

Involvement Report 2020–2021:

Adapting to change in challenging times





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Finding promise and renewed purpose at the most challenging time

Author: Mandy Owens, National Involvement Team

It has been said so often it feels like cliché, but you cannot reflect on 2020 without saying that it was an unprecedented year. People with sight loss have faced unique challenges – with so many aspects of their lives under threat. While everyone has faced disruption, people with sight loss have found everyday tasks like shopping, getting outdoors, socialising, accessing information and attending appointments become increasingly difficult and, for some, almost impossible to achieve. Hard fought independences have been challenged and people have been at increased risk of isolation.

RNIB, as an organisation, had to face new challenges too. To help the people who needed us the most, short term priorities had to change as we worked on solutions to get people access to food, medicines and other essentials in lockdown. At the same time, we faced cuts in face to face services and volunteering, a drop in our traditional fundraising activities and the pandemic forced a sudden move to remote or homeworking for most staff.

But there has been positive change too. As demand for essential services – through RNIB's Helpline – told us our support was needed more than ever, the importance of listening to our customers was re-emphasised,

with involvement of blind and partially sighted people an obvious priority. Our strategic aims were reviewed, and current business goals redefined.

The lived experience of blind and partially sighted people has continued to impact on RNIB's work. Taking on the challenges we set ourselves last year, we have involved more RNIB customers in projects from concept to completion. We have laid the foundations for better collaboration with customers through staff training, guidance and telling real stories that demonstrate the value of input from people with sight loss.

We are already looking to the future, with a new lived experience framework which allows us to demonstrate and monitor how blind and sighted people contribute to our work. We will be conducting surveys to help evaluate how well we are incorporating lived experience and the impact it has.

But, to make this work, we need your help. Whether you're a staff member or one of our customers, your support is valued. We need staff to continue to involve more blind and partially sighted people in pieces of work, and if you are a valued customer, we'd like you to share your experiences by joining our Connect Voices network.

David, Head of Innovation and Customer Voice, said:



“There has been a growing recognition at the most senior levels that authentic lived experience is critical everywhere in the charity.

There is an understanding that it is not enough to have people with lived experience sitting only on our trustee board. There is a genuine and growing appetite for people with little or no sight to play a part in all that we think decide and do and the value that lived experience can add to our work. We have made commitments to take a ‘whole organisation’ approach to developing this area of what RNIB is becoming, making it part of our organisational DNA.”



One final point: you’ll notice this is a report with a difference, we wanted to include audio links and further reading where appropriate so look out for the pink boxes throughout the report.

Thanks for reading. We couldn’t do this without your support.

If you have any feedback regarding this report or you wish to join the Connect Voices network, please contact RNIB’s National Involvement Team at Involvement@rnib.org.uk quoting ‘Annual report’.

How Lived Experience drove RNIB's response to the pandemic

Coronavirus has had a huge impact on the lives of everyone in the UK, but blind and partially sighted people faced their own unique set of challenges. It became clear from the calls received by our Helpline and our groups on social media that the pandemic was having a devastating effect on people's lives.

To hear direct from those affected, we started a programme of research in 'real time' during the first lockdown, gathering insights from over 400 blind and partially sighted people through surveys, well-being calls and facilitated discussion groups with our customers. Using Microsoft teams allowed us to reach people through any device, whether it be laptop, landline, tablet, or mobile phone. Looking into ways customers who are not online can get involved was noted in last year's report, so it was important to us to make these choices available.



Have a listen to what some of those involved in the discussion groups felt about the experience
rnib.in/1-Lockdown-Sessions

Our regional Community Connection teams also gathered information as part of their thousands of well-being calls. Consequently, RNIB has better understood the challenges people have been facing and was able to provide solutions, as well as much needed help and support, including;

Developing a new relationship with DEFRA to make priority home delivery slots available for blind and partially sighted people who needed them.

Working with the UK Government, the wider public sector and sight loss organisations to ensure blind and partially sighted people get access to the right information in the right formats.

