The role of a guide dog in the process of adjustment to visual impairment

Thesis

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Louise Banham

The Role of a Guide Dog in the Process of Adjustment to Visual Impairment

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Appendix 7

Do you wish to make any comments?

There are no further questions. Once you have completed this, please return the tape in the stamped addressed envelope provided as soon as possible.

Thank you once again for your help.

This is the end of the tape".
RESEARCH DIARY

14th January 1999
We have been advised to have our research proposal completed by the end of May this year in order to prevent delays later on. I thought I might begin to keep a diary of this entire research process as this would help me to structure my thinking, and it would be an essential tool should I decide to do a qualitative study. I have spent quite a lot of time thinking of ideas but the one that keeps coming back to me is concerning the psychological effects of companion animals. I am very interested in how animals are being introduced into clinical settings, particularly with children suffering from acute and chronic illnesses. I know that this is being done with children at Guys Hospital and it may be possible to develop a project around this.

7th February 1999
Having spoken to some past trainees and psychologists regarding my research idea, I am beginning to move away from doing any research with children because of the potential difficulties with ethics and recruitment. I have also spoken to a psychologist at Guy’s Hospital regarding the use of animals on paediatric wards and it seems that there would be problems in studying this, as the animals only visit for two hours a weeks, and also visit different children each time. However, I still want to pursue my interest in the relationship between humans and animals. I shall have to think some more about this.

25th February 1999
When talking with a friend about my dissertation I came upon the idea of studying the impact of a guide dog among people with a visual impairment. As my mother has a significant visual impairment (although no guide dog), this is something we have discussed on several occasions. I am assuming that a guide dog would lead to improvements in mobility and perhaps greater independence as a result, but I wonder whether it makes it generally easier to manage following the onset of a visual impairment? I imagine people might get the benefits of pet ownership, but I have no idea what role the guide dog assumes in relation to the owner, so this might not be relevant.

28th February 1999
I did a literature search on the computer and have not been able to find any previous work in this area, other than a study examining the end of guide dog partnerships. I rang the Guide Dogs for the Blind Association who also were unaware of any literature on the impact of having a guide dog. I spoke to Bruce Johnson, the psychologist at the GDBA, who is responsible for training puppy walkers about the human-dog relationship. He is a guide dog owner himself and thought this would be a very interesting research project. He said that his guide dogs have been invaluable to him, and feels sure that they improve owners’ confidence and wellbeing.
10th March 1999
I went to see a member of staff about exploring the relationship between guide dog and owner and came out feeling quite despondent because they were concerned about the lack of clinical relevance it presented. However, I imagine that even if a guide dog only aids mobility, that this could improve people’s quality of life and therefore adjustment to visual impairment? It made me realise just how ‘invisible’ this population are within clinical psychology services, even in older adult services where the prevalence of visual impairments is supposedly higher. Why is this when there are whole services specifically designed for people with other physical disabilities such as hearing impairments, head injuries and strokes? Surely the onset of a visual impairment, like other impairments, has the potential to cause significant disturbances in functioning and mood? It strikes me that any rehabilitation aid, albeit a long cane, Braille lessons or a guide dog could have a mediating effect on the impact that visual impairment has on people. Consequently, professionals working in the mental health field need to know about this, just as they would want to know about the impact of a social skills programme or behavioural training on a group of people with a visual or other type of impairment. It seems that just because a guide dog is not a ‘psychological intervention’, this is not a valid area of study, but clearly it could have implications for the psychological wellbeing of visually impaired people.

30th March 1999
I spent a day at the RNIB library in central London and found loads of articles about the psychological consequences of visual impairment. The literature suggests that adjustment to visual impairment is sometimes very difficult and via restriction of mobility, and reduced social support, depression can be a real problem. I also spoke on the telephone to a friend of one of my colleagues, who is visually impaired and has a guide dog. She has had a guide dog for eighteen months and described how it had improved her quality of life. It seems feasible therefore, that having a guide dog could reduce the difficulties that adjustment to visual impairment presents (e.g. through improving mobility and independence, reducing social isolation).

14th April 1999
Tony Lavender has agreed to be my research supervisor, which is good as he was helped me in the past with my small-scale research projects and is very thorough. I would also have liked to have a supervisor who works in the field of visual impairment but there appears to be nobody in the region that knows much about this area. Again, further evidence that this population does not appear to feature in service provision. Tony suggested a quantitative study, comparing 50 people with a guide dog and 50 people matched without a dog on a range of measures. This would enable me to determine the impact of the guide dog on adjustment as I could assess factors such as self-esteem, mood and quality of life. I found a study that reported how many people suffer grief reactions following the retirement or loss of their guide dog, so I think I will focus only on first-time guide dog owners, to avoid the possibility that this could bias the findings.

16th April 1999
Spoke to the Regional Controller at the Wokingham centre of the Guide Dogs for the Blind Association (GDBA). He said there is little chance of finding fifty people who are training
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with their first dog within the time scale available, as although a couple of hundred train in the South east every year, the majority have had a guide dog before. Alternatively I could study a wider group of owners who had had a dog in the past but this would mean matching with a group of visually impaired people without a dog. I think it would be very difficult to match and adequate control for any confounding effects. I'm also not sure whether the use of quantitative measures is really going to give me the depth of response I'm looking for. Somehow it doesn't feel appropriate to be imposing such standardised instruments when exploring such an unknown area of study. I'm beginning to think that a qualitative method might be preferable, as it would give me greater depth and insight into the experience of guide dog ownership. Talking with Tony I would need to aim for about 20 in-depth interviews with new guide dog owners in order to gain enough data for a reasonable analysis. As there is very little research in this area it seems that Grounded Theory would be a good way forward as this allows the researcher to develop new theory from the data. It would enable me to gain participants' own views about how the guide dog has affected their life. However, it seems incredibly daunting to think about the amount of work that this would involve, transcribing and analysing the interviews.

23rd April 1999
Met with Ray Smith, the Regional Controller at the GDBA who showed me around the Wokingham training centre. It was such an interesting visit. I didn’t realise just how intensive the training was. New owners stay there for three weeks and have to attend training classes every day whilst they are there. Ray emphasised that they would like to increase the number of people having guide dogs as it is only about 4,000 out of an estimated 1 million people with visual impairments. I talked with Ray about the possibility of finding new guide dog owners to interview, to explore what impact the guide dog had on a number of areas of a person’s life. He was very keen to help me find participants and believed that it should be possible to recruit this number from the Wokingham centre and one in Maidstone. I am feeling really positive about this research now and feel like I’ve already climbed one massive hurdle in being able to secure the help I need to recruit participants.

25th May 1999
I spoke to Peter Smith, the Training Manager at the Maidstone centre of the GDBA who has also agreed to help me find participants, although he admits that there are only four people as possibilities. This centre is smaller than the Wokingham one and has fewer people training there, and consequently, even fewer first-time guide dog owners. I have now managed to write a research proposal outlining exactly what I hope to achieve and have sent it to both Ray and Peter to see what they think. This has meant developing information and consent forms for participants, which raised the issue of how I present the material to them in a format they can access. I spoke with the RNIB who recommended I use font size of 16pt, as this would be easier for people with a visual impairment to read. I was aware that not everyone would be able to read print of this size and it felt very arrogant to be asking people for their help in a study if they weren’t even able to access information about it. So I have decided to also record the information onto an audiocassette tape and send this to each person to give them a choice of medium.

In writing the information sheet other issues have arisen. First, whether it's preferable to declare that my mother has a visual impairment or not. The literature appears to suggest that
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this could deepen understanding between the participant and researcher. Participants also
might feel reassured that I have some understanding of the impact of visual impairment and
this might feel less threatening. Oliver (1993) talks about the problem of non-disabled
researchers misrepresenting disabled people’s experiences. I want to try and avoid this as
much as possible which is why I am going to opt for grounded theory, as this puts the
language of participants centre stage. I also feel that participants might see me as more of an
ally if I disclose my mother’s visual impairment on the information sheet and therefore be
more open with me. This feels like the right thing to do although it really conflicts with how
I work as a clinician, when I never disclose any personal details to clients. I discussed it with
Tony and some friends who thought it certainly couldn’t do any harm to disclose this,
although I had to think about how much I would be prepared to elaborate on this should
participants wish to discuss it further with me.

15th July 1999
Everything is on track. I submitted my proposal to the external examiners whose feedback
was that it was a very interesting idea worth investigating. Both Ray and Peter were happy
with the proposal I sent them and agreed to help as soon as I was ready. I also managed to
get my research proposal into the Ethics Panel at the Salomons and am awaiting the verdict. I
am feeling pleased with myself as it means I have got the participant information sheet,
consent form etc all done, so I’m well on the way to having written my method section.

28th September 1999
Got through ethics first time and only had to provide information to the committee about how
I planned to dispose of the typed transcripts. I’m really pleased, another hurdle over! I have
also piloted the proposed interview schedule on my colleague’s friend with the guide dog,
which presented some interesting issues. When speaking to -------- in the pilot I was very
aware of feeling that talking about adjustment seemed so presumptive, as if it was an issue,
when perhaps it isn’t. She had been visually impaired since birth and it felt inappropriate to
be discussing adjustment to visual impairment, as she had never known any different. I do
not want to impose a viewpoint by suggesting that people will necessarily have problems
adjusting to visual impairment. I guess what I’m thinking is that there will be aspects of
visual impairment that are difficult to manage or which do impose barriers for people, which
are implicated in their decision to get a guide dog. Can I then say this constitutes a difficulty
in adjusting? I think I need to steer clear of this word adjustment and see what emerges from
the data before making any conclusions about this. I feel I am losing touch with what my
research questions are. Perhaps this is a good sign. I have obviously been influenced by the
data gained from the pilot and as this is about developing theory in this new area, I should not
be guided by my assumptions, but by the data itself. It would seem to be more about
understanding the meanings for individuals to have a guide dog in different areas, e.g. social
life, perception of themselves and themselves with a disability, changes in mood,
independence and mobility.

30th September 2000
I went to see Ray today who has identified 16 suitable people for me to target (Peter has
identified 4 people who could be potential participants). So altogether I have a total of 20
people to target that have qualified this year with their first guide dog. This doesn’t seem like
many, particularly as there is a high chance that many people could choose not to volunteer. Anyway I will worry about that later, I just have to wait now.

8th October 2000
I have spent all of this week at the Salomons having teaching about research and it made me feel that my project was just a sham. I also began to worry about my rationale and research questions. Is there enough evidence to suggest that VI people experience psychological problems following onset of visual impairment, or even if they were congenitally blind? Is it appropriate to be saying that a dog facilitates adjustment? I guess the pilot interview with ---- threw me. But on reflection she actually represented a different group from those I would like to interview for this project. She had been blind since birth and had had her dog for eighteen months, so adjustment might not have been an issue (which could explain why I felt unable to broach this with her), and memories of her experience before her dog were less accessible.

I think I need to include questions that elicit why some people may not feel able to request a guide dog, as this would indicate whether people were having difficulty adjusting to visual impairment or whether some other reason motivated it. For example, what motivated them to get a dog, how did they go about this, did they seek advice and if so from whom? Generally, I would like to get a comparative feel about the interview, i.e. mood before and after dog, social support before and after, quality of life before and after, independence and mobility before and after etc.

