

**Deaf Studies Trust  
in conjunction with Sense**

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Deaf Blind Worlds

**Summary Report**

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## **Executive Summary**

Although there have been considerable developments in the field of Deaf Studies and especially in the understanding of Deaf people as a linguistic minority and culture, there has been no corresponding expansion in understanding of people who are Deafblind<sup>1</sup>. This may be because they tend to fall between the different categorisation of Deaf and blind and also because their numbers are small and they tend not to form community groups. They appear to be isolated. This project came about from the realisation that there was something to be learned from studying this group and even though the costs might be high in terms of the data collection, there was value to be obtained for Deafblind people themselves as well as for the Deaf community and the hearing society.

Deafblind Words is a project set up by Deaf Studies Trust and Sense to meet with Deafblind people to talk about their lives and experiences. We also talked to Deaf people and then to groups of Deafblind and groups of Deaf people.

The aims were to

- a) examine the experience of being Deafblind
- b) determine if this was similar to Deaf people's experience
- c) discover if Deaf and Deafblind people can work together and whether the service role might be better supplied by the Deaf community (than the hearing community)

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<sup>1</sup> Throughout, we use the term Deaf (capital D) to refer to sign language users who are members of the Deaf community. Deaf implies a cultural affiliation. Deafblind (capital D) is used to refer to people who communicate primarily in sign language mode (either by BSL, or hands-on signing or by the use of a manual alphabet or by a personal manual system).

## Methodology

Typically, agencies dealing with Deafblind people use hearing-sighted staff to form their policies and use questionnaires as a means of evaluating their services. Other attempts to survey this population, tend to focus on needs but are set within a deficit model. That is, Deaf blind people are seen by definition, as deficient and their needs are described in terms of how the majority society can bring them up to the level of their own *normal* functioning.

Such approaches are damaging. On the one hand, they remove the Deafblind population from any position of power in regard to their own development and on the other, they set the terms of the support in relation to a hearing-sighted normality, which may be entirely inappropriate from the Deaf blind person's perception.

In DeafBlind Worlds, we wished to examine the world from the perspective of the Deafblind person. We did this by engaging with Deafblind people in every aspect of the research. The principal researchers and data collectors were Deafblind. It was their analysis which shaped the questions asked and the methodology used. DeafBlind people took part in the Steering group and were consulted throughout. Deaf blind people were re-visited and offered the chance as a group to interact and to discuss the findings. This latter was unusual – as we attempted to create a direct interaction among groups of Deafblind people – ie without guides or interpreters – something which, needless to say, they had never experienced before.

The nature of the data had then to be constructed within a Deafblind framework. This set major challenges in

- Finding the participants who were Deafblind
- Finding a means to convey to them the purpose of the research and persuading them to take part
- Arranging interviews, guides for the Deafblind person and for the Deafblind researchers

- Managing the transcription of video recorded interviews, when the researchers have sight problems
- Extracting qualitative analysis themes and codes which were grounded in Deafblind experience
- Finding an appropriate means to communicate and discuss internally
- Creating an effective dissemination plan

The project was carried out wholly in British Sign Language (BSL) – all meetings (weekly project meetings, partners' meetings, steering groups) were in BSL – with English translation where necessary.

## **Procedure**

In order to find Deafblind people we advertised extensively and we also travelled to meetings and used personal contacts. However, it was very hard to find Deafblind people. National agencies do not have lists of addresses of appropriate individuals who are easily contactable. It also seems that many Deafblind people are not used to replying directly by themselves. Trying to explain the project through a third party turned out to be arduous and unrewarding.

In the end we had agreement from 21 Deafblind people and 38 Deaf people. They lived in Scotland, England and Wales in different places. They were aged from 21 to 66 years with a range in gender, employment and marital status

Our researchers made visits to each person individually to explain about the project and what was involved in the interview.

All interviews were in BSL and sometimes with hands-on signing.

We asked many different questions. These included questions about:

- Communication choices

- Services received
- Lifestyle and experiences
- Contact with other Deafblind and Deaf people
- Aspirations

Deaf people were asked similar questions.