Helping the Department of Health and Social Care (DHSC) to create guidelines on how people with sight loss can be supported by others outside their home. It made clear that sighted guiding is permitted if people take the right steps to reduce risk.

Working with blind and partially sighted members of our community to develop guidance on the use of face coverings.

This research will inform our work over the next year, giving us a clear indication of what people want, need, or have a right to, in order that they are treated equally to that of sighted people, as well as feeling safe and supported, now and in the future.



Read the full report including all findings, responses and recommendations here: Final report – rnib.in/LWSL-Lockdown



Technology breaks more and more barriers down

This year we have used technology to break down more barriers as the initial lockdown gave us an opportunity to rethink how we engage people. We had to rely on remote methods, but we were able to work with people easier and quicker than before.

Previously, we might have been unable to work face to face with people as often as we'd liked, due to a lack of available resources, or budget constraints. Equally, people may have found meeting us a challenge, whether this be due to travel, mobility, or simply not having the time. Here are two examples of how technology has helped us:

Key insights into eye care in the pandemic

Our Marketing Business Partners worked with our Connect Voices network through an online survey exploring access to eye care appointments during 2020.

Staff wanted to evaluate the effectiveness of recent marketing communications, as well as gaining additional insight into how people were feeling about attending eye care appointments. Results from the survey helped the team decide what communications worked well and should be repeated, what barriers are still in place and how RNIB might be able to help people in future.

Surveys like this are a great way to get a snapshot of responses from a large group of people at once; they are quick and easy for people to take part in, no matter their location.



Liz from the team says:

"The insight into people's feelings and experiences increased our monitoring of the situation around

access to eye care appointments. It was shared with colleagues in Policy and Campaigns team and the Sight Loss Advice Service to support their work. Big thanks to the Involvement team and the Connect Voices network for their help."



The survey's results also helped produce new Eye Health material on our website here:

rnib.org.uk/advice/eye-health



Use the Navilens Go App to scan this code



	486kj	Fat	Saturates	Sugars	Salt
	115kcal	0.6g	0.3g	5.1g	0.20g
30g	6%*	<1%	1%	6%	3%

100g: 1621kj/382kcal

Pioneering technology makes our Kellogg's partnership break new ground

In October 2020, to mark World Sight Day, RNIB worked with Kellogg's, Co-op and NaviLens to trial accessible packaging of the Coco Pops breakfast cereal in more than 50 food stores across the UK. As one blind and partially sighted shopper told us, information on food packaging is often inaccessible.

"I tried to use the camera on my smartphone (to zoom in) but I wasn't very successful so had to ask someone else. If no one was available I would just have to guess the cooking instructions"

Research from RNIB revealed that nine in 10 blind and partially sighted people felt that information on food packaging was difficult, or impossible to read, so the trial used NaviLens' technology (rnib.in/NaviLens) which allows a smartphone to detect and playback labelling and allergen information to shoppers, enabling blind and partially sighted people to find out more about the product both instore and at home.

We wanted to hear the views of blind and partially sighted people and so the opportunity to get involved was shared through the Connect Voices network and other social media channels. Nearly 100 participants took part, each receiving the packaging through the post to test. Participants were then sent a survey to complete,

telling us which accessibility features they preferred and how they found being able to independently access this kind of information.

We had an overwhelming response to the survey, which clearly demonstrated the need for greater access to information on packaging.

Chris Silcock, Kellogg's Managing Director, explained:

"Over two million people in the UK live with sight loss and are unable to simply read the information on our cereal boxes. That's why we partnered with RNIB to trial special boxes of Coco Pops with NaviLens technology – a first for food packaging. If the trial is a success, we would hope that it could appear on more of our cereal boxes for visually impaired shoppers to access in future."

Since working with Kellogg's, RNIB have been actively collaborating with major brands from across the world to better understand the landscape and represent the demand for greater access to information on packaging.



Have you experienced the accessible packaging from Kellogg's? Search for the **'NaviLens Go'** app, download to your smartphone and scan the photo on the previous page.

