with sight loss in advance - this allows them time to take control of their own healthcare. However, blind and partially sighted people are still faced with barriers, leaving them in vulnerable situations, as one respondent explained:

“When having a new operation, everything was inaccessible, leaflets about the operation, food etc.”

There are no hard and fast rules on how to assist people with sight problems; however, sight loss awareness training would assist health and social care staff when dealing with patients with sight loss.² Just being aware of the possibility that the person you are speaking to has sight loss and may also be hard of hearing would make a difference. For example, when healthcare staff know a patient has sight loss, a personal greeting can give reassurance.

² Guiding a blind or partially sighted person, RNIB
<https://www.rnib.org.uk/information-everyday-living-family-friends-and-carers/guiding-blind-or-partially-sighted-person>

- **Speaking to someone at a voluntary sector organisation, for example my local carer centre, befriending service, or another organisation.**

The coronavirus pandemic has brought everchanging situations and uncertainty. Social connections have been put on hold due to physical distancing requirements and lockdown or localised COVID closure of social centres, hospitality, and other recreation venues. Access to the internet enabled our Community Connect team to continue to engage with Connect members who were feeling isolated and alone, by organising daily/weekly/monthly social connections via online platforms, which allowed people to stay connected.

RNIB conducted a UK-wide Impact Survey³ in May 2020, to understand the impact of the coronavirus pandemic on blind and partially sighted people's lives. It stated that some respondents reported positive and negative experiences, particularly where they were digitally enabled:

“All the webinars and focus groups set up by organisations means I have been talking to more people than I normally would before lockdown.”

“Video calling Zoom is a fab app but as soon as there is more than two people, I can't tell who is talking and believe it or not it makes me feel even more useless.”

The voluntary sector can be the “go-to” point of call for general queries from benefits and support, to campaigning about a lack of transport. Our Communication Failure? report⁴ found that some people with sight loss only found out about their entitlement to access appropriate formats about their health information after speaking to our organisation, as explained:

³ Impact Survey, RNIB May 2020

<https://www.rnib.org.uk/campaigning/priority-campaigns/inclusive-journeys/effect-lockdown-and-social-distancing-blind-and-partially-sighted-people>

⁴ Communication Failure? Review of the accessibility of health information for blind and partially sighted people in Scotland, RNIB Scotland, February 2020

<https://www.rnib.org.uk/sites/default/files/Communication%20Failure.pdf>

“Yes [I did know I could request health information in an accessible format], but only because I was told by RNIB Scotland staff.”

In addition, other useful resources including emotional and practical support at the point of diagnosis, were only highlighted for individuals following communication with third sector organisations, as in the case below:

“[ECLOs] ... are immensely supportive and knowledgeable and I was then aware of what is available to me, and how the ophthalmic service works... But I didn’t find out about this service within the hospital, I found it difficult to get the information. I got the details I needed from RNIB.”

Peer support was also recognised as an important component of seeking recommendations about local and national services, as one respondent shared:

“I would also ask friends if they knew someone I could speak to. Peer support is incredibly important - you learn the pitfalls and the positive ways of using the system. Understanding how you access the system.”

Using a website or online form that can be used by anyone in Scotland

Levels of digital uptake can be significantly lower for people with disabilities.⁵ Accessing online information, for example, filling in forms online, can be very time consuming or completely inaccessible.⁶ Visual barriers such as inconsistent font sizes prevent blind and partially sighted people from accessing information with ease. One respondent explained:

“Websites are very complex to navigate in general so when you have sight loss of any degree it becomes harder. It would be good to have a button to press so that the website becomes less busy and shows simple text.”

Listening to people’s experiences of accessible websites is a simple and inclusive way of identifying changes needed to ensure online information is accessible to all. It is important to carry out testing with end-users who

⁵ Spreading the benefits of digital participation, The Royal Society of Edinburgh, April 2014 <http://www.rse.org.uk/wp-content/uploads/2016/09/Digital-Report-High-Res-EQ5.pdf>

⁶ Ibid.

use health services.⁷ Checking for potential accessibility issues during web-building ensures that accessibility issues have been considered as one respondent agreed:

“[We need] Better user testing of websites.”