Following the initial analysis of the interviews, group meetings were set up for Deafblind and for Deaf people. In these meetings, a project update was given, Deafblind people were encouraged to interact and then as a group, to comment on the findings to date. This was very unfamiliar to most participants and we believe we are only part way towards a solution to Deafblind direct interaction. Nevertheless there were important comments and new data was provided.

Group discussions with Deaf people were also of interest but produced quite different insights.

Finally, several group meetings were set up with Deafblind and Deaf people together. These proved to be much less interesting for Deaf people and fewer of them actually attended. Again, direct interaction was major challenge.

### **The analysis**

Although there had been an initial construction of a structured interview, it became obvious when the video recordings of the interviews were examined that what had taken place was an interaction and that in order to adequately understand the richness of the data, a full qualitative analysis was needed. This was done by establishing a set of themes. These themes were somewhat different in the case of Deaf and Deafblind interviewees and are shown in Table 1.

Table 1: codes used to organise the data with definition

Deaf	Deafblind
D1 Access: Access to information or services	DB1 Independence: Might include feelings of independence/ skills used to gain independence/ times when can be independent
D2 Barriers: Deafness itself	DB2 Isolation: might include feelings of isolation/ skills used/ times when isolated
D3 Community: Contact with others	DB3 Hopes/ Plans/ for the future
D4 Dreams: Hopes	DB4 Contact with Deafblind: communication/ feelings towards other Deafblind/ conversations - functional or meaningful/ establishing understanding/ meeting opportunities
D5 Lack of awareness: experiences of others' lack of awareness	DB5 Contact with deaf: communication/ feelings towards deaf/ Deafblind perceptions of how deaf view Deafblind
D6 Isolation: Isolation from people	DB6 Emotions: happy/ Sad - reasons/ influences
D7 Attitude towards Deafblind: Experiences of contact with Deafblind people	DB7 Feelings of confidence, control
D8 Communication: Preferences of communication methods	DB8 Feelings of insecurity, loss of control
D9 Deaf Identity: Expressions of Deaf identity	DB9 Awareness of others: ways which Deafblind are aware of others/ level importance attached to knowing

D10 Happiness: Expressions of happiness and unhappiness	DB10 Awareness of environment: skills used to make sense of environment/ Deafblind picture
D11 Independence: Feelings of/about independence	DB11 Imagination: Thoughts when alone
D12 Reliance on others: Examples of needing support from others	DB12 Use of others: guides/ interpreters – when used/ feelings towards / reliance on others

The transcripts were then marked and submitted to QSR's N6 program for qualitative analysis. The subsequent reforming of the data was then analysed and brought together in sections of the main report.

## **The Results**

The data produced is very rich and is new – representing conversations between Deafblind people. We have examined most of this coded data and the extent of the main report on this is over 200 pages of text. There is still more to do and we will release the whole version as a published report during the summer 2007. The further analysis and the discussion of the implications will continue over the next year. The following are some of the key insights gained.

### **DeafBlind People**

There were seven males and fifteen females. Forty-one percent were aged 21 to 35 years. Around 85% of the group had a hearing loss since before the age of five years. Forty-one percent had acquired a sight problem by the age of ten years. Around 90% could not hear at close quarters; however, over a third were able to see at a distance of a metre in front of them. To that extent, we are not dealing with a group who have no access through sight at all. Most (77%) said they used BSL by preference but rather less

were married or living with a partner (only 27%) compared to what would be considered usual for Deaf people of over 50%. Very few were working, with the largest group (41%) declaring themselves unemployed.

**Independence** – Deafblind people feel independent in different ways from the usual way that carers and service providers think about it. They say for example

- Independence is being able to take care of their own personal needs.
- Independence might mean being *able to choose* when to go out or not to go out (ie it is not the act of going out)

Deafblind people think about these choices in terms of their own challenges, not in comparison to what society thinks of as normal.

**Isolation** - Most people consider that all Deafblind people are isolated and lonely. But some Deafblind people said

- they never felt isolated
- they only feel isolated because they cannot go out when they want
- and significantly, that they could feel isolated even when they are surrounded by other people.

The experience of a Deafblind person in a group is unusual. Deafblind people maybe unaware of who is in the group and what they are doing, except in the broadest terms. We found that Deafblind people attending Deafblind meetings often had no idea how many other Deafblind people were there and were commonly not able to interact with them. We found sometimes Deafblind people communicating through a guide/interpreter to another guide/interpreter to a second Deafblind person ... instead of directly.

