Written evidence submitted by Sense (ATW0075)

1. Introduction

1.1. Sense welcomes this opportunity to submit evidence on Access to Work. Deafblind people face many barriers to employment. Assistive technology and support workers funded through Access to Work are extremely important in overcoming these. However, deafblind people, and their employers, want to see improvements to Access to Work.

1.2. In preparing this submission, we consulted with deafblind users of Access to Work, as well as, where possible, their managers.

2. The Application and Assessment Processes

2.1. The application and assessment process causes difficulty for many deafblind people. Three issues are raised repeatedly:
   - inaccessible information, application forms and communication;
   - lack of knowledge of deafblindness, appropriate solutions and associated costs; and
   - unacceptable delays.

2.2. All of the deafblind people we have spoken to tell us that they have only ever received application information and forms in standard print. This is despite most having requested alternative formats, such as large print, email or braille. A small proportion (approximately 5%) later received information about the support that had been agreed in their preferred format. Many of the deafblind people we spoke to about this expressed concern that failure to provide accessible information and forms led to delays whilst they waited for assistance and loss of privacy, as someone had to assist them with completing forms.

2.3. This is further complicated for some deafblind people who have been told that they can only contact Access to Work by telephone, despite Access to Work knowing that they are deaf and, therefore, unable to use a telephone. However, others have used email to communicate with Access to Work. Access to Work’s approach to accessibility is inconsistent.

2.4. The multiplying effect of combined vision and hearing impairment can result in deafblind people having very different needs to people who are either blind or deaf. Many deafblind people have told us that assessors and Access to Work advisers lack understanding of the impact of combined vision and hearing loss and of the solutions that work for deafblind people.

2.5. For example, a deafblind person who used to communicate by a combination of using a cochlear implant and lipreading experienced further sight loss, making lipreading impossible. She requested Access to Work funding for communication support but was told that users of cochlear implants were expected to lipread, and that no communication support would be provided. The adviser failed to recognise that, without eyesight, lipreading is impossible. The deafblind person is currently on unpaid leave whilst she negotiates with Access to Work, but she is worried about her job security.
2.6. Deafblind people find themselves having to explain, provide evidence of, and justify their needs each time their Access to Work support package is reviewed and, sometimes, even between reviews. For example, a Sense employee – who communicates using deafblind manual (a form of tactile finger spelling), has been an Access to Work customer for over ten years and is currently awaiting the fifth review of her Access to Work package – has to justify each time why she requires deafblind manual interpreters rather than sign language interpreters. Her manager has received phone calls from Access to Work staff to challenge the hourly rate paid to deafblind manual interpreters because they could source sign language interpreters more cheaply. Whilst we recognise the importance of regular reviews, especially as many deafblind people’s needs will increase over time as sight and hearing deteriorate, it should not be necessary for deafblind people to repeatedly provide the same information and to justify their needs. Doing so takes up valuable time for deafblind employees, and their employers, as well as being demoralising for deafblind people.

2.7. The needs of deafblind people are diverse. Solutions that work for one will not necessarily work for another. For example, deafblind people communicate in many different ways such as sign language adapted to their individual visual impairment, hands-on signing, deafblind manual or clear speech to name just a few. We recognise that this makes it challenging for advisors to be knowledgeable about all of the needs deafblind people may have and the solutions available. For this reason, we believe it is important that Access to Work see deafblind people as experts in their needs and that Access to Work works with specialist organisations, such as Sense, to provide specialist information and advice, as well as training.

2.8. For many years, deafblind people have told Sense of unacceptable delays in waiting for Access to Work agreements to be put in place. However, in the last few months, deafblind people are telling us of increasing delays.

2.9. For example, a Sense employee who is deafblind and a wheelchair user has received funding from Access to Work for deafblind manual interpreters or electronic note-takers for meetings, and a support worker to assist with travel and inaccessible paperwork for the past ten years. She contacted Access to Work six weeks before her agreement was due to expire, to request for it to be renewed. However, fourteen weeks later, i.e. eight weeks after the agreement expired, she is still waiting for the process of renewal to begin. Meanwhile, Sense, as her employer, is having to pay for her support worker and interpreter costs, which is unacceptable and cannot continue indefinitely. This situation is putting the deafblind person’s job at risk.

2.10. To improve the application and assessment process, information and forms must be provided in accessible formats, deafblind people must have their needs assessed by people with understanding of deafblindness, and the process must happen in a timely way.

3. The Adequacy of Ongoing Support
3.1. Some deafblind people are satisfied with the ongoing support they receive from Access to Work. However, other deafblind people have told us about inappropriate assistive technology, too few hours of support and hourly rates for support workers that are too low to recruit people with the specialist skills needed.

3.2. A Deaf-visually impaired person, who accesses a computer using screen magnification software, and is starting to learn braille, requested Access to Work funding for screen magnification software that also can support a braille display. Access to Work instead agreed to fund screen reader software, which has no magnification function. The Deaf-visually impaired person was not aware that the software recommended did not include magnification and, therefore, purchased the recommended software, only to find that it was unsuitable.

3.3. A deafblind person, who communicates primarily using hands-on signing, needed interpreters for meetings and a support worker to assist with telephone calls and paperwork. At her most recent Access to Work review, the number of hours was reduced from fifteen per week to ten per week, despite there being no change in circumstances. This same deafblind person has been having a long-running dispute with Access to Work over the hourly rates. Access to Work has agreed an hourly rate that is approximately a fifth of the going rate for hands-on interpreters. The deafblind person is currently having to make up the difference, which is putting her in severe financial difficulty.

