## Respondent Information Form

**Health and Social Care Strategy for Older People**

**Please Note** this form **must** be completed and returned with your response.

Are you responding as an individual or an organisation?

[ ]  Individual

[ ] x Organisation

Full name or organisation’s name

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**Information for organisations:**

The option 'Publish response only (without name)’ is available for individual respondents only. If this option is selected, the organisation name will still be published.

If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.

The Scottish Government would like your

permission to publish your consultation

response. Please indicate your publishing

preference:

[ ] x Publish response with name

[ ]  Publish response only (without name)

[ ]  Do not publish response

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

[ ] x Yes

[ ]  No



## Royal National Institute of Blind People (RNIB) Scotland Response to the Scottish Government Health and Social Care Strategy for Older People

### **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]](#footnote-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 a growing older population is bringing challenges to health and social care services, adding additional strain to support, and leading to inconsistencies across Scotland.

The consultation poses a selection of questions under various topics; to highlight key points relating to sight loss we have replied to Place and Wellbeing - questions 1, 2 and 7; Preventative and Proactive Care - question 4; and Integrated Planning Care - questions 1, 2 and 9. The replies are based on previous RNIB/RNIB Scotland surveys, public consultation responses, literature review and specific consultation for this response.

**RNIB Scotland responses**

### **Place and Wellbeing**

#### Question 1. Do you have examples of communities, voluntary/third sector and public sector organisations working together to improve older people’s health and wellbeing and reduce any health inequalities which they experience?

#### Access to services

The coronavirus pandemic has brought everchanging situations and uncertainty. Social connections were 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 Survey[[2]](#footnote-2) 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. One respondent shared with us:

 "Biggar Action Group came out of the pandemic but continues to go today. This [group] links to people accessing hospitals with transport links..."

Some individuals also expressed that they believed more collaboration was needed between different sectors:

 "I don't think there are enough organisations that collaborate and there should be more. It would make things an awful lot easier."

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 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 2021[[3]](#footnote-3). 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.'

#### Question 2: Thinking about your physical health, what kind of advice and support would you need to help you make decisions about your health, care, and treatment?

It’s important for people to have choice and control of their lives to enable them to participate in activities. Without choice, blind and partially sighted people may be left stuck at home, as a person with sight loss shared with us.

"There is very little information [about physical health support], so if you don't know about it, you can't find out about it. I try to keep healthy by using a guide loop which takes me around the garden, and I use a stepper."

We should also not ignore the fact that just like everybody else, the population with disabilities is ageing. This means that over time provision will need to take account of multiple impairments. A person with complex needs including sight loss shared with us:

 "I wear hearing aids, which aren't substitutes for ears. Classes which use music… I can't hear the instructions, so I don't go. The people running the classes and the other people there want music on, so you feel like you're ruining other people's enjoyment. There are a lot of people who have hearing issues but don't have a hearing aid (and don't want one or think they don't need one) - and only those with a T-loop can access the looping system."

#### Question 7: What impact do you think the pandemic has had on your ability to access mental health services if you needed them?

The coronavirus pandemic brought change to the way services were delivered, including mental health support, with many being moved to virtual appointments. With additional support from local support, including GP services, individuals were able to access support when needed. For example:

 "I had to seek support, I got it luckily… it helped that I had a support worker, and she could see I was struggling. She advised me to contact the GP and I got counselling support. I had to spend a lot of time about what life is like as a blind person, which wasn't overly helpful. I had to seek help as I wasn't in a good place."

One other individual was able to continue their pre-covid support online, but also expressed the frustration about accessing this support via public transport before the pandemic:

 "I was already seeking help because of the issues I was having pre-covid. It went virtual and that was good, so I could continue the service. I also received support from charities - 'a buddy' from the Macular Society and RNIB supported me too.

 "The virtual help was much easier, instead of having to get to the appointment travelling 3-4 hours. Or I ask my husband to drive me as my informal carer. When people who are frailer, the distances which people are asked to travel - they don't have any clue about the travel distance time. Some of the buses don't connect well - it's hellish. The care side is lacking - you get the service, but you don't get the care about the whole service."

Awareness of services and resources including emotional and practical support at the point of diagnosis, have been known to only be highlighted for individuals following communication with third sector organisations, as in the case below:

 “[Eye Care Liaison Officers (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.”

Sight loss can have devastating consequences for individuals. Our RNIB Patient Experience Research[[4]](#footnote-4) 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 as77 per cent of patients said they would not have found or accessed support outside the hospital without access to an RNIB ECLO.

### **Preventative and Proactive Care**

#### Question 4: What would make access to leisure facilities or any other type of physical activity easier?

All too frequently a venue may be accessible, but the environment outside is not. This makes it extremely difficult for people with a visual impairment to access spaces, therefore resulting in social isolation and a need to stay at home due to environmental dangers, as a person with sight loss told us:

“People with sight loss don’t go out due to many reasons but one of them is clutter and danger. Not all crossing points are safe, with general directions to a venue on Google Maps or on the venue website, unclear about access for people who are visually impaired.”

One respondent expressed the need to be informed about what support is available when they arrive at leisure venues:

 "It's important to know what help is there when you get there. You don't always know what help is there when you go. If people don't know what a disability is, it can get complicated. COVID has caused difficulty and it has got busier as well. I think that COVID is used as an excuse to not provide sighted guiding etc."

