

RNIB **Northern** **Ireland** Community Engagement Report

R N I B
Northern
Ireland

See differently



A report identifying barriers facing
blind and partially sighted people
and key areas for action

February 2020

Contents

4	1. Executive Summary
4	How we engaged
5	Key themes throughout our engagement
5	Independence
5	Community connection
5	Local issues
5	Eye health and eye care
5	Supporting leadership and developing partnerships
7	2. Introduction
7	2018 was RNIB's 150th year and a unique moment in time
7	Priority 1: Equip blind and partially sighted people to live the life they want to lead
7	Priority Outcomes
8	Priority 2: Innovate and improve conditions in society so that blind and partially sighted people can live the life they want to lead
8	Priority Outcomes:
8	Priority 3: Transform RNIB to be a catalyst for change
8	Priority Outcomes
9	3. Background Context
10	How we engaged
11	What we sought to learn
11	What this report will focus on
13	4. What sight loss communities have told us from our engagement
13	Independence
13	Technology and equipment
14	Emotional support and life skills training
16	Accessible information from public services
16	Benefits advice and guidance
17	Social care and support for families and carers

18	5. Community connection
18	Development support for sight loss groups
21	6. Local issues
21	Transport
21	Public transport – the everyday experience of current services
22	Rural transport service access
24	Improving the experience of the sight loss community in health care
25	Navigating outdoor spaces and building design
26	Employment support
26	Public awareness of sight loss and its impact
27	7. Eye health and eye care
28	8. Supporting leadership and developing partnerships
30	9. Participants' ideas for action
30	Independence
30	Community connection
31	Transport
31	Accessible information from public services
32	Improving the experience of the sight loss community in health care
32	Navigating outdoor spaces and building design
32	Employment support
33	Public awareness of sight loss and its impact
33	Eye health and eye care
33	Supporting leadership and developing partnerships
35	10. Conclusion

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1. Executive Summary

In 2018, RNIB celebrated its 150th year. It was a time to look back and celebrate how far the lives of blind and partially sighted people have been transformed over the last century and a half. However, it was also a time to take stock and acknowledge the fundamental challenges that still remain for blind and partially sighted people.

In keeping with trends in most developed countries, statistics in Northern Ireland and the Isle of Man, reveal an increasingly ageing population. Sight loss affects people of all ages, but as we get older, we are increasingly likely to experience loss of sight. According to RNIB's calculations there are a projected 53,500 blind and partially sighted people in Northern Ireland and 2,000 visually impaired people in the Isle of Man.

The Northern Ireland Statistics and Research Agency (NISRA) published population data in May 2016, which detailed an expected 74.4% increase in the population over the age of 65, during the period from mid-2014 to mid-2039. Consequently, one in four people living in Northern Ireland, will be in this age category.¹

The increasing prevalence of sight loss over these next decades reinforces

the importance of working alongside the sight loss community, engaging with key partners and stakeholders in raising awareness of sight loss, placing related issues at the centre of public policy planning and bringing about unprecedented societal change.

For RNIB to identify the issues for prioritisation, we embarked on the first stage of our engagement work by connecting at a grassroots level with blind and partially sighted people across Northern Ireland and the Isle of Man through independent facilitation.

How we engaged

The first stage of our engagement work began in 2018 through 7 focus group events across Northern Ireland and the Isle of Man: Armagh, Belfast, Cookstown, Derry/Londonderry, Downpatrick, Enniskillen and the Isle of Man. We received in-depth feedback at these events from 130 blind and partially sighted people. Prior to implementing this programme of engagement, we consulted our community contacts across Connect, Campaigners' Active Network and participants of social activities. We explored how best to engage with the wider community (i.e. in focus group sessions, Facebook, Twitter and email) and developed a series of questions. This information

1 Northern Ireland Statistics & Research Agency (May 2016) 2014 Based Population Projections for Areas Within Northern Ireland; (P.9)

was captured in a co-produced action plan. We followed this up with three Big Connect events. At these events we provided the community with feedback on the central themes coming out of our initial engagement events and discussed together how we could address these issues moving forward. There was also an opportunity to capture people's views through online engagement. This was carried out via RNIB NI Facebook and all events were publicised by RNIB NI Twitter. Six short online videos were produced asking a series of key questions. This resulted in 2,400 people engaging in discussion and debate.

Key themes throughout our engagement

Throughout this community engagement process RNIB sought to connect at a grassroots level to look at how best we can ensure that:

- the voices of blind and partially sighted people are strengthened;
- blind and partially sighted people are equipped to live the life they want to lead;
- more effective relationships and partnerships are developed.

We heard a wide range of issues and concerns as well as details of positive experiences and constructive recommendations. The evidence gathered was analysed and the following are the key themes which were identified from our engagement:

Independence

- access to technology, equipment and training;
- emotional support and life skills training;
- accessible information from public services;
- social care and support for children and young people, families and carers.

Community connection

- development support for sight loss groups.

Local issues

- enhancing public transport services and expanding access to rural transport;
- involvement of the sight loss community in planning the design of outdoor spaces and buildings;
- employment support for blind and partially sighted people;
- greater public awareness of sight loss and its impact.

Eye health and eye care

- prevention of sight loss and addressing waiting lists.

Supporting leadership and developing partnerships

- ensuring government/public bodies work with blind and partially sighted people in the design of policies and services.

Our engagement revealed that while some people living with sight loss are living relatively independently, many others still face barriers on a daily basis in key areas such as: transport, accessible health information, receiving timely healthcare, community connection, employment, and general equality of access to services.

RNIB is fully committed to taking a collective planning approach which will be embedded in the next steps of facilitating more direct engagement between the sight loss community, key decision makers and stakeholders at a local and regional level. By taking this approach, we can collectively remove the barriers to people with sight loss.

2. Introduction

2018 was RNIB's 150th year and a unique moment in time

In 2018 RNIB celebrated its 150th year. It was a time to look back and celebrate how far the lives of blind and partially sighted people have been transformed over the last century and a half. However, it was also a time to take stock and acknowledge the fundamental challenges that still remain for blind and partially sighted people.

