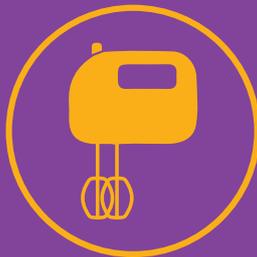




sense
for deafblind people

Realising aspirations for all

Improving access to employment for people who are deafblind



.....
Around half of all
disabled people are
currently out of work



Introduction

Deafblindness is a combination of sight and hearing loss that affects a person's ability to communicate, to access information, and to get around. People who are deafblind are also likely to have a range of other health needs in addition to their sensory impairments.

There are approximately 100,000 people of working age who are deafblind living in the UK. Many people with sight and hearing impairments are keen to enter the workforce – they want the opportunity to use and develop their skills, participate fully in the working world, make a contribution and earn a wage.

Despite this, the statistics on employment levels for this group are stark. Only 4% of 18 to 24-year-olds who are deafblind are in employment – a rate almost ten times lower than the employment rate of non-disabled young people. The employment rate of deafblind people over the age of 24 is just 20%,¹ which is almost four times lower than the national average.²

Within the broader population of disabled people, 46% are currently out of work, with the rate of employment 30% lower than that of non-disabled people.³ The situation is worse for people with multiple disabilities: research has shown the people with five or more impairments are 61% less likely to get a job compared to non-disabled people.⁴

Difficulty in entering employment is not the only issue disabled people face. When in work, disabled people tend to have lower paid jobs and earn less than their non-disabled colleagues.⁵ Many find it more difficult to progress their career, and few hold senior managerial positions.⁶

The Government pledged to take action to tackle the barriers faced by disabled people seeking employment at the last election. It made a manifesto commitment to halve the disability employment gap by helping a million more disabled people into work by 2020.

The following report is based on a series of focus groups and in-depth interviews with people who are deafblind about their experiences of working and looking for employment. The personal stories of the individuals featured in the report highlight many of the barriers faced by people who are deafblind as they seek to enter the labour market.

With the right support, people who are deafblind can and do take up a range of interesting and challenging roles. We are proposing a number of recommendations so that all disabled people who want to work, including those with more complex conditions such as deafblindness, can benefit from the extra resources the Government is putting in place.

¹ Annual Report of the Chief Medical Officer, Surveillance Volume (2012). On the State of the Public's Health

² Ibid.

³ Office for National Statistics, UK Labour Market, May 2016

⁴ DWP, *Fulfilling Potential: Building a deeper understanding of disability in the UK today*. Available at www.gov.uk/government/uploads/system/uploads/attachment_data/file/320509/building-understanding-main-report.pdf

⁵ Coleman, N., Sykes, W. and Groom, C. (2014) *Barriers to employment and unfair treatment at work*, EHCR

⁶ DWP, *Fulfilling Potential: Building a deeper understanding of disability in the UK today*. Available at www.gov.uk/government/uploads/system/uploads/attachment_data/file/320509/building-understanding-main-report.pdf

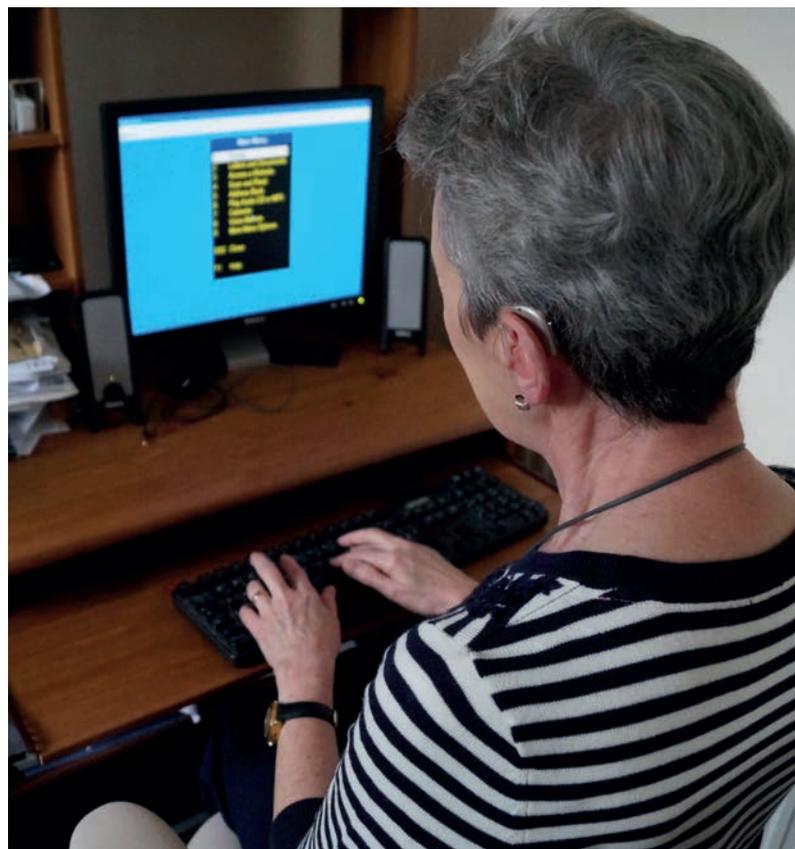
Executive summary

Our research shows that deafblind people face significant barriers when looking for work and seeking to remain in employment.

Barriers to finding and securing work:

- Employers often have a negative view of the abilities of deafblind people and are unsure how to support them. This means they can be reluctant to offer them employment opportunities.
- Recruitment processes can be inaccessible and particularly challenging for people with additional communication needs.
- Few people who are deafblind receive the support they need to make a successful transition into employment, including help to acquire the skills and qualifications they need in the workplace.
- People who are deafblind can have a profound fear of being discriminated against on the basis of their disabilities and can have low levels of confidence.
- A lack of access to communication support can mean people who are deafblind are unable to take up work experience or volunteering opportunities to facilitate a pathway into work.
- Physical access to workplaces can be a challenge for people who are deafblind – difficulties with mobility and independent travel were key issues highlighted.
- There is the perception that existing employment support programmes are targeted at disabled people who are perceived to be ‘easier to help’. People with more complex support needs can be excluded from employment support and few are offered the tailored, specialist support they need.
- There is a lack of awareness of existing employment support programmes among people who are deafblind, and referral mechanisms are poor.
- The current system links employment support with welfare benefits.

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Employers often have a negative view of the abilities of deafblind people, and are unsure how to support them.



- Individuals who are not required to look for work through the benefits system but wish to work rarely get access to employment support programmes.
- People who are deemed capable of work through the welfare benefits system can be forced to take part in employment programmes that are ineffective and inaccessible for them.
- More broadly, the Work Capability Assessment (used to determine who should be in receipt of Employment and Support Allowance) is not an effective way to identify who can and cannot work.
- Professionals who are employed to support people who are deafblind to find work, including Jobcentre Plus advisers, often have low expectations of their employment prospects.
- People who are deafblind struggle to access the social care and reablement support that would allow them to remain active in the labour market.

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Physical access to workplaces can be a challenge for people who are deafblind – difficulties with mobility and independent travel were key issues highlighted in our research.

Barriers to sustaining employment:

- People who are deafblind can face discrimination in the workplace, and employers can be reluctant to make the adjustments they need to perform their roles successfully.
- People who are deafblind often struggle to access the level of support needed from the Government's Access to Work scheme in order to perform their roles effectively.
- When in work, people who are deafblind are often excluded from informal communication and social events at work. This can have a negative effect on work satisfaction and career progression.
- There can be physical access issues related to work premises, such as poor layouts and issues with lighting and background noise.
- People who are deafblind often need more support to develop new communication methods and learn to successfully use assistive technology in the workplace.
- A lack of appropriate communication support at work can limit opportunities for training, promotion and gaining additional qualifications.

