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Volume I of III

Louise Banham

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

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**LOUISE BANHAM BSc MSc**

**THE ROLE OF A GUIDE DOG IN THE PROCESS OF ADJUSTMENT TO  
VISUAL IMPAIRMENT**

**A thesis submitted in partial fulfilment of the  
requirements of the Open University for the degree of Doctor of Clinical  
Psychology**

**NOVEMBER 2000**

**SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE**

AWARD DATE: 20 September  
2000

## **ACKNOWLEDGEMENTS**

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Possible recommendations for the delivery of services to people with a visual impairment were made, including closer links between voluntary, social and health professionals, and a greater consideration of the social model of disability. There were also suggestions of an increased role for clinical psychologists in the rehabilitation of people with a physical disability.

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## **1.0 INTRODUCTION**

The introduction begins by examining some facts about visual impairment and its consequences. The evidence that it can result in psychological distress will be discussed, along with the proposed mechanisms mediating adjustment to visual impairment. The introduction will then consider how guide dog ownership could impact on adjustment to visual impairment. As there is limited research in this area the literature on companion animals will also be drawn on. Arguments for utilising a qualitative methodology to explore the experiences of guide dog owners are then presented.

### **1.1 Towards a definition of visual impairment**

The 1995 *Health Survey for England* found that of the eighteen percent of adults reported to have a disability, eight percent had a visual impairment (Prescott-Clarke & Primatesta, 1997). It has been estimated that 1.7 million people in the United Kingdom have a serious sight problem (OPCS, 1989). Over ninety-five percent of these people have some residual vision, although they still face difficulty in doing everyday activities such as reading, travelling independently and preparing meals (Ryan & McCloughan, 1999). About fourteen percent experience sudden, traumatic loss of vision, whilst eighty-six percent experience a progressive deterioration (Evans, 1995).

Most eye disorders occur in older people which explains why almost ninety percent of people with a serious sight problem are over sixty (Evans, 1995). Age-related macular degeneration is the commonest cause of visual impairment in persons over sixty-five, in which the macular area of the retina progressively deteriorates, leading to permanent loss of central vision (Coakes, 1997). The main cause of sight loss in younger adults is

diabetic retinopathy. This untreatable condition affects people that have been insulin-dependent for many years, and can ultimately result in total blindness. Glaucoma and cataracts are also significant causes of visual impairment across the age span, although both are more amenable to treatment. Other causes include degenerative myopia, retinitis pigmentosa, and neurological disease (Coakes, 1997).

To become registered as blind in Britain by an ophthalmologist, a person must be 'so blind as to be unable to perform any work for which eyesight is essential' (National Assistance Act, 1948). This equates to anyone whose visual acuity with both eyes together is less than 3/60. There is no statutory definition of partial sight but for registration purposes those with visual acuity between 3/60 and 6/60 (ability to read the top line of an optician's chart) are eligible (Coakes, 1997). Registration brings certain benefits including increased tax allowances, supplementary benefits, free travel, tuition in Braille, instruction in cane use, free access to talking books and a reduced TV licence (Cullinan, 1986).

Sight loss affects the individual on a number of levels simultaneously, requiring changes to the way they think, feel and behave (Dodds, 1993). For those of working age, unemployment is a significant problem. A recent UK survey of disabled people in the labour market found that only fifty-two percent of a total 116,000 people with sight problems were in employment (Labour Force Survey, 1999). This leads to a loss of valued social roles and raises the risk of financial problems. They are no longer able to drive and as mobility decreases, the risk of accidental injury increases (Wulsin, Jacobson & Rand, 1991). There may be a loss of independence, environmental security,

recreational activities, meaningful interpersonal relationships and social support networks (Cherry, Keller & Dudley, 1991).

## **1.2 Evidence of psychological difficulties**

It is apparent that the onset or progression of visual impairment may require considerable adjustment, both physically and psychologically. Several studies have shown that some individuals with a visual impairment experience intense and protracted psychological distress, which suggests they find it difficult to adjust.

Karlsson (1998) explored indicators of distress according to degree of visual impairment in two groups of people, those under age sixty-nine and those above seventy. They found reports of psychological distress increased with poorer vision, and were more prevalent in younger people. Compared to those with partial sight, those who were blind were less content with their lives, were more likely to have experienced a crisis, had higher rates of depressive symptoms on the Health Anxiety and Depression Scale, and experienced more feelings of isolation. Furthermore, whilst sixty percent of the younger group reported depressive symptoms, only twenty-four percent of the older group did, which the authors suggested was a result of older people considering vision loss as a more normative event. This study should be interpreted cautiously however, as the data was derived from telephone interviews where the effects of respondent and experimenter bias are less easy to control. Furthermore, there seems to have been little attempt to control for other confounding factors, making it difficult to conclude the extent to which the depression and anxiety scores are related to visual impairment rather than any other variables.

Rather than simply a transitory response to loss of vision, some studies have found evidence that psychological distress can be persistent and severe. For example, Fitzgerald, Ebert and Chambers (1987) conducted a four year follow up study of patients with acquired blindness and reported the persistence of depression and anxiety symptoms in over fifty percent. A recent study by DeLeo, Hickey, Meneghel and Cantor (1999) also claimed that the effects of visual impairment might drive some people to commit suicide. They examined the case histories of suicides involving people with visual impairments. Of the twelve individuals, one had a history of mental illness and three had experienced other traumatic life events. However, in all cases, substantial anxiety about progressive sight loss had been reported and identified as a significant contributory factor in the suicide by close family members. Clearly the small sample size and retrospective nature of the study do not permit firm conclusion, but these findings suggest that sight loss can produce severe psychological distress, particularly when that loss is progressive.

Many studies in this area have been retrospective, which makes it difficult to determine the impact of visual impairment. However, Wulsin et al. (1991) conducted a prospective study of twenty-eight adults between the ages of eighteen and sixty, recently diagnosed with diabetic retinopathy. They found that as visual acuity decreased so did psychosocial adjustment, whilst reports of psychological symptoms increased. These results were only evident at eight-month follow-up, and had not been significant four months earlier, which led the authors to suggest that symptoms only emerge when people are able to acknowledge the full impact and consequences of the impairment.

It should be noted that other studies have failed to find evidence of psychological distress. Teitelbaum, Davidson, Gravetter, Taub and Teitelbaum (1994) measured depressive symptoms using the BDI in a group of eighty-seven male veterans, whilst controlling for health problems. No relationship emerged between visual loss and depression, but depression scores increased with the number of physical health problems. Although this study is inconsistent with other research it should be noted that the sample was not heterogeneous. First, male war veterans may exhibit a reduced tendency to report symptoms of depression. Furthermore, this group had good access to social networks and professional support, which has been found to be related to decreased depression in visually impaired people (Oppegard, Hansson, Morgan, Indart, Crutcher & Hampton, 1984).

In sum, there is some evidence of a relationship between visual impairment and psychological disturbance. However, this appears to vary according to the degree of visual loss and the rate of progression, as well as the age, and personal circumstances of those affected. The prospective study by Wulsin et al. (1991) seems more persuasive, but as the participant group also had an underlying chronic illness, it is not clear the extent to which psychological disturbance is related to the deteriorating vision or some other aspect of the illness. It is also important to remember that many disabled people are more socially disadvantaged, experiencing higher rates of unemployment and poverty. These factors alone could help to explain the occurrence of psychological distress.

According to Dodds, Bailey, Pearson and Yates (1991) psychological adjustment to visual impairment is characterised by low levels of anxiety, an absence of depression, a

positive attitude towards blind people, and a high sense of self-efficacy, self-esteem and acceptance of the impairment. Therefore the presence of depression and anxiety is suggestive of difficulties in adjusting to visual impairment.