Across the UK today, living with sight loss can be tough, with challenges around access to services, varying degrees of emotional support from the point of diagnosis and beyond, the fact that only one in four people of working age are in employment, as well as high levels of isolation and social exclusion. We know we need to find new solutions and new ways of delivering a world in which the equal participation of blind and partially sighted people is the norm.

In 2018, alongside relaunching our brand to encourage people to **See Differently** we also launched our new strategy with a core purpose of breaking down the barriers for people with sight loss. Our strategy incorporates a vision for a world where blind and partially sighted people participate equally and where people say: "I can lead the life I want to lead" and "I'm valued for who I am and not identified with the disabilities I have overcome."

We will focus on providing the tools that enable and support people with sight loss to transform their own personal experience, their community and, ultimately, society as a whole.

Within this strategy, RNIB focuses on three priority areas:

Priority 1: Equip blind and partially sighted people to live the life they want to lead

Our expert information, advice and specialist support helps equip blind and partially sighted people to take on the world.

Priority Outcomes:

- increase information access and control, particularly digital, by addressing cost, confidence and capability at scale;
- enable more people to move more quickly from diagnosis to confidence through a more effective and digitally enabled sight loss pathway.

Priority 2: Innovate and improve conditions in society so that blind and partially sighted people can live the life they want to lead

Priority Outcomes:

- build on the kindness of society to raise the understanding of sight loss in everyday life;
- achieve more accessible, inclusive and usable mainstream environments and solutions.

Priority 3: Transform RNIB to be a catalyst for change

Priority Outcomes:

- establish a leadership position as the experts in the lived experience of sight loss;
- make a bigger impact in everything we do;
- diversify our income portfolio;
- work to the highest of standards, fostering an agile, accountable and customer-focused culture.

3. Background Context

In keeping with trends in most developed countries, statistics in Northern Ireland and the Isle of Man, reveal an increasingly ageing population. Sight loss affects people of all ages, but as we get older, we are increasingly likely to experience loss of sight. According to RNIB's calculations there are a projected 53,500 blind and partially sighted people in Northern Ireland and 2,000 visually impaired people in the Isle of Man.

The Northern Ireland Statistics and Research Agency (NISRA) published population data in May 2016, which detailed an expected 74.4% increase in the population over the age of 65, during the period from mid-2014 to mid-2039. Consequently, one in four people living in Northern Ireland, will be in this age category. ²

The increasing prevalence of sight loss over these next decades reinforces the importance of embedding a networked approach to working alongside the sight loss community, key partners and stakeholders, to raise awareness of sight loss more widely, and to bring about unprecedented societal change. This approach will be the catalyst in driving the call for additional planning and policy development now, to ensure that Government best responds to the needs and concerns

of the growing number of citizens experiencing sight loss. One such issue, is the need for short, medium and long term planning to ensure timely and responsive ophthalmology treatment, and to ensure that blind and partially sighted people can fully participate at all levels in society.

Connecting and engaging with blind and partially sighted people is essential to ensure that local and regional plans are reflective of and responsive to the issues blind and partially sighted people face at a grassroots level. In essence, it's about working in a more collective way with the sight loss community, key partners and a wide range of stakeholders to ensure that we are citizen focused.

The goals of this collective approach centre on:

Strengthening the voice of blind and partially sighted people – to connect and amplify the voice of blind and partially sighted people, their families, friends and supporters, through peer-to-peer community networks and to society as a whole.

Equipping blind and partially sighted people to live the life they want to lead – to ensure the community is at the forefront of

2 Northern Ireland Statistics & Research Agency (May 2016) "2014 Based Population Projections for Areas Within Northern Ireland; (P.9)

change with RNIB and the wider sight loss sector, and the principles and aims of co-production are applied, i.e. raising awareness to bring about societal change – attitudinal and behavioural.

Developing effective relationships and partnerships – to build upon and develop effective relationships and partnerships as well as unifying the presence of the sight loss charity sector in localities for blind and partially sighted people.

Before the Northern Ireland Assembly collapsed in January 2017, it was in the final stages of agreeing a Programme for Government for 2016 – 2021. Of particular relevance to those living with sight loss, is Indicator 42 and the associated outcome plans, along with key strategies such as the Accessible Transport Strategy, Developing Eyecare Partnerships Strategy, Physical and Sensory Disability Strategy and the Disability Strategy.

With the restoration of the Northern Ireland Assembly in January 2020, there is an opportunity to make meaningful and demonstrable change for those experiencing sight loss in Northern Ireland. RNIB will continue to work to influence government and decision makers within the Department for Infrastructure (DfI), Department of Health (DoH), Department for Communities (DfC), Department of Education (DE) and the Department

for the Economy (DfE) around key issues such as accessible transport, safe streets, accessible information, prevention of sight loss and waiting lists.

For us to identify the key issues for prioritisation, this report outlines the first stage of our engagement work in which we connected at a grassroots level through independent facilitation to hear views on the issues and barriers blind and partially sighted people face in the world today.

How we engaged

To ensure that the engagement work was co-designed and co-produced with blind and partially sighted people, RNIB consulted with community contacts across Connect, Campaigners' Active Network and participants of social activities. These initial discussion sessions informed RNIB's engagement plan as to how best to consult with blind and partially sighted people across Northern Ireland and the Isle of Man.

After three meetings with the community and a further discussion with RNIB NI staff (including blind and partially sighted staff), we designed an engagement plan detailing the process and questions we were going to ask.

This plan involved a series of local focus group events involving 130 people across seven areas in Northern Ireland and the Isle of

Man, between March and April 2018. The locations were as follows:

- Armagh
- Belfast
- Cookstown
- Derry/Londonderry
- Downpatrick
- Enniskillen
- Isle of Man

Events were advertised through RNIB NI local teams, social media and the regional media. There was also an opportunity to capture people's views through online engagement. This was carried out via RNIB NI Facebook and all events were publicised by RNIB NI Twitter. Six short online videos were produced asking a series of key questions. This resulted in 2,400 people engaging in discussion and debate.