Recommendations

National level

- The Government should make more resources available for specialist support models targeted at people who have more complex support needs and are not likely to benefit from the Work and Health Programme.
- The joint Department for Work and Pensions (DWP) and Department of Health (DH) Work and Health Unit should use its Innovation Fund to trial innovative specialist support models.
- The link between welfare benefits and access to employment should be broken by making support voluntary and available to all disabled people, regardless of the benefits they claim.
- The DWP should work with the DH, Department for Education (DfE) and Department for Business, Innovation and Skills (BIS) to ensure deafblind people receive appropriate re-employment support at key stages. This should include support for the transition to adulthood and for individuals whose condition deteriorates.
- The Government should consider trialling the introduction of personal budgets for employment support.
- The Work and Health Programme should enable disabled people to choose their employment support provider, including the option of opting for specialist support.
- The Government should ensure disabled people have access to information about employment support. There should be greater transparency in relation to who the support providers are, what support they can offer, and the minimum quality standards disabled people can expect from them.
- The Government should implement a training programme for Access to Work specialist teams to increase their understanding of deafblindness and its impact on a person's ability to do their job.
- The Government should ensure Access to Work assessments of deafblind people are carried out by specialists who are trained in deafblindness.
- The Government should develop and implement a coordinated campaign to raise employers' awareness of the abilities and potential of people who are deafblind, and increase the understanding of the technologies that exist to support deafblind people in the workplace.
- Building on the Disability Confident accreditation scheme should support and recognise the employers who are taking specific steps to make their recruitment process more accessible for disabled people. The scheme should have a robust monitoring mechanism, which should involve disabled people.

- The Government should develop and implement a comprehensive training programme for Jobcentre Plus advisers to raise their understanding and knowledge of disability, including deafblindness. Advisers should be able to identify people's needs and refer them to the most appropriate support programme. They should also be able to meet the communication and access requirements of each individual.
- Providers should understand and support the use of assistive technology and development of new communication methods.
- Providers should better understand the demands of the local labour market and proactively reach out to employers, encouraging them to consider disabled applicants.

Local level

- Local authorities should ensure that people whose sight and/or hearing deteriorates have timely access to reablement services and assistive technologies that enable them to maintain the highest degree of independence.
- Local authorities should maintain funding for local employment support programmes and ensure these programmes focus on disabled people with complex needs.

Employment support providers

- Employment support providers should ensure that advisers are aware of the specific needs of deafblind people and how they differ from the needs of people with a single sensory impairment.
- Employment support providers should ensure that all communication is accessible and provide information in the formats that people need.
- Providers should establish close links with specialist health and social care services to support deafblind people and ensure that appropriate referrals are made to increase people's independence.

Employers

- Employers should promote an inclusive culture within the organisation by raising awareness about disability and promoting the specific steps staff can take to make their disabled colleagues feel included.
- Employers should ensure recruitment processes are accessible in order to encourage applications from disabled people.
- Employers should ensure disabled people feel confident and comfortable to disclose their disabilities and request adjustments.
- Employers should view spending money on adjustments for disabled people as an investment in the workforce.
- Employers should consider contacting specialist organisations if there is a need for advice on specific medical conditions.
- To address the multiple barriers disabled people face, employers should consider setting up specialist schemes to increase employment and promotion opportunities for disabled people. These include talent recruitment programmes or internships, mentoring schemes and additional training opportunities targeted specifically at disabled people.

Employment support for disabled people

The current context

Successive governments have recognised the need to invest in employment support for disabled people. There are currently a range of support options:

- Jobcentre Plus staff can help individuals by offering general advice and support with job searches. Every Jobcentre Plus has disability employment advisers, who have a better understanding of the barriers disabled people face and are able to offer more specialist advice. In addition, Jobcentre Plus can refer disabled people to local support providers or to national employment support programmes, where appropriate.
- The Work Programme is commissioned by the DWP. The programme is delivered by a range of national and local providers, who are free to develop their own models of support. The Government also commissions Work Choice, a specialist employment support programme aimed specifically at disabled people. In 2016, the Government is expected to commission the Work and Health Programme, which will replace the Work Programme and Work Choice. The Work and Health Programme will primarily be targeted at disabled people.
- Besides national programmes, there are a range of local employment support schemes commissioned by local authorities.
- Disabled people who work can get support from the Government's Access to Work scheme. Access to Work pays for adjustments in the workplace, including for those who are self-employed. This includes funding for specialist equipment, communication support, support workers, or help with travel for those who cannot use public transport. Access to Work also provides funding for support at an interview, work trials, traineeships and, in some circumstances, apprenticeships. Since October 2015 the Government has capped spending on Access to Work support packages, which is 1.5 times the average national wage.
- The employment support currently on offer is closely connected to the welfare benefits system. Disabled people who are not in work can apply to receive the Employment and Support Allowance (ESA). Claimants of ESA must complete a Work Capability Assessment (WCA) to determine whether they are eligible. The WCA assesses whether a person is thought to be capable of undertaking 'work related activities'. If the individual is found to be capable, they will be placed in the Work Related Activity Group (WRAG) of ESA, and automatically be entitled to employment support. If they are assessed as being incapable of working they will be placed in the Support Group of ESA, and will not typically be referred for support to find work.

The Government has committed to halving the disability employment gap.

- The Government has committed to halving the disability employment gap and has established a joint DWP and DH Work and Health Unit to develop strategies for improving work and health outcomes for working age disabled people. The Unit has been allocated a £70m Innovation Fund to build an evidence base and trial new models of support.
- The Government is expected to release a Green Paper on the employment of disabled people in autumn 2016.

A range of measures are also in place to encourage and support employers to offer employment opportunities to disabled people:

- The Equality Act 2010 protects disabled people from direct and indirect discrimination in employment, and requires employers to make reasonable adjustments for disabled people.



- In 1990, the Government introduced the Two Ticks scheme for employers. By signing up to the Two Ticks scheme, companies demonstrate that they are positive about employing disabled people. The Jobcentre Plus grants permission to join the scheme to employers who have made five commitments to make their workplace more disability-friendly, and to give disabled people a better chance at the recruitment stage.
- In 2013, the Government launched the Disability Confident campaign. The campaign features resources, roadshows and networking opportunities for employers to help them feel more positive about recruiting disabled people. It also seeks to equip employers with information on how they can support disabled people to fulfil their potential at work.

A joint Department for Work and Pensions and Department of Health Work and Health Unit has been established, which has been allocated a £70m Innovation Fund to build an evidence base and trial new models of support.

“I want to work”

Daniel

Daniel is deafblind and communicates using deafblind manual – a form of tactile alphabet. He is a proficient computer user, and uses screen reading software to access information. He is taking an Open University course and is interested in research.

Daniel has experience of volunteering and would like to work; however, careers advisers at school and college have not supported him to identify his strengths and possible career opportunities. He was not made aware that he could get support from Jobcentre Plus and does not know where it is – or how to get there by himself. There is also very little chance that advisers there will be able to communicate with him.

“It upsets me when people think I cannot do things, when I can. I would like to work; I really enjoyed volunteering, it gave me a chance to get out of my house, meet people and get used to the routine. I don’t know where to get support with finding a job. I wrote to my MP asking this question, but got a response about benefits. I know there are many people applying for jobs, but we often don’t get a chance because other people assume we are not capable, when it is not true.”