Digital adaptations to healthcare are advancing in Scotland.⁸ In the future this could reduce the need to attend physical appointments. There is an opportunity for blind and partially sighted people to be involved in future discussions about creating a fully accessible digital healthcare service. As one respondent suggested:

“Online vision services – to make a repeat prescription [online], could be considered or standardised.”

Question 9: For each of the below, please choose which factor you consider is more important in establishing a right to breaks from caring. (Please select one option from each line. Where you see both factors as equally important, please select ‘no preference’.)

- **Standardised support packages versus personalised support**
- **A right for all carers versus thresholds for accessing support**
- **Transparency and certainty versus responsiveness and flexibility**
- **Preventative support versus acute need**

We have no preference to declare in terms of the above bullet points, however, we feel it is valid to point out that many blind and partially sighted people we engaged with throughout this consultation process, told us that their main carer is a family member or partner. As highlighted further here:

“My husband is my carer and has been for a long time. He does a lot of my financial things. I have several disabilities - dyslexic, brain lesion, I have increasing sight loss, I am deaf and wear two hearing aids. I can function pretty well with the support of my husband but would need support if he wasn’t around.”

⁷ Website accessibility, RNIB <https://www.rnib.org.uk/rnib-business/website-and-apps/website-accessibility>

⁸ Scotland’s Digital Health and Care Strategy: enabling, connecting and empowering <https://www.gov.scot/publications/scotlands-digital-health-care-strategy-enabling-connecting-empowering/pages/3/>

Blind and partially people, and the people who care about them, can be uninformed about their options within adult social care and their rights to services - including respite care. This can put additional strain and pressure on households, with unpaid carers taking on additional responsibilities to look after their loved ones, as well as impacting on the independence of the person being cared for. As one example highlights:

“My mum is my main carer - (before the pandemic) I received two hours of support, two days a week (Wednesday and Friday morning). I would go into town with my support worker to the shops and go for drinks. I’ve really relied on this service as I’ve used it for seven years. I found it difficult as it felt like “cheerio, see you after the pandemic” - I felt very angry and it didn’t help my family.”

The pressure on families has vastly increased following the first pandemic lockdown in March 2020 - as Carers Trust Scotland reports, “Many unpaid carers found that they were spending more time caring, with less opportunity to get a break. Many felt the needs of the person(s) they care for had intensified, and found their responsibilities increasing because of other services being paused or closed. This impacted on unpaid carers’ mental and physical health.”⁹

Question 11: To what extent do you agree or disagree with the following statements?

There should be a nationally-consistent, integrated and accessible electronic social care and health record.

Accessible health information is crucial and the requirements of the Equality Act 2010 and Patient Rights (Scotland) Act 2011 should be met. The Act sets out the responsibility of the NHS to provide accessible information, including the requirement that “Communication about a patient’s health and wellbeing is clear accessible and understood”.¹⁰ A Charter of Patient Rights and Responsibilities¹¹ accompanied the Act. This summarised the existing rights and responsibilities of patients using

⁹ COVID-19 in Scotland 2020-21, Carers Trust Scotland
<https://carers.org/policy-and-strategic-influencing-in-scotland/covid-19-in-scotland>

¹⁰ Patient Rights (Scotland) Act 2011, Scottish Government
<https://www2.gov.scot/Topics/Health/Policy/Patients-Rights>

¹¹ Your health, your rights - The Charter of Patient Rights and Responsibilities, Scottish Government, 2012.
<https://www2.gov.scot/Resource/0040/00407723.pdf>

the NHS in Scotland, setting out that “You have the right to be given information about your care and treatment in a format or language that meets your needs.”

At present, Health Boards are not dealing consistently with how information is sent to blind and partially sighted people. Requests for accessible formats are not being correctly managed or not logged centrally to enable consistency.

