

# ‘THE EMOTIONS AND FEELINGS EXPERIENCED BY GUIDE DOG OWNERS IN THE APPLICATION, TRAINING AND WORKING OF THEIR GUIDE DOGS’

By

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**Declaration**

“I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and
2. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.”

Signature:  .....

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## **Abstract**

The guide dog is recognised worldwide as serving a primary role in providing safe, effective mobility for a person who is blind or vision impaired and can be the mobility aid of choice for a number of reasons (Gravrok et al., 2018; IGDF, 2011; Li et al., 2019). One reason is the relationship established between the guide dog owner and their guide dog, which can be a deciding factor for the choice to pursue guide dog mobility over other choices, such as the long cane or the use of technology to achieve independent mobility.

There is a dearth of research and associated literature investigating the emotions and feelings of people who are blind or vision impaired in their journey to guide dog mobility, in particular across the longitudinal process of applying for, training and working with a guide dog. Whilst recognising the primary role of the guide dog as a mobility aid, the purpose of this study was to stipulate the existence of a secondary role, by exploring the impact of a guide dog on the emotional wellbeing of guide dog owners. In doing so, this study sought to explore how the guide dog contributed to emotional wellbeing, for those who are blind or vision impaired across the process of applying for, training, and ultimately working with a guide dog. It was intended that the conclusions arrived at in this study would support in reflecting upon the wider significance of emotional wellbeing, framing and informing the work of organisations supporting those who are blind or vision impaired.

This longitudinal study adopted a phenomenological theoretical perspective to support an understanding of the lived experience of guide dog ownership, more specifically the impact of a guide dog on the emotional wellbeing of guide dog owners. A mixed (predominantly qualitative) methods approach was applied. Data were collected using semi-structured interviews and a Beck Depression Inventory (BDI) questionnaire. Following an initial pilot

study to determine the feasibility of the chosen methods, a main study of six participants from South Australia who are blind or vision impaired took place during the years 2011-2014. The main study collected data at four key milestones; the application process, the training with a guide dog, six months post training and twelve months post training. Findings of the study were presented as case studies, followed by thematic analysis examining self-reported emotions and feelings experienced throughout the longitudinal process. Results indicate the presence of factors that challenged participant's emotional wellbeing in the earlier milestones (application and training), however participants reported a substantially higher incidence of emotions and feelings associated with a more positive affect at the final milestone where they had been working with their guide dog for twelve months. This was largely due to the way participants' expressed the value of the guide dog in addressing challenges with daily living due to blindness or vision impairment, which contributed to feelings of increased confidence, independence, security and companionship. The recognition of the less-established secondary role of the guide dog in contributing to improved emotional wellbeing was also evidenced in a reduction in BDI scores and self-reported emotions and feelings of depression in the majority of participants, from the point of application to working with the guide dog for twelve months post-qualification.

This thesis is the first longitudinal study undertaken in Australia investigating the emotional complexities of guide dog mobility and provided valuable information in assessing the potential impact on emotional wellbeing that is evident in working with a dog guide.



## **Chapter 1 – Introduction**

### **1.1 Overview**

This introductory chapter defines key terms, provides an overview of the main issues this study endeavours to address, identifies aims of the study, and discusses how the findings in this study seeks to bridge the gap in current knowledge. This chapter also sets the scene for this study and provides an overview of subsequent thesis chapters. To assist the reader, appendix one provides a glossary of key terms used throughout this study.

Globally, blindness and vision impairment are increasing at an unprecedented rate; from 3.1% of the world's population in 1996 to 17% in 2017 (United Nations, 2017; World Health Organisation, 2017; World Health Organisation, 2018). Current data projects that this figure of people living with some form of blindness or vision impairment will continue to grow with a three-fold increase by the year 2050 (Balantrapu, 2017). The growing incidence might be construed as a new era of blindness and vision impairment, where existing health care services are at risk of being overwhelmed. The increased prevalence of blindness and vision impairment places a greater onus on government systems to ensure that service provision focuses on maximising independence in daily living to minimise impact at the societal level (Vision 2020 Australia, 2016). It is timely to consider whether the guide dog presents a possible solution to some of the challenges raised, by serving as a both a primary mobility aid and a conduit to emotional wellbeing, thus increasing the individual's capacity to negotiate their environment, interact with the dog as a companion, participate socially, and perform daily tasks (Sanders, 2000).

The purpose of this study is to identify the emotions and feelings experienced by guide dog owners who are blind or vision impaired as they go through the process of applying for,

training and ultimately working with their guide dog. This enables exploration of changes in emotional wellbeing throughout this longitudinal process. This thesis discusses the implications of the findings, specifically for the guide dog profession, and more broadly for organisations providing services and support to people who are blind or vision impaired. This study is needed because the evidence currently available is largely limited to research on the canine perspective; investigating breeding of the guide dog, puppy development, health, reproduction and training methodologies (Asher et al., 2013; Evans et al., 2015; Harvey et al., 2016; Serpell & Duffy, 2016). There is little literature on why people choose to have a guide dog, over other forms of mobility aids. There is some evidence to suggest that the decision for guide dog mobility may be correlated with an unmet need for companionship as well as the functional mobility support the guide dog provides (Whitmarsh, 2005; Wirth & Rein, 2008). The limited literature available in relation to guide dog mobility and the people who use them does not necessarily connect the experience of the person using a guide dog to their emotions and feelings.

The current lack of breadth in the guide dog literature demonstrates a dearth of understanding and conceptualisation of the emotional needs of people with blindness or vision impairment. Therefore, the contribution of this study to the current knowledge may potentially improve services delivered to people who are blind or vision impaired in identifying and supporting their emotional wellbeing needs, and create better pathways for guide dog mobility referrals. Most importantly, this study gives insight to guide dog mobility instructors (GDMMIs) in their understanding of their client, the client's emotional needs throughout the process, and the relationship between the human and the dog at an emotional level based on the needs for the dog as a guide.

## **1.2 Background and key concepts**

This next section addresses background information that assists in orienting the reader to vision impairment and guide dog mobility. Firstly, key definitions, statistics and the impact of living with blindness and vision impairment are detailed. Next, there is an overview of the disciplines that support mobility and independence for people who are blind or vision impaired, including both orientation and mobility training and guide dog mobility training. Then, there is discussion regarding motivations and reasons for an individual's choice between the different mobility aids and training available for people who are blind or vision impaired. Finally, some consensus is provided on current definitions of wellbeing and the significance of emotional wellbeing, in particular depression, for people who are blind or vision impaired will be addressed.

### **1.2.1 Blindness and vision impairment.**

Throughout this thesis, the terms blindness and vision impairment are used. There are differences between both terms, and as such the following definitions need to be considered. The rationale for defining these two terms is that firstly, they are universal and used consistently across the blindness and vision impairment sector, including as a baseline criterion for the acceptance for guide dog mobility services (IGDF, 2021). Secondly, these terms are recognised as clinical conditions with objective, measurable criteria used for diagnosis, based on the severity of vision impairment (AIHW, 2019; Royal Institute for Deaf and Blind Children, 2016; Scheiman, Wick & Steinman, 2014).

“Legal blindness” is a term used internationally, to describe an individual whose visual acuity is less than 6/60 (indicating that they are unable to detect at 6 metres what a person with normal vision can see at 60 metres), and a visual field of less than 10 degrees, with

uncorrected vision. A normal visual field is measured at 100-135 degrees (Scheiman, Wick & Steinman, 2014; World Health Organisation, 2019b).

Vision impairment on the other hand can be defined as a limitation in at least one of the functions of the eye or visual system, which cannot be corrected with refraction e.g. glasses or contact lenses vision (World Health Organisation, 2019b). Vision impairment most commonly affects visual acuity (the clarity of vision), visual fields (the normal range of what a person can see) and colour perception (the ability to discriminate colour) (Royal Institute for Deaf and Blind Children, 2016). Current epidemiological patterns continue to demonstrate a global increase in the incidence of blindness and vision impairment (World Health Organisation, 2017). When considering the global trend of increasing life expectancy in today's society (AIHW, 2017), age-related sensory impairment (including vision and hearing impairment) has affected an increasing number of elderly adults in the global aging population (Bourne et al., 2017). Statistics published by the Australian Institute of Health and Welfare (2019) demonstrated that 93% of Australians aged 55 years and above have a long term eye condition causing a vision impairment, in contrast to only 12% of people affected aged 0 to 14 years.

The World Health Organisation (2019a) suggests that there are currently an estimated 2.2 billion people worldwide who are blind or vision impaired. At a local level, nearly 12 million Australians (53.7% of the total population) have some degree of vision impairment, based on self-reported data (Australian Bureau of Statistics, 2015). One of the areas of daily living that people who are blind or vision impaired report as being significantly impacted by their vision impairment is reduced independence with mobility (Vision Australia, 2018).

The impact of blindness or vision impairment can be far reaching on daily living for people with these conditions (Senra et al., 2013). Any degree of blindness and vision impairment a person might experience will have an impact on their ability to cope, function and maintain independence in daily living, and the impact can be profound (Horowitz, Brennan & Reinhardt, 2005). In many cases, the experience of blindness or vision impairment impacts functional capacity as well as emotional wellbeing, creating fear and anxieties associated with the diagnosis and effect of vision impairment (Cimarolli et al., 2017).

### **1.2.2 Defining mobility, independence and mobility aids for people who are blind or vision impaired.**

Individuals who are blind or vision impaired often experience significant challenges in their endeavours to mobilise independently to access areas within the community (Vision Australia, 2018). The act of movement involves the skills of orientation and mobility. Orientation is recognised as a person's ability to identify their position relative to their environment, whilst mobility is defined as the physical skill of safely and efficiently moving about their environment (Novi, 1998; Virgili & Rubin, 2010).

Orientation and mobility training provides skills that enhance independence with travel through adaptation and compensation for the decreased visual information that the individual can obtain (Soong, Lovie-Kitchen & Brown, 2001; Virgili & Rubin, 2010). Orientation and mobility instructors (OMIs) are highly specialised in training and supporting individuals living with blindness or vision impairment to improve their quality of life by maximising their independence through mobility (Vision Australia, 2018). One method of training that OMIs apply is to support individuals with blindness or vision impairment to navigate their environment by utilising both their residual vision as well as information obtained from the

other senses. Training in the use of mobility aids such as white canes, technology such as Global Positioning Systems (GPS), and low vision aids (e.g. magnifiers) are one of the skillsets offered by OMI training (Novi, 1998; Virgili & Rubin, 2010). A white cane is used to swing from side to side in rhythm with the person's footsteps to detect tactile and auditory properties of their environment (Blasch & Suckey, 1995). Today, the white cane is universally acknowledged as both a mobility aid and an iconic form of identification for those who are blind or vision impaired (Blasch & Suckey, 1995).

Alongside and interactive with the field of orientation and mobility is the discipline of guide dog mobility, which provides assessment and training for people who are blind or vision impaired in the use of a guide dog as a primary mobility aid (IGDF, 2016). A guide dog is primarily trained to assist in finding destinations, ensure the safety of the guide dog owner and work to increase the guide dog owner's independence (IGDF, 2021).

### **1.2.3 Mobility aids – an individual choice.**

Although the white cane presents as being both affordable and portable, it is sometimes identified as unsuitable for some individuals as a preferred primary mobility aid. One such circumstance may be that the individual lacks confidence to travel alone with the white cane, a situation which has not been improved through the provision of specialist OMI training (Breslauer, 2010). In contrast, an individual may prefer the white cane as a primary mobility aid due to portability and low maintenance required to retain its use (Blasch, Wiener, & Welsh, 1997). It is therefore imperative that an individual who is blind or vision impaired is presented with an informed choice in selecting the most appropriate primary mobility aid that will enable them to maintain safe, effective and independent mobility.

The guide dog provides one alternative to the white cane, it being an obstacle avoidance mobility aid, compared to the long cane, which is an obstacle detection aid (Blasch, Wiener & Welsh, 1997). It is important to recognise in some countries (e.g. The Netherlands, France) however, that the guide dog is used in conjunction with the white cane (IGDF, 2016). This combination serves a function of expanding the awareness of members of the public, especially drivers, to the presence of a person who is blind or vision impaired (IGDF, 2016). Existing literature recognises the challenges that some guide dog owners face when encountering undesirable public responses toward their guide dog, something which warrants further intervention for increasing public education and awareness (Lloyd et al., 2008; McManus, Good & Young, 2021). The role of the guide dog can be summarised as providing safe and effective mobility, negotiating complex environments, and finding destinations as verbally requested by the guide dog owner (Gravrok et al., 2018). By negotiating terrain and obstacles, the guide dog affords more dynamic travel through ever-changing complex environments, such as a busy city street with peak vehicular and pedestrian traffic (Banham, 2000). Furthermore, guide dog mobility presents the opportunity to meet emotional wellbeing needs through companionship with the dog (Banham, 2000). A harness is worn by the guide dog when working, which acts as both an internationally recognisable icon for guide dog mobility and the method by which haptic information is transferred via the harness handle to the owner about the environment and the guide dog's direction of travel (Tellefson, 2012; Wiggett-Barnard & Steel, 2008). Haptic information utilises a person's sense of touch and is a key factor in the use of the harness when working and communicating with a guide dog (Wiggett-Barnard & Steel, 2008).

The precise role a guide dog will play in their owner's life is variable. One of the many services that a guide dog school provides is training their guide dogs to be skilled in

navigating their owner through complex and dynamic environments (IGDF, 2011). Whilst it is widely recognised that guide dog ownership provides a person with greater independence and improved mobility, there is an emerging evidence base to support a broader positive impact on the life of their owner by providing companionship, greater confidence, changed social identity and increased social interaction (Banham, 2000; Sanders, 2000; Whitmarsh, 2005).

By seeking to expand our understanding of emotions and feelings experienced by guide dog owners, we have acknowledged the potential for recognising a more holistic role of the guide dog. A role that to date, has primarily been a mobility aid, identifying landmarks and avoiding obstacles, to now acknowledging the potential for emotional support and contributing to the emotional wellbeing needs of people who are blind or vision impaired. If the guide dog does in fact serve a role in supporting improved emotional wellbeing of guide dog owners, and this was more widely recognised, then the choice to pursue guide dog mobility may be one that is influenced by the desire to have one's emotional needs met. Equally, the different stages of applying for, training and ultimately working with guide dog may yield different emotional experiences, contributing to either a positive or negative affect (Lloyd et al., 2009; Whitmarsh, 2005). Thus, it is important to acknowledge the longitudinal journey toward guide dog mobility, and what emotional experiences are evoked in this process. In doing so, an understanding of whether the recognised primary role of the guide dog in providing safe mobility is augmented by a secondary role of contributing to improved emotional wellbeing may be further explored.



#### **1.2.4. The wellbeing and emotions of people who are blind or vision impaired.**

Services to address the difficulties that people who are blind or vision impaired experience with regard to mobility and independence, are vital to supporting their wellbeing and quality of life (Senra et al., 2013). For the person who is blind or vision impaired, there is an increased risk for social isolation and reduced emotional wellbeing in circumstances where a lack of independence, in particular with mobility, goes unsupported (Horowitz, Brennan & Reinhardt, 2005; Nyman et al., 2012).

Although consensus regarding a global definition of “wellbeing” remains difficult to ascertain (De Chavez et al, 2005; Diener, 2009; Seligman, 2011; Spratt, 2017), there is a degree of unanimity in the health literature that acknowledges how wellbeing constitutes three key components (Kahneman, Diener & Schwartz, 1999; Ryan & Deci, 2001; Ryff, 1989; Waterman, 1993). These three key components of wellbeing that were used within this study, and are defined below:

***Emotional wellbeing*** – incorporating the hedonic theories of happiness and pleasure as contributors to wellbeing, whilst acknowledging that negative affective states, such as depression and anxiety, lower wellbeing (Delle Fave et al., 2011; Ryan & Deci, 2001; Ryff, 1989; Waterman, 1993).

***Personal fulfilment*** – integrating the eudaimonic, spiritual, positive emotional functioning and life satisfaction around feeling personally fulfilled (Delle Fave et al., 2011; Ryan & Deci, 2001; Ryff, 1989; Waterman, 1993).

***Social wellbeing*** - being able to form and maintain warm and trusting relationships with others, thereby generating suitable social capital and allowing regular social interactions (Ryan & Deci, 2001; Ryff, 1989; Waterman, 1993).

For this study, the emotional component of theories on wellbeing is of particular significance, as the purpose of the study is to explore the emotions and feelings, in particular depression, as experienced by guide dog owners who are blind or vision impaired. The premise is that having a negative affect, such as the emotional state of depression associated with a lack of confidence and independence with negotiating the environment, has a direct impact on wellbeing for a person who is blind or vision impaired (Ishtiaq et al., 2016; Kempen et al., 2012; Marques-Brocksopp, 2011; Nyman et al., 2012). In turn, this has a devastating effect on the ability of the person to reach a state of wellbeing (Ryan & Deci, 2001). For the purpose of this study, positive affect is described as happy, joyful, and pleased; and negative affect as unhappy, frustrated, and depressed.

As this study seeks to explore the emotions and feelings of guide dog owners who are blind or vision impaired, it is important to establish a degree of consensus on the definitions of emotion and feeling. This is not a straightforward task as the theoretical and practical demonstrations of emotions and feelings are both complex and convoluted. When examining the existing literature, it is evident that the definition of certain emotions and feelings varied among researchers (Imbir, 2017; Keltner, Oatley & Jenkins, 2013; Ortony & Turner, 1990; Wierzbicka, 1994; Wong, Kuang & David, 2020.). Emotions and feelings are the measure of one's engagement with the world; both a source of meaning and information (Frijda, 1986; Keltner, Oatley & Jenkins, 2013; McLeod & McLeod, 2011). A point of differentiation between the two is that emotions are generally understood to be specific and distinct, such as anger, often associated with physiological changes in the body, as well as an action or response (Awang-Rozaimie, 2011; Frijda, 1986; McLeod & McLeod, 2011; Wong, Kuang & David, 2020). Alternatively, feelings are multi-faceted and non-specific, often associated with a mixture of emotions and thought processes which result in a subjective interpretation of the

feeling experienced (McLeod & McLeod, 2011). With the purpose of this study being to gain a greater understanding on the emotional wellbeing of guide dog owners, it is important to gather data on both the specific and distinct emotions, as well as the more subjective and nebulous feelings that participants report.

As Nyman et al. (2012) identified in their meta-synthesis that depression is a commonly reported emotion experienced by those who are blind or vision impaired, it is important to have consensus on the definition of depression; one that is largely recognised by blindness organisations on a global level. The World Health Organisation (2010) provides a universal definition of depression as that where the individual “presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy and poor concentration” (World Health Organisation, 2010). The American Psychiatric Association (2013) provide other internationally recognised definitions, this time for depressive disorders, in their Diagnostic and Statistical Manual of Mental Disorders (DSM5). These definitions and corresponding guidelines provided by The American Psychiatric Association (2013) are largely used for supporting consistency in the assessment and diagnosis of mental disorders at an international level (American Psychiatric Association, 2013). As such, The World Health Organisation (2010) definition has been selected for informing a conceptualisation of depression in this study, as it is concerned with the understanding of depression as an emotional state.

It is acknowledged that there are many other definitions of depression other than those offered by the DSM5 and World Health Organisation, and many theoretical perspectives to reflect these definitions. For example, Johnstone’s Power, Threat, Meaning framework identifies depression as part of the narrative around distress and as such proposes

identification of patterns of dysfunction rather than diagnosis and labelling. (Johnstone & Boyle et al., [2018a](#); Johnstone, 2019). For people who are blind or vision impaired, the relationship to depression may be multifactorial as well as variant in frequency of distribution. In a recent study by Osaba et al. (2019), the prevalence of depressive symptoms was found to vary between 14% and 44% in patients with a vision impairment. Many of the factors pertaining to experiencing depression for people who are blind or vision impaired centre around the impact of vision loss on their daily activities, feelings of vulnerability with reduced personal safety, and frustrations they endure when not being able to find solutions to the impact of sight loss (Osaba et al., 2019). In a recent study by Van Munster et al. (2021) a participant in the study notes, “My husband cannot fix this. A guide dog cannot solve this. I am the only one who can solve this, but I have to act now.” (Van Muster et al., 2021, p 3). In addition to the internal processes associated with depression and blindness or vision impairment is the impact of environmental factors such as sight loss organisations and their interactions. For the guide dog organisation community, there are many standards in the provision of services, breeding and training of guide dogs, training of clients in their use, but very few devoted strategies in dealing with mental health and in particular depression as part of the relationship with the client. (IGDF standards, 2020)

In addition to depression, there are a range of other emotions and feelings which contribute to either a positive or negative affect which are also addressed in this study, and therefore required some consistency in their reporting. For the purpose of consistency in the reporting of emotions and feelings in this study, a definition and summary of each is discussed and provided in alphabetical order (see appendix two). Emotions and feelings are an experience unique to each individual, and therefore self-report is identified as one of the most reliable

forms of identification, although subject to limitations of the individual's emotional literacy and expressive language skills (Wong, Kuang & David, 2020).

### **1.3 Research question, aims and scope of the study**

The primary role of the guide dog is to provide safe and effective mobility for a person who is blind or vision impaired and has sought out guide dog mobility to enhance their independence (Gravrok et al., 2018; IGDF, 2011; Li et al., 2019). With acknowledgement to this primary role of a guide dog, the purpose of this study is to postulate there is the existence of a secondary role, by exploring the impact of a guide dog on the emotional wellbeing of guide dog owners. The research question that this study seeks to answer is: how does the guide dog impact upon the emotional wellbeing of the guide dog owner, across the longitudinal process of applying for, training and ultimately working with a guide dog? In answering this research question, the study sought to address the following four broad aims:

- 1) To explore whether and how the guide dog contributes to emotional wellbeing.
- 2) To investigate whether depression had a significant impact on emotional wellbeing for those who are blind or vision impaired across the longitudinal process of applying for, training, and ultimately working with a guide dog.
- 3) To specify the temporality of emotional wellbeing for those who are blind or vision impaired across the longitudinal process of applying for, training, and ultimately working with a guide dog.
- 4) To reflect on the wider significance of emotional wellbeing in framing and informing the work of organisations supporting those who are blind or vision impaired.

