

# Disability Living Allowance (DLA) for Deaf People

**A BDA Survey** 

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## 1 Introduction & Overview

The Government is proposing a new scheme to replace Disability Living Allowance (DLA) with the Personal Independence Payment (PIP) scheme which will be introduced between 2013-2014, after consultation with disabled people in England, Wales and Scotland. It is intended that the benefit remains a non-means tested payment for disabled people in and out of work, in order to try and ensure they lead full and independent lives.

This report is a summary of 89 responses to a survey sent out by the British Deaf Association (BDA) to deaf individuals regarding Disability Living Allowance (DLA).

The BDA is a Deaf people's organisation. It campaigns for BSL to have legal status as a language and for the right of deaf children to have a bilingual and bicultural education. Local campaigns concentrate on the right of deaf people to access all areas of society through British Sign Language (BSL). The BDA also aims to empower deaf BSL users through a variety of programmes:

- Personal and community advocacy support;
- Youth activities;
- BSL teaching for deaf people to become BSL teachers;
- Employment and Campaigns.

Deaf BSL users also discussed whether or not it would be beneficial to be part of the wider Independent Living Movement (ILM).

A debate to explore how disability groups could work together in the wider ILM was also held by Independent Living in Scotland (ILIS) in February 2012. Three outreach workers and two other Deaf participants from the British Deaf Association (BDA)'s Participation project attended. Comments made at the 'question time' style debate - which focused on the theme of 'them' and 'us' – are noted in this report where relevant.

As well as information on disability and Independent Living, other forms of information were also given at all the consultation meetings, as Deaf BSL users often have little opportunity to meet and discuss matters that affect them. This additional information is included in a separate section within this report for those who may want to know more about the lives of Deaf BSL using respondents.

## 2 Significant Findings

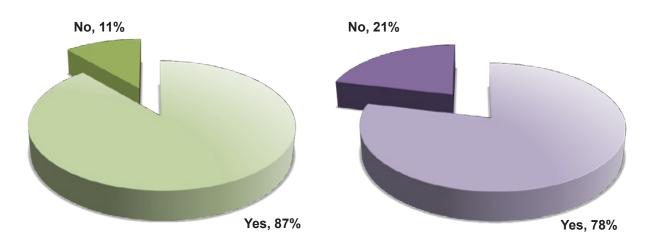
The findings clearly show how important the DLA care component is for deaf people in living full and independent lives. 88% of respondents rated it of 'high' importance.

Respondents raised concerns that current provision is not enough, and that they are reluctant to challenge what they do receive as they fear that it may be reduced.

The BDA is concerned that the feedback shows 87% of respondents said they found it difficult to meet new people, with a further 78% of these avoiding going out because they find it hard to talk to people. This includes BSL users, SSE users and those that lipread (see Fig 1).

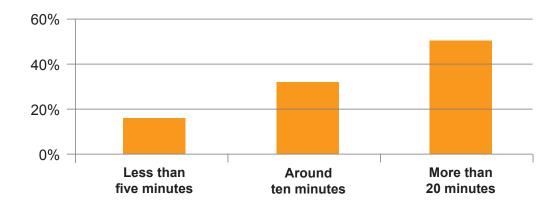
#### Do you find it hard to meet new people?

## Do you avoid going out because you find talking to people hard?



Another finding was that more than half (51%) of respondents felt it would take more than 20 minutes to write a short piece of writing, with a further 31% taking around 10 minutes to do the same task.

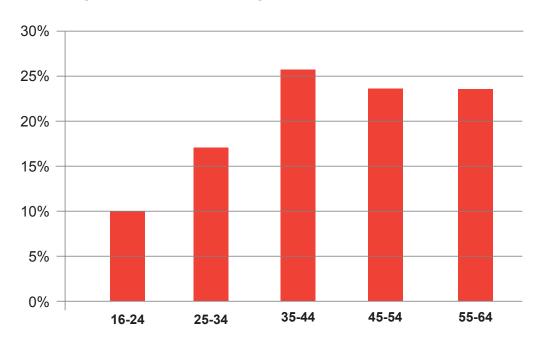
#### How long does it take to write a short letter or e-mail (200 words long)?



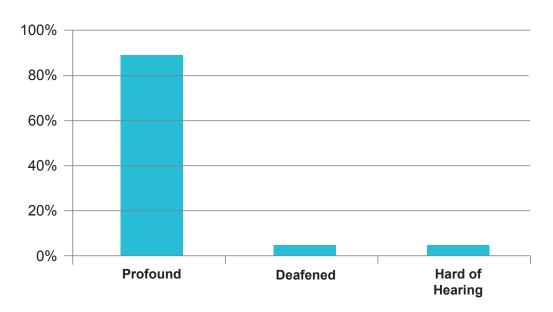
# 3 Respondent Profile

There were 89 individual responses to the survey. Most respondents were profoundly deaf and aged between 35 and 64. The majority were aged between 35 and 44.

