



Scotland

See differently

Royal National Institute of Blind People (RNIB) Scotland Response to the Scottish Parliament Inquiry into Health Inequalities

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 break down barriers that lead to health inequality for blind and partially sighted people. An inconsistent postcode-lottery of service provision is exacerbating the increase of inequity. RNIB Scotland considers it vital that this inquiry implements the necessary change to decrease the ever-present imbalance of health and social care services.

The consultation poses a selection of questions; to highlight key points relating to sight loss we have replied to Questions 10, 11, 12 and 15. The replies are based on previous RNIB/RNIB Scotland surveys, public

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

consultation responses, literature review and specific consultation for this response.

RNIB Scotland responses

Question 10. What actions would you prioritise to transform the structural inequalities that are the underlying cause of health inequalities?

Digital inclusion

Levels of digital uptake can be significantly lower for people with disabilities.² Accessing online information, for example, filling in forms online, can be very time consuming or completely inaccessible.³ 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 use health services.⁴ 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.”

² 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>

³ Ibid.

⁴ Website accessibility, RNIB <https://www.rnib.org.uk/rnib-business/website-and-apps/website-accessibility>

Digital adaptations to healthcare are advancing in Scotland.⁵ 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.”

Accessible health information

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”.⁶ A Charter of Patient Rights and Responsibilities⁷ 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.”

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?”⁸ report which found that blind and partially sighted people lacked

⁵ 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/>

⁶ Patient Rights (Scotland) Act 2011, Scottish Government <https://www2.gov.scot/Topics/Health/Policy/Patients-Rights>

⁷ Your health, your rights - The Charter of Patient Rights and Responsibilities, Scottish Government, 2012. <https://www2.gov.scot/Resource/0040/00407723.pdf>

⁸ Op cit, Communication Failure?, RNIB Scotland, 2020.

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 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.

General Practitioners

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.⁹ 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 11. What has been the impact of the pandemic both on health inequalities themselves and on action to address health inequalities in Scotland?

Access to services

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.

RNIB conducted a UK-wide Impact Survey¹⁰ 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

⁹ 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>

¹⁰ 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>

Communication Failure? report¹¹ 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:

“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.”

Rehabilitation services

The coronavirus pandemic put additional pressure on services as demonstrated by the delivery of the rehabilitation service then run by RNIB Scotland 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

¹¹ 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>

was able to carry out every week - normal service would be approximately eight visits per week per worker.

This was reflected within the Health and Social Care ALLIANCE report 'Framework for supporting people through recovery and rehabilitation improvement programme: Report of third sector responses to self-assessment tool' in October 2021¹². It states that, 'the third sector have an extremely dedicated workforce, which has ensured their flexibility in coping with the changes since March 2020. Many have put extra support in place to deal with the increased pressure, yet despite this, there is still a lot of pressure on the sector to provide more with less and there is a risk of staff burnout if this is not addressed. There are potential issues with skills shortages, particularly of sight loss officers, due to training issues, and funding insecurity can make recruitment a challenge.'

Social care

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 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.

¹² 'Framework for supporting people through recovery and rehabilitation improvement programme: Report of third sector responses to self-assessment tool', Health and Social Care ALLIANCE, October 2021 <https://www.alliance-scotland.org.uk/blog/resources/report-of-third-sector-responses-to-self-assessment-tool/>

Question 12. Can you tell us about any local, regional or national initiatives throughout the pandemic, or prior to it, that have helped to alleviate health inequalities or address the needs of hard to reach groups? How can we sustain and embed such examples of good practice for the future?

Eye Clinic Liaison Officer (ECLO) and counselling service

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 Research¹³ 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.¹⁴

RNIB is the only provider of ECLO services in the UK which has been nationally recognised by UKOA (UK Ophthalmology Alliance), which recognises ECLOs as integral to the patient pathway within Ophthalmology Services. RNIB ECLO services have also been peer-reviewed by the British Medical Journal.

¹³ Eye Clinic Liaison Officer Evaluation Report, RNIB, March 2021: <https://www.rnib.org.uk/sites/default/files/UK-ECLO-Evaluation-Report-March-2021.pdf>

¹⁴ Eye Clinic Liaison Officer Evaluation Report, RNIB, March 2021: <https://www.rnib.org.uk/sites/default/files/UK-ECLO-Evaluation-Report-March-2021.pdf>

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. ¹⁵

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...”

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

¹⁵ Ibid.

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.

RNIB Community Connect

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.

Question 15. What role should the statutory sector, third, independent and private sectors have in tackling health inequalities in the future?

Sensory impairment training

At present, the wider health and 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.¹⁶ 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.

Providing accessible formats

Our Communication Failure?¹⁷ 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.

¹⁶ 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>

¹⁷ Ibid.

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