#### **1.4 About the study**

Whilst the current literature on guide dog mobility will be reviewed at a global level, the focus of this thesis is to explore the emotions and feelings experienced by a sample of guide dog owners living in South Australia. Part of the rationale for conducting this study in South Australia more specifically, is that the researcher was employed as the guide dog services manager for the Royal Society for the Blind (RSB), the organisation through which the participant sample was recruited. Another rationale for conducting the study in Australia is that there is a strong commitment to the rights and needs of people with disabilities, including blindness and vision impairment. This commitment is embodied in social practice and legislation, such as the Commonwealth Disability Discrimination Act 1992 (Commonwealth of Australia, 1992). Furthermore, Australia revolutionised its provision of services to those living with a disability by the introduction of the National Disability Insurance Scheme (NDIS) in 2013 (NDIA, 2018). Established by the National Disability Insurance Scheme Act 2013 (Commonwealth of Australia, 2013), the NDIS has sought to increase the choice and control of those living with blindness and vision impairment in Australia, through the provision of individualised funding for reasonable and necessary supports that help the person participate in their daily life and reach their goals (NDIA, 2017; NDIA, 2019).

Data on the emotional wellbeing of participants are gathered via individual participant interviews at four key time points along the longitudinal process of applying for, training and ultimately working with a guide dog. This study uses Interpretative phenomenological analysis (IPA). The rationale for selecting a theoretical perspective of phenomenology is that it enables detailed inquiry into the way phenomena is experienced (Rodriguez & Smith, 2018; Smith, 2018a). IPA, more specifically, acknowledges the diversity between experiences reported by individuals who have encountered a specific phenomenon, such as guide dog

mobility, by recognising that the focus of the individual's attention (the elements which they "bracket") had a direct impact on their perception of this lived experience (Apostolescu, 2019; Arnett, 2017). Consistent with the theoretical perspective of phenomenology, IPA serves as the methodology which enables the researcher to explore the emotional experiences of each participant as an individual through the presentation of case studies. This is followed by a thematic analysis of the collective emotions and feelings experienced by guide dog owners in the application, training and working of their guide dogs. The rationale for examining the emotional experiences of participants as a collective is to identify those that are most frequently reported as having fluctuated in some way (i.e. increased or decreased) throughout the four key milestones of the longitudinal study, and the impact this has on the participants' emotional well-being.

### **1.5 Positioning the researcher**

In establishing the scope and assumptions underpinning this study, it is important to provide an overview of the experience of the researcher and his relationship with participants. Further discussion about methods that were adopted in this study to reduce the potential for researcher bias is explored in subsequent chapters. The researcher has 30 years of experience working as a qualified GDMI and OMI, both in Australia and the UK. In addition to working in GDMI and OMI-specific roles, the researcher has also held a number of senior management roles, and currently serves on the accreditation committee of the International Guide Dog Federation (IGDF); the membership-based guide dog school accreditation governing body with approximately 96 member schools worldwide. The researcher is employed as the RSB guide dog services manager at the time the study was conducted. The researcher's primary field of interest has always been in the relationship between the person and the dog, and the psychosocial impact of blindness and vision impairment, and how the

dog influences the experience of achieving independence. Further details regarding researcher's positionality are provided in chapter three (see section 3.3.4 and 3.6).

### **1.6 Contributions of the study to the knowledge**

The contribution of this study to the existing body of knowledge is evidenced by the number of ways it can potentially serve in closing the current gap in the guide dog literature relating to an improved understanding and conceptualisation of the emotional needs of people with blindness or vision impairment. Firstly, through exploring the emotional needs of the person who is blind or vision impaired. Secondly, by seeking to identify the emotions and feelings experienced throughout the longitudinal process of applying for, training, and ultimately working with a guide dog. Thirdly, by endeavouring to understand whether the guide dog serves a multifactorial role for participants of this study, primarily through the provision of safe mobility, and by potentially fulfilling a secondary role by contributing to improved emotional wellbeing.

### **1.7 Thesis outline**

This thesis is structured into eight chapters as follows:

Chapter one, by way of introduction has defined key terms and provided an overview of the causation and aetiology of the key issues this study has sought to address. Furthermore, it is identifying the aims of the study and how its findings are bridging the gap in current knowledge.

Chapter two presents a systematic review of the current literature on guide dog mobility, and emotions experienced by guide dog owners. This involves a critical appraisal of the literature



and identified gaps in the literature in relation to understanding and conceptualising the emotional needs of people with blindness or vision impairment, and the potential role of the guide dog in promoting emotional wellbeing.

Chapter three provides detailed description of the qualitative methodology adopted for the purpose of this study, in obtaining and analysing the data on the emotions and feelings experienced by guide dog owners who are blind or vision impaired. Methodology was discussed and justified in order to validate its use across the longitudinal process of applying for, training and ultimately working with the guide dog; to identify any changes in emotional wellbeing of participants throughout these key stages.

Chapter four will present the findings in the form of participant narratives. These data will be used to immerse the reader in the emotional journey across the longitudinal process of applying for, training with and using a guide dog, as experienced and reported by the guide dog owner themselves.

Chapter five proceeds to analyse the findings from the research through the first stage of thematic analysis, where emotional themes will be presented according to individual stages of the longitudinal process. This supports the reader in gaining a greater understanding of the emotional experiences and needs of guide dog owners at the key milestones of guide dog ownership.

Chapter six proceeds with the second stage of thematic analysis, presenting the key emotional themes that participants reported to have fluctuated significantly across the entire longitudinal process of applying for, training and ultimately working with a guide dog. This secondary

stage of thematic analysis further expands the reader's understanding of the emotional experiences of a guide dog owner, and the capacity for a guide dog to improve the guide dog owner's emotional wellbeing.

Chapter seven strengthens the understanding of the emotional experiences of guide dog owners in this study, by linking key findings of this study back to the theoretical perspectives and literature in chapters two and three. The rationale for this is to assist in gaining a deeper understanding of the emotions and feelings experienced by guide dog owners, factors which influence these emotions and feelings, and how guide dog services may, in the future, better equip themselves to address the holistic needs of applicants and clients. It is intended that this new knowledge derived from the study will be used to inform the guide dog industry and lead to improved service provision by addressing the emotional needs of potential and current guide dog owners.

Chapter eight brings the study to a conclusion with a summary of the findings, strengths and limitations of this study, and ultimately some key recommendations for future research and opportunities to further improve the knowledge gap.

## **1.8 Summary**

This introductory chapter defines key terms and provides an overview of the causation and aetiology of the key issues this study has sought to address. Furthermore, it identifies the aims of the study and how its findings have bridged the gap in current knowledge. This first chapter has introduced the reader to the concept that people who are blind or vision impaired have needs relative to their condition, for maintaining independence with mobility and their emotional wellbeing. Secondly, the reader is now cognisant that the role of the guide dog has

been identified as potentially a multifactorial one, whereby their primary role of providing safe mobility may be augmented by a secondary role of contributing to improved emotional wellbeing.

Chapter two expands on the literature about current definitions of blindness and vision impairment, historical changes in the conceptualisation of these key terms, and implications for the sector. Furthermore, the impact of blindness and vision impairment is outlined, at the individual, national and global levels. The rationale for such a chapter is to familiarise the reader with relevant knowledge, from a systematic review of the literature, and seeks to establish the quality and extent of existing research relative to the secondary role of the guide dog in contributing to improved emotional wellbeing of the guide dog owner.

## **Chapter 2 – Systematic Literature Review**

### **2.1 Background**

This chapter presents a systematic review of the current literature on guide dog mobility, with respect to the emotions experienced by guide dog owners. Details regarding the methods and results serves to establish an understanding of the current research in relation to conceptualising the emotional needs of people who are blind or vision impaired, and the potential role of a guide dog in promoting emotional wellbeing. Finally, the identification of gaps in the existing literature serves to validate the need for the current study as a contribution to the research in the area of emotions experienced by guide dog owners.

Approximately 85% of sensory information received from the environment is obtained through vision; therefore, many people who are blind or vision impaired have difficulties with independent travel in different environments (Long, Boyette & Griffin-Shirley, 1996; Ripley & Politzer, 2010). Blindness and vision impairment have a substantial effect on wellbeing and independence in daily life for individuals whose sight is affected (Senra et al., 2013). The impact on autonomy and independence is linked to a reduction in emotional wellbeing (Alma et al., 2011). In particular, there is a high incidence of anxiety relating to a diagnosis of blindness or vision impairment which poses a risk to mental health (Alma et al., 2011). Previous studies demonstrate that those experiencing a loss of functional independence in activities linked to community access, such as driving and reading, report a reduced quality of life (Burmedi et al., 2002). One measure of a person's independence is reflected in their ability to mobilise safely in their home and community. The implications of blindness and vision impairment on the opportunity to participate in society, both socially and economically, is evident in the way in which vision impairment is understood to impact on

one's capacity to achieve independence with mobility and other daily activities (Long, Boyette & Griffin-Shirley, 1996; Van Munster et al., 2021).

There are currently eight providers of guide dogs in Australia. The providers are state and territory based, with one national organisation and six associations. The Royal Society for the Blind (RSB) is based in South Australia and independent from other guide dog associations, providing services to only South Australian clients. It is important to establish this contextual information to acknowledge that those who are seeking guide dog mobility in Australia have a degree of choice and control regarding the service provider from whom they wish to receive their guide dog from. One's perceived level of choice and control over their own environment and the ability to influence desired outcomes impacts directly on health and wellbeing (Van Munster et al., 2021; Wallston et al., 1987).

The primary role of a guide dog is to provide safety and efficiency of mobility, as it can be trained to find destinations and avoid obstacles along the journey. For many people who are blind or vision impaired, the choice to apply for a guide dog may be as simple, or complex as the need for more effective mobility and more confidence in mobility (Wiggett-Barnard & Steel, 2008).

The secondary role of a guide dog is unique to other mobility aids; in that it provides opportunity for companionship and improved emotional wellbeing through the very presence of the guide dog as a sentient being (Miner, 2001; Edwards, 2002). Case studies and anecdotal evidence provided by professionals in guide dog mobility suggest that guide dogs serve as companions, providing an emotional connection and building the confidence and self-esteem of recipients (Miner, 2001; Edwards, 2002).

The difference in the financial cost of a guide dog, when compared to more affordable mobility aids (e.g. long cane) infers a need for sound evidence to justify the funding of guide dog mobility. In 2016, the National Disability Insurance Agency (NDIA) in Australia commissioned a team of researchers to undertake a review on the effectiveness of assistance animals (including guide dogs) to inform decisions made about their funding (Howell, Bennett, & Shiell 2016; NDIA 2020). In this process, the NDIA acknowledged that the existing evidence to support the use of dogs to assist individuals who are blind or vision impaired with their mobility was established, however evidence to acknowledge other roles performed by guide dogs and assistance dogs is limited (Howell, Bennett & Shiell, 2016; NDIA, 2020). The availability of valid and reliable research to support not only the recognised primary role of the guide dog in providing safe mobility, but also the secondary role of contributing to improved emotional wellbeing, is therefore likely to impact access to funding for a guide dog through the NDIA in Australia (NDIA, 2020).

## **2.2 Aim**

This systematic literature review establishes the quality and extent of existing research relative to the secondary role of the guide dog in contributing to improved emotional wellbeing of the guide dog owner. It is intended that this information be used to establish how the current study adds depth and understanding by addressing gaps within the literature. The question that this systematic literature review seeks to answer is what is the current evidence surrounding the role of a guide dog in contributing toward the emotional wellbeing of the guide dog owner?

## **2.3 Methods**

This next section provides an overview of the methods and processes for undertaking the systematic literature review. Firstly, there is deliberation about the criteria that is applied when considering whether an article will be included in the review. Secondly, an outline of the key terms and truncations for the database searches is provided. An overview of the search strategy follows which includes both the databases and specific tools that support the researcher in undertaking this systematic literature review. Finally, the process by which data is extracted from studies for inclusion within the systematic review is presented in brief.

### **2.3.1 Inclusion/exclusion criteria.**

The initial scoping of the literature conducted for the content of section 1.2 reveals there is limited literature specifically regarding the self-reported impact of guide dog mobility on the emotions and wellbeing of people who are blind or vision impaired (Banham, 2000; Sanders, 2000; Whitmarsh, 2005). Therefore, this review is not limited to peer reviewed academic articles nor empirical studies (such as randomised and pseudo-randomised control trials). Instead, the systematic literature review seeks to locate existing primary studies to establish the evidence base relevant to the research question. Furthermore, due to the limited available literature on this topic, inclusion is not limited to a specified time period.

The following criteria (table 2.1) is applied when identifying studies for inclusion in the literature review, to support a comprehensive search strategy, ultimately yielding only articles of relevance to the research question:

**Table 2.1**

*Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• Adult participants who are currently in the process of either applying for or working with a guide dog, or who have previously worked with a guide dog.</li> <li>• Participants who have been reported as legally blind or vision impaired.</li> <li>• Outcome measures included self-reported impact of guide dog ownership on wellbeing and emotions.</li> </ul>	<ul style="list-style-type: none"> <li>• Studies not published in English language</li> <li>• Studies involving mixed samples (e.g. guide dog owners and owners of other types of assistance dogs (guide dog being a subset of assistance dog) or guide dog owners and white cane users, where results for the sample of guide dog owners were not reported separately from those within the sample using a different mobility aid/type of assistance dog.</li> </ul>

**2.3.2 PICO.**

PICO is an acronym that is used to identify existing literature regarding a specific population, intervention, comparison and outcome of interest (Frandsen et al., 2020). The PICO is a tried and validated tool for evidence-based practice and enables detailed exploration for systematic literature reviews by defining the research elements of a review question (Frandsen et al., 2020; Methley et al., 2014).

For the population of interest, this literature review acknowledges the international definitions of legal blindness and vision impairment that have been established in section 1.2.1. With regard to the intervention, this literature review acknowledges a guide dog as a dog trained by a guide dog school whose membership is accredited by the International Guide Dog Federation (IGDF). These rigorous methods applied to accreditation and membership of the IGDF guarantee a demonstrated commitment to best practice in these guide dog schools'



methods for assessment and training of clients, dogs and staff. Outcome measures of interest for this systematic literature review are levels of emotional wellbeing and emotional experiences, according to participant self-report. Specific search terms for emotions are selected based on the themes emerging from the initial scoping of the literature conducted for the content of section 1.2. These terms are those associated with theories on emotional wellbeing and negative affective states contributing to reduced emotional wellbeing in people who are blind or vision impaired (Horowitz, Brennan & Reinhardt, 2005; Marques-Brocksopp, 2011; Nyman et al., 2012; Ryan & Deci, 2001; Ryff, 1989; Waterman, 1993). The following keywords outlined in table 2.2 are those used to search for appropriate literature.

**Table 2.2**

*PICO and search terms*

PICO	Definition	Search Terms
Population	Individuals with a diagnosis of legal blindness or low vision.	(Legal* and blind*) OR (low and vision) OR (sight and loss) OR (vis* and impair*) OR blind*
Intervention	Guide dog mobility.	(Guide and dog and mobility) OR (guide and dog*) OR (seeing and eye and dog*) OR (dog* and for and the and blind) OR (assistance and dog*)
Comparison	N/A.	N/A
Outcome	Self-reported impact on emotions and emotional wellbeing.	Emotion* OR (mental and health) OR depress* OR anxiety* OR wellbeing* OR independen* OR mobility OR isolat* OR lonl*

### 2.3.3 Search strategy.

Databases pertaining to literature on allied health, and human-animal interactions are comprehensively searched for this review, including Emcare, MEDLINE, Cochrane, Embase,

PsycINFO, Informit, Scopus, and Web of Science. Database searches are conducted using the search terms specified in table 2.2, and limits are applied to filter for studies that have adult samples and are available in English language articles only. The rationale for these limits is that the research question is relevant to the emotional wellbeing of adult guide dog owners, and the researcher does not have access to translation services for the purpose of conducting this literature review. In order to ensure a thorough search, delimiters and truncations are used (see table 2.2).

Two specific tools support the researcher in undertaking this systematic literature review; an innovative approach using the combination of the PRISMA Flow Diagram (Moher et al., 2009a) and McMaster Critical Review Form (Letts et al., 2007). Whilst this systematic literature review is not designed to strictly follow the PRISMA statement checklist, the PRISMA Flow Diagram (Moher et al., 2009a) is used due to its capacity to enhance the reporting and transparency of screening and decision-making regarding articles that are excluded from the review (Moher et al., 2009b). In order to then critically appraise studies selected for inclusion in this review, the McMaster Critical Review Form (Letts et al., 2007) is used. The McMaster Critical Review Form (Letts et al., 2007) is a tool with both qualitative and quantitative versions of the form, thus allowing exploration of a range of primary data sources, and ultimately directing selection of those of the highest quality and relevance to the research question.

#### **2.3.4 Data extraction.**

The extracted data from included studies is presented in table 2.3 and in narrative form to provide a comprehensive overview of the literature. The self-reported outcomes of guide dog mobility on emotions and wellbeing of guide dog owners are extracted for each of the

included studies. Other important information, including sample size and characteristics, demographic data, data collection methods and main findings is also extracted (see table 2.4). The McMaster critical appraisal score is recorded for each study. Findings are then synthesised so that outcomes can be compared and contrasted. Subsequently, key themes emerging from the data are noted and interpreted in relation to the research question.

## **2.4 Results**

To report on the main findings from the systematic review, this next section commences with an explanation of the process the researcher undertook to identify studies for inclusion from the total number of articles yielded from the database searches. Following this, a critical appraisal of the included studies is presented, using the McMaster Critical Review Form (Letts et al., 2007). Finally, an overview of the methodology and demographics of each of the included studies is discussed, along with a summary of each study presented in table format.

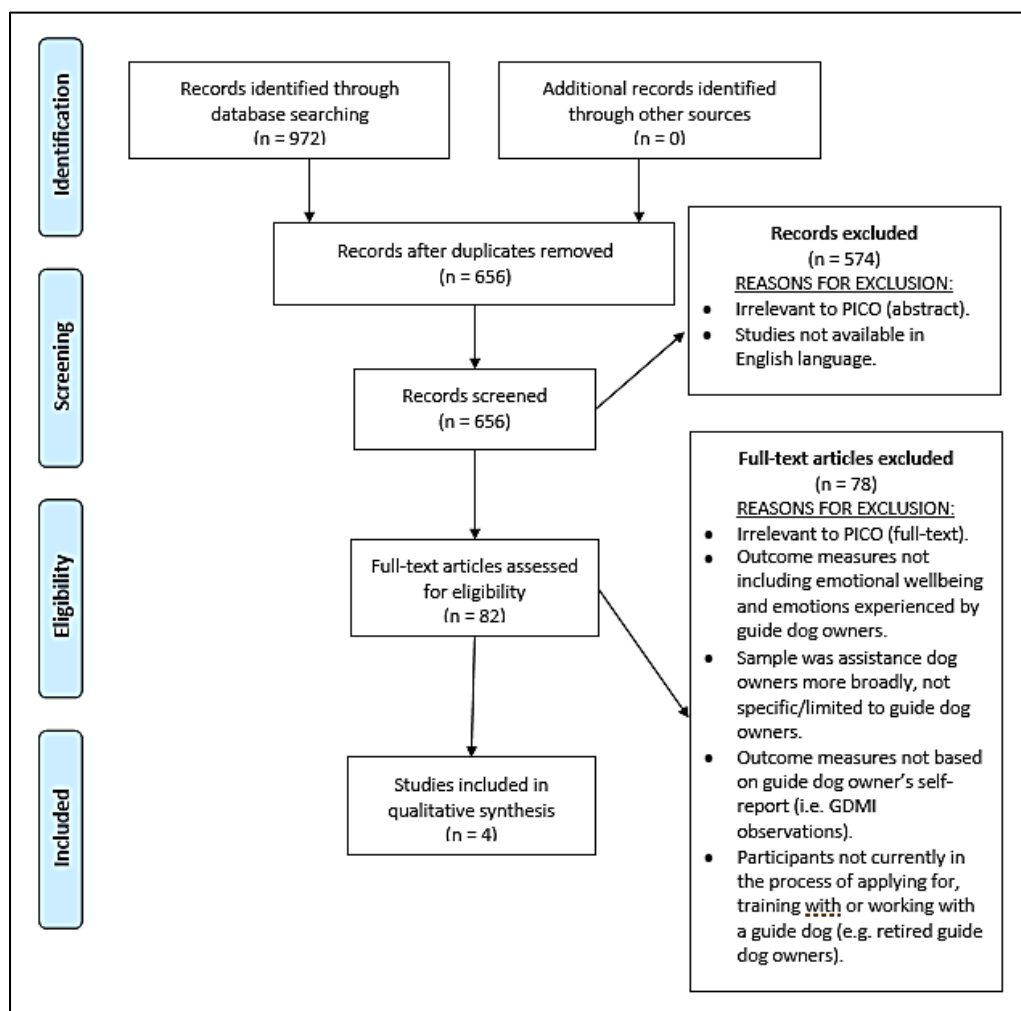
### **2.4.1 Overview of the included studies.**

The PRISMA flow diagram below (figure 2.1) illustrates an overview of the process following the comprehensive database search, whereby four primary research articles were identified as meeting the inclusion criteria from the 972 articles located. The first stage of screening involved the removal of any duplicate articles from the search. Then, the second stage of screening involved reviewing the title and abstract for each article, at which stage a total of 574 articles were excluded due to a lack of relevancy to the PICO or not being available in English language. The secondary screening stage involved reading the full text articles for the remaining 82 studies to determine their eligibility against the PICO and established criteria. The most frequently occurring reasons for exclusion included a lack of relevancy to the PICO, such as studies where outcome measures were not focused on a self-

reported impact of guide dog ownership on wellbeing and emotions, or studies that explored the impact of assistance animals more broadly (see appendix three for full details). Whilst the studies excluded at the secondary screening stage are not of relevance to the literature review, they provide insight into the researcher’s understanding of other areas within guide dog research including guide dog behaviour, the welfare of guide dogs and other assistance animals, and guide dog training methods (Audrestch et al., 2015; Fallani, Prato Previde & Valsecchi, 2007; Harvey et al., 2017; Ng et al., 2015; Refson et al., 1999; Serpell & Hsu, 2001).