In order to further understand the relationship between visual impairment and psychological adjustment, it is helpful to look at the models that define physical disability. These demonstrate how definitions represent a common discourse against which the individual with a visual impairment evaluates themselves, and in which the perceptions of others are shaped.

### **1.3 Models of disability**

#### **1.3.1 Medical model**

The traditional medical approach to disability as elaborated by the Royal College of Physicians (1986), regards a physical impairment as a disorder requiring medical intervention. The World Health Organisation (1980) adopted this medical definition as the international norm, distinguishing between loss of function (impairment), reduced ability to perform every day activities (disability) and social disadvantage (handicap). The British Psychological Society's report, *Psychology and Physical Disability in the National Health Service* (BPS, 1989) highlighted several criticisms of the medical definition of disability. Fundamentally it implies a 'norm' from which people who deviate are seen as abnormal, and focuses on deficits, rather than individual strengths. Consequently, this results in people being labelled according to their deficits, resulting in social devaluation and discrimination. This may help to explain why individuals find it hard to adjust to disability. It also implies that any acquired impairment is necessarily a

‘tragedy’ for the individual, encouraging the need to seek ‘normalisation’ through a striving after cures and rehabilitation (Camilleri, 1999). Finally, there is little consideration of other factors that might influence the level of disability.

### 1.3.2 Social model

Others argue disability is a social phenomenon that is explained not by the functional defects of the person but in the way socially constructed barriers (for example in the design of buildings, transport systems and employment opportunities) have ‘disabled’ people with an impairment (Oliver, 1990). Proponents of this model reject the ‘personal tragedy model of disability’, arguing that its emphasis on converting disabled people into ‘able-bodied’ ones, simply reinforces prejudice against disabled people and maintains their exclusion from society (McLellan, 1997). The implication of the social model is that rather than ‘curing’ and changing disabled people to fit the existing social structure, the physical and social environment needs changing to accommodate them, as no amount of individual effort at ‘adjustment’ to impairment can remove its effects (Abberley, 1993). However, although many people have embraced this model, it is not without its criticisms. French (1993) argued that the focus on socially constructed barriers excludes a consideration of the personal experience of disability, whilst Morris (1991) complained that it denies the embodied experiences of pain and affliction that are common for many people with impairments.

### 1.3.3 Psychological models

According to the medical and social models, everyone should have difficulty adjusting to a physical impairment, but this is clearly not the case. Psychological models appear to

bridge the gap in understanding how some, but not all individuals have difficulty adjusting to visual impairment. One argument follows that whether physical impairment has a negative psychological impact depends on the individual's personality and the type of lifestyle that is valued (Finkelstein & French, 1993). A number of personality and individual factors have been identified to determine adjustment to physical disability (BPS, 1989), including attributional style, personal control, learned helplessness and cognitive representations of disability.

A second argument states that some individuals may be socialised into experiencing distress because of the way in which society responds to impairment (Abberley, 1993). The effects of social stigma, limited access, unemployment and poverty can hinder the individual's social and emotional development (Finkelstein & French, 1993). From this perspective people with impairments absorb negative attitudes about disability both before and after becoming disabled, and therefore, may be more prone to experience depression as a result.

A third perspective argues that the occurrence of mental health problems may arise out of the failure of services to strengthen the individual's coping abilities to enable them to adapt their lifestyle (BPS, 1989). This perspective highlights how the response of health and social services may be implicated in adjustment to impairment.

There is insufficient space to discuss all these factors in terms of how they affect adjustment to visual impairment. However, those factors that have been specifically



reported to mediate the relationship between visual impairment and adjustment will now be examined, although it should be noted that this is not an exhaustive list.

#### **1.4 Factors implicated in adjustment to visual impairment**

##### **1.4.1 Self-esteem**

According to Tuttle (1984), self-esteem is a sense of self-satisfaction that determines how events are interpreted. It is based on a sense of self-worth acquired during childhood, and a sense of competence developed during adulthood (Coopersmith, 1967). Reportedly, many individuals with a visual impairment suffer a 'catastrophic' loss of self-esteem (Dodds, 1993), and this appears to be the fundamental mechanism through which the impact of visual impairment results in psychological distress (Shute, 1991). The effects of stigma and reduced self-efficacy are two of the ways in which self-esteem may be deleteriously affected.

##### **Stigma**

Being registered as blind or partially sighted means being labelled as belonging to a minority group identified as being 'different' from the majority (Dodds, 1993). Some individuals may be stigmatised by their appearance, whilst others may be stigmatised by the equipment they use, such as a long cane (Welsh, 1997). Such labelling may cause individuals to view themselves in light of these stigmatising attitudes, making it difficult for them to accept their disability (Coughlan, 1997). One disabled writer has commented on how being labelled as 'impaired' leads to feelings of shame and dehumanisation which make it very difficult to maintain positive self-esteem (Camilleri, 1999).

Disabled people have talked about trying to conceal their impairment in order to subscribe to ideas of 'normality', and therefore, avoid the anxiety and rejection of others (French, 1993b). If they successfully conceal their disability they are spared the difficulties associated with being labelled, but at the same time they compromise their own safety and integrity. For example, Welsh (1997) reported that forty percent of people, who rarely used a long cane because of a wish to avoid the stigma, had been struck by a vehicle at least once. Further, by concealing their disability they will be faced with others having inappropriate expectations of them that they are unable to meet, which can negatively affect self-esteem (Griffin & Kendall, 1989).

### **Self-efficacy**

Dodds (1989) proposed a model, formulated around Bandura's (1977) self-efficacy theory that described how visual impairment plunges the person into a state of incompetence, which can lower self-esteem and produce depression. Self-efficacy refers to the belief that one can successfully perform intended behaviours. Those with a sense of high self-efficacy feel they are likely to succeed, whilst those with low self-efficacy believe they will fail, so try to escape the task in some way or another to avoid this (Dodds, 1993). Each individual develops a view of themselves based on their abilities, achievements and relationships with others that determines their perceived self-competence (Coughlan, 1997). It follows that loss of these aspects of the self, incurred through visual impairment, will lower self-efficacy. The degree to which this impacts on self-esteem would seem to be highly individual, depending on the personal value of the attribute, ability or relationship that has been lost (Coughlan, 1997).

Researchers have identified some restrictions frequently imposed by visual impairment that may be particularly likely to lower self-efficacy and impact on self-esteem. People with visual impairments often find their inability to make eye contact or detect visual cues, make it more difficult to communicate with people (Welsh, 1997). Consequently, they may withdraw from social situations, feeling no longer able to assume an equal role. Related to this, an increased dependence on others for help with mobility and living skills may feel demoralising, and this too has been associated with lower self-esteem (Beach, Robinet & Hakim-Larson, 1995). Finally, the high rates of unemployment and poverty found in this group, and the greater dependence on government benefits may reduce self-esteem (Coughlan, 1997). This may be particularly true in western cultures that value autonomy and equate independence with maturity and worth (Tuttle, 1984).

#### 1.4.2 Service Provision

It is likely that adjustment to visual impairment is also influenced by the quality of response from health, social and voluntary agencies. In the UK, each local social services department has a statutory duty to provide services for people with visual impairments and every individual should have a comprehensive assessment of their needs (HMSO, 1990). Low vision services aim to reduce the disabling impact that a visual impairment can have through the provision of aids, information about entitlements, training and sometimes, emotional support (Ryan & McCloughlan, 1999). These services are a form of rehabilitation, the aims of which are to enable individuals to recover lost independence and to restore personal control (Stevenson, 1999).

