## RNIB Scotland logoRoyal National Institute of Blind People (RNIB) Scotland Response to Scottish Parliament Health, Social Care and Sport Committee National Care Service (Scotland) Bill - Call for Views

#### Demographic questions

* Are you replying on behalf of an organisation or as an individual? Organisation
* If organisation: What is the name of your organisation? RNIB Scotland; What is your job role? Director, RNIB Scotland
* Would you like to be involved in future engagement work? Yes. If so, please provide your email address? james.adams@rnib.org.uk

#### Introduction

RNIB Scotland welcomes opportunities to fully consider the implications of the National Care Service (Scotland) Bill and forming associated structures, recognising its role in securing the best possible services for blind and partially sighted people across Scotland.

With rates of sight loss expected to rise in Scotland, we need to take a fresh approach to responding to those who rely on health and social care services across the country.

Whilst we recognise that many of the statutory instruments and regulations creating a National Care Service for Scotland are still to be determined, we hope there will be an inclusive and accessible approach throughout its development. This will help to enshrine human rights and to ensure that the needs of those who rely on services remain at the forefront.

#### Consultation Question: 4. Is there anything additional you would like to see included in the Bill and is anything missing?

We welcome the opportunity to respond to National Care Service (Scotland) Bill (thereafter “the Bill”) Call for Views. However, given the breadth and depth of the questions posed in the consultation document, we have confined ourselves to answering question 4 only. Our response identifies several priority areas we would like to see included in the Bill. Specifically, we believe the following have key implications for blind and partially sighted people living in Scotland:

1. Smooth transition for users
2. Sight loss pathway
3. Public information campaign
4. Accessible information - the right to this and replicating social security amendments on accessible information in this Bill
5. Registration
6. Patient records (electronic patient records
7. Right to rehabilitation
8. Carer - rights to breaks/assessments

#### 1. Smooth transition for users

Reform is challenging. Lessons need to be learned from past restructuring and public service reform, for example, police and fire reform, college sector regionalisation, and the development of social security responsibilities in Scotland. Reports in these sectors have shown that difficulties in implementing some elements can have a significant negative impact on vulnerable people who rely on care and support, including blind and partially sighted people.[[1]](#footnote-1)

We would like to see clear pathways, so that individuals accessing care and support, do not experience any disruptions to the services they receive. Whilst principles underlying legislation may be well-intentioned, delivery is dependent on the resources, time, and effort of everyone involved.

People reliant on health and social care services, as well as those involved in their direct delivery, must be involved at every stage, with clear communication and mutual trust being built in from the start.

Implementation of previous reform has sometimes resulted in changes in criteria to access support, care package reviews, with reductions in hours or support provided.[[2]](#footnote-2) Individual family members and unpaid carers may find themselves taking on the burden of care and responsibility, which places even more stresses and strains on families and communities.

Specific provisions are also required to enable smooth transitions from child/adolescent to adult services. This must involve valuing individual outcomes, and greater transparency about how decisions are reached and by whom.

Users of service must have access to information about their care arrangements in their preferred format. They shouldn't have to resort to lodging formal complains before they obtain information in suitable formats. Failure to provide these results in delays, inconsistencies, and frustration.[[3]](#footnote-3)

Better training and awareness of the access needs of blind and partially sighted people must become a mandatory requirement for all staff in health and social care settings (see more below in our Section 2. Sight loss pathway).

We would also like to see options explicitly laid out in the Bill so people can access independent advocacy, as well as information, and advice, as early in the process as possible, to enable them to navigate any changes.

#### 2. Sight loss pathway

The current sight loss pathway for people with sight loss in Scotland varies, leaving a post code lottery for care and provision, with some areas receiving less than suitable information and support at critical intervals in their sight loss journey.

We would like to see a uniform approach across Scotland which provides support, information, referral pathways to rehabilitation services and Third Sector organisations to people with sight loss. For example, RNIB Scotland provides Eye Care Liaison Officers (ECLOs) in NHS settings, giving emotional and practical support at the point of diagnosis.

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 we ensure that healthcare staff have good, up to date, communication skills, it can be virtually impossible for people with sight loss to follow what is happening in their appointment.

#### 3. Public information campaign

Trust and respectful relationships are essential for the delivery of good services, and a public information campaign would help further endorse this approach throughout the development of the National Care Service.

Plans for the new service must be clearly communicated to the public, with additional provision for accessible formats made available as early on as possible.

Provisions to reach out to those at greater risk of exclusion should also be made, including people with visual impairments, people from Black and Ethnic Minority Groups (BME), those whose first language isn’t English, and people with low levels of literacy, etc.

Involving disabled people and people with lived experience in shaping public information campaigns, can help build a shared sense of understanding and endorse co-production. Resources, time, and effort are required to structure this in a meaningful and collaborative way. This also means being open and transparent about how changes proposed by the Bill will unfold, with timescales and plans in place.

RNIB Scotland welcomes dialogue with Ministers, and others involved in driving the Bill's implementation, to ensure the needs of blind and partially sighted people don't go unmet, as we have sometimes encountered in the past.