**Figure 2.1**

*PRISMA Flow Diagram (Moher et al., 2009a)*



#### **2.4.2 Critical appraisal of the included studies.**

According to the McMaster Critical Review Form (Letts et al., 2007), the methodological quality of the four studies under review vary greatly, with scores ranging from 9/24 (38%) to 19/24 (79%). Three of these articles were sources from a peer-reviewed journal (Miner, 2001; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008) and one is a study published as a chapter within a book (Steffens & Bergler, 1998). All the included studies reviewed the relevant background literature and are unanimous in their reporting of gaps in the literature. Reported gaps in the existing literature primarily focus on the lack of reliable phenomenological studies regarding the lived experience of guide dog ownership, and the range of secondary benefits that guide dog mobility yields for its owners, such as companionship and emotional wellbeing (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008). One of the key weaknesses that two of the four included studies (Steffens & Bergler, 1998; Whitmarsh, 2005) exhibit is their lack of explanation of the theoretical perspective underpinning their studies. Being explicit about the theoretical perspective when describing the methodology of a study is of great importance, as it allows the reader to understand assumptions that likely influenced the researcher's choice of methods and analysis of findings (Creswell & Clark, 2018). Without knowing the theoretical perspective of Steffens & Bergler's (1998) and Whitmarsh's (2005) studies, it is difficult to ascertain what assumptions guided their analysis and whether findings are a true representation of the participants' lived experience of guide dog ownership.

**Table 2.3**

*Critical appraisal of included studies using the McMaster Critical Appraisal Tool for Qualitative Studies (Letts et al., 2007).*

Item	Study			
	Miner, 2001	Whitmarsh, 2005	Wiggett-Barnard & Steel, 2008	Steffens & Bergler, 1998
1) Clear study purpose	No	No	Yes	No
2) Relevant background literature reviewed	Yes	Yes	Yes	Yes
3) Appropriate study design	Phenomenology	Not Addressed	Phenomenology	Not Addressed
4) Theoretical perspective identified	Yes	No	Yes	No
5) Methods appropriate	Observation/ Interviews	Interviews	Interviews	Interviews
6) Purposeful sampling applied	Yes	No	Yes	Yes
7) Sampling done until redundancy in data reached	Yes	Not Addressed	Not addressed	Not Addressed
8) Informed consent obtained	No	Yes	Yes	Not Addressed
9) Description of data collection site reported	No	Yes	Yes	No
10) Description of participants reported	No	Yes	Yes	Yes
11) Researcher relationship with participants described	No	No	No	No
12) Assumptions/biases of researcher identified	No	Yes	No	No
13) Procedural rigor used in data collection	Not Addressed	Yes	Yes	Not Addressed
14) Data analyses were inductive	Yes	Not Addressed	Yes	Not Addressed
15) Findings consistent with & reflective of data	Not Addressed	Yes	Yes	Yes
16) Decision trail developed	No	Not addressed	Yes	Not Addressed
17) Process of data analysis adequately described	No	Not Addressed	Yes	Not Addressed
18) Meaningful picture of phenomenon under study emerged	No	Yes	Yes	Yes
19) Evidence of credibility	Yes	No	No	No
20) Evidence of transferability	Yes	Yes	Yes	Yes
21) Evidence of dependability	No	No	Yes	No
22) Evidence of conformability	No	Yes	No	No
23) Conclusions appropriate given study findings	No	Yes	Yes	Yes
24) Findings contributed to theory development	No	Yes	Yes	Yes
Total	9	13	19	9

### **2.4.3 Methodology and demographics of the included studies.**

Only two of the included studies (Miner, 2001; Wiggett-Barnard & Steel, 2008) clearly identify their theoretical perspectives, both of which are phenomenological in nature. A theoretical perspective of phenomenology is deemed appropriate given the exploratory nature of this area of research in seeking to understand the lived experience of guide dog ownership, more specifically on the impact on wellbeing and emotions (Arnett, 2017; Charlick et al., 2016; Miller, Chan & Farmer, 2018). The remaining two studies (Steffens & Bergler, 1998; Whitmarsh, 2005) do not specify a theoretical perspective underpinning their studies. From the four studies included in this systematic review, the total number of participants are 458, inclusive of both male and female populations, aged 18 years and over.

Miner (2001) recruited their sample in the United States, the sample from Whitmarsh's (2005) study were living in the UK, the study by Wiggett-Barnard and Steel (2008) included participants from the Western Cape of South Africa, and guide dog owners in Germany were recruited by Steffens and Bergler (1998). Three of the included studies (Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008; Steffens & Bergler, 1998) recruited only participants who were currently using a guide dog as their primary mobility aid, while the study by Miner (2001) recruited a sample of both current and past guide dog owners.

Methods of inquiry for the four included studies vary. Miner (2001) and Wiggett-Barnard and Steel (2008) utilised a qualitative method of inquiry (individual participant interviews), whereas Whitmarsh (2005) and Steffens & Bergler (1998) adopted a mixed methods approach reporting on both qualitative and quantitative measures (also individual participant interviews). The use of a mixed method study design supported Whitmarsh (2005) and Steffens and Bergler (1998) to identify the frequency at which certain

advantages/disadvantages were reported by participants, thus allowing a deeper understanding of what the most significant of these were.

All four of the included studies gathered data by way of individual interviews. The majority of studies (Miner, 2001; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008) report on both the benefits and disadvantages that guide dog ownership has on emotional and social wellbeing, while Steffens and Bergler (1998) identify only benefits on emotional and social wellbeing. Overall, all four of the included studies observed that guide dog ownership has a greater degree of emotional and social benefit than disadvantage, thus resulting in a degree of improved emotional and social wellbeing for the guide dog owner. These findings are further discussed and explored in section 2.5.1.



**Table 2.4**

*Summary of studies included in the review*

Study	McMaster (2007) CAT Score	Sample	Population (P); Intervention (I); Control (C); Outcome (O)	Outcome Measures	Main findings
Miner, 2001	38%	n=8	<p><b>P</b> = Current and past GDOs living in USA, aged 18+ years.</p> <hr/> <p><b>I</b> = GD ownership.</p> <hr/> <p><b>C</b> = N/A</p> <hr/> <p><b>O</b> = Self-reported impact on emotional and social wellbeing.</p>	<p><b>Themes that emerged from 1:1 semi-structured interviews (qualitative inquiry):</b></p> <hr/> <p><i>Emotional &amp; Social Benefits:</i></p> <ul style="list-style-type: none"> <li>• ↑Confidence</li> <li>• ↑Independence</li> <li>• Changed Public Interaction</li> </ul> <hr/> <p><i>Emotional &amp; Social Disadvantages:</i></p> <ul style="list-style-type: none"> <li>• Changed Public Interaction</li> </ul>	<ul style="list-style-type: none"> <li>• Guide dog ownership resulted in increased confidence and independence for the 8 GDOs who participated in the study.</li> <li>• Changes in public interaction when using GD had both benefits (e.g. a conduit to initiating positive social interaction with others) and disadvantages (e.g. intrusive questioning about the dog from strangers).</li> </ul>
Whitmarsh, 2005	54%	n=404	<p><b>P</b> = Current GDOs living in the UK, aged 18+ years, predominantly Caucasian (99%), majority registered as legally blind (95%).</p> <hr/> <p><b>I</b> = GD ownership.</p> <hr/> <p><b>C</b> = N/A.</p> <hr/> <p><b>O</b> = Self-reported impact on emotional and social wellbeing.</p>	<p><b>Self-report from 1:1 semi-structured interviews (quantitative and qualitative inquiry):</b></p> <hr/> <p><i>Emotional &amp; Social Benefits:</i></p> <ul style="list-style-type: none"> <li>• ↑Independence (81%)</li> <li>• ↑Confidence (27%)</li> <li>• ↑Companionship (30%)</li> <li>• ↑Socialisation (16%)</li> </ul> <hr/> <p><i>Emotional &amp; Social Disadvantages:</i></p> <ul style="list-style-type: none"> <li>• ↑Unwanted social attention (7%)</li> <li>• ↑Grief/loss when the dog retires/dies (5%)</li> </ul>	<ul style="list-style-type: none"> <li>• Guide dog ownership had a greater degree of emotional and social benefit than disadvantage for the 404 GDOs who participated in the study.</li> </ul>

THE EMOTIONS EXPERIENCED BY GUIDE DOG OWNERS

Study	McMaster (2007) CAT Score	Sample	Population (P); Intervention (I); Control (C); Outcome (O)	Outcomes Measures	Main findings
Wiggett-Barnard & Steel, 2008	79%	n=6	<p><b>P</b> = Current GDOs living in the Western Cape of South Africa, aged 18+ years, registered as legally blind.</p> <hr/> <p><b>I</b> = GD ownership.</p> <hr/> <p><b>C</b> = N/A.</p> <hr/> <p><b>O</b> = Self-reported impact on emotional and social wellbeing.</p>	<p><b>Self-report from 1:1 structured interviews (qualitative inquiry):</b></p> <hr/> <p><b>Emotional &amp; Social Benefits:</b></p> <ul style="list-style-type: none"> <li>• ↑Confidence (mobility-related)</li> <li>• ↑Companionship/affection/love</li> <li>• ↑Pride</li> <li>• ↑Independence</li> </ul> <p><b>Emotional &amp; Social Disadvantages:</b></p> <ul style="list-style-type: none"> <li>• ↑Undesirable social response (unwanted social attention or social avoidance from others.</li> <li>• ↑Public ignorance regarding access rights</li> </ul>	<ul style="list-style-type: none"> <li>• GD ownership improved emotional and social wellbeing for the 6 GDOs who participated in the study.</li> <li>• Participants reported that GD ownership had both pros (increased independence, companionship/love and pride) and cons (i.e. increased responsibility and time caring for the dog, lifestyle adjustments etc), which are important to contemplate when considering a GD for a primary mobility aid.</li> </ul>
Steffens & Bergler, 1998	38%	n=40	<p><b>P</b> = 80 Blind individuals; 40 GDOs and 40 non-GDOs, living in Germany (<i>NOTE The sample of 40 GDOs were isolated and reported on for the purpose of this review</i>)</p> <hr/> <p><b>I</b> = GD ownership.</p> <hr/> <p><b>C</b> = N/A.</p> <hr/> <p><b>O</b> = Self-reported impact on emotional and social wellbeing.</p>	<p><b>Self-report from 1:1 structured interviews (quantitative &amp; qualitative inquiry):</b></p> <hr/> <p><b>Emotional &amp; Social Benefits:</b></p> <ul style="list-style-type: none"> <li>• ↑Affection/love/tenderness" (98%)</li> <li>• ↓Loneliness (68%)</li> <li>• ↑Independence (68%)</li> <li>• ↓Nervousness due to "quiet relaxed walking" (18%)</li> <li>• ↓Fear regarding orientation (10%)</li> </ul>	<ul style="list-style-type: none"> <li>• Overall, GDOs report a reduction in their amount of everyday stress, and an increase in the amount of everyday pleasures they experience.</li> </ul>

Note: GD = Guide dog; GDO = Guide dog owner; GDM = Guide dog Mobility

## **2.5 Synthesis**

In order to synthesise the results yielded from the systematic review, this section identifies the key findings emerging from analysis of the studies included. Secondly, these key findings regarding the emotional wellbeing of guide dog owners across the longitudinal process of applying for, training and ultimately working with a guide dog are considered in relation to their application to practice in the guide dog service industry. There is also some discussion about the relative strengths and limitations of the literature review; how these impacts upon the way these findings are interpreted, as well as influencing and directing the focus of future research.

### **2.5.1 Key findings.**

This next section explores two of the key emerging themes from analysis of the studies included in this systematic literature review. Firstly, how guide dog mobility is associated with social and emotional benefits for the guide dog owner. Secondly, that guide dog mobility is associated with a degree of negative interactions with members of the public which are reported as having an adverse impact on the emotional wellbeing of guide dog owners.

***2.5.1.1 Emerging theme #1: “guide dog mobility was associated with social and emotional benefits for the guide dog owner”.*** When reviewing the range of emotions experienced by guide dog owners, according to self-report from the owners, all four included studies report an increase in positive emotions however only one of the studies (Steffens & Bergler, 1998) reports a reduction in negative emotions, including reduced fear, nervousness and loneliness. The highest reported emotional and social benefits (including an increase in positive emotions experienced by guide dog owners) are increased independence (Miner,

2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008), confidence (Miner, 2001; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008), and feelings of companionship/affection/tenderness/love (Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008).

Increased independence is reported by all four of the articles included in this systematic review, as a social and emotional benefit reported by guide dog owners (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008). More than half of the guide dog owners who participated in studies conducted by Whitmarsh (2005) and by Steffens and Bergler (1998) expressed they experienced an increase in their feelings of independence through using their guide dog, as this had resulted in improved participation in social, family and employment activities. Findings from the study conducted by Wiggett-Barnard and Steel (2008) further support this notion whereby their participants reported that an increase in mobility-related confidence is associated with an increase in perceived independence with daily living, which then supports an increase in social contact with others. One participant reports; “She (guide dog) gives me independence again. I can go out again, I can go to the shops, I can walk to where I want to be” (Wiggett-Barnard & Steel, 2008, p. 1019). The comparison between feelings of independence when using a guide dog versus being accompanied by another (sighted) person is explored in Miner’s (2001) study, whereby a higher proportion of guide dog owners report greater independence and freedom when using their guide dog, compared to being led by another (sighted) person. This would suggest that guide dog owners may perceive an increased level of independence when using their guide dog, which in turn relies on them for daily care such as feeding, grooming etc.

Increased confidence is another of the three most frequently reported social and emotional benefits by guide dog owners in this systematic literature review. Utilising a mixed methods

approach, Whitmarsh's (2005) study reports that the proportion of participants who expressed the different emotional and social benefits of guide dog ownership. An increase in confidence was expressed by a minority of guide dog owners from Whitmarsh's (2005) study; 22% of male and 31% of female participants. Miner (2001) reports qualitatively on participant's emotional and social experiences of guide dog ownership. In Miner's (2001) study, guide dog owners expressed that the use of their guide dog provided them with a feeling of increased confidence and positivity with respect to dealing with daily life events; "Slowly I started getting more confidence... being able to do the errands... the confidence he gave me and then the bond we had was just awesome, I mean he really did give me a whole new world..." (Miner, 2001, p. 186). Wiggett-Barnard and Steel (2008) found in their study that guide dog ownership also resulted in increased confidence, in particular with regard to mobility, as participants experienced improved mobility with a guide dog when compared to their use of a long cane. Participants experienced that the guide dog provided safer travel, in particular by enabling improved access to unknown environments, even to the degree where they felt comparable to a fully sighted individual; "It definitely gives you self-confidence. You can almost, can I say, you can almost compete with what sighted people can do. You can operate in your own right" (Wiggett-Barnard & Steel, 2008, p. 1020).

Feelings of companionship is the third most frequently reported social and emotional benefit by guide dog owners in this systematic literature review. In Whitmarsh's (2008) study, a total of 36% of participants who lived alone and 22% of participants who lived with others reported an increase in feelings companionship after having commenced a working relationship with their guide dog. Whilst these figures demonstrate how only a minority of participants identified companionship as an emotional benefit of guide dog ownership, they do demonstrate an increase from the number of participants who retrospectively reported companionship as an emotional benefit at the point of applying for their guide dog (only 5%

of all participants). Interestingly, the majority (90%) of all participants in Whitmarsh's (2008) study reported in retrospect that their motivation for pursuing guide dog mobility was to achieve improved independence and safety with mobility. These findings suggest that perhaps guide dog owners are still primarily motivated to pursue guide dog mobility for the primary purpose of improved mobility, and may not recognise the secondary benefits, such as companionship with the dog and others, until they start using the guide dog. This finding indicates a need to recognise the more holistic benefits of guide dog ownership at the stage of application, so that benefits secondary to mobility support (including independence, confidence and companionship) may be made explicit for the purpose of guide dog referral.

Wiggett-Barnard and Steel (2008) identify a strong theme emerging from their participant interviews, whereby the guide dog was clearly perceived by their guide dog owners as capable of providing companionship, reciprocal affection and even having some shared personality traits with their guide dog owners. Findings from Wiggett-Barnard and Steel (2008) also suggest that this perceived companionship and acceptance by their guide dog could also serve as a conduit for self-acceptance and increased self-esteem. The significance of companionship with a guide dog is clearly justified in the study by Steffens and Bergler (1998), where 98% of participants identified feelings of affection, love and tenderness as a benefit of guide dog ownership. 88% of participants described their dog as a "comrade and faithful partner", and 68% reported their guide dog prevented or reduced feelings of being alone and loneliness (Steffens & Bergler, 1998, p. 7).

A richness of qualitative data regarding these "secondary roles" of a guide dog has indeed emerged from the literature in this systematic review, providing a foundation in which to build on with the main study, in further exploring the emotions experienced by guide dog

owners across the longitudinal period as they apply for, train with and work with their guide dog.

***2.5.1.2 Emerging theme #2: “guide dog mobility can be associated with negative responses from and interactions with the public that were perceived as having an adverse impact on the emotional wellbeing of guide dog owners”.*** The highest reported emotional and social disadvantage to guide dog ownership is an increase in negative emotions relating to undesirable social responses to the guide dog, such as unwanted social attention or social avoidance from others, public ignorance regarding access rights for the guide dog (Miner, 2001; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008). Findings from Wiggett-Barnard and Steel’s (2008) study report how participants experienced a general lack of public awareness toward people with disabilities, which extended to the functioning and rights of guide dogs as well. Participants reported their experience where a lack of awareness by certain personnel (e.g. security guards) impacted negatively on their ability to access public spaces with their guide dog; “I was denied entrance at a computer internet shop...I wanted to send an email and the guy told me that he could not accommodate me, because there was no space inside the shop and the dog would scare the other customers away” (Wiggett-Barnard and Steel, 2008, p. 1022). Whitmarsh’s (2005) study reports only a low proportion of participants (7%) who experienced unwanted attention from others when using their guide dog in public spaces. Participants in Miner’s (2001) study reported changes in how members of the public interacted with them following acquisition of the guide dog, however most viewed the guide dog as an “icebreaker”, whereby facilitating improved interactions with others, while others viewed this as an invasion of their personal space. It is important to acknowledge that the theme of undesirable public response toward their guide dog is the highest reported emotional and social disadvantages to guide dog ownership across studies in this systematic literature review. Furthermore, the impact of undesirable public response is

recognised as meaningful by guide dog owners throughout their overall experience of guide dog ownership.

### **2.5.2 Relevance to practice.**

Having a thorough understanding of the emotional and social changes a person who is blind or vision impaired experiences when using a guide dog as their primary mobility aid has several significant implications for the guide dog service industry. In the first instance, there is an impact on the decision made by guide dog staff as well as the informed choice that a person who is blind or vision impaired makes when seeking referral for guide dog ownership.

Understanding the emotional needs of the person who is blind or vision impaired has relevance to how applicants are selected and matched to their guide dog, how training programs are implemented, and how guide dog owners cope with the stressors in the day to day use of the guide dog (e.g. undesirable social responses to the guide dog). For example, if a person who is blind or vision impaired presents with a low degree of social confidence then they may be better matched to a guide dog that is not exuberant in its behaviour as this could create some level of discomfort or embarrassment by the guide dog owner from the likelihood of unwanted social attention that the behaviour of the guide dog may elicit.

Another example could be where a person who is blind or vision impaired presents with a lack of confidence due to increased dependency on others for their mobility needs, and a desire for increased companionship and social interaction with others. The evidence obtained from this systematic literature review suggests that appropriate referral for guide dog ownership may then potentially serve to primarily address confidence and independence with mobility, whilst potentially increasing companionship and social interaction as a secondary outcome.



### **2.5.3 Strengths of the literature review.**

Several factors strengthen the results of this systematic review. One such strength includes how the PICO and inclusion/exclusion criteria were carefully designed to support the location of four included articles whose outcomes measures were reported in a similar way so that outcomes could be easily compared and contrasted between studies. Therefore, results of these studies are pooled in order to gain a greater understanding of the most commonly reported emotional and social benefits, as well as some of the emotional and social disadvantages, as reported by guide dog owners.

Use of the McMaster Critical Appraisal Tool for Qualitative Studies (Letts et al., 2007) assisted in acknowledging that the findings of three out of the four included studies (Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008) contributed valuable data for the purpose of theory development, and future practice/research in the area of guide dog service delivery. An example of this is the valuable findings emerging from Whitmarsh's (2005) study, where the perceptions of guide dog owners on the benefits of guide dog ownership extended beyond merely that of a mobility aid (including increased companionship and social contact). Interestingly, these benefits of guide dog ownership were not preconceived benefits prior to owning their guide dog, but rather were realised after guide dog owners commenced working with their guide dog. The implications of these findings from Whitmarsh's (2005) study is that many of the benefits of guide dog ownership (i.e. beyond that of a mobility aid) are not well recognised within the blind and vision impaired population. The implication of this is that the prescription of guide dog mobility to meet a range of needs evidenced by the client may be limited due to a lack of recognition of the broader range of benefits that guide dog mobility can have for a person who is blind or vision impaired.

#### **2.5.4 Limitations of the literature review.**

There are several factors limiting the outcomes produced by this systematic review, which are reflective of the acknowledged gap in the literature regarding a lack of current, reliable phenomenological studies on the secondary benefits of guide dog ownership, such as companionship and improved emotional wellbeing (Howell, Bennett & Shiell 2016; Miner, 2001; NDIA, 2020; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008). The lack of relevancy and recency in research produced in this area meant that a time period for publication was not specified in the inclusion criteria, so that as many potentially relevant studies as possible could be captured.

A further limitation of the data in this review is that only two of the studies (Whitmarsh, 2005; Steffens & Bergler, 1998) utilised not only a qualitative measure of the emotional and social experiences of guide dog ownership reported, but also a quantitative measure regarding how often individual participants reported having experienced certain emotions, and how intense or significant these emotional experiences were perceived by the participants. The remaining two studies (Miner, 2001; Wiggett-Barnard & Steel, 2008) included only a qualitative measure of the emotional and social experiences of guide dog ownership. Thus, these two studies are unable to indicate which emotional experiences were reported most frequently, or the perceived intensity and significance of these emotions, according to the guide dog owners who participated (Miner, 2001; Wiggett-Barnard & Steel, 2008). The importance of being able to not only recognise specific emotions, but also to understand the significance and intensity of emotional experiences, as consciously reported by the individual, is consistent with recent psychological research (Baumeister et al., 2007; Feldman-Barrett et al., 2007; Reizenzein, 2020; Warren, 2020) and aligns closely with a phenomenological perspective (Arnett, 2017; Charlick et al., 2016; Miller, Chan & Farmer, 2018).