The effects of not receiving information in a preferred and accessible reading format should not be underestimated. This is leading to people with sight loss feeling unable to take control of their own health needs whilst their patient confidentiality can be compromised.

This was discovered through research for our “Communication Failure?”¹² report which found that blind and partially sighted people lacked confidence when considering requesting accessible formats from their health service. This was put down to feeling “a burden” or not wanting to be seen as “difficult”. They do not feel that they can enforce their rights to access information, as one respondent explained:

“No [I do not feel confident], because I worry I’m not worthy enough as I can just about manage with standard print for short lengths of time.”

Some respondents expressed a lack of trust in the health service and instead used their own supportive technology to make documents accessible at home, as one respondent explained:

“It’s easier to do it myself on a scanner so I don’t ask for information. If you’re ringing, they wouldn’t be there.”

Patients rely on good communication to ensure that they understand their health information and needs. For most people this is achieved through printed information, but for a person with sight loss, printed information is often inaccessible. Around 178,000 people live with a significant degree of sight loss in Scotland, so the need for accessibility is high.

We welcome the new Once for Scotland Electronic Patient Record within ophthalmology, as the first of its kind in Scotland. This will lead to better, consistent information, that will provide accurate documentation of what

¹² Op cit, Communication Failure?, RNIB Scotland, 2020.

accessible formats blind and partially sighted people. In addition, we can see the benefits of a national system, which may provide a more consistent log of requirements.

Question 14: What elements would be most important in a new system for complaints about social care services?

Our Communication Failure?¹³ report research asked people with sight loss, “Do you feel confident to request and/or complain when you have not received your health information in the correct format?”, people fed back to us about lacking confidence when considering requesting accessible formats from their health service. This was put down to feeling “a burden” or not wanting to be seen as “difficult”.

Some respondents expressed a lack of trust in the health service and instead used their own supportive technology to make documents accessible at home, as one respondent explained:

“It’s easier to do it myself on a scanner so I don’t ask for information. If you’re ringing, they wouldn’t be there.”

Due to a lack of awareness and understanding of what accessible health information is available to them, some blind and partially sighted people were left feeling disengaged and disempowered. More work must be done to ensure that all accessible options are clearly stated, providing people with sight loss with the information they need to manage their healthcare needs.

Question 16: Should a National Care Service use a measure of experience of those receiving care and support, their families and carers as a key outcome measure?

Feedback and input from service users and their carers is invaluable and would provide the National Care Service with deliverable markers and measures that will ensure that services are delivered ground-up, rather than top-down. Health and social care should be people-led, with lived experience at the heart of service provision, with the flexibility to adapt services that are person and relationship-centred.

The COVID-19 pandemic only highlighted frustrations within social care when services were paused. People with sight loss received no consultation or feedback about when the service would be resumed and

¹³ Ibid.

were left feeling disengaged and disempowered. A lot of learning can come from these situations, as conveyed by one of our respondents:

“We have to stop social care being de-prioritised due to issues like the pandemic. People were as disabled as they were, even during the pandemic - so it’s criminal that social care support was stopped - this was awful. Listening to people on RNIB calls... people’s mental health was affected. Even during lockdown, people could have (been supported to have) gone out for a walk, and not stopped. I don’t think the pausing of services should ever happen again.”

The voice of lived experience is essential, including people who live with sight loss and/or a sensory impairment. Without acknowledging these personal stories, services will become detached from the reality of how health and social care impacts on people’s daily lives - but by including individual accounts, this information can be used to implement change and provide innovative responses.

Question 35: Should the National Care Service be responsible for overseeing and ensuring consistency of access to education and professional development of social care nursing staff, standards of care and governance of nursing?

At present, the wider social care workforce isn’t trained as a compulsory measure to assist people with sight loss, so the total workforce isn’t used effectively – as a result, assessments are poorer (both for rehabilitation and care needs), sight loss may go unrecognised, and services are inappropriate.