11th October 1999
I am panicking now because eight people have responded already to my mailing last Thursday and all eight of them have agreed to take part. At this rate, I might have to interview all 20, which I do not want to do as they all live so far away, and realistically I only need to interview about twelve people for the purposes of this dissertation. I really did not expect to be in this position, where I'm hoping some people won't consent, but it does demonstrate that people want to talk about their experiences, and that it is a valid area of research.

20th October 1999
I now have 13 people who have responded to my request and all have consented so far. I did my first interview today with a man who lost his sight only last year. It produced a lot of good information it seems, certainly a lot of stuff to back up my ideas, for example, the dog being a social facilitator, improving mood, increasing mobility. It seemed that adjustment to visual impairment was very much of an issue for him given that he had lost his sight so recently. He described how it had dramatically changed his life, he became unemployed, lost his flat and found himself immobile. It appeared that a cane was not able to provide him with any independence, but the dog had given him the mobility he needed to be able to get out and about and meet new people. This suggested that the dog was better at helping people to manage difficulties associated with visual impairment.
**5th November 2000**

Following the research seminar the idea of incorporating a question to assess the participant’s contact with different services emerged. It does not really fit into the theme of the impact of having a guide dog so I am not entirely sure about its applicability. However, it would provide some interesting information and could always be omitted later I guess. Certainly with regard to my Mum’s situation, the issue of service input is an important one. She was offered some help upon being registered partially sighted but since then has not received further offers. As her sight has worsened she has begun to lose confidence and as a result, finds it very difficult to assert herself and ask for what she needs. I wonder if other visually impaired people also feel like this?

It feels like a difficult issue, particularly in light of the reading I have begun to do regarding the social issues concerning disability. Mike Oliver proposes the social model of disability which argues that people are disabled not because of a physical impairment but because the social and physical world does not permit equal access to the other activities able bodied people take for granted. He argues that the move towards community agencies providing services for people with physical disabilities implies that they need a service and effectively maintains their dependency on others. From this position you could argue that the failure of social or voluntary agencies to contact visually impaired people after initial visits is positive in that they are not assuming people will have ongoing difficulties and are allowing people the right to live independently. However, there is plenty of evidence in the literature, that losing your sight in adulthood ca be very debilitating for some people depending on the meaning of that impairment for the individual. From this viewpoint it could be argued that people in this position might find it more difficult to access services when they require them, either from social services of mental health services perhaps. In which case, it might be important for these individuals to be offered an on-going service or follow-up in order to get their needs met.

There is also the issue that for many people after they have been registered their eyesight deteriorates further, which may mean that they unexpectedly find it difficult to continue their usual activities. At this point people are having to adapt and may require some additional help, for example a long cane, a guide dog or equipment in the home. If they are unable to adapt they may be prone to experiencing symptoms of depression or anxiety despite having coped relatively well beforehand. It seems as though it would be easy for people to slip into this position fairly quickly. At this point would they a) even know where to contact services? and b) would they feel able to motivate themselves to ask for them?

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**24th November 1999**

Conducted three more interviews today and it was exhausting! They were all very interesting, particularly the last two as I seemed to develop a good rapport with these people. It possibly reflected a gender difference as I have noticed that the other two participants who were male certainly volunteered less information, I found myself working harder to get them to discuss their experiences. They do appear to be supporting my initial ideas, although it seems that some unexpected findings are emerging regarding the problems associated with the public being too interested in the dog that they distract it when its working. I also did not expect people to be having as many difficulties with accessing buildings as is emerging. It shocked and angered me to think that these people were being refused entry to places because of their impairment.
Despite the interesting data that emerged today, I have begun again to worry about the validity of my whole project. I feel like I am just having a conversation with people about their dogs! I have also been concerned that I am not asking the right questions or accessing the 'right' information to answer my research questions. The literature on qualitative processes seems equally vague on this issue. Some say your questions should be clear, others say that they evolve. When I'm doing the interviews I often find myself providing information about what others have found to open up new areas of discussion with people, but I'm afraid this is biasing the results. However, according to Strauss and Corbin (1998) this is appropriate in grounded theory in order to develop the data that emerges.

I think my present anxieties are around because my research all seems to be going so smoothly. It's making me think that I am not doing it properly or thoroughly enough. The fact that my group is not a clinical one is also concerning me. It's being made worse by my reading on disability issues, which is making it more difficult for me to think about the concept of adjustment at all in relation to visual impairment. I feel like a pious fraud elicitng information about visual impairment to answer my research questions. What right have I got to be even attempting this? What right have I got to be assuming that a guide dog improves adjustment to visual impairment? Who am I to assume that adjustment is even an issue for these people? It feels like I am going to have to introduce a clinical perspective, i.e. talk about mental health difficulties following onset of an impairment or about the struggle to be impaired in a non-impaired context, just to fulfil the criteria set by the examiners when really I feel it should be talking about the wider issue of being disabled in our society and what that means. I feel that by doing this research I am contributing to the disempowerment and 'dependency culture' surrounding physically 'disabled' people. I am not sure how I am going to resolve this at present.

19th January 2000

Did an interview today with a man of 58 who lost his sight three years ago. It left me feeling quite depressed and frustrated. He has not been able to find a job since losing his sight and felt that the rehabilitation worker he saw was putting pressure on him to accept this situation, rather than helping him develop his existing skills. He seemed really depressed and hopeless and spent his day doing very little. It was also markedly affecting his wife as her role had changed and she felt that her husband's low mood was affecting her. I felt really outraged that these people are not getting the help or support they need to be leading more fulfilling lives.

I thought about people who'd had strokes or head injuries, and those with chronic illnesses who do receive psychological input almost as a matter of course. How do they get access to psychologists? I guess they typically come into acute medical services from which they are referred, whereas people with a visual impairment are usually only seen as outpatients by ophthalmologists who then discharge them, only to do follow-ups every six months. There do not appear to be established links between ophthalmologists and mental health services. Perhaps at another level rehab workers who visit people with visual impairments are not trained to know whether somebody is psychologically distressed and not coping, so therefore it does not get addressed? Or perhaps there is simply no identified means of referring people on? It is certainly an argument for joint working, that if social services or rehab workers employed by them detect a person to be requiring psychological help, that they can make
direct referrals to psychology services. Or perhaps psychologists could get involved in training rehab workers to detect when people may be demonstrating signs of depression.

8th February 2000
I interviewed a man of 31 today who lost his sight as a result of a hereditary disease. I felt emotionally exhausted at the end of it and quite upset. He was forced to give up work but had decided to become a consultant and advise companies on how to deal with visually impaired clients. His enthusiasm for this was inspiring. Yet there was another side to it: not feeling safe enough to go out at night, finding his leisure activities had been restricted, feeling socially isolated. The more people I talk to, the more I realise that the onset of visual impairment (and to a lesser extent, the progression of visual impairment) has dramatic consequences with the potential for serious psychological distress. There are so many barriers in their way because the world is just not geared up for people with this impairment. What’s more services seem to be reinforcing this view in their focus on the person’s deficiencies, rather than working with them towards the development of new and rewarding lifestyles.

Although I set out originally to simply address the impact of a guide dog, the prominence of people’s negative reactions to visual impairment are so prominent I feel that this cannot be ignored. It has struck me that even people who have been visually impaired for a long time are still disabled by the stigmatising reactions of others or the physical barriers that make it difficult to access public transport for instance. As I go on with this study the more angry I feel about the concept of exploring individual psychopathology as a factor in ‘poor adjustment’ to physical disability, to the neglect of the social and wider contextual factors which are implicated in this.

15th February 2000
I’m so glad I learned to touch type years ago! I have been able to transcribe the interviews relatively quickly, which is a real bonus. I’ve now started doing initial line-by-line coding on the first few interviews. It’s so time-consuming and I keep worrying whether I am coming up with adequate or valid codes for the data. It feels like such an arbitrary, subjective process doing the analysis in this way even though I can see its benefits. I suppose I’m worried that I’m not going to be able to capture the meaning and importance of the interviews with the people I’ve met, that in some way I won’t be able to do their experiences justice. I cannot help but feel that they have been so disempowered by services in the past there is a danger that I will reinforce this if I do not accurately reflect their experiences through the analysis. At the moment this feels like an extremely tall order, given the sheer amount of data.

10th March 2000
I had my last research interview today. I felt really pleased that I could now tick this off as another step forward towards producing the final thesis. I also felt pleased that I had obtained 13 interviews, which I felt had produced some very rich data, although I am feeling totally overwhelmed by the sheer amount of it. I want to try and keep the coding as close to the data as possible by doing line-by-line coding, but it is so time-consuming, I really don’t think it will be possible to do them all like this. I have been weighing up the pros and cons of using the NUDIST package to help me with the analysis. After having coded three interviews by
hand I thought it might be quicker to use the computer system. However, trying to understand the bloody manual is like trying to read Japanese! I am also attempting to write a draft of my introduction and getting really anxious about it. I am worried about being able to construct it in a logical way so that the rationale is clear, whilst being careful not to present the difficulties associated with visual impairment as stemming from individual psychopathology.

27th March 2000
I am feeling totally exhausted and becoming increasingly worried about getting this done in time. The data analysis seems endless, although seems quicker now that I have decided to use NUD.IST. I have stopped doing line by line now and have moved onto larger pieces of text where appropriate. It seems totally unclear how I am going to develop a structure out of all this data, and more fundamentally whether or not it has produced anything of real value. I can't help but think at the moment that I have just got pieces of text about a dog, just common sense. I discussed my thoughts about this with Tony who was able to reframe it all much more positively. He pointed out how issues of attachment to the dog were emerging, as were issues of identity being changed as a result of this attachment. When he said this these themes seemed so clear, but I am finding it difficult to see the data objectively as I am so immersed in it all the time.

20th April 2000
I have now completed all the initial coding and am now moving towards the creation of categories and subcategories. There are obvious patterns emerging from the data that appear to suggest four broad categories. The first relates to the consequences of the impairment, the second to how people decided to get a dog, third to their experiences of training, and fourth to the actual effects the guide dog had on their life. It seems quite hard to trust myself to label the categories in case they are not representative enough of the codes that subsume it. I keep re-checking them and then changing their titles. However, it seems that this is just a natural process of analysis according to Strauss and Corbin. They report how new ideas continually emerge as the analytic process goes on, and that it is necessary to re-code as the properties and dimensions are developed.

5th May 2000
I am feeling quite calm about all this at the moment, but perhaps this is a danger sign. I have managed to do nearly all the coding now, although I realise that actually the process could be endless. The more I look at the data, the more ways in which it could be interpreted it seems. This has led me to worry that perhaps my interpretation of the data is flawed, but fortunately Tony and the other people I have shown the emerging analysis to seem to be in agreement with most of my categories. I presented the analysis at a psychology meeting this week and felt that my coding had been validated according to the responses I received from people. I am now attempting to write the results section, but am struggling to think about the best way to present it in a way that makes sense to the reader, but which also does justice to the material that has emerged. There is so much of it I am probably going to have to be quite strict about what I can include in this section. It is so frustrating that we only have 20,000 words in which to present this dissertation as I could easily take up at least 15,000 of those with my results.
13th May 2000
It seems that an overall model is beginning to emerge from the mass of codes that I have amassed, which represents the four categories that emerged earlier on. The data is detailing participants experiences prior to and after having the guide dog and although my focus was originally on just exploring how the dog has impacted, I cannot help but feel the consequences of visual impairment are a fundamental stage in the model, and should not be separated out. Therefore, it appears that a sequential model is emerging.

