

**Written evidence submitted by The Royal National Institute of Blind People (RNIB) (CVD0029)**

**About Sight Loss in the UK**

Every day 250 people start to lose their sight	At least half of all sight loss is avoidable	More than two million people have sight loss	350,000 registered blind or partially sighted	Age-related macular degeneration is the leading cause of blindness in adults.
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**Summary**

The Royal National Institute of Blind People (RNIB) is the UK’s leading sight loss charity and the largest community of blind and partially sighted people. Every day 250 people begin to lose their sight. We want society, communities and individuals to see differently about sight loss. In our 150th year RNIB renewed our focus on creating a world where there are no barriers to people with sight loss.

RNIB submitted a response to the Unequal Impact Inquiry, looking at the effects of the lockdown on blind and partially sighted people focusing particularly on the impact of social distancing, access to groceries, inaccessible information, eye health and vision rehabilitation, and made recommendations according to how these issues could be addressed in three weeks and six months' time.

This supplementary submission looks in more detail at access to information on coronavirus, services and the effect of lockdown on the mental health of blind and partially sighted people.

As we move out of lockdown the disproportionate impact of social distancing measures on blind and partially sighted people is set to be felt even more deeply, as it is near-impossible for people with sight loss to socially distance, impacting on independence and anxiety levels.

**2. The effectiveness and accessibility of Government communications and consultation with disabled people during the pandemic**

RNIB campaigned for and welcomes the appointment of a Senior national lead for accessibility. We are working with her to try and embed accessibility across all Government communications about coronavirus.

While some progress has been made, it has been inconsistent and slow. Our offers of help have been welcomed by some government departments and rejected by others and we are far from ensuring that accessibility is embedded into government communications from the start.

For example, the recent letter sent to 2.2 million people who are shielding was ready to be sent without consideration given to accessible formats. RNIB approached NHS England and NHS Improvement offering to provide alternative formats for the letter, suggesting that those who needed them could order the appropriate format through the RNIB Helpline.

A sentence to this effect was included at the top of the letter and when the letter was issued, over two hundred people from within the shielding population phoned RNIB to request alternative formats. Although this was better than previous correspondence relating to coronavirus from the Government, anyone who couldn't see the large print information at the top of the letter would still have missed out on vital information about shielding as it was provided in a format that was not accessible to them.

Disappointingly, when a letter to people shielding in Leicester was sent out subsequent to this, no consideration was made for the provision of alternative formats. Given how quickly we were able to respond to the demand for alternative format requirements for the general shielding letter, it was disappointing that this wasn't considered just a week later. This inconsistency is unacceptable and unnecessary.

The NHS Accessible Information Standard (AIS) 2016 and the Equality Act 2010 make it clear that people in England have the right to accessible information and communication support. There is a legal obligation and a practical safety requirement to ensure blind and partially sighted people receive information about coronavirus in a format they can read so they and their communities can stay safe.

Through our work on accessible information, we have also been identifying the inaccessibility of the test, track and trace system for blind and partially sighted people. As a result, we are pleased that the Department of Health and Social Care has recently run a user trial with blind and partially sighted people on the accessibility of home testing kits. We will continue to work with Government to ensure an accessible testing process is developed as a result.

However, the fact that a system was rolled out where the two main ways to get a test – at a drive in centre or through a home testing kit – were not accessible to blind and partially sighted people is another clear example of how accessibility is not built in to Government programmes.

## **Recommendations**

- The Government must develop and consistently implement processes to ensure accessibility is built into communications from outset in line with the Equalities Act (2010) and the Accessible Information Standard (2016).
- NHS England and NHS Improvement (NHSEI) and Public Health England (PHE) must monitor implementation of the Accessible Information Standard by NHS Trusts, ensuring that patients receive information in the format they require.
- The Government must ensure that the test, track and trace is accessible for blind and partially sighted people

### **3. Disabled people's access to food and the effectiveness of the Government's response to reported problems**

In our previous submission, RNIB and other sight loss charities referred to the extensive campaign we ran on the availability of priority supermarket delivery slots, and the issues that many blind and partially sighted people were experiencing getting food during lockdown. Over 22,000 people signed the RNIB, Guide Dogs, Visionary, Thomas Pocklington Trust and Vision UK petition which we submitted to Defra in mid-April and RNIB met with various Ministers and Shadow Ministers to discuss this issue.

Further research which we released in May showed 74% of blind and partially sighted respondents were either very or quite concerned about getting access to food while 21% of people reported that they had had to ration food.

At the beginning I did go to the shops as I normally would the staff were very panicked ... and didn't know what to do I felt embarrassed ... this has made me really worried about this I'm going to manage once lockdown is lifted

RNIB was informed about the development of Defra's 'non-shielded vulnerable' programme of work, which has secured priority delivery slots for people struggling to access food. It was announced by the Secretary of State on 26 April that local authorities would be able to refer into this

scheme, at which point RNIB called for national coverage and clarity on timelines.