Consistent sensory impairment training for all social care nursing staff would be invaluable - whether this is the responsibility of the National Care Service or NHS - a better approach to training support, to provide sighted guiding training, for example, would be useful.

Unless healthcare staff have good communication skills, it can be virtually impossible for people with sight loss to follow what is happening in their appointment. One respondent suggested:

“Training for health service staff about disability support.”

There are no hard and fast rules on how to assist people with sight problems; however, sight loss awareness training would assist

healthcare staff when dealing with patients with sight loss.¹⁴ Just being aware of the possibility that the person you are speaking to has sight loss and may also be hard of hearing would make a difference. For example, when healthcare staff know a patient has sight loss, a personal greeting can give reassurance.

Question 53: How should we ensure that whatever mental health care elements are in a National Care Service link effectively to other services e.g. NHS services?

RNIB has been delivering an Eye Clinic Liaison Officer (ECLO) service across the UK for over twenty-five years giving a wealth of expertise and knowledge. ECLO services enable patients to access critical early intervention support to help them to remain independent, manage their sight condition and to access both local and national support services.

Sight loss can have devastating consequences for individuals. Our RNIB Patient Experience Research¹⁵ suggests that many patients leave the eye clinic with little understanding of their eye condition, how best to maintain any functional vision they may have, and how best to live their lives with sight loss. As many as 77 per cent of patients said they would not have found or accessed support outside the hospital without the ECLO.

The service works to ensure anyone with a sight loss diagnosis can access support at a time which is right for them, helping them to retain their independence, continue doing the things they want to do and continue to fully participate in society. After seeing the ECLO, 93 per cent of patients reported that they were either “well informed” or “very well informed” of support available.¹⁶

RNIB is the only provider of ECLO services in the UK which has been nationally recognised by UKOA (UK Ophthalmology Alliance), which

¹⁴ Guiding a blind or partially sighted person, RNIB
<https://www.rnib.org.uk/information-everyday-living-family-friends-and-carers/guiding-blind-or-partially-sighted-person>

¹⁵ Eye Clinic Liaison Officer Evaluation Report, RNIB, March 2021:
<https://www.rnib.org.uk/sites/default/files/UK-ECLO-Evaluation-Report-March-2021.pdf>

¹⁶ Eye Clinic Liaison Officer Evaluation Report, RNIB, March 2021:
<https://www.rnib.org.uk/sites/default/files/UK-ECLO-Evaluation-Report-March-2021.pdf>

recognises ECLOs as integral to the patient pathway within Ophthalmology Services. RNIB ECLO services have also been peer-reviewed by the British Medical Journal.

We have also identified the cost savings to health and social care with the provision of an ECLO service by reducing falls, helping people to stay independent for longer, maximising their income and managing their sight condition and coming to terms with diagnosis. In addition, we have the potential to deliver these services remotely within communities, in a COVID-safe environment, which also offers greater flexibility.

ECLOs not only provide essential support to patients, ensuring they receive timely information on a range of topics which matter to them, but they are also indispensable to the functioning of hospital eye departments. Ophthalmology departments in Scotland are under enormous pressure and demand will continue to increase as the number of people with sight loss in our ageing population goes up.

Early intervention can help maintain greater levels of independence and can help reduce the risk of longer-term depression. Through appropriate and timely referral to Low Vision Services, local societies' resource centres and other local community-based services, the ECLO can support patients to access aids and adaptations, home improvements, training and support that can make a difference to their ability to maintain independence through best use of functional vision. Accessing these services as early as possible is recognised within the rehabilitation and health promotion fields to be crucial in improving longer term outcomes. Via ECLO intervention 84 per cent of patients were referred to services outside the hospital. Of these, 64 per cent had used the services and 27 per cent were intending to.¹⁷

The interdependence of care to carry out everyday tasks is also important and should not be underestimated. Links to services that can support people with day-to-day tasks, such as helping them pick out the clothes they want to wear for the day, will ensure that people have a voice, choice, and control of their physical and mental wellbeing. One respondent explained:

“... If someone's rights are being taken away from them then this impacts on their mental health... You suddenly begin to feel like you're less of a person...”

