

# Understanding the need of blind and sightloss communities in Redbridge



Final Report: June 2023

With Support from Vision Foundation

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## Definition of Terms

We use the following definitions in the report:

**Blind** Someone who has been identified as Severely Sight Impaired on a Certificate of Vision Impairment form from an eye hospital, and then registered blind by their local authority.

**Partially sighted** Someone who has been identified as Sight Impaired on a Certificate of Vision Impairment from an eye hospital, and then registered partially sighted by their local authority. condition.

**Visually Impaired/ Visually Impaired People** – these terms are used to describe anyone who has some sightloss whether mild or severe.

## 1 Who are One Place East?

One Place East exists to enable disabled people and those with health conditions in Redbridge and across East London to have choices and improved lives.

We:

- Provide accessible information and advice.
- Improve access to services.
- Provide advocacy and support individuals to have a voice.
- Provide services so people are healthy, happy, and part of the community.
- Creating sustainable models of peer support. We are run by and for disabled people, ill health, long-term conditions, dementia and people with a learning disability or autism people with lived experience of mental.

One Place East have always supported some people with a visual impairment who access our services. Over the last few years, we have started talking to more people with a visual impairment and it became clear many people locally were experiencing difficulties. This included people finding it hard to get work but also accessing other services that would help combat loneliness, raise self-esteem, and support the development of work ready skills.

In May 2022 One Place East were awarded monies to carry out research focused on understanding the experiences of people with visual impairments in Redbridge. The aim was to consider people's experiences of finding work and staying in work.

## 2 Research Team

The two people leading on the research have been Owais Niaz and Erica Miles.



Owais has a severe sight impairment. He lives and works in the London Borough of Redbridge and has been seeking permanent work since leaving college in 2006. Over the last years Owais has set up his own Community Interest Company to support the Visual Impaired Community in Northeast London. Owais

continues to work with One Place East on various projects close to his heart. He has excellent connections with the Pakistani and Muslim communities within the local area and has generously shared his own experiences of growing up with sightloss.

Owais has been integral to the development of the research using his own experiences to help guide the direction of our questions and aims. Owais will be leading on the delivery of the focus groups and information sharing sessions.

Erica started working for One Place East in December 2021 as a Policy and Liaison Officer. Erica has worked with disabled people in many roles within local government and the voluntary sector.

### 3 Research Design



## Looking at existing research findings:

At the start of the project, we agreed that it would be helpful to find out more about what was already known about finding work whilst living with a visual impairment.

Lots of research has already been carried out that tells us what is happening nationally. We used this information to think about what questions we wanted to ask people.

We explored both the barriers and some of the things that really helped people get into work.



**Existing research highlights some important concerns:**

# KEY FACTS

- 1 in 4 registered blind and partially sighted people are in employment. This has not significantly changed since similar research was carried out in 1991 [1].
- People born blind or who lost their sight in childhood are less likely to ever enter the labour market, with 76% of this group never having a job compared to 96% of people who lost their sight over the age of 30. (2)
- 'Registered blind and partially sighted people with a degree or higher still only have the same chance of getting a job as someone with no qualifications in the general public (3)

## Barriers to Employment

Vision Foundation identify 3 problems areas that may act as barriers for blind people gaining and staying in work.

Other research that we looked at (1,2,3,4,) also reinforced these findings.





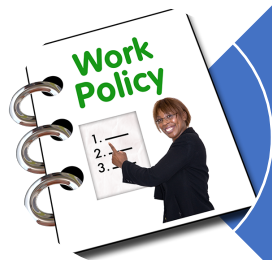
### Personal Barriers

Low self-esteem, inappropriate skills for roles applied for, low aspirations, difficulties in understanding and coming to terms with diagnosis.



### Societal Barriers

Stigmatisation, prejudice, lack of role models in positions of work



### Programmatic Barriers

Lack of signposting to key services or inaccessibility of the Government's Access to Work Program

## Enablers

Most research focuses on difficulties people experience rather than when things have worked well for people.

Some indicators of things that make a difference include mentoring, parental expectations around success and support of employers.

We have tried to find out some of the things that have helped to make a difference for people as well as the problems in finding work.



## Research Participants

We used data published by Royal National Institute for the Blind Sight Loss Data Tool (RNIB, 2022) to help inform the numbers of participants we wanted to reach.

Looking at the data, 7530 residents in Redbridge live with sightloss.

Only 475 people have registered as partially sighted or blind between the ages of 18-64.

We aimed to reach between 1-5% of the total population of people experiencing sightloss in the borough.

All participants gave their consent to take part in the research.

## Research Methods



### Online Survey:

The survey explored questions about people's experiences of education, theirs, and their family's aspirations, as well as the experiences of seeking work and the workplace.

Sections explore respondents:

- Personal characteristics e.g., age, gender, ethnicity
- Understanding and coming to terms with sightloss.
- Educational journey
- Experiences of finding employment with a sightloss
- Support from employers when a diagnosis happens within the workplace.
- Experiences of living independently
- Experiences of accessing local services in Redbridge

## One to One Interviews

Interviews took place both face to face and via zoom. The format of the meeting was conversational enabling a more personalized exploration of topics covered within the survey.

## Focus Groups

We had planned to conduct focus groups as part of the research project we were unable to reach enough people with lived experience of visual impairment to make this feasible.

# 4 Participant Participation

## Survey responses

We had a total of twenty-one responses to our survey. Of these we believe ten people fulfill our criteria for the research.

This required someone to have a visual impairment and to live in Redbridge.

## Interviews

We conducted five interviews and we have highlighted key messages within section 6.

An edited version of the interviews is available Appendix 1.

We think these accounts are a valuable insight into how people have been supported both through the education system and within the world of work to prepare for and find employment.

We have tried to ensure that there is no identifying information about participants. Characteristics such as names, possibly gender, places and organisations names have been changed. Characteristics including ethnicity, age, and faith have not changed.

Minimal editing has taken place in presenting interview data, where this has occurred it has been to aid readability, but participants words remain all their own.

## Engagement



### What worked well?

- The research team worked well together, and all decision made relating to design were made jointly.
- The lived experience of one of the researchers helped to ensure we took a comprehensive approach when it came to exploring potential barriers to employment.
- Generic local services have engaged well with the project. Details of the research project were publicised with local authority and third sector partners, who actively promoted the research via online platforms.
- We have used the existing One Place East networks to recruit participants.

- We reached our aim of engaging 1-5% of blind and sightloss community.
- The survey is quite long, and we had worries this may put people off. This did not seem to be the case. Over 80% of eligible people answered all questions.
- The research enabled us to make valuable links with other organisations within the borough.
- The research enabled us to better understand and subsequently work to improve what we offer as an organisation to blind and sightloss communities in Redbridge.