What we sought to learn

In each focus group event and through our online platforms, the following questions were discussed with blind and partially sighted people:

1. As a blind or visually impaired person, what do you feel moved you towards independence and/or keeps you as independent as possible?
2. As a blind or visually impaired person, how connected do you feel within your community? What would make you feel more included in community life?
3. RNIB wants blind and partially

sighted people to be at the heart of what we do. Looking ahead, how can we work together so that blind or visually impaired people have the opportunity to shape our work? In what ways would you like to be involved working together with RNIB and others for the sight loss community?

4. What issue or shared interest would really spark blind or visually impaired people to work together to change/improve things for other blind and partially sighted people in their communities?
5. What can we, as RNIB and the sight loss community, do to raise awareness to people of the importance of caring for their eyesight?
6. Realistically, what could RNIB and others work on with the sight loss community over the next year or two which you think would make a real and positive difference?

What this report will focus on

Through our engagement, we heard a wide range of issues and topics. The evidence gathered was analysed and the following key themes were identified:

- Independence;
- Community connection;
- Local issues;
- Eye health and eye care;
- Supporting leadership and developing partnerships.

In the next section, responses and

comments have been grouped together under each theme. Verbatim comments relevant to the themes have also been included from participants, to ensure that local voices and views are faithfully reflected from the focus group discussions and online engagement.

The report closes with a section entitled "Participants' ideas for action". These are suggestions from the sight loss community on future actions they would like to see undertaken and which stakeholders could engage with across communities, to make demonstrable progress on the issues highlighted.

4. What sight loss communities have told us from our engagement

Independence

“Dignity and independence are so important. Every blind and partially sighted person is different and distinctive with their own situations.”

Belfast Focus Group Participant

The need for accessible transport was highlighted by participants as being of major importance. Safe, accessible transport is central to the wellbeing, independence and daily lives of blind and partially sighted people. While there have been great strides in improving access to transport, there is still a long way to go and barriers to travel remain one of the most common issues reported by people with sight loss. Access to transport is explored in more detail under Section 6, Local issues in this report.

The ability to work and to be able to stay in work was a signifier of personal independence. After the value of accessing employment support to stay in work, receiving ongoing assistance in the workplace was viewed as a significant factor in maintaining employment as a blind or partially sighted person. Therefore, the comments relating to employment support warrant further discussion. Employment is explored in detail under Section 6, Local issues in this report.

Technology and equipment

“The RNIB IT Support Officer has been remarkable in his support with assisted technologies and showing me the software, the equalisers, to get me up to the point where I can actually study at that level [university studies] without vision. With that support absent, I could not realistically have continued my studies.”

Enniskillen Focus Group Participant

Five key themes were pinpointed through our engagement regarding technology and equipment. Participants described how assistive technology had transformed their lives and highlighted the importance of technology training which was said to make life easier and enable life opportunities. It was also felt that the training was enhanced when delivered by peers. The importance of a personal touch and connection when accessing technology or training was said to build confidence and independence.

The role of technology was described as transformative in accessing information as a blind or partially sighted person and in providing assistance with the tasks of daily life. People accessed equipment and support via a variety of channels – RNIB, low vision clinics, rehabilitation,

social workers and sensory support teams. The types of technology identified as being used in daily life were wide-ranging and included:

- Smartphone apps such as Seeing AI, Pocket Eyes and Colour Share
- Alexa
- Audio books
- BT 195 directory service
- Magnifiers and zoom on tablets/computers/phones
- Motion sensed lights

One of the best practice models highlighted by participants was the training in IT skills provided previously through RNIB's Online Today programme, a funded project which ended in 2018. The local access and outreach approach of this service in travelling to different locations and supporting people with IT updates and training, had a powerful impact on the blind and partially sighted people who used it. Such training enabled online access to practical services and information, making everyday life easier.

It is also important to note that many spoke of the positive impact of involving blind and partially sighted people as trainers and co-trainers. Having a blind or partially sighted person demonstrate IT technologies and other related skills, enhanced the learning experience as they could explain from a lived experience perspective.

Technology support and training is a vital gateway to educational attainment and personal goal fulfilment. IT skills varied greatly, as did access to technology and Wi-fi. While access to equipment and technology was identified by participants as important, a face-to-face, personal connection with people involved with technology support and training was viewed as being of equal standing. The combination of the two was said to build confidence and independence.

Emotional support and life skills training

"When you are dealing with sight loss, you undergo lots of emotions and those emotions block personality traits. By being in a group with other sight impaired people, it doesn't matter what their age might be, you feel more confident and a bit more comfortable with yourself. Your personality traits start then to come out again, and you feel more you."

Cookstown Focus Group Participant

Counselling was considered by participants to be a key emotional support. Although people can access telephone counselling, face-to-face sessions in the initial stages of sight loss was viewed as highly preferential. The early stages of diagnosis for many was one of the most difficult times in coping with sight loss. Additionally, a recurrent theme

arising from the engagement process, was the importance of connecting with others, to receive emotional support in the event of sight loss and reclaiming independence. This could be with either blind and partially sighted peers in local groups, or through dedicated services for the sight loss community.

“Confidence building classes are vital to independence. People need confidence to get over their embarrassment to ask for help.”

Derry / Londonderry Focus Group Participant

Many blind and partially sighted people stated the vital importance of local groups, and meeting other blind and partially sighted people, in reshaping their lives and confidence after sight loss. Companionship, understanding, lived experience and practical knowledge from these peer relationships provide real, human support for people at some of their most challenging times.

In addition to emotional support and the significant benefits of peer connection, life skills training was viewed favourably. Learning how to navigate the world and everyday life tasks by accessing training, marked for many, a turning point in becoming more independent. Accepting help, asking for help and having the confidence to do so, was seen as equally important to independence. Across a number of locations, groups have actively delivered life skills and

confidence training for members.

The major milestone of transitioning from school to adulthood and the support available for younger blind and partially sighted people during this process was also discussed. Although it was recognised that there were many programmes to support younger people with disabilities into further education and work, it was not clear what provision existed specifically for younger blind and partially sighted people.