It seems again that our ideas of isolation have to be re-considered.

**Future Plans/ Dreams** - If there are no plans, then the danger is that carers will make decisions for the Deafblind person and often



these decisions will limit their possibilities later on. Our results show that

- Deafblind people may find it hard to think about the future. It is easier to think about what is happening now.
- Deafblind people worry about losing their eyesight in the future.

However, these points hide a very significant question in regard to the future – is it the Deafblind person's future or the future of the services? Some Deafblind people became upset when asked about the future – the reason was clear: concern for their personal well-being and the real frustration of not being sure that they can control their own lives. When we look at the results on independence it is clear that we need to begin to find ways to guarantee the future self determination of Deafblind people not simply to make them dependent on services. We need to give a framework where they can look forward and not be stuck in the present.

**Meeting other Deafblind People** - It is usually obvious that people need to meet others with similar interests and experiences. We think about this as most important to a person's identity. It is vital for culture especially in Deaf culture. However,

- Some Deafblind people have *never* met another Deafblind person
- Some Deafblind people *only* have friends who are also Deafblind
- Others believed that people with Usher's and Deafblind people were different.
- Deafblind people do not have experience of communicating in a group.

We think this last point is very important. If people never have a chance to talk to each other and to share experiences – to learn other people's point of view – they have no way to move forward.

It seems apparently inevitable, that there is no “broadcast” mode for Deaf blind conversation. Because of the need to provide hands-on, then Deaf blind people may be only physically able to interact with one person at a time. Solutions on offer tend to be the use of a hearing intermediary – meaning that the first message is translated to English and then back to hands-on BSL. The resulting information loss is significant. The alternative is only available to people with sufficient sight – which is signed message presented in a sufficiently large visual frame – where the viewers can take in the message but cannot easily interact with it.

**Meeting Deaf People** – It was our basic hypothesis that the natural home for Deafblind people might be within the Deaf community. However, when we surveyed Deaf clubs and associations in the early stages of the project, we found virtually no provision for Deafblind people at Deaf clubs. From the interviews, we discovered that

- Many people continued their involvement with the Deaf Community. Using BSL and being able to communicate with people was thought to be positive.
- Other people said they did *not* go to the Deaf club. This was for different reasons:
  - they felt it was boring;
  - Deaf people ignored them;
  - Deaf people did not know how to communicate;

This was a significant finding as it went against our expectations. The Deaf community was not seen as a friendly environment for many people. This was despite the fact, that many people had grown up Deaf and as full members of the community. As a result of the onset of blindness, they were not any longer a part of that community.

**Feelings of Confidence/ Control** - One aspect which was mentioned repeatedly was the personal feeling of confidence.

- Deafblind people feel confident when they can communicate successfully with other people

- Deafblind people find different ways to take control e.g. asking a receptionist to tap them when it is their turn to go to see the doctor.  
Another example was choosing to sit in a certain position on a train so they could feel air when the door opens.

**Feelings of Insecurity/ Loss of Control** - However, Deafblind people can lose confidence and feel insecure as a result of loss of control of the situation. This was very important for the Deafblind people who told us

- they feel apprehensive when arriving in a new environment.
- they are constantly aware of possible dangers e.g. worrying about tripping up
- they are shocked when other people bump into them

These aspects are of great significance not purely in physical sense but in a personal management. If the person is not given the time and opportunity to master the conditions of that environment, they will feel apprehensive about going into that situation.

**Reliance on Others** - Most, but not all Deafblind people, use other people for support with particular tasks. This may be communication, guiding, it may be particular tasks like help in reading a letter, help with their children. Sometimes these people are professionals; at other times they are family/ friends. Deafblind people expressed different views about using other people.

- Using guides is the means for Deafblind people to get out of their home. This means that they feel independent. Other people said they HAD to use a guide and HAD to accept this, but this meant that guides were not seen as a positive part of Deafblind person's life.
- Deafblind people often did not use interpreters AND communicator guides. It was either/or. The interpreter controls the flow of information, leaving the other interactants to take initiative; the communicator guide is meant to be more

proactive in relating to the environmental features, however, is more likely to take control from the Deafblind person.

