

Response to The Office for Disability Issues (ODI) On the Consultation "Fulfilling Potential"

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Introduction

The British Deaf Association (BDA) is a Deaf-led membership organisation. It campaigns for the right of Deaf people to access all areas of society through British Sign Language (BSL), and for the right of deaf children to have a bilingual¹ and bicultural education. We aim to empower Deaf BSL users through a variety of programmes:

- Personal and community advocacy support including training Deaf people to become advocates
- Youth activities including training Deaf people to become youth workers
- BSL teaching including training Deaf people to become BSL tutors

We refer to British Sign Language (BSL) which became a recognised language in its own right by the UK Government in 2003. BSL is different from English in that it uses grammatical features such as signing space, placement, agreement verbs, facial expressions and movement variations. It also has a different sign structure from that of English, which means that it is not possible to have an exact 'word for sign' translation.

Our members and users tend to define themselves as culturally Deaf with a first or preferred language of BSL, accordingly we will use the capital 'D' to refer to Deaf adults. Because many deaf children grow up without access to adult Deaf people thus missing out on learning BSL and about Deaf culture and norms, we will use the lowercase 'd' to refer to deaf children. Deaf people also define non-deaf people as 'hearing' people.

This document is our response to the Consultation paper 'Fulfilling Potential'. It is shaped by the responses that we elicited from our members and users at a series of consultation meetings in England. Our staff team focused on a series of headings:

- Family
- Education
- Employment
- Health

Because the discussion was free-flowing, it was inevitable that some audiences focused more on one topic than another. The returns we obtained indicate that audiences concentrated much more on family and education than employment and health mainly because of time.

For obvious reasons, we have not used every comment made at the consultation meetings. The quotes chosen are indicative of the comments made.

We are also carrying out a number of consultation meetings for the respective parliaments of Scotland, Northern Ireland and Wales.

¹Bilingual education in this context is taken to mean teaching by the use of British Sign Language and English (or one of the indigenous languages e.g. Welsh or Gaelic). Bicultural education involves learning about Deaf identity and culture as well as hearing culture.

We are aware that our members and users share many similar experiences to those who have lost their useful hearing in later life, whether this be a gradual process (hard of hearing people) or a sudden process (deafened people). While some people with hearing loss subscribe to our values and indeed are members, there were no such persons present at our consultation meetings. This document therefore should be read as a response from Deaf people who are primarily BSL users.

In the document there will be references to 'interpreters'. This denotes someone who has achieved the highest level of training in BSL and has received training in interpreting skills².

²Further information available from Signature (formerly CACDP) – see www.signature.org.uk

The questions - our responses

This next part sets out our responses to each section.

Realising Aspirations

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

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

The two recurring themes in this section are lack of communication access or information. Whether this is within families where the parents are hearing and the child is deaf, or working in an employment setting, or being a Deaf parent, or just as a Deaf adult trying to access various services or information, the major issue is communication.

For instance, our respondents commented on the continuing failure of current services to give adequate information to hearing parents who have just found out they have a deaf child. The following comments show their concerns:

"Not enough information is given to parents; they are only given the basic information."

"If you have a deaf baby, the medical community look at that negatively, we need to think about giving information to parents of deaf children, such as where they can learn sign language, and a balanced view should be presented to the parents."

"You meet a doctor, other professionals and representatives of services, but Deaf people aren't involved in that process so you don't get to meet any Deaf person to get a perspective."

"I know this family – their child was born deaf and they didn't know what to do, they were given medical advice which was negative, and the child was growing up not being able to communicate with their parents and wasn't doing well educationally. The parents weren't given the advice they needed to make sure their child was part of the family."

The pain of growing up in a hearing family and missing out on communication is also illustrated by these comments.

"I missed the opportunity to have a real family life as I was away from home in a residential school with only a limited time at home."

"I'm the only Deaf person in the family and it was difficult to share anything so I fell out with the family and lost touch as I grew up. It is very hard."

"When I was born, my father was shocked I was deaf. He did some research and he learned sign language. My mom was not interested nor was my sister. It broke my heart when my dad died. I have to write things down for my mom. All my 5 children are hearing and they can all sign which shocked my mom and sister."

"I always use my brother or sister to act as my voice when I'm with the family – often people will just put thumbs up to me and don't bother trying."

For Deaf parents communication is also a major issue when dealing with health or school authorities. These quotes illustrate the frustration of not being able to take care of their own children to the level they feel they ought to.

"Deaf parents don't get full information; for example, when schools are closed, they announce them on the radio! We only find out when we arrive at the school."

"I asked for an interpreter for the parents evening and the school said there was no funding."

"I feel there isn't enough information given to Deaf parents to enable us make the right choices of schools for our children."

"My eldest is at school now and I get very little information. The school wrote me a note but I didn't understand it. Whenever I asked for an interpreter they used to put barriers in the way."

"I found things very difficult when I got letters from the GP full of technical jargon."

"I would be watching TV programmes for children without subtitles, and I couldn't share that with my hearing daughter."

