

Title **Professor**

First name **Bencie**

Last name **Woll**

Email address

The Equality Act 2010 defines a disabled person as someone with a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

Do you consider yourself to be a disabled person, according to this definition?

- Yes
- No
- Prefer not to say

Are you submitting comments on behalf of an organisation?

- Yes
- No

Organisation **United Kingdom Council on Deafness**

Job title **Trustee**

UKCoD is the umbrella body for voluntary organisations working with deaf and hard-of-hearing people in the UK. Its mission is to assist organisations and the sector as a whole to maximise the positive impact they have for deaf people, providing access to specialist information, conferences and collaborative working opportunities, whilst providing a collective membership voice to political and cross sector partners.

This response has been prepared by Professor Bencie Woll on behalf of the UKCoD Trustees.

## RESPONSE OF UKCOD TRUSTEES TO ODI CONSULTATION 2012

### REALISING ASPIRATIONS

#### 1. What ideas do you have that could make a difference to you in getting an education, getting a job or being able to live independently?

There is evidence from the USA<sup>1</sup> that further and higher education has a substantially enhanced benefit for young deaf people, compared to the benefit for hearing young people, but only if students are directed to appropriate courses, education is completed and qualifications obtained. Existing support services for deaf students are not focussed on helping students to complete their studies but rather on providing support during the courses themselves.

Lifelong education and re- training possibilities following hearing loss acquired during an individual's working life are not well supported. This reduces the individual's chances of remaining in employment or changing career.

An integrated approach to career counselling<sup>2</sup> and to sustaining study to achieve qualifications is likely to result in a substantially greater percentage moving into employment. However, there are no UK data available and there is a need for an appropriate evidence base. Approaches should include:

- Development of individual and customised personal appraisal and a personal development plan (for both education and employment.)
- pre-entry Deaf Awareness training for professional staff and colleagues/peers
- Independent mentoring and review
- Appropriate communication support, including support often not available to those with acquired hearing loss such as speech-to-text, lipspeakers and electronic note-takers
- Customised course design and associated learning materials
- On line customised support networks
- Flexible and appropriate funding support mechanisms eg.ATW, benefits
- Customised work experience
- Independent environmental equipment audit and provision

#### 2. What would help you manage better at times of change in your life?

#### 3. In those situations, how are you supported or held back by other people?

There is often poor continuity between services at times of change and transition – for example, between school and further or higher education, between FE/HE and work, etc. or where a person experiences hearing loss during working life.

Access to Work support is usually not set up until after a person has started a new job. This means that at the point of starting employment, new employees may be without communication and equipment support. This in turn creates an environment in which the new employee misses out on induction procedures and cannot function

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<sup>1</sup> Schley S et al. Effect of Postsecondary Education on the Economic Status of Persons Who Are Deaf or Hard of Hearing. *Journal of Deaf Studies and Deaf Education* 16:4 Fall 2011

<sup>2</sup> Since the vast majority of deaf students are mainstreamed, they do not have direct access to specialist career services.

effectively. Deaf and hard-of-hearing people would benefit from access to customised information and support (full options and choice) and seamless support provided by specialist professionals. For those who develop deafness during working life, there is insufficient general knowledge of different forms of communication support especially at work. Access to Work is not well understood by both employee and employer. This in turn creates the situation where a person may lose a job following acquired deafness due to lack of knowledge of potential support available.

## **INDIVIDUAL CONTROL**

### **4. What helps you to have choice and control over your day-to-day life and the support you get?**

Probably the biggest single barrier between deaf people and the rest of the community is reliance on the telephone as the primary means of doing business, contacting support services etc. Innovative technology which relies on mobile telephony, for example, such as car parking, seriously disadvantages deaf people. Those organisations which take the trouble to provide viable alternative business channels are much appreciated, but there is a need to design public services to meet different needs, and to provide support in BSL but also to written, rather than spoken, information.

### **5. What else would help you to have more choice and control over your day-to-day life and the support you get?**

One of the main support needs of deaf people is for communication support: in accessing public services, health services, employment, etc. There are currently different routes to accessing such support depending on the service, although in general the service provider also organises and provides communication support for the most part. These arrangements may result in services not meeting the needs of the deaf person, being delayed while communication support is arranged, or not being available at all. There should be consideration of whether some allocation for communication needs should be made directly to the deaf person so as to provide them with choice in support. One example is the provision of personal support for deaf-blind people. For those who are sign language users, another deaf person may provide the most appropriate and satisfactory service because communication needs – so critical to a deaf-blind person, can be met. Deafened and hard-of-hearing people on other hand need speech-to-text support as the main communication support as much as inductive loop systems. Support services meeting individual needs must be available when requested and the service providers need greater awareness of these needs and the various means of support.

More generally, choice and control would benefit from more information, budgetary control, improved awareness and customised service delivery from mainstream service.

**6. What would help you to access services and activities which suit your needs? For example education, transport, housing, health, social care, and sport, social and recreational activities.**

People with hearing loss experience greater difficulties in accessing health services and receive a lower standard of health service across the board, affecting both people with age-related hearing loss and sign language users, and cuts across acute and preventative health services. This has negative implications for both prevention and management of long term conditions for people with hearing loss.

This has been reported in both US and UK studies. For instance, in the US, Pandhi found that hard of hearing people are around twice as likely to report difficulties in accessing healthcare<sup>3</sup>. They were also more likely to experience delays in accessing care. Healthcare providers also reflected these findings; doctors reported that they asked fewer questions of deaf than hearing patients<sup>4</sup>.

In the UK people with hearing loss avoid going to see their GP because of communication problems. Similarly, they are more likely to report that they have been left unclear about their condition because of communication problems with their GP or nurse<sup>5</sup>.