All four of the included studies (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008) only collected participant data at a single point in time, and thus are limited by their inability to observe any changes in emotions experienced by guide dog owners across the longitudinal process of ownership. Furthermore, the four studies are inconsistent in their reporting of what stage of guide dog ownership their participants were currently at (e.g. recently commenced working with a guide dog, or had been working with a guide dog for 12 months), and therefore it is difficult to ascertain the impact this would have on the results obtained regarding participant's emotional experiences.

Some of the limitations on outcomes produced by this systematic review were identified throughout the process of critical appraisal using the McMaster Critical Review Form (Letts et al., 2007), thus were reflected in the studies' critical appraisal tool (CAT) scores (see table 2.4). For example, conformability was identified as a limitation with the potential for researcher bias across all four of the included studies (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008), as the researcher's role and relationship with participants was not adequately described. Furthermore, three out of the four studies (Miner, 2001; Whitmarsh, 2005; Steffens & Bergler, 1998) did not indicate whether a decision trail was used, that being the process by which the data were transformed into themes for further analysis, thus limiting the ability to determine consistency between study results and findings.

#### **2.5.5 Implications for future research.**

Upon examining the collective data obtained throughout the process of systematic review, a number of key indicators have been identified to direct the focus of future research. One recommendation for future research is a study design where the collection of participant data

regarding emotional experiences occurs at more than one point in time. Such a design would allow for observation of any changes in emotions experienced by guide dog owners across the longitudinal timeframe of ownership. This is vital to identify changes or improvements in emotional wellbeing before and after guide dog ownership, to determine whether the guide dog serves a secondary role in improving emotional wellbeing of guide dog owners.

Of interest, is that only one of the included studies identified an increase in feelings of grief and loss when the guide dog either dies or retires, as one of the key emotional and social disadvantages to guide dog ownership (Whitmarsh, 2005). This finding may indicate that other study samples either had not yet experienced the loss of a guide dog or did not identify this loss as a significant disadvantage of ownership. Thus, future research could further explore the process of losing or retiring a guide dog, and the impact this has on the emotional wellbeing of guide dog owners, as this is a significant milestone in the partnership between guide dog and guide dog owner.

An area of methodological rigor that future research should focus on improving is conformability. This can be addressed by clearly establishing the researcher's theoretical perspective and designing studies that reduce potential for researcher bias. For example, if the researcher has an existing relationship with study participants, then data collection should be undertaken by an independent third party, and data blinded for the researcher to analyse.

## **2.6 Summary**

This systematic literature review sought to explore how the guide dog impacts upon the emotions and emotional wellbeing of the guide dog owner, across the longitudinal process of applying for, training and ultimately working with a guide dog. When synthesising the results of the four included studies, it was established that guide dog ownership has a greater degree

of emotional and social benefit than disadvantage, thus resulting in a degree of improved emotional and social wellbeing for the guide dog owner. The existing literature on the emotions of guide dog owners as they apply for, train and work with their guide dog is limited in a number of ways. Firstly, the limitation of credibility in the four included studies (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008) as data were collected at only one point in time, and thus cannot report whether these emotions experienced by guide dog owners fluctuated over time, and whether the guide dog ultimately serves to improve their emotional wellbeing. Furthermore, only two of the included studies (Whitmarsh, 2005; Steffens & Bergler, 1998) utilised both a qualitative measure of the emotional and social experiences of guide dog ownership, as well as a quantitative measure of how frequently and intensely these emotions were perceived by the participants. The remaining two studies (Miner, 2001; Wiggett-Barnard & Steel, 2008) utilised only a qualitative measure of the range of emotional and social experiences, and thus could not conceptualise the frequency and intensity of emotional experiences, something that is identified as significant to a theoretical perspective of phenomenology (Arnett, 2017; Charlick et al. 2016; Miller, Chan & Farmer, 2018).

This study therefore seeks to address some of the shortcomings of the existing literature identified throughout this systematic review, by adopting a more rigorous methodological design involving a quantitative measure on the frequency, intensity and significance of self-reported emotions and feelings in the sample population. Furthermore, the credibility of the literature is supported through the application of a longitudinal study design for observation of any changes in emotions and feelings experienced by guide dog owners across the timeframe of ownership.

## **Chapter 3 – Methodology**

### **3.1 Overview**

This chapter presents a summary of the methodology adopted for implementation in this research study. Firstly, the key features of the research design are detailed, with justification given as to the rationale for selection. Secondly, theoretical perspectives of the researcher and this study are illustrated, so that the reader may understand the position and motivations for the study conducted. Next, a summary of participant characteristics and research methods are provided, followed by ethical considerations. Finally, an appraisal of the study design is presented, including both the limitations and potential value of this research, such as for enhancing service delivery to those living with blindness or vision impairment.

### **3.2 Research design**

This section addresses the fundamental features, including both description and justification, of the approaches adopted for this study. This includes a longitudinal method of data collection, where results are presented as case studies, followed by a thematic analysis of the emotions experienced by guide dog owners in the application, training and working of their guide dogs. Details of thematic analysis are discussed briefly in this section, but expanded on in section 3.5.5, when discussing the data analysis procedures. Following this, the mixed methods approach applied to this study is explained. Finally, the details of the two stages of data collection are provided, including a preliminary pilot study and longitudinal main study.

#### **3.2.1 Case study approach.**

Case study research, although difficult to provide a single unified definition for, is generally understood to be the study of a social phenomenon and is conducted within the a single or collection of “cases” (Swanborn, 2010; Yin, 2011). A case may consist of a person,

organisation, community, or cultural group. Case study research is carried out in the context of the case's natural environment, and is used to examine and understand a phenomena during a set time frame. Multiple data collection methods are commonly recruited, with one of the key methods used being interviews and existing documentation (Swanborn, 2010). More specifically, a multiple-case studies design is employed to support phenomenological inquiry in this study; utilising an in-depth approach with a sample inclusive of multiple cases to explore the time and space-bound phenomenon of their lived experience in applying for, training and working with a guide dog (Alpi & Evans, 2019; Chmiliar, 2010; Scholz, 2011; Scholz & Tietje, 2002; Yin, 2003; Zach, 2006).

In order to appreciate the decision for pursuing a case study design with multiple cases, it is important to consider both the advantages and disadvantages of this approach which influenced the researcher's informed choice. A case study approach is considered advantageous on many counts for the purpose of this study. Firstly, a rich understanding of a lived experience (such as guide dog ownership), not just the cause and effect of a single variable, which is a method of inquiry that is, for example, addressed in experimental designs (Zainal, 2007). The case study approach selected for this study enables access to cases in their natural environment, so that direct interviewing and investigation may take place, as derived information would not enable an understanding of the participant's lived experience to be attained (Krusenvik, 2016). Furthermore, direct (face-to-face) interviewing within their natural environment (e.g. the participant's home) was identified by all participants as their preferred method of interviewing, when offered alternatives such as a phone interview or direct interviewing at the Royal Society for the Blind (RSB) premises. Case studies are flexible in their approach and recognised as suited for studying single or multiple cases through application of qualitative, quantitative or mixed methods study designs (Zainal, 2007). Case study design is therefore acknowledged by the researcher as well-suited to

facilitating an exploration of the lived experience of guide dog ownership with a small sample of guide dog owners (cases), using a mixed (predominantly qualitative) methods approach, which is detailed further in section 3.2.3 (Creswell & Clark, 2018; Johnson, Onwuegbuzie & Turner, 2016; McKim, 2017).

One of the fundamental values of case study research acknowledged in the researcher's decision is that case studies have the capacity to aid in the development of new knowledge in areas where current research is limited, that serve as a valuable foundation for more rigorous future research studies (Krusenvik, 2016). This is of particular value as the systematic literature review in chapter two identifies a significant lack of existing, and more so, current research in the understanding of emotions experienced by guide dog owners.

Disadvantages and limitations of case study design are also considered carefully in this decision-making process. Firstly, case studies are often criticised for lacking in rigour; especially where there are often only one or two researchers collecting data. This opens up greater opportunity for equivocal evidence or researcher bias which may taint the data and inadvertently sway the results and analysis of research information (Crowe et al., 2011; Zainal, 2007). When reflecting on the criticisms presented by Crowe et al. (2011) and Zainal (2007), it is important to identify that the researcher recruited a total of three interviewers for the purpose of data collection in this study design. The reason for not having the researcher engage in data collection directly relates to his position of employment as Manager of the RSB guide dog service at the time the four milestone interviews were conducted, and the ethical considerations this may have if the researcher was to conduct the interviews himself (please see section 3.6 for a more detailed discussion of ethical considerations impacting this decision). Although the decision to exclude the researcher from the process of data collection and instead recruit three independent interviewers is more a pragmatic decision rather than a



methodological one, it is important to recognise the inadvertent impact this may have in somewhat improving the rigor of this study design. Having three independent interviewers collecting and deidentifying the data not only addresses an important ethical consideration in the study's design, but in part, reduces the potential for bias in the study's results (Crowe et al., 2011; Zainal, 2007). Furthermore, it is interesting to note the work of Krusenik, (2016), who argues this notion that case studies lack rigor, and instead insists on the capacity of case studies for yielding detailed and relevant data. This standpoint argues that data yielded by a case study design, that occurring within the case's natural environment, is incredibly difficult to take out of context, indicating higher internal validity and therefore esteeming the value of a case study design, which this research upholds (Krusenik, 2016).

Another limitation of case study designs that is widely recognised is that the data collected cannot necessarily be generalised to wider populations and may not be considered useful or relevant beyond the sample group studied (Crowe et al., 2011; Krusenik, 2016; Zainal, 2007). We may take inferences and hypothesise based on the outcomes of a case study; however, it does not afford the ability to generalise, and nor is this a purpose that the case study design promises to fulfil (Crowe et al., 2011; Thomas, 2012). In fact, as Thomas (2012) highlights, generalisation of research data is not always necessary as some of the most insightful and valuable research derived about a lived experience has been yielded through case study designs that are paired with a systemised approach for analysing the data and drawing meaningful conclusions. As a measure to address challenges with generalisability with a case study design, the researcher provides sufficient detail of the sample and procedures, as transparency is acknowledged as one such method to address concerns with the limited ability to generalise findings with a case study design (Crowe et al., 2011).

A further challenge associated with case study design is the sheer volume of data this approach elicits for the researcher, due to the nature of inquiry and data collection methods for the purpose of understanding lived experiences (Crowe et al., 2011; Zainal, 2007). Consequently, there is a greater risk for poor management and organisation of data, especially where resources are limited. Indeed, Swanborn (2010) concurs by emphasising the higher level of organisational skills required by the researcher in managing and ultimately analysing the large volume of data that case study design yields for the researcher. With this in mind, the researcher is adopting a structured and transparent approach for the organisation and analysis of the data, which is detailed further in section 3.5.

### **3.2.2 Longitudinal temporal frame.**

Consistent with phenomenological investigation, the study involves semi-structured interviews conducted individually with participants, to obtain an in-depth “picture” of the emotional experience of guide dog ownership and observe any fluctuations throughout this process (Wilson, 2015; Swanborn, 2010). Information is gathered over the course of four “milestones” identified in the experience of guide dog ownership. These four milestones are when participants are in the process of applying for a guide dog, whilst undertaking formal training to work with their guide dog, six months and then again at twelve months following successful completion of their training or “qualification” with their guide dog. Information about the main events surrounding each of these four key milestones is discussed in detail throughout chapter 5.

Varied methods of inquiry were considered for use in the study; however, strengths of the longitudinal design are identified as best suited to the research question, in particular for addressing the third aim of this study which is to specify the temporality of emotional wellbeing for guide dog owners across the four milestones identified. When the temporal

features of other methods were considered, the lack of time with a cross-sectional design was identified where data collection at a single point in time would fail to provide a baseline that subsequent data could be compared to (Lobiondo-Wood & Haber, 2014). Furthermore, the single point of data collection in a cross-sectional design would serve to provide weaker evidence of causality, as it is difficult to establish a temporal relationship between the emotional journey in the stages of achieving independence through guide dog mobility, especially if relying upon retrospective recall of these experiences (Lobiondo-Wood & Haber, 2014).

In contrast to a cross-sectional design, the way in which a longitudinal study design interacts with its participants has features that best aligns with the research question and the case study approach. Participants of a longitudinal study are examined and followed independently of one another, focusing on maximising the depth of their responses and early identification of trends to be investigated (Cimarolli et al., 2017). Furthermore, the collection of data from participants over several points in time supports to establish a baseline in the first interview, which serves to assist with evidencing change in emotions and feelings over time, so that a comprehensive picture of the phenomenon under inquiry is obtained (Cimarolli et al., 2017).

As a longitudinal design has been selected as most appropriate for gaining an understanding of the emotions and feelings experienced by guide dog owners in the key milestones of application, training and working of their guide dogs, the limitations of this study design are also acknowledged. Such limitations included the increased risk for threats to internal validity, such as a higher incidence of confounding variables (e.g. complex and challenging issues relating to the participant's social circumstances) and loss to follow-up. That is either a loss of participant data or the participant themselves becoming unreachable before the data collection is complete (Carrière et al., 2013). Efforts to mitigate the potential for a loss to

follow-up include the regular follow-up, monitoring of contact details and maintenance of the existing relationship with participants that the RSB has in place. The potential for factors external to the experience of guide dog ownership (e.g. relationship breakdown, loss of family members) having an impact on outcomes, is addressed through ensuring a review of any significant changes to the participant's life at each milestone interview, so that this information is then considered in the data analysis.

### **3.2.3 Mixed method research.**

For the purpose of this study, a mixed methods approach (QUAL-Quant) is applied and involves a predominantly qualitative method of inquiry via individual interviews, which is strengthened by quantitative measures presented in the longitudinal case studies and thematic analysis (Creswell & Clark, 2018; Johnson, Onwuegbuzie & Turner, 2016; McKim, 2017). The principal quantitative measure used is the Beck Depression Inventory (BDI); a questionnaire that comprises 21 items and is designed to investigate the symptoms of depression, their intensity and impact on everyday life (Koenes & Karshmer, 2000). The BDI questionnaire is carried out with each of the four milestone qualitative interviews (a total of four questionnaires completed with each participant) to measure changes in psychometric data throughout the guide dog owner's process of applying for, training and then working with their guide dogs. This mixed methods design is predetermined at the onset of the research, and processes are implemented as planned (Creswell & Clark, 2018; Plano-Clark 2014, Yu & Khazanchi, 2019). Further details regarding the design and administration of the mixed methods research approach are discussed in section 3.5.

When contemplating a mixed methods approach, the researcher carefully considers both the benefits and the challenges that are presented when undertaking the study. One of the benefits of a mixed methods approach is acknowledged in the emerging evidence which supports its

capacity to provide a more inclusive approach for populations with a disability. Existing research provide evidence of the ways in which people with a disability face a greater risk for exclusion and barriers to participating in research, despite their capacity to meaningfully contribute to the evidence-base of treatment and intervention research within the fields of health and disability care (Ciemnecki & CyBulski, 2007; Kroll, 2011; Kroll, Neri, & Miller, 2005; Nastasi et al., 2007).

Inflexible, inaccessible and inappropriate data gathering measures are one of the factors recognised as contributing to the exclusion of people with disabilities from participating effectively in research. Such data gathering measures which may impact on a person who is blind or vision impaired includes written questionnaires that are not offered in alternative print, a lack of flexibility with respect to the interview location and order in which questions are presented, and a lack of sufficient training of investigators to effectively communicate with individuals who are not sighted (Kroll, 2011; Kroll, Neri, & Miller, 2005; Nastasi et al., 2007). The common feature throughout the existing literature, is that people with a disability may face exclusion or barriers to participation in research when studies are not flexible or sensitive enough to allow for the necessary accommodations that enable meaningful communication with members of the research team (Ciemnecki & CyBulski, 2007; Kroll, 2011; Kroll, Neri, & Miller, 2005; Nastasi et al., 2007).

The researcher accounts for flexibility regarding the location and mode of interview, as well as the order in which questions of the semi-structured interviews are presented, which are led by the individual participant's preference and needs. All written materials, including consent forms and interview questions (BDI and semi structured interviews) are offered in alternative print formats for those participants that wished to retain a copy of these documents or use a scanning device to refer to them. Furthermore, interviewers recruited for the study undergo a

period of training that equip them to facilitate communication regarding potentially sensitive information with people who are blind or vision impaired (see section 3.5.3 for further information on the interviewer training process). Whilst there is a growing evidence base to support a mixed method approach for researching contextual factors and the lived experience of interventions for people with disabilities, the implementation of both qualitative and quantitative research methods requires careful planning. This is so that researchers can achieve a balance between upholding a rigorous and efficacious approach whilst demonstrating innovation to support inclusion of these populations at risk of marginalisation (Kroll, 2011; Kroll, Neri, & Miller, 2005; Nastasi et al., 2007).

The need for more mixed methods research that utilises a predominantly qualitative form of inquiry into the emotional experience of guide dog owners, with a form of quantitative measure to report on the frequency and intensity of emotional experiences is identified in the systematic literature review (see section 2.6) as necessary for addressing the gap in phenomenological research on the emotional wellbeing of guide dog owners (Arnett, 2017; Charlick et al., 2016; Miller, Chan & Farmer, 2018). As the severity of a vision impairment has a direct relationship with an increased incidence of depression (Kivett, 1979; Nollett et al., 2019; Rees et al., 2013), the researcher made the decision to explore standardised measures to assess for signs and symptoms of depression in adult populations. In order to achieve a quantified measure of the impact of guide dog ownership on the incidence and severity of depression as a significant feature of the emotional journey experienced, the quantitative Beck Depression Inventory (BDI) was selected for implementation throughout the study (Beck et al., 1961).

One of the key challenges the researcher experienced in implementing a mixed methods research design was ascertaining a sample size that suited a predominantly qualitative method

of inquiry, whilst incorporating a quantitative measure in the BDI questionnaire. Qualitative inquiry tends to utilise smaller, purposefully recruited samples to gain an in depth understanding of the lived experience (Merriam, 2009; Vasileiou et al., 2018). Conversely, quantitative methods of inquiry often warn against the use of interpreting measures gathered from smaller samples as too small a sample can limit the confidence a researcher has in their findings, and the ability to extrapolate these findings to make broader inferences about the wider population being studied (Barr et al., 2012; Creswell & Clark, 2018; Faber & Fonseca, 2014). The researcher considered these implications, however acknowledges that this study involves a predominantly qualitative method for exploring the impact of a guide dog on the emotional wellbeing of guide dog owners. In recruiting a smaller sample of six guide dog owners for the main study, the researcher acknowledges this research produces an in-depth, case-oriented analysis of the experience of guide dog ownership, where the ability to generalise findings may be somewhat limited (Barr et al., 2012; Creswell & Clark, 2018; Vasileiou et al., 2018).

#### **3.2.4 Pilot and main stages.**

The first stage in this research is a pilot study, utilising a cross-sectional interview design where each of the small sample of four participants are interviewed individually. The pilot study sample was recruited through the RSB, incorporating two current guide dog owners and two applicants for guide dog mobility. The pilot sample is indicative and reflective of the demographic of participants ultimately recruited for the main study sample.

The purpose of the pilot study is not to gather and synthesise data relating to the research question. The pilot study serves to test the feasibility of a mixed method data collection approach and the refined development of a final interview tool. This is so that any necessary adjustments to the tools and approach used for data collection can be implemented prior to

conducting the main study. An adjustment made prior to data collection in the main study is to ensure that participants have the option of meeting with the interviewer at a location where their guide dog could be present for the training and post qualification milestones, as this was reported as a preference by the two participants in the pilot study who already had a guide dog.

Both the researcher and interviewers gain mutual benefit through participation in the pilot study, where shared dialogue supports the interviewer to understand the expectations of the researcher, while the researcher has a greater understanding of the skills of the interviewer to conduct the interviews. This shared experience of the pilot study allows for discussion about technique and explanation of hypotheticals to ensure the interviewer has a clear understanding of their part in the study and the expectations of the researcher.

The initial pilot stage is followed by a main longitudinal study to address the research question. The researcher opts for an intensive approach by focusing on the small sample of the entire population of (six) guide dog owners who have applied to complete their initial period of training through the RSB within a specific 12-month period. This intensive approach with a small sample allows for the researcher to study the phenomena of applying for, working and subsequently training with a guide dog in depth; to describe the changes that occur throughout this period of time and factors which influence individual experience, as described by the individuals themselves (Swanborn, 2010).

### **3.3 Theoretical perspectives**

This section addresses the way in which knowledge is understood, processed and analysed for the purpose of this study. This commences with an overview of ontology and epistemology, followed by how this thesis was philosophically positioned to approach the relevant



knowledge. Next, there is a discussion of how a theoretical perspective of phenomenology underpins this study design and informs the way data were collected and analysed for interpretation. Finally, the positionality of the researcher himself is presented and discussed. This assists in establishing an understanding and transparency of how the researcher's professional experience and interests contribute toward the development of this study, and highlight areas for potential bias that are addressed in the research design.

### **3.3.1 Ontology and epistemology – an overview.**

An investigation into the emotions and feelings of people who are blind or vision impaired, who choose to apply for and use a guide dog, has a subjective element to the analysis. From a theoretical perspective, such analysis relies on a constructivist ontology. By definition, the ontology of qualitative research has a strong constructivist framework (Tuli, 2010). This constructivist ontology of qualitative research stands in contrast to the positivist ontology which aligns with quantitative inquiry. Positivists hold that an understanding of phenomena is both “real” and “apprehendable”, able to be confirmed through objective experimentation and logic (Lincoln & Guba, 2000; Slevitch, 2011). Constructivists support a different notion, whereby truth and meaning are subjectively constructed by the individuals who have lived experience of a phenomenon (Elkind, 2004; Lincoln & Guba, 2000). This study upholds the subjective method of inquiry postulated by a constructivist framework, as it seeks to understand the impact of a guide dog on the emotional wellbeing of guide dog owners, as reported by the guide dog owners themselves. Data collection for this study is based on self-reported emotional experiences and changes in emotional wellbeing, having recognised that the reality of this phenomena is resulting from those cognitive processes triggered by a lived experience of applying for, training and working with a guide dog.