“People often say after having a guide dog that they wish they had done it earlier. When you see people out with a Guide Dog and that sense of confidence and achievement, it also gives the confidence to try other things in life.”

Downpatrick Focus Group Participant

The use of a cane or guide dog was emphasised as essential for independence. The cane was highlighted as an essential aid for independent everyday living. However, a number of people said that they initially didn't want to use it as they felt it could make them vulnerable by indicating that they were blind or partially sighted. For members of the sight loss community who had a guide dog, they described this as life-transforming in terms of feeling more independent.

Accessible information from public services

"... as a blind person, I believe the one thing that makes the most difference to my independence as an adult man living in NI today is, access to information in a format that works for me. Sometimes that's accessible websites, sometimes that's services that will email or text you instead of inaccessible print and sometimes, it's just good asking the question, what would work for you?"

Facebook Group Participant

The sight loss community, across the board, flagged inaccessible information from public services as a major barrier to being independent. The format and print of personal communications were not accessible for many. This was particularly the case from public sector services. Examples of such communications included:

- medical appointments correspondence
- voting registration
- benefits forms and guidance
- ATM keypads
- financial services information
- signage in public buildings

"In this day and age, surely, it's reasonable to expect equal access to an appointment letter from the hospital or a benefit form. And what about casting your vote in an election? Again, the inequality is mind blowing. I wouldn't mind but the technology exists. It's here. It's just that organisations don't seem to be able to change."

Facebook Group Participant

The receipt of inaccessible information from a range of public services and the lack of movement in resolving this issue was cited as an ongoing source of frustration reflected by many during our engagement. The sight loss community was clear that sending notification of health appointments by text, email or large print letter would be effective solutions. The value of every blind and partially sighted person individually reinforcing their need for accessible information about their own personal health care was also emphasised. Ensuring that blind and partially sighted people received forms such as benefits information in accessible formats was regarded as being essential.

Benefits advice and guidance

"With PIP you receive [a] form with over 30 pages of questions. They sent me a print letter informing me I would go on the waiting list to be seen. How am I meant to read that? How am I meant to fill in the question form?"

Cookstown Focus Group Participant

The very practical barriers the sight loss community face in managing a changed benefits system was commented on by many during the course of our engagement. Benefits are a financial cornerstone of maintaining personal independence for many blind and partially sighted people. In the UK we are currently amidst some of the most major changes ever made to the benefits system, with the introduction of new benefits and assessment processes such as Personal Independence Payments (PIP). Such change has also brought with it much anxiety and concern as people attempt to navigate the new system of benefit applications.

Social care and support for families and carers

“Consistent domiciliary care being provided to me at home is important. The services are being stripped away and when you think about independence it’s about living in your own home.”

Derry / Londonderry Focus Group Participant

Participants of our engagement process raised the importance of quality social care as well as support for their families and carers. Access to social workers and domiciliary care packages, particularly for blind and partially sighted people with more complex health conditions and mobility issues, was considered vital to the ability to remain independent

and to stay at home. The consistency and familiarity of care workers coming to their home, was also an important factor for the sight loss community.

“When you get the news [that you are losing your sight], you’re in shock first of all and you don’t know what to do and it’s more or less left up to yourself as to what to do next.”

Enniskillen Focus Group Participant

Access to guidance and information is pivotal for families to feel less disempowered when a loved one suffers sight loss. Families and carers stressed the need to know what is available locally, to enable them to support the independence of their loved one.

5. Community connection

"I live on my own and I think it's very important to have contact with other people with the same disability."

Enniskillen Focus Group Participant

The focus group sessions provided a wealth of feedback and views on the importance of community connection. This ranged from the role local sight loss groups play in connecting communities, the value of support for sight loss groups as well as other models which have developed capacity. Views were expressed that community hubs operate as a vital connector for sight loss groups. Community outreach also provides this cohesion at a local level. It was also felt that local groups and services could be promoted more extensively and that collaborating across community-based groups could enhance communication.

Many participants noted their involvement in local groups that provide an array of activities ranging from social events, information sessions, sport, dancing, exercise and wellbeing activities, book clubs, creative arts, group outings through to lobbying and campaigning. One participant noted that participation in such activities helps "you build up your own confidence and other people's confidence."

"I live in an isolated area and if wasn't for this group, I would have given up. I was in a very dark place. This reflects not just on me but my immediate family."

Cookstown Focus Group Participant

Many participants noted the valued role local sight loss groups and other groups play in keeping people connected to their local communities. Groups provide multiple benefits for blind and partially sighted people including:

- companionship, camaraderie, social interaction and fun;
- a sense of purpose and contribution;
- access to information about other services or support;
- a feeling of belonging and reduced isolation;
- increased independence and less reliance on family members;
- a way of learning new skills and coping strategies.

Development support for sight loss groups

There is a vibrant network of groups offering a range of activities and information to blind and partially sighted people in local communities. During our engagement many participants spoke of the community development support provided by RNIB (i.e. Community Access, Connect and campaigning support) and other

organisations and how it has assisted groups to grow, develop capacity and connect with others in their local community.

"We recently held an eye health information day in Omagh which was really successful. We had guest speakers and somewhere in the region of 50 or 60 people attending. We want to do this every year."

Enniskillen Focus Group Participant

The importance of face-to-face contact to engage and connect blind and partially sighted people with groups and services in their communities was deemed paramount. In areas where groups had a base to meet, the positive impact on creating a sense of community and connection was obvious.

It was emphasised that to connect blind and partially sighted people to local community groups, services and activities, the geographical differences (rural and urban), local community and transport infrastructure needed to be acknowledged. In short, it was felt that a one-size-fits-all approach to creating community connections was seen not to work.

Throughout our engagement, local sight loss groups provided great examples of reaching out to other blind and partially sighted people in the promotion of activities in their local community. Having a local

focus was also viewed as important to embedding engagement models such as RNIB Connect.

"We know that there are a lot more people in the area with sight loss who just end up sitting there becoming reclusive. It would be great as a group if we could somehow contact them and bring them along with us."