## What challenges have we faced?

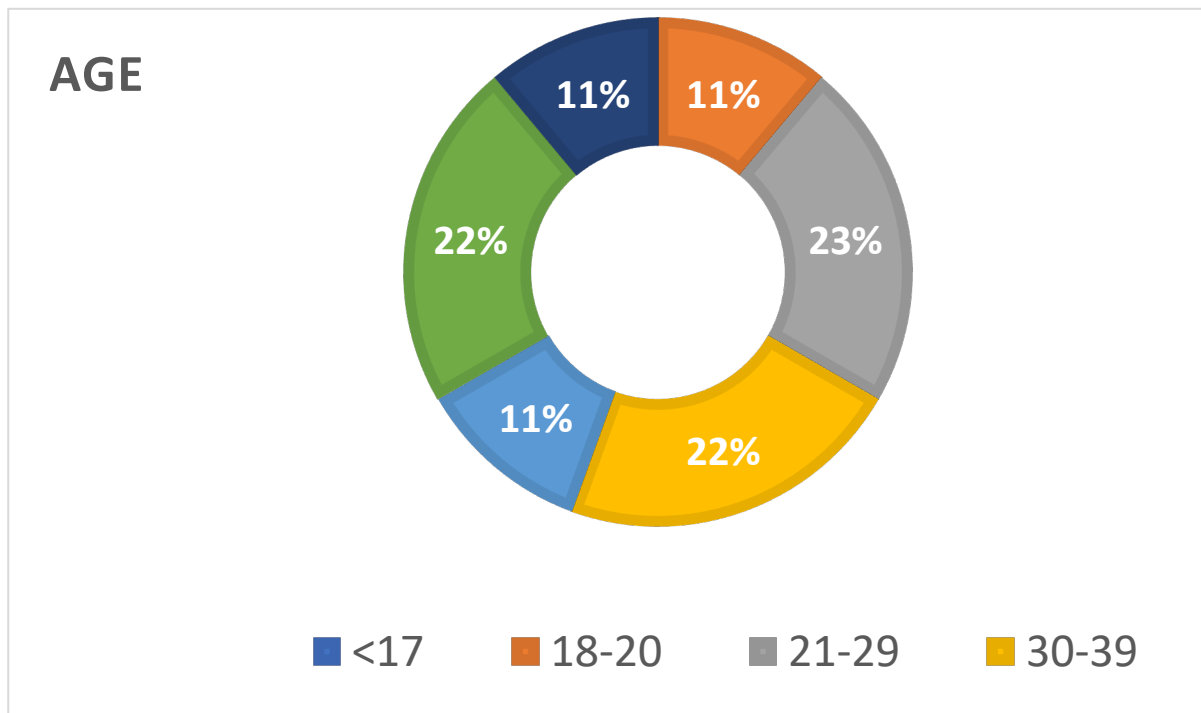
- Our target for participants was based on the estimation by the RNIB of everyone living with sightloss in Redbridge. This figure is 7530m and we wanted to reach between 1-5%. However only 475 people within the borough have registered as having partial or severe sightloss. Using these figures, we should have aimed to reach between 4- 19 people.
- Nine of the ten people we count as genuine participants have registered their sightloss. This supports the argument that we should have focused efforts on a smaller cohort. We have reached around 2.5 % of people with registered sightloss within the borough based on this revised number.
- One Place East have consistently provided services that welcome people with disabilities, including those with a visual impairment, but we did not have strong relationships with the few specialist providers operating in the borough.

Without the support of these organisations, it was challenging for us to have direct contact with our target participants.

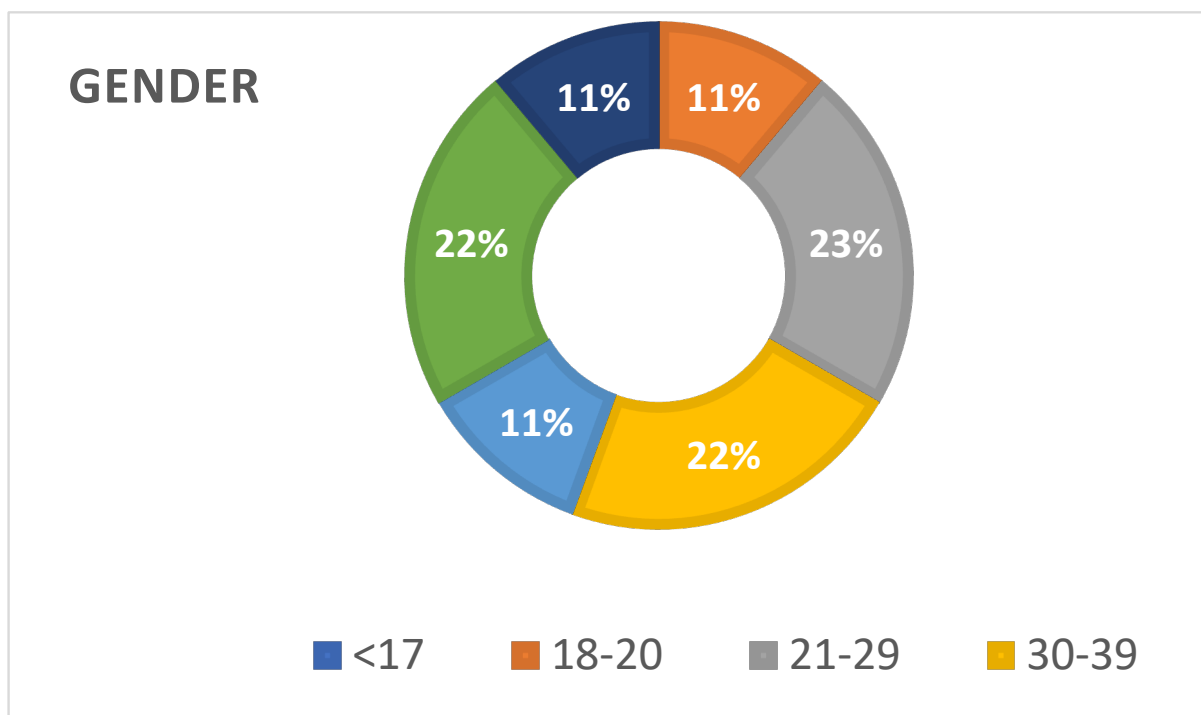
- The timing of the launch of the survey during the summer months when people are holidaying may have made it difficult for people to respond. This is especially true of smaller organisations who are often reliant on volunteer support and may lack the capacity to respond to enquiries.
- Whilst we contacted eye clinics serving Redbridge, we had no engagement from NHS colleagues. This may reflect current pressures.
- The terminology we used may have impacted the responses from potential participants. For example, the Chairperson of one local group questioned whether the research focus would be of any interest to people who experience low vision. Whilst we did our best to give reassurances, we wanted the research to be inclusive decisions may have been based by key community members to not encourage and share links as widely as we would have liked.
- We offered to visit the few groups and services we were aware of within the borough by either contacting named people directly and through contact with the Sensory Services team. We were not able to secure any meetings with people and no contacts came forward via this route. The explanation was Covid had changed working practices and that some groups were no longer taking place in person.
- Most participants with sightloss that completed the survey did so with our support. We offered this on all promotional material, however we found that the most effective means of recruiting participants was to directly approach someone with lived experience and offer support. Other agencies may not have been able or felt it appropriate to offer this kind of support.

## 5 Findings so far

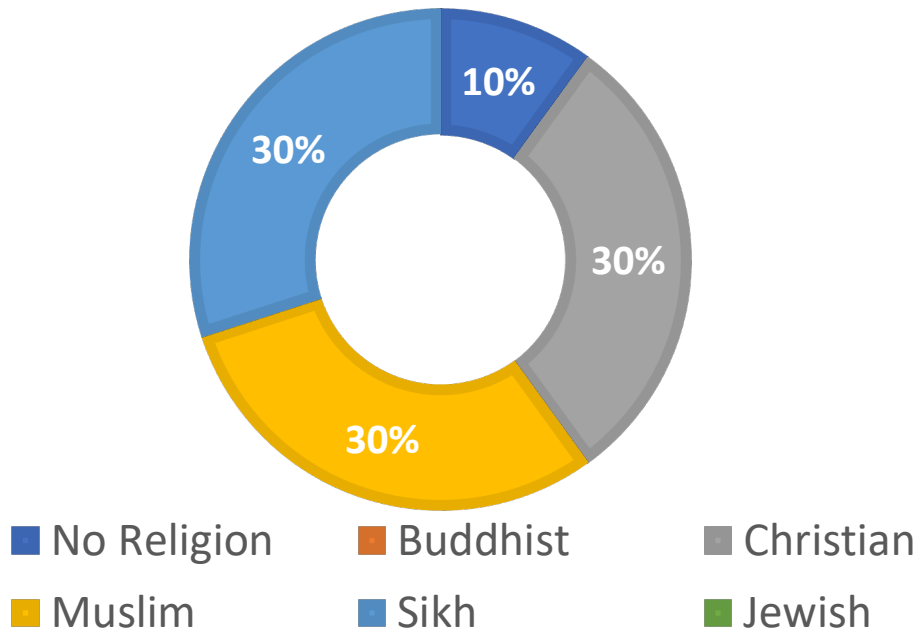
### Profile of participants:



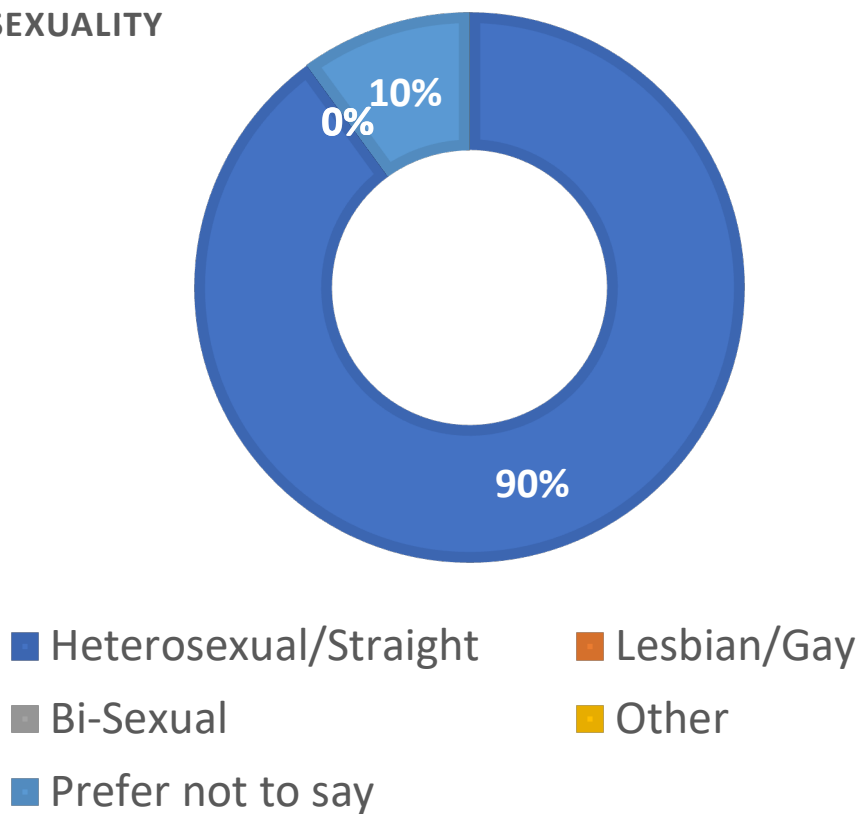
We have at least one participant in every age category apart from seventeen and under.



## RELIGION

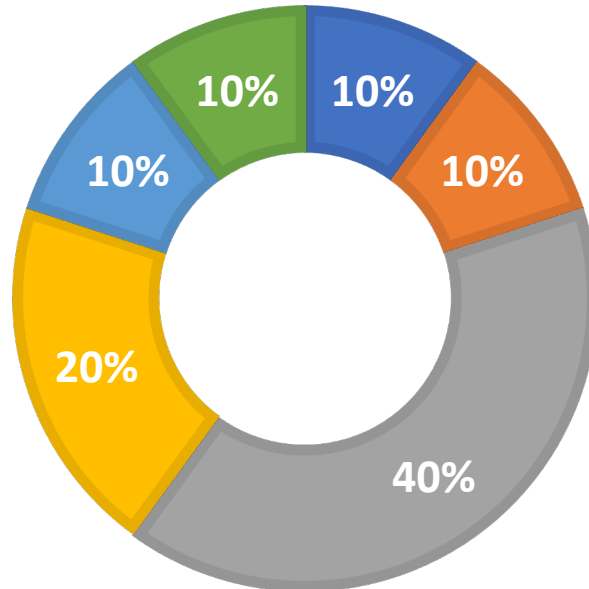


## SEXUALITY





## ETHNICITY



■ English

■ European

■ Indian

■ Pakistani

## Multiple disabilities – the headlines

- 60% people identified as having some other form of disability in addition to their sight loss.
- 40% people identified as having some form of learning disability in addition to their sight loss
- 20% people identified as having hearing loss in addition to their sight loss

## Understanding your sightloss – the headlines

- 20% of people said they did not understand the reason for their sightloss
- 90% of people said they had a chance to talk to a medical professional about their diagnosis.

- 70% of people said they had not had a chance to talk to a counsellor about coming to terms with their condition.
- 90% of people responding were registered with a partial or severe sightloss.

## Education Headlines

Seven out of ten of our respondents were either born with sightloss or were diagnosed with sightloss prior to finishing their education (which could be up to age 25).

We explored what support was available at school and college to help prepare for the world of work.

- Four out seven people said they did not feel that academic staff at school supported their academic success.
- 4 of 7 people said they thought they had no Statement (pre-2014) or an Education Health and Care Plan (EHCP) in place. These outline the legal duty for the local authority to support the academic success of the identified pupil.
- 5 of 7 people said they did not feel their school or college had prepared them well for the world of work.
- Few people identified any planning taking place for what would happen when they left school. Most had no transition plan (2 of 7), or regular meetings to help plan (2 of 7) or meetings with a Connexons' or other information worker who could give details of future options (3 of 7).
- People had inconsistent opportunities to participate in work experience through school placements (4 of 7), limited opportunities to gain work experience through internships (1 of 7), Saturday jobs (1 of 7) or placements whilst completing their studies (1 of 7)

We also explored parent and carer expectations for their children whilst they were at school:

- Five out of seven parents expected their child to gain good qualifications.
- 5 of 7 parents expected their child to have friendships outside of school.
- 3 of 7 parents expected their child to join in with out of school clubs and extra-curricular activities.
- 1 of 7 parents expected their child to one day have a romantic relationship.
- 2 of 7 parents expected their child to get a job when they left school.

### **Support for people receiving a diagnosis in the workplace – the headlines:**

Three out of our ten respondents received a diagnosis in the workplace that they were losing their sight.

- All participants reported they had a referral to occupational health via work.
- Only one participant reported an employer making reasonable adjustments: the purchase of specialist software.
- All participants said that they did not feel supported by either their manager, or their team. Participants' needs were not reviewed by their managers.

### **Securing work -the headlines**

All respondents completed this section which explores people's experiences of seeking work.

- Ten percent of participants had a permanent full-time contract.
- Fifty percent of participants identified as being employed. This included volunteer roles with paid expenses (20%), part-time permanent role (10%) and contract work (20%)
- Most people who had been for an interview let the employer know in advance the nature of their disability (6 of 7)
- Thirty percent of people believed that their manager had not provided support for them within their role.
- Eighty percent of people were aware of access to work and 40% of people had used this at some point.
- Forty percent of people had not heard of and were unaware of employer's duties under the Equality Act
- Reasonable adjustments made by employers when it was known participants were entering a workplace with sightloss included: providing software, specialist equipment one-seventh, generic equipment two-sevenths and support worker two-sevenths.

### Independent Living

- Forty percent of people had no desire to live independently at the current time and were happy living with family.
- Twenty percent of people identified that they felt pressure from family to remain living at home.
- Fifty percent of people said that they were worried about how they could financially manage if they were to live independently.
- Forty percent of people felt they did not have the practical skills to manage.
- Forty percent of people said they did not feel they would manage to live alone emotionally.

- One hundred percent of people wanted and used multiple methods of staying in touch with people, both electronically and in person.

### Redbridge Services

Only two respondents partially completed this section, eight participants completed fully.

- Seven out of eight respondents identified Redbridge Sensory Service as the agency responsible for registering someone's sightloss.
- 4 of 8 participants identified One Place East as an organisation they currently or have previously used.
- 6 of 8 participants identified a national or London based organisations as one they had previously used.
- 4 of 8 people identified some kind of work-related support service as an organisation they had previously used. This included, Blind in Business, DWP and Thomas Pocklington
- 3 of 8 people currently or had previously used social services, or a reablement service.
- 3 of 8 people had used IAPT and Counselling Services.

One person added the comment that more services would be welcome but particularly something that would address the needs of the local black and minoritised ethnic communities.

## 6 Case Studies – Key Findings



**All our participants experienced disrupted, often difficult educational experiences at school.**

- Missing school due to treatments or during a period of diagnosis
- Decisions about what educational providers would offer the best opportunities for children were made by professionals and families. This meant children moved from mainstream to specialist schools.
- Multiple disabilities or conditions. This forced most of our participants to 'rank' their needs when they may have competing symptoms.
- A lack of advice and guidance and encouragement from local authority and educational services to enshrine children and young people's rights to education with the legal backing that would have been offered by a statement and since 2014 an Education Health and Care Plan.
- A range of experiences, from feelings of not fitting in, being physically and emotionally bullied, and feeling the only way to survive is to fight back.