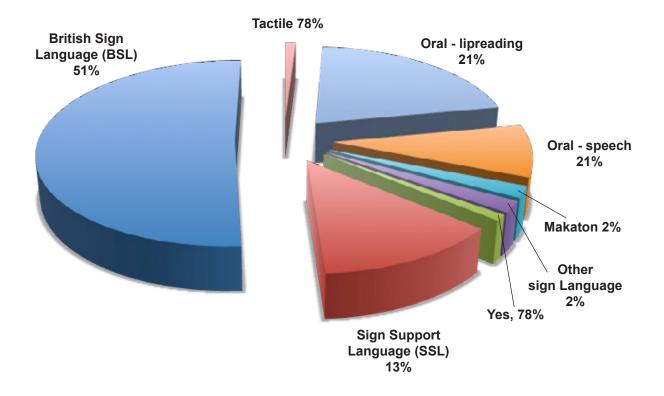
### Percentage of Respondents per Age Group



#### **Respondents Level of Deafness**



More than half (51%) of the respondents were British Sign Language users (BSL) and a further 13% used Sign Supported English (SSE) as their main communication mode.

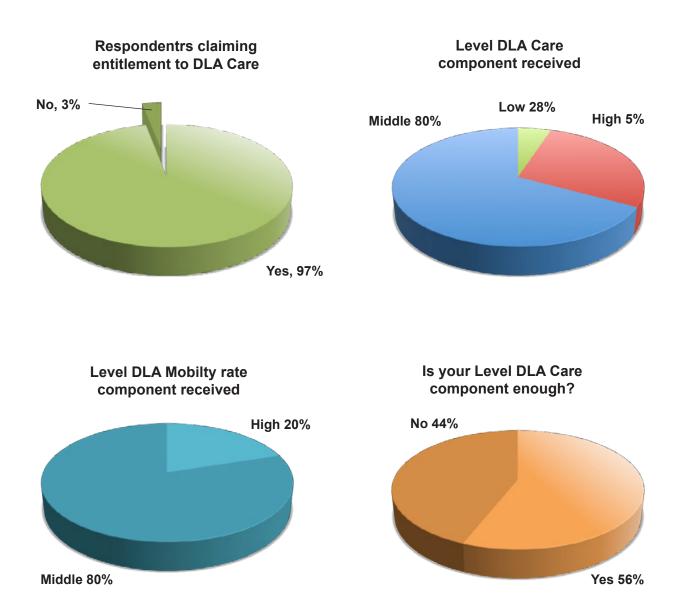


The majority of respondents felt they could read written English (87%), didn't have any additional physical difficulties (60%), mental health issues (82%) or other impairments (70%).

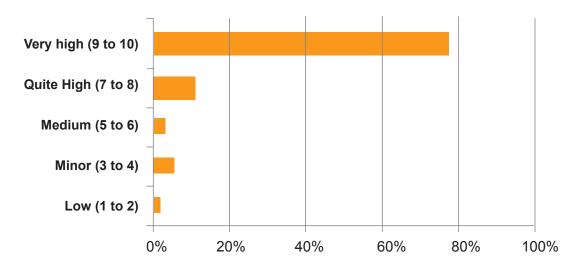
Although many respondents felt they could read and understand written English, the respondents' own comments (all can be found in Appendix 1) demonstrate the level of written English used. The BDA believes that many of these individuals find English language difficult, especially with forms and documents. This matches people's responses on how long it would take to write 200 words.

## 4 Disability Living Allowance (DLA)

Respondents were asked about their DLA care and mobility components regarding whether they claimed their entitlement and what level they received. Most respondents claimed the DLA Care component (97%), and felt it was of 'very high' importance (77%), and although the majority received the middle level of care benefit (67%), 44% said this was not enough to meet their needs.



#### Importance of DLA Percentage



## 4.1 What is your DLA care component used for?

Appendix 1 is a record of all the original qualitative information gathered about the DLA Care Component.

**Appendix 2** is a record of all the information given about the DLA Mobility Component.

In summary, the majority of comments indicate that their DLA care component is spent on:

- Specialised equipment, particularly to ensure their health and safety at home;
- Communication support including paying for interpreters and communication support workers for social events, activities outside of work, and appointments where communication provision is not supplied;
- Communication support specifically with written English;
- Additional costs incurred as a result of deafness.