Daniel has been looking for work online and talking to friends about opportunities. With the right support, he believes he can get a job. Daniel claims the Employment and Support Allowance and is in the Support Group. He is not required to look for work to receive his benefits – but does not know about existing support programmes. In any case, current provision would generally be unsuitable for deafblind people like Daniel, who needs specialist support to help develop skills and confidence. Daniel would also need a tailored placement and a job coach to help him learn how to function in a mainstream workplace, as well as help so that his colleagues are able to learn how to communicate with him.

.....
“I know there are many people applying for jobs, but we often don’t get a chance because other people assume we are not capable, when it is not true.”



Finding and securing work

The statistics clearly demonstrate that people who are deafblind are among the most marginalised when it comes to finding and sustaining meaningful employment.

To gain a clearer understanding of the barriers faced by people who are deafblind in relation to finding and securing employment, Sense carried out a range of in-depth interviews. We spoke to deafblind people who are currently working in a variety of roles in the public, private and voluntary sectors, and to deafblind people who would like to work and have been actively looking for employment.

We asked them to describe the barriers they had experienced in finding and sustaining employment, and discussed possible solutions and the support they need. A number of barriers were identified.

Employer attitudes

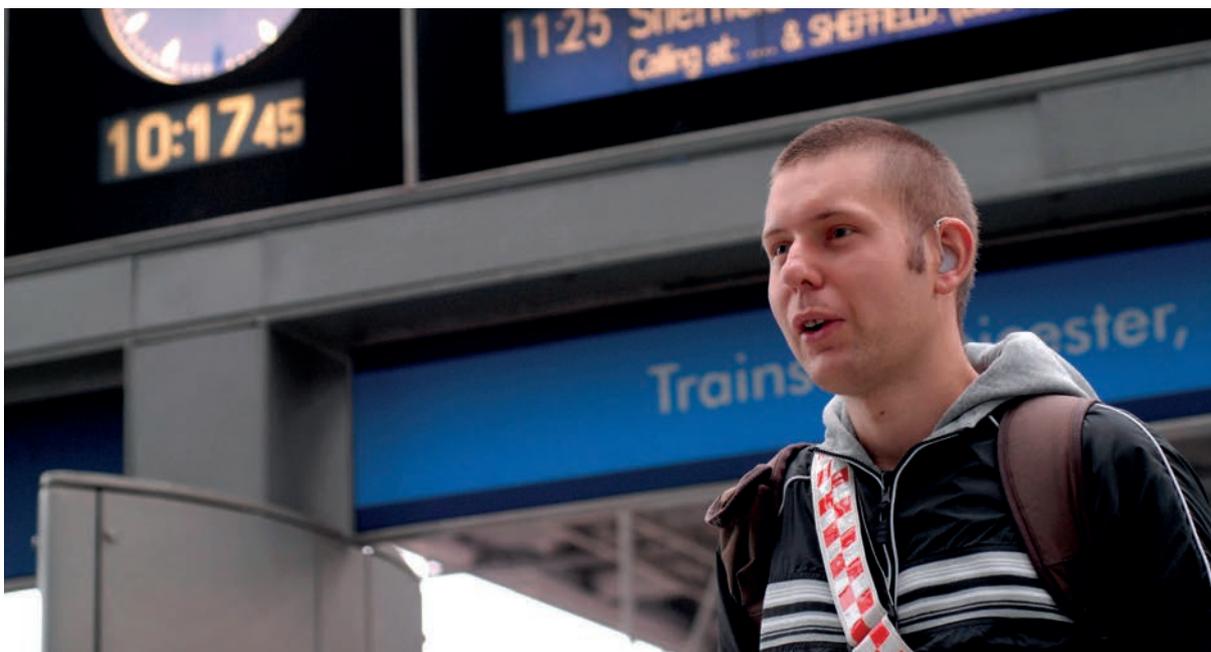
People who are deafblind cited the negative attitudes of prospective employers as one of the main barriers preventing them from gaining employment. For people who use alternative methods of communication, such as British Sign Language, this barrier was particularly significant.

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“I have lost count of the amount of times where I’ve come second. It makes me suspicious – why am I never third or fourth? After a while you start to wonder. This is why you question whether to highlight your disability at application/ interview stage.”

There was a strong feeling among the people we spoke to that employers are reluctant to employ disabled people – particularly those who have more complex needs. People who are deafblind shared examples of employers raising health and safety concerns, worrying about the potential cost of support and insurance, and being unaware of the assistive technology and support on offer.

People who are deafblind told us how sometimes they have to battle the expectation that they will work on a voluntary basis, as employers assume they cannot contribute as much in the workplace as non-disabled people. They would like the Government to do much more to make employers aware of the value of disabled people. One said:

“I believe that the Government should spend money on awareness rising. So that employers know that deafblind people are definitely capable of doing work and doing it well.”



People who are deafblind also felt that employment support providers could make a big difference to their prospects of getting a job by reaching out to potential employers and encouraging them to consider disabled candidates. This has to be done in a way that ensures equality for disabled people, and promotes a message of ability.

Despite the Government's attempts to encourage more employers to offer opportunities to disabled people, it was not felt that initiatives such as the Two Ticks scheme or Disability Confident have made a significant difference for people who are deafblind. This may be because both of these schemes require a minimum commitment from employers and lack monitoring mechanisms to ensure compliance.⁷

Accessibility of recruitment processes

Recruitment processes, which typically involve sending a CV, attending an interview and undertaking assignments, is often

inaccessible. This makes it more difficult for people who are deafblind to show employers what they are capable of.

Several people felt disadvantaged in formal recruitment processes because of their disabilities. One person who is currently employed told us:

"I don't believe deafblind people have a chance to get a job through a formal recruitment process. Even as someone with my skills and experience, whenever I have applied through a formal process, I have not got the job. And that includes with organisations I have worked for already."

Employers' lack of awareness about sensory impairments and disability can mean that the needs of people who are deafblind are not taken into account. Their communication requirements are often not met and their style of communication is frequently misinterpreted.

⁷ There has not been an independent evaluation of the Disability Confident campaign; however, research has shown that the majority of employers who used the Two Ticks symbol did not fulfil the commitments required by the scheme. Hoque, K., Bacon, N. and Parr, D. (2014) *Employer disability practice in Britain: assessing the impact of the positive about disabled people 'two ticks' symbol*, Work, Employment & Society, 28, 430-451

One person told us:

“I was once told I had come second to another candidate and the only difference was the other person was more engaging. The panel did not take into account the fact that I was using Speech to Text and had to concentrate on reading the screen. The same panel sat with their backs to strong sunlight meaning I was struggling as my sight is extra sensitive to strong light.”

In spite of the fact that people who are deafblind are protected by the Equality Act 2010, it is clear that many can experience discrimination from employers. Fear of discrimination may mean that some individuals choose not to declare their disability on application forms or CVs. Several described turning up to interview without the appropriate support or adjustments. Even those who ask for adjustments for an interview do not always receive the support they need.

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“I applied for a domestic assistant job at a hotel and asked the prospective employer for communication support [at the interview] and they said yes. But when I came in, they talked to me orally and I could not talk back as I use BSL to communicate. I asked them if I could use a computer to communicate but they said no. I left, feeling upset and frustrated once again.”

