# My Voice 2015: Capturing the voices of the ‘Hard to reach’

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## Executive summary

At the end of 2015 RNIB published ‘My Voice 2015’ the largest survey of registered blind and partially sighted adults in the UK. However, there were certain people affected by sight loss that the Survey could not reach including those:

* with dual sensory loss;
* caring for someone with sight loss and complex needs;
* living in care homes; and
* who aren’t fluent in English.

To fill this gap in knowledge, RNIB commissioned interviews with blind or partially sighted people who are in one or more of these groups. Eleven interviews were undertaken. Though this is a small and very mixed group, a number of key themes emerged from the interviews, with suggestions for better meeting needs and maintaining wellbeing:

1. **People frequently valued opportunities for social contact and ways to enable these should be supported.** A befriending scheme and a telephone talking group were talked about positively. These opportunities should be made available to those who have both sight and hearing loss, and those who are carers.
2. **Activities that people enjoyed before their sight deteriorated are missed ways to enable people to maintain their involvement or find good replacements should be identified.** An example of where this had happened was a tandem experience for someone who had been a keen cyclist, with a plan for the care home to obtain a tandem on a permanent basis. Talking books was cited by a number of people as a way of enabling them to keep reading. For younger people this would apply to opportunities to be in employment.
3. **Sight loss services are encouraged to consider if they can better meet the needs of individuals with other health conditions and issues.** Services could look to extend their offer to those with dual sensory loss, complex needs, and people for whom English is a second language.
4. **Both family and ‘paid for’ carers, and supports, are valued.** Vision Rehabilitation workers were among those who helped enable independent living. Family were often providing a lot of support and care. ‘Formal’ care providers, either individuals or teams, who provided stable, consistent care were seen as especially beneficial, enabling relationships to be built up.

## Background

In late 2015 RNIB published the findings of the My Voice survey, an extensive survey of the experiences and circumstances of registered blind and partially sighted adults in the UK (see [www.rnib.org.uk/myvoice](http://www.rnib.org.uk/myvoice)). This was the largest survey of its kind; over 1,200 registered blind or partially sighted people participated. However, there were certain groups of visually impaired people that My Voice could not reach. The survey was carried out over the telephone in English, and this was a barrier to certain groups participating, such as those:

* from minority ethnic backgrounds who do not speak English fluently;
* with hearing and sight loss;
* with complex health conditions making telephone communication difficult; and,
* living in care homes.

RNIB is there for everyone affected by sight loss, so it was important that the voices of these groups were also heard. Therefore, we commissioned an external research consultancy, ResearchAbility, to carry out additional in-depth interviews with people from these groups. This was done with the support of interpreters in three instances. In the case of three participants with complex health conditions where an interview was not possible we interviewed their carers about their own experience s.

Most of the interviews were conducted with people who were first contacted through recruitment for the My Voice survey and were unable to take part in the telephone interview, but who still wanted to be involved in the research in another way. The exception to this was four interviews with blind or partially sighted people living in a care home. To contact these participants we reached out through professional networks and these four interviews were carried out in a care home operated by a local sight loss society which specialises in care for elderly people with sight loss.

In total eleven interviews were conducted. Some participants fell into a more than one of these groups. For example, two participants had sight loss, hearing loss and did not speak English fluently. Three interviews with carers took place. Six men, four women, and one husband and wife, who cared for their son with complex needs, were interviewed. Ages ranged from 30 to 97. People were from across the UK.

These interviews were not designed to be representative of all blind or partially sighted people within these groups, but to explore the experiences of individuals and to consider the themes and issues arising. The following sections report on these themes.

## Valuing social contact

All those participating referred to the importance of social relationships and either how they benefited from current supportive relationships or were saddened by the absence of them.

A number talked of relationships with family and friends that they valued. Sheila, who has dual sensory loss, values spending time with her friends, going to the cinema, shopping, swimming and attending a church group for Deaf people. This was in contrast to contacts with other residents where she lives. She struggles to communicate with them because they speak fast and she finds it hard to keep up. She tries to lip read but it can be hard, and it gives her a headache.