In the early stages of onset in particular, individuals are likely to feel frightened and have questions about their future. The willingness of professionals to offer information, to listen to worries and respond to them, is an important factor in reducing distress (Coughlan, 1997). Unfortunately, people with physical impairments have directed an increasing number of criticisms at professional agencies. Glendinning (1997) reported how people are often disadvantaged by the variable quality and poor co-ordination of services that fail to account for individual needs. Support for this comes from a recent review which found evidence of deterioration in services promoting rehabilitation on both sides of the health and social care divide through the 1980s and 1990s (Nocon & Baldwin, 1998).

In the UK, low vision services have been described as 'fragmented and patchy' (Dickinson, 1995). A report commissioned by the Royal National Institute for the Blind (Ryan & McCloughlan, 1999), revealed a number of specific complaints that emerged in a survey and through focus groups with people that were visually impaired. First, many respondents felt they received inadequate information about the potential help available to them after diagnosis. Second, many respondents felt they waited too long before being seen by professionals, and they wanted help from one central place rather than from different agencies. Third, respondents wanted greater choice, particularly regarding the range of low vision aids available. Another important finding to emerge was that thirty percent of respondents expressed a need for 'someone to talk to about negative feelings'. This mirrors more general findings of a lack of counselling and support for disabled people (Royal College of Physicians, 1986). In sum, it appears that there is a large gap between demand for services and their provision, which may mean that people with

visual impairments are not receiving the support, information or training they require to aid their adjustment.

## **1.5 Guide Dogs**

It has been shown that the consequences of visual impairment are widespread, affecting the person on many levels. One of the ways individuals may try to limit the restrictions imposed by their impairment is through acquiring a guide dog. There are around 4,500 guide dogs working in Britain at present (GDBA, personal communication), helping both partially sighted and blind individuals. Anyone over sixteen can apply for a guide dog. Individuals undertake three weeks intensive instruction at a residential training centre, and the dog works on average seven years, during which dog and owner develop a close relationship. Although guide dogs are primarily mobility aids, anecdotal reports and the scant evidence available on the effects of guide dog ownership (e.g. Zee, 1983), has suggested they serve a much wider function for the individual. This research will be discussed below, but as this is limited, the literature on companion animals will be drawn upon in an attempt to understand how guide dog ownership may impact more fully on adjustment to visual impairment.

### **1.5.1 Evidence of how the guide dog impacts on adjustment**

After an extensive literature search, the researcher found only one published study that had specifically addressed the impact of guide dog ownership on adjustment to visual impairment. This was a study by Zee (1983) published in a book about companion animals. Zee distributed non-standardised questionnaires to thirty-one guide dog owners in America. Respondents were asked to describe the nature of the bond with their dog

and outline how the guide dog relationship helped them deal with difficulties caused by the visual impairment. It is not clear how the results were analysed, but a number of positive findings emerged. According to respondents, the dog was characterised as loyal, devoted, reliable and predictable in its behaviour. Owners regarded the dog as a supportive friend or family member, and planned to keep it following its retirement. The owners also reported being able to detect their dog's mood and vice versa, illustrating how the relationship was far closer than with a pet dog. Furthermore, the guide dog had reduced social barriers between themselves and the public, and the relationship had given them greater control over 'destructive emotions'.

Clearly this study has many flaws, including a small, self-selected sample and a methodology that was not validated. Only those who had experienced positive effects may have volunteered to participate. However, it suggested the importance of the bond between guide dog and owner, and the positive effects of the relationship in enhancing social contact, and in reducing negative feelings associated with visual impairment.

### 1.5.2 Benefits of companion animals

It is possible to draw on the literature on companion animals to gain further insight into how a guide dog may facilitate adjustment to visual impairment. There is growing evidence of the benefits of a range of companion animals for both physical and psychological health, across all age groups (e.g. Garrity, Stallones, Marx & Johnson, 1989; Serpell, 1991; Zasloff, 1996). Pets have been reported to provide an important source of unconditional love, security and companionship, as well as giving the opportunity for play and relaxation (Siegel, 1990). These factors suggest a close

relationship with a pet has a stress-reducing effect. This is demonstrated further in studies which found that people over the age of sixty-five who indicated a strong attachment to their pets, had lower levels of anxiety (Wilson & Netting, 1983) and depression following a bereavement (Garrity et al., 1989). Consequently, clinicians have maximised on the positive effects of interaction with pets, by introducing them into therapeutic settings (Beck & Meyers, 1996).

Given the reported closeness of the attachment between guide dogs and their owners (Zee, 1983), this evidence suggests the guide dog relationship might confer many benefits in terms of companionship, relaxation and the reduction of psychological distress.

### 1.5.3 Animals as social facilitators

Further evidence to suggest the guide dog relationship may facilitate adjustment to visual impairment comes from research that has found animals fulfil an important social role. Visually impaired people often evoke stifled and embarrassed behaviour from sighted people that creates a social barrier. Sighted people may be unclear about how to respond to someone with a disability and choose to avoid them altogether (Thompson, 1982). Not only does a guide dog enable the individual to access their social environment more easily, there is evidence that it can reduce the social awkwardness that many people exhibit in the presence of a person with a disability. For example, Zee (1983) reported that guide dog owners had twice as many conversations with strangers when out walking, than people using a long cane. Similar findings have come from studies of people using wheelchairs who have dogs especially trained to help them. Eddy, Hart and Boltz (1987) found that passers-by smiled and engaged in more conversations with wheelchairs users

who had dogs, compared to those without a dog. This effect is not confined to those with disabilities, as research has shown that people with companion animals are perceived more positively than those without animals (Beck & Meyers, 1996). This may be particularly valuable to individuals with visual impairments who are prone to being stigmatised when using a long cane, and who may feel socially isolated.

A working dog could bring further psychological benefits. A prospective, randomised controlled study by Allen and Blascovich (1996) explored the effects of having a service dog among wheelchair users. Forty-eight participants were divided into two groups, those who obtained a dog one month into the study, and those who received the dog in the twelfth month. Data from standardised questionnaires were collected over a two-year period and revealed that all participants showed substantial improvements in self-esteem and psychological well being within six months after receiving their dogs.

### **1.6 Rationale for study**

The existing literature exploring the bond between humans and companion animals suggests several psychological and social benefits associated with guide dog ownership that could potentially facilitate the process of adjustment to visual impairment. It is clear that the guide dog performs functions beyond its primary role as a mobility aid and evidence suggests companion animals bring many benefits that would be particularly beneficial for those with a visual impairment. These include enhanced social contact, ability to cope with negative emotions and companionship. The aim of this study was to explore the impact of the guide dog relationship on the process of adjustment to visual impairment. It was hoped that this might be able to influence decision-making regarding



the rehabilitation of visually impaired people, as well as contribute to the literature on companion animals.

Furthermore, there is nothing in the academic literature that addresses the factors that lead individuals to volunteer for a guide dog. This study aimed to understand the context within which this happens, to explore how individuals managed prior to acquiring a guide dog, and to determine what help they received from professional services. It was thought that contextual issues might reveal further information to explain why a guide dog was chosen, perhaps identifying consequences of the visual impairment that were particularly difficult, or highlighting particular patterns in relation to how others responded.

The aim was to concentrate only on first-time guide dog owners. This was for two reasons. First, it was thought that the impact of the dog might be more salient for new owners and therefore, experiences relating to this might be easier to recall. Second, it has been documented how the retirement or loss of a previous guide dog can produce psychological distress (Nicholson, Kemp-Wheeler & Griffiths, 1995). It was thought that this potentially confounding factor could be removed by interviewing first-time guide dog owners.

### **1.7 Research Aims and Questions**

In the tradition of grounded theory, no specific hypotheses were generated, but the following research questions were used to guide the interviews.

1. What impact did visual impairment have on participants?
2. What were participants' experiences of health and social services?