Gaining the right qualifications and skills for work

Having a relevant qualification is one of the key factors in determining whether disabled people are able to secure the type of employment they desire. Despite this, young people who are deafblind are rarely supported to secure the qualifications they need. This is often due to the poor quality careers advice on offer, low expectations from educational professionals, and a lack of proper transition planning for young people. Some young deafblind people also need support in acquiring independent living skills, learning to travel, communicating with others independently, and using technology to maximise their access to information. The young deafblind people we interviewed thought that transition planning was not always focused on a job outcome and did not take into account the jobs that exist in the area where they live. This means that although they obtain qualifications, they are not always able to get a job.

Young people who are deafblind want to work, but to do this they need good transition planning and access to high quality careers advice. There needs to be a greater focus on a job outcome and skills development so that young people are supported to gain the qualifications and experiences that enable them to get a job. Many young deafblind people need support to build their confidence and resilience, which will help them feel positive about their abilities and enable them to take on the challenges they face. Learning how to function in a mainstream job is also an important element of transition support for young deafblind people.

Access to relevant qualifications is not only an issue for deafblind young people. People who want to gain qualifications in later life can struggle to secure reasonable adjustments from further education institutions, whilst other avenues of skill acquisition, such as volunteering, are also limited.

Maintaining confidence and resilience

As well as having to convince employers that they are the best candidate for the job, people who are deafblind need to be able to talk confidently about their disabilities, and how the additional barriers they face can be dealt with.

However, it takes confidence to directly address the misgivings employers may have, and to focus attention on your abilities. Some people are confident and articulate when talking about their disability, but others find it difficult to talk openly about the challenges they face with people they don't know. This is especially true for young people looking for their first job.

Where people who are deafblind had negative experiences of seeking work, their confidence and belief in their own abilities was severely affected. There is very little support available to help build confidence and enable individuals to feel empowered and positive about their abilities. We heard that mentoring, peer support and positive role models are an invaluable part of this process.

Social isolation can have a profound impact on an individual's confidence and their resilience when looking for work. Deafblind people, especially those who have been out of work for a long time, may not have social networks they can rely upon to build confidence and support when looking for work. A lack of social connections can also limit opportunities to find out about jobs, network and socialise with informal connections, and obtain advice and support from people in employment.

Gaining work experience

Paid work experience was perceived as a good way to gain skills and a useful route into longer term employment. However, at present there are very limited opportunities for deafblind people to gain work experience. This is especially true for young people, who find it almost impossible to get Saturday or summer jobs, or work part-time while studying.

Volunteering was also seen as a good way to learn what work looks like and acquire valuable skills. However, people who are deafblind reported that they often find it difficult to secure appropriate volunteering opportunities. Currently, there are no government programmes that contribute to the cost of the support needed to join volunteering initiatives. In such cases it would be left to a potential employer or the deafblind person to arrange the necessary communication, transport or financial support.

Transport

For many people who are deafblind, inaccessible public transport and the lack of support with travel can be a deciding factor in whether they apply for a job. For others it is a barrier preventing them from attending courses to develop skills. Although deafblind people who work can get travel support from the Government's Access to Work programme, this support is not always available for those who are looking for work, especially those who do not take part in employment support programmes.

“It takes time to build confidence”

Bethany

Bethany is 23. She was born deaf and began to lose her vision as a teenager. At college, teachers advised her to train to be a hairdresser – despite the fact that her sight was deteriorating.

“I did not like college. We did the same things every day and I wanted to do more. I had to come to terms with losing my sight and learn how to live with this. I felt isolated and very insecure. When I left education I had no luck finding a job and ended up staying at home with my family.

“I then found out about Sense. I started to get involved in different activities. The local authority funded communicator guide support for me. I started going out, meeting people and this built my confidence. I started

to volunteer and am now looking at setting up my business. I feel positive about my future. I have started to learn how to use a long cane and can go to some places independently.”

Building confidence and resilience is especially important for young deafblind people, and there are many ways to do this. Sense developed a model of short breaks, which is geared towards supporting young people to develop independent living, choice making and self-help skills, and encourage the use of assistive technology. The short breaks provide a natural environment to establish a baseline of skills and desired goals and outcomes. It also helps young people to expand their social networks and support each other.





Employment support programmes

It has been widely accepted that the Government's Work Programme is failing to meet the needs of disabled people.⁸ Providers are spending less money on supporting disabled people than non-disabled people.⁹ The system also encourages providers to overlook those who they perceive as harder to help and concentrate on those who are closer to the labour market. The Work Choice Programme, which was specifically designed to support disabled people with more complex needs, has also failed to achieve its purpose. It has supported people with more moderate needs, the majority of whom did not claim disability benefits.¹⁰

Deafblind people who took part in existing employment support programmes told us that providers often struggled to understand their needs. Although some specialist provision for people with sensory impairments is available, the individuals we spoke to did not have a chance to access it early on and instead were pressured to apply for jobs they were not able to do or attend inaccessible training sessions. Deafblind people with higher levels of qualifications told us that providers struggled to find appropriate placements for them, meaning they had to search for possible opportunities themselves. Those who undertook voluntary work could not get the support they needed, such as help with travel, specialist equipment to access information or interpreters.

Because of the complexity of their needs and the expense of communication support, it was felt that people who are deafblind are seen by providers as harder to help and less likely to get a job. This can deter employment support providers from taking them on or providing appropriate levels of assistance.

In 2016 the Government will replace its existing schemes with a new Work and Health Programme. Deafblind people are keen that whatever replaces current initiatives meets their needs. They should be given the opportunity to play a much more active role in choosing the support provider as well as planning and evaluating their support. Active participation will not only ensure they receive appropriate support, it will also help to foster a feeling of ownership and responsibility for career development.

In order to ensure that specialist support programmes are targeted at the people who need them, there needs to be a robust referral process and advisers who have a positive attitude towards disability and understand the barriers disabled people face.

Jobcentre Plus advisers

The deafblind people we spoke to reported that Jobcentre Plus advisers have very limited knowledge and understanding of deafblindness, and low aspirations for people who are deafblind. A common experience reported to us was being deterred from attempting to find employment in favour of claiming welfare benefits. One person told us:

"When I lost my job I went to Jobcentre Plus, they were patronising. They were encouraging me to go on the benefit where you were not required to work at all. They seemed surprised that I wanted to work. Going there was pointless. They have Disability Employment Advisers but good luck trying to get a job with one."

⁸ Only 11 % of ESA claimants referred to the programme get a job outcome. The success rate is lower for people with long-term conditions (9 %) and even lower for people who received incapacity benefit in the past (5 %).

⁹ NAO, The Work Programme, June 2014

¹⁰ DWP, Work Choice official statistics, May 2015

Advisers were often unable to see the potential in people who are deafblind and had little concept of how they would be able to work. Sadly, even individuals with a long employment history experienced this kind of attitude. A negative response from Jobcentre Plus advisers had a significant impact on confidence and left deafblind people isolated without any structured support. People who did receive support faced low expectations in relation to the kind of jobs they should apply for.

A lack of awareness means that advisers are unable to accurately identify the needs and barriers a person may face. This has an impact on the quality of their advice and the accuracy of referrals for further support. For people who use alternative methods of communication or need information in alternative formats, a lack of awareness can lead to access needs not being met.

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 “When they call my name, I can never see who to go to. Then they gave me a form, which I could not read, because the font was too small. I told them, but they said I should try harder.”

Deafblind people looking to set up their own business or become self-employed also struggled to obtain advice and support from Jobcentre Plus advisers. Some were told they could not take advantage of the New Enterprise Allowance because of their high support needs; however, this prevented them from accessing support from the Government’s Access to Work programme.