Ontological positions describe what entities exist or can be said to exist, and also what kind of relationships exists among basic categories of being (Guba & Lincoln, 1989). The paradigm directed by the ontology in this research establishes our understanding and knowing in relation to the emotions and feelings for a person who is blind or vision impaired. What is difficult to determine are the myriad of influencers in the separate worlds of people with sight and people without, the parameters are too wide. In order to understand the concept of emotions and feelings for the person who is blind or vision impaired, as separate to the sighted person, the researcher must draw ontological data from the reality formed by both empirical worlds. (Goertz & Mahoney, 2012).

Whilst ontology seeks to discover what knowledge is, epistemology proceeds to examine ways in which this knowledge may be accessed, how it should appear and relationships that exist between the researcher and the knowledge they pursue (Guba & Lincoln, 1994; Hofer & Pintrich, 2012). It is therefore relevant to address how the researcher approaches investigation of the research question, and in doing so, what ontological and epistemological assumptions underpin this approach. These assumptions are addressed below in establishing the philosophical positioning of this thesis.

### **3.3.2 Philosophical positioning of this thesis.**

The researcher adopts a constructivist ontology and the search for an epistemological understanding about the emotions and feelings experienced by guide dog owners. The use of a constructivist perspective, which is most common in the social sciences, allows the researcher to investigate the research phenomenon in detail and is consistent with a theoretical perspective of phenomenology (Tuli, 2010). This is because a constructivist approach dismisses the existence of universal truths or categories for human experiences, and rather acknowledges that individuals form their own unique understanding and knowledge of

the world through the way in which they reflect on lived experiences (Pilarska, 2021).

Phenomenological inquiry seeks to understand the unique and personal way an individual perceives the phenomenon they have experienced and therefore aligns well with a constructivist ontology (Arnett, 2017; Pilarska, 2021). Ulin, Robinson and Tolley (2004) emphasise the value of a relationship which a researcher is able to develop with their participants over a prolonged period of time, something that is achieved within the design and implementation of this longitudinal research study. The researcher is not conducting interviews with the participants in this study due to the ethical concerns regarding the potential impact that participating in the study may have on their application for a guide dog (see section 3.6.2 for further details on ethics in the study design). As such, independent interviewers are recruited and appropriately trained to undertake the interviews with participants on the researcher's behalf. Where possible, contact with an interviewer is consistent so that participants can develop a relationship with their interviewer over the course of several milestones.

### **3.3.3 Theoretical perspective underpinning this thesis.**

A phenomenological perspective is adopted to support the study design. It dictates how the research is conducted and how findings are analysed (Arnett, 2017, Smith, 2018b). In essence, phenomenology is concerned with the study of the way in which phenomena is experienced, the things that appear within an individual's experiences and what meaning these have to the individual (Moran, 2002; Smith, 2018a). The field of phenomenological research studies a person's conscious experience, meaning what the individual subjectively reports having an awareness of within the phenomena of interest (Smith, 2018a). Later in this section, Interpretative Phenomenological Analysis (IPA) will be introduced which enables the researcher to conduct thematic analysis in detail on the participants' emotional experiences. Phenomenology is considered radical from an empirical perspective, as it

positions the researcher to understand the perception of a phenomena within the context it is experienced, without the influence of preconceived assumptions (Arnett, 2017; Sokolowski, 2009).

The phenomenon of interest for this study is the process of applying for, training and ultimately working with a guide dog, and the conscious emotional experiences which are reported subjectively by the participants who are blind or vision impaired as they are engaged in these events. In this thesis, participants are presented as case studies, so that an in-depth understanding of their unique experience, as reported by the participant themselves, may be understood, before further analysis of the sample as a collective for the purpose of informing broader claims (Krusenvik, 2016; Zainal, 2007). Phenomenology validates the diversity of experience in human experiences, meaning that two people undergoing the same phenomena may report differently on their experience (Arnett, 2017; Moran, 2002; Smith, 2018b).

Husserl, who is recognised as the founder of phenomenology as a formal field of research, describes the concept of bracketing (Arnett, 2017). This concept proposes that the focus of an individual's attention within a phenomenon (the elements which they "bracket") is believed to have a direct influence on how they subjectively describe their perception of this experience (Arnett, 2017). This explains how the emotional experiences reported by two different people undergoing the process of applying for, training and ultimately working with a guide dog may differ greatly, as the elements they attend to or "bracket" within these phenomena may vary depending on a number of factors specific to the individual (Apostolescu, 2019; Arnett, 2017).

Phenomenology, as a field of research, has observed developments which extend from Husserl's notion of "bracketing" as a central contribution to phenomenological research, and has projected into a multiplicity of perspectives within this field (Arnett, 2017; Sokolowski,

2009). There is a lack of consensus among researchers as to whether one central method of phenomenological research remains, as there is a growing acknowledgement of multiple perspectives, one of which is interpretative phenomenological analysis (IPA) (Arnett, 2017; Miller, Chan & Farmer, 2018) which served as the methodology for this study. IPA is used in this study as a perspective to enable the examination of the meaning participants applied to the significant life experience of guide dog ownership, and then take this one step further to bracket and interpret these meanings through thematic analysis of the emotions and feelings reported (Biggerstaff & Thompson, 2008). IPA and the concept of “bracketing” is applied by means of purposeful exploration of elements within these experiences that influence the participant’s subjective report of the phenomena, but may easily be assumed as insignificant and therefore overlooked in the context of daily life (Finlay, 2011; Pietkiewicz & Smith, 2014). The inductive nature of IPA is especially valuable to this study as the researcher has not needed to rely on existing literature, which has been recognised as limited on the topic, to inform the process of thematic analysis (Biggerstaff & Thompson, 2008). Instead, the IPA approach enables the opportunity for accurate description of participant’s lived experiences and factors they attended to which influenced their description of this, with the opportunity for new or unexpected findings to emerge (Biggerstaff & Thompson, 2008; Finlay, 2011; Pietkiewicz & Smith, 2014).

It was established earlier (see section 2.6) that there is a lack of credible and relevant literature about the emotional wellbeing of guide dog owners, with the majority of existing data being collected at only one point in time with limited understanding about emotions and feelings experienced or sustained over time (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008). By undertaking research on the emotions and feelings of guide dog owners over a longitudinal time frame using an IPA perspective, the researcher is reporting not only on these emotional experiences but also the elements

within these experiences the individual participants attended to and are influenced by (Smith & Osborn, 2015). Use of an IPA perspective supports the exploration of each participant as an individual case, recognising that they each attend to and make sense of varying elements throughout their own unique experience of applying for, training, and working with a guide dog (Charlick et al., 2016). Subsequently, the researcher is then able to analyse this information as a collective and propose more general statements about the longitudinal experience of guide dog mobility (Charlick et al., 2016).

### **3.3.4 Researcher's positionality relevant to this thesis.**

The researcher has 30 years of professional experience working in the field of guide dog mobility, and orientation and mobility. During this time, he has worked in a variety of roles ranging from guide dog instruction, as in training the guide dog and the client, and orientation and mobility, which requires formal education and accredited skills sets necessary to conduct training of the client with mobility aids other than the guide dog. In addition, the researcher has held a number of senior management roles, including that of Research Manager with Guide Dogs UK (the largest provider of guide dogs in the world). The researcher has worked both in Australia and the UK, including his current role on the accreditation committee of the International Guide Dog Federation (IGDF) and as a member of the Education Committee for Assistance Dogs International (ADI). The researcher's primary field of interest has always been in the relationship between the person and the guide dog from a human-animal interactionist position, as well as understanding the psychosocial impact of blindness and vision impairment, in particular how the acquisition and use of the guide dog influences their ambitions of achieving independence.

At the time this study was conducted, the researcher was employed as the guide dog services manager for the RSB. The researcher was able to gain full support and cooperation of the

RSB as an organisation to participate in the study, having ensured internal ethical requirements were met. In order to mitigate potential researcher bias, measures for the blinding of participant's interview data were confirmed to minimise this risk to the internal rigour of the study design.

It is possible that the researcher's positionality on the topic of emotions and feelings experienced by guide dog owners, which is influenced from a lifelong career with people who are blind or vision impaired, could impact on the design, data collection process and data analysis within this study. However, the focus of this study was narrowed down following a comprehensive review of the literature which served to guide the development of the research question and aims. Further significant consideration is given to identify and mitigate the potential for the researcher's positionality on the topic to impact the study design and findings, the priority of which is to protect the participants in their exploration of the research question. Specific details regarding research ethics are discussed in greater detail in section 3.6.

### **3.4 Research participants**

Information regarding participants for this study is presented next. This begins with an overview of the target population, followed by the recruitment process the researcher executed to secure the sample group to participate in the longitudinal case study. Finally, a detailed profile regarding the participants of this study is also presented.

#### **3.4.1 Target population.**

According to the most recent statistics from the Australian Bureau of Statistics (ABS, 2015), nearly 12 million Australians (53.7% of the total population) have some degree of vision impairment, based on self-reported data. The Royal Society for the Blind (RSB) is a provider

of services to South Australians living with a severe vision impairment, delivering 69,762 hours of service and supports in the 2018-2019 financial year (RSB, 2019). Within its scope of services, the RSB offers guide dog services to assist those with a severe vision impairment to travel confidently and independently in the community (RSB, 2020). The most recent statistics from RSB (2019) indicate that they currently have 71 RSB guide dogs trained and working with their guide dog owners.

### **3.4.2 Recruitment.**

Recruitment began with the researcher initiating contact with RSB Board and senior management, to gain their consent and cooperation for participation in the study. Information regarding ethics approval for the study was provided to the RSB Board and managers, and discussion took place between the researcher, members of the Board and members of senior management regarding procedures to ensure client confidentiality, consent for individual participants and anonymisation of any data gathered.

Once the RSB senior management team provided their consent, and subsequent had been gained from participants, guide dog instructional staff from the RSB guide dog service proceeded to contact clients who would be eligible to participate in the study.

### **3.4.3 Profile.**

The study consists of two sample groups; first to conduct a pilot study to demonstrate validity of the chosen data collection methods, and then a main longitudinal study to address the research question. Four participants were chosen for the pilot study, including two current guide dog owners, and two applicants for guide dog mobility who would have been trained before the main study was conducted. The main study sample consisted of six applicants, who had no previous experience of guide dog mobility and were yet to enter the process of



training and working with a guide dog. As the sample for main study incorporated the entire population of guide dog applicants at the RSB in a 12-month period, no further selection criteria could have been applied to the sample included in this study. Use of the total population of guide dog applicants for the RSB is necessary as this total number is reflective of all the applications received due the newness of the guide dog school and the resources available to train clients. Therefore, all applicants were invited to participate in the study, and all chose to participate. An overview of the participant characteristics is summarised below in table 3.1.

**Table 3.1***Participant characteristics*

<b>Pilot Study</b>			
Participant	Age (years)	Gender	Household/ living situation
Daniel	41	Male	Living with parents
Sue	63	Female	Living with spouse
Steve	72	Male	Living alone
Jack	64	Male	Living alone
<b>Main Study</b>			
Participant	Age (years)	Gender	Household/ living situation
Max	68	Male	Living alone in a low dependence housing complex
Bill	62	Male	Living in a shared house in a small one-bedroom bungalow
Bob	60	Male	Living alone
Stan	51	Male	Living with spouse
Todd	28	Male	Living with spouse and 3 children
Gwen	55	Female	Living with spouse

\*Note that names and ages have been changed for the purpose of participant deidentification.

**3.5 Research methods**

The methods applied for the implementation of data collection and analysis procedures in this study are now discussed. This includes an explanation and justification of the process for

designing and administering the longitudinal series of four semi-structured interviews with a main study of six participants across a period of four key milestones. Furthermore, there is a description of the process whereby the data collected during the interviews are processed and then analysed for interpretation.

### **3.5.1 Purpose.**

As this study focuses on gaining an understanding of the emotions and feelings experienced by guide dog owners, various primary data gathering methods were considered carefully for implementation. With the intention of the researcher to obtain in-depth descriptions about the phenomena of guide dog ownership, with respect to the emotions and feelings experienced by the guide dog owner and the meanings they bring to this experience, interviewing is selected as the primary data gathering method for the study (Alshenqeeti, 2014; Berg, 2007; Kyale, 1996; Schostak, 2006).

The researcher carefully considered the various methods of interviewing, to ensure best fit for the purpose of inquiry. The semi-structured interview was selected, as it allows a degree of controlled flexibility for the interviewers and participants, to further elaborate on the relevant areas raised within participant responses (Alshenqeeti, 2014). The semi-structured method of interviewing is recognised as having the capacity for examining the participant's experience of a phenomena in-depth, in a way where the interviewer can ask questions further to those prescribed, that allow a thorough understanding of the answers provided (Harrell & Bradley, 2009). A set list of questions is utilised by the interviewer that require a response and ensures that discussion is maintained within the parameters of the study. Flexibility is permitted regarding the order questions are posed, with opportunity for the interviewer to add some additional probing questions to fully explore all areas relevant to the study (Rubin & Rubin, 2005; Berg, 2007). Individual interviewing is considered most appropriate for the purpose of

this study, as the sensitivity of discussing potentially delicate areas of the participant's mental health and emotional wellbeing is deemed inappropriate for the more time-efficient method of focus groups (Harrell & Bradley, 2009).

### **3.5.2 Process for Interviews.**

When giving consent to participate in the study, participants elect to undertake a series of four sequential interviews with an independent, third-party interviewer. Participants are contacted by the independent interviewer (having already given consent to RSB staff to participate and be contacted) to arrange a time and venue of the participant's choice, to undertake the semi-structured interview and Beck Depression Inventory (BDI) Questionnaire. All participants in this study elected to have the interview and questionnaire undertaken at their own residence. Each interview and BDI takes approximately two to three hours to complete. Interviews are semi-structured in design, whereby the third-party interviewer refers to a series of qualitative questioning, both formulated and open-ended. Interview questions can be posed to the participant in a flexible order to allow participants the opportunity to describe their own views and emotions and feelings relative to their lived experience of guide dog mobility, in keeping with a phenomenological study design. The full schedule of questions from each of the four milestone interviews are listed in appendix four. Some example questions used in the study are:

- Can you tell me about why you have made the decision to apply for a guide dog?
- How do you think having a guide dog will make a difference in your life?
- How do you think having a guide dog will make you feel?

Each of the four milestone interviews has a set of prescribed qualitative questions, which follows the above procedure with the addition of some questions relevant to the participant's stage in the process of application or training with their guide dog. The BDI questionnaire

(see appendix five) is undertaken at the end of each semi-structured interview, to support a consistent process for all participants across the four milestone interviews. Furthermore, the interview questions are designed to be open-ended, allowing a freeflowing structure to the discussion between the interviewer and participant. The researcher is concerned that if the closed-ended questions of the BDI are to precede the interviews, it may restrict participants' responses to the open-ended questions and potentially skew the conversation to one that is focused predominantly on emotions and feelings contributing to a negative affective state. Interviews are audiorecorded and transcribed verbatim by interviewers, in readiness for the researcher to subsequently undertake thematic analysis of key themes emerging at each of the four data collection points, and also present as individual case studies across the longitudinal time frame.

### **3.5.3 Administration.**

Once consent from individual participants is gained by RSB staff, the researcher is then able to contact the individual participants directly, to confirm their consent to participate in the study, and to have a third-party interviewer contact them to schedule their first of four interviews. The following section provides an overview of the training provided to the third-party interviewers in preparation for their field work, followed by a summary of how interviews are administered.

**3.5.3.1 Training third-party interviewers.** The three interviewers over all four stages are students completing either a Master of Psychology or a Master of Occupational Therapy. Preparation for the interviews involved selection of interviewers based on their academic progress, and evidence of a recent National Police Check. The initial supervisor for this study is the head of psychiatry at the University of Adelaide (prior to a decision by the researcher to transfer the candidature to Flinders University), and thus facilitated the recruitment process.

Following recruitment, the interviewers are themselves interviewed by the researcher and the supervisor, to ascertain their understanding of blindness and vision impairment. Part of this preparation of the interviewer includes a role play, whereby the researcher and supervisor pose the questions to the interviewer, so they can gain a lived experience of the interview process from the participant's perspective. Another rationale for the provision of this training is to adequately prepare interviewers for engaging in potentially sensitive discussions whilst undertaking the interviews and BDI questionnaires with participants. These discussions can act as a trigger precipitated by disclosure and present a risk to the safety and emotional wellbeing of either the participant or interviewer themselves.

As part of the risk management approach, clear instructions are presented to participants prior to the interview, giving them opportunity that if they felt in any way compromised or at risk, to curtail and cease the interview without explanation. Additionally, this same instruction is conveyed to the interviewer, with the additional conditions that reasons for curtailment or cessation are fully documented and discussed at the earliest opportunity in a debriefing session with the researcher and supervisor. As a number of these interviews are conducted in the participant's home, the interviewer is instructed to call the researcher prior to entry into the home and immediately on leaving. The interviewer is also asked to commit a text to their phone memory which they could send if they felt unsafe in the interview environment.

**3.5.3.2 Administration of milestone interviews in the field.** Prior to interviewing, consent forms are provided to the participants in their preferred format (e.g. Braille or large print). Ethics approval documentation is also provided in the participants preferred format at the same time as the consent forms are distributed. Permission, on receipt of the consent form, is then obtained by the researcher for the third-party interviewer to contact participants to schedule the first interview. Interviewers contact each participant via phone to schedule

their interview. Only one of the pilot and two of the main study participants is required to undertake interviews via phone due to their rural location, while all other interviews are conducted in person, at the participant's house, as this was expressed as their preferred mode of interview. A month after the four pilot studies are conducted and validation of interview process (in particular, the semi structured interview questions) has been confirmed, the above process is repeated for interviewing the six main study participants.

#### **3.5.4 Data processing.**

Each participant interview is recorded on a Zoom H4N Multidirectional Digital Recorder and replayed by the interviewer using headphones whilst alone in a secure environment for the purpose of transcribing verbatim. Prior to presenting the interview transcriptions to the researcher, interviewers are responsible for de-identifying all participant data by providing a pseudonym for each. Pseudonyms remain consistent across the four longitudinal interview stages so that data could be effectively tracked and grouped for each participant of the study, in preparation for data analysis by the researcher. All of the deidentified, typed transcripts and interview recording files are stored on the secure University of Adelaide Cloud drive, and also on an encrypted, password protected internal hard drive on the researcher's computer.

#### **3.5.5 Data analysis.**

In the first instance, interviewers compile the recorded interview data for each of the six main study participants, immediately following each of the four milestone interviews. Interviewers then transcribe the recorded interviews verbatim, and note the participants' emotion or feeling, expression and use of non-verbal cues as they describe their emotional experiences. The researcher then undertakes a comprehensive review of all the written transcripts, so that any amendments to interview methods and questioning for subsequent milestone interviews can be made. Once all four of the milestone interviews are completed, the researcher begins a

thorough review of the transcribed interviews in chronological order, in preparation for the presentation of case study narratives and subsequently a thematic analysis of the collective data. By immersing himself completely in this data, one participant at a time, the researcher is able to then construct a comprehensive narrative of the longitudinal “lived experience” that each participant communicated throughout their four interviews. Beck Depression Inventory (BDI) scores are also calculated and presented longitudinally as part of each case study, to provide a quantitative measure of depressive symptoms across the four key milestones. The purpose of presenting the longitudinal data in case study form is to support an intensive approach for the phenomenological method of investigation, whereby seeking to obtain an in-depth understanding of the lived experience of guide dog ownership, in particular the impact of the guide dog on emotions, feelings and wellbeing (Wilson, 2015, Swanborn, 2010).

Once the case studies are completed, the researcher returns to the original transcripts and commences the process of thematic analysis (Braun & Clarke, 2006; Braun & Clarke, 2020). The emotions and feelings experienced across the four key milestones (application, training, six months-post qualification, and 12 months-post qualification) are then summarised based on the themes emerging from all six participant’s interviews at that key point in time. The rationale for conducting this thematic analysis is firstly, so that comparisons can be drawn between these four key milestones by observing fluctuations in self-reported emotional wellbeing to indicate at which times the guide dog owner may present with greater emotional needs and require additional supports. Secondly, to establish whether the guide dog ultimately serves an augmented secondary role of contributing to improved emotional wellbeing of their guide dog owner, 12-months post qualification with their guide dog.

Thematic analysis is conducted by means of manual coding, whereby the researcher inserts a margin into each individual transcript in which to document key emotion and feeling-based

terms and phrases identified within the transcripts, across the entire participant group (Fereday & Muir-Cochrane, 2006). Please see appendix six for an extract from a participant's annotated interview transcript. These key emotion and feeling-based terms and phrases serve to indicate the experience of specific emotions and feelings at the point in time where the participant is being interviewed.

Once all 25 transcripts had been coded, the researcher then clustered themes according to a broader emotional and feeling-related experience that can be acknowledged across different participants, to identify common emotions and feelings across the sample group. Once all themes had been clustered, the researcher reflected on how many participants reported experiencing this emotion or feeling, how often and how the emotion or feeling is described as experienced by each participant during the particular milestone in the longitudinal study. Using a phenomenological perspective, a qualitative narrative of how these emotional and feeling-related experiences were described by individual participants was analysed. Thematic analysis of depression as an emotion is further supported by a quantitative measure of the incidence and severity of depression, using the BDI questionnaire at each of the four milestones. A total of 33 emotions and feelings were identified throughout thematic analysis of the interview transcript; however this was then reduced to 25 for discussion in the thesis. In brief, the researcher's reflections described above, regarding how many and how often participants reported these emotions and feelings, supported the decision regarding which emotional and feeling-related themes were included in the discussion. This is because any emotions that are reported by no more than one participant at any one of the four key milestones was excluded from further analysis (please refer to section 5.1 regarding more details of this decision-making process). The above approach to analysing the data enables the researcher to proceed in discussing the significance of specific emotions and feelings, across the longitudinal timeframe and reflect upon changes in emotional wellbeing.



### **3.6 Research Ethics**

This section addresses the ethical considerations relevant to this research study. This begins with an overview of the process undertaken in gaining ethics approval, followed by a description and justification of the ethical considerations within the design of this study.

Following this, there is a thorough description of the procedures undertaken to ensure ethical integrity within the field work of this study. Finally, the details regarding ethical management and analysis of the data collected are now provided.