15th May 2000
Having had supervision yesterday I have decided to go ahead and use a sequential model to present the data. This will ensure that those experiences participants' described in response to losing their sight will not be lost amongst the impact of the guide dog. I am pleased about this, partly because much of the data on the consequences of visual impairment does support existing theory about the effects of visual loss. But also the data appears to be suggesting quite strongly that it is the physical and social barriers that this group face that make it so hard for them to adjust. This needs to be communicated as it counters the argument that is so dominant in the medical arena that difficulties in adjustment are associated with individual psychopathology. This study will be able to provide some further support that consequently, people who lose their sight are vulnerable to experiencing psychological distress and do have difficulty adjusting, particularly when they receive such inadequate support from professional agencies.

1st June 2000
I've been thinking about whether to have a higher-order category specifically on the remaining difficulties people have despite owning a guide dog. There are however, disadvantages associated with several of the categories and to separate these out on there own might make the results seem disjointed. I will just have to find some way of attending to these when describing the advantages of the guide dog, without distorting the balance of the findings as they stand. Thinking about this more I have to admit to being surprised at just how many problems seem to be associated with the public's perception of the guide dog, and how difficult it is for people to manage these. I wonder if they receive training on how to deal with the public? It doesn't seem like it!

17th June 2000
I've just finished a draft of my results section! Whilst I am pleased with the model that I have presented I am unhappy that I have not got the word length to include more of the participant's quotes that exemplify the emerging analysis. I am concerned that it will all appear very distanced from the interview material and my original aim of giving participants a 'voice' will be lost in the process of fulfilling the criteria for this doctorate. It's so frustrating!

20th June 2000
I am trying to sit down and write the discussion section to tie all the pieces together. I am finding this extremely difficult, as it requires adjusting from looking at small pieces of data to inspecting the data as a whole and trying to construct an overall perspective. I feel like I have
lost the overall flavour, as I have been working on the analysis and results for so many weeks, becoming accustomed to seeing it in pieces. Perhaps another reason why I am finding it so hard to begin writing this is because I have become so involved in the data through working so closely with it. It’s as if I cannot step aside from the participants’ perspective. I so desperately want to present the findings in a way that does not lead to further disempowerment or misrepresentation, but the pressure to do this is making me freeze.

29th June 2000
It is now clear why I was having so much difficulty trying to write the discussion. Having presented a draft of my results to Tony, it seems that I have not quite captured the underlying storyline within the data. This is the aim of selective coding, the final stage of grounded analysis. Strauss & Corbin (1998) note that trainees often become so caught up in the finer details of their data that they are unable to obtain the distance necessary to commit to a central theme to explain it. Talking with Tony this morning has helped me to gain some distance and see a pattern emerging from within it. My initial assumptions were that the guide dog aided adjustment to visual impairment and served more functions than simply a mobility aid. Indeed, the data does appear to support my early ideas, which has led me to worry that I have let this influence my analysis. However, Tony and other people who have read my drafted results also seem to agree that the overall story is about the role of a guide dog in the process of adjustment to visual impairment.

I began to feel cautious again about the use of the word adjustment because in terms of the social model of disability it can be seen as a pejorative term that leads to assumptions that the response to an impairment is always a negative one. Clearly this is not the case for everyone. I guess my struggle with the word adjustment refers to the fact that a proportion of my participants had not recently lost their sight, many of them had been visually impaired for years. In this event adjustment did not seem an appropriate word. However, when I looked through the literature, researchers emphasise the importance of considering the stage and degree of visual impairment, highlighting how it is not typically a static condition, but one which may progress over time or fluctuate. These people did apply for a guide dog after deterioration of their eyesight that caused them to have difficulties in mobility, independence and all the consequences associated with that. Arguably they had to re-adjust to changed circumstances. My anxiety about the term adjustment also stemmed from its use within health settings where failure to ‘adjust’ is seen as a pathological failure of the individual. However, the findings from this study have highlighted just how important physical and social barriers are in the process of adjustment to a visual impairment and the fundamental role of the social model in understanding their experiences.

16th July 2000
I have finished it! I somehow managed to get all the points I wanted to cover in my discussion and seem to be just within the word limit. Overall I am pleased with how the study went and particularly with the data that emerged, which I feel has important implications for both low vision and mental health services. I am absolutely exhausted and looking forward to some time off!
The processes involved in creating the second stage in the model, ‘decision processes in acquiring a guide dog’, from initial codes obtained through line-by-line coding through to the final categories, are outlined below. This took place through a number of steps.

Following initial coding of all the interviews a number of codes stood out as representing ‘decision processes in acquiring a guide dog’, as this seemed an important category in itself (step 1). These initial codes are listed below on the left. The number after each code details the number of participants’ whose response was given this code. These codes appeared to represent three higher-order categories, namely ‘influence of others’, ‘factors against getting a guide dog’ and ‘reasons for wanting a guide dog’. Each code was placed into the category it suggested (step 2 in the middle below). Following step 2 the higher-order categories were broken down into further categories according to their constituent properties (step 3 on the right below).

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<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
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<tr>
<td>Friend suggested getting a guide dog (1)</td>
<td>Influence of others</td>
<td>Suggested source</td>
</tr>
<tr>
<td>Guide dog owner recommended getting dog (2)</td>
<td>Influence of others</td>
<td>Suggested source</td>
</tr>
<tr>
<td>Ophthalmologist suggested guide dog (1)</td>
<td>Influence of others</td>
<td>Suggested source</td>
</tr>
<tr>
<td>Rehabilitation Officer suggested the guide dog (3)</td>
<td>Influence of others</td>
<td>Suggested source</td>
</tr>
<tr>
<td>Social worker suggested guide dog (2)</td>
<td>Influence of others</td>
<td>Suggested source</td>
</tr>
<tr>
<td>Talking with other owners (4)</td>
<td>Influence of others</td>
<td>Suggested source</td>
</tr>
<tr>
<td>GDBA very truthful about the dog (2)</td>
<td>Influence of others</td>
<td>Using help of experts</td>
</tr>
<tr>
<td>GDBA interview was helpful (1)</td>
<td>Influence of others</td>
<td>Using help of experts</td>
</tr>
<tr>
<td>Talked to staff at the GDBA (2)</td>
<td>Influence of others</td>
<td>Using help of experts</td>
</tr>
<tr>
<td>Feeling persuaded by other owners (2)</td>
<td>Influence of others</td>
<td>Using help of experts</td>
</tr>
<tr>
<td>Wanting to avoid obstacles (4)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
<tr>
<td>Fed up having accidents (3)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
<tr>
<td>Struggling to walk around (2)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
<tr>
<td>Feeling confined to the house (1)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
</tbody>
</table>
Following step 3, it was decided that the categories within ‘factors against getting a guide dog’ could not be analysed or reduced further (see table 7, appendix 13). However, it was thought that the categories corresponding to ‘influence of others’ and ‘reasons for wanting a guide dog’, could be further analysed (see Tables 6 and 8, appendix 13). Consequently, categories derived from step 3 were analysed further in terms of their subcategories (step 4 below).

**Influence of others**

<table>
<thead>
<tr>
<th>Suggested source</th>
<th>Step 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family or friend</td>
<td>Other guide dog owner</td>
</tr>
<tr>
<td>Professional person</td>
<td>Professional person</td>
</tr>
<tr>
<td>Professional person</td>
<td>Professional person</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Suggested source</th>
<th>Step 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDBA honest account</td>
<td>Seeking info from GDBA</td>
</tr>
<tr>
<td>Seeking info from GDBA</td>
<td>Discussing with owners</td>
</tr>
</tbody>
</table>

**Reasons for wanting**

<table>
<thead>
<tr>
<th>Reducing isolation</th>
<th>Increasing independence</th>
<th>Reducing isolation</th>
<th>Increasing independence</th>
<th>Reducing isolation</th>
<th>Increasing independence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not relating to dog</td>
<td>More restricted lifestyle</td>
<td>Concealing impairment</td>
<td>Worries about training</td>
<td>Worries about training</td>
<td>Not relating to dog</td>
</tr>
</tbody>
</table>

**Factors against a dog**

<table>
<thead>
<tr>
<th>Not relating to dog</th>
<th>More restricted lifestyle</th>
</tr>
</thead>
<tbody>
<tr>
<td>More restricted lifestyle</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Appendix 9</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Enjoyed having dogs in the past (4)</th>
<th>Reasons for wanting</th>
<th>Reducing isolation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A real dog lover (1)</td>
<td>Reasons for wanting</td>
<td>Reducing isolation</td>
</tr>
<tr>
<td>Expected it would enable more active lifestyle (1)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
<tr>
<td>Cane caused arm pain(1)</td>
<td>Reasons for wanting</td>
<td>Reducing isolation</td>
</tr>
<tr>
<td>Fed up people not recognising the impairment (1)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
<tr>
<td>Considering getting a pet dog anyway (1)</td>
<td>Reasons for wanting</td>
<td>Reducing isolation</td>
</tr>
<tr>
<td>Wanting more independence (3)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
<tr>
<td>Wanted better mobility (2)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
<tr>
<td>Hate slow walking pace with the cane (1)</td>
<td>Reasons for wanting</td>
<td>Increasing independence</td>
</tr>
</tbody>
</table>

| Unsure about getting on with Labrador (1) | Factors against a dog | Not relating to dog |
| Worried about the responsibility involved (2) | Factors against a dog | More restricted lifestyle |
| Not wanting impairment to be made obvious (1) | Factors against a dog | Concealing impairment |
| Worried about the training being too hard (1) | Factors against a dog | Worries about training |
| Not wanting to do residential training (1) | Factors against a dog | Worries about training |
| Not a dog lover (1)                      | Factors against a dog | Not relating to dog |
| Worried they wouldn’t get on with dog (1) | Factors against a dog | Not relating to dog |
| Anticipate reduced activities (2)        | Factors against a dog | More restricted lifestyle |
| Expect dog to be refused access (1)      | Factors against a dog | More restricted lifestyle |

<table>
<thead>
<tr>
<th>Using help of experts</th>
<th>Discussing with owners</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDBA interview was helpful (1)</td>
<td></td>
</tr>
<tr>
<td>Talked to staff at the GDBA (2)</td>
<td></td>
</tr>
<tr>
<td>Feeling persuaded by other owners (2)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Appendix 9</th>
</tr>
</thead>
</table>