3. What decisions did participants make regarding ownership of a guide dog?
4. What were the main ways in which having a guide dog impacted on participants' lives?
5. In what way did guide dog ownership impact on the following areas: mood, identity, personal relationships, work and leisure activities, mobility, and independence?
6. How did participants describe the relationship with their guide dog?

### **1.8 Reasons for a qualitative methodology**

To investigate the experiences of first-time guide dog owners a qualitative methodology using Grounded Theory (Glaser & Strauss, 1967) was deemed most appropriate.

#### **1.8.1 Epistemological reasons**

The choice between a quantitative and qualitative methodology requires decision-making at a philosophical level concerning the generation of knowledge. Whilst the quantitative paradigm subscribes to the premise that there is an objective truth, the qualitative paradigm honours a social constructionist approach which emphasises there is no single truth, only multiple interpretations (Charmaz, 1995). One of the criticisms directed at existing disability research is that it has been located within the medical model, and consequently directed by positivist assumptions, experienced as oppressive (Oliver, 1996). This has resulted in disabled people being distanced from the research process, their voices remaining unheard and misunderstood. Oliver (1996) has argued for the need to develop an “alternative, emancipatory approach” to research, based on empowerment and reciprocity. He believes it is important to encourage participants'

reflexivity regarding the research issue to enable researchers to identify with them. It was thought that a qualitative methodology would go some way to meeting these goals and allow for the development of theory regarding the impact of guide dog ownership that was representative of the participants' views, rather than the researcher's. This reflects a wider policy emphasis towards giving more attention to service users views in the planning and monitoring of health and social services, as echoed in the Government's White paper, *A First Class Service* (DoH, 1998).

### 1.8.2 Technical reasons

As noted by Strauss and Corbin (1998), research that attempts to understand the experience of persons in a particular situation lends itself to qualitative methods, especially when the aim is to explore areas about which little is known. The aims of this research were exploratory with no fixed hypotheses about the results, and so a qualitative methodology suited well. It was hoped the data produced from semi-structured interviews could be used to generate new theory (Strauss & Corbin, 1998) about the psychological sequelae associated with guide dog ownership, and influence decision-making regarding the rehabilitation of visually impaired people. Aside from this, there were several technical reasons for not adopting a quantitative design. Fundamentally, there were unlikely to be enough first-time guide dog owners available for participation to fulfil the requirements for a reliable statistical analysis. Discussions with the GDBA, revealed that there would be approximately forty new guide dog owners completing their training within the time frame of this study. This number was calculated to be too small for a well controlled, between measures quantitative study. It was also anticipated that there would be great difficulty in matching these individuals with a group of visually

impaired people without guide dogs. Furthermore, a repeated measures study that involved assessing participants before and after acquiring a guide dog was not deemed feasible because the entire process, from application through to completing training typically takes over a year. Participants would not have spent adequate time with their dog to be able to comment reliably on its impact. However, of overall importance in deciding not to use a quantitative method, was the belief that it would not provide the depth of material required to answer the research questions.

## **2.0 METHOD**

### **2.1 Design**

This study employed a cross-sectional within group design and qualitative methodology, utilising a semi-structured interview format. The Grounded Theory approach (Strauss & Corbin, 1998) was used to guide the data collection and analysis. This approach was utilised as it emphasises the inductive generation of theory from the data, rather than one where data is collected to test preconceived hypotheses (Seale, 1999). It is particularly suitable for under-researched areas where the aim is to develop an understanding of participants' experiences (Punch, 1998). This was chosen in preference to Content Analysis, and Interpretive Phenomenological Analysis (Smith, 1995), neither of which it was believed, would have captured the emerging issues in sufficient detail, or allowed for the development of theory. Furthermore, the small number of first-time guide dog owners available for participation and the length of time taken to process an application for a guide dog precluded a meaningful quantitative analysis using between or within-group designs.

### **2.2 Participants**

The participants were thirteen individuals with a visual impairment, who had trained with, and subsequently acquired ownership of, their first guide dog. The sample consisted of eight males and five females, aged between 28 and 82 years, with a mean age of 51 years. Ten people lived with a spouse or partner, two were single and one was divorced. Eight of the participants were unemployed, three had jobs and two were retired. The length of time participants had been visually impaired ranged between one and 47 years, with a mean of 13 years. All participants had some residual vision that was

either peripheral or central. Length of guide dog ownership ranged from four to 12 months, with a mean of eight months. These details are summarised in Table 1.

**Table 1. Participant details presented in the order in which they were interviewed**

Participant	Age	Gender	Marital Status	Occupation	Duration of Visual Imp	Cause of visual impairment	How long had dog
1	28	M	Single	Unemployed	1 year	Lever's Disease	6 mths
2	55	F	Single	Unemployed	Since age 8	Unknown	5 mths
3	53	M	Married	Unemployed	4 years	Diabetic retinopathy	4 mths
4	31	F	Married	Customer Advisor	Since age 2	Unknown	6 mths
5	57	M	Divorce	Unemployed	25 yrs	Diabetic retinopathy	9 mths
6	82	M	Married	Retired	2 yrs	Stroke	6 mths
7	58	M	Married	Unemployed	3.5 yrs	Diabetic retinopathy	8 mths
8	67	M	Cohab	Retired	2 yrs	Diabetic retinopathy	9 mths
9	61	M	Cohab	Unemployed	14 yrs	Cataracts and glaucoma	10 mths
10	33	M	Single	Consultant	8 yrs	Genetic Macular degeneration	12 mths
11	55	F	Married	Unemployed	4 yrs	Glaucoma and cataracts	10 mths
12	29	F	Married	Admin Asst	Since birth	Cataracts and glaucoma	10 mths
13	53	F	Married	Unemployed	27 yrs	Retinitis Pigmentosa	9 mths

### 2.2.1 Inclusion and exclusion criteria

All participants met the following selection criteria.

#### **Inclusion criteria**

1. Never owned a guide dog before.
2. Completed training with their guide dog at a Guide Dogs for the Blind Association (GDBA) centre within the last twelve months.
3. Been at home with their guide dog for at least three months.

- 
4. Were registered as either 'partially sighted' or 'blind'.

### **Exclusion criteria**

1. Presence of a significant learning disability that prevented them giving informed consent.
2. Presence of a significant hearing impairment that prevented participation in an interview.
3. Non-English speaking.

### 2.2.2 Sampling issues

The aim was to obtain multiple perspectives of guide dog ownership from individuals approaching the subject from a variety of different backgrounds and experiences. This is known as 'open sampling' within the grounded theory methodology (Strauss & Corbin, 1998). Sampling was therefore open to all possible first-time guide dog owners in the Southeast who met the inclusion and exclusion criteria, a total of twenty people. Thirteen people consented to participate, (a response rate of sixty-five percent), and they constituted the sample. This response rate was regarded as very good, and it was thought this reflected the importance of the guide dog relationship to the owner. The researcher also believed it validated the rationale for the study in demonstrating that first-time guide dog owners were keen to discuss their experiences.

A central feature of grounded theory is the concept of 'theoretical sampling' in which sampling is not a discrete stage predetermined before conducting the research, but evolves during the research process (Strauss & Corbin, 1998). Ideally sampling

continues until theoretical saturation occurs, that is, the data no longer show new theoretical elements (Punch, 1998). However, in reality theoretical sampling is problematic, and researchers typically have to sample on the basis of what is available (Strauss & Corbin, 1998). For this study, the number of first-time guide dog owners available for participation was small and time was limited, so it was not possible to undertake theoretical sampling in its purest form. An attempt was made by conducting the data collection and analysis in phases, so that following each block of five interviews, the data was analysed for emerging categories which then guided further questioning.