One person reported:

“I did not pursue the scheme when I was setting up my business. I was advised that due to my needs and support requirements they felt that what was on offer was very limited. Setting up a business requires a lot of social networking and I could not find a way to get the communication support for this.”

When faced with advisers who are unable to understand their individual situation – and who are influenced by preconceived ideas of deafblindness – people were often left to deal with barriers on their own. This creates a hostile attitude towards existing back to work support among disabled people.

Many Jobcentre Plus advisers do not have enough time to spend on individual cases, which limits the advice they can offer. The caseload of advisers supporting claimants on ESA is significantly larger than that of those who support Job Seeker’s Allowance (JSA) claimants.¹¹ This makes it even harder to provide good quality advice or spend time trying to understand an individual’s circumstances.

People who are deafblind told us that they need specialist employment support from someone who is able to assess their needs and identify the barriers they face. It is also clear that this support should identify strengths and the biggest enablers for each individual. This requires a good understanding of deafblindness.

Arguably, the need for highly skilled and more disability aware Jobcentre Plus advisers will only increase with the roll out of Universal Credit (UC). Job coaches in UC have a much bigger role and more discretion. Unless this problem is addressed, Sense is concerned that deafblind people will not benefit from employment and in-work support.

¹¹ Work and Pensions Committee, *The role of Jobcentre Plus in the reformed welfare system*, Second Report of Session 2013-14

“I felt like a number, not a human being they were trying to help”

Gary

Gary has Usher syndrome, a genetic condition that affects vision, hearing and, in some cases, balance. After losing his job, Gary claimed the Employment and Support Allowance and was subsequently referred to the Work Programme, which failed to address his support needs.

“No one asked me what I wanted to do and what I could do. They quickly dismissed my aspirations to find an administrator job and told me to concentrate on customer service roles, such as a call handler at a call centre. It did not register with them that I had a hearing impairment.

“I was later sent on training sessions, where I could not see and hear what was being said. I had to come in and apply for jobs, and they assigned a person to help me do this as I could not see the screen and they didn’t want to adapt it for me. The lady just quickly read the jobs to me and sometimes applied without even letting me know. I later found out that she had a target to meet before lunchtime. The whole experience was awful; I felt like a number, not a person.”

Gary would have benefited from a personalised approach aimed at building his



confidence and encouraging independence. The support provided did the opposite. Advisers could have installed screen reading software on the computer and checked whether or not Gary needed to develop his computer skills to apply for jobs effectively. This approach would also have encouraged his independence. Instead, staff read the jobs to Gary and applied on his behalf.

Gary’s basic access needs were not met and it made it harder for him to benefit from the support he received. It might have been more effective to assess the demand in the labour market and reach out to employers who are actively recruiting staff to encourage them to consider employing Gary, rather than helping him to apply for the jobs he did not want and was not able to do. Gary finished the programme without getting a job, and continues to look for work himself.



Janice

Janice is deafblind; she has no useful vision and wears a hearing aid. She is a former Paralympic swimmer who won medals for Great Britain. She lives with her husband and daughter, and has a long history of employment, working in the civil service and for voluntary organisations. However, she lost her job a few years ago and went through a long period out of work. Janice explored different avenues of support to find employment but found the Jobcentre Plus extremely unhelpful.

“I went to Jobcentre Plus and asked them to help me look for work, and was told just to claim ESA. I had some support from an adviser based at a health service, but she also did not have an understanding of what I could do and what support I would need to do a job. At some point she suggested I would be a good communicator guide for another deafblind person!”



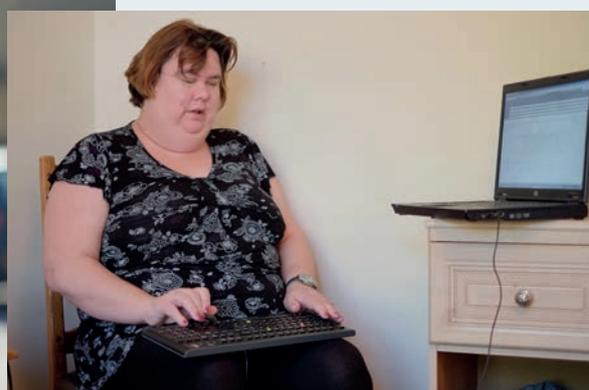
In addition to general career advice and help to find a job, Janice needed practical support with filling in application forms and formatting documents. Janice had to use valuable time with her communicator guide to do this, which took time away from other essential support, such as shopping, attending medical appointments and looking after her daughter.

“Communicator guide time is in high demand in my house. I need my communicator guide to help me with job searching; however, social services do not always recognise the importance of this.”

When her current role was advertised, Janice received help from her communicator guide to fill in the application form. It is not always possible for blind people to see whether the documents they create on a computer are formatted well. Untidy application forms can give a bad impression and be the main reason why people are not called for an interview. Janice believes she got an interview because her communicator guide helped her with the form filling.

.....
“I need my communicator guide to help me with job searching; however, social services do not always recognise the importance of this.”

**“Lack of awareness
and poor expectations
prevent us from getting
the right support”**



Links to welfare benefits

Research suggests that existing employment support programmes do not reach the majority of disabled people, with only one in ten accessing structured support to help them to find employment.¹² The majority of deafblind people we spoke to did not have the opportunity to benefit from the existing employment support programmes.

Conversations with people who are deafblind strongly indicate that the link between employment support and the welfare benefits system actively prevents people who are the furthest away from the labour market from getting the support they need.

The vast majority of working age deafblind people are placed in the Support Group of ESA, following a Work Capability Assessment (WCA). Some have health conditions that mean it is impossible or impractical for them to work. However, many in the Support Group would like to work despite the challenges they face – but are not given enough information about existing employment support, unlike those placed in the Work Related Activity Group (WRAG).

Although people in the Support Group can request to take part in work related activities, very few do out of fear that this may affect their benefit entitlement.

For some people placed in the WRAG, mandatory attendance at employment support programmes is sometimes inappropriate. This is the case for people with progressive conditions, or those with recently acquired deafblindness, who need time to learn to live with their health condition.

Separating disabled people into ‘can work’ and ‘can’t work’ through the WCA fails to take an individual’s aspirations and wishes into account. The link between benefits and employment support should be broken, and the support should be available to all disabled people, no matter what benefits they claim. People who are deafblind told us that the WCA does not accurately identify and separate people who can and cannot work. This is because an emphasis on functional abilities is not sufficient to determine whether an individual is capable of work as it does not consider a person’s ability to work, the barriers they may face in the workplace, or issues when looking for work.

Social care and reablement services

Deafblind people looking for work often face inaccessible websites, communication difficulties, and do not receive the right support to attend interviews.

There is also a large group of people who acquire a sight or hearing impairment in later life. In order to stay in work or to get a new job they may need to learn new communication methods or how to use assistive technology. Unfortunately, it is often a long wait to get this support – and some do not receive it at all. One person told us:

“My vision has deteriorated and I cannot use a computer anymore. I have screen reading software, but I know I am not using it well. If I only had some help to learn how to use it, it would make it so much easier for me to look for work.”

¹² Purvis et al (2014). *Fit for Purpose: Transforming employment support for disabled people and those with health conditions*. Centre for Economic and Social Inclusion. Available from: <http://cesi.org.uk/publications/fit-purpose-transforming-employment-support-disabled-people-and-those-health-conditions>

.....
Only one in ten disabled people access structured support to help them find employment.