- One participant spoke about the injustice of the responsibility for raising awareness about sightloss, being their job or role. A task they feared would further separate them from their peers.
- Having to adapt to a different system of education e.g., having to learn braille after having started to learn English.
- Lack of access to appropriate equipment as identified by the person rather than the professional with responsibility for identifying and sourcing equipment.
- One participant describes how school professionals lack.

**Some of our participants described a period of having to adjust and come to terms with their diagnosis:**

- People often seemed unclear or unable to describe their diagnosis.
- Often the people we spoke to receive a diagnosis in childhood. As adults they are trying to understand the details of their condition retrospectively, unable to speak to the clinicians who may have played a critical role in their diagnosis and in some cases treatment options.
- One of our participants was given a message from a medical member of the team, to hold on to hope as medical advancements could mean they could regain sight in the future.
- Most of our participants describe some extremely low moments as they have struggled to come to terms with the implications of their diagnosis.

All of participants were at different points in their journey to finding work, but we did want to highlight some key messages:

**Experiences of seeking work**



- One participant identified that their sightloss and disability was a barrier to gaining employment. They felt they were often dismissed during shortlisting and interview stages of employment.
- Three of our participants spoke about identifying third sector organisations or companies that better understand diversity as places that they would want to work.
- One of our participants gives an account of their memories of having a Blind Persons Resettlement Officer. This dedicated role is one that the participant seemed to value.

### Experiences with employers

- The historical account given by the retired participant provides an insight into a hostile workplace for someone with sightloss, even though the opportunities to seek and find work sound as though they may have been easier.
- A couple of our participants describe employers as unable or unwilling to make reasonable adjustments.

### Positive Experiences

- A couple of our participants described professionals from health and education settings as key people that helped transform their lives.
- Where people are undertaking roles in positions where their lived experience of living with sightloss/disabilities is valued by the organisations they are employed by or volunteer for.

## 7 Analysis



We are using the framework offered by Vision Foundation and discussed in section 3 of the report to explore the extent to which our participants' experiences support earlier findings about both the barriers and enablers people can face finding work.

### **Personal Barriers**

Survey and interview responses highlighted the difficulties that people face when receiving their diagnosis. Most people agreed they had opportunities to talk about their medical issues, but as the case studies reveal the impact on people's lives receiving a diagnosis is devastating and the lack of counselling support available is not serving blind and sightloss communities well.

Where people can develop a positive self-image and gain esteem through volunteering and work opportunities, people are

demonstrating skills in advocacy, innovation, entrepreneurship that are currently being undervalued at a wider societal level and by potential and existing employers.

### **Societal Barriers**

Survey data identifies that whilst parents may be ambitious and hope that their children will go on to gain qualifications, they are less likely to feel confident that they will be able to play a full role and lead an independent life, where work and relationships are part of the mix. Without positive role models parents can have low aspirations for their children.

The accounts of bullying described by our participants, and survey indicates most participants have encountered either physical assault, exclusion from their peers and that evidence of this has been present in both educational settings and the workplace.

The emphasis for blind people themselves and those with sightloss to educate, fightback, inform, raise awareness rather than this being the responsibility of education settings or employers.

### **Programmatic Barriers**

We believe problems start at school and education settings are not preparing young people for the world of work well. Findings highlight numerous barriers to academic achievement for children and young people.

We are concerned that younger people under twenty-nine in Redbridge and across Northeast London have few opportunities to meet others with similar shared life experiences. We recognise this may be a small number of people who fit this criterion, but the risks

associated with the isolation and sense of hopelessness people describe is devastating.

Even when our participants describe having parents who were excellent advocates on their behalf, the experiences described indicate parents of school age children may struggle to access the right support and advice.

We believe all parents of children with sightloss should be informed of and understand their child's right to an Education Health and Care Plan (EHCP).

This places a legal duty on the local authority to meet the specific needs of a child rather than a more generalised duty.

Work experiences where these are facilitated were generally positive but happened infrequently. Placements were also cherry picked as they offered a safe environment for the participating student.

Only one person that responded to either the survey or interview was currently in full time employment. Most employment opportunities for those with sightloss, who responded to our research, were in precarious work contracts, working part-time hours with temporary contracts. This reflects wider findings, but locally is indicative that it is mainly third sector creating opportunities for people.

Support within the workplace was poor, whilst most of our respondents were aware of access to work, less than half had used it. The current legislative framework was viewed by our participants with a mixture of derision and scepticism. One interview participant described computer equipment being taken away from a disabled friend as soon as the funding for his placement ended.

These accounts may not be representative, but they add to a narrative that the current programmes offer little opportunity for employees and much more geared for employers.

Considering the limited scope of the research, we would like to note that the historical account of the support offered by a BPRO, was an interesting model. What impressed us, was the understanding and focus that the BPRO would have working solely with people with a visual impairment. Whilst the workplaces described sounded difficult environments our interviewee was confident; he could walk out of a job on a Friday and into a new one on a Monday.

## **Actions One Place East has taken since undertaking the research.**

1. We have offered space to a small Community Interest Company, Vision Ability, to run coffee mornings using our space and have promoted these through our networks.
2. We have successfully applied for a small grant that will enable One Place East to run twice monthly events in person and online for Visually Impaired People in the borough and beyond. We aim to give people a space to come and meet others and talk about their experiences. We will use a peer model of support and ensure groups are led and run by those with sightloss.
3. We are committed to trying to improve employment pathways for people with sightloss and other disabilities and long-term health conditions both within and beyond the organisation. We have established routes that encourage people to make the shift from using our services, to designing and delivering services. Many employed staff have followed this route within the organisation.

We will also use the dedicated space we are creating for blind and sightloss communities to explore what further measures we can take to support them develop work ready skills and confidence and ensure appropriate signposting to sightloss charities offering employment support.

4. We have offered meeting room space and support to the Low Vision Network in Redbridge. We will happily promote any events for visually impaired people in the borough through our social media platforms and via our own existing contacts.
5. We have met with colleagues from SENSE and offered our support and backing to get behind their calls to update the Sightloss Pathway information and protocols for Northeast London for people with a learning disability.
6. We have started to produce our online newsletters in a spoken word format. We aim to discuss whether these could be distributed through the talking newspaper service in Redbridge.
7. We will share our report with all local authority departments where we feel there may be a benefit to people hearing the messages from blind and sightloss communities.
8. We will continue to explore avenues of funding in the short and longer term that would enable us to offer services that will help local people with severe and partial sightloss improve their work readiness.

## Recommendations

9. We would ask local Council colleagues and partners in Health to commission a review of the 'Sightloss Pathway' for Redbridge. This was last developed in 2015. The current information and contacts are of date. This is not a widely published pathway but offers people a comprehensive overview of available services and descriptors of what to expect at various stages of someone's sightloss journey. Any such pathway needs to be maintained so that information is relevant and reflective of current service provision.
10. We would ask that further work is undertaken to improve the online content for people newly diagnosed or moving into the borough. Contact details are available for the Sensory Services team but no information about events, groups or advice is available on the main Local Authority website or via the Social Enterprise Sensory Specialists who are delivering Sensory Services for Redbridge.

Finally, we support the Vision Foundations own 'Call to Arms' within See My Skills Report, published in 2021.

## References

1. RNIB (2022) Sight Loss Data Tool Version 4  
Accessed on: 18<sup>th</sup> October 2022  
Available at: [Sight Loss Data Tool | RNIB](#)
2. Slade, Edwards, and Crawley (2020) Employment for blind and partially sighted people in 2019. RNIB.
3. Slade, Edwards, and Crawley (2020) Employment for blind and partially sighted people in 2019. RNIB.
4. Slade, Edwards and White (2017) Employment status and sight loss. RNIB



## Appendix 1

### Case Studies

#### Anan's story of finding work

*Anan is a Muslim woman in her early thirties. Anan lives at home with her parents. She started her own business and works part-time for a charity.*

I went to a mainstream school and when I was around nine that is when I started realising something was not right. I started getting lots of headaches and eye strain. I went to the Doctor and that's when I found out the reason that I was getting headaches and stuff was because I was losing my eyesight.