Connect Voices moves to the next stage

Listening to the voices of blind and partially sighted people – and what they have to say – is central to RNIB’s work and underpins our ambition to be experts in the lived experience of sight loss. Connect Voices is the route for people to take to help us achieve this.

Founded two years ago, it gives opportunities for people to have their say and contribute to our work in real time, both online and off. Our online network made a move to Facebook in July 2020, increasing membership to 602 blind and partially sighted people (as of 1 April 2021).

In last years report we prioritised communication and integration of Connect Voices. Given the limitations of our current database, the move to Facebook has given those already familiar with social media a much simpler joining process.

Offline, we’ve increased the publicity of Connect Voices on RNIB’s Connect Radio with the introduction of a new fortnightly slot. This regular round up of opportunities provides people who aren’t online the chance to take part.

RNIB

Connect Voices

“I have been more involved in Connect Voices during the pandemic especially during the first lockdown where I had to shield and now in this second lockdown too. It has massively helped my wellbeing, I have something to aim for, look forward to, and some structure.”
Connect Voices member

Positively, a survey to our members in 2020 showed that

75%

felt that being part of Connect Voices also supported their mental health.

As one Connect Voices member told us:

“It has helped me to look outside of my home and to be able to help has assisted with my mental wellbeing. I’m usually out volunteering for RNIB so this helps me keep motivated and feel of worth as I do like to assist others like me who have a visual impairment.”

Connect Voices shared

175

internal opportunities
last year

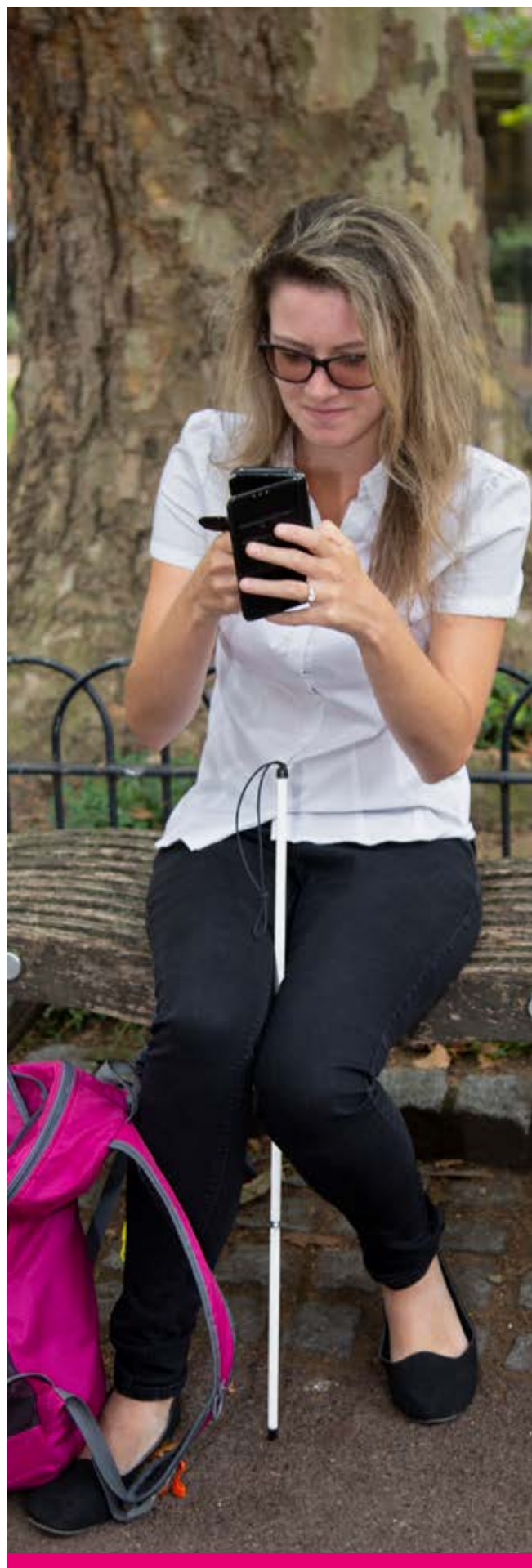
Connect Voices has become well established in the organisation as the route staff can take to source blind and partially sighted people to support their work, with 175 internal opportunities posted to the group last year (April 2020 – March 2021).