Research shows that access to social care and reablement support would allow many people with sensory impairments to stay active in the labour market.¹³ For example, people can use their communicator guide or personal assistant

to help with job applications, or to guide them to interviews or other appointments.

Despite this, several deafblind people highlighted that they have struggled to access appropriate social care and reablement support. The number of hours of social care support people receive is usually low – and not everyone can afford to use it to look for work.



¹³ Saunders A., Douglas G. and Lynch P. (2013) *Tackling unemployment for blind and partially sighted people*. RNIB

Challenges to sustaining employment

Discrimination

Sadly, many people who are deafblind experience discrimination. We interviewed people who were dismissed from their jobs because they could not see sufficiently well or because their employer refused to make small adjustments, such as allowing flexible working or avoiding evening shifts.

People who acquire deafblindness while in work can struggle to hold on to their jobs, as some employers are reluctant to make adjustments or contribute to the cost of support. Very few people are aware of the fact that they can challenge discrimination and others are reluctant to do so fearing that they might lose their job as a result.

Securing support through Access to Work

Some people who are deafblind need ongoing and costly support to enable them to work. It is not reasonable to expect employers to offer this and so it is provided by the Government. The Access to Work programme is an important lifeline for disabled people in work. However, there are a number of issues, many of which were highlighted to us:

- There is a lack of awareness about Access to Work and the types of support it provides. None of the people we interviewed, including those who had received support in the past, were aware that it can be used to cover the cost of support at interviews.
- In order to receive a full payment, an application for support needs to be made within six weeks of starting a job. However, not everyone is aware of their support needs at this stage.
- The length of time it takes to put a support package in place means that some people lose their jobs.
- The assessors, including specialists commissioned by Access to Work, do not always have a good knowledge of deafblindness and the impact of dual sensory loss on a person's ability to communicate, access information and travel. Deafblind people often have to dispute recommendations that work for people with a single sensory loss but do not work for them.
- It is difficult to change or amend support packages. People whose conditions deteriorate and who may need further support as a result struggle to go through the reassessment process and increase their packages.
- The specialist skills of workers who support deafblind people are often not recognised, meaning that deafblind people become caught in disputes about the rates of pay their support worker should receive. People who are self-employed face reams of paperwork along with a very stringent financial test, and do not always have access to the support they need at the start-up stage.

- People who are deafblind feel that employers' knowledge of Access to Work is poor. One person said: *"I always have to explain Access to Work when I go for interviews. One time the panel were so surprised that such a programme exists, they asked me to prove to them that it does."*

Typical experiences of Access to Work:

"I have been overwhelmed with paperwork. It seemed like individual people were just making new demands. They expect you to do a lot of invoices/paperwork but I do not have secretaries. They do not want to understand my level of need and support. They are saying I am very expensive and put every obstacle in my path. They are meant to be there to help us into employment but they actually make it so much harder."

"Access to Work sent an assessor who had no experience in deafblindness. He would make stupid recommendations. For example, he said because I had one-to-one support, I do not need a braille computer. This caused an 18 month battle. How are you meant to work and have these battles with agencies that are meant to help you work?"

People who are deafblind thought that some of the current initiatives, including personal budgets trials, a video relay service for contacting Access to Work, and future web portal could improve their experiences. However, they still felt there was a need for better awareness of deafblindness among Access to Work staff and better quality assessments for Access to Work packages, which could be improved by ensuring assessors have knowledge of deafblindness and understand the impact it has on a person's ability to work.

Feeling included at work

People who are deafblind are often excluded from informal day-to-day communication within the workplace. Many felt unable to socialise and build informal relationships with colleagues, and some believed that they had been intentionally or unintentionally excluded from social events at work. Physically being at the workplace but not feeling part of a team not only impacts on an individual's sense of wellbeing at work, but also on the person's ability to do their job well. This aspect of work is not always appreciated by colleagues and line managers. It is also often overlooked when decisions about the level of communication support are made.

.....
"I was really upset when my colleague invited everyone to her birthday except me. She assumed I wouldn't go anyway."

Informal communication often happens spontaneously and it is not always possible for those who use alternative methods of communication to get the right support. This is seen as the biggest barrier; however, formal support is not always necessary when other people make an effort to be more inclusive. Learning some signs or the deafblind manual alphabet; using other methods of communication, such as texts, messengers or emails; or just remembering that a deafblind person is a member of the team and taking steps to include them can make a huge difference. We heard:

"I often find out about things that have been decided over a quick catch up long after. My colleagues do not realise that unless they make an effort to share information with me, I will not know about it. I cannot hear quick conversations and sometimes won't even know that people had one."

“Organisational culture matters”

Sam*

Sam’s sight and hearing deteriorated significantly in his forties. Today, he feels that his best chance of gaining employment is with organisations who work with and for people with sensory impairments. His current job is well below what he would expect taking into account his experience, knowledge, skills and qualifications. Despite glowing appraisals and tangible successes he does not feel he has progressed in the same way as other colleagues.

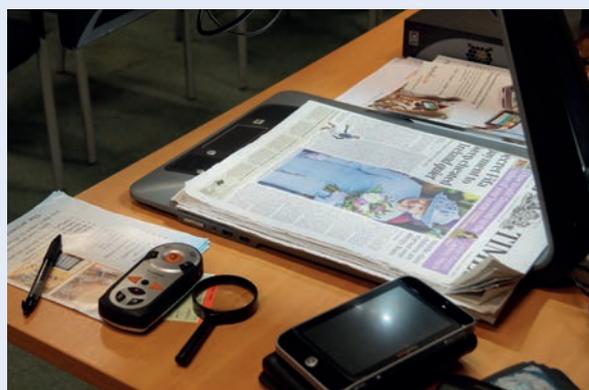
To do his job Sam needs adapted equipment, including a large smartphone, a large monitor with retina sharp display, portable CCTV magnifier and magnification software. Sam also needs communication support at meetings, training and conferences. He relies on Speech to Text Reporters (STTRs) to provide this support; however, only two people supply the service where he lives. He says:

“My employer tries to be supportive, but sometimes it is hard. When meetings are called at short notice I often can’t take part. Our technology and phone systems are incompatible with Next Generation Text Relay.

“On the other hand, there has been increased awareness and willingness to accommodate me among my colleagues. It all requires supportive leadership. People now tend to print materials for me in a larger font or provide more clear handwritten notes. I think this happened because a member of the senior management team saw how I was excluded at a staff Christmas event. I was given the opportunity to educate my colleagues about my sensory loss and my access requirements. I will keep reminding people, especially new people. Sometimes organisations are just not sensory aware.

“I have not done a lot of lifelong learning since I left university. At work, I have done some work related training courses where Access to Work covers communication support costs. However, I am often competing for jobs with people who have taken other steps to develop, including taking courses at universities. I have not been able to further my education as learning centres cannot afford to pay for the communication support.”

*Not his real name



“Spending money on adaptations for disabled people is an investment”

Jo Ann

Jo Ann is deafblind and communicates via lipreading. She is a senior manager at a large company. Jo Ann has worked all her life and has always been supported by her employer. At work she requires adjustments, such as special computer software, and needs to sit in a certain position during meetings in order to lipread.

“I’ve been very fortunate in my career. I’ve been able to engage with my employers and get them into a mindset to think of what I can do, as opposed to what I can’t do. And I think it is very important that everyone adopts this attitude. Not only does it help the sense of wellbeing, but it gives you the sense of empowerment and makes you feel good about what you can achieve in life. Whilst it is good to be aspirational, it is about managing expectations and finding a job where you can maximise your talents.”