## 4.2 Equipment

There was much feedback on the need for specialised equipment for in the home in order for deaf people to feel safe, and be able to live more independent lives. The most frequently referred to items were the telephone, flashing fire alarms and doorbells, and vibrating alarm clocks:

'To pay for equipment to meet my needs at home'

- 'To compensate for the difference between a hearing person and me. e.g. I have to pay more for a flashing alarm device – it is more expensive than a normal fire alarm'
- 'The lack of communications during travel and leisure times. It also helps with buying special technical equipment for my safety e.g. vibrating alarm clock, flashing light doorbell'
- 'I need broadband services to enable me to have a webcam while hearing people use their free minutes on their mobile phone. I use DLA for broadband and landline services plus a laptop with a webcam. The laptop usually lasts for a few years' \*

# 4.3 Communication support for non-work related activities and appointments

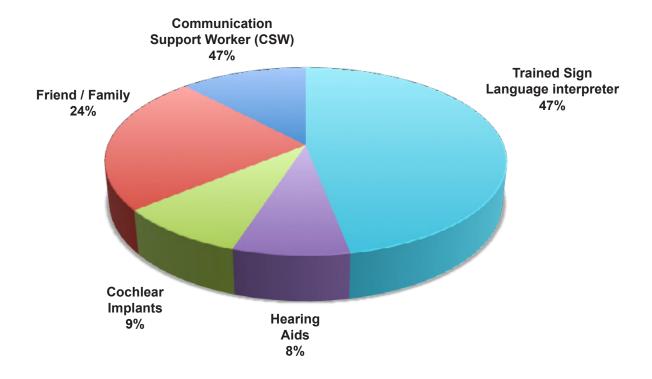
The need for interpreters, communication support and help with translation was commented on frequently. This is for social and leisure activities, as well as medical appointments and formal meetings not related to work, but that an individual might want to be involved with. They would need to pay for support in order to access the information as their hearing peers would.

- 'I need help with understanding what professionals are saying e.g. when I see my GP I don't always understand or and sometimes do misunderstand which puts my health at risk'
- 'I use it for interpreters so I can access meetings at evenings, such as council meetings, heritage association meetings, or the deaf club to enable more access for hearing people. I also pay for lessons in activities such as sport so I can improve my skills and knowledge'
- 'Paying for an interpreter at private events, or special equipment that social services don't provide'
- 'Often use DLA to pay for signers e.g. community group, local residents' groups, family reunions, pub, social events, and meetings. But I pay a lot more than what I receive from my monthly DLA'
- 'To pay towards the cost of interpreters so I can communicate with my doctor, bank staff, or tradesmen who come to my home'.

<sup>\*</sup> Note: These comments have been edited for ease of reading. The originals are in Appendix 1.

## **4.4 Communication Support**

The survey also asked them specifically who or what currently helps them with their communication. 47% said a 'Trained Sign Language Interpreter' helped them communicate, with a further 12% opting for a Communication Support Worker.

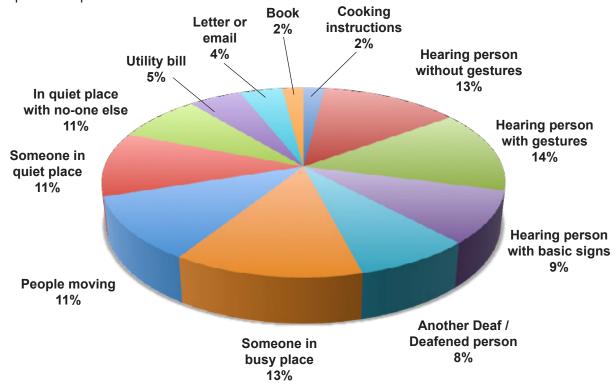


There were also frequent references to family and friends for communication needs, and often respondents relied on family and friends for access.

- 'My son always signs and acts as an interpreter for me'
- 'Having a family member / friend with me when I am socialising is essential. Without them I would need to rely on the sensitivity and patience of the people I was with and I would be too anxious to risk this'
- 'Interpreter, communication support worker, those who can sign, those who are lip-readable, note-takers

## 4.5 Who or what do you need help understanding?

While 47% of respondents rely on a trained Sign Language Interpreter, and a further 31% a Communication Support Worker, the following categories were identified as requiring specific help.