## **2.3 Data Collection**

### **2.3.1 Rationale for Interview Format**

Data was obtained from participants during face-to-face interviews using a semi-structured interview schedule (Appendix 1), designed to last between one to one-and-a-half hours. An interview was thought to be the best method of data collection because it would allow a more in-depth study of participants' experiences. It would also enable the researcher to explore the meanings associated with events, and provide the flexibility to enable the pursuit of new themes as they emerged. In addition, a discussion about guide dog ownership would inevitably raise sensitive issues related to coping with a visual impairment, which could cause distress. The interview method is ethically more sound in that it enables the researcher to facilitate rapport, monitor the participant's response to the questions and re-evaluate should the participant become distressed (Smith, 1995).



### 2.3.2 Development of the interview Schedule

The interview questions were developed after discussions with several people. Initial questions were generated through informal meetings with people known to the researcher, who had a visual impairment, but no guide dog. Further questions arose from a review of the literature concerning the impact of visual impairment, and the therapeutic use of animals. These questions were shaped and revised following discussions with two guide dog owners, the GDBA and a clinical psychologist working in the field of physical disability. The overall design of the interview schedule (Appendix 1) was guided by the suggestions of Smith (1995).

### 2.3.3 Piloting the interview schedule

The interview schedule was piloted on a visually impaired person who had owned a guide dog for one year. This person was contacted via a colleague of the researcher's. Following the pilot several revisions were made, including the addition of a question regarding long cane use. It was also thought that questions regarding the impact of the guide dog needed to be more open-ended to avoid forcing participants' responses. It was decided that the researcher would note the responses given by participants to these questions, to use as prompts for further questioning later in the interview.

The issue of people needing to talk about their experiences of adapting to sight loss also emerged from the pilot. This clarified the importance of assessing the impact of the interview on each participant, and of providing information about services they could contact for information or support should they wish to.

#### 2.3.4 The interview schedule

The interview schedule followed the broad structure outlined below. It was not rigidly adhered to, but rather used as a guide to facilitate discussion in particular areas.

##### **Section 1: Background Information**

This section recorded demographic information including the participant's gender, age, marital status and occupation. It also recorded details of their visual impairment and the extent of their remaining vision, as well as the length of time they had owned their guide dog.

##### **Section 2: Decisions to Get a Guide Dog**

Participants were asked how they came to a decision to get a guide dog and about the process of acquiring the dog. They were also asked about some of the difficulties they faced in doing this.

##### **Section 3: Impact of having a guide dog**

This section began with a general question about the impact the dog had on the participant's life and was followed by questioning about its impact on a number of areas including: mobility, independence, personal relationships, identity, mood, response of others and work and leisure activities.

##### **Section 4: Relationship with the guide dog**

The participant's were asked about the nature and importance of the bond with their guide dog, and how this differed from relationships with other pets.

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## **Section 5: Contact with services**

This section examined contact with professional services following the onset or progression of visual impairment. This included the ease at which they accessed services and the type of help they received or would like to have received.

### **2.4 Procedure**

#### **2.4.1 Ethical Considerations**

The research design was developed in accordance with the British Psychological Society's Ethical Principles and Guidelines (1998) and the Division of Clinical Psychology Professional Practice Guidelines (1995). The Salomons Ethics Panel was approached and approval was obtained to carry out the research (Appendix 2). The Panel requested one amendment to the Information Sheet for participants, as a question had been raised about when the typed interview transcripts would be destroyed. The researcher wrote to the Ethics Panel assuring them that both typed transcripts and interview tapes would be destroyed by September 2001 at the latest (Appendix 3). This was also made clear in the Information Sheet. The main ethical issues in this research concerned the potential for the interview to cause psychological distress, as well as issues regarding consent, confidentiality and debriefing. These issues are discussed as they arise in the following sections on briefing procedures and the interview format.

#### **2.4.2 Recruitment Procedure**

This study was conducted with the collaboration of the managers of two GDBA centres in the Southeast of England (one of whom was the Regional Controller). The researcher first met individually with both managers to explain the aims of the study and to ask if

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they would consider providing access to first-time guide dog owners. Both managers agreed, but they did not want the researcher to have access to individual records. Consequently, the inclusion and exclusion criteria were discussed with them and they identified a pool of twenty individuals that were suitable. The managers were responsible for distributing the following to each of the twenty individuals:

- a) Endorsement from the Regional Controller of the GDBA, acknowledging support of the research and requesting participation (Appendix 4).
- b) Information Sheet for participants (Appendix 5)
- c) Consent Form (Appendix 6)
- d) Audiotape of the Endorsement, Information Sheet and Consent Form.
- e) An SAE addressed to the Researcher.

### **Briefing procedures**

As the sample group had varying degrees of visual impairment, consideration had to be given to the means by which they were informed and recruited. It was decided that the information sheet and consent form would be produced both in writing (using a larger font size of 16pt as recommended by the Royal National Institute for the Blind) and on audiotape. This gave people a choice about which medium to use. The printed and audiotaped versions of the Information Sheet were identical, except for additional instructions on the audio version to enable individuals to navigate their way around the tape (see Appendix 7 for audiotaped version).

The Information sheet outlined:

- a) The nature and aims of the research and what was required of participants.

- 
- b) The intention to audiotape the interviews if permitted.
  - c) The issue of confidentiality and anonymity of the material.
  - d) The right to withdraw at any time.
  - e) The contact number of the researcher so that they could approach her to discuss the research directly.

The Information sheet asked individuals to give their decision about participation using either the printed (Appendix 6) or audiotaped consent form (Appendix 7) and then to return this to the researcher in the SAE. (Only one participant replied using the audiotape version). Participants also indicated their decision about the interview being audiotaped, and to the use of any material they provided being used anonymously in subsequent reports. Those individuals who consented were telephoned by the researcher to arrange a convenient time and venue for the interview. The GDBA did not wish the researcher to make further contact with the seven people who did not respond to the request for participation, and so no further efforts were made to recruit them.

### **Interview procedure**

Participants were given the choice of being interviewed either at home, at a GDBA centre or at the Salomons. All participants chose to be interviewed in their own home. On arrival the researcher introduced herself and participants were asked if they were still willing to consent to the interview, and for it to be audiotaped. Once the tape-recording equipment was set up, participants were informed about confidentiality and their right to withdraw (see Appendix 1 for points covered at this stage). Finally, before switching on the tape recorder, the researcher asked participants if they had any further questions. The

interview schedule (Appendix 1) was then used to guide the interviews, which lasted between sixty and ninety minutes. The researcher made notes during the interview of any pertinent issues that emerged so these could be explored in more depth later in the interview.

A protocol was devised so that if at any time participants showed visible distress the interview would be suspended and the researcher would use her therapeutic skills to deal with this immediately, before checking whether the participant wanted to continue.

### **Debriefing**

At the end of the interview, prior to switching the tape recorder off, participants were asked if there were any issues they wanted to discuss which they felt had not been covered. They were given the opportunity to obtain further information about the study and to discuss any concerns arising from the interview, whilst the researcher monitored for any unforeseen negative effects. A further protocol was devised whereby in this instance the researcher would spend more time debriefing and suggest the participant contact local services to seek further help or advice. In addition all participants were given a contact number for the researcher and research supervisor.

Finally, consent to use the material anonymously was re-checked and it was explained that they would be contacted again to be given the opportunity to comment on the findings. They were asked which medium they would prefer to receive this feedback in.

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## **2.5 Data Management**

The interview transcripts were analysed using Grounded Theory, which is a means of developing theory that is grounded in the words and language of the participants (Charmaz, 1995). The interviews were conducted in groups of five and the analysis followed each group. In this way the emerging concepts were introduced in subsequent interviews to guide further questioning. Grounded Theory provides an explicit set of procedures for data analysis (Strauss & Corbin, 1998). These were followed for the purposes of this study. The analysis was undertaken on computer using the software package QSR NUD.IST.