In late 2020, Connect Voices added a new research element, called the Connect Voices Tracker survey, that ensures we hear from people more often and allows us to respond swiftly to emerging needs.

Each version of the quarterly survey features a range of topics to help RNIB understand how people are feeling and measure our impact to create the right changes at the right time. We hope to reach at least 400 people each quarter, through Connect Voices and our offline channels to ensure we get the most representative views as possible. Ultimately, findings will directly shape RNIB's priorities and future focus.



Hear a summary of our findings from October – December 2020 here rnib.in/2-Tracker-Survey-Q3



Informing our campaigning as the world changes

In 2020 everything changed dramatically for blind and partially sighted people and we continue to feel the impact of those changes.

It's crucial RNIB, as an advocate for people with sight loss, ensure our campaign work is targeted where it is most needed. With this in mind, we decided to undertake a review our campaign priorities for 2021, working with our campaign volunteers to get an authentic understanding of the day to day challenges people were experiencing. Doing so helped us to prioritise our campaigns for the year ahead. This is one area we have improved in line with our goal last year of: working towards a culture of involving people from the very beginning.

Ten volunteers joined our virtual discussion group in which we considered key issues such as transport, technology, eye health, education and employment, prioritising them in order of importance.

The discussion proved to be a lively exchange, with volunteers sometimes differing in opinion and raising compelling arguments in terms of how we prioritised future work. It also allowed us time to talk more candidly about where campaigners felt RNIB would have most impact and the additional knowledge and skills needed to campaign effectively.

Lindsay, Campaigns Manager added;

"This approach was invaluable as it made certain that our work was informed by the right people, whilst also helping to build volunteers understanding of RNIB, our processes and how and why certain decisions are made. It was a thoroughly enjoyable session"

Lived experience provides us with the evidence we need to share with both central and local government, helping us to make a real case for change on a range of issues. Everyone knows and understands their own experience, our role in campaigns is to draw that out and turn it into a collective voice. Next, we will meet with various staff teams to hear their thoughts and collectively, the feedback will define our future campaigns.



Steve, one of our key campaigners in this discussion, had the following thoughts
rnib.in/3-VolSteve-comments

Supporting the Statutory Inquiry with a review of RNIB's constitution

In February 2020, RNIB's Board of Trustees established a group of more than 30 blind and partially sighted people, known as Constitutional Members, to consult on changes to our organisational structure and constitution (i.e. our Royal Charter and Bye-laws).

The Charity Commission for England and Wales' Statutory Inquiry into RNIB concluded with a report ([rnib.in/safeguard-report](https://www.rnib.org.uk/charity-commission-report)) that made a number of recommendations, including the need for us to make some changes to our governance.

The Constitutional Members were a deliberately diverse group of people, including those from regional and country networks, members of Connect Voices, long-standing volunteers and members from our Board Committees. We also included people from the world of business and the public sector, some of whom had worked with RNIB previously and some who hadn't, to bring a different perspective to discussions.

In April and May 2020, RNIB consulted with the members on amendments to its constitution. Meetings were held remotely with Ellie, our then Chair of Trustees, and Matt, our CEO joining each group. The Board reviewed the outcomes and agreed the amendments proposed by the members.

The Constitutional members work had concluded at this point. However, feedback from the members also made a clear and compelling statement that the proposed changes to the charity's constitution should be seen as part of wider organisational improvements, bringing the voice of people with lived experience of sight loss into all levels of the RNIB's work. Trustees agreed, and the second phase of work started, looking more closely at three key themes:

Trustees' relationship with sight loss, covering education as well as understanding of sight loss and ongoing engagement and communication.

Reviewing RNIB's Involvement strategy and associated structures.

Training and development to support blind and partially sighted people to better contribute to RNIB's work, or that of any other organisation, including at board level.