I had to stop going to the mainstream school I attended and was sent to a special needs school with provision for blind pupils. The whole concept was completely different. It did affect my education and stuff because I had to take time off and it was a completely different system of learning.

At that time. I was obviously all over the place. Saying to myself 'What's going on?' It was not easy.

Familywise, I didn't make a big fuss out of it. I didn't want my family to struggle. It was difficult for them to adapt to it. It was a big shock. I thought 'How am I going to deal with this it is like my life had completely ended and I thought I would have to rely on people. I was blind but I didn't really know about it, what the diagnosis would mean. I thought my future, my career and everything had ended, but now it is not the case.

At college I met my support worker she really helped me a hell of a lot. She had experience around visual impairment and everything. I started getting the right support to help me. I was lucky.

Whilst I was at college, I got a paid work placement opportunity with an organisation that gave me a good insight about what to expect in a workplace. When I then started looking for work, I thought that would make it easier. It didn't it was so impossible; it was very frustrating.

Applying for jobs can be difficult. I put in my application form and then I don't hear back at all, or I get a message to say, 'sorry you have not been shortlisted for interview'. Filling in application forms can be tricky, if they are online, they may not be accessible. What I find easy, is when they say send a CV and a personal statement. The thing is nobody is going to change their decision about giving me an interview or taking me on, so I just don't bother to complain about it.

Some organisations have not taken me on because of my condition. There was one organisation recently. I had a meeting and explained to them I have a disability and I also have a support worker who will be able to help me with some of the work and stuff. But they wanted me to do everything on the day and they just didn't take on board that I would need some extra time or that things would need to be done in a different way.

My good experiences would be, where people are supportive and are provided with the right technology. Often very small things can make such a difference and you just appreciate it.

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that I would need some extra time or that things would need to be done in a different way.

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I have overcome some of the barriers I faced by deciding to do voluntary with lots of different organisations, building up my experience. Eventually it did lead me on to some paid employment although it was a nightmare journey. Now, I want to really help the disability community, spread awareness. Obviously, my speciality is visual impairment because I am, but I want to pass on the message that you can overcome barriers.

There is not enough going on in Redbridge right now.

If I had a magic wand, it would be different things would be more accessible. I would make sure that there would be more going on. I would like to see better employment opportunities and good access to assistive technology within the borough from charities, and just things going on to help visually impaired people be more active.

## Laal's story of living with a learning disability and a visual impairment

*Laal is a man in his 50s from a South Asian background. He has both learning disabilities and a visual impairment and lives with relatives who help care for him.*

'I have got an eye that doesn't work properly or very well. I can't see anything out of it because it is a lazy eye. That's what the optician calls it and the people at the hospital. I've had it since birth.

I used to go to a normal school, and they contacted my doctor and told them to put me in a special needs school. I went to all the special needs schools in the area. My parents didn't know how to get me the right help and didn't want me to be at school for a long time. I enjoyed school: French, English and Maths. Me and my friend used to get bullied. I saved them from the bullies.

I've had a social worker involved since I was a little boy. I have been all round the system. If you get one social worker, you are never likely to get the same one again. I speak to some of them on the phone.

I wish I could get a job, but my disabilities won't let me. The managers need to get the workers to do some training. The shops I go in round here, they don't train their workers to work with people with learning disabilities.

I volunteer for a charity. I get to meet the community. I want to meet people in the community and people with learning disabilities. I can speak 4 different languages a little bit. I have lots of the same experiences as the people the charity work with. Sometimes professionals don't communicate properly with the elderly. They can't speak their language. That's the language barrier. Some people don't speak English. They don't speak English at all.

I said to them in the meeting. Don't use other colours on the letters you send to me and print them in large print for everybody that you send them out to with learning disabilities.

They wanted me to volunteer at weekends and I said, 'no that is not going to happen'. I want to spend quality time with my family at the weekends'.

There are other jobs I didn't get because of my learning disabilities; my sight didn't come into it. I met a lady when I went for my health check, and she had a lazy eye. We made a joke of it.

## Sanika's story of moving to the UK with a sightloss condition.

*Sanika is a man in his early 20s from South Asian origins. He had been living in Europe moved with his family to the UK.*

I am severely sight impaired or blind. My parents noticed when I was 3. I have a condition called Retinitis Pigmentosa. For me this is a kind of night blindness. We moved from South Asia to Europe and the Doctors in both countries said there is no treatment for my problem. When I was very little, I was so good, I was doing everything independently but for the last 6-7 years my sight is getting bad. There is no medicine and no treatments. The Doctors said my sight would deteriorate but I didn't believe them. They said maybe in a few years there will be a treatment but still there is nothing.

I had plans as a little boy but now everything has changed there is nothing the same. I wanted a family. There is nothing I can do with my future. I was good in studies I always wanted to become something and make my parents proud. But now because of my condition, my health, and my eyes, I am always at home doing nothing. Just thinking about this.

When I came to the UK, I went to the college for one year. I had difficulties seeing the blackboard, but I was able to read my books with a magnifier. It was very supportive, there was always help. They were reading for me from the blackboard or giving me the equipment to do things but I was not able to use the computers so they always helped me so I can use my i-pad to zoom in on the words. There were always very supportive teachers. In Europe as well I had support from my teacher, she was very helpful, she is in contact with me until now. She always asks how you are doing and everything.

When I was in college, I was thinking I want to continue my studies. I don't want to stop my studies. There was this period my eyesight if I ranked it from 1-10 it was like 6. When I finished my first year of ESOL my rank dropped from 6-7 to a 2. I was so worried about this, and I went into depression about this. I couldn't accept things. So, now I am trying to come back and meet people. It is so difficult for me, and it is still now as well. I can't do nothing. I used to do my things independently shower and choose my clothes. But now I dress up in what my mum gives me.

When I was in Europe there was an organisation. It was the Blind Organisation. I didn't know about it, but then my doctor said, it was good to go to them. I am a very closed person I don't like to meet people because I get scared. Telling them I have got this problem. When you are at school, telling friends you have got this problem they don't want to be your friends sometimes. They make a joke of you, and they treat you badly as well. There were nice friends as well and families, but you know at school there is always 2-3 people who make fun of you. So, at school I was always not telling anyone that I have got this problem.

When I came here from Europe. I didn't know I could apply for ESA (Employment Support Allowance) or PIP (Personal Independence Payment). Then my mum started a job as a carer. The man she cares for told me to go to the Dr and that we can apply for these benefits. When we came here the first year, she was working but we didn't know about the services and help I can get here in the UK, the different benefits that I can apply for.

So, my mum and dad they are very supportive, very kind. I sometimes say to my mum how can I thank you. You are doing too much for me. You are doing your work as well and you are doing my work. I am big now it was my job to work and give money to you and you can do whatever you want. But you are working, and I am just sitting at home. It is just hurts me sometimes. My mum she is very,

very sweet. She always motivates me and says, 'we are just happy that you are with us.'

I can't even go for a walk on my own because my health, I have started using a cane. But it was so difficult for me because, if I walk for 5-10 minutes, I just feel dizziness.

When I left college, I tried to work in a large warehouse. I think it was not even a month, just a few weeks. Because of my sight going downhill, just down and down. So, I just resigned.

I told them that I have got this problem. I use glasses. They are like it is RP it is just a night blindness but we have lights in so you should feel comfortable. I was checking the products and the expiry dates. It was so difficult; it was like I can't see nothing. My health was not good as well. My parents told me to resign.

I think because my health is not well, I will be no good working. I can't concentrate. My headaches start. I feel dizzy and tiredness in my body. I can't work now. But maybe in the future if I feel well, and there is a treatment for my eyes, and I get my eyesight back. Then definitely. There is always a hope in my mind that maybe a treatment comes. When I resigned from that job. There was one thing set in my mind I can't work. I am scared if I work in some place, and I am not able to do it they will fire me.