Cookstown Focus Group Participant

There was a palpable desire across groups to increase their capacity to connect more with other blind and partially sighted people who were unaware of what was available locally. The role local health and social care services played in signposting, was seen as pivotal to how blind and partially sighted people learned about what they could access within their locale.

The sight loss community was keen to expand the ways in which local community groups and services were promoted by:

- more coverage in the local press of sight loss group activities and meetings;
- increased use of Talking Newspapers for community connection;
- enhanced signposting across services, i.e. directories;
- home visits to blind and partially sighted people to cover local information about activities and support;

- blind and partially sighted people getting trained up to outreach and connect with other blind and partially sighted people in their area.

“There are loads of hubs around the city where communities are coming together, working with each other and sharing resources and it works.”

Derry/Londonderry Focus Group
Participant

Many sight loss groups have cultivated a wide range of relationships with other local sight loss, community and disability groups in their areas. These relationships are mutually beneficial for sharing information about group funding, activities, facilitators, speakers, resources and community connections.

From our discussions, groups were enthusiastic about more collaboration across services and groups in their areas to reach more blind and partially sighted people. Collaboration was also viewed as another way to address resource and funding issues.

6. Local issues

During our engagement there were strong, correlating themes of what was needed to enhance the quality of life, the equality of access and opportunities for the sight loss community. These included:

- enhancing public transport services and expanding access to rural transport;
- improving the experience of the sight loss community in health care;
- consideration of the sight loss community in outdoor spaces and building design;
- employment support for the sight loss community;
- public awareness of sight loss and its impact.

Transport

Transport was a core issue raised at all engagement events. For many it impacted substantially on how independent they felt and was identified by those we engaged with as a priority focus for future work. This section provides an analysis of the main points raised during the community engagement discussions.

Public transport – the everyday experience of current services

Many participants provided their own personal experience of using public transport services. The main areas of discussion centred on:

- audio description on public transport;
- equality of access and cross-border travel;
- transport staff and awareness of visual impairment.

“Sometimes if you are on public transport and you go to somewhere up the country, sometimes you might not know where a bus is stopping. You should be able to have [audio] announcements about stops like they have on trains or other places.”

Enniskillen Focus Group Participant

The lack of audio description on transport in rural and other towns outside major cities, was seen as a prime area for improvement, as the above quote illustrates. Travelling from A to B on public transport and just simply knowing the different stages of the journey is a basic need and a very practical issue. Many participants stated that expanded audio description across existing services would significantly enhance the personal experience of people with sight loss to travel confidently and independently.

"We are running a SmartPass equality campaign to have the same as they have in the Republic and in Scotland, Wales and England. As partially sighted, a half-fare doesn't even get you across the border. Also, in all the other regions I am talking about, you can take a travel companion or a friend with you for free."

Derry/Londonderry Focus Group Participant

Members of local campaigning groups commented on how they are lobbying for more equality of access to public transport for blind and partially sighted people and their accompanying guides. Many felt that their ask of fully subsidised travel for partially sighted people travelling in Northern Ireland and cross-border would significantly increase independence, quality of life and wider access to services.

Practical realities shape the personal experience of transport for people with sight loss. Poor experiences can impact on the willingness to readily use public transport. While many participants offered praise for the standard of service they had received from transport staff, examples were also given of negative experiences.

Examples shared with us included: trying to explain to transport staff the difficulties of stepping up on and off transport; the bus moving before being seated; seeing ticket payment options; not seeing clear

screen partitions in the ticket and driver booth; or simply knowing when to get off. Another example from conversations in the Isle of Man, highlighted that even where audio announcements were available on public transport, staff have on occasion not turned it on.

Rural transport service access

"Buses during the day [are] OK but after 6pm in the evening we are prisoners in our own home. We can't get out; most of us live on our own and taxis are not feasible. We want to go out and have fun just like everyone else."

Enniskillen Focus Group Participant

The effect of isolation on wellbeing and independence is poignantly captured by the comment above from a visually impaired person living in a rural area of Fermanagh. Transport is one of the dominant issues which has an impact on people's ability to access services and activities independently whether appointments, shopping, work or meeting up socially to feel part of community life. This is particularly so in rural areas.

From our engagement, issues about access to local rural transport services centred on three main themes:

- times and availability of rural transport;
- cost;
- restrictions on where services operate.

Many participants reported that in a number of rural areas, office hours for booking transport were limited to 9am–4pm with general access to rural transport (unless for group hire) stopped at 6pm. In another rural area, transport was limited to three days a week for regular users due to the demand for the service and its own capacity to meet demand. The issue of intermittent daytime operating hours and evening access presents a picture of fragmented transport access which the sight loss community is eager to address.

“For me to run into town in a taxi it’s about six miles each way which can cost between £18 to £26 per round trip at night.”

Enniskillen Focus Group Participant

Changes in taxi services in some rural areas, combined with the cost of hiring rural transport as an individual, were seen as barriers to accessible travel for many blind and partially sighted people in rural communities. The cost of hiring transport for sight loss community groups so members can travel to activities was another prohibitive factor in connecting with blind and partially sighted people in rural areas.

“The rural transport is a good service for the Tandragee area, but I can’t go to Portadown at all. It’s just more or less the same distance but they won’t give you the transport into Portadown, which is three miles away, due to the rural transport boundaries.”

Armagh Focus Group Participant

There are several rural community transport companies operating in Northern Ireland. A number of these services operate on old boundary agreements which limit where blind and partially sighted people can travel to. The local council boundaries changed in Northern Ireland in 2015, but the boundaries where rural transport services pick up and drop off have not altered and are smaller in their scope. Another restriction cited was the difficulty with town and country connections, particularly for accessing hospital or health appointments.

From our engagement we also heard how improved experiences of public transport were helped by public transport staff being made aware of a passenger’s visual impairment. It was felt that having a similar approach to the Just a Minute (JAM) card currently used for people with autism and learning disability could discreetly raise awareness of passengers with sight loss.

While Northern Ireland has made great strides in improving access to transport, there is still a long way

to go and barriers to travel remain the most common issue reported by people with sight loss. As highlighted above, transport has been a distinct focus for local lobbying (such as CAN's work campaigning for cross-border subsidised fares).