In her nineties, Joyce has lived in the specialist residential care home for five years. Although it took her a while to get used to living there, she is now ‘interested in everything’*,* and has made some good friends, including a friend who she’s very close to. They like the same things and Joyce is able to help them get around, because she has some sight whereas they don’t have any. George also mentioned the opportunities for social contact at the care home, joining coffee mornings and has friends that he enjoys talking to at mealtimes.

Some individuals were visited by family very regularly; had supportive neighbours who looked out for them; went out to religious meetings, such as their local gurdwara; or skyped their children and grandchildren when they lived further away. Leonard had tried attending support group meetings for his eye condition, but found them to be dominated by women, though he had enjoyed the trips they organised. He was regularly participating in a facilitated telephone group, talking with others with sight loss. Two individuals talked about enjoying their weekly contact with a befriender as part of a scheme organised by their care home; George enjoyed having this opportunity to talk to someone. For Fred, a life-long cyclist, he had enjoyed going out on a tandem ride with his befriender.

For some individuals, opportunities for social contact were more limited than they wanted and something they missed. Arthur had recently moved into the residential home but felt abandoned there by his family and friends. Ahmed was living in a homeless hostel, where there were drug users and frequent arguments. Although Gurpreet takes a bus to her local gurdwara every day, where she sees friends for lunch, and family visit daily, she is at home alone for much of the rest of the day.

Some talked about not being able to take part in particular social activities because of communication difficulties or not being able to go out because of sensory problems and/or mobility problems. Sheila, with dual sensory loss and learning difficulties, explained that social groups with other visually impaired people were often inaccessible, particularly in very noisy environments, where it becomes even more difficult to hear what someone is saying. Poor sight also makes communication through lip reading very difficult for her.

Among carers, isolation could be part of their experience. Andrew cares for his wife with vascular dementia and a number of eye conditions, and they don’t have family close by. The local carers’ network meetings are on weekdays when he is at work, and his wife is unable to attend weekday social groups as they don’t provide transport. As a result, he reflected: “we become a bit insular”.

## Loss of interests, hobbies and employment,

Interviewees talked about how sight loss in later life, sometimes combined with other health conditions, such as problems with mobility, had reduced the extent to which they could participate in activities they had valued. Although her sight was poor from birth, and now in her mid forties, Sheila had worked in a fast food outlet until her sight had deteriorated further and she had had to stop work. Jean was active in fundraising for her church but her deteriorating sight had affected this and her Parkinson’s compounded difficulties. Fred, who had lost his sight quickly in his eighties, missed going to the pub and had little to occupy his time outside of meal times, with the exception of the radio. Leonard had to give up driving and playing golf. Joyce had to give up painting and embroidery. Arthur had to give up driving, which meant that he was unable to get to the start point to go rambling, his main recreational activity.

Talking books, and listening to the radio, brought pleasure to several individuals and/or enabled them to stay in touch with the outside world. For example, George enjoys listening to talking books, particularly murder mystery, history and war stories. He likes listening to the radio, especially cricket matches and has his own radio in his room, which gives him access to all local radio stations.

## Good services make a difference

A number of individuals talked about positive experiences from the services they had been in contact with to help them adapt to sight loss; live independently; help them access, or provide, care and equipment; and continue to pursue their interests. These services included schools, voluntary sector organisations, resource centres, GPs, social workers, psychologists, speech therapists, vision rehabilitation workers, individual carers, local authorities and private care companies.

Leonard receives a ‘first class service’ from Macular Society and RNIB. From RNIB he got a talking watch and magnifiers and receives talking books. A volunteer from the Macular Society helped Leonard set up a computer and iPad at home and visited him to provide ongoing technological support.