If I am working in a place and I tell them I have got this problem with my eyes, they may say that they can make things easier for me. But there is always something with my health. My headaches start or dizziness or I am concentrating on something. It is just difficult with my health. Just for me to be here is a very big thing. It is the first time I am talking to someone about my problem. I think it is a very good step.



## Syed's route to higher education.

Syed is from a South Asian background. He is currently studying for a degree at university. He does lots of volunteering work and advocacy work for sightloss, disability and charities supporting people who have experience of living with brain tumours.

### **Support around diagnosis**

My visual impairment is caused by a childhood tumour. My parents noticed when I was younger that I wasn't picking things up as my siblings had. I got referred to an eye hospital and they realised that it was brain tumour. So, I had chemotherapy when I was young, and my life was basically spent at hospital whilst I was at nursery and primary school.

When I was about 10 years old the tumour started growing again. So, while the chemo had suppressed it for a little bit, um it started growing again, so I went for chemo again. Since then, it has been stable, and it has decreased in size. The location of the tumour means that they haven't been able to operate on it and I don't think they ever will be able to. So, I think that it's about keeping it contained and that's where the sight loss comes from.

I think it was challenging because I was so young. As I have got older, I have just wanted to have someone sit down and explain what everything is about. Why I have had effects to the cancer treatment I received but my tumour was never considered to be cancer. I am registered disabled because of my visual impairment not because of my tumour. I have tried to speak to with my consultants because all of them are looking at different things. The explanations haven't been consistent.

I had an appointment with the 'Late Effects Team', and I assumed 'Oh great now I am going to find out what actually happened'. That

wasn't the case. They were looking from now to the future. So, my answers were still in the air. Whilst I have everything on paper, and I know 70% of what I am talking about 30% I have no idea. I am not sure I will ever know to be honest. The thing I have learned is everyone looks forward rather than backward. It's like: 'How are we going to support your education?' how are we going to get your Education Health and Care Plan? 'How about your Disability Support Allowance?' what about this, what about this. We don't take a step back and think what has happened.

I sat down with mum, and we spoke through everything that had gone on. Mum and dad, they only remember so much and understood only so much at that time, because everything happened so fast. I think part of the healing process of what has happened has been having opportunities to talk about it.

### **First memories of school**

Primary school was probably the best years of my life. It was probably the toughest in terms of my medical stuff, but it was probably the most fun, the most enjoyable and I didn't feel isolated. I felt supported, I felt understood, I didn't feel alone, and I think I think yeah, I really enjoyed it there.

However, I look back and all the support wasn't in place. They kind of assumed that all the technology was on a par. I remember getting a magnifier that was ordered on amazon which was basically a sheet of plastic that did absolutely nothing.

I think with things like reading like that I just sort of got on with it I didn't really challenge or ask why I was struggling. Me wanting to pick up the Chronicles of Narnia, but I can't because it is a size 8 font and things like that. None of the books were accessible. For a bit I looked into RNIB book share and I got loaned books and these were

coming out in massive text and I am thinking I can't take an A4 part 1 of 9 of a Harry Potter book, it's just not going to work, But we gave it a go and I guess I just sort of plodded along with it and I didn't think anything of it.

This was when I first started reception. I think sightless educational service visited once every half term. Um, just to check and everything but I look back and I think there could have been so much more support. I know touch typing for example. It was done but it was done in a way that was more fun than useful. It wasn't helpful, and I remember going up to the front of the class to the whiteboard because I couldn't actually see it. It wasn't easy, but I think the childhood side of me just thought it must be what everyone else is doing so I just sort of got on with it. I think the other thing with primary school was there was a lot of bumps a lot of falls. I think I was in the medical room quite a lot of every week and I love my sport, but I didn't particularly like the tumbling and the rolling around everywhere but yeah. I think again the staff knew the treatment I was going through and sort of understood.

I think probably the best thing about being diagnosed when I was younger is that there was a sense of care. A sense of friendliness that I don't think you get when you are older. I remember before I did my radiotherapy, they had to do a mould and they did it on my hand first and they painted it gold. So that I could have one just so I could have some fun with it. There was a sense of you are going to be ok, we are going to be here for you. Whether it was creating a calendar, going to see a play specialist before and after the radiation things like that and I think those things really, really did help. I remember every single one of those.

## Secondary school years

When I went to secondary school there was stairs everywhere. It was massive. It was good in the sense it had a SEN department. The support was there, or at least I thought the support was there. It was fine in years 7 and 8 and the departments were good, and the staff were helpful. Then suddenly when I was in Year 9, we were left with one member of staff to support the whole year which was around 360 students.

I think from then on, I knew that I had to stand on my own 2 feet. I used to wander around handing in information that outlined what adjustments I needed from the sightloss education service. I would ask my teachers, 'Am I going to do a test?'; 'Am I going to be in a separate room?'; 'Have you given me extra time?'. It was an absolute nightmare, but I just remember getting on with it. Some would get the picture. Some would try, some wouldn't at all. When it hit year 10 and 11, I tried to talk to the department heads, senior members of staff. I tried to explain that my visual impairment is more than just my visual impairment. It says clearly that I have a brain tumour, how this impacts me and what adjustments I need, even though it doesn't say those 2 words.

I think about going to school I have this frustration. They have the information from the Sightloss Education Service that outlines what I have got. It outlines everything. It doesn't say specifically brain tumour, but it says what the brain tumour is and every single time it is overlooked. I had done some public speaking at some charity conferences and my consultant was pushing for me to do an assembly to raise awareness. They were thinking that would be good to make my teachers aware, but I didn't want to make my peers aware at the same time. Why do I have to draw attention to myself and make myself even more isolated than I am?

What I did with this teacher was say, 'Look Miss, I am sure you are trying but you clearly don't understand where I am coming from.' I showed her this video of me giving a speech using the words cancer, and brain tumour and then she started crying. I was thinking now you have realised the extent of my visual impairment. It is not just about wearing glasses. They don't fix it. It is so much more.

My mum and dad were told many, many, many times that I didn't need an Education Health and Care Plan. We assumed that those letters from the sightloss education service would be enough to let's say hold them accountable for the support and the requirements needed. I think the EHCP plan only came into consideration at 6<sup>th</sup> form once all the GCSEs went to pieces. By the time I was in the 6<sup>th</sup> form that was when we were that even if I got a Plan by that time, I would have my grades and it would be too late. When I was in Year 12 the school said the SEN Department is second to none, you don't have anything to worry about. We were given all the reassurances after everything in GCSEs had fallen apart but the same thing happened again. I think at this point it got worse, because obviously I was taking it more to heart. I understood everything that happened. Despite me again trying to support myself and explain to these different teachers what it really meant, and I think a part of that was probably because I felt really isolated because I was studying subjects with practical work included.

One of my main tutors tried, I think someone in his family, one of his children had a disability, when I spoke about GCSEs he said, 'How has this happened, how did this happen?' Your school gave you the wrong paper they made you sit it; how is they are printing exam papers on the day with 100 loose sheets being given to you? How is that even possible?' I said, 'Well I don't know, but what I do know is that I need a new fresh start and I am hoping this school will give it to me and he said, 'We will'.

That fell to complete pot in my Year 12 mocks. That teacher I had to call him into the room, and I said 'Sir look, I have opened paper 1 of the standard paper and page 1 of my modified paper that the exams team have given me. The moderated paper starts with question 2, so where has question 1 gone?' The diagrams are not clear'. He had no words because the SEN department didn't speak to my department. It was just the same narrative over and over again. Once again, the grades that were predicted in my year 12 were below what I was aspiring for my year 13 and for my university. So again, another conversation with the head of 6<sup>th</sup> form and he said 'Look we understand we have made a mistake and we apologise for that, and my grades were predicted in line with my grades needed for university. It put me in a very difficult position, I was thinking so what are my grades? What is my ability and what can I achieve? Because nothing was ever properly done where I could credit myself for doing well or how I could improve because I didn't know what I was doing wrong. Because I couldn't see the damn paper.'

### **The University Experience**

And this narrative keeps going on and on to this day with the university. They have said they will carry my first-year grade over to my second-year grade because they have failed me so much. How is that ok? I could have just completely have flopped this year and just thought you are going to have to give me last year's grade because you have completely failed me. Yet that wasn't the case. I worked my absolute butt off to try and make something out of it.