There were some concerns about professionals being too ready to use children as interpreters as there is a shortage of interpreters and of funding for social situations:

"Professionals say to my daughter – 'Can you tell your mum?' – I object to this, I never use my children to interpret for me but I know it happens often."

"I asked recently for an interpreter for my grandma's funeral and couldn't get one, so my mother interpreted which was hard for her as she was upset too."

"I have three hearing daughters who can sign. One interprets for me at the doctors or at other places where interpreters are not provided."

In an educational setting, the main issue once again is about achieving access through communication. At one workshop, the facilitator asked how many of those present would have liked their teachers and the school environment to be fluent in sign language, almost everyone present put their hands up in favour.

"I had a teacher who had been trained to use the oral method – he'd just come out of training and was absolutely shocked that I couldn't lipread him!"

"It would take months to learn how to lipread one teacher and every time we got used to one teacher they would change them and we would be back to square one having to learn how to lipread them."

"I went to mainstream school and I wanted to join the drama group but they said there was no money for access."

"I went to an oral school – there were no CSWs³, interpreters or Typetalk⁴"

"I went to an oral school but I couldn't understand anything and I was almost expelled."

³Communication Support Worker

⁴Text Relay service linking textphones with voicephones

Many comments were made about difficulties at work. Again these concerned communication and information which restricted opportunities.

"I had a problem with English so they said there was no chance of promotion because of that. The cuts in Access to Work have made that virtually impossible."

"I used to work as a secretary I had to stay at Level 1 for eight years while other people got promoted. Because they told me as a Deaf person I couldn't get promoted."

"I book interpreters but sometimes the wrong level (meaning not adequate enough) turns up."

"I've recently graduated. If I don't put that I'm Deaf on my CV I get an interview but then people back off – more awareness is needed."

"I had an interview. The Interpreter was booked but unfortunately didn't show up. The manager came out with 2 other men. And I said 'where is the Interpreter?' and he pointed to one person there who was hard of hearing himself and I signed 'what is your name?' He didn't understand. I said: 'Sorry this meeting is cancelled, I am off'. The manager came to me and said 'I am so sorry we will book a qualified Interpreter – will you come back?' but two weeks later I still hadn't heard anything."

Individual Control

- **Question 4.** What helps you to have choice and control over your day-to-day life and the support you get?
- **Question 5**. What else would help you to have more choice and control over your day-to-day life and the support you get?
- **Question 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.
- Question 7. How can you be involved in decisions that affect your local area?

It is clear that for many Deaf people a key issue is communication and the supply and quality of interpreters. What seems to be less important is having members of staff within the organisation who can use BSL at the appropriate level, perhaps because many Deaf people would consider this to be unrealistic. Deaf people are only too aware of staff turnover and know that training staff in BSL is never-ending. There were several comments around the need for properly trained interpreters as these comments show:

"More funding is needed for interpreters and communication support. Also these people should have access to proper training and we, 'the Deaf community', monitor these people like a watchdog scheme."

"In one hospital they have an in-house interpreter but the problem might be that it's the wrong gender. We need to match the interpreter to the person."

"I made an appointment to go in with an interpreter and it became clear. It is so important for things like parents evening and plays and assemblies. Before there was Interpreter provision I felt lost and didn't know what was going on, now I have an Interpreter that goes with me and feel it is more equal now."

"I think interpreters should be available for job interviews without incurring cost for the potential employer. This puts them off employing deaf people."

Many Deaf adults are concerned about deaf children. They see deaf children joining Deaf activities in early adulthood and many have poor communication skills. There is often a sense of wanting to improve things for the next generation, but not knowing how to.

"I am worried about the cuts – they are affecting deaf children. I worked in a secondary school and I noticed that those who went to mainstream primary school were already behind those who went to deaf school. The council does not understand that."

"Many young deaf people now have a cochlear implant – they are still deaf, but they don't fit into the deaf community nor do they fit in with the hearing community. This could lead to mental health problems."

"Some CSWs who work in college are great but others aren't. There needs to be a benchmark."

There were several ideas of how matters could be improved. Some of these were specifically for children.

"Children have the opportunity to learn a language in school so why not BSL? There should be a GCSE in BSL."

"Children's programmes are very educational and there should be money for a signer or subtitles."

"When I was at school I didn't have signing, I learnt nothing, then I started going to the Deaf club and I had role models to learn from which gave me confidence. They changed my life for the better."

"It is important deaf children have role models who can empathise and understand what it means to be Deaf."

"If you teach a child how to communicate they will be less frustrated. So many families say they want to learn sign language, they should have funding to pay for lessons."

"I think there should be Direct Payments for deaf children so they could pay for CSWs or interpreters so they can join after school clubs."

Other ideas were more about how existing services could be improved.

"Some areas have Video Relay Services – we need more of this available at doctors, dentists etc., this would solve some of the problems."

"I went on holiday – and only got limited information. There should be a DVD or they could even provide a factsheet for people to read rather than just saying 'it's nice!"

"The Government should give us a budget to control our support."