124
<table>
<thead>
<tr>
<th>Reasons for wanting a guide dog</th>
<th>Step 3</th>
<th>Step 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wanting to avoid obstacles (4)</td>
<td>Inc. independence</td>
<td>Obstacle avoidance</td>
</tr>
<tr>
<td>Fed up having accidents (3)</td>
<td>Inc. independence</td>
<td>Obstacle avoidance</td>
</tr>
<tr>
<td>Struggling to walk around (2)</td>
<td>Inc. independence</td>
<td>Improved mobility</td>
</tr>
<tr>
<td>Feeling confined to the house (1)</td>
<td>Inc. independence</td>
<td>Greater independence</td>
</tr>
<tr>
<td>Enjoyed having dogs in the past (4)</td>
<td>Reducing isolation</td>
<td>Wanting a pet dog</td>
</tr>
<tr>
<td>A real dog lover (1)</td>
<td>Reducing isolation</td>
<td>Wanting a pet dog</td>
</tr>
<tr>
<td>Expected it would enable more active lifestyle (1)</td>
<td>Inc. independence</td>
<td>Greater independence</td>
</tr>
<tr>
<td>Cane caused arm pain (1)</td>
<td>Inc. independence</td>
<td>Improved mobility</td>
</tr>
<tr>
<td>Fed up people not recognising the impairment (1)</td>
<td>Reducing isolation</td>
<td>Highlighting impairment</td>
</tr>
<tr>
<td>Considering getting a pet dog anyway (1)</td>
<td>Reducing isolation</td>
<td>Wanting a pet dog</td>
</tr>
<tr>
<td>Wanting more independence (3)</td>
<td>Inc. independence</td>
<td>Greater independence</td>
</tr>
<tr>
<td>Wanted better mobility (2)</td>
<td>Inc. independence</td>
<td>Improved mobility</td>
</tr>
<tr>
<td>Hate slow walking pace with the cane (1)</td>
<td>Inc. independence</td>
<td>Improved mobility</td>
</tr>
</tbody>
</table>
INTERRATER RELIABILITY STUDY

Instructions for Rater

The aim of the inter-rater reliability study is to determine the extent to which an independent rater agrees with the categories I have generated from the responses given by participants in an interview about guide dog ownership.

I have provided you with 63 different segments of text produced by all the participants about three different areas relating to visual impairment or guide dog ownership. I have also enclosed a ‘category’ rating scale that includes all the categories I generated.

To begin with I would like you to read each quote carefully. As you do so I would like you to think about three questions. First, how do participants say they cope with visual impairment? Second, what are some of the disadvantages of guide dog ownership outlined by participants? Third, what impact does the guide dog have on participants’ mood?

The segments of text are numbered from 1 to 63. Reading each segment of text, I would then like you to put its corresponding number against the category you think it best fits into on the rating scale. Continue this process until all the segments have been put into a category.

Thank you for your help
### CATEGORY RATING SCALE

<table>
<thead>
<tr>
<th>Category</th>
<th>Numbered Segment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. How do participants say they cope with Visual impairment?</strong></td>
<td></td>
</tr>
<tr>
<td>A) Avoiding activities</td>
<td>56, 11</td>
</tr>
<tr>
<td>B) Trying to conceal their visual impairment</td>
<td>27, 58, 57, 13</td>
</tr>
<tr>
<td>C) Taking anti-depressants</td>
<td>49</td>
</tr>
<tr>
<td>D) Forcing themselves to do things</td>
<td>42, 33, 3, 20, 46</td>
</tr>
<tr>
<td>E) Learning to live with their impairment</td>
<td>58, 64, 24</td>
</tr>
<tr>
<td>F) Turning to family or friends for support</td>
<td>85, 82</td>
</tr>
<tr>
<td>G) Seeking counselling</td>
<td>89, 28</td>
</tr>
<tr>
<td>H) Getting information about their condition</td>
<td>7</td>
</tr>
<tr>
<td><strong>2. What are some of the disadvantages of Guide dog ownership given by participants?</strong></td>
<td></td>
</tr>
<tr>
<td>A) Fear it would restrict their lifestyle</td>
<td>30, 54, 14, 43</td>
</tr>
<tr>
<td>B) Fear they would not be able to relate to the dog</td>
<td>52, 37, 36</td>
</tr>
<tr>
<td>C) Worries about the training process</td>
<td>41, 61</td>
</tr>
<tr>
<td>D) Not wanting their impairment to be obvious</td>
<td>39, 60</td>
</tr>
<tr>
<td><strong>3. What impact does the guide dog have on Participants’ mood?</strong></td>
<td></td>
</tr>
<tr>
<td>A) General improvement in mood</td>
<td>32, 10, 35, 5, 53, 45</td>
</tr>
<tr>
<td>B) Guide dog responsibility enhanced mood</td>
<td>46, 12, 23, 9, 41</td>
</tr>
<tr>
<td>C) Increased personal confidence</td>
<td>51, 1, 18, 12</td>
</tr>
<tr>
<td>D) Guide dog makes owner laugh</td>
<td>38, 16, 48</td>
</tr>
<tr>
<td>E) Improved mobility enhanced mood</td>
<td>26, 34, 19, 8, 44</td>
</tr>
<tr>
<td>F) Dog aided adjustment to impairment</td>
<td>40, 23, 7</td>
</tr>
<tr>
<td>G) Feel more motivated</td>
<td>17, 13, 15</td>
</tr>
<tr>
<td>H) Dog helps owner cope with stress</td>
<td>62</td>
</tr>
<tr>
<td>I) Increased social contact improved mood</td>
<td>63</td>
</tr>
</tbody>
</table>
### Inter-Rater Reliability – Percentage Agreement

<table>
<thead>
<tr>
<th>Category</th>
<th>Agreed total</th>
<th>Percentage Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. How do participants say they cope with visual impairment?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A) Avoiding activities</td>
<td>2/4</td>
<td></td>
</tr>
<tr>
<td>B) Trying to conceal their visual impairment</td>
<td>3/3</td>
<td></td>
</tr>
<tr>
<td>C) Taking anti-depressants</td>
<td>1/1</td>
<td></td>
</tr>
<tr>
<td>D) Forcing themselves to do things</td>
<td>4/4</td>
<td></td>
</tr>
<tr>
<td>E) Learning to live with their impairment</td>
<td>3/3</td>
<td></td>
</tr>
<tr>
<td>F) Turning to family or friends for support</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>G) Seeking counselling</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>H) Getting information about their condition</td>
<td>1/1</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>18/20</strong></td>
<td><strong>90%</strong></td>
</tr>
<tr>
<td><strong>2. What are some of the disadvantages of guide dog ownership outlined by participants?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A) Fear it would restrict their lifestyle</td>
<td>4/5</td>
<td></td>
</tr>
<tr>
<td>B) Fear they would not be able to relate to the dog</td>
<td>2/3</td>
<td></td>
</tr>
<tr>
<td>C) Worries about the training process</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>D) Not wanting their impairment to be obvious</td>
<td>1/1</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>9/11</strong></td>
<td><strong>82%</strong></td>
</tr>
<tr>
<td><strong>3. What impact does the guide dog have on participants' mood?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A) General improvement in mood</td>
<td>5/7</td>
<td></td>
</tr>
<tr>
<td>B) Guide dog responsibility improved mood</td>
<td>6/7</td>
<td></td>
</tr>
<tr>
<td>C) Increased self-confidence</td>
<td>4/4</td>
<td></td>
</tr>
<tr>
<td>D) Guide dog makes owner laugh</td>
<td>3/4</td>
<td></td>
</tr>
<tr>
<td>E) Improved mobility enhanced mood</td>
<td>3/3</td>
<td></td>
</tr>
<tr>
<td>F) Dog aided adjustment to visual impairment</td>
<td>2/3</td>
<td></td>
</tr>
<tr>
<td>G) Feel more motivated</td>
<td>2/2</td>
<td></td>
</tr>
<tr>
<td>H) Dog helps owner cope with stress</td>
<td>1/1</td>
<td></td>
</tr>
<tr>
<td>I) Increased social contact improved mood</td>
<td>1/1</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>27/32</strong></td>
<td><strong>84%</strong></td>
</tr>
</tbody>
</table>
Appendix 11

FEEDBACK REPORT TO PARTICIPANTS

15 June 2000

Dear

Thank you for taking part in the research interviews about guide dog ownership a few months ago.

I enclose a report detailing the most important findings that emerged when all the interviews were looked at together. I have developed a model to try to understand these findings and this is made up of four stages.

The first stage describes the difficulties people had in the process of adjusting to visual impairment. The second stage is about how and why people decided to get a guide dog, and the third relates to peoples’ experiences of being matched with a dog and the training itself. The fourth and final stage describes the way in which a guide dog impacts on peoples’ lives and how it affects their adjustment to visual impairment.

I will be writing a longer report, which I will send to the Guide Dogs for the Blind Association, so that the organisation can find out what people thought about guide dog ownership. I am also hoping to send this to a journal on visual impairment, and to a magazine that is interested
in the relationship between humans and animals, and how this can be therapeutic.

I would be very interested to hear any comments you have about what I have written. In particular, I am interested to hear how well you feel it fits with your experience of guide dog ownership and whether there are any parts you do not agree with. In addition, I am keen to find out whether you think any important things have been left out.

I have included a stamped addressed envelope for you to send any comments, should you wish to. Alternatively, if you would like to phone me to discuss it, I can be reached on 01892 507665. If I am not there you can leave a message and I will phone you back.

Thank you once again for taking part in this research.

With best wishes

Louise Banham
Psychologist in Clinical Training
Feedback Report

People's experiences of guide dog ownership

Stage 1 – The impact of visual impairment

Many people reported reduced independence and a loss of social roles after losing their sight, which together led to increased isolation. This was accompanied by feelings of depression and frustration, as well as a feeling of being stigmatised by people. In the process of adjusting different coping methods were tried. At times people avoided things, whilst at other times they faced things head on.

One of the ways people tried to regain some independence was using a long cane, but this was overwhelmingly unpopular. It was not very effective in ensuring safe mobility and many people felt stigmatised using it. It seems that the service received from professional agencies, including social and voluntary services, were not very helpful in addressing the difficulties people had as a result of their visual impairment. Consequently, it appeared that people were unhappy with the way they were coping, and so they were seeking alternative ways to improve this.

Stage 2 – How and why a guide dog was chosen

For a large majority of people, the initial idea to get a guide dog was suggested by somebody else. Primarily, people wanted an increased level of independence and mobility, and to reduce feelings of isolation. However, it was not
always an easy decision to make, as there were some fears that the responsibility involved with a guide dog would be even more restricting. Some people were also worried that they would not be able to get on with the dog. The decision to go ahead with a dog seems to have been aided by talking with other guide dog owners or with staff at the Guide Dogs for the Blind Association.

**Stage 3 – Being matched with a dog, and training**

The majority of people felt they were matched quickly with a guide dog and it seems that everybody was pleased with the dog they had been given. Regarding the training itself, several people had enjoyed the facilities there and benefited from having other trainees and staff to discuss anything with. However, some people felt isolated during the training and thought there were high expectations placed on them by the Association about how they should present themselves and have the dog behave.

**Stage 4 – The impact of the guide dog**

It appeared that the guide dog had a significant impact on peoples’ lives.