Jean talked about how her mother Virginia, at 96 with Parkinson’s, AMD and cataracts, is ‘fiercely independent’ and determined to stay in her own home. The Continuing Care Fund pays towards the cost of carers who work in three main shifts spread throughout the day. They know the carers well and the set-up is good, though the manager of the care company has recently moved on so the family are now in the process of getting to know the new manager. The team that care for Virginia is fairly stable and it is uncommon for care to be provided by a stranger. The support that they provide is hugely valued by the family because it means that Virginia is able to live at home as she wishes. Jean said her mother ‘would have died of a broken heart’ if she had needed to go into a care home.

Andrew’s wife, with both sight loss and dementia, has a single carer who stays with his wife while he’s at work. Although Andrew knows his wife would rather have him with her, the ‘absolutely marvellous’ carer has been with them consistently for several years, supported by local authority funding. Without the carer he wouldn’t be able to work.

Ahmed, with hearing, sight and mental health problems, knows he can use the ‘drop-in’ facility of his local sensory team. He lost his symbol cane on one occasion and went there for a replacement. One of the workers speaks his first language and she looks after him when he attends. He is aware that they have a social group that meet and go on trips, for example, to the seaside or to local exhibitions, though he doesn’t often feel well enough to go.

Experiences of services were not always positive. Arthur talked about a lack of support at the time of his sight loss. A long, positive relationship with his GP came to an end when he retired and the GP who took over Arthur’s care was not very caring, often getting his medication wrong. When asked what would have been helpful to him at this time, he replied that he wanted someone to care for, and take an interest in, him.

Sheila talked about struggling at her first school because her sight and hearing impairment were not really catered for. In contrast going to attend a college in Canada, in her late teens, was ‘like discovering a whole new world’ and she began to develop self-confidence. Learning American sign language opened up communication, and the college provided interpreters and access to technology.

Gurpreet described being diagnosed with a serious sight condition by a doctor speaking English, although she has a limited understanding of the language. The doctor told her that she had lost her eyesight and that she would not be getting it back. Gurpreet was extremely distressed on hearing this news, however fortunately a doctor who shared her language was passing and spoke to her about her diagnosis, explaining that she would not lose all her sight.

David and Jane rely on formal carers to visit their son Stephen, who has a range of complex needs, each day. However, since a longstanding carer who had worked with Stephen for many years left about eighteen months previously, there have been many occasions when the company providing two days of his care each week telephone and say there are no carers available. David described that during this period, Stephen had 14 different carers, which is not helpful as he becomes agitated if things are not as he is expecting. David noted that in order to make something happen ‘you have to make waves’.

Although services may be available, participants didn’t always feel able to take advantage of them. For Andrew caring for his wife, transport for her to attend groups whilst he was at work was an issue. Gurpreet had not heard of sight loss charities, but felt that not being able to read or write in English would be a barrier to accessing them. Sheila found that, although welcoming, communication was too challenging at her local blind society, as a result of her hearing and sight loss. They used Scottish sign language, which is not her preferred format, and the noise level was also a problem. David and Jane described how organisations with a focus on sight or hearing loss are not really appropriate for them as their son Stephen’s needs are so complex.

## Adaptations for people with sight loss, and with other conditions

Many interviewees talked about aids and adaptations that made life easier. Gurpreet benefitted from rails and a shower that had been fitted for her husband after his stroke. Responding to Leonard’s dual sensory loss, Social Services fitted a special light and installed a loop system in his home, which enabled him and his wife to watch TV, albeit with Leonard sitting very close to the screen. Fred benefited from support in relation to equipment and mobility, but a speaking watch has been invaluable. George and Fred were both keen to take advantage of an adapted tandem that their care home is fundraising for.

Interviewees with health conditions in addition to sight loss mentioned that some commonly used equipment and adaptations are not accessible to them. Sheila described how her poor sight made it hard to locate and retain her small hearing aids. Screen readers are not an appropriate solution due to her dual sensory loss because she cannot hear the audio. Andrew’s wife, Leanne, used to be an avid reader, however, Andrew has researched every possible gadget that might help, but was unable to find anything that suited her. The degree to which they slowed reading down meant that Leanne lost her enjoyment of reading and now her dementia means she would no longer remember what she had read.