#### **3.6.1 Gaining ethics approval.**

For the purpose of gaining ethics approval for this study, the researcher applied through the Human Research Ethics Committee at Adelaide University in South Australia. This process involved submitting a detailed proposal of the study design, including procedures for recruitment, conducting field work and the management of participant data during data collection and analysis stages of the research. Furthermore, relevant documentation, such as participant information sheets and consent forms were approved by the ethics committee (see appendices seven and eight for copies of the participant information sheet and consent form). Ethics approval was later transferred and extended to Flinders University in South Australia, due to the researcher's change in higher education institutions (see appendices nine and ten for ethics approval documentation). Details of the ethical considerations and the relevant protocols for this study will now be discussed below.

#### **3.6.2 Ethics in study design.**

The researcher did not engage directly in conducting any of the participant interviews for whom he had responsibility regarding their assessment for a guide dog, nor did he have any non-anonymised data in his possession. The rationale for this is to address any concerns

regarding the potential impact that participating in the research may have if any of the participants were ultimately unsuccessful in their application for a guide dog, in particular due to the researcher's position of employment as manager of guide dog services at the RSB.

To address this, two strategies were proposed and implemented:

1. All participants of this research project are interviewed by an independent interviewer, trained by the researcher and his supervisor; and
2. The researcher is not involved in the assessment or allocation of a guide dog for study participants, but instead devolves this responsibility to another RSB manager and training department employee.

By removing the researcher from the clinical assessment or allocation of a guide dog to study participants, any risk to the confidentiality, anonymity and integrity of the participant is minimised, as could their pursuit of guide dog mobility as their goal. It should be noted however, that due to the proximity of the researcher to direct client service, that total exclusion from being aware of any such intervention is virtually impossible.

No drugs or invasive interventions and no threat, wellbeing or welfare issues are created for the guide dog. As such there is no need to consider any ethical approval to have the guide dog present during the interviews and consider its wellbeing or welfare other than as accompanying the participant who took sole responsibility for their guide dog. The interviewer is instructed to not interact with the guide dog at any time unless there is a safety or wellbeing issue and if that occurred to inform the participant or call the researcher or the supervisor.

All information about the study is provided prior to interview in the participant's preferred format and prepared by the print alternative department at the RSB. Those participants who

volunteered to participate in the study are required to sign their copy of the consent forms and return them to print alternatives prior to the first interview.

### **3.6.3 Ethics in the field.**

Discussion regarding the rationale for recruiting three independent interviewers due to the potential conflict of interest in the researcher conducting the interviews himself is addressed in section 3.2.1. As part of the provision of training to the interviewers, special attention is given in educating them to identify signs of emotional distress or coping difficulties in the participants. If this is observed, the interviewers are instructed to take rapid course of action in bringing this to the attention of the researcher and/or supervisor who would take immediate action as responsible, mandated notifiers. In addition, the interviewers would use their mobile phone to store a safe text to send to the researcher a) when they arrive at the home of the participant; b) when they leave the home of the participant; and c) should they at any time feel unsafe or compromised during the interview and seek intervention from the researcher and/or the supervisor.

In addition, the interviewers are trained to detect any signs in the interview that the guide dog was being mistreated or there are concerns for its safety and wellbeing. Again, with the process of notification to the researcher and/or supervisor, who would in turn take immediate action to notify the RSB and put in place an intervention strategy. The interviewers are selected on their ability to show empathy and understanding to people who are blind or vision impaired and a level of maturity in conducting interviews of such a sensitive nature. The three interviewers over all four stages are students undertaking to complete either a Master of Psychology or a Master of Occupational Therapy.

The interviewer conducts the interviews, inclusive of the BDI questionnaire. The interviews are conducted by telephone or face to face interview, following analysis of the outcomes of the pilot study. Some interviews are conducted by telephone (one participant from the pilot and two from the main study), even though direct interviewing within their natural environment (e.g. the participant's home) is identified by all participants as their preferred method of interviewing. The rationale for the interviews that were conducted via phone is that these participants were living in a rural location, and the interviewers are not able to travel the substantial distance to undertake interviews in a timely manner. Existing research has examined the strengths and limitations of telephone interviewing, when compared to the use of in person interviewing in qualitative research (Block & Erskine, 2012; Mackintosh, Fryer & Hill, 2009; Sturges et al., 2004; Trier-Bieniek, 2012; Vogl, 2013). There is evidence to support how telephone interviews may limit the type and quality of data collection, such as a lack of ability to detect changes in non-verbal cuing which may be acknowledged as an additional source of information (Block & Erskine, 2012; Trier-Bieniek, 2012). However, a number of researchers argue the strengths of the phone interview and confront perceptions regarding its limitations when compared to interviewing in person (Mackintosh, Fryer & Hill, 2009; Sturges et al., 2004; Vogl, 2013). Studies by Sturges et al. (2004) and Vogl (2013) report no significant difference when examining outcomes yielded from both in person and phone interviewing for semi-structured interviews, and thus challenge the reluctance to use telephone interviews for qualitative inquiry. Mackintosh, Fryer and Hill (2009) report a preference for interviewing in person for participants that have hearing impairments, where English is their second language, or those who have receptive or expressive language difficulties. These issues are not present for any of the participants for this study, and while the interviewer is not able to access the participant's use of non-verbal cuing, this is not considered significant as the use of verbal report and other social cues (e.g. intonation of

speech) provide the interviewer with the necessary data regarding self-report of emotions and feelings experienced by participants.

Where the interviewer conducts a face-to-face interview, they encouraged the participant to meet in an open environment that is guide dog friendly (for those interviews where a guide dog is present) but afforded privacy for the discussion. If the participant wishes to be interviewed in their home, the interviewer informs the supervisor and the researcher of the timing and location of the interview and contacts them via text or phone call on entering the house and on leaving. It is agreed that if the interviewer cannot be contacted after three hours from when the interview was scheduled to commence, then the police will be called.

In the eventuality that a participant discloses that they have a physical or psychological health problem, the interviewer is instructed to recommend that they see their General Practitioner (GP). Furthermore, if any of the participants obtained a BDI score that indicates symptoms of moderate, severe or extreme depression, then the interviewer would tactfully explain the test results and recommend seeing their GP for follow-up.

If a participant discloses that they have a serious psychological health problem that poses an immediate threat, (e.g. are suicidal), the interviewer is instructed to contact the researcher as soon as practicable. Subsequently the supervisor is notified, and Assessment and Crisis Intervention Services would be contacted if the need for assistance is immediately urgent.

Upon completion of each interview, the interviewer asks if there are any questions relating to the study and the next stage of the study (for the main study participants only) and then thanks the participant for their time and contribution. The interviews for the main study, both telephone and face to face, are digitally recorded with the participant's permission. These

recordings are then transcribed by the interviewer with all identifying comments, participant names and guide dog names (where relevant) deleted. The interviewer keeps an audit trail of all information and data and forwards the de-identified transcriptions to the researcher for data analysis.

#### **3.6.4 Ethics in the management and analysis of data.**

All hard copy information (e.g. signed consent forms, typed transcripts) are stored in a locked filing cabinet in the supervisor's office within the University. All of the deidentified electronic information (e.g. typed transcripts, interview recording files) are stored on the secure University of Adelaide Cloud drive, and also on an encrypted, password protected internal hard drive on the researcher's university issued computer. Electronic files are later transferred from the University of Adelaide to Cloud storage at Flinders University, due to the researcher's change in higher education institutions. All participants are offered a transcript of their interview in their preferred format. If desired, participants are to be provided with a summary of the results at the conclusion of the research.

Confidentiality is consistently upheld throughout data analysis, via the use of pseudonyms for each participant. The use of pseudonyms is imperative in the development of written case studies and thematic analysis, where quotations are used to maintain the integrity and accuracy of participant's self-report of emotions and feelings they experience. For both the pilot and main studies, a number of other measures are also adopted to ensure anonymity for the participants. Any identifiable information is changed for the purpose of deidentification, including the names of people and dogs, ages of participants and their dogs, dog breeds, and other identifiable information specific to family members. These measures to safeguard the anonymity of participants ensure that the data gathered for analysis is not used to impact the relationship that participants have with the researcher or the RSB. The researcher maintains

his management role in conjunction with his duties and deferred any intervention to other guide dog mobility instructors (GDMI)s within the RSB to deal with any issues arising from the interviews, the data or intervention by the study supervisor following reporting from the interviewer.

### **3.7 Appraisal of the study design**

It is important to establish the limitations as well as the strengths and relative value of this study design, as this should support the reader to carefully consider how they interpret outcomes yielded. Firstly, by considering the strengths of an innovative design this study's unique blend of well-established methods (including a predominantly qualitative design with some quantitative features), gathering data via a series of longitudinal case studies, and a thematic analysis of participant's self-reported emotions and feelings. Secondly, the potential for this study to address gaps and contribute to the existing knowledge of the emotions and feelings a guide dog owner experiences will be discussed. The risks and potential biases associated with self-reported outcome measures are acknowledged, while appreciating the limited alternatives for gathering data on subjective human experiences, such as emotions and feelings. Finally, limitations within sampling procedures are discussed.

#### **3.7.1 Methodological innovation.**

A longitudinal study design was selected as it is well-established as ideal for exploring lived experiences that may change over a period of time (Plano-Clark et al., 2014). Although mixed methods approaches are increasing in their use, little attention is given in the existing literature regarding how to incorporate a longitudinal study with a mixed methods approach, and how to manage these complex designs so the researcher may drill deep into the rich strata of the phenomena being investigated (Van-Ness, Fried & Gill, 2011). This research study utilises this innovative method of inquiry, by combining a longitudinal case study design with

an embedded mixed methods approach (Hale & Napier, 2013). The embedded design acknowledges the quantitative method of inquiry as serving a supportive role to the more predominantly qualitative data on emotions and feelings experienced which is yielded through participant interviews (Almalki, 2016). The rationale for utilising quantitative measures in this study is to strengthen the understanding gained of the phenomena of guide dog ownership, by identifying the intensity and frequency of emotions and feelings reported across the sample group. The application of an embedded mixed methods design is ideal in circumstances where only a minimal amount of quantifiable data is required and serves only to strengthen the understanding and interpretation of qualitative data (Almalki, 2016). In descriptive terms, this shows the proportion of value extracted from the data as being “QUAL” compared to “quant” in the ratio in weighting of the nature of data to be collected and analysed for this research study.

### **3.7.2 Potential for contribution to knowledge.**

There are several recognised limitations within the existing research, which are considered and addressed within the design of this study in order to contribute toward and strengthen the knowledge base regarding the emotional wellbeing of guide dog owners. The first of these is the use of a longitudinal study design, whereby participants are interviewed at four milestones in time across the process of applying for, training and working with their guide dog. Much of the existing literature on the emotions and feelings experienced by guide dog owners is identified as limited in reporting changes in emotions and feelings over time due to study designs often collecting participant data at just one point in time, relying on retrospective, present and prospective participant report in a single interview (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008). This study has been designed with consideration to improving credibility and creating a greater



understanding of the guide dog owner's lived experience across four key milestones, so that fluctuations in emotional experiences and wellbeing may be documented and analysed.

Another way in which this study design seeks to address the limitations in the current literature is by adopting a mixed methods approach using an embedded design; incorporating some quantitative measures to enhance the predominantly qualitative method of inquiry by identifying which emotions and feelings are reported most frequently by guide dog owners. A substantial proportion of the existing literature on the emotional experiences of guide dog owners utilises only a qualitative method of inquiry, which means that one cannot ascertain which emotional experiences are reported more frequently or identified as more important by guide dog owners (Miner, 2001; Wiggett-Barnard & Steel, 2008). This study incorporates two key quantitative measures to support in demonstrating the significance of the qualitative data on emotions and feelings reported by participants; firstly, the Beck Depression Inventory (BDI) and secondly, through quantitative measures embedded within the thematic analysis to demonstrate which emotions and feelings are reported most frequently across the sample.

### **3.7.3 A reliance on self-reported outcome measures.**

This study places a heavy reliance on the accuracy and reliability of self-reported outcome measures, which in itself, placed risk for numerous biases within the results. For this study, the self-reported outcome measures rely heavily on a participant's emotional literacy, expressive language skills and insight into their emotional and feeling-related experiences relating to the phenomena of vision impairment or blindness and pursuing guide dog mobility. It is well-documented that self-reported outcome measures, in particular those relating to emotions and behaviours, present a substantial risk of reporting bias (Gonyea, 2005; Rosenman, Tennekoon & Hill, 2011). Furthermore, as this longitudinal study involved four key milestones for data collection, the risk for response-shift bias is also present. This

occurs when the participant's frame of reference alters across data collection points, in particular where the altered frame of reference is targeted by the intervention, in this case, guide dog mobility (Rosenman, Tennekoon & Hill, 2011). The reason for this may be that the introduction of a guide dog has altered the participant's understanding of certain emotions and feelings, and their own emotional wellbeing, thus introducing opportunity for bias in their report at each of the key milestones (Rosenman, Tennekoon & Hill, 2011; Sprangers & Hoogstraten, 1989). The data collection tools identified (semi structured interviews and standardised BDI questionnaire) are chosen to assist with consistency and reduce the likelihood of response-shift bias across the four key milestones. With respect to measurement bias however, this is difficult to control for as there is little alternative to self-reported measurement with respect to the outcome of emotional and feeling-related experiences. It is therefore important for the reader to be made aware of this potential for measurement bias by the participant reporting their emotional and feeling-related experiences, when interpreting and utilising the results of this research study.

#### **3.7.4 Sampling.**

There are considerations with respect to the sample which required further elaboration on the potential limitations as these may have some impact on the interpretation of results yielded. Firstly, the size (N) is relatively small however this was reflective of the population from which the sample is drawn. Indeed the sample represents the entire population of successful applicants for RSB guide dogs in the annual period. Although it is not possible to gather a larger sample group from this population unless other guide dog schools volunteered to participate in the study, it is still important to note the limitation this may place on the ability to generalise findings beyond the small population studied, however this is not a goal of this study.

### **3.8 Summary**

This chapter has sought to present an overview and rationale for the methodology adopted for implementation in this research study. By clarifying the theoretical perspectives and frameworks underpinning this study, the reader may now understand the position and motivations for the study conducted, and even begin to speculate on applications for the findings yielded. This is particularly the case now that participant characteristics have been provided in adequate detail. Considerable detail has been given in describing and exploring the ethical considerations for this study, which has involved gathering, managing and analysing sensitive data on participant's self-reported emotions and feelings across the time period of applying for, training and working with their guide dog. Finally, by exploring both the strengths and limitations of the chosen research design, the reader is able to understand areas of caution with respect to interpretation and application of findings. In addition, the reader may also appreciate ways in which the study has sought to assemble an innovative combination of methods to contribute to the knowledge base which may in turn be used for application within a range of contexts. Such contexts may include the improvement of direct guide dog mobility services to those living with blindness or vision impairment, the continuing education of professionals working in the field, and the development of innovation within guide dog mobility and ancillary services at the organisational level.

## **Chapter 4 – Participant Narratives**

### **4.1 Overview**

The purpose of this chapter of participant narratives is to give insight and more detailed understanding of the impact that applying for, training and working with a guide dog has made on the participant's emotional states, at an individual level. The interviews yielded rich data capturing each participant's lived experience of blindness and vision impairment, and the history of their lives prior to the decision to apply for a guide dog. The interviews also demonstrated how emotions and feelings are connected to the participants' experiences, in particular those related to the process of applying for, training and working with a guide dog. Six participants were interviewed at four time points; whilst awaiting the outcome of their application for a guide dog, just after they began training with their guide dog, six months and again at twelve months after having completed training with their guide dog. The following provides a description of each participant, detailing their demographics and key points of interest about their lives relevant to having a guide dog.

### **4.2 Participant one – “Max”**

Max, a 68-year-old man, was living alone in a one-bedroom unit in a shared low dependence housing complex. He had lived there for more than three years since the death of his partner. English was Max's second language. He did not have much of a social life and often felt lonely and isolated. Max was in good health, apart from his vision impairment. He was completely blind, having lost most of his sight at the age of eight years. He had good mobility using a long cane as his preferred mobility aid and had good orientation but found travel difficult in new or complex environments. Max had experience with animals in the past, having owned dogs, and his partner having had a cat.

Max applied for a guide dog to assist him in maintaining his independence and mobility. He was looking forward to forming a strong bond with a guide dog: “I will live [sic] because he is going to be my buddy, my partner”. Max anticipated that having a guide dog would assist him in travelling to unfamiliar places, facilitate meeting new people and reduce his feelings of isolation and loneliness. His opportunity to go out independently was greatly reduced at this time due to his need to use the cane, which even though he was proficient with its use, it made him feel vulnerable.

Max states that he is a very private person and by this he means he does not actively seek the company of others often. His housing situation was such, that even though living alone; he felt that the neighbours were a nuisance. Thus, two primary reasons for his application for a guide dog were for the potential for companionship and friendship, and that having a guide dog would allow him to leave the complex where he lived. His reason for leaving home as often as he could was due to the poor relationships he had with his neighbours. Max felt that having a guide dog would in some way compensate for the lack of human interaction in his life and offer him freedoms and opportunities he did not have prior to guide dog ownership. Max felt that his neighbours were watching him and listening to his phone calls, causing him high degrees of anger, stress, anxiety and frustration. Max felt that he had low self-esteem and poor self-image as neighbours, friends, acquaintances and even people he met in passing had treated him like a fool.

Since his application Max felt that he had not received much feedback from the guide dog school. He was frustrated by this delay. He had been looking forward to getting his guide dog and believed this would change his whole life and give him something to look after and something to look after him. Max completed a Beck Depression Inventory (BDI) as part of the application interview process and his score using the BDI score was 16. The scoring

system for the BDI indicated he was experiencing a mild mood disturbance (see appendix five for BDI questionnaire and scoring).

The second interview was conducted while Max was currently in training with his first guide dog, Holly. The training program took three weeks and Max was in the second week, having received his guide dog on the first day of the program. Holly, a Labrador cross breed, was present at the interview. Holly was matched to Max based on a number of parameters such as Max's preferential walking speed, his height, weight, personality as well as his mobility requirements and social needs for a guide dog.

Max's issues and arguments with his neighbours continued. He felt that the neighbours were monitoring his movements, listening to his phone calls and generally commenting on his lifestyle and living situation. Max felt that these intrusions had significant bearing on his wellbeing and emotional state, and while he appeared flippant in his response to these events, he continued to report frustration and anxiety as a result. The net effect of the intrusions for Max was to justify his perception that people were not worth the investment and that he was better off without them, focussing therefore on his pursuit of guide dog mobility. Max stated that Holly had been integral in reducing his stress, because he had been able to get out of the house independently and as often as he liked.

Max stated that the arrival of the guide dog had made a positive impact on his life. He felt that he had taken to and adopted the training methodologies well and utilised 99% of the instructors' comments and had kept strictly to them adding only 1% of adapted changes for his own needs. Max felt that because the training methodologies were focused on creating a bond and working partnership with his guide dog, in fact that they were bona fide in their intentions and were not being used to undermine him or make him feel devalued as a person.

Also, he felt that the training gave him a newfound status and title as a guide dog owner, someone to be trusted with the precious and valued item that was Holly. He felt he had a strong bond with the guide dog at this point and that they had a mutual understanding of each other. Max stated that since the arrival of the guide dog he no longer felt depressed, and the presence of the guide dog had addressed his loneliness. Max's previous feelings of anger and low self-esteem and feeling like a fool were dissipated as he felt the guide dog did not judge him. Max felt the guide dog had been well received by Max's friends creating a social conduit through which he could control the interaction and deflect attention from him, when he didn't want it. Furthermore, Max reported how he had occasionally refused to interact with members of the general public on the grounds that the guide dog was relatively new to working with him and that they needed to avoid distraction. On occasions where the general public recognised and commented on the efficiencies of the partnership between Max and his guide dog, this feedback gave Max a sense of pride in the guide dog and its abilities.

In an incident at an ATM Max stated that he had realised how strong his bond was with the guide dog as Holly reacted to a person standing in an intimidating manner behind him and that gave signs to Max that there was a threat. This event cemented the relationship even more and Max found more confidence in the guide dog. "I would be a little bit lost if I was to lose the dog now, I don't think I would ever replace it again". This bond created a very strong reaction from Max of protectiveness towards the dog: he claimed he would resort to violence if anyone interfered with the guide dog. Max felt that the guide dog made him more relaxed and this was reinforced by friends who commented on his changed attitude, "I used to be a spiteful little bastard....I am more relaxed too because I really don't give a rats, I don't care what people think or say". It is noteworthy that Max's BDI score remained at 16 (mild depression) at the second (training) interview, despite Max reiterating there was a strong bond between Max and Holly.

At the time of the third interview Max had completed training with Holly and had qualified for six months and was working the guide dog independently. Max was still having ongoing issues with his neighbours, which has left him angry, frustrated and stressed and feeling under constant scrutiny from them. The housing situation was of such concern to Max that he took every opportunity to take his guide dog out and go for a walk towards a destination such as the shopping centre or the pub. Max still played music occasionally and took his guide dog with him everywhere. He felt very positive and proud about people making comments about Holly and used these comments to interact with people and demonstrate his sense of humour with comments about the guide dog and its capabilities. Max was fiercely protective of Holly and stated that this bond was reciprocated. Max reported that the guide dog was a “bossy female” and reflected on the anthropomorphic relationship he had with his guide dog, who he also reported was his best and trusted friend.

A frustration that Max experienced was that people sometimes wanted to interact with his guide dog by patting it which made him unhappy, and sometimes he perceived he reacted to this request with sarcasm and cynicism. The dichotomy of feeling proud of his guide dog when people made comments and people stopping to interact with his guide dog appears significant as it highlights the impact on Max’s emotional state when people overstep the boundaries he was comfortable with such as interacting with the guide dog without his permission.

Max was also feeling stressed and unhappy about a complaint that had been allegedly levelled against him by the neighbours, regarding the accusation that Max had been mistreating the guide dog. He was quite angry about this and wanted to take legal action



against the complainant. He felt the bond with the guide dog was as strong as ever to the point that “now I go around with Holly, wherever I go she goes, because she is my mate”.