Many people reported feeling happier and more self-confident since having the guide dog, and that overall their quality of life had improved. It seemed that this was related to caring for the dog which distracted them from negative feelings, and the increased mobility and independence it brought.
Whilst the guide dog did generally improve people’s level of independence, the responsibility for caring for it often restricted their lifestyle and the dog was not able to restore full independence. However, everybody reported that guide dog mobility was better than using a long cane. The dog was better at avoiding obstacles and gave people greater freedom and confidence when travelling. People were also able to locate places more quickly and easily and felt the dog enabled them to walk in a more upright position that did not feel as stigmatising.

It seemed that the guide dog had a large impact on the public, who generally were fascinated by the guide dog and wanted to interact with it. As a result the owners had more social contact with the public and felt the guide dog was able to overcome some of the barriers associated with their impairment. This meant that they felt less stigmatised and were proud to be seen with the guide dog compared to their reluctance to using the cane. Many people had become known in their neighbourhood and had developed new friendships because of their increased contact with the public.

However, people described difficulties associated with the public’s response to the guide dog. Many people had problems with the dog being distracted when it was working, or would find themselves being completely ignored and held up whilst the dog was being made a fuss of. Although people did challenge the public when they interfered too much with the dog, it seemed that there was a certain degree of pressure to be a good ambassador for the
Guide Dog Association. Consequently, people felt they had to be polite to the public at all times, which was not always easy, and so some resorted to trying to avoid contact with them altogether.

A further problem was being refused access to places, particularly by those whose culture disliked dogs altogether. Restaurants and taxis appeared to pose the most problems and it meant that often they had to plan ahead and enquire about access before going out. Whilst the guide dog was accepted by the family and in the workplace, people did also experience difficulties when seeing friends who were not very keen on dogs.

Finally, the relationship between dog and owner appeared to be a very close one. The working relationship with the guide dog was described as a partnership and generally people thought the dog was an excellent worker. They commented on putting their whole trust in the dog to guide them safely.

Furthermore, the companionship the dog provided appeared to be extremely important. People talked about the dog as if it were human, commenting that it was a loyal, loving companion, and that they were 'in tune' with each other. Consequently, people were very attached to their guide dog, more so than with a pet dog, and were already thinking about when the dog would retire and how they could maintain contact with it. However, because of the closeness with the dog, as in human relationships, it
appeared that occasionally people did like to go out without the dog.

Overall, it seemed that the guide dog had brought many positive changes to peoples’ lives, making them happier, more self-confident and independent. Whilst the public intrusion and access problems were difficult to manage, the guide dog did reduce the social isolation and stigma associated with visual impairment. Furthermore, although the responsibility for the dog could be restrictive at times, the guide dog was a trusted worker and companion that was able to provide many of the positive qualities found in close human relationships. In sum, it seemed that the guide dog did help people to cope better with their visual impairment.
COMMENTS

1. How well do you feel the findings fit with your experience of guide dog ownership?

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........................................................................................................................................
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2. Are there any points that you disagree with?

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3. Do you feel that any important things have been left out of this report?

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Any other comments?

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........................................................................................................................................
........................................................................................................................................
I: Can you tell me how long you’ve been visually impaired?
P: Where are we now, it was the Christmas of 97, just over two years. I had a heart attack immediately after Christmas. We’d come back from our children on the Saturday night and I drove right home from (nearby town) and I’ve driven for 64 years so I mean I love driving in all weathers and everything but I hated that night. It was a wet day like this, and for some reason I don’t know what was wrong. When I got home I said to the wife, that was the worst drive I’ve ever had. I can’t understand it, you know. I went to bed, six-o clock the next morning I had a heart attack. So it was obviously something building up. Went into the hospital and was discharged a week later from Intensive Care and the following week I had a stroke (pause) and the stroke just took the sight.
I: Straight away?
P: Um, just suddenly. Anyway I was sitting in that chair watching Tele. Ten o clock news, full head and shoulders of newscaster and suddenly the whole screen apart from a little bit up in the corner blacked out. My wife was in the kitchen and I called out and said what’s wrong with the Tele? She came in and looked at it and said nothing’s wrong with it. I was sitting there and I turned round to look and said, but you can see there’s something wrong with it. And as I turned round to look at it all I could see was one eye and the top of her head, it just blacked completely out like that.
I: That must have been really frightening!
P: It was frightening really, yes. They told me the problem I’ve got, they call it hominus hemiopia. It’s, if you can imagine, it’s sort of like both eyes cut down the middle and everything that side is completely black. It’s brain damage actually, it’s damaged the... They said there was a clot went from the heart, after the heart attack, and damaged the optic nerve, permanent damage you know.
I: So do you have any residual vision at all?
P: Just a little, um, I can see a little bit on the right and I’ve got a little bit of, sort of I suppose you’d almost class it as tunnel vision. It’s like looking down a little tube and I can see little spots, same as if I look at my hand I can only see just a little bit of my hand, you know. And to demonstrate how it’s gone I can sort of see that my hand is there but if I move it to there, its gone completely.
I: So you’ve got some central vision then?
P: So I’ve still got a little bit of central vision but all the periphery’s gone you know. So it was rather a shock and after being fit and well. I was as fit as a fiddle before.
I: And after it happened did you have much support from various agencies, sometimes social services might be involved?
P: Well social services was very long winded you know and of course, being in that sort of situation my wife didn’t know quite who to turn to you know. But the social services
they eventually did come after my wife blew her top several times (laughing) you know, to try and get some help. And er, I eventually had a lady come along to teach me long cane training and that went on for a bit and she had to leave and gone on to another course, and she put me in touch with Guide Dogs, and (GDBA trainer) she came down here and took me right through long cane training, you know. And at that time one of my ladies at... I’d connected up with a local blind association, used to go swimming every week with about twenty odd blind people, and one of the ladies who’s done a lot for guide dogs talked to me about guide dogs and she said, ‘how do you feel about applying for one?’ That’s what opened it up you know. Applied for one and I had two people come down and they interviewed me for about three and half hours and took me out for a walk with the handle to see how I reacted to it, and it went from there and I eventually got my dog.

I: So you say that somebody else initially suggested the idea to you?

P: Yes, it was one of our ladies who’s been blind for many, many years and had quite a few guide dogs you know, and she chatted to me about it and said you’d probably find the dog invaluable you know. So when they came down and um checked me over as to what they thought, and said yes, okay, that was it. I was a little bit disillusioned afterwards because when a lady came down to teach me long cane training, um, she wondered that I was doing so well with my long cane that I wouldn’t need a dog. It rather frustrated my feelings at the time but eventually um, they decided that they would have me up for three days back in March last year and just check me out with a couple of dogs and see how I react in comparison with a long cane. After those three days, they said no you need a dog. So it went from there. So I eventually went up in the June last year and had my training.

I: I’m quite interested in the decisions people have made as to why they’ve got a dog. You said that somebody suggested that and they were thinking that you were doing quite well with the long cane, what was it for you that made you think, well yes I am, but I’d quite like to get a dog?

P: Well I don’t know really, um...Another one of my colleagues in the Blind Association, cos being in the blind association there are three or four that have got dogs and talking to them about how, what a difference it’s made to their lives and getting about, I just felt that perhaps, that particularly having dogs all my life, we’ve always had a dog, I thought well it would be nice if it’s going to help me with obstacles and things. I mean even with a long cane you can still run into things and I had one or two nasty experiences with it, particularly having a cyclist run into me and things like that, and I thought well perhaps if I have a dog it might be more useful. And believe me he’s proved his worth. Yes, I feel absolutely confident with him. I can literally go out and shut my eyes and walk with him and I know he’s going to get me there safe.

I: So you say that from your point of view it felt as if the dog would give you a little bit more trust in going out, more confidence, but you suggested that there might have been some resistance from the guide dogs. Were there any other barriers that made it more difficult for you to get the dog?

P: Um, I don’t know. I don’t think so. I mean when (GDBA trainer) came down and um, I say this other chap too, they interviewed me for about four hours, took me out, explained all the good points about it and the bad points and that business. I felt convinced afterwards it would help me and they seemed quite happy that I would qualify all right for it, you know. So it’s really gone on from there you know.
I: So you did your training last June, so you must have been home with (dog’s name) since about July, is that right?
P: About July, yes that’s right, so it’s just about the six months. And he seems to be proving his worth better every day really because he’s got to the stage now where I can walk from here to (village), which is about a mile to the shops, and he knows his way all round (village). If I ask him to take me to the Baker’s shop he takes me, if I say I want the bank, or the vet, you know, he just knows his way, you know. He tries the crossings for me and everything, it’s marvellous really.
I: So no regrets?
P: Oh no, not at all! No, no.
I: That leads me into the main part of my study really which is about the changes that have occurred in your life since you’ve actually had your dog, so just thinking generally, what would you say have been the major changes for you?
P: Giving me confidence I think when I’m out because when I first went out on my own with my long cane, there was that sort of apprehension, you know, as to whether I was safe really, particularly you have like cyclists coming along on the pavement, or parked cars and things like that, and walking into obstacles and I had one or two nasty experiences where I walked into lamp posts. Because being blacked out on this side I can have somebody standing say right there and I just can’t see them at all, so you can imagine if you’re walking towards a lamp post, I had one or two nasty knocks on my shoulder and my face you know. But I felt in view of that, they explained that a dog is walking just that little bit ahead of you and he would guide you and make sure you don’t run into things. He does prove his worth because I mean I can be walking along and sometimes not see a lamp standard and he’ll just veer me round it and I sort of afterwards, if I turn completely like that and try to get a little bit of this vision round there I can see a bit you know. I sometimes wonder what’s he done there and I go round like that and there’s this lamppost. All kinds of things that he walks around.
I: It’s amazing, they do it so well don’t they?
P: Oh they do, he’s really marvellous. He just won’t let me walk into things, I mean he literally walks right across my path and stops me dead. And er, we had some works going on along the road here one day and I was going up the other side there and he just cut across and stopped me and with the training they give us the off-kerb obstacles. I said to him, find the kerb, and got him onto the road but he realised this obstacle was jutting out right out onto the road so he, I could sense he wanted me to cross the road, so I listened for traffic and we went across the road, he turned left the other side, we went another thirty or forty yards up and he turned the kerb to get me back to the other side. I thought well if he can do that for me, he can do anything really.
I: So he can react to unpredictable situations as well?
P: Yes, yes, really marvellous. He certainly won’t let me cross the road if there’s any traffic movement. I mean if there’s somebody the other side of the road messing about with their car, probably, you know, to back into a drive or something, he just won’t go across until he’s sure that’s alright, you know. Which is good really.
I: So he’s increased your confidence about going out?
P: Oh absolutely, absolutely yeah! And he’s made my wife feel happier too because she used to sort of worry about me you know, when I’m out. You know, ‘be careful, don’t cross the main road, and don’t do this’. She um, she didn’t like me crossing this road here at one time and then there’s a main road that runs across there and one day when she
was out I thought well if I go on my own she won’t know so I went, I made sure I crossed the main road right. The first time I ever walked to town I used to say to her, it would be nice to go down to town. She said well, no, with the traffic lights and all that, would you be safe? But I thought well I’ve got to make myself go places and be very careful listening and all that and I found that I was able to walk down to town, cross the crossings, you know, quite comfortably. But since I’ve had him, I feel even more happier about it.