### **Open Coding**

Open coding constitutes a first level of conceptual analysis and began with the researcher familiarising herself with the data by transcribing, and then reading the transcripts. Next, the transcripts were subjected to line-by-line analysis so that the coding could be developed from the 'ground up'. This enables the researcher to gain sufficient distance from their own and their participant's assumptions to see the material in a new light (Charmaz, 1995). As it is very time-consuming, ten interviews were analysed by labelling larger pieces of text expressing a single concept, albeit sentences or longer phrases. This was conducted with reference to Strauss & Corbin (1998) who emphasise the importance of abstracting a label that is suggested by the context in which an event is located. Each code, together with a numerical reference to the specific transcript and piece of text it was extracted from, was stored on NUD.IST. This coding process was continued for all transcripts until a total of 1932 initial codes had been generated.

The second stage of open coding involved collating the identified codes into higher order categories through a process of comparative analysis (Strauss & Corbin, 1998). This involved grouping basic codes that seemed related to each other, under more general headings to develop preliminary categories. For example, the following two codes 'guide dog veers owner around obstacles' and 'owner less likely to bump into objects on the pavement', were grouped to form the preliminary category, 'guide dog gives improved obstacle avoidance'. These categories were noted in NUD.IST along with the codes and text that defined them. Throughout open coding the researcher was noting potential core categories that could be used in theory building.

### **Axial coding**

Axial coding constitutes the second stage of data analysis, where the preliminary categories that emerged from open coding are developed in terms of their properties and dimensions to form higher categories and subcategories (Strauss & Corbin, 1998). To do this the preliminary categories were compared with a view to the possible relationships between them. For example, several preliminary categories were identified as constituting a higher order category of 'consequences of visual impairment'. These were analysed in terms of their dimensions and properties to form five distinct subcategories, including, 'feelings triggered by visual impairment' and 'coping with visual impairment'.

### **Selective Coding**

This is the process of integrating and refining the categories to form an overall grounded theory. This is achieved by deciding on a central 'core' category that explains 'what the research is all about' in the form of a 'storyline' (Strauss & Corbin, 1998). This last stage



involved diagrammatically representing related concepts as an initial theoretical model for understanding the experience of first-time guide dog ownership (see Figure 1).

### **Memos**

Memos (Strauss & Corbin, 1998) were used throughout the open, axial and selective coding stages on the NUD.IST system to record the researcher's thoughts on how categories related and how they could be developed in terms of their properties and dimensions. These are notes the researcher writes to herself to form a record of how their thinking evolves within the analytic process. It means that researcher's biases and assumptions can be made explicit and challenged, thereby making the process more reflective. This was supplemented through the use of a research diary (Appendix 8).

### **2.6 Validity and Reliability**

Unlike quantitative research, which is concerned with minimising error to achieve generalisable findings, qualitative research lends itself to understanding participants' perspectives, exploring meanings and to developing theory (Elliott, 1995). Given that multiple meanings are implicitly assumed, traditional positivist researchers have been highly sceptical about the credibility of qualitative findings (Elliott, Fischer & Rennie, 1999). However, recently researchers have begun to forward suggestions about what constitutes good qualitative research (Elliott, et al., 1999; Seale, 1999; Stiles, 1999), outlining a set of procedures that can be adopted to assess reliability and validity. Several of these procedures were employed in this study. They are outlined below.

**Auditability**

This is probably the most distinctive feature of qualitative research and is an attempt to make the research process as explicit as possible (Tindall, 1994), whilst enhancing its credibility (Seale, 1999). Rather than attempt to minimise the researchers own biases and assumptions in relation to their influence on the interpretative process, these are made explicit to aid the reader in understanding the data, and in conceptualising possible alternative understandings (Elliott et al., 1999). A research diary was kept throughout the study to provide a 'reflexive account' of the process (Appendix 8). In addition, an example of the analytic procedures used to understand the interview data can be seen in Appendix 9. These created an 'audit trail' (Lincoln & Guba, 1985), by which the reader could evaluate the credibility of the findings.

**Inter-rater reliability**

To assess the reliability of the final categories, inter-rater reliability checks were carried out on the coded data. An independent rater was given quotes and asked to assign them to categories generated by the researcher. The degree of convergence with the researcher's coding was recorded in terms of percentage agreement (see Appendix 10). The results are presented in section 3.2.

**Respondent validity**

Strauss and Corbin (1999) have argued that validation is implicit within grounded theory as the researcher is constantly comparing their interpretations against the data, making changes and then re-validating these against further data. However, to maximise validity, it is important to check the accuracy of the researcher's conceptualisation with

participants, to reduce the possibility that the researcher misinterpreted their meaning (Maxwell, 1998). Showing the data to the participants invites them to participate in inter-rater reliability and therefore improves the credibility of the research. In this study, respondent validity was obtained by feeding back the emergent analysis to participants in the form of a short report. They were asked to comment on how well they felt the criteria explained their experience, and to highlight any omissions or inaccuracies (Appendix 11).

### **Generativity**

According to Henwood and Pigeon (1995), the quality of a piece of research should be judged by its generative power. In other words the extent to which it is capable of producing implications for clinical practice and further research. This is considered in section 4.

### **Rhetorical power**

The quality of the research should also be judged by its rhetorical power, i.e. the extent to which others working in the field are convinced by the findings (Seale, 1999), and it is ultimately for the reader to decide. The researcher aimed to achieve rhetorical power by presenting examples of the data, and by obtaining participants' feedback on the analysis.

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### **3.0 RESULTS**

#### **3.1 Proposed theoretical model**

The grounded theory analysis generated 1932 initial codes. Through further open and axial coding, categories were generated, compared and contrasted, and subcategories developed. The result was the emergence of sixteen higher-order categories (see Appendix 9 for an example of how the higher-order categories were generated). The final stage of the analysis, known as selective coding, involved integrating these categories to form a representative theoretical scheme, or 'central category' (Strauss & Corbin, 1998). Selective coding suggested the central category, (i.e. what the research was all about), was the 'role of a guide dog in the process of adjustment to visual impairment'. The emerging data suggested four dimensions underlied this central concept, which seemed best exemplified in terms of a sequential theoretical model. The model is presented in the results section to provide clarity and structure for the reader. It is presented in diagrammatic form in Figure 1. It should be noted that the research questions have not been used as a framework for discussing the results. Instead, the proposed model was used to present the responses to the research questions.

The first stage of the model contains five higher-order categories that concern 'adjusting to visual impairment'. It describes the limitations imposed by visual impairment and the feelings it triggered, both of which made it more difficult for participants to adjust to the impairment. Participants adopted different methods of coping in the process of adjusting. The long cane was used and professional services were involved, but neither aided the process of adjustment satisfactorily. It seemed that dissatisfaction with their level of adjustment led participants to contemplate getting a guide dog, the second stage of the