In 2015, RNIB NI published *Get on Board*, a research study of the transport needs of blind and partially sighted people in Northern Ireland. The findings from this study have informed our campaign and lobbying activity to date and there is much overlap with the transport findings of this report. The 2015 research uncovered four key areas where transport barriers existed in Northern Ireland: affordability, availability, accessibility and awareness.

The *Get on Board* report made fifteen recommendations. These included:

- free travel for partially sighted people, and free travel for companions of blind and partially sighted passengers;
- adequate government funding for community transport;
- the abolition of community transport cancellation fees;
- a strategic and consistent approach to community transport provision across Northern Ireland, ending the current postcode lottery;
- more frequent Translink services in rural areas, particularly during the evenings and weekends;

- the extension of audio announcement systems across all Translink bus services;
- government and transport providers to sign up to RNIB's Bus Charter (subsequently led to Translink signing up in March 2016).

To raise awareness of this piece of research, RNIB presented to the then Committee for Regional Development at the Northern Ireland Assembly. RNIB has also shared the research findings with elected representatives, civil servants working in the Department for Infrastructure and officials within Translink. The findings have also informed the Department for Infrastructure's draft *Accessible Transport Strategy*.

Improving the experience of the sight loss community in health care

Beyond the accessibility of health care information, which was raised earlier in this report, it was communicated by participants that there needs to be more awareness from professionals about the sight loss community's specific needs in receiving health care. Points include:

- how blind and partially sighted people are treated as patients in hospitals;
- how treatments and diagnoses are explained;
- how professionals are trained in sight loss awareness.

Common experiences of blind and partially sighted people include not knowing where to go for hospital appointments or admissions and the locations of food and other necessities not being explained during a hospital stay.

“It is very, very important that we as blind and partially sighted people or some agency should be there training doctors and young health care students about sight loss.”

Belfast Focus Group Participant

A number of participants spoke personally of the challenging and difficult experience of receiving news about sight deterioration. It was discussed how local sight loss groups and representatives have been proactive in raising awareness of the impact of a sight loss diagnosis and the practical ways professionals can engage with the sight loss community to optimise their experience of health care, from a clinical, emotional and psychological perspective. Sight loss community representatives have also been involved in health and social care training of students in local universities and institutes. Extending the training time on sensory impairment, the scale of training, and access to training information by other channels (e.g. online or on CD), were still considered work in progress. It was also highlighted that there were communities of older blind and partially sighted people in residential and nursing homes where care staff would benefit from sight loss training.

Navigating outdoor spaces and building design

“Street furniture (e.g. sandwich board signs) is a problem. We have spoken to local businesses who move it at first but then sometimes an hour later it is back again. It’s an ongoing thing we have tried to campaign on for years.”

Derry/Londonderry Focus Group Participant

Discussions from our engagement highlighted the range of hazards the sight loss community face in navigating the public realm, such as:

- uneven and badly maintained streets and pavements;
- kerbless ‘shared spaces’ road layouts and poorly designed road crossings;
- signage which was difficult to read;
- uncut and overhanging hedgerows;
- cars parked on pavements;
- street furniture and freestanding commercial signage.

The involvement of the sight loss community in the design of public buildings, and buildings adaptations required for blind and partially sighted people, was seen as essential. Like outdoor spaces, many public buildings and premises – particularly newly built or refurbished spaces – did not adequately factor in the navigation and use of buildings by blind and partially sighted people.

Many blind and partially sighted people mentioned difficulty in finding their way around buildings or sustaining at worst, injury from poor design and layout.

Hazards encountered included:

- glass entrance doors;
- poor lighting;
- no yellow markers on steps;
- frosted screens or Perspex partitions at counters;
- shops leaving packaging or crates unattended in aisles.

Employment support

“We need our MHKs [elected representatives, Isle of Man] to do more work for us. It's attitudes in the workplace which make a difference.”

Isle of Man Focus Group

Securing and retaining paid employment was a priority for many in the sight loss community to maintain independence. Many participants provided examples of their own personal experiences in the workplace. These included:

- lack of adequate training or development once employed;
- poorly adapted work conditions (e.g. absence of assistive technology or essential software updates and adaptations);

- commitment of employers to follow through on workplace support once in post.

Many people with sight loss expressed worry that they will be unable to find work or stay in their current job due to their sight loss.

Public awareness of sight loss and its impact

“People can get very frustrated with you about everyday things as they don't understand sight loss, getting them to understand more would be good.”

Armagh Focus Group Participant

A crucial part of continued public education cited by participants was the need for equality and awareness training for services and businesses. Assisting a more in-depth understanding of the variations of sight loss was also supported by many blind and partially sighted people when exploring this topic. It was felt that little was known about the broad range of sight loss conditions.

There was also a widely held view that in addition to the work already undertaken, there needed to be much more general awareness raising with the public at large about sight loss and its impact. For example, public awareness campaigns designed to highlight issues faced by the sight loss community were favoured.

7. Eye health and eye care

“You go to the dentist for check-ups as this is seen as important but there is not the same awareness around eyesight and eye checks.”

Armagh Focus Group Participant

This topic generated a wealth of discussion ranging from participants keen to learn about breakthrough treatments and medical research, to the lived experience of accessing timely health care in hospital and community settings. Participants were also interested in learning more about artificial eyes and preventative measures to safeguard eye health.

There was concern about the speed of follow-up appointments with a new diagnosis or in the event of deterioration in vision. It was acknowledged that health services faced major challenges and delays across all programmes of care. However, the sight loss community viewed extended waiting times for treatments and operations for sight as unacceptable, given that conditions can deteriorate irreparably in the interim.

Learning what the sight loss community can access for their eye care after diagnosis and treatments was a key consideration. This was also an issue for families who wanted information about what was available locally, when and how. The point was also raised that services may not be available in all areas. Campaigning

for timely and consistent treatment and access to health care was seen by participants as a priority area for lobbying by RNIB and other stakeholders.