I: So it sounds like there’s a real trust in him and that he’ll protect you?

P: Absolutely yes. When I first started with him and they used to say to me eventually you’ll have to put your whole trust in the dog you know, I thought this is going to be hard you know. I mean I’ve always had a dog and walked it but you never feel that you’re trusting the dog implicitly you know. But the time’s come now I do, I absolutely put my whole trust in him you know, it’s marvellous really.

I: So there’s an increased sense of confidence. What other things have changed since you had (dog’s name)?

P: Well only that I can get about to places which in the normal way I used to find difficult. Recently my trainer introduced me to travelling on the buses. That’s helped quite a bit, you know, a little bit awkward at first you know, getting on and off buses. The first time I got on the bus, he um, decided he wanted to sit on the seat (both laughing). As I sat down he jumped on the seat next to me, I had my change in my hand, he knocked that flying. Course I had all the other passengers looking for my money! (Laughing). I thought oh goodness, this isn’t working out too well, but after two or three times he’s used to the drill now, and he’s marvellous really. He sort of, where he used to sort of, want to go ahead of me, now he’ll wait and I can just see his head turning round looking at me as if to say, ‘you’re alright, you know, this is the way’. So it’s really wonderful, I can’t explain it really, any more fully.

I: So what impact has that had on your life. I mean does it mean that you’re now able to do things that you weren’t able to do before, or have you regained more independence?

P: Well regained a lot of my confidence and independence, yes definitely. And um, when I go out places, I mean I go, once a week I go to a stroke club, just to give my wife a day that she can do what she likes. And um, it’s only about ten minutes walk up the road and I’ve only got to say something to him, I mean there’s a chappie there, he and I get on well together. I say well come on, we’re going to find (friend’s name) today. He’ll take me right up there, he’ll walk me into the gateway. When you get into the building you go down quite a few different passages, turning corners and that, he knows his way right the way through, takes me right in. And um, he’s so good with people, he loves meeting people, you know. Of course they love to meet him and stroke him, everybody knows (dog’s name), you know (both laughing). So it’s made me feel so different you know, and where I used to be out with my long cane, walking and I’d sense people passing me and not even saying hello, good morning or what, it used to feel very lonely at times. I used to go out onto a cuckoo walk, the old disused railway, and I sometimes walk two or three miles along there and back on my own with my cane and sense people passing me, no one would say hello, good morning, how are you, you know. But since I’ve had him, people do stop. They say hello! Oh what a lovely dog you have and all that. So socially it’s helped a lot you know.

I: And you used the word different, I feel so different you said?
**P:** Well I do actually, I don’t know what it’s done for me, it’s given me a lift really somehow, where I was really down before and you know, I felt every day was a problem day as it were, now I feel so happy, we’ve got into a routine and that you know, I say he knows his way around everywhere. If I go round to the paper shop and say to him as we go, ‘come on we’ll go and find the paper shop’. One evening I came home from a blind association and it was dark, they dropped me here by a little minibus and my wife said on we didn’t get the paper today. I said ‘I’ll go round and get it’. But she said, it’s dark now. I said don’t worry, I’ll get that you know, and I literally couldn’t see anything, so I said come on find the paper shop. He took me down to the corner, across the road here, cross the next road, turned right, up to the top there, straight into the paper shop. I thought well if I’ve got that trust in him, well it’s marvellous, you know.

**I:** So that lift that you’ve got, I’m just wondering is it about being able to do things you couldn’t do so easily before, is it confidence, is it the barriers that are broken down in social situations? What would you say is the most important?

**P:** Um, I don’t know really, um. It has broken down social barriers obviously and helped there but um, I feel before when I used to go with the long cane I was having to really concentrate all the time, really hard you know, to make sure I wasn’t running into things, even with that. I mean if I tell you that one day I walked down the road and one of the big blocks off a gatepost, a big thick square thing had fallen on the kerb. Now using my long cane, my long cane missed it, just went over the top of it and I tripped on it. So you know, there was always that danger there, that you could trip over and fall, but with him, he’ll stop you. Now another little example um, we’ve had some cold weather and we had freezing weather about three weeks ago, and going between here and the Stroke Club there was a water hydrant that had apparently been overflowing all night and as I got to it a lady called across the road, she knew me, she said (participant’s name), she said stop please where you are, don’t move. She came across and said there was about four square yards of ice right across the pavement so she took me out into the road and got me past it. When I came back from there after lunch I thought how he’s going to react to that if it’s still there, and it was, it was still freezing. As we got down towards it and I sensed it, he pulled me up and I gave him the usual tap, you know, find a way, comes round behind me, up to the kerb, into the road, down past the road back onto the verge, so he obviously was aware of that as a danger you know, so... When I go out on frosty mornings when there’s still a bit of frost on the pavement which can be a bit slippery, I noticed he steadies his speed down a little bit to make sure I don’t slip. So he’s fantastic, can’t explain it you know.

**I:** So that fear, I could really sense when you were saying that, the fear of not being able to see things and not having the cane, it’s completely different. So has the fear gone now?

**P:** I would say so yes. I just don’t have any sort of fear now really because I just know he’s so attentive and watching all the time you know.

**I:** So before when that fear was there and you didn’t have (dog’s name) did you still go out as much?

**P:** Well I used to force myself to go out because I knew I’d got to because, now my wife is very arthritic and she can’t walk and she can just about walk from the car to go down to the superstore and do a bit of shopping, but to walk from here to the top of this road would be a real task for her you know. So where we used to do a lot of walking together now she can’t do it as well. So I’ve literally had to force myself to go and walk and when
I had a heart attack they said to me I ought to walk two to three miles every day, so that was the incentive you know. But as I say, with him now, it's so different.

I: So he's actually helping to maintain your health as well?

P: Oh yes, I'm sure of it! I mean, I'm quite physically fit now, it's just this wretched business of not being able to see that's the problem you know. When I think that in my stroke club that I belong to, I meet quite a few there that had strokes, one chap in particular he's like me, he's lost his sight. He's had a speech impediment too, there's two or three others there that have had paralysis down the side, you know, and I think well at least I'm physically fit. So I can get out and about and walk which keeps me fit and healthy, it's just the problem of the sight really. But as I say, we're overcoming it, it's a daily challenge.

I: Would you say that having (dog's name) has helped you to deal with that? Do you think having a dog has made any difference to your mood?

P: I think it has because I used to get very low sometimes. I mean I've never told my wife this but I've almost had sort of suicidal feelings at times, you know, I wish to god I could end it you know. Um, and I know from things that I've been told and things that have been read to me that when you have these strokes sometimes you do get that sense of depression you know. I do get down days obviously, but one thing that has helped me, I was introduced to a chap in (town in next county) I've never met him, but he's taught me Braille. Um, it was purely an accident really cos I love Jazz and I used to get jazz CD's from a chap up there. After I had this loss of sight I told him and he was so taken back by it and while we were talking and said he'd been looking at his computer screen and there was a chap in (town in next county) who's totally blind, he seems to pick the same sort of things that you pick. He gave me his phone number, I was a bit reluctant but I did eventually say to my wife, I think I'm going to have a go. I phoned him up and we had about an hour's chat and he was literally over the moon to think I should contact him and then he said do you know Braille at all, I said no. He said I teach Braille, I'll put the alphabet and some tests in the post and see what you think. Well he started me off, that was about a year ago and he's got me right through Grade one and Grade two and er, we write to each other regularly and we phone each other up once a week. I used to sort of speak to him on the phone and he cheers me up so much. When I was down I'd sometimes get on to him and he'd say, how are you? And I'd say Oh, I don't know, I'm really down in the dumps this week, everything seems to be going wrong. He'd talk to me like a Dutch Uncle you know. He's a bit younger than me but he's given me so much confidence. He's totally blind, no light at all and he's really given me a boost, and yet I've never met him. Hoping one day I will.

I: That's really nice.

P: So and I think meeting other people in the same situation does help you a lot. When it first happens to you, you just think you're an isolated one on your own and why should it happen you know? But having met so many now that are blind, it's a new life really, totally new life.

I: What difference has it made being in a situation where people do talk to you more, and you have said that people approach you more readily, what has that been like for you?

P: Well that means a lot really now, because I'm getting to know people by their voices really which does help a lot. I do get caught out sometimes, and I have to think what voice is that you know. Sometimes if they get very close to me I can just begin to pick out shapes and features, but to casually glance round at people, they're just sort of forms
Appendix 12

to me really. It’s certainly helped. Since I’ve had the dog, of course they, there’s that tendency for them to want to speak to you, I don’t know what it is about the dog, but it seems to attract attention, you know. Sometimes it gets a little bit difficult when people come up and talk to the dog when you’re walking the dog and I saw (GDBA trainer) and I met her three weeks ago at a meeting, I was telling her about his and she said well perhaps you could have one of those sleeves that you put on the handle, ‘please do not distract me I’m working’. And since I’ve had that and used that I find that people don’t come up and distract us as much.

I: How do people distract you?

P: Well sometimes you can be walking along and the dog will be attracted by them and he’ll suddenly pull you away and suddenly a voice will say, oh we’re just stroking your dog you know. It’s a little bit disconcerting sometimes you know, particularly if you’ve given him instructions where you’re going and somebody sidetracks you. But on the other hand I don’t like to not let people come up and stroke him because it’s a good image, the dog out, and if people think you’re like that they won’t want to talk to you will they?

I: Does it in any way make it more difficult to have the trust if you know that when people are out, that sometimes he can get distracted?

P: No he’s pretty good, because if I sense any distraction at all I say no, no (dog’s name), like that, come on, reinforce what I’ve already told him. He responds very quickly. I’ve never had an occasion yet where I can’t control him, as soon as anything’s distracted him, it could be another dog, or anything like that, I suppose, I say no (dog’s name), straight on and he responds straight away, which is good really. Otherwise if he started to pull away it would cause problems that, you know. But no, no he’s been marvellous really.

I: Have you found that the longer you’ve had him, the trust has been a gradual process?

P: Oh yes, it’s improved all the time. Because when I first had him I wondered how long it was going to be before I could say I shall put all my confidence in him. It was fairly quick really, it was in a matter of two or three weeks that I was beginning to feel that I could really rely on him you know.

I: And did you notice in that time any changes in your, in the way you feel about yourself and your mood?

P: Oh I think so. I think he helps tremendously, there’s no doubt about it. If I’m ever feeling a bit down or something like that, I mean I notice, he’ll come up and he’ll sit with me and he sort of squats down, puts his back to me and he’ll lean on me sometimes. I think well, it’s like having a pal really, and it sort of just gives you that bit of a lift you know.

I: Do you think they know? Another person I spoke to said that his dog seems to sense his mood?

P: I’m inclined to think they do really. Yes because if ever I’ve been really down or anything’s happened like that I’m sure he’s aware that something’s not quite right. Almost as though then he’s got to be close to you. Sometimes he’ll come up if I’m sitting here and he’ll just rest his chin on your knee and things like that you know. As if to say, I’m here you know. Yeah.