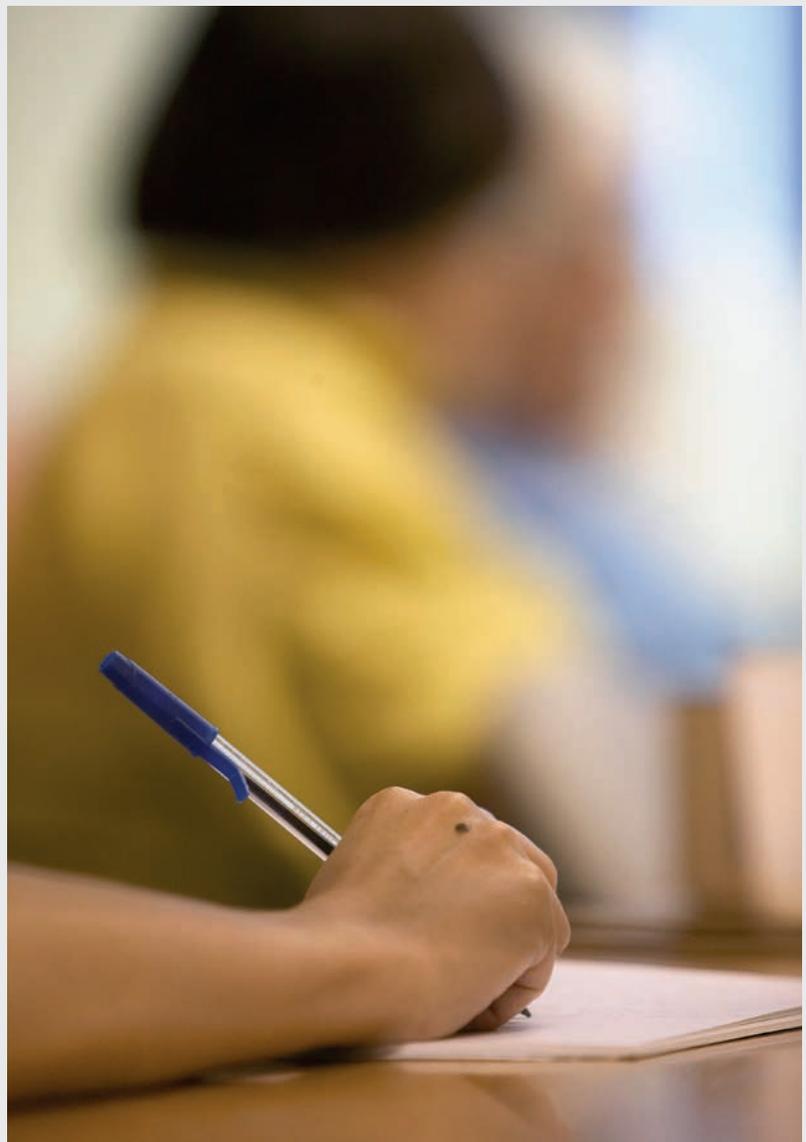
“The key to success for me is being open and honest about what I can do and what I can’t do. I am not shy to go into a meeting room and rearrange where everyone sits for me to get the maximum benefit of communication. We all have different needs and these just happen to be mine.”

“It is about working with your employer and changing the mentality of reasonable adjustments into a return on investment. When I talk to my line manager about the product they buy for me, I think it is right that I make a commitment on what I can offer back to the company.”

At present there is no good way of knowing whether a company is genuinely interested in employing disabled people. Although the Government supports the ‘Positive about disability’ sign or Two Ticks scheme – which requires employers to agree to five commitments – the research has shown that the scheme is ineffective.¹⁴ In many people’s view it is a tick box exercise rather than a genuine attempt to diversify the workforce.

“There is no point in getting a job interview if they know before you arrive that you are not going to be suitable. In my case I arranged all the interpreters and within two minutes of the interview I knew I wasn’t going to get a job. They just wanted to tick a disabled box. It is so patronising and much worse than not being called for an interview at all.”

¹⁴ Hoque, K., Bacon, N. and Parr, D. (2014) *Employer disability practice in Britain: assessing the impact of the positive about disabled people ‘two ticks’ symbol*, Work, Employment & Society, 28, 430-451



A key theme in our interviews with deafblind people was the value of peer support or mentoring schemes. These help to build an individual's confidence and give them the chance to share experiences. Occasionally, people may find it more helpful to access a supportive network of others who face similar barriers. It will always be for deafblind people to explain what their needs are and how they can be supported to do a job. Peer support also empowers individuals to challenge discrimination in a positive way and improve the culture within an organisation.

Physical barriers

People who are deafblind may also face physical barriers to employment, such as the layout of buildings or levels of lighting or background noise. This can be particularly true in older buildings.

Many who use computers or technology have problems with accessibility. Not all software is accessible for people with sensory impairments and, moreover, it may be incompatible with assistive technology. This is especially true in relation to internal systems developed by organisations. This is mainly because accessibility requirements are not always built in when such systems are developed. Incompatibility problems can become more acute when existing software packages are updated. Upgrades to the operating system, for example, usually necessitate an upgrade of assistive technology. People who are deafblind told us that it takes time and results in an additional cost to access information on their computer after significant software upgrades.

“It is frustrating that in this day and age accessibility of the IT infrastructure is an add on. Why can't things be made accessible from the start? It is all very well having these add ons such as screen readers or magnification software but frankly they don't always work. Accessibility of IT infrastructure for us is like wheelchair access for people who use wheelchairs.”

Opportunities for career progression

There was also a feeling among the people we spoke to that deafblind people are given fewer opportunities for promotion. This is because colleagues or managers often make incorrect assumptions about their career aspirations. It is also difficult for many to learn new skills and gain new qualifications, as neither Access to Work nor further education institutions pay for communication support at training courses.

Those who had positive experiences at work had to be assertive and proactively educate their managers and colleagues about their abilities, needs and barriers. Not everyone has the confidence to do this, and many are not given the chance. It is therefore important to establish peer support and mentoring programmes in the workplace.

.....
“My employer runs a disability network; it is open to all disabled employees. We meet every two or three months. It has been a great support for me.”



If a deafblind person progresses to a managerial role, they may have to go the extra mile to establish their authority. One person stated:

“Finding people with the right attitude is difficult. I have had staff where I would give people instructions and they would just do what they think is best. Assume that I won’t notice or realise. People find it hard to accept a deafblind person as their boss – they think because they have the advantage of sight and hearing, they know best.”

Once people have jobs, therefore, it is important to ensure they can progress in their career. Employers need to be given better quality advice on how they can support disabled people.

Conclusion

Our research found that people who are deafblind can – and want – to work. Currently, just one in five people who are deafblind have a job, and that is down to the many barriers they face. In gathering material for this report we met deafblind people who are department managers, software developers, civil servants, teachers, administrators and care workers. Some successfully ran their own companies, such as a bike shop, a theatre company or an accountancy firm.

The low employment rate of people who are deafblind is a consequence of the multiple barriers they face. Our research has shown that far too often deafblind people are written off and considered unable to work.

Deafblind people who are looking for work face negative attitudes from employers, fear of discrimination, inaccessible recruitment processes and difficulties using public transport. We found that young deafblind people do not always receive high quality employment support during their transition to adulthood and often lack the qualifications, experience and skills to enable them to secure employment. Many deafblind people who acquire their impairments in later life do not have access to reablement services, which are designed to help them to live with their condition and to maximise the use of technology and alternative communication methods at work.



.....

Deafblind people who are looking for work face negative attitudes from employers, fear of discrimination, inaccessible recruitment processes and difficulties using public transport.