- Booking of professional services is done through organisations. Deafblind people feel restricted by this as they cannot have a guide when they want. Sometimes the guide they were expecting is changed at the last minute. Sometimes it means they cannot stay out as long as they want.
- Deafblind people also like going out with a guide because they can communicate with the guide; to some extent the guide becomes a friend.

We think there are some very important issues here. First, is the issue of control. Most Deafblind people book guides through organisations. This means organisations have control and Deafblind people have to fit in with when guides are available. Organisations may also take responsibility for an individual's allocated funding. Again the Deafblind person's control is reduced. Schemes such as Direct Payments, which some Deafblind people use, allow the Deafblind person control of own finances, but the lack of freelance guides, still forces the Deafblind person to go through organisations – who limit further self-determination.

There is a clear link between aspects of independence, control and how Deafblind people use other people. The provision of guides may be seen as 'solving a problem' of providing a way Deafblind people can get out of their homes with someone who can facilitate communication – the Deafblind person is therefore seen by service providers as becoming more 'independent'. Yet through this process, Deafblind people remain dependent on organisations and the Deafblind person's control of his/her own life has been reduced.

A second issue is the relationship between Deafblind people and their guides.

Most of the time, Deafblind people go out with their communicator-guide as a pair. It is not usual for the pair to go out with or to meet additional people.

Also communicator-guides are often involved in very personal areas of the Deafblind person's life, i.e. shopping for personal items, being involved in doctor's appointments. All these factors can mean that very intimate relationships are built up between Deafblind people and the guide. Deafblind people may view their guide as their 'friend', particularly if the Deafblind person's wider social circle is limited. This creates a very strange relationship between a guide, who is a paid professional, and the Deafblind person who views the guide as their 'friend.' This complex area of relationships need to be explored further.

### **Deaf people's responses**

In contrast to these revelations about Deafblind experience, we already have a great deal of research on which to build our description of Deaf people. In this report, we can move from a description of the participants to their views about Deafblind, assuming that much is already known about Deaf people's everyday experiences.

A total of 38 Deaf participants were interviewed. Of these, 36 transcripts were used in our analysis.

There were 20 men and 55% were married or living with a partner. Seventy-six percent were white – a low figure which was partly due to trying to find more people in ethnic groups. The average age was 42 years. Almost all (95%) could not hear speech but only 38% had learned BSL before the age of five years. This figure is below the national figures which are usual in this type of study, and may be as a result of choosing Deaf people who had had limited contact with Deafblind people previously.

Over 80% said that they preferred to sign and to be signed to. Only 45% were in work. In the Deafblind group only 18% were working.

### **What Deaf people said**

We asked about "access" as it is a very important issue for the Deaf community. We thought this would produce a list of all the problems of access. However, it also told us about the way Deaf

people think about access – expressed through their confidence in others as if it was a way of building trust in others. If a Deaf person sees access to another person (or to service) to be effective, then it improves their likely faith in that person or service. Access is then happening – it is not just about information flow.

This view has also support in respect of barriers to development – which can be internal or external. In this case it may be the Deaf person's perception as much as the actual barrier which affects participation.

Most of the group claimed to be in contact with other Deaf people and with the Deaf community at least weekly. This would be a major factor in identity and self-assurance where there are perceived peers and equality. However, people also picked up on the negative aspects of small communities – “back-stabbing” for example.

Nearly all the Deaf people (90%) claimed to be happy with life. This seems odd because all of the work we do is based on the idea that Deaf people's lives need to be improved. What they say probably means that they have a balance in daily life where what they want to do is changed to suit what they can achieve. This means there is less stress. It does not necessarily mean that all Deaf people are satisfied with life.

Deaf people often said that hearing people were not Deaf Aware – what they mean usually is that these others do not know how to communicate.

Perhaps the most important point was how **Deaf people relate to Deafblind people**. Usually Deaf people said they did not know how to communicate (the same response that hearing people have in regard to Deaf people). It was as if Deafblind people were “foreigners” – even though they share the same experience in growing up and probably can sign. Deaf people said they did not know how to interact with Deafblind people.