I: Ah. One of the other questions I wanted to ask you was about the impact of having a dog on your family relationships.

P: Well when I first hinted about being interested in having another dog my wife wasn’t too happy. Her point of view is what happens if you’re unwell and he’s got to be taken
out and so on, you know, things like that. And one thing she did say is if you’re going to have a dog, I don’t want a big dog, and of course he turned out to be a big dog (both laughing). But she’s got so used to him now, I think she’d miss him if he went. Yes I mean he’s as much a part of the household now as anybody you know. And also whilst she shouldn’t really be controlling him in any way, he does respond to any orders she gives him you know. If she told him to go and sit down, or stay there (dog’s name), he’d do it. But at the same time I still think he knows I’m the boss man you know. That’s one thing the trainer said to me, she said to my wife when she came, now you’ve got to take a back seat for a bit you know, he’s the boss. So he responds to her in the same way, which is good really.

I: How have other people in your family responded to you having (dog’s name)?

P: Well my son he loves, literally loves him. I mean he’ll get down on his knees and romp with him and all that. His wife has always been a cat person and didn’t like dogs at all, but we went away with them last September for the week, and cos I had to take him out in the mornings to spend him and there wasn’t a place within the confounds, I had to walk quite a distance, she would get up in the morning and walk with me to make sure I was safe and got there. And she so fell in love with him, she said if ever you want to retire him or anything, I’ll have him you know (both laughing). She’s absolutely changed her attitude to dogs. We had a day up there at Christmas with him, she was over the moon with him. Yeah, so it’s good really. And my daughter’s got a retriever and we were worried as to how they would react because he started getting a little bit aggressive her retriever because another dog bit him, but I took note of what my trainer told me, how to meet on neutral ground and all that. Eventually got them together in the house and they were good pals. So we’re quite pleased about that.

I: I guess it is a big responsibility isn’t it having a guide dog, all the caring they need.

P: It is really, there’s a lot to do really you know, but um, we manage all right.

I: Um, what would you say are the disadvantages of having a guide dog?

P: Well, the only disadvantage I can think of is the fact that he, he has to have a free run you know, perhaps once a week or something like that. And this time of the year we have to go down to the recreation ground, near here. But you go down during this wet weather and it’s so swampy, you know, that when you’re walking round you can feel your feet squelching in the wet and that becomes a bit of a difficulty really, having to let him go and free run. I did have a funny thing happen when I first took him down on my own. I let him go with his bells on and all that, but he came back smelling horrible! I couldn’t understand it so I went to put his collar back on and then I felt something on my hands and I was conscious of the fact that he’d got some muck all over him. Now I was stuck in the middle there, my wife was back home here, I hadn’t got any towel with me or anything to wipe him. Fortunately, I had my mobile phone in my pocket and I stood in the middle of this recreation ground and phoned her and she came down with wet towels and dry towels and we cleaned him up you know (laughing). But that was the only sort of funny side about it. But that’s the only disadvantage sometimes, if you’re free running them and you’re in a spot where you can’t see things too clearly you know. I mean when he leaves me I can only just see there’s a light, I can sense it’s an animal running like that as he gets in the distance. I can just see him and I blow my whistle and he comes back to me. But I say, with this sort of weather, that’s a little bit of a disadvantage really.

I: Is it because of the fact that he could get very dirty and you couldn’t clean it off or are you concerned he won’t come back?
P: Oh no I think he’ll come back all right to me. It’s just the fact that if he gets really dirty it’s how to cope with it. What I do now is take a small haversack on my back with a towel and things in it and if he does get a bit like that I can attempt to clean it up you know. But it’s only during this winter period that it’s like that. Come the dry weather there’ll be great fun with him you know.

I: So no other disadvantages?

P: No I don’t think so no, not that I can think of. I know sometimes when it’s pouring with rain and I know he’s got to go out for a walk (laughing) but then I’ve got a storm outfit with leggings and I put them on and away we go you know. He’s quite happy cos if he gets wet and I towel him down when he comes back, oh, he thinks that’s great fun you know.

I: What’s it like having such a great responsibility to care for him?

P: Oh I think its fine, cos it gives me something to do, something to think about you know. Whereas before I’d be sort of at a loss, you know, and you get a bit tired of just sitting doing nothing. I mean I’ve got tapes to listen to and things like that, um, I’ve got a bit of Braille that I can read, I get stuff from the RNIB. I’ve got a strip light with a large magnifying glass, sometimes I can read a bit of large print, you know. Um if I want to write a letter I can do it with the word processor, I do it touch typing you know. And I seem to be able to get away with that by increasing the font very large but I can’t stick at it for long, you know, five minutes or so and it’s too much for me. It’s the light that’s the problem, the brightness. It can make your eyes really ache. But I find that light is really critical to me since I’ve had that, even the indoor ones. I find in the evenings when the lights are not as good, it’s hard work to try and begin to see you know.

I: So having (dog’s name) here, it sounds like in a way it gives you a sense of purpose in a way?

P: It does, it does really. You’ve hit the nail on the head there, that’s very true. You feel there’s an obligation that you’ve got to do something you know and I really enjoy it. Yeah. Everybody tells me what a lovely dog he is, I wish I could see his... If I can get him in the right light and right position, I can just begin to see what his face looks like. I hear people coming up to me saying on what a beautiful dog. It’s a bit embarrassing sometimes when I hear ladies saying ‘oh aren’t you a darling?’ and I say are you talking to me or the dog? (Both laughing).

I: One other aspect I’m interested in is how people’s identity as a visually impaired person is different with a dog and without.

P: What do you mean?

I: I guess it depends on the amount of sight you have and the impact it has but I’m working with somebody at the moment for instance who lost her sight through a brain tumour and she’s finding that people have lots of assumptions about her because she can’t see very well and she’s finding it very hard to be herself because a lot of people treat her in a particular way. Since she’s had a dog and she see’s herself differently.

P: Oh I see. I don’t know. One of the things I find it difficult to get over to people is, I mean I go out to various functions and that you know and when you’re there with a group of people, perhaps I’ll be sitting down at the dining table chatting away um, you can’t make eye contact with people, can’t look across the table and nod and you’re just completely lost, so you’ve got to rely on other people approaching you. That’s the thing that I find very difficult to get over to people. We were at a function the other day where we were about fourteen of us and we were having a, we have it once a year, a nice meal
somewhere, and they were all chatting away and my wife said to me are you okay. I said yeah, I feel a bit out of it, like that. And um, she called over to one of them and must have pointed to me or something and (friend's name) came over and talked with me and that was my first contact across the table, you know, way across and er, I don’t think people that have got sight realise that. It doesn’t hit home to them that you can’t see them and you can’t...you use your eyes so much unconsciously don’t you? I mean even in the home here with my wife and I think even now, although its two years, she’s still, there’s still things she hasn’t got to grips with. I mean she might say to me you’ve left so and so there and I say, Oh have I, she says yes on there. I say on where. On the piano she says. Well I don’t know its there. Once or twice she’s said to me oh you haven’t put that away. When you’ve got your sight you don’t think about things, your eyes catch sight of something and you think I must remember to put that away or whatever, when you can’t see it, it doesn’t register you know. And that is the problem often, I can leave things standing for days and not know they’re there at all. I suppose really, I’m trying to think back as to when I had my sight, things like that didn’t always register you know. You went through life and sort of remembered things and spotted things and I suppose it’s your eyes telling you all the time, they’re on the lookout for things aren’t they?

I: Does (dog’s name) in any way help with that?

P: Well I wonder (long pause). He’ll always find his lead for me and things like that if I can’t find it you know (laughing). I say to him where’s your lead (dog’s name) and he goes off, he finds it you know. I ask him to find things for me and he does go to them. It’s very strange because if the postman comes particularly with those bits of Braille I have I may not hear the postman and he’ll come walking in here with one of my letters and bring it up to me. So it’s little things like that that help. He’s always listening for the postman and he always tries to pick the stuff up. I came down the other day and I had about three different cases of talking tapes and I found them on the floor here where he’d brought them in and dropped them here for me (both laughing). Yeah, so he helps a bit like that you know.

I: Before you said people approach you more when you’ve got a dog and you said that in a way our eyes are visual cues, and that if you can’t see it is more difficult to engage with people, does having a dog, do his eyes in a way act to...

P: I wonder. Sometimes when I’m out I’m conscious of him pulling me over or something like that and it’s probably somebody I know is coming along and he’s spotted them and knows it and then I hear a voice saying Hello (dog’s name). I suppose there’s little things like that where his eyes are helping you know. And the very fact that he can take me to a shop that I ask him to is something. Very strange because the bakers where I go to they’ve got a little restaurant on the side and both times I’ve been down I’ve decided to go in. I go down and get the bread every week on a Thursday you know, and I’ve got in and had a cup of coffee or a sandwich or something. Having done it once, if I go in the Baker’s shop he’s torn between do I go up to the counter or do I go in there, so he often usually takes me straight round the restaurant because he knows that when he gets round there they’re all calling, hello (dog’s name) you know (laughing). But then when we come out of there he knows his way back to the counter and he’ll go up to the counter and sit you know, so he does help me tremendously like that. I mean he often wants to go places that he thinks I want to go like that, anticipation they call it, for instance I’ve taught him to find post-boxes you know. We’re out and I say find the
letterbox and he’ll go right up to the letterbox. So he does help a lot there, the fact that he’s getting to know things that I need.

I: Would you say that since having (dog’s name) there’s been any change in your social life at all?

P: Well I suppose it’s helped with contacting people and being able to talk to them better and that. As far as going out anywhere is concerned I mean sometimes we go to the theatre in (nearby town) and we take him with us you know. Not that he’s doing much except making sure I find the steps all right. But as far as making a difference to my social life I mean I don’t know. There’s the Blind Association that I go to, cos he loves coming there because he meets two or three other dogs and they’re quite pals when they get together you know.

I: And you said you keep in contact with people you’ve trained with?

P: Oh yes, yes, although they’re a fair distance some of them. Although there is one that lives in (local village) and I do go swimming with him every week. Well he’s the Chairman of our Blind Association and he takes the party swimming every week to a school in (nearby town). We go there on a Tuesday morning, about twenty of us.

I: You said earlier that there’s also increased contact now because people will now talk to you because of (dog’s name) as well.

P: Yes there has been more social contact in that respect.

I: So generally if I was to ask you about your quality of life now, compared to how it was before, would you say it was better or worse?

P: Oh it’s definitely better, yes definitely better. It’s made a tremendous difference to my outlook on life too, I mean I feel I’ve got a companion with me all the time, you know, which does make all the difference.

I: When you say a change in your outlook, what do you mean?

P: Well er, where I used to have a long cane and went out I felt absolutely on my own, isolated as it were and I’d make myself go out some days. My wife would say well are you going out for a walk today, I said yes I’d go out somewhere and I’d probably walk three or four miles. I’d come back and I’d think to myself I don’t know really, a lonely life you know. Because it’s quite true that people pass you and whether they’re reluctant to speak to you, you know, a little bit apprehensive of how you’ll react or not I don’t know. But I say since I’ve had him people just want to talk to you.