Audio Hear members talking about the importance of bringing lived experience

into RNIB's work

[rnib.in/4-Constitutional-Members](https://www.rnib.org.uk/4-Constitutional-Members)

In August to October 2020, staff representatives and the National Involvement team facilitated nine online discussion groups and liaised with members via email and phone to develop an action plan to realise these themes.

Involving people outside of the organisation can be a daunting prospect, but this example of a successful collaboration on highly sensitive and sometimes complex matters has proved that we can overcome any perceived barriers.

Encouragingly, most of the original constitutional members continue to remain engaged with us in some way, either through this work, as members of our Involvement Advisory group or the Connect Voices network. Through these channels they continue to share their lived experience and work with us to embed the changes they have helped to shape.



Mark, Constitutional Member reflects on his experiences and how his opinion of the RNIB has changed: rnib.in/8-Marks-opinion-of-RNIB

Dan, Head of Organisational Effectiveness, considers the contribution from blind and partially sighted people:



“I’ve seen two really tangible shifts this last year, involvement of people through the Constitutional Members process, and listening in real-time to how

people were being affected during the first lockdown. These have materially sharpened our focus – particularly on emotional wellbeing and access to information, both of which have ripple effects across all other areas if they are not addressed. This helps us substantially in setting achievable targets that have meaningful impact for people, which is something that RNIB has struggled with previously”

Making the most of local lived experience

2020 saw us breathe new life into our local customer groups, the Network Committees.

Renamed Local Action groups, or Advisory groups, lead volunteers continue to work with the Community Connection teams to look at ways of reaching more blind and partially sighted people, while ensuring the work itself represents the diverse cultures and demographic of the UK.

In turn, the community connection teams utilise the knowledge and lived experience at grassroots level to further develop services and support needed in their region. Our work in devolved nations is a great example of what we can achieve.

In Scotland, the group has been integral to the work RNIB has done on Accessibility of Voting. Our volunteers co-produced our response to the Electoral Commission's consultation; took part in Scottish Government focus groups and have taken part in trials of new accessible voting methods led by RNIB Scotland – in partnership with the Scottish Government, Electoral Commission and the Forth Valley Sensory Centre.

One visually impaired voter told us:

“When voting in the 2019 General Election, I had to ask staff members at the polling station to reposition the Tactile Voting Device twice before I could cast my vote. Even then, I left the polling station not sure if I'd cast the vote I wanted.”

Ongoing work with blind and partially sighted people can only improve the accessibility and confidentiality of voting for thousands of people with sight loss in Scotland.

James, County Director, added:



“I would like to thank the tremendous contribution made by our volunteers who work with us to ensure that accessible information is made

available in the devolved Scottish Social Security system. Improvements were also made to the accessibility of the transport system. RNIB Scotland would not be the social change innovator that it is without our work with the blind and partially sighted community.”

In Wales, campaigners and the Action and Advisory group have been central to raising the profile of the RNIB Cymru manifesto "A Wales without barriers for people with sight loss" which is a crucial opportunity to influence the next Welsh Parliament in the elections taking place in May 2021.



Campaigner and Advisory group member, Tafsila Khan, is the face of our manifesto and her powerful video highlights the barriers she faces in the built environment. RNIB Cymru's manifesto calls for the 2021 Senedd elections – RNIB – See differently. <https://bit.ly/3uQfAB8>

Our blind and partially sighted volunteers have been central to focus groups commissioned by Welsh Government to outline the barriers that they face in accessing voting and we are working closely with the Welsh Government and Electoral Commission in Wales.

Ansley Workman, RNIB Cymru County Director, added:



"There is no doubt that the direct voice and experience of blind and partially sighted people is making a difference. We have seen many politicians have 'lightbulb' moments when talking to blind and partially sighted people about the everyday barriers they face. We wait to see how the next Welsh Parliament ensures that we have a Wales without barriers for people with sight loss"

The local Action and Advisory Groups are a work in progress and will continue to be developed in conjunction with blind and partially sighted people in 2021.