Deaf people valued ease of communication and said the time taken was very significant; Deafblind people pose problems for Deaf interaction – being slower and different.

On the topic of awareness there was a striking and rather negative finding. Some Deaf participants expected the wider hearing community to be aware of Deaf issues/needs/capabilities and to take responsibility for improving the situation. This expectation of the hearing community's awareness of deaf issues/needs/capabilities was perceived to be a *right* and lack of such was perceived to be discrimination. Yet it was a common perception amongst participants that it was the responsibility of Deafblind people or other authorities associated with Deafblind people to ensure that Deaf people had awareness of Deafblind issues/needs/capabilities. In other words, a double standard was in operation. Deaf participants expressed an expectation that they would be provided with the means to increase their awareness so that they might adjust their behaviour or increase their understanding. There was no sense of responsibility or initiative for this to occur on the part of Deaf people themselves.

This was emphasised in the context of responsibility to each other as expressed within a community context. There was an indication from some participants that participation in the Deaf community involves commitment, responsibility and obligation – both to activities and duties and to other known and unknown Deaf people – especially Deaf children. This may indicate that the Deaf participants were willing to accept perceived responsibilities in return for perceived benefits. By contrast, the data indicates that some Deaf participants perceived interaction with Deafblind people as being hard work, requiring patience, time consuming and a responsibility that they were reluctant to accept. There was no assumed obligation and responsibility to others in the same way as towards other Deaf people.

This feeling of difference was very strong. Deaf people were able to view Deaf people with some sight problems as still related to the deaf community, they did make a clear distinction between those

who had Ushers and those who were “Deafblind”. In the former case the degree of adjustment required might be quite small.

Although we believed that Deaf people and Deafblind people were similar in experience, we now think that it will be difficult to bring them together.

## **Group Responses**

We arranged group sessions for Deafblind people and for Deaf people separately.

These were held in Cardiff, Bristol, Birmingham and London. Other attempts to set up groups in Glasgow and Peterborough met with failure either because the participants were not responding or because people withdrew at the last minute.

The Deaf groups had a dual function to allow discussion of the results so far and particularly Deaf-blind relations and also to work through a brief Deafblind awareness training programme. The latter was moderately successful and well received although given the nature of the responses from Deaf people in personal interviews, it assumed less importance; since it became clear that a much more thorough and extensive community programme would be necessary.

Although some of the Deaf participants had experience with Deafblind people and were helpers or informal guides, the majority confirmed the responses reported above. Deaf people consider Deafblind people to be very different and not a responsibility of the Deaf community.

## **What Deaf people said**

In the group sessions with some of the results explained, Deaf participants tended to repeat the same points. They agreed that Deafblind might feel left out in the Deaf club.

*...we are outside in the hearing world; then in deaf club we are relaxing in BSL saying whatever we want. Sometimes I go to them and say ‘how are you’ but mostly I want to see*



*my friends. Time is short in the Deaf club. I say 'see you later'. When I am with my friends enjoying signing; then I forget about them. When I go back to them I feel like 'why do I feel selfish?' In real life it is a hearing world.*

They also suggested that the Deafblind might set up their own clubs inside the Deaf club. However, at the heart of it was an agreed view of not really knowing what to say to Deafblind people – ie they were like foreigners.

### **What Deafblind People did**

In actual fact, the content of the discussion was less significant than the conduct of the meeting and the way in which Deafblind people participated. Most of the comments reiterated the findings of the individual interviews rather than taking the discussions further. However, observations on the way the meetings unfolded were very instructive.

For Deafblind people, the meeting structure was a little different. We adopted a system of 'speed dating'. This exercise involved participants forming pairs and communicating directly with each other, having agreed communication choices between themselves. The pairs were given 5 minutes and then everyone rotated until such a time that everyone had directly communicated with all other participants. Participants were instructed to introduce themselves and share a little about their everyday lives. In the later meetings, participants were instructed to find out something interesting about their conversation partner. After the exercise was finished outcomes and experiences were related back to the whole group. This again served to remind participants of who else was present in the room

One of the significant issue which arises is how the group is to be managed by a Deafblind researcher. Just as it is problematic for Deafblind to take part, it is also an issue for the Deafblind leader of the group. It became obvious that a new means of structuring the meetings would be needed in future. Whenever there were Deaf or hearing guides present, there was temptation for them to intervene to clarify or to make sure some of the group kept up.