I: So that feeling of isolation is not there?

P: Oh absolutely gone yes. Absolutely gone. It used to worry me sometimes and sometimes it would be perhaps a cold day and I’d think to myself shall I go out or shall I not, you know. Knowing that you’d probably be out for an hour, a couple of hours walking and not meeting a soul really, hearing people go by and not speaking. It’s difficult because my wife said to me, oh why don’t you say hello to them, call out, but it’s difficult. You sense people coming and you can’t say, oh hello, you don’t know who you’re talking to really do you?

I: So it’s like you’re in your own world really, within another world.

P: Absolutely, yes like being in a cage as it were you know. Another little thing I found difficult to, is we get children, a lot of children around you know, and sometimes children will want to talk to you and um, with all the things that go on today you know, you feel a little bit embarrassed because people might see you talking to a kiddie and not realise you’re blind you know, but kiddies don’t know any barriers like that, they’ll talk to you,
you know, without any question and often there's a little embarrassment really as to what
you should do.
I: I guess with having a dog it would certainly demonstrate you have a visual
impairment?
P: Well having a dog yes, because I'll get kiddies come up and say can I stroke your
doggie and things like that you know. It's lovely really to let them do it and he is so good
with children. They can put their arms round him, pull his tail and he doesn't worry at
all.
I: So you can have quite an educative role really it sounds?
P: Oh yes, really. He's a lovely boy and he'll let you take hold of his toys and throw
them for him, he's just full of play. But as soon as he gets his harness on he's ready for
work.
I: Yes, somebody once said to me it was like he put on a business suit his dog.
P: That's right, yes. As soon as he gets that harness on he's just on duty you know.
I: Okay, well the last section now is a bit more about your relationship with the dog?
You said you had dogs before, how would you describe your bond with (dog's name)?
P: Um difficult really, I mean when I've had dogs before there must have been a bond
between us you know, because I used to walk my dog, used to talk to him you know.
You sort of think your dog understands you because they react to things you say. Um I
think the same with him really, I've bonded so well with him and he understands
everything I say to him, I'm sure of it. And I've only got to click my fingers or put my
finger up like that and he'll obey me. Yesterday I was at the Stroke club and we always
have a session of short mat bowling in the afternoon and I wanted to go out to the toilet
and I've always left him on the lead. And yesterday I thought to myself I'll leave him off
it, I'll let him just go free and he laid down beside me and sat and watched the balls and
that and then I wanted to go out and said Oh (dog's name) stay there. Away I went and I
must have been gone nearly five minutes, came back he was still there. You know, it's
marvellous really and yet there were other people moving around, he could have easily
been sidetracked by somebody speaking to him you know.
I: So with a normal dog, it wouldn't necessarily have been the same?
P: Oh no it wouldn't have done because I mean another dog that's not trained, they
would just go off or respond to anybody, any call.
I: So again that real trust there.
P: It is, it's really marvellous.
I: And you said he's a companion?
P: Oh no doubt about that, a real companion.
I: How is it different to a human companion?
P: Well course it is because with a human companion you can talk and things like that
but I've often said I wish he could talk (both laughing). On the other hand it may not be a
wise thing because he may be telling me a few things (laughing). But it's surprising how
they, I'm sure they seem to understand what you say to them you know. Er because um,
oh various things, I've said to him ever since I've had him you know, I'll tell him if
(wife's name) upstairs, I say go and find (wife's name), and away he goes you know.
You think well he obviously understands English you know. To give you one funny
example of that. We were out in Spain, my wife and I, going for a lovely walk and we
came to a spot where there was a narrow path between the cliff and the end of a garden,
and there was only a yard and half and there was this fierce dog, really showing his teeth
and barking at us you know, and I was saying going on buzz off like that. In the end my wife said to me he probably doesn’t understand English. Course I was pretty good on Spanish at the time and I thought oh what is it for dog, go away you know. And I said it to him in Spanish and he went. So I thought afterwards, he’s a Spanish dog you know (both laughing). But it’s marvellous to me how they understand our language isn’t it really?

I: So he’s a companion and somebody you can put a lot of trust in. What difference has that really made to you would you say?

P: Well I think it’s made all the difference really yes. It makes you feel there’s something worth living for in life, having a companion like him. He’s just there every day you know, and he’s so trusting and so reliable and they give you back so much more.

I: What does he give you back?

P: Well I don’t know, it’s that feeling of er, somebody that knows you and somebody that wants to be with you you know. And if you tell him he’s a good boy he wags his tail, he knows it. His response is terrific isn’t it? You are a good boy aren’t you, yes we know that (talking to dog’s name).

I: So would it have been different if you had had a pet dog for example?

P: Oh I think so yes, a tremendous difference yes. Yes because of the obedience and the response to commands and things like that. Plus of course how he takes you safely around everywhere. We’ve had several occasions where, I mean one day it was a very windy day and I had like a creaky fence ahead and as I got almost to it, the whole fence came over and he must have sensed it just prior to that and was straight round in front of me and stopped me. This fence crashed down and I thought well that was miraculous really because I could have been right there under it and you just don’t know, he could have knocked you over, done all kinds of things.

I: It really sounds like he is someone who is really looking out for you, the whole time.

P: Oh there’s no doubt, he is. I mean even, a wheel disc from a car was lying on the pavement one day and he stopped me, went round it and I thought what the dickens was that and I sort of kicked it with my foot and I realised what it was then, it was a disc you know. The same if there are any big puddles in the pavement he’ll walk around them, he takes me right round them.

I: Your relationship with him sounds very good.

P: Oh it is really, it’s incredible. I could not believe it.

I: Is it better than you expected?

P: I think so yes, I think so. Yes, it was hard to sort of visualise what it would be like because once you get hold of that handle and start walking it’s a totally different feeling than you’re expecting when you first start. I mean you get that sort of back and forth movement as they walk, their body I suppose, you know. At first I couldn’t sense what he was doing, but now I can sense any slight deviation to the right or to the left and I just go with him automatically.

I: Do you have thoughts about what will happen when (dog’s name) will retire?

P: I do, it often goes through my mind. Because having had dogs over the years and having to have them put down, it’s quite traumatic you know. I’ve often wondered, I’ve sort of said to myself he’s not being put down, he’s being retired, going to somebody to have a nice restful life you know. But I was listening to the local radio the other evening and a lady said she’d had guide dogs for forty years, she’s had about five, and they asked her how she felt when it comes to let them go. She said well it’s like losing a friend.
really, you know, you’ve been with them so long, it’s a bit hard, but then you know they’re going to somebody who’s going to give them a good retirement. They give you the option of keeping the dog if you can but then I mean my wife’s 76 and I’m 82 so whether we’d be able to do that I don’t know. So that’s in the future.

I: I don’t have any more questions to ask you. Is there anything you feel we’ve left out or that you would like to talk more about?

P: You’ve covered quite a lot of ground. I can’t think of anything else I don’t think no. No. Except every day is a challenge with blindness you know. I think that’s the only way you can look at it, you come up against all these problems, but there’s no doubt about it, he does ease a lot of them.

I: So you are still learning to adjust to having a visual impairment?

P: Yes, the consultant told me my sight would never come back. It’s got a bit worse actually. When it first happened they registered me partially sighted. But then I said to my doctor several times can I go for a re-assessment and he said you can see light can you. I said yes I can see a bit of light. Well he said I don’t think there’s anything else he can do for you. Until GDBA trainer came down with the long cane, I was talking to her about it, she said if I was you, I’d keep on to your doctor to get a re-assessment. One day I was down there with my wife and chatting with him and I said I’m not seeing things as well as I did before and he said he would send me for another test. I went through the field test on the computer and afterwards he said, I’m sorry to have to tell you but you’ve got to be registered blind now. So it’s just one of those things you know.

I: From your point of view, now you’ve had some time to think, that would have been more helpful to you, at that time to help you cope with it all better?

P: Well I think if we could have got some help from Social Services quicker than we did it might have helped. See one big problem was that after I’d had this heart attack and this business they told me that I would be going to see the consultant again within the month but didn’t get an appointment and eventually my wife really blew her top with them and it was only because of that we were able to get anywhere and we had to go privately. We had to go and see the ophthalmologist privately, had to see the neurologist privately. And the hospital told us after six or eight months that I got lost in the system. It was really frustrating because I couldn’t see where it was going to end. From my point of view I couldn’t even think where I was going even, and there I was thinking is there anything I can do. Can they tell me anything, you know and explain to me what’s happened. It was only because my wife was able to get this privately that we were able to go and see the ophthalmologist and when I went down to see my doctor he said what do you want me to do? I said can’t you get me to see somebody to tell me what is really wrong. My doctor should have sent me to an ophthalmologist automatically. There was such a long delay that we did it privately. That was the biggest problem I think, getting things moving. Then they gave me some long cane training and that went on for weeks and weeks, I had to keep ringing them up and pestering them and in the end er, had somebody come along you know.

I: At any point did anybody offer you any counselling?

P: None at all.

I: Do you think that would have been a good idea if they had?

P: It might have done, my own son suggested it might be a good idea. He said it might be worth speaking with your doctor and asking him if there is anybody who could help. I think it probably would have helped because my friend in (next county) who I’ve never
met, I said to him one day, you know (friend's name) you’ve been more like a counsellor than anyone else. He said oh come off it, I’ve only just had a chat, just trying to be helpful. I said talking to you has made a tremendous difference to me, helped me to unload a little bit of my problems you know. I think it would have done if I could have gone to a counsellor, it would have put my mind at rest a bit. You’d think with blindness they would adopt the attitude of 'my goodness, this chap he can’t see a thing and er, we’ve got to help him' you know. No I think that would have helped a lot. I don’t know what it is about Social Services but they don’t seem to have their priorities right do they? Well I know even when it came to the question of supplying me with a long cane and this person that came here, and said ‘we’re limited in what we can do, we haven’t got the facilities and all that’ you know, and yet they say there’s a tremendous lot of wastage with their finances.

I: I know the guide dogs are moving more into rehab now aren’t they so they will do more cane training?
P: That’s right yes (long pause)
I: Okay, well I have no further questions. Thank you very much for your time, I’ll turn the tape off now.

(DEBRIEFING followed)
PARTICIPANTS RESPONSE TO FEEDBACK REPORT

COMMENTS

1. How well do you feel the findings fit with your experience of guide dog ownership?
   Very well in most instances

2. Are there any points that you disagree with?
   I agree with what you say but didn't always agree with the emphasis of the report and the lack of emphasis given to the centrics.
   Also, the survey isn't very good.
   Much better than last year.
   I do the regular wrong perception because they are not using it properly.

3. Do you feel that any important things have been left out of this report?

Any other comments?

Sorry for the delay, been away.
Appendix 13

COMMENTS

1. How well do you feel the findings fit with your experience of guide dog ownership?
   Most of the report does apart fromStage 1. Probably because I lost my sight as a child and while I was in a school for the visually impaired which did not have a cushion.

2. Are there any points that you disagree with?
   No

3. Do you feel that any important things have been left out of this report?
   No

Any other comments?
I look forward to seeing the larger report.