Behind the scenes we were working with Defra to ensure that RNIB could refer through to these slots from our Helpline so that blind and partially sighted people across England would be able to access the scheme. We were delighted to be able to refer inbound callers to delivery slots from the end of May and were able to publicise the availability of these slots to our service users from mid-June.

The civil servants working on this scheme have been constructive, helpful, and a credit to Defra. However we first raised this issue with the Secretary of State at the end of March, and the slow speed of the roll-out and the decision to prioritise local authorities as the main referrers to the scheme has meant that access to the slots via national charities came too late to help the majority of people who needed it in the early weeks of lockdown.

Nonetheless we are pleased to now be able to refer blind and partially sighted people who need this support through to the slots that Defra has reserved, and we are well-placed to deal with any subsequent lockdowns. For those who have been referred through RNIB it has had a real impact on their quality of life. One 91 year old man who was referred through the scheme told us:

We don't have immediate family to help so this was a little godsend as we feel too nervous to do the shopping with social distancing. I was relying on support from volunteers for a long while but then got support from RNIB... The adviser was very helpful and everything fell into place, [the supermarket] got in touch after a couple of days.

We remain concerned about the broader impact of social distancing on blind and partially sighted people's ability to access services and businesses as lockdown eases. Social distancing is inherently visual, and rules are largely being enforced by visual means – tapes on the floor, signage, new queuing systems, sign-in lists, seats taped off to indicate they are out of use – for example.

Our research, released in mid-May, showed how social distancing rules were impacting on blind and partially sighted people's independence, with two thirds (66%) saying they felt less independent than before lockdown, and 80% of all respondents reporting the way they shop for

their essential shopping has changed, with half as many blind and partially sighted people visiting stores independently.

It is very hard to know how to keep 2 metres away from people when you can't judge distance... I can't see the markings on the floor, so have been shouted at... I ended up in tears. It's not my fault that I can't see the floor markings.

It's essential that businesses and service providers know how to ensure changes they make to enforce social distancing are accessible to blind and partially sighted people. This could include tips on how to share information in accessible formats, for example, and how to share new information verbally as well as in signage or leaflets. How public transport operators provide assistance – usually done through close-contact guiding - will also need to be considered. RNIB has made contact with civil servants and are hoping to contribute to the creation of this guidance and these provisions are likely to be considered reasonable adjustments under the Equality Act.

### **Recommendations**

- Defra should on-board all local authorities to the 'non-shielded vulnerable' access to food programme and publicise as widely as possible the priority delivery slots available
- The Government should issue guidance to service providers, businesses and employers to explain how to make social distancing measures accessible

## **4. Disabled people's access to healthcare services, including treatment for COVID 19 and access to other healthcare services**

NHS eye care staff made tremendous efforts during the lockdown to ensure that patients requiring time critical sight saving treatment received it. However, uncertainty about the risks involved, and insufficient information and communication meant that a high proportion of patients failed to attend these vital appointments.

A careful balance is needed between providing sight-saving treatment and containing the spread of coronavirus, particularly amongst ophthalmology patients most of whom are elderly. However, as lockdown is eased and services are resumed we are very concerned about how eye care services will cope with the backlog in eye care patients.

Ophthalmology is the largest outpatient speciality. Prior to the lockdown the Healthcare Safety Investigation Branch and the Get It Right First Time Ophthalmology programme identified the lack of capacity in eyecare was resulting in thousands of patients experiencing delays in their eye care appointments causing hundreds of people to lose vision. RNIB is hearing from patients, particularly those with conditions like glaucoma that require ongoing monitoring, who are fearful that delays in their appointments will result in avoidable sight loss.

### **Recommendations:**

- The Government should include messaging about eye care services in the NHS Open for Business communication campaign
- The Government must ensure increased funding for NHS eye care services as we come out of lockdown to deal with the backlog as well as previous pressures on the system
- The Government must consider increasing capacity in eye health through provision of improved IT to enable better utilisation of the whole eyecare workforce and remote consultations

## **5. The mental health of disabled people, including the effects of isolation, access to mental health services and the implications for disabled people of temporary changes to the Mental Health Act**

### **Anxiety about keeping to the rules**

Social distancing measures have had a profound impact on the mental health, confidence and independence of significant numbers of blind and partially sighted people. Many people depend on a guide to get out and about but one in four (25%) blind and partially sighted people told RNIB they don't have someone in the same household as them who can guide. The close contact required when guiding means many people have lost this way of leaving the house, leaving people feeling much less independent.

We are pleased that the creation of 'social bubbles' means that some more isolated blind and partially sighted people will be able to create a bubble with relatives or friends, but tailored guidance is still needed.

More than half (52%) of the respondents to our Living with Sight Loss in Lockdown research were concerned or anxious about following the social distancing guidelines correctly.

Because I live alone the isolation has been very difficult. I would usually go for walks with friends or family. However they are so fearful of being fined as they live outside of my household .... I felt like I had been making so much progress before lockdown and now it's as though I have taken 10 steps backwards.