A further US study underlines the importance of having a language-concordant provider (one that provides information in their preferred language). Those receiving information in American Sign Language were more likely to receive a flu vaccination. The study concludes that language-concordant patient-provider communication is associated with higher appropriate use of preventive services<sup>6</sup>. This is also likely to be the case in the United Kingdom, and highlights the importance of services that meet the needs of sign language users.

For all deaf people, remote access to services – for example, the possibility of making doctors' appointments by e-mail – can substantially reduce initial access problems. A personal communication support budget and/or a video interpreting relay service would empower the deaf person to ensure appropriate communication support to meet their personal needs. Better deaf awareness training would reduce many of the communication difficulties as would a more active policy on requiring service providers to ensure that technological aids such as loops, information screens, etc. are not only installed but working. Services should include:

- Awareness Training
- Recognition of need
- Consultation, representation and influence on mainstream service design and delivery
- Customised service development with recognised minimum standards of service access and provision

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<sup>3</sup> Pandhi N, Schumacher JR, Barnett S, Smith MA, *Hearing loss and older adults' perceptions of access to care*. Journal of Community Health. 2011 Oct;36(5):748-55.

<sup>4</sup> Ralston E, Zazove P, Gorenflo DW, *Physicians' attitudes and beliefs about deaf patients*, Journal of the American Board of Family Practice 1996 May-Jun;9(3):167-73

<sup>5</sup> RNID, *A Simple Cure*, 2006

<sup>6</sup> McKee MM, Barnett S, Block RC, Pearson TA. (2011) Impact of communication on preventive services among deaf American Sign Language users. *American Journal of Preventive Medicine* 41(1): 75-79.

- Appropriate resourcing
- Performance monitoring against acknowledged minimum standards and targets

## **7. How can you be involved in decisions that affect your local area?**

There is little possibility for a deaf or hard-of-hearing individual to get involved in local consultation on equal level with hearing people unless the public consultation organisers advertise different forms of communication support to be available if requested. When the availability of such support, in the form of BSL interpreting, Speech to Text reporting, or even inductive loop systems, is not advertised, deaf and hard-of-hearing people will feel excluded from participation.

Although there are many positive features of an increased move to localising services, this may lead to a reduction in access to specialist expertise. The provision of services by a professional with the necessary communication skills as well as domain expertise is important, and even more so where individuals have complex disabilities, and should be preferred. The third sector is well-placed to work in partnership with the public sector, especially where there is a move to local and generic service provision. We support:

- Community capacity building with confirmed engagement, consultation and supported representation processes
- A "Champions" programme identifying key individuals and groups to influence mainstream service development and associated resource allocation
- A Budgeted communication support strategy.

## **CHANGING ATTITUDES AND BEHAVIOURS**

### **8. What works well in changing the way other people treat disabled people?**

Enhanced deaf and disability awareness is important in helping people understand the challenges posed by deafness. Such awareness training is important from childhood onwards. Such education is a crucial part of changing the public mind-set, and needs to be tackled early on with regard to all disabilities, not just hearing loss. Deaf Awareness, including information about the range of different communication needs, should be made compulsory in Education, the Health Service, and in local and national government. By ensuring full access, the provision of qualified communication support enables active participation of deaf people and helps others to recognise their contribution.

The official status for the language that would be achieved through the proposed BSL bill will also change attitudes and consequently, behaviour. Targeted actions needed include:

- Opportunities for work/volunteer placement in Deaf environment
- Early intervention- enhanced presence of Deaf Awareness and Sign Language in the school curriculum
- Focussed disability training, allowing sufficient insight and awareness to be achieved as opposed to condensed disability training with restricted impact/content.
- Increased "media" exposure

**9. What else is important in changing the way other people treat disabled people?**

A strong legal framework is an essential prerequisite to changing behaviour. There needs to be a more efficient and simpler way of addressing disability discrimination in relation to deaf and hard of hearing people. At the moment there is no straightforward local or national monitoring service to receive complaints.

**10. What can we do to make sure that everyone recognises the contribution that disabled people can make?**

As indicated in the response to Question 7, there needs to be enhanced, marketing, media, profiling, and formal recognition. A Champions' programme would also enhance visibility of deaf people and their contribution.

**11. Do you have any suggestions for how we should implement and monitor the Disability Strategy once it is developed?**

There is limited data available, especially at local level, on the numbers of deaf people in the UK. Because of the low incidence of severe and profound deafness, sampling studies do not provide reliable data; the 2011 Census is likely to provide better data, but plans to discontinue the Census, and its infrequency, mean that this also provides poor information as a basis for service planning. This is a matter of concern since monitoring the Disability Strategy relies on having adequate data on the population.

A more systematic, joined up registration system (collating information from audiology, education, employment service and social welfare, benefits) similar to that created for visual impairment, would provide a more comprehensive data bank for profiling, monitoring and resource planning. Local review panels with statutory organisations including deaf representation/Champions are needed to identify initial strategy, and monitor and evaluate data, in order to feed into regional/national profiling mechanisms and service improvement targets.

It is crucial that all cross sector services recognise the need to budget for resources to meet deaf/disability requirements at the design stage rather than as belated additions to mainstream provision, which then becomes more costly and protracted. A mandatory question "Have you considered the needs of disabled people- please quantify" in all service design specifications, monitored by a Champion's representative, would be a useful starting point.

**12. Is there anything else you would like to tell us? Do you have any other ideas you think we should include in the Disability Strategy that you haven't covered in your responses so far?**

Formal recognition and engagement with UKCoD, the key infrastructure deaf organisation, could provide a platform to establish an appropriate and user-led framework for effective strategic development and review.