This could undermine the Deafblind leader. In order to overcome this we consider it important to have trained Deafblind facilitators. However, despite the challenges and the apprehension of some participants in talking directly to a stranger using hands-on (something they had never done before) there were noticeable changes in confidence as they became more familiar with the procedure.

There were also other interesting aspects which occurred. In this case the differences in sightedness led to problems:

*In one example when a hands-on signer was communicating with visual frame signer, both were following/ partaking in conversation; however the visual frame signer was interrupted by someone else and turned to look away. The hands-on signer was unaware this had happened and carried on signing to himself.*

The intention to create group settings for Deafblind people was only partly realised but enough was learned to make it a real possibility for development in the next project.

### **Final Groups for Dissemination of Findings**

It was intended to organise meetings with both Deaf and Deafblind participants but at the late stage in the project when enough of the data had been processed, it became difficult to convince both Deaf and Deafblind participants to return for further sessions. In the end, we were able set up sessions in London, Birmingham and Cardiff. One issue which emerged was that it was hard to arrange joint meetings – Deaf people were usually at work or otherwise engaged during the day – while Deafblind people rarely go out at night because of the light.

Deafblind participants were allowed time to discuss a number of issues and again interesting points arose. There was immediate agreement that it was important for Deafblind people to meet and initially the reasons for this focused on aspects of shared experience such as experiences of night blindness, communication problems. However, upon further discussion, participants began to

think about the issue of which ‘shared’ element was the most important. Is it the common language i.e. BSL (and therefore excluding Deafblind people who use other communication systems), or is it the ‘shared’ element of the experience of being deafblind irrespective of communication choice. The discussion was not conclusive but clearly indicated the need for further study in this area.

Most of the other reported findings were examined and there was broad agreement on their accuracy. One area which was probed more deeply was the role of guides for Deaf blind people. This can be encapsulated in the example below and the question it raised:

If a guide was with a Deafblind person at the pub, should the guide be part of the conversation? Should the guide remain separate? Some participants felt it was acceptable for the guide to take part in the conversation, while others felt the guide should not be involved. One person gave an example of where a guide had been in the same room as the Deafblind person but difficulties developed because the guide had left the Deafblind person to go and have a conversation with another person. The participant felt that the guide should have remained with the Deafblind person throughout.

This opens up the whole question of professionalism versus companionship and the need for independence of the Deafblind person through the control over their own interactions. This remains a hugely complex issue which will benefit from much more detailed study

## **Conclusions**

Although the results indicate much in common in the Deaf and Deafblind experience, we have discovered a huge gap in the perception of the two groups with respect to each other. The simple proposal at the outset that Deaf people would form a better group to support Deafblind people than hearing people is not yet supportable. Deaf people at present just see Deafblind people as foreign and time consuming.

At the same time, Deafblind people use the same descriptors for the Deaf community as Deaf people used in the past for the hearing community.

Perhaps the most important finding has been the now rather obvious one that Deafblind people do not form groups. While somewhat simplistic, it is however, intensely significant. Many of the Deafblind people we met, had never been able to discuss their experiences with another Deafblind person. Even those who attended meetings where there were other Deafblind people were seldom able to carry out direct conversations with other Deafblind people. They found it quite difficult to be introduced to a new Deafblind person and then to try to have a conversation.

The limitations which are inadvertently created by the provision of guides or the marginalisation produced when the guide is a friend or a relative (and cast in the role of a carer), ensures that Deafblind people have hitherto been unable to form social groups or even consensus groups. There are significant obstacles to conducting Deafblind-only meetings such as how to overcome the limitation of pairwise interaction but given time and some opportunity, it seems likely that human need to share with other people who are the same will find an effective solution.

### **Next steps**

There is more analysis to conduct on this data set and this will be carried out over the next year. On the one hand we will produce an extended report on the detailed qualitative analysis of the interviews in several formats – DVD in BSL, Braille and also in text. There will also be an accessible website with the same information.

However we expect to move on to more data collection and more work on group interaction among Deafblind people. It is important that service providers and friends and relatives are more aware of the view of the world from the Deafblind person's perspective.