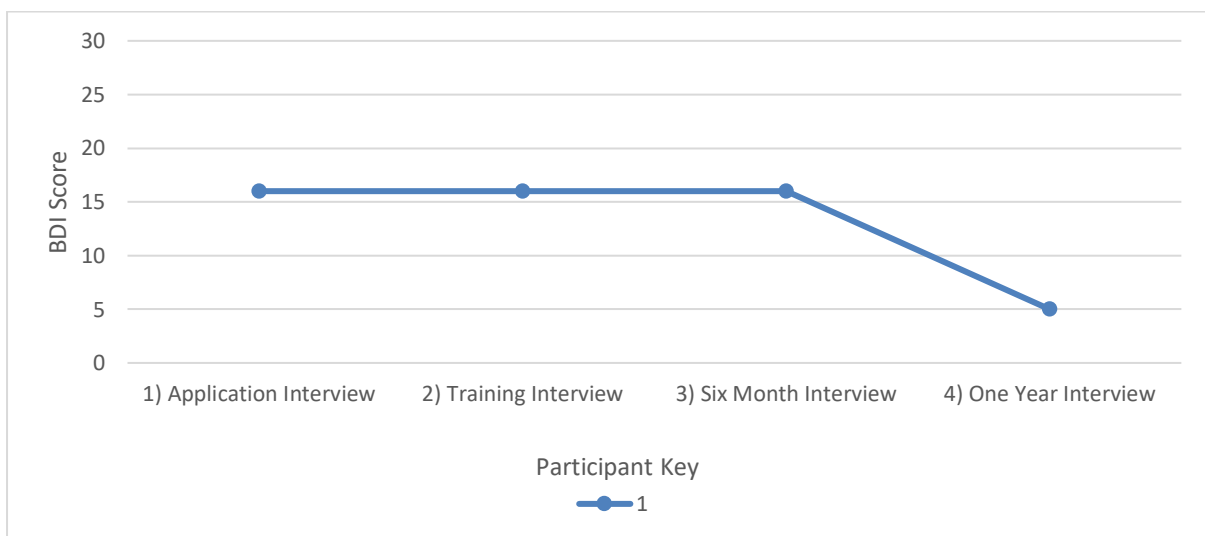
Max reported that there were some initial technical working issues with the guide dog’s behaviour, which had caused Max some concern and raised his anxiety levels, in part because he felt that he was compelled to work her to her best ability to impress the neighbours who had made the complaints about his treatment of Holly. These initial training problems in the working relationship with Max raised more feelings of anger and frustration in relation to the complaint that had been levelled against him. “She’s beautiful, you can’t complain about a dog like that”. Max felt that if the issues persisted and he felt victimised and bullied by the neighbours he would have no option but to return his guide dog and reapply. This caused Max some very deep emotional anxiety and direct anger towards the neighbours resulting in several conflicts and altercations. Interestingly, Max’s BDI score once again remained at 16 (mild depression) at the time of the third interview.

Max felt that his health was deteriorating, and that having Holly was contributory to his state of positive wellbeing at the time of the fourth interview; giving him purpose both in terms of exercising and caring for the guide dog. Max now felt concerned and anxious about his current health state, as he felt he had timed his life span to coincide with the guide dog’s working life; “and so, I was rather pleased that I was able to get a dog so that we could spend about five or six useful years of life together. That was fine, and it worked out wonderfully well, except for now I have these health issues, so now I am not sure what that will mean for me and Holly.”

Holly had made a significant impact on Max, so much so that he felt he was no longer quite so self-centred, as he now had somebody else to think about; he felt he would not be without her now. He felt that Holly had added a sense of safety to his walks, especially where traffic was concerned. Max felt that having Holly in his life had changed some of his beliefs, and that even with poor health this experience had given him new direction and purpose; “this is a new ball game completely, with a guide dog. It’s demanding, but I’m so happy to do it, because if for no other reason; an interest.”

**Figure 4.1**

*Longitudinal BDI Scores for Participant One - "Max"*



**Table 4.1***Longitudinal self-reported emotions and feelings for Participant One - "Max"*

<b>Emotion/feeling</b>	<b>Milestone 1</b>	<b>Milestone 2</b>	<b>Milestone 3</b>	<b>Milestone 4</b>
+Acceptance	√			
+Anxiety	√			√
-Anxiety		√	√	
+Apprehension	√			
+Companionship		√	√	√
+Confidence		√		
-Confidence	√			
+Depression	√			
-Depression		√		
+Discontentment	√			
+Empathy				√
+Frustration	√	√		
+Grief	√			
+Happiness	√			
+Hopeful	√			
+Independence		√		
+Loneliness	√	√		
+Motivation	√			√
+Protective			√	√
+Sadness	√			
+Security		√		√

\*Note re: prefixes: "+" indicates feeling/emotion reported; "-" indicates a reduction in feeling/emotion reported.

At the time of the fourth interview, Max's BDI score had reduced; from a consistent score of 16 (indicating mild mood disturbance) across the first three milestone interviews, to a score of five (indicating ups and downs that are considered normal) after Max had been working with his guide dog(s) in total for 12 months. See figure 4.1 above for a longitudinal summary of Max's BDI scores across the four milestone interviews. A more detailed discussion of the BDI scores across the longitudinal time frame has presented in the thematic analysis of depression in section 6.2. See also table 4.1 above for a longitudinal summary of Max's self-reported emotions and feelings across the four milestone interviews.

### **4.3 Participant two – “Bill”**

Bill was a 62-year-old man who lived at the rear of a shared house in a small one-bedroom bungalow. He had lived there for six months since his last relationship ended. Bill had several previous marriages and adult children from those relationships but had not been in contact with them at all which had left Bill sad about the loss of his family. “I can’t cry. I’ve finished crying”. Bill had a poor social life and had been limited in opportunity to get out more by the difficulties he experienced with his mobility. This lack of independence left Bill isolated, lonely and anxious about his future.

Bill regularly used a white cane, which he found 90% useful and had reported he was losing the little sight he had. He had lost most of his sight in February 1996 when he worked in the building industry, on high-rise scaffolding. Bill felt that the sight loss at the time was attributable to being tired and he was distraught and depressed to find that there was a medical condition associated with his vision impairment.

Since losing his sight Bill worked and volunteered in a number of roles in blindness agencies, particularly in the area of blind sports. Bill had good health and played a variety of blind sports, which had been one of his few social outlets. Bill stated that even his time with blind sport had been difficult as his ex-partner and their infant son attended a lot of the same blind sporting functions. This had made Bill feel anxious and stressed which he reported had led to further breakdown in his vision, self-esteem, and coping. Bill had not been given access rights to his son which had also caused anxiety and stress. He felt self-conscious about returning to clubs he knew well due to the issues surrounding his recently ended relationship. This made Bill anxious and self-conscious, lowered his self-esteem and motivation to get out more, and resulted in him being isolated and withdrawn. Bill felt he had lost a lot of friendships due to these issues.

He had increasing difficulty with mobility and independent travel, which left him frustrated and stressed making road crossings and travelling not only to known destinations but to new places. This created more anxiety and depression as Bill enjoyed walking, sometimes up to 20 kilometres a day. When he talked about his vision impairment, Bill felt stigmatised and judged by people who could not understand this, frustrated by having to give explanations of his vision abilities “because people don’t understand sometimes it’s hard to do things”.

Bill had applied for a guide dog to increase his mobility skills and to travel to broader, new destinations as well as visiting places he knew but could not get to anymore. Bill also reported that having a guide dog would be companionship for him. Bill had been frustrated and concerned with the waiting period for a guide dog. He had concerns over whether he would be successful in his application for a guide dog and whether he could look after one. Bill felt that, as he had applied for a guide dog before his vision completely failed, he would experience a smoother transition to becoming totally blind. Bill reported he had grown up with dogs, even breeding them at one point. Bill felt that having a guide dog would give him much needed companionship, friendship and something to care for. “If I have a dog then the dog can help me. Then if I lose a bit more, then I have my friend”. Bill felt that the dog might also work as a “guard dog and be another body to stop some of the riff raff”. Bill completed a Beck Depression Inventory (BDI) as part of the application interview process and his score using the BDI score was 30. The scoring system for the BDI indicated Bill was experiencing moderate depression (see appendix five for BDI questionnaire and scoring).

The second interview was conducted while Bill was in training with his first guide dog, Nancy. Bill had been in the third week of a three-week training program, having received his guide dog Nancy on the first day of the program. Nancy, a cross bred Labrador was matched

to Bill based on a number of parameters such as Bill's preferential walking speed, his height, weight, personality as well as his mobility requirements and social needs for a guide dog.

Bill stated he had experienced problems with Nancy's behaviour: this ranged from digging in the back garden to pulling him over and off his feet when she was in harness, which caused him shoulder pain. He reported that he was going to persevere with the training in order to overcome these issues. He was frustrated and concerned by the dogs' change in behaviour since the time of its arrival, including the apparent interest Nancy had in other dogs, which meant Bill could not take her to some places where he knew there would be problems. This made Bill very apprehensive about trusting Nancy in the company of other dogs, including other guide dogs, an important feature of his social interactions in blind sports, and he felt stressed as he had not been in control of her at these times.

Bill reported that he felt the guide dog was beautiful and a great companion and there were times when he felt really pleased with their bond and her behaviour, especially in the house. Bill found some of her characteristics funny and amusing, particularly the way he felt Nancy had been contributory in training him to help with her toileting routine. He felt that her work was good and they both enjoyed long walks with him not having to look down to protect himself from oncoming obstacles. Bill reported that he was still nervous and apprehensive about the impending loss of vision and there was a sense of frustration that he could not forestall this event. "I would rather have gone deaf or lost an arm or something like that, but not my eyesight".

The relationship with his family made him feel depressed. The relationship with his recent ex-partner had caused Bill anxiety and fearfulness. Bill reported a history of bitter disputes, arguments and residual anger, in his dealing with his ex-partner. He reported that the way these altercations left him feeling emotionally about the circumstances surrounding his

relationship her, he was reticent about taking the guide dog over to meet his son. “I can’t take the dog there, (ex-partner’s house) because they would probably kill the dog”. In addition, there had been times when Bill felt that his only option was to walk away from all the activities and aspects of his life that he had previously enjoyed taken pleasure in, and that thinking about this caused him additional anxiety and stress. Bill also felt concerned and anxious that his ex-partner would break a court order; denying him any access to his son, which combined with the newly developing issues with Nancy’s behaviour and his perceived social isolation, made him feel sad. Bill felt that going for long walks with Nancy alleviated his stress, on occasions where Nancy would work without behavioural concerns or related incident.

Bill reported that while there were ups and downs that had been frustrating, that the guide dog was great company and “did not back answer me, throwing things at me, whatever whatever”. He expressed however, that he was frightened of being reported by the public for what could be perceived as firm handling of Nancy, although he felt he was following the instruction given to him by his GDMI, in the use of corrections to modify Nancy’s behaviour. It should be noted that the RSB follow IGDF standards in their use of positive reinforcement in all of their training, and this would have been the model of behavioural modification recommended. Bill stated that Nancy had been a great help and had been a distraction from his stressors, by going for walks three times daily and stopping for coffee together, but Bill felt he may have to hand Nancy back due to the ongoing pain he had in his shoulder. It is noteworthy that Bill’s BDI score reduced from 30 at his application interview (which indicated moderate depression) to eight at his training interview (which indicated that these ups and downs are considered normal).

At the time of the third interview, Bill had completed training with Nancy and had qualified for six months, working the dog independently. After much anxiety and stress in the decision making, Bill had decided to hand Nancy back for remedial training to address the behavioural problems he was experiencing and until such time as his shoulder injury had recovered and that the school had committed to work on some of the training issues Bill had experienced.

Bill reported that for 75% of the time, Nancy was doing well, but for the other 25% “she wasn’t able or wouldn’t do it. I had to go her way; she wouldn’t go mine.” Bill felt responsible for some of the breakdown in Nancy’s work and felt out of control by his inability to command the guide dog. He stated that Nancy was a beautiful and loveable guide dog, and they had a good relationship and bond. Bill felt an element of pride and happiness in the way Nancy behaved in public but was aware that he had to be vigilant all the time to stop people interacting with her. He felt that when Nancy wasn’t working well or there were too many distractions that he lacked control in some environments, particularly shopping centres and this had been embarrassing. He also felt that Nancy had become protective of him and he was frightened that she might become protectively aggressive and he would not be able to control this behaviour. Bill felt stressed and frustrated at being unable to take Nancy places he wanted to go, and his shoulder injury had been getting progressively worse. He felt he could not rely on Nancy and had lost trust in her to behave as he, and his friends, who made comments, expected a guide dog to.

Bill felt that Nancy was a good companion and that even if he had not get her back, he would certainly have applied for another guide dog. He reported that Nancy had bonded well with his friends and the people in the shared house, that Nancy had helped him with his most fearful travel issues, including road crossings, and had helped him to travel to places he wouldn’t normally. As Bill had returned Nancy for remedial training, he was informed that if



the staff could not correct these behavioural issues in her work ethic there was a possibility that Nancy would be withdrawn from service as a guide dog. At the prospect of Nancy's future as a guide dog in doubt and her not coming back to him, Bill reported that he was upset "because I lost my mate." Interestingly, Bill's BDI score recorded at the third (six-month post training) interview had increased from eight (indicating ups and downs that are considered normal) at his second interview, to 16 (indicating a mild mood disturbance).

At the time of Bill's fourth interview, he had completed training with his new guide dog Ruby following the return of Nancy to the guide dog school on the grounds he could not work with her, and her behavioural issues made returning her to working with Bill irreconcilable. Bill felt that this match with Ruby which was about 5 months old now was the best it could be, and he would hate to lose her. Bill stated that Ruby was a big part of his life and that he felt safe in the knowledge he could travel without incident with her. Bill felt that he had occasionally put himself in danger by travelling without his guide dog and when he had a number of close calls in terms of accidents with cars and people this brought home his need and reliance on the dog as a mobility aid, a companion and a way of maintaining his independence. He felt that the guide dog "was his eyes, we are partners, great friends".

Bill stated the comparison between his first guide dog and his new guide dog was a positive one. Bill enjoyed the fact that friends and family could interact with Ruby, and he trusts that Ruby will be obedient when she meets people. Bill reports this in comparison to his first guide dog, with whom he felt unsure about how she would behave when meeting new people, resulting in Bill's feelings of anxiety, especially in traffic situations. Bill reported increased participation in social activities and leaving his home since he had commenced working with his second guide dog, Ruby, as he felt safer travelling with her. Bill felt that his first guide dog had elements of inconsistency in her work but that he felt he could trust Ruby all the time

in all situations. Bill recognised that he was still in the early stages of working with Ruby, however he felt that the lessons learnt with Nancy would give him greater insight in meeting any potential challenges with Ruby, as well as being alert to potential issues and how to address these with his GDMI. Bill stated that in a conversation with a friend he felt this guide dog was substitute for the family he no longer had. “I have to have something, some company”.

**Figure 4.2**

*Longitudinal BDI Scores for Participant Two - "Bill"*



**Table 4.2***Longitudinal self-reported emotions and feelings for Participant Two - "Bill"*

<b>Emotion/feeling</b>	<b>Milestone 1</b>	<b>Milestone 2</b>	<b>Milestone 3</b>	<b>Milestone 4</b>
+Acceptance	√			
+Acceptance (by others)				√
+Anxiety	√	√		
-Anxiety		√	√	√
+Apprehension	√			
+Companionship		√	√	√
+Confidence		√		√
-Confidence	√			
+Depression	√			
-Depression				√
+Discontentment	√			
+Frustration	√	√		
+Grief	√			
+Happiness	√			
+Hopeful	√			
+Independence				√
+Loneliness	√			
-Loneliness		√		
+Motivation	√			√
+Sadness	√			
+Security				√

\*Note re: prefixes: "+" indicates feeling/emotion reported; "-" indicates a reduction in feeling/emotion reported.

At the time of the fourth interview, Bill's BDI Score was six (indicating these ups and downs are considered normal). Of interest is how Bill's BDI scores fluctuated across the longitudinal time period; with periods of increased symptoms of depression at the first (application) and third (six-month post qualification) interviews. See figure 4.2 above for a longitudinal summary of Bill's BDI scores across the four milestone interviews. A more detailed discussion of the BDI scores across the longitudinal time frame has been presented in the thematic analysis of depression in section 6.2. See also table 4.2 above for a longitudinal summary of Bill's self-reported emotions and feelings across the four milestone interviews.

#### **4.4 Participant three – “Bob”**

Bob, a 60-year-old man, had been living alone in a three-bedroom house. He had lived there for most of his life and was now alone following the death of his mother, four years ago. He was one of six siblings with two still living, his two siblings, one of whom lived close by. Bob used to be employed in light mechanical industrial work. He used to drive but stopped when his vision was so poor that he had experienced several accidents. Bob felt that losing his licence was the worst day of his life.

He reported that he did not have much of a social life and often felt lonely and isolated, more so since he lost his licence. Bob had been actively seeking the services of volunteers to take him out fishing on his boat. He had not been on the boat for two years. Bob had few social contacts, especially since the death of his mother, and still had the same cleaning lady but stated that he paid her for an extra thirty minutes to share in a cup of tea. “Just for a chat and some company”.

Bob was in good health, apart from his vision impairment. He was now almost completely blind, having lost his vision as a child of three, the result of German measles with the remainder of his vision lost in the past few years. He had experienced poor mobility when using a long cane as his preferred mobility aid but had good local orientation being a long time resident of the suburb he lived in. He found travel difficult in new or complex environments; he relied heavily on his sibling who took him to perform activities of daily living such as shopping. Bob had experience with animals in the past, and always had dogs, having lost his last one a year ago.

Bob applied for a guide dog to assist him in maintaining his independence and mobility, particularly as a frequent destination for him was the pub to have a few beers. He felt

frustrated when he bumped into people using the long cane and felt that a guide dog might prevent this from happening. He reported that since the death of his last dog he felt he could benefit from a guide dog even though he felt there were many processes, which initially caused him some concern in their complexity and depth that he had to go through to get a guide dog.

Owning a guide dog for Bob meant potentially having more freedom and Bob was eagerly anticipating the time when his guide dog would be there and his reliance on other people would decrease. Bob reported that he had been lonely on weekends “because no-one comes and visits”.

Bob had some anxiety about the development of the next-door property as he felt this might cause some concern for the new guide dog with rubbish blowing into his yard. Bob demanded of the builder that this issue was resolved before his guide dog came to live with him. He reported that having a guide dog would make him feel happy, as he would have an animal around again. He had been waiting on the list for about a year with no matches available. Bob completed a Beck Depression Inventory (BDI) as part of the application interview process and his score using the BDI score was 25. The scoring system for the BDI indicated Bob was experiencing moderate depression (see appendix five for BDI questionnaire and scoring).

The second interview was conducted while Bob was currently in training with his first guide dog Fred, a pure-bred Labrador. Fred was matched to Bob based on a number of parameters such as Bob’s preferential walking speed, his height, weight, personality as well as his mobility requirements and social needs for a guide dog. Bob reported that the training with Fred was very strenuous, as he had a lot to remember and apply, but reported this had been a

worthwhile investment as Fred listened carefully to him and did as he was asked. Bob was in the final week three of his training at time of interview.

Bob felt good that his training and work with the guide dog was going well and he had achieved the results of his hard work in training. He reported that he had been keen to test Fred's skills in finding the way to destinations. Bob had felt some apprehension and anxiety about the possibility of losing even more of his sight although had been stable at time of interview, but which over time might impact on his ability to work with his guide dog. Bob expressed concern that if he lost his sight totally, he might not have the confidence to travel with his guide dog.

The training program Bob had participated in was tiring and he "was not used to walking this much." Bob felt that the exams during training were stressful and the training process on the whole had been strenuous. He had positive feelings towards the guide dog and felt there was a clear positive distinction between using Fred and a white cane. He stated that Fred allowed him a fluid movement in the environment that could position him safely in and around objects as well as find potential dangers. The cane, whilst comfortable to use, gave him little feedback about the world he was travelling in until he bumped into something or collided with people who were moving in front or beside him. Bob also felt that he missed his cane as he had to rely on Fred now to make decisions and he missed the familiarity and comfort he associated with use of the white cane that were not evident yet with Fred. Bob felt that as Fred took on more responsibility in determining their travel that he missed some of the decision making even if those decisions led to him bumping into things. Bob reported that he "has to get used to it, that's all". Bob reported that he occasionally trips over Fred at home when the guide dog is lying in passage areas in the dark; Bob was amused that Fred was

learning to get out of the way quickly. Bob had some anxiety regarding the impending visit from “the big chief” to sanction the qualification as a working team with Fred.

Bob expressed an increase in his self-confidence and self-awareness as a result of working with Fred and an even more increased confidence and enthusiasm in learning how to find new destinations, although Bob felt fearful of crossing major roads. Bob’s sibling helped with some daily living tasks however Bob reported they was keen to reduce their contact and see Bob working more independently with Fred. It was their wish to have Bob catching buses independently and for them to observe a tangible change in Bob’s lifestyle and independent mobility. Bob’s recent experience of using public transport was reported positive and reinforced his belief that having Fred would improve his confidence and independence. Bob had some concerns and was stressed about the general public patting his guide dog and the fact he couldn’t see if this happened.

Fred had been responsive to Bob’s expectations and cues, which pleased Bob. Bob recognised the beginnings of a bond. He reported that he had good feelings when Fred was near him and had long anthropomorphic conversations with Fred. Bob had been very pleased with the feedback from the trainers who collectively felt Bob was doing well and were very positive in their praise and support of his efforts. He reported that Fred was a good gardener, actively digging, and that having him around was a good thing. He felt that he was now teaching Fred new tasks and expectations for his needs with a concern that he may not be teaching Fred the correct commands.

Bob felt the experience of working with Fred and recognising the guide dog’s skills in daily activities, such as finding destinations, had justified the initial trepidation and anxiety about making the application for and training with a guide dog. He felt pleased and happy with the

concept that he could give commands like “go in the shop and go find the counter, and the guide dog stands across you like that out of the road, it’s amazing, ask the animal”. It is noteworthy that at the second (training) interview, Bob’s BDI score had reduced markedly; from 25 (indicating moderate depression) at the first interview to four (indicating these ups and downs are considered normal).