They have no answer for it and no accountability either. It's the same thing. The university fails or the institution fails, and the student must find some sort of remedy for themselves, or the university finds some sort of remedy for them. But it is never going to be good

enough for your sighted or non-disabled peers. Their experience is what the education system is built for.

For the last year especially with the university I just put the brain tumour side on hold, and I just focused on the visual impairment, and I started using a white cane because I thought everyone looks at me and you don't see anything. I put glasses on, and it is like oh, everyone wears glasses so what is different? And it is like my glasses help me to some extent, but they don't fix the whole issue. With the white cane I assumed maybe this will make the lecturers realise more than once that they have an obligation to fulfil accessibility requirements and holding a white cane isn't the same thing as wearing glasses. Unfortunately, it was like it wasn't even there. The people that noticed it were my peers, because not one of them was holding one.

I went into a lift with someone from the university. Someone much older than I was probably doing masters or PhD. They looked at me and went, 'oh what is that, why are you carrying that?' and I was thinking it's a white cane and because I am sight impaired well severely sight impaired, and he went 'well you don't look sight impaired' and I am thinking what I say. So, I think I just said, 'well maybe you should look into it a little bit more about what carrying a white cane, or the various canes actually means. If somebody doesn't look visually impaired or hearing impaired, or anything impaired or has a disability how do you justify it because they won't believe you. I have got a Certificate of Visual Impairment which says I am severely sight impaired.

No one in these institutions is held or accountable for the mistakes, I wouldn't even say mistakes, I would say failures even though legislation such as the Equality Act is no place, they still completely

ignore it. When I came into 6<sup>th</sup> form, I thought I want to do my masters and maybe a PhD but the rate I am going I don't want to do anymore education.

### **What support would make a difference?**

I have always put my vision as the reason why I get support. I am very fortunate that mum and dad are big advocates for me. They will push and push and push. Especially when I was younger. Now I am in an institution where mum and dad can't get involved. It makes me question how many students the university has failed and how many of them have given up I guess I have my Certificate of Visual Impairment to back me up in that sense, and that is all I have ever known. I have my disability not because of my brain tumour but because of my visual impairment. I don't think I am expecting a lot. I used to get 25% extra time in my exams. That increased to 50% in my A 'levels and 50% at university.

Rest breaks, that is something that has come up. This was suggested at 6<sup>th</sup> form and picked up again at university because they thought, if you are getting it at 6<sup>th</sup> form then surely, you should get it at university. Then increased size font I should be getting something like size 18. But I have always had a tablet or something at hand to make my life easier. I guess with textbooks things like RNIB book share exists but not all books are there and not all of them are available. The good thing with the university library services is that they contact the sellers directly and get the books straight from them. The book is not modified but at least I have a digital copy where I can zoom in.

Disability Support Allowance was something I was entitled to when I joined the university. But you either get a very, very good advisor who understands your needs and puts the money to use. Or you have an advisor who says no you can't have i-pad because you



already have an older version, and we can't update it for you. They are sending me mixed messages. I have come to university, and I am entitled to DSA so surely this means that they would be providing stuff for my course. I go to my DSA advisor, and she says, 'oh no, no, no, we don't provide you things specifically for your course'. So, I am thinking, so what do you provide it for? For me to get to university? You can't provide me with mobility support because you say that is the local Council. So, I then get RNIB involved, and they provide me support from home to the university. When I get on campus, they say oh no we don't do that, that should be the disability team. They are saying 'you should do that'. So, me and mum, have just been basically finding grants for i-pads, laptops. Things that I know are going to support me without having to justify it to somebody or a team that won't understand.

I assumed, when I got Disability Support Allowance that this would be great but there is an accessibility issue in how this is accessed. Many, many students have said that the DSA (Disabled Support Allowance) makes them feel ill and more disabled and that is how I feel. It is supposed to be supporting you as a disabled student, but it makes you feel more disabled because you are trying to justify every piece of equipment.

They will say we can supply you with this magnifier and I am saying I have never used such a Magnifier that is catered for a blind person, and it was never offered to me when I was younger. I have always had a tablet or a laptop and now I am asking for a mainstream piece of technology, and you can't even give that to me. My laptop and tablet are both about 2 years old and they were both given from different grant giving trusts.

**What helps to develop resilience?**

My family have been an inspiration to me. But I think I developed my own sense of determination when I went into secondary school. I realised I was different but that different was ok. I would say to myself you have been through cancer treatment; you are sitting here in a class, and you are doing well. All those little things. I think there is something in me that has got me to where I am today. I have got that extra experience, that extra fight in me that my peers don't have.

I was one of those kids that would get picked on because I was visibly different sometimes. Maybe I would sit at the front with all the naughty kids. Not because I wanted to but because I had to, or I would stay after class to speak to the teacher. I was always isolated in that sense. In terms of friendships, it has become more easy as I have got older to find people that love me, for me, for the skills that I bring to the table. Passion, creativity, innovation, and that is where I have felt that I am connecting with people. I think that is such a key skill for the workplace, but I think you must feel comfortable with yourself, with your values, what you stand for. How your disability shapes or doesn't shape you to make those strong friendships. That is something I cannot say I had when I was younger.

### **Preparing for the world of work**

We were told we had to do work experience in year 10 or year 11 if we wanted to progress to the following year. I don't think that was an accurate reason. I think it was a reason just to get everyone off their bums to do something. I think this is somewhere where my mum and dad were a bit worried about me venturing out into the world when I was as vulnerable as I was. I did my work experience in a special school. It was a nice safe environment and I wanted to give back.

At university do you have those opportunities to do work experience, but I think it really is dependent on you. I registered with the disability support team. I must go to employability, I must be the one going to employability saying I am severely sight impaired, registered disabled and I want to do this placement. This is something that I had been thinking of in my first and second year. Then the questions arise: 'Do I mention on my CV that I am severely sight impaired?', 'Do I need to write a cover letter?', 'Do I need supporting evidence', 'Do I need to show that I have been doing this' or do I bring up the issues of my disability and severe sight impairment at interview? Now for me personally I haven't really had any jobs outside of university, so I have just been applying to be an ambassador for the university and stuff like that. To just get a little bit of work here and there.

I think for me my work is so intertwined with my visual impairment if an employer wants me, they are going to need to work with my disability and accept the advocacy work I do on the side. Otherwise, I don't think I want them. I think that's a good thing in some ways.

Regardless of what an institution has to say, they will either love the work that I do on the side, or they won't. If the company is not accessible, not being supportive. I don't think I want to work for them. I think that is a discussion that is very hard to have with mum and dad. They have a view that it may be better to keep things under wraps. Which I understand. Then there is less judgement, less pity. I know over the last 2 years I can't let go of what I have achieved in this space, because I know it is big. The one thing that I think sets me apart from every single one of my peers is the work I do on the side, because nobody else can relate to it. It's my experience, my journey, and my opportunity that I have created off my own back. I have proudly put that on my CV. I have put the work I have done with the charities I volunteer with.

University should have a responsibility to at least have the conversation with disabled students about planning for careers and

accessing work experience opportunities. I do remember one of the Employability Team members suggested a 'disability passport' but that was the only bit of advice.

I think the workplace can be an amazing place, I don't know what it feels like because I am not there yet, but I am very close to it. For me my main worry and frustration that we have such big companies saying we want diversity, we want inclusion, we don't want people to feel excluded, but what are they actually doing to encourage more disabled people to get there. They are going to need qualifications, if those qualifications aren't accessible how are they going to get into the workplace?

I think to get to the workplace, to get to your dream role, in any, there must be such a fight to get to that point.

## Dave offers a perspective of growing up with sightloss in an earlier generation.

**Dave is a white British man of retirement age. He currently lives independently.**

### **School years**

I started off at a mainstream Primary School and then I went to school for partially sighted children, but I still struggled at this school as I found the text sizes that were being used to small. I ended up going to a school for blind children it was a boarding school, but this was hard too.