¹⁷ Ibid.

RNIB Scotland has a counselling service which is accredited by the British Association of Counselling and Psychotherapy and adheres to their high ethical standards. Since January 2016 we have supported over 735 people across the country via our counselling services, with seven people currently awaiting counselling support.

Each client has a maximum of eight sessions of counselling which costs RNIB £50 per session, in total £400 per person. That equates to an investment of £294,000 for people's mental health from charitable resources. We currently have 1.2 full-time employed counselling staff focussed on Scotland.

As we deliver sessions online and over the phone, our counsellors can work in any part of the country and our experience indicates that most referrals come from Dundee, Edinburgh, and Kilmarnock.

We value the opportunity to work in partnership within the National Care Service to support blind and partially sighted people after diagnosis of sight loss.

Question 64: Are there other changes that should be made to the membership of Community Health and Social Care Boards to improve the experience of service users?

We agree that representation from a person with sight loss and/or a sensory impairment on the Community Health and Social Care Board would be an essential component of ensuring that services are delivered with people in mind.

However, this must be done in the most appropriate and considerate way, as one respondent commented:

“[The National Care Service]... needs to be done in partnership with blind and partially sighted people, including ethnicity... It always seems to be the same people who have a visual impairment that are around the table - so we need real comments and solid evidence... You need to ensure that the people who are advising you, is not just hard work, but it's a quality experience which is paid - and not taken for granted.”

Additional points were raised that:

“I would prefer for it [the Social Covenant Steering Group] to be a “working group” rather than taking on advice from people, and listening,

but then [the National Care Service] still going to do what they planned to. I feel like I hear the same stories, so it makes me think that no change is happening.”

To provide better inclusion, further consideration must be made about the accessibility of these meetings, and the time constraints that people may have - for example caring responsibilities. As one of our respondents fed back:

“Boards... will need to make sure that there isn’t a transport barrier for people attending... There needs to be flexibility if they have caring responsibilities - virtual, telephone and face to face.”

We have received confirmation from individuals with sight loss that they would like to be included in any future groups which are established following this consultation.

Question 68: Do you think this Structure of Standards and Processes will help to provide services that support people to meet their individual outcomes?

Commissioners should focus on establishing a system where a range of people, including people with lived experience, unpaid carers, local communities, providers, and other professionals are routinely involved in the codesign and redesign, as well as the monitoring of services and supports. This system should form the basis of a collaborative, rights based and participative approach.

Question 73: Is there anything you would add to these core principles?

We want information and services to be accessible under the Equality Act 2010 and Patient Rights (Scotland) Act 2011, which sets out the responsibility of the NHS to provide accessible information, including the requirement that “Communication about a patient’s health and wellbeing is clear accessible and understood”.¹⁸

¹⁸ Patient Rights (Scotland) Act 2011, Scottish Government
<https://www2.gov.scot/Topics/Health/Policy/Patients-Rights>

A Charter of Patient Rights and Responsibilities¹⁹ accompanied the Act. This summarised the existing rights and responsibilities of patients using the NHS in Scotland, setting out that “You have the right to be given information about your care and treatment in a format or language that meets your needs.”

Question 91: What would make it easier to plan for workforce across the social care sector?

There are still huge numbers of people who have been assessed as needing a care package, including for basic items such as food and medication, who have been waiting for many months as there is no capacity from care providers to support them. As one social worker shared with us:

“... This is largely due to difficulties in recruiting and employing staff in this field, which of course is largely out-with the local authorities’ control... However, it still results in large numbers of vulnerable adults continuing to be at risk because they are not having their basic care needs met. In many cases it will result in an admission to hospital which increases priority for accessing the scant resources which are available, and the person will in the end receive a service [often after waiting in hospital for some time though which brings its own risks].