Current support programmes are not working for deafblind people. The majority of people who are deafblind do not access existing schemes, and those who do often find them unhelpful. Sense believes people who are deafblind should be offered a chance to access support schemes that meet their needs, no matter how far from the labour market they are.

It is essential that the new Work and Health Programme fulfils its ambition to help disabled people with more complex needs to find employment through short to medium-term support. However, people who face more significant barriers to employment, including some deafblind people, are likely to need specialist long-term support models designed to meet individual needs.

It is also important to remember that, for some people who are deafblind, work is not an option and they should not be made to look for employment if it is not appropriate. However, these individuals may still benefit from involvement in a broader range of activities that encourage active citizenship and enable them to learn new skills, build confidence and feel included within their communities.

Our research shows that the barriers deafblind people face do not disappear after they have secured employment. People who are deafblind often feel excluded, face physical barriers and feel that career progression is limited. Many people who are deafblind need ongoing support to enable them to communicate effectively and to access information. The support from the Access to Work programme is critically important in helping deafblind people to maintain employment and further their career. Deafblind people told us, however, that the scheme does not always function effectively and they often struggle to access the support they need.

.....

Sense believes people who are deafblind should be offered a chance to access support schemes that meet their needs – no matter how far from the labour market they are.

Employers have an important role to play in ensuring the Government fulfils its manifesto commitment to halve the disability employment gap. Future support programmes, therefore, should place a greater emphasis on working with employers to help them understand the potential and abilities of disabled people, including those who are deafblind.

“I always wanted a job and now my dream came true”

Halima

Halima is one of many interns supported by Project SEARCH in East London, which runs as a partnership between The Whitefield Academy Trust and Barts Health NHS Trust.

Project SEARCH was established in 1996 at Cincinnati Children’s Hospital. It is a supported internship programme for young people with learning disabilities and/or those on the autistic spectrum. It is a unique, business-led, one-year school to work programme that takes place entirely in the workplace. The programme is based on a total workplace immersion approach, which facilitates a seamless combination of classroom instruction, career exploration, and hands-on training through worksite rotations. The project has a success rate of over 78%.

Halima is visually impaired and has learning difficulties. She joined Project SEARCH in the last year of her formal education. At the time, she lacked self-confidence and needed support with the simplest of tasks. Halima also had little appreciation of the work environment and what it might entail.

During the programme Halima tried a range of roles and a variety of tasks. This included administrative work, such as opening the post and crossing appointments, greeting visitors and directing patients to where they needed to be, and helping to feed, talk to and reassure patients. Halima is fluent in Urdu and was able to help patients communicate their needs and concerns to nurses and doctors. Halima’s caring attitude and ability to listen were greatly valued by patients and staff, and as a result she was given a Barts Health Hero award.

The main objective of Halima’s Project SEARCH support team was to help her to learn how to do tasks independently, breaking them down into smaller elements and enabling her to master these one by one. As she grew in confidence, the support was gradually withdrawn.

Halima also received travel support and long cane training, which enabled her to travel independently to work and navigate effectively around the hospital.



By trying a range of roles that required different skills Halima realised that she was passionate about becoming a housekeeper on the ward. Halima shadowed an experienced housekeeper to learn how to do the job, and when a position became vacant she successfully applied for and secured the role.

“I have just started my job as a housekeeper on a ward. I like that I was able to go and work on different wards and learn different skills, but the most important thing the project did for me is it got me a job. I can now earn money. I already made some friends on the ward. I always wanted to have a job and now my dream came true.”



The project works in a holistic way, addressing each young person’s individual needs. The support provided is broad, and besides teaching skills needed to do the job, it may include work with the individual’s family, benefits advice, help to build social networks in the workplace, coaching and practicing interview skills.

Recommendations

National level

- The Government should make more resources available for specialist support models targeted at people who have more complex support needs and are not likely to benefit from the Work and Health Programme.
- The joint Department for Work and Pensions (DWP) and Department of Health's (DH) Work and Health Unit should use its Innovation Fund to trial innovative specialist support models.
- The link between welfare benefits and access to employment should be broken by making support voluntary and available to all disabled people, regardless of the benefits they claim.
- The DWP should work with the DH, Department for Education (DfE) and Department for Business, Innovation and Skills (BIS) to ensure deafblind people receive appropriate re-employment support at key stages. This should include support for the transition to adulthood and for individuals whose condition deteriorates.
- The Government should consider trialling the introduction of personal budgets for employment support.
- The Work and Health Programme should enable disabled people to choose their employment support provider, including the option of opting for specialist support.
- The Government should ensure disabled people have access to information about employment support. There should be greater transparency in relation to who the support providers are, what support they can offer, and the minimum quality standards disabled people can expect from them.
- The Government should implement a training programme for Access to Work specialist teams to increase their understanding of deafblindness and its impact on a person's ability to do their job.
- The Government should ensure Access to Work assessments of deafblind people are carried out by specialists who are trained in deafblindness.
- The Government should develop and implement a coordinated campaign to raise employers' awareness of the abilities and potential of people who are deafblind, and increase the understanding of the technologies that exist to support deafblind people in the workplace.
- Building on the Disability Confident accreditation scheme should support and recognise the employers who are taking specific steps to make their recruitment process more accessible for disabled people. The scheme should have a robust monitoring mechanism, which should involve disabled people.

- The Government should develop and implement a comprehensive training programme for Jobcentre Plus advisers to raise their understanding and knowledge of disability, including deafblindness. Advisers should be able to identify people's needs and refer them to the most appropriate support programme. They should also be able to meet the communication and access requirements of each individual.

Local level

- Local authorities should ensure that people whose sight and/or hearing deteriorates have timely access to reablement services and assistive technologies that enable them to maintain the highest degree of independence.
- Local authorities should maintain funding for local employment support programmes and ensure these programmes focus on disabled people with complex needs.

Employment support providers

- Employment support providers should ensure that advisers are aware of the specific needs of deafblind people and how they differ from the needs of people with a single sensory impairment.
- Employment support providers should ensure that all communication is accessible and provide information in the formats that people need.
- Providers should establish close links with specialist health and social care services to support deafblind people and ensure that appropriate referrals are made to increase people's independence.

- Providers should understand and support the use of assistive technology and development of new communication methods.
- Providers should better understand the demands of the local labour market and proactively reach out to employers, encouraging them to consider disabled applicants.

Employers

- Employers should promote an inclusive culture within the organisation by raising awareness about disability and promoting the specific steps staff can take to make their disabled colleagues feel included.
- Employers should ensure recruitment processes are accessible in order to encourage applications from disabled people.
- Employers should ensure disabled people feel confident and comfortable to disclose their disabilities and request adjustments.
- Employers should view spending money on adjustments for disabled people as an investment in the workforce.
- Employers should consider contacting specialist organisations if there is a need for advice on specific medical conditions.
- To address the multiple barriers disabled people face, employers should consider setting up specialist schemes to increase employment and promotion opportunities for disabled people. These include talent recruitment programmes or internships, mentoring schemes and additional training opportunities targeted specifically at disabled people.



sense
for deafblind people

About Sense

Sense is a national charity that supports and campaigns for children and adults who have sensory impairments and complex needs. We provide tailored support, advice and information to individuals, their families, carers and the professionals who work with them.

We believe that each person has the right to choose the support and lifestyle that is right for them; one that takes into account their long-term hopes and aspirations.

Our specialist services enable each individual to live as independently as possible, offering a range of housing, educational and leisure opportunities.

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