The children at the blind school used the braille but by the time I started learning Braille I think it was too late. I couldn't get the hang of the braille. The only exam I did was in Pottery. I got a grade 2 in pottery.

I was very good at English; I could write the braille, but I couldn't read it. That's what happened. It was stricter you had to do it. If you didn't do it, they didn't encourage you. It was much stricter. You could not treat a childlike that today.

It was the first time I was away from my family. I would come home weekends. It was a dysfunctional family; my parents didn't get on. That's a different story. I suppose my parents thought I could get qualifications, but it just didn't happen. I was more, I am more of a practical learner. I learned more when I left school than when I was at school.

I used to come home from school on a Friday and on a Saturday, I used to go out with this kid round the corner on the bike. We used to go for miles. When you are away from your area like I was at boarding school you don't get to know the other kids that are your

age. Kids can be nasty and so therefore, I did have scraps with other kids it is just part and parcel. Kids used to call me 'Blandy' I was spat at; people would throw stuff at me. No lie. It was all for their entertainment. But I used to get my own back. My mum used to say to me, you need to stand up to them. I had to.

My parents they would just let you get on with it sort of thing. I wanted to do a paperbound when I was at school, but I couldn't do it. My mate did the milk round I wanted to do it with him, but he said Well you can't see the door numbers can you, so that was that I couldn't do it. I used to go out washing cars when I was at school.

In those days you went from school to higher education there was a residential college that got you ready for work. You were away from home. You meet different people who come from all over the country. You start getting friendships, then you start going drinking and one thing leads to another. That's what me and my friends used to do. In that place they done telephony, they done engineering, they done woodwork, typing. The males they wanted them to go and do manual work. It was like a college for people like us who couldn't get into other colleges. That's how it was. You didn't have any of this computer stuff nothing like this voice activated stuff. You either went to these places and they got you into work. You used to have BPRO. A blind person's resettlement officer they would get in touch, and they would say, have they got any vacancies in any workshops. I came out of college, and I was out about 3-4 weeks and then the bloke came round my house, and he goes we have got you a job to go to. It was in the city. So, he says come and have a look at and see what you think. It was this bloke he was in charge. I can still hear his voice he would go 'you come here; we will get you working in the bedding'. So yeah, fair enough. The other floors they did liquid soap and shampoo stuff and then another floor talc and stuff and then, well fair enough. We had the basement, ground floor first and second floor for bedding. That's where I worked.

What let me down was my sewing. It's my fingers see. So, they said you be a porter, well I done that for over 20 years.

The Blind Person's Resettlement Officer, they came and saw you in work. If you had any problems, you could phone them up and they would come and see you. The workplace they didn't want you to do that because the council they used to give you a grant for you to go to the place. Without that grant the employer might have been less willing. The people in charge at these places were not very good. If you told them you, I would tell my Local Authority what you are doing to me and they would say well go on then you do that and well I did, I did. The bloke from Redbridge he came down and he has come down to see. He has gone in the office and the managers come out and said 'well there is someone to see you.

So, I went in there and I said to the foreman, and I said I want you to stay here, and he goes why? and I go because this here is my BPRO and you are going to sit here and explain to him how you have been treating me. Right and I turned round, and I said to him I wasn't going to let him out the door and I said you are going to tell him how you have been abusing me.

They didn't like that, the foreman he didn't like that not one bit. No one stuck up for you.

I don't work now I got medically retired. I worked at the factory for about 20 years and then I went to another place. They shared the building. They were like packing and stuff. Same sort of thing happened. They say lightning can't hit twice but it did. I got on alright with the governor but the people the supervisors they were like me, like us, but they were rubbish. It's like where I was working before, I was earning good money I was doing things like stock taking. We would do things like that put everything in its rightful place. When I went to the second place. It got so bad where I was with what was happening. I thought things might get messy, violent if I stayed and I

thought I don't want to lose my job. I spoke up about it and it just got worst. I spoke to my BPRO I said I can't stay here they have made it so hard. I thought it was best if I walked away. I spoke to the Chief Executive, and I told him what was happening. I said you have put these people in charge, and you are responsible for that, and they are responsible to help us. I said they are ripping you off left right and centre, they are thieving left right, and centre and I said, 'so it is down to you to catch em I've told you'. Next thing I said I want a transfer. He said 'Well I can't do it now, I said Well I leave here Friday and I don't want to come back here no more. I want to go somewhere else. Monday, I got a transfer and to start with that was alright. It was another workshop. It was a piece of cake to start with they would pick you up drop you off with a minibus. I thought well that's easy but then well things started to get a bit nasty there. These people don't stick up for themselves. Well, it turned out the bloke that was a supervisor he couldn't even read and write. I said I don't know how you do it. I don't know how you got this job mate. He went ballistic. I said your mate over there, you are only looking after yourselves. Then the chap in charge, nice man, he came and spoke to me, and I said I want to talk to the governor. I said I can't have this. I have walked away from one place, and I have come here, and this is all going on again. He said, 'Well try and stay'. I said 'Ok.' Well next thing I turned up for work, after a weekend, and it gets towards Wednesday or Thursday, and I think no I can't have this. I find out round on the other site they got a charity working with blind people. So, I asked the person round there for a transfer. When I got round there it transpired, I have come back to get my stuff and there is like police in the building. I said what's going on here. It turns out the bloke in charge, the one at top he was thieving left, right and centre. They used to put their cars under cover. They used to come down. You know the doormats, that go on the floor mats made from coconuts, heavy duty we used to make em to size. They were worth a lot of money; they were nicking em. I tell you it's true.



I then went to a charity they were doing commercial work and I stayed there. Making PVC folders. They were all charities that I worked for but doing Commercial Work it was better than Remploy, I was getting paid a decent work. It got to the point I was having seizures I was having epileptic fits, I passed out on the underground about twice. So, then my doctor he goes, I was drinking as well, and I was like, and I thought something has got to give. He is thinking about medical retirement. I went back in a couple of weeks and this Dr says medical retirement no problem. Best thing I ever done.

If you were late on that first job that first foreman was so horrible for no reason, so nasty to a certain few people. Just because he had it hard years ago. You know. If he had a bad hair day, then we did.

I always liked having a few drinks and stuff, but only at weekends. Then I started drinking more because of work, and my medication didn't mix.

Access to work is a rip off it's been there for years, the reason why I say it's a rip off. They say they will give you a job you accept it, and they only have funding for a certain length of time, and you must go through all the process again. To see if you can get the allowance again. I haven't used it myself. I know people that have it is a total waste of time.

The Equality Act is a rip off you tell the employer you need software for your computer sometimes they might do it for you, but a lot of ems are not interested. Basically, what that is just to massage the figures. I am a realist. I will tell you how it is they try to make it look good. The council or the people that be, want to make it look like they are helping people get into work. This chap I know he had access to work. He was working from home he had a job at the bank. All his equipment was in the office. When he was at home, he goes to me don't talk to me about work they are not going to sort out my computer no more. The person came took all the equipment away.

Not good. You do know if you are, the council are obliged to give you equipment. Also, the RNIB you can apply for a grant for equipment that is once every 3 years.

I live in my own flat now I manage by myself. My friend helps me, and I help her. I stay in touch using my phone. I meet my friends in person too. On my computer it is voice activated and I can email people. I like staying in touch.

The talking books and calibre audio library are good things. That's for when I get old. I can just sit there and listen to books. I be honest disabled people not just me, you got the transport, dial a ride, taxi card, door to door service. TFL since this pandemic they don't run the buses late anymore. Redbridge have got to understand the dial a ride is a disabled bus for disabled people but will only stop at certain places. That is pathetic you need it to go to your home. The taxi card is limited rides, I don't know if Redbridge pay into the card anymore, I think it is the Mayor of London. When it started in the early 80s the taxi card was abused but you phone for a taxi after a certain time at night you can't get one for love or money. It's all very well these councillors saying this or that, but they should be on the receiving end of what we are on. This helps us get around. It infringes on my human rights. Some people in wheelchairs they won't pick them up. The door-to-door service you can't always get them and now they say you must pay over the phone before you would pay the person. Maybe someone was putting the money in their own pocket. It's not as good as it used to be. It feels as though things are getting worse not better.