For instance, the public health messages which surrounded the coronavirus pandemic showed that information must be accessible, consistent, and clear, from the start. Government letters throughout the pandemic, contained vital information, but were often inaccessible, resulting in confusing and unclear guidance for people with sight loss.[[4]](#footnote-4)

Blind and partially sighted people are often dependent on others reading information out to them, which undermines their right to confidentiality, as well as meaningful choice and control over decisions related to care and support options.[[5]](#footnote-5)

The information needs of blind and partially sighted people cannot continue to be treated as an afterthought, and systems must be in place to make alternative formats readily available on request, whether that’s large print, braille, or audio.

#### 4. Accessible information - the right to this and replicating social security amendments on accessible information in this Bill

There must be accessible and clear routes of communication, so people know how to request independent information and advice, about what any changes mean for them, as well as support to help navigate health and social care systems. This will help avoid/prevent resistance to change as well as build a sense of genuine and achievable co-production.

We have seen bold action in the areas of Social Security reform and would like assurances that Inclusive Communication and Accessible Information will be enshrined as a statutory duty, explicitly laid out in the National Care Service Bill, and not as an “add-on” at the end.

For example, we would like to see provisions in place, as explicitly outlined in Social Security (Scotland) Act 2018, PART 1 Promotion of take-up Section 4 (Inclusive Communication) [[6]](#footnote-6) and Section 5 (Accessible Information).[[7]](#footnote-7)

This should also be underpinned by monitoring systems to ensure requests are acted upon and resourced properly. Whilst the National Care Charter is a positive development to provide individuals with a framework to access their rights, and services realise their responsibilities, there must be explicit statutory definition of accessible formats and inclusive communication laid out separately in the Bill.

This would also help reinforce the General Comment 5 on Article 19 Convention on the Rights of Persons with Disabilities (UNCRPD) and ensure that all decisions concerning living independently in the community must be appealable and enforceable as a right and an entitlement.[[8]](#footnote-8)

#### 5. Registration - what is happening and who will be responsible, resumption of annual reporting.

We would like to see the Bill, along with secondary legislation, take a robust approach to reviewing the process and purpose of all services and systems which impact on blind and partially sighted people living in Scotland.

This may include the process and purpose of registration of severely sight impaired and sight impaired people across Scotland. The sight loss registers are currently maintained by or on behalf of a local authority; to inform the provision of social work, rehabilitation, and other services.[[9]](#footnote-9)

Whether digitisation and changing needs means we should now review the process and what the purpose of registration remains to be seen.

However, there are important considerations around accountability and responsibly, of local authority, health and third sector’s role in ensuring the consistent application of data gathering and information across Scotland.

The Audit Scotland Briefing Paper on Social Care highlighted that an inability or unwillingness to share information was slowing the pace of health and social care integration.[[10]](#footnote-10) An inability or unwillingness to share information, along with a lack of relevant data, means that there are major gaps in the information needed to inform improvements in social care.

We are concerned about the transfer of powers from local authorities to maintain registers of blind and partially sighted people without carefully examining the process of registration and involvement of health professionals.

Whilst national CVI (Certificate of Vision Impairment) processes have been in place since 2018 we are aware of regional variations as to how registers operate in each local authority area, which has sometimes resulted in discrepancies in data gathering and collection.

Within the context of a National Care Service, consideration might be given to modernising the existing system for Registration through digitisation and management as part of a National Register of blind and partially sighted people.

This could have the potential to markedly improve communication, hold useful information and provide improved services for those on the register. Clearly, the localism of the registers would need maintained for local care service provision.

At the point of registration, we would like to see the patient’s preferred format data captured and entered onto the patient record, potentially onto their nationally held Registration entry, ensuring all documents issued thereafter are accessible, and in the patient’s preferred format.

#### 6. Patient records, electronic patient records (data) & containing information about an individual's preferred formats.

Questions exist on how what administration systems will be used within a National Care Service, Ultimately, individuals should be able to access information held about them as part of GDPR (General Data Protection Regulation) arrangements.

Consideration also needs to be given to how this information is made accessible to blind and partially sighted people, to respect their dignity and confidentiality, as well as containing information about an individual's preferred formats.

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.

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 would like to explore if the system underpinning the National Care Service can be linked to the CVI process, electronic patient record, and with an automatic link to the Scottish Care Information (SCI) Gateway. [[11]](#footnote-11) This would reduce the need for people with long term health conditions to continually provide medical information when accessing health and social care services.

Ultimately, however, any information shared between health, social care, and third sector, must be done in timely, safe, secure, and accessible formats, to prevent unnecessary delays in access to support, and make sure people on the receiving end of support and services, are genuinely involved in decisions affecting their lives.

One of the weaknesses of the current system is that health and social care records are not shared across connected sectors, nor do they necessarily evolve with individuals as they age and transition from one service to another, for example, from child/adolescent services to adult services. This results in people having to continually explain their situation and requirements – which can include having to repeatedly recount traumatic experiences.

The National Care Record offers a fresh opportunity to ensure robust provision of accessible formats is made available on request, whilst also driving a greater sense of collaboration and inclusion within the workforce and meeting the needs of those who rely on services.