A number of participants discussed their experiences of undergoing operations for artificial eye implants and described how they found these procedures difficult. Experiences of pre and post-procedure services shared by participants in this engagement were very different. It was suggested that more information was needed for patients approaching this procedure. Psychological support was also seen as an essential part of treatment and recovery.

There was widespread support for continued campaigns to stress the importance of regular eye check-ups. The partnership between Specsavers and RNIB in promoting checks to defend against avoidable sight loss and its nationwide media campaigns, were praised and welcomed.

Other campaign and lobbying ideas to emphasise the importance of preventative care included widening access to free eyesight tests. In addition, a compulsory eyesight test for school leavers at 16 was suggested as a means to educate young people about eye health and eye care.

8. Supporting leadership and developing partnerships

During our engagement, there was a recurring view that there should be a step change in how RNIB and other agencies could work with local groups and sight loss communities. Themes included strengthening relationships with local sight loss groups as well as recognising and supporting diverse, local leadership voices. A desire for continued open communication leading to partnership working was also expressed, as was the importance of keeping services person-centred and involving the sight loss community in decision-making.

“We want to have more face-to-face conversations like this and more channels of open communication. Communicate with people more and bring them together like today.”

Belfast Focus Group Participant

Members of local sight loss groups were keen that other stakeholders gained more detailed knowledge of their work as a first step in strengthening relationships. A number of participants spoke of their experience of engaging with voluntary organisations and other agencies working at a regional and national level. In addition, how local sight loss groups are communicated with was noted as important. Groups wanted more face-to-face and regular communication with

organisations whom they could work with to build their capacity.

There was also an appetite for sight loss groups to have links with other groups and networks with a shared interest in key campaigning issues (such as disability networks) at a local and regional level.

“RNIB has been so supportive of local CAN groups... we find it very difficult to get people involved and young people. Young people are campaigners and we need their voices too.”

Belfast Focus Group Participant

Another strong theme from the engagement was the need for charities and agencies working with the sight loss community to acknowledge and understand more about the different experiences of people with sight loss. As highlighted in other parts of this report, there are very specific issues regarding how blind and partially sighted people access support as individuals and groups in various geographic locations.

Younger people taking part in this engagement process, also emphasised the need for services to think about what age appropriate support and involvement opportunities were offered to them, to encourage their

participation. Younger people also wanted a recognition of their voice and life experiences to be reflected in the wider discussion on living with sight loss.

Another key talking point was how other stakeholders communicated with sight loss communities and groups. Different groups and individuals shared experiences where at times they did not feel like a leader or equal partner in meetings / discussions with voluntary organisations and other agencies. The engagement approach undertaken by RNIB for this piece of work was welcomed as an inclusive process, with communities wanting more local communication at a grassroots level. Participants also indicated that they were keen to learn about the work of other agencies / organisations for the sight loss community and how resources were being spent. For the sight loss community, effective and transparent communication was seen as a vital aspect for openness and building trust for more partnership working moving forward.

“We need to have these conversations about hard choices as a sight loss community. It would be good to have the space to talk and explore all the choices and alternatives as we are not going to get everything we have suggested.”

Belfast Focus Group Participant

During our engagement, there was a distinct worry that efficiency drives and lack of funding would result in the loss of core and person-centred support services. The short-term nature of funding – especially for community and voluntary sector programmes – created anxiety that the range and accessibility of services was shrinking across communities.

Everyone was aware of the different financial and operational pressures affecting services across sectors. People realised that hard decisions have to be made but wanted to be informed and part of the decision-making process. The need for wider involvement of blind and partially sighted people as leaders in discussions about services featured strongly.

9. Participants' ideas for action

Throughout this engagement process we received many excellent recommendations from participants for consideration by RNIB, the wider sight loss community and other key stakeholders. The topics outlined below, provide a flavour of the key recommendations from the community on all the themes discussed in this report. These ideas for action will assist with the overall planning for the next steps our work.

Independence

A variety of suggestions emerged about how independence could be further enhanced for the sight loss community. These included matters relating to technology training, access to technology support, as well as counselling and training such as:

- working to develop more outreach technology training in rural areas;
- continuing to meet regularly with local political representatives in rural areas, such as Fermanagh, in relation to Wi-Fi access to support independent living using technology;
- exploring the possibility of setting up a social enterprise IT training company for the sight loss community;
- developing better local collaboration and/or joint training with other counselling organisations;

- continuing to engage with social work teams in relation to the referral processes for peer support and emotional support;
- developing more life skills training and courses to support the transition of younger blind and partially sighted people from school;
- creating educational CDs (or other formats) which can provide information on services and resources which help with daily life tasks for people experiencing sight loss;
- undertaking a mapping exercise to see the full range of training available for the sight loss community.

Community connection

The engagement process highlighted a number of ways to enhance the profile and capacity of local groups to work in their communities and connect with more people experiencing sight loss. This was a major topic of discussion during the engagement process. There was a host of innovative suggestions about how local sight loss groups could be assisted. Ideas for consideration included:

- identifying and building working relationships with existing community and voluntary organisations and networks who could support sight loss groups in their work on the ground, and assist with general development and capacity issues;

- running dedicated recruitment campaigns with local groups to build a bank of new volunteers to support activities;
- offering more assistance and training for groups on how best to promote sight loss issues and activities in the local press;
- continuing to use the RNIB Connect website pages and websites of other relevant organisations to facilitate information sharing and signposting;
- making more use of community TV to promote the work of RNIB, local groups and other agencies;
- exploring opportunities for more creative outreach, such as having sight loss events or sessions within wider community festivals;
- having drop-in centres or spaces at set times and dates for blind and partially sighted people in different local areas in community spaces (such as the library or leisure centre).

Transport

Many suggestions were made about how to build on the campaign work related to accessible transport. Everyone consulted was keen to explore with other stakeholders how transport could be better co-ordinated, expanded and enhanced to improve access for the sight loss community, particularly in rural areas.