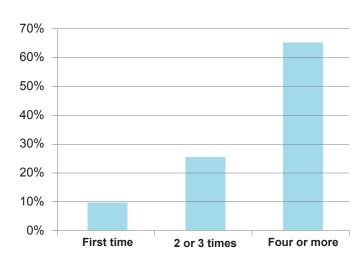


Frequent difficulties with the public were highlighted, such as

- Lip reading bus drivers who have facial hair, or those who mumble, and don't understand me asking for destinations',
- · doctors, dentists, contractors, banks'
- 'HMRC, council, bank, shops (if buying expensive things like washing machines, bed, or a car'.

More than 90% of respondents said they needed comments repeating twice or more, with 65% needing 4 repeats.

This highlights the need for communication support in order to understand and access what people are saying. Many respondents are using their DLA Care Component to try and meet this need.



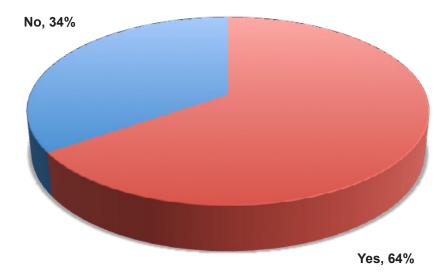
# 4.6 Understanding and writing English

In addition to BSL services, respondents made frequent reference to understanding written English, and the need for help with understanding and completing forms as well as writing documents in English themselves.

- 'I frequently have communication break-downs and also need help with letters or forms. I rely on my family for help or use a BSL interpreter. Without them I wouldn't be able to get it right. Forms are never easy to follow – I prefer plain English – if I have to buy something for my daily needs etc.'
- 'I need help for communication break-down as I can't read or write very well. Things like the BT bill requires me paying someone to help me fill out the forms etc. Also I need interpreters'
- 'I need help for the small print on contracts, and with bills'.

Respondents were asked if they required help in understanding information about banks and loans, to which more than half (64%) confirmed they did.

It is clear that for many respondents the value of the DLA Care Component is being able to pay for communication support to access and translate written information.



## 5 Conclusions and issues for consideration

It is clear that many deaf people – regardless of their communication modes – struggle to cope with everyday activities such as communicating with people who provide services or with official letters and forms. There is some help for reading official letters and filling in forms for deaf people (the BDA provides this in South Wales and North Scotland) but provision is generally patchy throughout the UK. CABs often do not have the requisite communication skills to provide this and the BDA believes that this is an area in which there is need for much improvement.

It is also clear that the largest proportion of the care component is spent on communication access which helps to reduce the struggle to gain access to services freely available to the rest of the community. Respondents talk about paying extra for communication needs and 78% of respondents avoid going out because they find talking to people hard. This is likely to have a huge impact on their well-being as being cut-off from other people reduces their chances of keeping positive mental health. The BDA believes that this needs to be addressed in some way. Finland and Sweden have addressed this issue in a different way and the BDA believes that this should be investigated with a view to introducing a similar scheme.

The current Equality legislation is robust. However the pathways to achieving fair and equal access to services are daunting to many people. Current obstacles are the complaints system and recourse to legal remedies (which also require access through interpreters and are not freely available). These are much greater when an individual is struggling to understand how the system works and has difficulty with English. The BDA believes that a clearer pathway for deaf people to complain or present a legal case for access to information is essential.

## 6 Appendix 1 – Respondents original comments

## 6.1 What is your DLA Care Component used for?

- 'Need help to understanding from professional are saying i.e. seeing GP but not always understand or may misunderstand which it could serious effect my health in danger'
- 'To buy adapted equipment, sign language classes for my parents'
- 'To pay for equipment to meet my needs at home, to pay for travel to my nearest deaf club'
- · 'To pay for an interpreter to help understand communication without missing out of feeling isolated or ignorance'
- · 'My English is not bad but my grammar and syntax is always problem so I need help some help me to correct it'
- 'To compensate for any difference raised between hearing person and me. E.g. having pay for flashing alarm device – expensive than normal fire alarm;
- 'I use the DLA to pay for interprets that's not provided by the event/appointment makers e.g. job interviews'
- 'It enables me to have a companion when out socially to assist with communication when I am not wearing hearing aids (because of chronic ear infections and general health of ears, I am unable to wear hearing aids all the time and have to chose to wear during working hours or couldn't do my job)'
- 'I use it for interpreter for access to meetings at evenings out by out of hours for example council meetings, heritage association meetings, deaf club more access for hearing people, use activities like sport access for learning skills to improve my knowledge to understanding clearing'
- 'Travel costs to meet deaf people, and attend events which are accessible but not necessarily local'
- 'To see subtitled films at the cinema'
- 'To pay for extra electricity used having lights on for lip-reading
- 'Paying interpreter at private events, special equipment that social services don't provide'
- 'Lack of communication to the public (a quite difficulty to communicate with the bus driver, shops, hospitals, doctors)'
- 'For Interpreting costs'
- 'I need help with communication and special equipment for home'
- 'Lack of communications during travel and leisure times, also having to buy special technical equipment for my safety e.g. vibrating alarm clock, flashing doorbell'