Bringing the sector together to understand the lives of blind and partially sighted people better

In 2020, national charities, RNIB, Guide Dogs and Thomas Pocklington Trust have come together to launch a major research study, uncovering the realities of life for blind and partially sighted people in the UK today.

This exciting and important piece of research will help us get a better understanding of the experiences of blind and partially people, in turn helping us to offer the right kind of support and make a more positive difference to people's lives.

RNIB has done this kind of research in the past, although these reports are now somewhat outdated.

What is new is that the sector has come together to work collaboratively on a new piece of work which is much bigger in scale than we have ever seen before, creating a shared understanding and giving us the evidence to determine which organisation is best placed to tackle specific issues.

It's also the first time we have explicitly addressed the complexities of emotional wellbeing and self-identity at different stages of sight loss, as well as that of friends, family, and carers.

Across the charities, we held conversations with nearly 800 blind and partially sighted people, discussing a wide range of topics including their sight condition, wider health and wellbeing, employment and benefits, use of technology and their social life.

We explored what improvements people think are needed to increase their independence and better their quality of life. We also held in-depth interviews with customers; grouped by demographic; to find out exactly how they felt about the topics that were important to them.



Our participants recognised the value of speaking to a wide range of people and appreciate the opportunity to take part and have their voices heard:

“Any research that we want to provide answers must be good and take a broad view not just one person’s view, like me. I have strong view on certain things and some other people might not see things in the same way, because maybe the area they live in could be better or worse than mine’

Male participant aged 72.

The full programme of research is very nearly complete, and we are currently collating and evaluating the findings. We have also put in place a customer group for the research, to guide the decisions we make; ensuring that past our initial conversations, blind and partially sighted people will remain key to this work.

The findings will be shared cross the charity sector and provide us with a much-needed benchmark to work from. Doing so will allow us to better support people with what matters to them, and design services, products and campaigns which better reflect their needs.

Hilary, Head of Research and Insight



“This ground-breaking piece of research has only been made possible by the participation of hundreds of blind and partially people who have given up their time to take part. I would personally like to say a heartfelt thanks to everyone who has been involved and given their views.”

RNIB's new National Involvement strategy

Following the Constitutional Members' consultation, we worked with existing participants to create a new look Involvement strategy for 2021.

This strategy encapsulates exactly how we will work together with blind and partially sighted people over the next year and turns our value of having 'blind and partially sighted people are at our heart, influencing everything we do' into a reality; so it's crucial we involve people in its creation.

The previous strategy made a great start, laying the foundations and putting systems in place that made it easier for staff to source and work with people and for people to get involved. Throughout 2019 and 2020, we created our 'Connect Voices' network of customers, developed an interactive training programme to upskill staff and instilled the voice of blind and partially sighted people in our recruitment process, ensuring people are able to input into decision making on who we employ.

Working together over three months, the Involvement manager and seven people from the original Constitutional members consultation reviewed the previous strategy and developed a more relevant and current strategy for the future.

Sue, National Involvement Manager said::



"During the discussions the customers were very open and honest about what had worked well and what could be improved. That was sometimes

uncomfortable to hear – no one likes to hear when things haven't gone well, but it was important to get the full picture so we could move towards finding solutions. One of the main issues the customers raised was the lack of quality information and communication, particularly from Trustees and Senior leaders. This point also came up in another piece of work, so it confirmed there were issues that we needed to address."



Constitutional Member Andrea, who took part in this work, gives her thoughts here: rnib.in/6-Andrea-The-Involvement-Strategy

When we spend time talking to people so openly, it serves as a timely reminder that we tend to use certain language that isn't well understood outside of RNIB. The group highlighted that words we use regularly do not translate well to the public. We are going to move away from jargon and talk more about 'working with blind and partially sighted people' as this has a clearer meaning for everyone and better articulates what we want to say and do.

Another interesting conversation looked at how we measure the contributions from people through their lived experience and the value this has. It is a difficult thing to be able to measure and it was interesting to hear customers talk about how they felt their contribution should be recognised.