Uncertainty around what's permitted under the rules has been a main factor leading to loss of independence, as blind and partially sighted people have been confused about where and when they can expect assistance and what steps they should take to keep everyone safe. We have been working with civil servants to clarify this issue. The Scottish Government has confirmed that it is possible for a blind or a partially sighted person to be guided by someone from outside their household, emphasizing the importance of limiting the time spent at less than two metres from each other and of wearing a face covering and maintaining good hand hygiene.

Blind and partially sighted people in England, Wales and NI need clarity too as soon as possible.

### **Mental health**

As well as having an impact practically - on access to food, ability to exercise, or attend medical appointments – the impact of social distancing and lockdown is also impacting people psychologically:

I live alone and feel isolated and alone for the first time in my life. I am also very acutely aware of my sight impairment in ways I am not usually.

By not being connected to my groups, I've felt very lonely and isolated, vulnerable and depressed. On several occasions I just stayed in bed being apathetic. My motivation has gone.

Rehabilitation Officers for People with Vision Impairment (ROVIs) have also told RNIB that the people they are working with are experiencing heightened anxiety and depression resulting from isolation. And more than half (54%) of blind and partially sighted people told our Living with Sight Loss through Lockdown researchers that their sight loss was

stopping them from getting out as much as they would like during lockdown.

Of those blind and partially sighted people who have been able to leave the house during this period, almost two thirds (65%) found maintaining a two metre distance with other people difficult, and nearly half (48%) were concerned or anxious about catching the coronavirus.

RNIB's counselling service now has a seven and half month waiting list. As people lose their independence and become more isolated levels of anxiety and depression are likely to increase. It is important that there is access to mental health support where it's needed.

### **Public awareness**

Blind and partially sighted people have overwhelmingly reported that more needs to be done to educate the general public about the challenges faced by visually impaired people around social distancing. Many people with sight loss are unable to keep two metres away from other people and guide dogs are not trained this way. Blind and partially sighted people who haven't been able to keep their distance have reported being confronted by passers-by or being so nervous about breaking the rules that they have lost confidence and are concerned about leaving the house.

People don't understand what a white cane is for which makes you a target for comments like, "2 metres, give me some room"!

Some blind and partially sighted people told RNIB they felt people wearing masks in public were withdrawing and not engaging as much with those around them, which has implications for the provision of assistance.

Is it important that public awareness of the challenges of social distancing is increased, to reduce confrontation and increase understanding.

### **Recommendations:**

- The Government should create tailored guidance for blind and partially sighted people on social distancing. Clear rules on guiding would help people understand their options and reassure people that they are not breaking the rules.

- The Government should ensure adequate provision of mental health services for disabled people who are feeling less confident or independent because of additional challenges caused by the pandemic.
- The Government should communicate to the public why people with hidden disabilities such as sight loss find it more difficult to social distance, and reduce the stigma on people unable to do so.

## **6. Social care for disabled people in their homes and in residential care settings, including the effects of easements to duties in the Care Act and the approach to monitoring and review of these changes**

Vision rehabilitation is fundamental for ensuring that people who develop significant sight loss can continue to live independently. Its impact can be transformational, allowing people to remain active and self-reliant, while reducing costs to NHS and social care. The OPM Group detailed case study savings of £3.2m from services costing £900k in its 2017 report “Demonstrating the impact and value of vision rehabilitation”.

Prior to the coronavirus pandemic, we were aware of a backlog of people in England waiting for referrals, in some cases for longer than of 12 months. Historically, vision rehabilitation has not been prioritised within local authorities, particularly given their financial constraints. Vision rehabilitation services are not monitored by CQC and there is no centralised collection of performance data, which has not helped this.

There has also been variation in resource allocation and the depth of support provided between local authorities, along with a national shortage of specialist ROVIs. In areas where there are no Eye Clinic Liaison Officers in post it is also common to see slower referrals from NHS Consultants. Meanwhile many individuals with a diagnosis of sight loss may not have heard of ROVI services and may be unaware of their rights, and the nature of support that should be available.

RNIB has also heard anecdotal reports that some local authorities are planning a “Year 0” approach to waiting lists, as services are re-opened, deleting existing waiting lists and starting afresh, which would delay those who have been waiting for an assessment and service still further.

Reduction in independence and confidence among many blind and partially sighted people increases the risk of individuals requiring more support, with a consequent increase in need for assessed care services

and of additional risks of falls and injuries. Lack of provision of early intervention vision rehabilitation services has been shown to disproportionately increase health and social care costs elsewhere in the system. (OPM Group, 2017, “Demonstrating the impact and value of vision rehabilitation”).

**Recommendation:**

- The Government should emphasise that the practice of deleting existing waiting lists is not acceptable, and that existing waiting lists should be reassessed by a specialist ROVI, to ensure those most at risk are prioritised.
- The Government must ensure that, as COVID-19 restrictions are relaxed, vision rehabilitation services are prioritised and not disadvantaged by wider adult social care pressures.

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