“I think the lack of statutory resources to meet basic and enduring care needs should be kept on the agenda so that government continue to be fully aware of the impact of reducing budgets and cutting services. And that it is not enough to introduce approaches of self-management and using community assets - this will never negate the requirement for basic statutory services for a significant number of adults with health and social care needs.”

Vision rehabilitation services are also crucial to ensuring blind and partially sighted people remain as independent as possible. Still today, there is a poor understanding of what vision rehabilitation support is and why it’s needed - rehabilitation is more than just acute care; it is a preventative measure for maintain quality of life at home.

¹⁹ Your health, your rights - The Charter of Patient Rights and Responsibilities, Scottish Government, 2012
<https://www2.gov.scot/Resource/0040/00407723.pdf>

There are currently approximately 2,100 Occupational Therapists in Scotland²⁰ and around 200 vision Rehabilitation Officers (ROs) across the UK²¹. With 178,000 people currently living with low vision in Scotland, that would equate to one Rehabilitation Officer (ROs) per 890 people with sight loss if every person required rehabilitation support.

These latest statistics show an alarming decrease in ROs, with the pandemic only increasing the number of people waiting for rehabilitation support.

Everyone should feel like they have a right to rehab - people should not have to choose between no support at all or seeking alternative assistance privately. This not only could cause a financial burden to those who may already have to source additional help from other services for other needs but is expanding health inequalities for those who cannot afford assistance.

The coronavirus pandemic has put additional pressure on services as demonstrated by the delivery of our rehabilitation service in Edinburgh and the Lothians from March 2020 - March 2021.

This was done under contract to the local authority. The rehabilitation service provided specialist assessment, training, information and advice about mobility, communication, independent living skills and low vision assessments.

This service was restricted to urgent visits only due to local and national lockdowns, severely reducing the amount of home visits each worker was able to carry out every week - normal service would be approximately eight visits per week per worker.

Due to this, the current waiting times for rehabilitation in Edinburgh and the Lothians has increased from around four months for a non-urgent referral to 12 months plus. This has had a particular impact on clients who were shielding and/or were unable/unwilling to receive a visit from an RO during the small window when restrictions lifted slightly in autumn 2020.

²⁰ Occupational Therapist, NHS Scotland Careers
<https://www.careers.nhs.scot/careers/explore-our-careers/allied-health-professions/occupational-therapist/>

²¹ Workforce Survey Report 2017, Rehabilitation Workers Professional Network, <https://www.rwpn.org.uk/page-7745>

Remote rehabilitation support has worked in a very small number of cases and usually where the person doesn't have additional issues such as a cognitive impairment or a hearing impairment for example or has a carer/family member who can assist. However, in addition, rehabilitation is much more "hands-on", with ROs finding it challenging to provide low vision aids without them seeing the situation and demonstrating the equipment.

When the Scottish Government "See Hear Strategy"²², a strategic framework for meeting the needs of people with a sensory impairment, was introduced, there was short-term funding to support academic diplomas within Scotland. However, we have been told that this did not fulfil the critical gap already present.

At present there is no training facility in Scotland for Rehabilitation Officers for Visual Impairment (ROVI), so there is currently no sustainability to increase the ROVI capacity within Scotland.

There is a real opportunity here to establish an integrated service, nationally and locally, where vision rehabilitation joins up with other services, including optometry, ophthalmology, and local societies. In addition, further funding is needed to increase the amount of ROs in Scotland, and to proactively establish further education in the nation to grow a strong vision rehabilitation workforce to sustain ongoing demand.

Case study one

"Before the pandemic, I was receiving social care support from a service in Ayr. When the pandemic happened, I received a letter from Sense Support that my support would be paused. Not fair to pause vital support for people who are really in need. Recruitment - one thing my mother has been told about why my recommencement has taken so long, is because the workforce is leaving. What will the SG do in terms of recruitment to ensure that these services are back up and running ASAP? I can't always rely on support from my parents as they work.