A desire for more campaigning and engaging with transport providers

at a local level was highlighted. Recommendations included:

- mapping the current transport resources within each area;
- linking with other groups to see how transport hire costs could be shared (such as jointly co-ordinating trips with other groups);
- fundraising across groups to cover transport costs;
- expanding the use of volunteer drivers for the sight loss community by recruiting and training more drivers in rural areas;
- engaging better at a local level with Health and Social Care Trusts to look at the best way people in rural areas can access transport more easily for health appointments;
- creating strong, local campaigning groups, i.e. developing the CAN model, with a focus on local transport issues;
- continuing to work with and influence transport providers and planners regionally for expanded use of audio announcements on public transport.

Accessible information from public services

To enable the sight loss community to have practical access to important information as citizens and users of public services, the following suggestions were made about how this could be improved:

- the development of text messaging services across all sectors;

- exploring ways of using phone or other technology (e.g. a Voice Post Box) where public services could leave you a message.

Improving the experience of the sight loss community in health care

Much of the discussion reflected very different personal experiences of the sight loss community in accessing health care. There were many good examples of positive health care experiences as well as suggestions on how this could be improved by:

- increasing the number of volunteer guides in hospitals trained in helping blind and partially sighted people;
- continuing to review the referral process from community care to community services to ensure people have all the information about what is available to them in their area;
- having more information about technology support available in Low Vision Clinics.

Navigating outdoor spaces and building design

The overarching aim of progressing work on this issue was to enable more direct involvement of the sight loss community with relevant stakeholders involved in rural and urban planning services across communities.

Recommendations included:

- engaging with relevant stakeholders such as local councils about issues related to public spaces for the sight loss community and how infringements are enforced (e.g. poor maintenance of streets, parking);
- linking with planners and elected representatives to raise awareness of the needs of the sight loss community in the design of spaces and places;
- identifying and highlighting local examples of poor street signage.

Employment support

Based on the desire to create and encourage more accessible employment options, the following recommendations centred on setting exemplars, changing workplace cultures and employers' awareness of the needs of blind and partially sighted employees:

- for voluntary organisations and other agencies working with the sight loss community to continue to encourage blind and partially sighted people to apply for employment within their organisations and review this process regularly;

- checking the possibility of partnering with trade unions and employer organisations about accessing sight loss awareness training packages;
- exploring the possibility of offering employers workplace assessments for blind and partially sighted employees to ensure Section 75 compliance (where relevant) and appropriate support in work;
- providing better information and training to employers on assistive technology.

Public awareness of sight loss and its impact

Everyone at the engagement events wanted sight loss to be given much more public prominence. Overwhelmingly, public health and awareness campaigns were seen as the main vehicle for change. Recommendations for action included:

- more targeted media campaigns in relation to sight loss and prevention to raise awareness with the general public;
- continuing to highlight sight loss issues at a local and regional level with increased partnership with other organisations working in similar fields.

Eye health and eye care

In relation to eye health and eye care, there were two main strands of work identified – to maintain high profile campaigns about eye care and to communicate information about

progress in medical treatments. Ideas for action included:

- continuing to lobby the Department of Health with regards to ophthalmology waiting lists using a wider partnership approach across the sight loss sector and a broader media campaign;
- working with health agencies to review the capacity of community nursing services to support aftercare for eye conditions and treatments;
- increasing the number of eye health information and awareness raising days both locally and regionally as well as joining with other local and regional events where feasible;
- keeping people informed about new treatments through RNIB and other relevant communication platforms.

Supporting leadership and developing partnerships

From our engagement, there was a genuine sense that groups were keen to build on the regional engagement undertaken and develop opportunities for partnership which would benefit local sight loss communities and groups, working together on issues which they wanted to progress. Suggestions for future collaborative work were varied, vibrant and creative. They covered three main themes, from forging local partnership links, to campaigning and how best to enable opportunities for sharing resources.

Suggestions included:

- continuing to engage with the sight loss community and other stakeholders to look at the rural isolation of blind and partially sighted people and how this can be addressed;
- developing a regional consultative forum, appointing group members from the sight loss community, to facilitate co-ordinated engagement with decision makers;
- community groups and regional organisations to continue making more use of social media and other media in general;
- CAN groups raising the profile of their local campaigning work and successes;
- focusing attention on attracting younger blind and partially sighted people to get involved in campaigning;
- looking at ways of developing more cross-border connections with other sight loss groups and organisations;
- exploring options where sight loss groups can establish a community hub with other groups and agencies;
- collaborating better with existing support networks to identify funders and general resources for the sight loss community.

It is clear from the rich mix of suggestions which participants shared at the regional engagement events, that the sight loss community has a diverse range of ideas for action. These suggestions will assist in future engagement with a range of stakeholders, including those in the community, voluntary and statutory sectors, and in agreeing actions to the issues detailed in this report.

10. Conclusion

Throughout this community engagement process RNIB sought to connect at a grassroots level, working through co-production to look at how best we can ensure that:

- the voices of blind and partially sighted people are strengthened;
- blind and partially sighted people are equipped to live the life they want to lead;
- more effective relationships and partnerships are developed.

In each of the key areas identified by the community, blind and partially sighted people voiced their lived experience, concerns, reflections and recommendations for a partnership approach to effecting change, in order to live independent lives based on equality and effective collaboration.

What is clear from this engagement process is that while some people with sight loss are living relatively independently, many others still face barriers on a daily basis in relation to several areas such as: transport, accessible information, timely access to health treatment, community connection, employment access, and general equality of access to services across the board.

Groups working at a local level and regional organisations within the sight loss sector continue to work hard to ensure that blind and partially sighted people are partners in the

social change process. However, it is also clear that more effective work needs to be done by everyone across all levels, if people living with sight loss are to fully participate in society.

Therefore, a more extensive and co-ordinated collaboration is required through a co-design and co-production approach, if government policy and planning is to reflect the needs of the sight loss community.

RNIB is fully committed to a collective planning approach that will continue to be embedded in the next steps of direct engagement between the sight loss community, key decision makers and stakeholders at a local and regional level.

Responding more effectively to and planning inclusively with blind and partially sighted people will help break down the barriers outlined in this report and create a world where those with sight loss can participate equally and fully.

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