We've started to look at how we measure lived experience in RNIB and the value this brings. We will start by gathering feedback through questionnaires and having simple conversations with people who have supported us. This will provide us with a benchmark as to what good involvement looks like and the value this has not only to the work, but to customers, staff and the organisation as a whole.

We now have a bigger and better strategy to take us into 2021. The aims of the strategy are:

We will use simple language to describe how we work with blind and partially sighted people, removing terminology that is confusing.

We will develop a way of measuring the value lived experience brings to RNIB's work.

We will review and improve how we communicate about the lived experience of sight loss to internal and external audiences.

We will simplify our structures for working with blind and partially sighted people to allow for creativity and flexibility in how we do this

There is no doubt that the insight gained from people has been significant in creating the vision we have today and with the continued support from blind and partially sighted people, we're confident we will achieve these aims.



Recorded especially for this report, RNIB's Development Director, Keith, talks about his hopes for the RNIB and the importance of working together with blind and partially sighted people. rnib.in/7-Keiths-Thoughts

During a time of reflection, customers share their thoughts on the RNIB

"Before Connect Voices I felt that the RNIB were quite sight orientated and only aiding the elderly. I can see that they are changing, and they are coming around to new technologies and the ways in which we can change things for the good of each other. I have really enjoyed being a member of Connect Voices during lockdown. It's got me involved a lot more than other things have done before. I like the fact that you post about campaigns and get people to contribute as sources of information. Thank you so much for involving me with Connect Voices."

Alex, Connect Voices member.



"I have been involved with the RNIB for many years but my love for volunteering for the organisation has most definitely grown over the last 9 months during the Coronavirus pandemic and also my appreciation for the organisation and its impact and role in our community. I have seen the RNIB make huge strides during the pandemic and I have been amazed at how I have felt that my opinion has been valued by a large organisation. I have a renewed love and appreciation for the organisation and look forward to many more years volunteering with the RNIB."

Vivienne, Long-Standing Volunteer



“When I started at the RNIB it was as a volunteer lead in the South of England. I learned to set up and facilitate group sessions, and arrange a venue, which I had done a few days before lockdown. Then of course lockdown happened, and we started phone groups instead. This was a massive learning curve as I’d never done anything like that before. This year though, the virtual way of connecting has brought me great friends all over the country. I had never volunteered anywhere before, and now, because the RNIB taught me that my life skills and lived experience were valuable, I lead the phone group, I am governor of our Local Health authority and have been involved with RNIBs Constitutional Members consultation. Thank you RNIB.”

Karen, South West Action Group Member



“I’ve been a volunteer for RNIB since around 2012 and more recently I have started to see an increase in things people can get involved with. I have become a Connect lead, which means I get to work with staff and volunteers, which has increased my confidence. I’m part of the Communications Advisory panel and help put together the regular Volunteer update. We are able to discuss what and how communications are sent out and if anything is incorrect, which has been a big problem in the past. I believe that the panel are really helping to get this right. Overall, I feel that, we’re really being listened to which is a great feeling and it is lovely to be able to make a difference.”

Amanda, Long standing Volunteer.



Summary: Ellie Southwood, RNIB Chairperson, 2017 to 2020.



It's been another important year for RNIB's commitment to involving blind and partially sighted people in all we do. Regularly involving people from across the UK is critical for our credibility and for ensuring we're representative of a range of experiences. We're continuing to reach out further to increase the diversity of people involved with us and we are particularly keen to see the experiences of blind and partially sighted people from BAME communities reflected more prominently in our work.

I'm delighted that blind and partially sighted people were involved in recruiting my successor Anna as Chair. This feedback was invaluable in influencing our decision – I'm really grateful for the time that volunteers

give so generously to our recruitment processes. The insight of our customers is a valuable asset; and one which will continue to help us recruit RNIB staff in future.

Over my 10 years as an RNIB Trustee, I've seen huge shifts in how we involve people in our work. It's not always easy for large, well-established organisations like ours to open themselves up and find inclusive and meaningful ways for people to shape and inform our work. I'm proud of the progress we've made and look forward to this becoming an established hallmark of how RNIB serves blind and partially sighted people in future.

Ellie Southwood

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