"Access to Work is so frustrating and the process is so limiting. You have a limited allocation but sometimes you have other meetings, but you have to do without. That's not fair."

"What about a Deaf version of NHS Direct?"

"We need support from Deaf representatives within ATW so we can have fair budgets."

A recurring theme was how Deaf people could be better represented in services. The BDA has picked up this theme from other consultations. Many Deaf people have no confidence in services that work with or are for disabled people. They feel that the disability umbrella is too broad and that Deaf people get lost in that.

"I would like there to be a Deaf watchdog – people could vote for that, it could be a monitoring body."

"Think about the different departments, they should be accountable and appoint Deaf people within their ranks to ensure access."

"There could be a Deaf candidate in every constituency – or at least a minimum number because we don't have any Deaf MPs."

Changing Attitudes and Behaviours

Question 8. What works well in changing the way other people treat disabled people?Question 9. What else is important in changing the way other people treat disabled people?Question 10. What can we do to make sure that everyone recognises the contribution that disabled people can make?

The major issues concern BSL and improving people's awareness of Deaf people.

"The biggest barrier is communication and most deaf children are born to hearing parents and they don't have any idea of what to do. If you have a deaf baby, there must be funding to help the family to learn signing."

"I think all NHS staff in audiology clinics should learn sign language."

"It is difficult with hearing people, for example going shopping or going to the cinema. I tell them I am Deaf and they still speak to me. It would be good if they could write things down or even learn sign language in school. Some people know nothing about deafness – my husband did not."

"Teaching people to be Deaf aware should start in primary school."

"We do need more interpreters to be more accessible for family issues including leisure activity."

"More Deaf awareness is needed in the NHS."

"For older people we need Deaf carers."

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

It seems clear from the responses at the consultation meetings that Deaf people need to be involved in the implementation and monitoring of the Strategy. This would enable the Deaf community to access the process directly through Deaf people they know or know of.

This exposure to Deaf people in general increases the accountability and opportunity for Deaf people to have their say in matters that affect them.

Whatever is decided in the implementation, it is clear that BSL interpretation must be available at each stage throughout the process.

Those administering the implementation and monitoring the Strategy should also receive Deaf Equality Training to assist them in understand the issues involved.

Monitoring the Strategy will require further consultation meetings which the BDA is happy to arrange and report back on.

Conclusion

It is clear that many Deaf people do not share many of the day to day concerns of people with other disabilities; for example, there was very little discussion about self-directed support, or about care needs. The discussions were about access to information and being able to communicate with the wider hearing community. There was some underlying anger at the persistent failure of public services to accept responsibility for providing communication access. As one participant suggested:

"We need legislation to support our rights."

Whether the subject was about counselling, welfare, health care, or sports at the local sports centre, the message was mainly the same. We are not asking for special provision – we are asking for access. As one Deaf parent complained:

"Because of communication cuts, my son now can't play in his football team because he can't access the training or the team talks."

The Government's Strategy should consider how best to improve communication access and access to information so that Deaf people are not dependent on specialist staff to explain and liaise with the wider hearing community on their behalf.

The British Deaf Association - BDA

Vision

Our vision is Deaf people fully participating and contributing as equal and valued citizens in the wider society.

Mission

Our Mission is to ensure a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is respected and fully protected, ensuring that Deaf people can participate and contribute as equal and valued citizens in the wider society. This will be achieved through:

- Improving the quality of life by empowering Deaf individuals and groups;
- Enhancing freedom, equality and diversity;
- Protecting and promoting BSL.

Values

The BDA is a Deaf people's organisation representing a diverse, vibrant and ever-changing community of Deaf people. Our activities, promotions, and partnerships with other organisations aim to empower our community towards full participation and contribution as equal and valued citizens in the wider society. We also aim to act as guardians of BSL.

- 1. Protecting our Deaf culture and Identity we value Deaf peoples' sense of Deaf culture and identity derived from belonging to a cultural and linguistic group, sharing similar beliefs and experiences with a sense of belonging,
- 2. Asserting our linguistic rights we value the use of BSL as a human right. As such, BSL must be preserved, protected and promoted because we also value the right of Deaf people to use their first or preferred language.
- **3.** Fostering our community we value Deaf people with diverse perspectives, experiences and abilities. We are committed to equality and the elimination of all forms of discrimination with a special focus on those affecting Deaf people and their language.
- 4. Achieving equality in legal, civil and human rights we value universal human rights such as the right to receive education and access to information in sign language, and freedom from political restrictions on our opportunities to become full citizens.
- 5. Developing our alliance we value those who support us and are our allies because they share our vision and mission, and support our BSL community.

Current Activities

The BDA operates in Scotland, Northern Ireland, Wales and England delivering:

- Community Development work
- Community Advocacy support
- Youth, Children and Families programmes
- BSL services
- Policy and Campaigns work
- Membership support through Area Deaf Associations/Special Interest Groups
- Information provision using British Deaf News and its bi-lingual website
- Fundraising and PR

Contacting the British Deaf Association

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