Thousands of people with sight loss face challenges getting around their local area every day. An RNIB survey ‘Who put that there!’ found that over a three-month period, 95 per cent of blind and partially sighted people said they had collided with a pavement obstacle and one third that they had been injured when walking outside. Some said they were so intimidated by the risks outside they ended up staying at home and becoming isolated.[[5]](#footnote-5)

Advertising boards, bollards, bins, cars parked on pavements, over- hanging branches or shrubbery (as well as hanging baskets) and 'shared space' schemes were the most common obstacles encountered.[[6]](#footnote-6) Within ‘Scotland’s Accessible Travel Framework’[[7]](#footnote-7), accessible streets are recognised as a key component of travel confidence, ‘… One of the key issues for disabled people is the ability to get to transport, including negotiating paths which have various obstructions such as wheelie bins and advertising boards.’ One respondent shared with us:

 "The biggest problem is the lack of frequent public transport, and sanitation. Physical infrastructures that cause barriers for people… Subscribing might be a way forward, rather than a reliance on getting going if you're coming from a place with no physical activity."

### **Integrated Care Planning**

#### Question 1: Tell us about any social care or other outside help with everyday living that you (or a family member) have received in your own home? Question 2: What was your experience of these services?

The COVID-19 pandemic only highlighted frustrations within social care when services were paused. People with sight loss were either not consulted or received no 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.

In addition, training and support services which allow people to maintain their independence when diagnosed with an eye condition, were sometimes left to adapt to their environment by themselves due to the increase in service demand following the pausing of social support, as a person with sight loss shared with us:

 "I got my long cane training. I had to wait over a year for it, as I was on a waiting list because of COVID. [They] weren't good at keeping in touch - I understood, but I felt a bit abandoned. Various bits of my care have been paused and I've been left to my own devices. [The trainer] explained when she came about what else they could to adapt the house and accommodate my declining sight (within 2-3 sessions). I had to use my own cane skills which they don't recommend, but I needed it to maintain my own independence."

#### Question 9: Tell us about your experience of any health care appointments you have had in the last 2 years:

#### • which healthcare services did you use?

#### • what type of appointments did you have (e.g. face to face, phone, video)?

#### What additional support would you need to make it easier?

Accessible buildings give blind and partially sighted people the confidence to attend hospital and GP appointments 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. A blind person shared with us:

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

The coronavirus pandemic added to the frustration felt by people with sight loss due to physical distancing measures within General Practitioners and hospital environments, as an individual with sight loss told us:

 "When I needed regular blood tests at the GP surgery, the difference between [the greeting of] reception and nurses was astounding. During COVID, it was strict - the receptionist didn't give me sighted guiding, didn't show me the toilet and was abrupt about me washing my hands. As soon as the nurse came out, she was wonderful."

In addition, a similar story was shared with us:

 "I had an MRI scan at the Royal Infirmary - the person at the desk guided the taxi driver to where I should sit, and then [the driver] left. I sat there waiting, but it turned out we were guided to the wrong place. So, the taxi driver came back and asked reception what had happened to my appointment, and they said, 'he's missed it'. So, I had to go to another hospital a couple of weeks later."

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. A partially sighted person 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.[[8]](#footnote-8) 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.

The needs of people with sight loss should be considered before a health appointment. This not only gives visually impaired people the time to fully read and understand treatment information but allows them the opportunity to ask questions. Blind and partially sighted people are still being left in vulnerable situations due to the lack of accessible healthcare information before treatments, as one respondent explained:

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

 "We have a reading machine, which is helpful as we receive letters which are inaccessible. So, if we can get a number [off the letter], then we can call them and ask for help"

Due to the impact of the pandemic, there are ongoing delays to treatment, which is leaving blind and partially sighted people feeling a lack of control of their health needs, as two blind individuals told us:

 "Spoken to my GP by phone, which enabled me to speak to my diabetic specialist nurse in the community clinic. That was successful. Did bloods face to face which allowed me to talk to the nurse. [But] there's still a lack of personal [support]… I haven't spoken fully to a diabetic nurse since September [2021] when I was put on insulin. It's definitely 'flying at the seat at your pants' for people with certain conditions. It's quite a strain."

 "I don't know what's happening within the clinics in [my health board area], but they don't seem to be functioning well, so I haven't been called back for a check-up appointment. Because of COVID, there are a lot more delays and difficulties now, I understand that, but I'm beginning to lose my patience."

#### For further information please contact

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1. A National Statistics Publication for Scotland: Registered Blind and Partially Sighted Persons, Scotland 2010, Scottish Government, 2010. [↑](#footnote-ref-1)
2. 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> [↑](#footnote-ref-2)
3. '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/> [↑](#footnote-ref-3)
4. Eye Clinic Liaison Officer Evaluation Report, RNIB, March 2021: <https://www.rnib.org.uk/sites/default/files/UK-ECLO-Evaluation-Report-March-2021.pdf> [↑](#footnote-ref-4)
5. RNIB, Who put that there! The barriers to blind and partially sighted people getting out and about, 2015. [↑](#footnote-ref-5)
6. RNIB Scotland, Scotland: Street Charter toolkit, 2015. [↑](#footnote-ref-6)
7. Transport Scotland, Going Further: Scotland’s accessible travel framework, 2016. <https://www.transport.gov.scot/media/20113/j448711.pdf> [↑](#footnote-ref-7)
8. 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> [↑](#footnote-ref-8)