3.4. The combined effect of vision and hearing impairment means that deafblind people’s needs are different to those of people with a single sensory impairment. Deafblind people will often need more support, and for that to be provided by people with specialist skills that are in short supply, such as sign language interpreters with additional skills and experience in hands-on or visual-frame signing and knowledge of the extra visual information they need to provide to a deafblind person. Such specialist support is costly. Similarly, the specialist equipment needed by deafblind people can be more expensive. For example, a hearing-blind person may be able to use a computer with speech output whereas, a deafblind person may require a more expensive refreshable braille display. Providing this support is essential if deafblind people are to work, come off out of work benefits, and pay taxes.

4. Clause 340, or the 30 hour rule, and the salary cap

4.1. The Access to Work policy states in clause 340 that, if "a Support Worker is required full time, for example 30 hours or more a week, Access to Work will normally fund on the basis of an annual salary rather than an Agency worker employed on an hourly basis." The combined effect of the application of clause 340 and the salary cap of £30,000 for a salaried worker is reducing the ability of deaf and deafblind people to choose appropriate staff to meet their needs.

4.2. Employees and their manager’s report feeling increasingly pressurised into accepting a salaried member of staff even when it is clear that a salaried worker cannot offer the flexibility, or the technical expertise, appropriate for the deafblind person to be able to effectively carry out their
role. The salary cap of £30,000 for a support worker is compounding the problem, as some deaf and deafblind employees need highly specialised support which inevitably comes at a cost.

4.3. Further it appears that to overcome the presumption in favour of a salaried worker, there is a requirement to advertise the role for a minimum of 2 months, in order to prove that the salaried support worker position cannot be filled.

4.4. A Sense employee has an ongoing dispute with Access to Work in relation to the application of the 30 hour rule and the salary cap:

4.5. This employee is Deaf, communicates using sign language, and is visually impaired, with a very limited visual field. Her job requires that she attends meetings and delivers training across the UK and attends international conferences. She also has management responsibilities for a team with diverse communication needs. This means that she requires a support worker who is experienced with working with a restricted visual field and who can provide communication and other support in a wide range of different settings.

4.6. She currently uses freelance interpreters, with a range of different qualifications and experience, to suit the particular assignment. However, she was told that, because she requires more than 30 hours communication support each week, funding would be capped at £30,000 and that she should employ a salaried interpreter rather than using more expensive freelance interpreters.

4.7. This employee has tried to reduce costs by using cheaper, less qualified and experienced interpreters but found that her ability to do her job was severely compromised. There are a limited number of interpreters who have the skills and experience to work with someone with the combination of deafness and visual impairment that this employee has, and who can provide support in the wide range of settings that this employee works.

4.8. Progress is now being made on this particular case and Sense hopes that an agreement will be reached shortly. However, this has taken several months of negotiating with Access to Work. The employee concerned has benefitted from support from Sense, which may not have been available to deafblind employees of other organisations in similar situations.

4.9. Clause 340, or the 30 hour rule, and the salary cap are not working for Deaf and deafblind people. While we welcome the Department for Work and Pensions’ review of the policy, it is Sense’s view that, if the Government is indeed committed to supporting disabled people into and in work, it should repeal clause 340 with immediate effect and set the salary cap at a level that allows Deaf and deafblind people to recruit qualified interpreters.

5. The Effectiveness of Access to Work
5.1. Access to Work is extremely important to deafblind people. It enables them to work when without it they could not. However, in order to be effective, the issues outlined above need to be addressed. They are:

- Improving the application and assessment process;
- Ensuring that Access to Work packages are awarded at a level that sufficiently covers specialist equipment and support;
- Repealing clause 340 with immediate effect; and
- Setting the salary cap at a level that allows Deaf and deafblind people to recruit qualified interpreters.

5.2. In addition, we would like to see:

- Disabled people being able to agree a provisional support package, prior to a job offer, so that support could be put in place quickly once a job is secured. At present, some people have to wait for weeks or months before starting a new job, whilst Access to Work support is agreed and arranged. In some cases, this leads to the job offer being withdrawn;
- Access to Work re-imbursement claim forms to be provided in accessible formats, with accessible ways to complete them.

6. About Sense

6.1. Sense is the leading national charity that supports and campaigns for children and adults who are deafblind. We provide expert advice and information as well as specialist services to deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have sensory impairments with additional disabilities.

7. About deafblindness

7.1. Deafblindness is a combination of both sight and hearing difficulties. Most of what we learn about the world comes through our ears and eyes, so deafblind people face major problems with communication, accessing information and mobility.

7.2. The barriers faced by deafblind people are different to, and greater than, those experienced by people with a single sensory impairment. People with a single sensory impairment are able, to some extent, to compensate by using their remaining intact sense. Deafblind people are not able to do this. The interaction of sight and hearing difficulties results in unique deficiencies in the information available to deafblind people about the world around them.

7.3. Deafblind people are often unable to benefit from services, equipment and systems designed for people with a single sensory impairment. The needs of deafblind people are complex and unique and their support needs are high.

7.4. There are many causes of deafblindness. These include premature birth, birth trauma and rubella during pregnancy, which can cause babies to be born deafblind. Some genetic conditions also result in deafblindness. And any of us can become deafblind at any time through illness, accident or as we grow older.
7.5. People who are born deafblind often have additional disabilities, including learning and physical disabilities.

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