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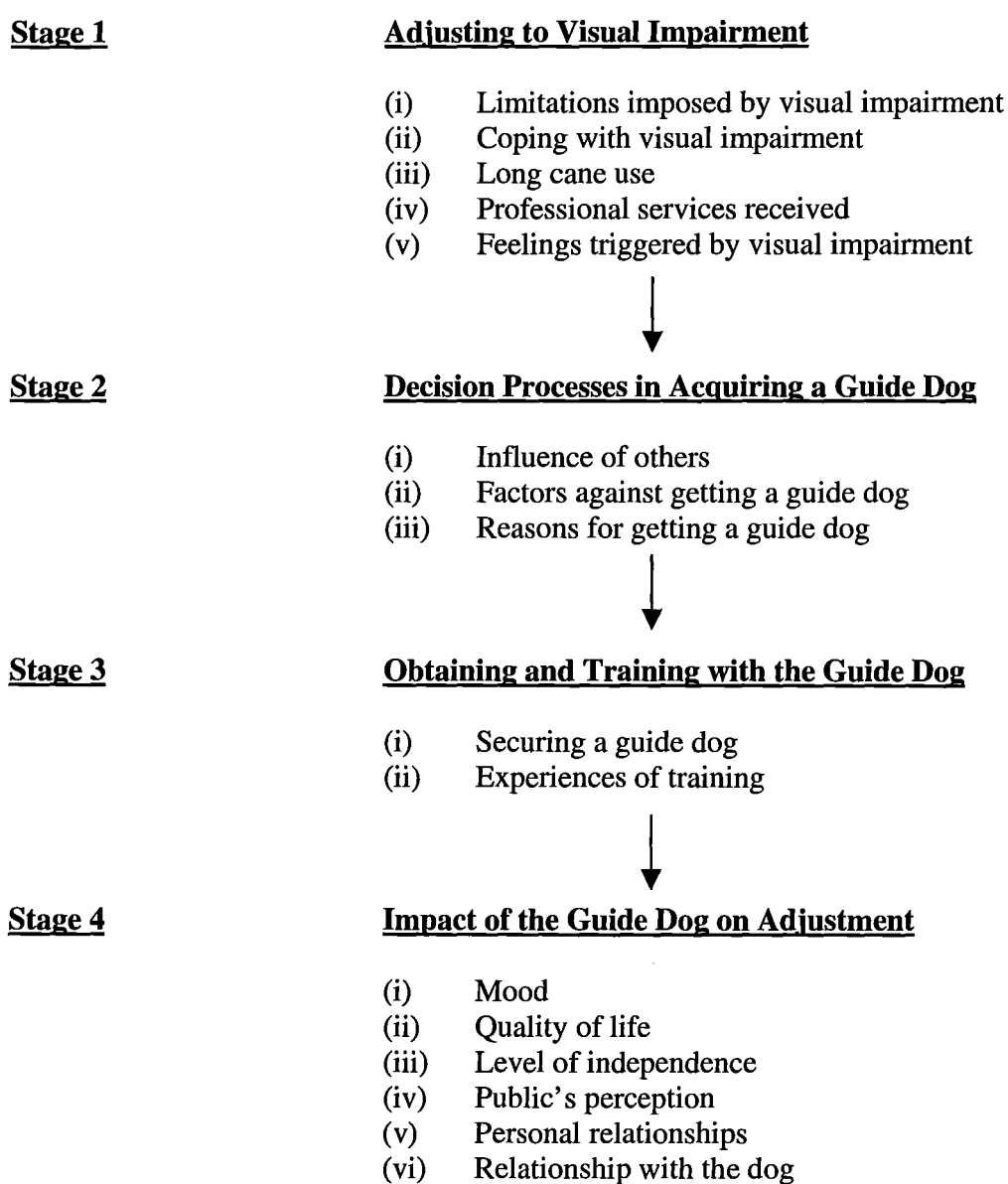
model. This stage addresses the ‘decision-making processes involved in acquiring the guide dog’, where a desire for greater independence and reduced isolation was weighed up against the disadvantages of acquiring a dog. The third stage explores participants’ experiences of ‘obtaining and training with the guide dog’. Whilst the process of securing a dog was perceived positively, there were certain aspects of the training that seemed to make the early process of adjusting to the dog more difficult.

The fourth and final stage of the model refers to the overall impact of guide dog ownership and how this affects adjustment to visual impairment. Participants described general improvements in their mood, quality of life, level of independence, and personal relationships. Participants also described the relationship with the guide dog, and the impact of the public’s perception of the dog. The latter led to increased social contact and status for participants, but at the same time created a number of difficulties that could be seen to compromise their adjustment.

The results are presented in four sections, corresponding to the four stages of the theoretical model. Within each section the higher-order categories are presented in terms of a table outlining their underlying categories and subcategories, the main findings of which are briefly reported. The numbers in brackets within the tables refer to the number of participants who gave this response. Exemplary quotations from the interviews were extracted to illustrate some of the categories. Where part of an extract has been edited this is indicated by ellipses (e.g...). Each extract is followed by the participant’s identifying number (0-13) and either an M or F (male or female) to distinguish their gender. The numbers in the square brackets refer to the numbered categories in the table

to which the quotation belonged. A full, unabridged interview is presented in Appendix 12. The results of the inter-rater reliability and respondent validity studies are presented at the end of the Results section.

**Figure 1 – Diagrammatic representation of the proposed theoretical model to understand the role of a guide dog in the process of adjustment to visual impairment**



### **3.1.1 ‘Adjusting to Visual Impairment’**

From the analysis emerged five higher-order categories of data describing participants’ attempts at ‘adjusting to visual impairment’. Each of the categories appeared influential in their motivation towards acquiring a guide dog.

#### **‘Limitations imposed by visual impairment’**

Table 2 illustrates the categories that emerged to describe participants’ views about the limitations imposed by visual impairment.

**Table 2. Participants’ views about the ‘limitations imposed by visual impairment’**

<b>Categories</b>	<b>Sub-categories</b>
Loss of roles/relationships	1. Unemployment (6) 2. Restricted social life (5) 3. Problems talking to sighted people (4) 4. Financial difficulties (1) 5. Multiple losses occur simultaneously (1)
Reduced independence	6. Increased dependence on others (7) 7. Loss of independence (6) 8. Unable to drive (2) 9. Takes longer to do things (2)

Limitations focused around two main categories, ‘loss of roles and relationships’ and ‘reduced independence’. Regarding the loss of roles, ‘unemployment’ was a significant problem [1] and several people reported having a ‘restricted social life’ [2]. This appeared to be partly related to difficulties communicating with people because of an inability to read visual cues [3].

*“I can’t get a job at all you know...I’ve tried and they just said I’m a liability” (M, 7) [1]*

*“I’ll be sitting with a group of people but you can’t make eye contact with them, can’t look across the table and nod, and you’re just completely lost” (M, 6) [3]*

The other significant limitation was a ‘loss of independence’ [7]. This was related to problems with mobility, and resulted in an increased dependence on other people [6] which most participants were unhappy with.

*“I was virtually housebound, in all day...I felt I had no independence at all” (F, 13) [7]*

It can be seen that these limitations posed significant barriers to adjustment.

### ‘Coping with visual impairment’

Table 3 illustrates the categories that emerged to describe participants’ views about coping with visual impairment.

**Table 3. Participants’ views about ‘coping with visual impairment’**

Categories	Sub-categories
Avoiding	1. Avoiding activities (4) 2. Trying to conceal visual impairment (3) 3. Taking anti-depressants (1)
Active coping	4. Forcing yourself to do things (4) 5. Learning to live with impairment (3) 6. Turning to family or friends for support (2) 7. Seeking counselling (2) 8. Seeking information about the impairment (1)

Participants used two main strategies to cope with their visual impairment, ‘avoiding’ or ‘active coping’. ‘Avoiding activities’ [1], or attempts to conceal the impairment [2] were common coping strategies used by participants.

*“I didn’t accept I had a disability...because I look relatively normal, I could hide it” (M, 10) [2]*



Alternatively, participants adopted more ‘active coping’ strategies. Of these, ‘forcing yourself to do things’ [4], and turning to others for support [6, 7], were common, although some felt it was just a matter of learning to live with it [5].

*“If you don’t get out there you get depressed...it’s all about focusing and getting out there” (M, 10) [4]*

It seemed that when confronted by the limitations engendered by visual impairment, participants tried different ways of coping in the process of adjusting.

#### ‘Long cane use’

Table 4 illustrates the categories that emerged to describe participants’ views about their use of a long cane prior to getting the guide dog.