However, the right adaptations can make a huge difference to a person with more complex needs. Sheila described how staff at a resource centre had been very friendly and took time to understand her requirements. Whilst using a white cane to tap was unsuitable due to her level of hearing loss, they found a cane with wheels through which vibrations helped to alert her to obstacles. Two individuals described how iPads were effective tools for them. Sheila described how she uses hers to identify what she is looking to buy in shops: she can write the word and also show a picture. She also uses it to book train travel or hotel accommodation.

## People making the best of things

It was clear that some individual’s were really struggling with their situation. Arthur felt unloved and unhappy at his need to move into residential care. Ahmed was experiencing depression in response to complex family problems. Jane and David described the increasing challenge of looking after their son Stephen with very complex needs.

Some people, although finding many aspects of their situation difficult, appeared to be very unwilling to complain, making the best of things. Leonard has dry AMD which had resulted in him having little sight in his left eye and his right eye is deteriorating, but that is ‘just something that I have to get on with’. Although Fred misses many aspects of his previous life, such as going for a pint, he explained that ‘there’s nothing else to be done than get on with it’. He had moved into the care home as it took the pressure off his children, and is now hoping to start swimming and wants to go tandem riding again.

George, having only light perception since birth, is now living in the care home, however, his advice to someone experiencing sight loss would be to try and do as much as you can yourself, rather than relying on other people, because that way ‘you’re not really living a life of your own’.

Jean discussed how she and her siblings provide support to their mother with AMD and Parkinson’s which, combined with ‘paid for’ care, enable her to stay in her own home. Although she findsher caring responsibilities hard ‘you just do it’.

A couple of those interviewed appeared to have particularly high levels of resilience in responding to their sight loss, and other health conditions. Despite, hearing, sight and mild learning difficulties, Sheila is swimming, travelling, going out with friends, involved in her Deaf church and using her ipad to shop and make travel arrangements. Joyce, living in the care home, described being saddened at not being able to paint or embroider due to declining sight but stated that ‘you have to start thinking about what you can do, not what you can’t do’, is now ‘interested in everything’ and has begun a new close friendship.

## Summary and Implications

Many of the needs of these individuals are the same as those of blind and partially sighted people generally, such as a need for social contact, wanting to carry on engaging in valued activities and wanting consistent services. Some of the current services and provision do meet these needs well. However, barriers arise when the mainstream offer isn’t adapted to take account of the additional challenges people face such as having both hearing and sight loss or not speaking English fluently. We need to increase our understanding of these groups so that we can equip services to better adapt to cater to as wide a range of individual needs as possible. This would enable them to better support opportunities for people to live independently, maintain active lives and retain wellbeing.

Although only a small number of interviews with a very varied group of people, we have identified a number of themes, with implications for those that design and deliver services for, or to include, people with sight loss:

1. **Participants frequently talked about valuing opportunities for social contact and ways to enable these should be supported.** A befriending scheme and a telephone talking group were initiatives talked about positively. Opportunities should be made accessible and available to those who have both sight and hearing loss, and those who are carers.
2. **Activities that people enjoyed before their sight deteriorated are missed and services should explore ways to enable people to maintain their involvement, or find appropriate replacements.** An example of where this had happened was a tandem experience for someone who had been a key cyclist. RNIB ‘Talking Books’ was cited by a number of people as enabling them to keep reading. For younger people opportunities to be in employment would be welcome.
3. **Sight loss services are encouraged to consider if they can better meet the needs of individuals with other health conditions and situations**. Services could look to extend their offer to those with dual sensory loss, complex needs, and people for whom English is a second language.
4. **Both family and ‘paid’ carers, and supports, are valued**. Vision Rehabilitation workers were among those who helped enable independent living. Family were often providing a lot of support and care. ‘Formal’ care providers, either individuals or teams, who provided stable, consistent care were seen as especially beneficial enabling relationships to be built up.

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