"My mum is my main carer - two hours of support, two days a week (Wednesday and Friday morning). Go into town with my support worker to the shops and go for drinks. I've really relied on this service as I've used it for seven years, I find it difficult as it felt like 'cheerio' see you after the pandemic. I felt very angry and didn't help my family. I'm a

²² See Hear Strategy, Scottish Government, 2014
<https://www.gov.scot/publications/see-hear>

young person with advanced needs, the stress also brought up my seizures (32-33 epileptic seizures due to the pandemic). I'm grateful for the support my parents give, but things are going to get out of hands. A guy who used to work for Sense Support, he has now offered to privately support me - nothing has been arranged or set in stone, but this might be something he can do alongside of his work at a nursing home. I'm fed-up waiting.

"I've got a friend who lives in Renfrewshire, whose service has just been resumed. So, I don't think this is fair cos of the postcode lottery."

Case study two

"[Self-directed Support] ...when I moved out of my own house in 2004, I was getting a support worker to help me read my mail and general housework, to be as independent as possible. I had this for several years, and then it stopped. They stopped it, as they said I didn't need it anymore as they didn't think I needed it, which I didn't agree with. I've not had this service for eight years, and I really miss this as it allowed me to keep on top of it. I've got cerebral palsy as well as being blind, so this service really helped. I'm not sure why it stopped..."

"I was a cinema goer, and really enjoyed it. I went a few times a week, so I asked for Self-directed Support, but they said that they didn't do this, so they requested I sought volunteer support, but this didn't happen. I ended up trying to figure out how I get to Aberdeen which is 40 minutes away on the bus - this included four buses there, and then four more buses back (an eight-and-a-half-hour round trip). Self-direct Support should help people deliver this support. It was the Local Authority that said they didn't offer SDS support. I don't have a carer, so I think they should deliver this service as well."

Case study three

"I have over 20 years' experience of using health and social care services. I started to use them before leaving home... I've always had to interact with it since I was a child, technical support, and rehab - but as I got older and went to university and got home, culturally, Muslim women don't move out on their own, so if I was going to move out, I had to say that I was getting additional support and there were other people around me. So, this is when I had to interact with social care and look into a personal assistant (PA). But the issue that I had with this system, is that because I have a visual impairment and I can sort of cook on my own, get dressed on my own... they didn't think I required that human person,

but I needed to be enabled to leave home and needed to give the confidence of my family that I had this support.

“This support [PA] gave me management skills as I had to learn to manage someone, I had to learn to interact with people, how to manage budgets, and personnel skills. It allowed me to complete my Masters in Personnel and Resources, to live further afield, to a big part of London and then move to Scotland. And I continually learn, and the people that support me continually learn - and this is a big important factor for me.

“But... when it breaks down and it can break down... When I advocated as a visual impaired person for my mum, I was seen as a lesser being because I was visually impaired with less knowledge, despite having 20 years’ experience of social care support. And this is a loss to the system, so for me when things break down and you don’t get the right person who will take risks, then it can be really dangerous and lead to dangerous situations. This is basically what happened to my mum and how we eventually lost her... We tried to get additional support but by this time her health had decreased even more, and we were in a house fire together and that’s basically how she died. I seriously believe that a breakdown of care and support, and that not listening to us, led to me losing her. And that’s a real experience which shouldn’t happen. I now live in that fear.

“People don’t realise people’s history... and the trauma they have been through in their lives. People don’t always have one requirement and you have to plan to develop and manoeuvre those requirements... And social and health care if they can interact is so important.

“People go into hospital for a variety of different situations, and sometimes people’s packages get taken away, but if they had that additional support from the care worker, it would free up time for nurses to figure out what the person requires, it would mean a much comfortable process. You shouldn’t have to lose one thing to be supported by another - they should work in parallel. It would decrease the pressure and then you wouldn’t have bed-blocking.”

For more information please contact:

Laura Jones
Senior Policy Officer (Health and Social Care)
laura.jones@rnib.org.uk