#### 7. Right to rehabilitation

Rehabilitation should be offered to support people diagnosed with sight loss. This is a vital service to allow those with sight loss to live independently, to manage their day-to-day tasks safely and with confidence.

Currently there are lengthy delays experienced by people diagnosed with sight loss to access rehabilitation services. Waiting times vary across local authority areas. Delays are mainly caused due to a lack of staff employed as vision rehabilitation experts.

We recognise and welcome the proposals to implement a national Low Vision Service. However, at present, access to rehabilitation aids vary across local authority areas with some providing only the most basic equipment, leaving the burden of costs with the patient.

We believe that access to vital equipment should be available across Scotland, allowing people with sight loss lead a full and independent life.

#### 8. Carers - rights to breaks/assessments

RNIB Scotland supports right to breaks for carers. Many people with sight loss are carers and/or have family members caring for them. They do not necessary realise their rights to request a carer’s assessment, which prevents them from accessing support and breaks.

Any attempts at enshrining the rights to breaks for carers, must be met with a commitment in spending towards suitable respite for the cared for person, to fully realise the benefits, with planning and resources put in place.

Steps also must be taken to recognise the unique experiences of carers, and not treat them as one group. For example, carers, may be managing their own long-term condition/impairment whilst caring for someone else. Some may be working in paid employment, but also managing caring responsibilities at home or elsewhere. Young carers may be caring for a family member/relative, whilst also in education.

There should be recognition of the dual caring role, which exists in some couples, whereby both require support, but provide care dependant on their impairment/long term condition needs. There must be flexible and adaptive approaches to enabling carers identify and take up breaks based on their own needs.

Flexible, regular access to short breaks for all unpaid carers should be strongly encouraged because it is an essential element of Self-Directed Support that results in good personal outcomes for people who access social care, families, and unpaid carers.

#### Contact:

James Adams, Director, RNIB Scotland - james.adams@rnib.org.uk

1. Social care briefing (Audit Scotland, 2022), available at: https://www.auditscotland.gov.uk/uploads/docs/report/2022/briefing\_220127\_social\_care.pdf [↑](#footnote-ref-1)
2. My Support My Choice: People’s Experiences of Self-directed Support and Social Care in Scotland (The Alliance et al, 2020), Available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/10/ALLIANCE-SDSS-MSMC-National-Report-Oct-2020.pdf> [↑](#footnote-ref-2)
3. #  RNIB Webpage: A two-year battle for accessible information (2019) available at: <https://www.rnib.org.uk/rnibconnect/two-year-battle-accessible-information>

 [↑](#footnote-ref-3)
4. Living with Sight Loss through Lockdown in the United Kingdom (RNIB, 2020) available at: <https://www.rnib.org.uk/sites/default/files/RNIB%20Briefing%20-%20Impact%20of%20social%20distancing%20on%20blind%20and%20partially%20sighted%20people%20-%20England%20%28002%29.docx> [↑](#footnote-ref-4)
5. Communication Failure (RNIB Scotland, 2019), available at: https://www.rnib.org.uk/sites/default/files/Communication%20Failure.pdf [↑](#footnote-ref-5)
6. Social Security (Scotland) Act 2018 (legislation.gov.uk) Section 4. available at: <https://www.legislation.gov.uk/asp/2018/9/section/4/enacted> [↑](#footnote-ref-6)
7. Social Security (Scotland) Act 2018 Section 5. Recognition of importance of accessible information. Available at: <https://www.legislation.gov.uk/asp/2018/9/section/5/enacted> [↑](#footnote-ref-7)
8. OHCHR | General comment No.5 on Article 19 - the right to live independently and be included in the community, webpage available at: <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live> [↑](#footnote-ref-8)
9. Source: [https://www.gov.scot/publications/registered-blind-partially-sighted-persons-scotland-2010/pages/5/](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.gov.scot%2Fpublications%2Fregistered-blind-partially-sighted-persons-scotland-2010%2Fpages%2F5%2F&data=05%7C01%7Ckirstie.henderson%40rnib.org.uk%7Cf3028502c82c40adc68108da84dacaf5%7C5d45337cd19243fcaa5805557c9171bc%7C0%7C0%7C637968372624626789%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=DdyrYf24TVdL0ZpH8%2FgV7oszuGjjVkqco4ZL7WfRL5E%3D&reserved=0)) [↑](#footnote-ref-9)
10. Social care briefing (Audit Scotland, 2022), available at: <https://www.audit-scotland.gov.uk/uploads/docs/report/2022/briefing_220127_social_care.pdf> [↑](#footnote-ref-10)
11. [SCI - Scottish Care Information](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.sci.scot.nhs.uk%2Fproducts%2Fgateway%2Fgateway_prod_overview.htm&data=05%7C01%7CCatriona.Burness%40rnib.org.uk%7C2bfedae5d68a4ffbf9a208da90097d95%7C5d45337cd19243fcaa5805557c9171bc%7C0%7C0%7C637980667681475603%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=WjgAjMin4uMGcGmyG3%2FX5CyvqoO4S5JL6I%2F%2FPP%2BAw%2FU%3D&reserved=0) [↑](#footnote-ref-11)