- 'Communication break down and need help with letter forms. Rely on family for help and BSL interpreter. Without them I won't be able to do it right and form never easy to follow plain English is for me. I had to buy something for my daily need every day etc.'
- 'I get someone to interpret me when I go to see GP, hospitals. I use text direct to contact some companies such as BT as I can't use an ordinary phone. In the noisy environment, people find themselves difficult to understand what I say as my speech is limited'
- 'To compensate for low earnings and lack of career prospects'
- 'To pay for my transport costs to get to my current employment'
- 'To translate written English especially jargon or other important letters I often go to social service for translation as there is no other access. i.e. bsl translation video'
- 'For stronger broadband (because of the videotelephpony); for extra equipment e.g. extra babyphone; for hearing dog (food, vet visits etc.)
- 'Transports'
- 'Personal Care'
- 'For deaf communication break down, I can't read or write very well. BT Bill to pay someone to help me fill out the forms etc. also interpreting'
- 'Accessibility where there aren't any for communication i.e. interpreters. I also use it to pay cinema, theatre as they are reduced fares'
- 'To pay for adaptions in my house so that I can be fully independent and care for myself"
- 'To aid my mobility and travel to meet up deaf friends to have socially because of local deaf clubs closed and also to support my advise for my English to read letters and health information'
- 'Help with my daily care needs and equipment to assist my care needs'
- 'To travel to my friend and ask them to help me translate from English to BSL. I'm very isolate and no communication in small town'
- 'Often use DLA to pay for signers e.g. community group, local resident, family reunion, pub, social events, meetings. But I paid lot more than monthly DLA payment'
- 'To pay for communication support to get around'
- 'Cost of living as it is very expensive and my salary is low'
- 'I use DLA for help with interpreters as communication supports'
- 'Buy equipment for deaf'
- 'Travel see deaf friends as too far live'

- 'Pay family help me dentist or other appt'
- 'Pay support help me use phone quickly for doctor or paybills'
- · 'Communication request and problem over speech impairment. Problems in the English written'
- 'For purchase and maintenance costs of equipment etc. to help with my personal needs due to my deafness. Any other associated costs where I need support'
- · 'As local council has cut funding for alerting devices as door bell, flash etc., so need DLA to fund it'
- Need pay broadband services for webcam services while hearing people use their free minutes on their mobile phone so DLA fund for broadband and landline services plus pay laptop and webcam as usually laptop last for few years'
- 'I live in a rural area, no one locally to me is able to use BSL. I need to travel to get attention. Additional costs for instance'
- 'interpreters for doctors/family occasions/shopping/sometimes use translate write English to BSL'
- 'Extra costs of deafness i.e. equipment'
- 'To pay towards the cost of interpreter hire (doctor, bank staff, home visits by tradesmen'

## 6.2 What is your DLA mobility component used for?

- 'I almost keep repeatedly run over due to unable hear vehicles'
- 'Transport to deaf centres / deaf gatherings'
- · 'I probably should have claimed for mobility allowance but too concerned that on reassessment I could lose what I already had with care component'.
- 'To get around and visit the doctors / hospital'
- · 'To pay for taxi as cannot speak where I want to go at bus or train staff. Or something happen underground or wrong bus. Paper with address to taxi driver and take me direct to place safely'
- 'Can not walk more than 5 minutes'
- 'So that I can be driven to in taxis etc as I cannot drive due to my epilepsy'
- 'Also I go over my siblings for help. I use DLA for petrol to see my siblings and asking for help letter or form or problems etc'
- 'For loss of social life due to my deafness affecting my well-being as a result of my employment'
- 'To get around with a guide, travel in the dark etc'
- 'To aid my shopping I cannot carry heavy loads I need car which I have blue badge and also travel to work that I cannot walk far and cannot access buy transport locally'
- 'For taxi's'
- 'As a compensation for lack of access for travelling. Train and tube announcements via tannoy when I cannot hear. No subtitles on English films on planes'
- 'Help with mobility, using car and public transport'

## The British Deaf Association – BDA

#### **Vision**

Our vision is Deaf people fully participating and contributing as equal and valued citizens in 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 everchanging 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.

# Campaigning for Equal Rights for Deaf people!