**Table 4. Participants’ views about ‘long cane use’**

Categories	Sub-categories
Increased stigma	1. Cane feels like a stigma (6) 2. Negative advertisement of impairment (3) 3. Less social exchanges (3)
Difficult to use	4. Bumping into objects (3) 5. Requires great concentration (2) 6. Physically painful to use (1) 7. Forces a slower walking pace (1) 8. Lacked confidence to use cane (1)

Participants’ gave two main reasons for their reluctance to use a long cane. The first referred to the ‘increased stigma’ they felt when using the cane [1]. This was related to it being perceived as a negative advertisement for visual impairment [2], which participants felt deterred others from speaking to them [3].

*“I think having a white cane is a stigma, I hated being seen with a white cane” (F, 2) [1]*

The second reason referred to the cane being ‘difficult to use’. It required ‘great concentration’ [5] that appeared to result in a slow walking pace [7], yet participants still found themselves ‘bumping into objects’ [4].

*“Even with a long cane you still run into things and I had one or two nasty experiences where I walked into lampposts” (M, 6) [4]*

Participants were very dissatisfied with the cane, partly because it was not very effective in ensuring safe mobility, but also because of the stigma associated with it. It did not seem to remove the limitations associated with visual impairment and so as a rehabilitative tool, it was not helpful in facilitating adjustment.

#### ‘Professional services received’

Table 5 illustrates the categories that emerged to describe participants’ views about the professional services they received from health, social and voluntary agencies.

**Table 5. Participants’ views about the ‘professional services received’**

Categories	Sub-categories
Inadequate service response	<ol style="list-style-type: none"> <li>1. Under-resourced (8)</li> <li>2. Inadequate help getting entitlements (6)</li> <li>3. No information about what was available (5)</li> <li>4. Had to push to get help (5)</li> <li>5. Delayed response (5)</li> <li>6. Individual needs ignored (4)</li> <li>7. No named contact person (3)</li> <li>8. Services vary locally (2)</li> <li>9. Focus on deficiencies, not skills (2)</li> <li>10. Poor system instils defeat (2)</li> </ol>
Services required	<ol style="list-style-type: none"> <li>11. To be able to discuss negative feelings (4)</li> <li>12. Help with specific needs (2)</li> <li>13. Helped more quickly (1)</li> <li>14. Overall co-ordinator of services (1)</li> <li>15. Follow-up check (1)</li> <li>16. More information (1)</li> </ol>
Helpful service response	<ol style="list-style-type: none"> <li>17. Offered a range of services(3)</li> <li>18. Medical team very responsive to needs (2)</li> </ol>

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Three categories emerged, the largest of which described the ‘inadequate service response’ received. Participants felt they received ‘inadequate help getting benefits’ [2] or information about the services available [3], and felt that individual needs were ignored [6].

*“We didn’t even know about the carer’s allowance my wife could have been getting...there may even still be something that we could be entitled to...we don’t know, there’s nobody coming” (M, 8) [2]*

They often waited a long time to see professionals [5], and were irritated that they had to ‘push to get help’ [4]. Not surprisingly, some felt defeated about getting the services they were entitled to [10].

*“The biggest problem was getting things moving...I had to keep ringing and pestering them” (M, 6) [4]*

*“I think the system is geared for people to give in...The system relies upon making it so difficult for you to get what you’re entitled to” (M, 3) [10]*

The second largest category comprised participants’ views about the ‘services required’. Most salient was ‘to be able to discuss negative feelings’ with someone [11]. They also wanted more individualised help [12] and an ‘overall co-ordinator of services’ [14] to make the process more efficient.

*“Someone who would actually take the time to sit and listen...you don’t necessarily need reassurance, you need a sounding board so you can sort it out in your own head” (F, 11) [11]*

The third category pertained to ‘helpful service responses’ to which three participants felt that they were ‘offered a range of services’, [17] and two felt that they had received good medical care [18].

An overwhelming number of participants had serious complaints about the service response to their visual impairment, although some clarity about what was required did

emerge. It seemed that the service input failed to address the limitations imposed by visual impairment, and therefore did not aid the process of adjustment.

### 'Feelings triggered by visual impairment'

Table 6 illustrates the categories that emerged to describe participants' views about the feelings triggered by visual impairment.

**Table 6. Participants' views about the 'feelings triggered by visual impairment'**

Categories	Sub-categories
1. Frustration (5)	
2. Stigmatised by public reaction to impairment (4)	
3. Depression (3)	
4. Worry about future (2)	
5. Suicidal feelings (2)	
6. Hopelessness (1)	
7. Feeling more vulnerable when out (1)	

'Frustration' [1] and depressed mood [3, 4, 5, and 6] were the most common responses.

Of concern was the fact that two participants reported suicidal feelings [5].

*"I used to get very low sometimes. I mean I've never told my wife this but I've had suicidal feelings at times, you know, wish to god I could end it" (M, 6) [5]*

Participants also described feeling stigmatised by others reactions to their visual impairment [2], and this was related to them feeling more vulnerable outside [7].

*"These kids were taking the mick out of me because of my white stick and on the way home they followed me and gave me a good kick in" (M, 1) [2]*

Participants reported experiencing a number of negative emotions, which suggested they were having difficulty adjusting to the limitations imposed by their visual impairment, and were seeking alternative ways to address this.

### 3.1.2 'Decision Making Processes'

In the context of their difficulties and the ineffectiveness of the cane, three higher-order categories emerged pertaining to participants' decision to get a guide dog.

#### 'Influence of others'

Table 7 illustrates the categories that emerged to describe participants' views about the influence of others in their decision to get a guide dog.

**Table 7. Participants' views about the 'influence of others'**

Categories	Sub-categories
Suggestion source	1. Family or friend (1) 2. Other guide dog owner (2) 3. Professional person (6)
Using help of experts	4. Discussing decision with other owners (6) 5. Seeking information from GDBA (3) 6. GDBA give honest account of dog's impact (2)

It seemed that other people influenced participants' decision about a dog in two main ways. First, they were influential in initially suggesting participants got a dog [1, 2, 3]. Interestingly, despite the perceived inadequacy of professionals, they were responsible for suggesting a dog to half the participants' [3].

*"They just filled in a load of forms and got me to sign them...cos everything was just a big shock...the next thing I know they're ringing to tell me they've got a dog for me" (M, 1) [3]*

Second, participants used the 'expert' help of those with knowledge and experience of guide dogs to aid their decision making, either other owners [4], or staff at the GDBA [5].

*"They interviewed me for about four hours, took me out, explained all the good points about it and the bad points. I felt convinced afterwards it would help me" (M6) [5]*

Whilst participants were dissatisfied with the long cane, it appeared that many had not previously contemplated a guide dog. Other owners and professionals were influential in both initiating the idea and helping participants' make a decision.

#### 'Factors against getting a guide dog'

Table 8 illustrates the categories that emerged to describe participants' views about the 'factors against getting a guide dog'.

**Table 8. Participants' views about the 'factors against getting a guide dog'**

Categories	Sub-categories
1. Fear more restricted lifestyle (5)	
2. Fears about not relating to guide dog (3)	
3. Worries about training process (2)	
4. Wanting to conceal visual impairment (1)	

Of most concern to participants was a fear that responsibility for the dog would lead to a 'more restricted lifestyle' [1], whilst others feared they would not be able to relate to the guide dog [2], particularly those who had never had a pet dog before.

*"I thought about the absolute commitment...I thought it might be restricting and take away the independence I'd got, that I'd become totally dependent on something else" (M, 8) [1]*

#### 'Reasons for wanting a guide dog'

Table 9 illustrates the categories that emerged to describe participants' views about the 'reasons for wanting a guide dog'.