At the time of the third interview Bob had completed training with Fred and had qualified for six months and was working the guide dog independently on a number of known and well-practiced destinations. Bob reported he enjoyed taking Fred to the shops and on recreational walks, and that he needed to be alert to Fred’s challenging behaviour such as sniffing and his interest in food. Bob was pleased that he had a small amount of residual vision with which to keep watch on any challenges offered by Fred. Bob felt he had been very supportive of the guide dog and recognised that Fred was young and unlike any dog he had previously had as a pet. Bob felt he had a strong and close bond with Fred and that the guide dog listened and was friendly towards him. Bob felt the relationship he had with Fred was so close that he would not ever have to use physical control or aggression with the guide dog.

Bob felt clear that Fred was a guide dog and that he had no other roles such as guarding, so any misbehaviour such as barking at strangers would not be tolerated. Bob had a sense of pride and comfort that his sibling liked Fred a lot and felt positive about comments they and people in shops had made about how well-behaved Fred was. This had motivated Bob to work hard on any behavioural issues, such as jumping, so that he could remain proud of Fred. Bob reported he felt sad about the death of his previous dog prior to Fred, and that this loss had been a strong motivation for his pursuing a guide dog in addition to increasing his independence. He felt that having Fred was a positive experience, but one that “keeps me on my toes and keeps me busy”. Bob was stressed about the guide dog pulling, “he pulls my arm



out the socket sometimes”, but felt that he had the confidence, motivation and skill to control this behaviour in the longer term, recognising that overall having Fred had been helpful and had improved his confidence, self-esteem and ability to travel independently.

Bob perceived Fred as occasionally being “like a little kid”. Bob therefore had to develop coping strategies to deal with Fred’s behaviour and to get the best working performance from the guide dog, including an hour walk daily. He had to change his routine to accommodate Fred’s preferences, which Bob found amusing “I want to watch the news about half past six and he wants to play. We have a good bond that way”. Bob had some anxiety and stress regarding telling people not to touch Fred, and this upset him to the point where he wanted a clear message on the harness saying, ‘do not touch’. At the time of the third interview, Bob’s BDI score remained at four (indicating these ups and downs are considered normal).

At the time of the fourth interview Bob had been successfully working with Fred for one-year post training. Bob still felt a lot of frustration about his vision impairment and felt some of this frustration was offset by his ability to take Fred out and visit friends and his sibling. He felt depressed about the limitations of his vision. As a keen gardener, Bob had experienced a complete sense of loss of the visual experience and the enjoyment that visual stimulus might bring, which he commented on as “what a beautiful flower, I just wish I could see that!”. Bob felt that the initial problems he had working with his guide dog were resolved now and that all he wished for was better health to allow him to get out more often with Fred. Fred had become a friend and companion and that as they worked well together there was a strong bond so much so that Bob feels disconnected when the guide dog is not with him.

Bob had experienced a number of dichotomous paradigms in having Fred and his previous experiences without his using a white cane. Bob felt much safer with Fred but got frustrated

and annoyed with people who interacted with the guide dog without his permission. He felt this was rude and showed a complete misunderstanding of the role of the guide dog or his vision impairment. This included bus drivers and taxis who used to ignore him when he was out without the guide dog. The quandary Bob was experiencing was whether it was better to have Fred present with him in certain situations along with the frustrations that working with Fred brought from people around him, or to endure the feeling of loneliness when Fred was not present with him. Bob stated that if he didn't have his guide dog "I'd feel like there was something missing. Like I said before, about the time I went to the bank and left Fred home, straight away I thought, I don't feel comfortable, there's something missing".

**Figure 4.3**

*Longitudinal BDI Scores for Participant Three - "Bob"*



**Table 4.3***Longitudinal self-reported emotions and feelings for Participant Three - "Bob"*

<b>Emotion/feeling</b>	<b>Milestone 1</b>	<b>Milestone 2</b>	<b>Milestone 3</b>	<b>Milestone 4</b>
+Acceptance	√			
+Acceptance (by others)				√
+Accomplishment				√
+Anxiety		√		
-Anxiety		√	√	√
+Companionship		√	√	√
+Confidence		√		√
+Depression				√
+Frustration	√		√	√
+Gratitude				√
+Grief	√	√		
+Happiness	√			√
+Hopeful	√			
+Loneliness	√			
+Motivation	√			
+Security		√		√
+Trust				√

\*Note re: prefixes: "+" indicates feeling/emotion reported; "-" indicates a reduction in feeling/emotion reported.

Bobs' BDI score at the time of the fourth interview was four (indicating these ups and downs are considered normal). It is important to observe that after scoring in the moderate depression range at his initial (application) interview, that Bob achieved a consistently lower score (ups and downs that are considered normal) from the second interview onward; the time he commenced training with his guide dog. See figure 4.3 above for a longitudinal summary of Bob's BDI scores across the four milestone interviews. A more detailed discussion of the BDI scores across the longitudinal time frame has been presented in the thematic analysis of depression in section 6.2. See also table 4.3 above for a longitudinal summary of Bob's self-reported emotions and feelings across the four milestone interviews.

#### **4.5 Participant four – "Stan"**

Stan, a 51-year-old man, was living with his partner on a 20-acre property in a four-bedroom home. He had lived there for ten years. He had not much of a social life and often felt lonely

and isolated, primarily due to the distance between the very rural property and the nearest town and the poor public transport system in place. At the time of the first interview, he had been unemployed for three years, prior to this period of unemployment had been working part-time in the nearest town in a dispatch centre, having been made redundant from his previous position and career as an IT manager.

Stan was in good health, apart from his vision impairment. He had some residual vision which he used to good effect. He had been diagnosed with his vision impairment in his early 20's at which time he was still driving and playing contact and non-contact sports. In the past ten years Stan reported that his vision had deteriorated significantly and its value to him now had diminished to the point where it had little value. Stan reported that he had difficulty with daily activities, "can't go out to a shop and buy things like other people... you know, a shop somewhere, you're looking at signs, can't look at bus signs. I bump into things all the time, even things around my own home".

He had mobility issues and reported that pride precluded him from using a long cane. He had one that he used rarely and poorly, depending on lighting conditions. He had poor orientation, had difficulty travelling in and around his rural property and surrounding areas and found travel difficult and stressful in new or complex environments. Stan had experience with animals in the past, having owned dogs, and currently had two Labradors living at home.

Stan applied for a guide dog to assist him in maintaining his independence and mobility. Stan reported that he was influenced in his decision to apply by several people who felt a guide dog might assist him get back into the workplace. Stan had been reluctant to apply and was concerned that if the guide dog was no use to him, he would have to give it back. Stan had been worried that there would be more deserving people who would use the guide dog to

better effect than him and that if he had a dog, it might lose its skills before he found a job where the guide dog would be of more value to him. Stan felt he was not the ideal candidate for a guide dog but that if he didn't press on with the application, he might not find the employment he wanted. Stan felt imprisoned by his situation which caused him stress and anxiety about his isolation and loss of independence as well as his uncertain future.

Stan felt that if he had a guide dog it would be of value to him in travelling in and around the city which is where he saw his future employment and saw the guide dog as a valuable mobility aid in that respect. He feared injury caused by the rural environment, particularly falls. He also stated that he had anxiety and felt stigmatised by his vision impairment and that having a guide dog would reduce some of those feelings as he felt the guide dog was more acceptable. "I'd rather stay home than go out with a white cane".

Stan reported that he would feel safer using a guide dog, even on his own property where he was frightened of walking into barbed wire or gates. Stan felt that the guide dog would increase his confidence and sense of security. He felt that his partner was directing him to the application for a guide dog to increase his self-esteem and agreed that might be an additional benefit. In addition, he felt there were benefits from the companionship of having a guide dog even though he had two dogs still living with him. Stan felt a guide dog would truly be his dog and be able to do things with him. Stan completed a Beck Depression Inventory (BDI) as part of the application interview process and his score using the BDI score was 15. The scoring system for the BDI indicated Stan was experiencing a mild mood disturbance (see appendix five for BDI questionnaire and scoring).

The second interview was conducted while Stan was currently in training with his first guide dog, Barry, a large Labrador cross breed. Stan was in the third and final week of the training

program, having received Barry on the first day. The day before the interview Barry had been returned by Stan to the school as Stan felt worried and stressed that Barry had jumped a fence. Thus, Stan had no guide dog at the time of the interview. It should be noted that guide dogs are not permitted to jump fences as part of their duties, and that such behaviour exhibited by Barry was seen and judged by professional training staff as unacceptable and could lead to potential risk to the guide dog or owner. This was the justification for withdrawal and reassessment of Barry.

Stan was very upset by the behaviour that ended the working relationship with Barry. Stan felt that Barry had jumped a number of fences to be with him and Stan felt stressed and anxious that Barry might begin to worry or even kill his neighbour's sheep. Stan felt that Barry had jumped the fences to be with Stan but that he could not take the risk of him with sheep from that point on. He was distressed about this possibility throughout the interview. Stan was very concerned and worried about having to tether Barry to correct the jumping behaviour or alternatively to keep him inside all the time. Stan felt that this was not possible as he had 2 other dogs at home, and he could not bring himself to do it. This was causing Stan some anxiety at the prospect of being asked to tether him by the school prior to returning Barry. He had no hesitation in remaining on the list for another guide dog as he felt his circumstances and need for the guide dog had not changed and employment was still his primary goal. Stan still felt concerned that he wanted a guide dog to increase his potential for employment opportunities and the guide dog had limited value to him in any area other than getting to work and home, making him more marketable to potential employers. Stan felt coerced by his partner who had made certain he pursued the application.

Stan reported that it was very early in the training that he realised he didn't have enough work for Barry at this time in his life. He persevered with the training and found that Barry

was useful in the town where he worked part-time which justified his belief that he would benefit from the guide dog when he got a job in town. He took Barry to his holiday home on the weekend and found it much easier to use a sighted guide. “to be honest, in some places it’s just easier to go with my partner than to hook up a guide dog”. Stan persevered until the last few days prior to returning the guide dog, when he began to jump fences.

Stan had worked with Barry in a neighbouring town and had difficulties controlling him which left Stan feeling frustrated and disappointed, and with feelings that he had no control over the guide dog. On a similar occasion Stan felt that Barry was only useful in areas where Stan knew where he was going. He felt he had confused Barry as he had followed his partner through the town, and they had changed direction too quickly for Barry to cope with. This made Stan feel anxious and distressed about the use of the guide dog and the limitations he had set himself in having a guide dog. Stan felt that if he worked in town this situation would have changed as he would have better orientation and the need for the guide dog would have been increased as would the workload. To this end, Stan felt he would still pursue having a guide dog in the future.

Stan felt the whole experience of having a guide dog had been traumatic. Even in areas where he had been familiar with the environment he had not relaxed or been comfortable with Barry around, especially in regard to the experience of Barry jumping the fence. This had created anxiety and hostility and he reported that in relation to the partnership between Barry and Stan being unsalvageable, Stan felt that “if I was a brave man I would have stood up to my partner and the instructor and said I told you so, but you know I figured they know that”.

Stan reported that he had mixed emotions about having had Barry. In town he felt liberated and in other ways had felt awkward and uncomfortable. He felt that there was trust and

confidence in the guide dog when it had worked well but anxiety and frustration when it hadn't. He reported that he had established a strong bond with Barry and that may have been the catalyst to Barry jumping fences in an effort to get to Stan. Stan felt terrible when the guide dog had to go and felt sure the guide dog did too. He felt that choice had been removed from him in having the guide dog, "you know my partner was very happy, they said initially it's your choice, but it really wasn't my choice [laughs]".

Stan felt overwhelmed by the training and the amount of information he had to absorb. Barry had some behavioural issues when he first arrived and began work, but Stan felt these had not been too big an issue. Stan had to exercise control and authority over Barry to get the required result of good working practice. Stan had been impressed by how much Barry had to do to work effectively and how much work Stan had to do to keep Barry working well.

Stan felt that the whole experience of having Barry has been too difficult and that the decision to have a guide dog and the training had been a very emotional time with the result that Barry had to be returned making the whole process worse. The dichotomy of having the guide dog working well and then not having had purposeful work for the guide dog made Stan rate the experience as a low point. "I'm not feeling particularly good at the moment, you know, for obvious reason, I thought it was a nice guide dog and we were getting along ok, it's just for the dog's sake I could no longer have the guide dog". Stan's BDI score was 13 at the time of the second (training) interview, indicating a mild mood disturbance.

At the time of the third interview Stan had failed to complete training and therefore had not kept Barry for six months post qualification. Stan had given the guide dog back but found that the training, as a process for providing instruction and support in how to work with a guide dog was good and met all the requirements he needed to work the guide dog effectively. Stan reported that Barry had been most useful to him in the local town near where



he lived but that there had been some training issues such as the guide dog sniffing and not responding to commands. Stan wondered if this had been his lack of control over the guide dog that had created behavioural problems.

Stan felt there was an emotional bond with Barry but that this was short lived given he had given the guide dog back. Stan was worried Barry would be shot by his neighbours as a sheep worrier. Stan felt it was unfair to keep Barry as an inside dog which had been the recommendation from the school, this conflict caused Stan some concern and anxiety about what do to.

When out with Barry, Stan felt that he had not got the full use out of owning a guide dog and that most times when he went out, he went with his partner who would guide him, which made Stan feel a bit awkward about having applied for the guide dog and having worked Barry while in the company of his partner. It was only on those occasions when Stan went out by himself that he reported Barry was really helpful.

Stan felt that Barry or any guide dog would have been useful to him if he were working which had been his motivation to have a guide dog in the first instance. Not working and not being able to travel into the nearest town independently as Stan lived on a rural property left Stan feeling that Barry was underutilised and concerned that Barry could be used by someone who could benefit from him. Stan felt that Barry was a lovely dog, had good temperament and his only problem when working him was that people would always want to talk to him and occasionally pat Barry.

Stan felt that if the issues with Barry could have been resolved to his satisfaction without tethering the guide dog up then they would have formed a strong relationship. Stan had no

problems being strict with the guide dog in terms of monitoring his behaviour and keeping the rules suggested to him in check, such as strict dietary control. Stan still had his name on the list for a guide dog with the stipulation that the dog can't jump and that he will only get one when he finds work and preferably in the city. Stan said he loved dogs, and this was one of the motivations in getting a guide dog "oh yeah, I love dogs, and he was a lovely dog and I was happy with him. He got along well with the other two dogs we have". During the third interview, Stan's BDI score remained at 13, indicating a mild mood disturbance.

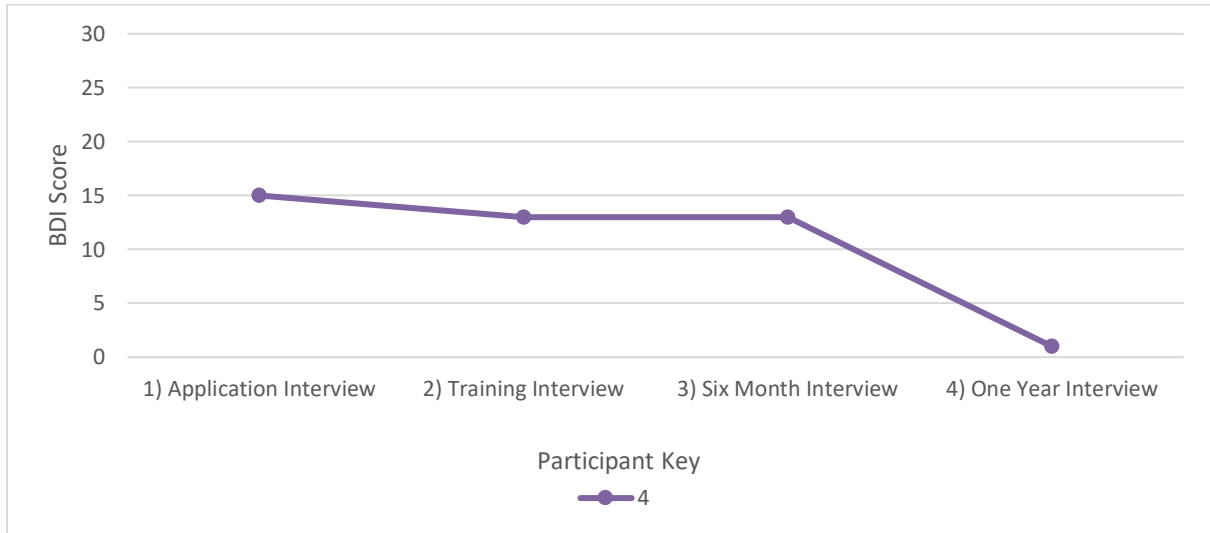
At the time of the fourth interview Stan had still not decided on reapplying for a guide dog but was much closer to making that decision and had now made some inroads into factors contributing to an application. Stan felt that with the support of his partner in his decision-making process, he needed to have another guide dog as there was a potential for him to be working. "I won't be able to work in the city without another dog". Stan felt that having a guide dog would improve his mobility and increase his independence, this was the primary reason for a future application. When dealing with the public Stan felt stigmatised by his vision impairment, although there were some people who offered assistance to him. He felt that people looked at him differently because of his vision impairment, however reported that he could deal with that much better "if that sign was a dog rather than a cane".

These feelings of self-worth and issues surrounding self-esteem also impacted on Stan's decision to apply for a guide dog in so much that he was concerned about whether he deserved a guide dog. "I think they understand I don't want to waste a good dog, and I don't feel I deserve a dog unless I have a use for it". Stan felt his partner and family were very eager for him to get a guide dog and that this encouragement made the decision to apply much easier even though he held reservations and did not want to challenge his partner's belief the guide dog would be good for him. Regardless, Stan had felt that his confidence

improved when he was using a guide dog, and this extended into his mobility and feelings of safety when making travel decisions such as crossing roads.

**Figure 4.4**

*Longitudinal BDI Scores for Participant Four - "Stan"*



**Table 4.4***Longitudinal self-reported emotions and feelings for Participant Four - "Stan"*

<b>Emotion/feeling</b>	<b>Milestone 1</b>	<b>Milestone 2</b>	<b>Milestone 3</b>	<b>Milestone 4</b>
+Acceptance	√			
+Anxiety	√	√		
-Anxiety		√	√	
+Apprehension	√			
+Comfort				√
+Confidence		√		√
-Confidence	√			
+Depression	√			
+Enjoyment				√
+Frustration	√			
+Gratitude				√
+Grief	√			
+Hopeful	√			
+Independence				√
+Loneliness	√			
+Motivation	√			√
+Security				√

\*Note re: prefixes: "+" indicates feeling/emotion reported; "-" indicates a reduction in feeling/emotion reported.

Of interest is that Stan's BDI scores remained in the mild mood disturbance range, until the time of the fourth interview where it had reduced to a score of one, indicating ups and downs that are considered normal. See figure 4.4 above for a longitudinal summary of Stan's BDI scores across the four milestone interviews. A more detailed discussion of the BDI scores across the longitudinal time frame has been presented in the thematic analysis of depression in section 6.2. See also table 4.4 above for a longitudinal summary of Stan's self-reported emotions and feelings across the four milestone interviews.

#### **4.6 Participant five – "Todd"**

Todd, a 28-year-old man, lived with his partner and three children in a three-bedroom family home. They had lived there for several years. Todd's social life revolved around family activities, both he and his partner worked, and when he returned home from work he took the children out, often to the park or for a walk Todd felt that they had a quiet life with few

friends but that as the children got older he would need to be more active in attending and following their pursuits such as sport and school. At the time of the interview, he worked full time in a gardening supplies business.

Todd had good health, apart from his vision impairment, which he felt he had from birth. He had some residual vision which he used effectively but that was subject to change due to environment and lighting conditions; he had no vision at all at night. Todd reported that he was frustrated with some tasks such as using computers and missed driving. "So when it comes to driving, and doing certain things, just can't do them. It's either illegal or just too hard to". Todd had good mobility but felt stigmatised using the white cane, with which he had been trained but never used "you see people looking at you, bit embarrassing, that's one of the reasons with the whole guide dog thing".

Todd had experience with animals in the past, having owned cats and birds but never a dog. The fact that he had never had a dog before had been some concern to Todd; he reported it playing on his mind. He also reported being worried that he might not get access to places with his guide dog and this would cause him some anxiety. With these reservations discussed at length with the training staff and in agreement with his family and support, Todd felt comfortable with his decision to proceed with an application for guide dog mobility and expressed he had been looking forward to getting his guide dog. He perceived the arrival of the guide dog as being a new chapter in his life, new challenges and new responsibilities in looking after the guide dog. In addition, he had prepared the family for the arrival of the guide dog but was still a little stressed about how the children would accept the guide dog and hoped they would be careful not to jump on it. He reported that he felt a mixture of excitement and apprehension but overall was keen to begin the process, which was another issue of concern and caused some stress as he had negotiated time off with his boss to be

trained, which had been complicated and difficult to secure. Todd had actually passed up the opportunity of training with the first guide dog he was offered because of the difficulties in getting time off work.

Todd applied for a guide dog to assist him in maintaining his independence and mobility. He was looking forward to working with the guide dog and forming a relationship, which he acknowledged might have been interesting as he had never had a dog before. He felt he would have a companion but also there would be little need for people to guide him as he would have his guide dog. "I'll probably be a bit more free, without having to ask someone to have my hand on their elbow or something like that to haul me around".

The dog would assist Todd, he felt, in negotiating more complex environments, particularly uncontrolled and even controlled road crossings which caused him a high degree of fear and anxiety, especially at night, or when using public transport. Todd felt that having a guide dog would assist him in travelling to unfamiliar places with his family. The guide dog would bring him closer to his family, in terms of sharing the care of the guide dog, facilitate meeting new people who would like to know more about the guide dog and reduce his feelings of isolation and loneliness. He felt that there might be some issues with some members of the family who may not accept the guide dog, particularly if the dog had to travel, for example, in his sibling's car which might cause some resentment. Todd felt this was something he had to sort out.

Since his application Todd remained philosophical about the time spent on the waiting list. He felt that the dog would come along when it did and as he was in no particular hurry that would be fine. He reported that he had applied for the guide dog to assist him if and when his vision finally was of no value to him and he felt that having the dog would be an asset in

adjusting to no vision; “once my sight does go, it will be easier to adapt to the surroundings and things like that if I’ve already had the training with the dog”. Todd completed a Beck Depression Inventory (BDI) as part of the application interview process and his score using the BDI score was 6. The scoring system for the BDI indicated these ups and downs are considered normal (see appendix five for BDI questionnaire and scoring).

The second interview was conducted while Todd had been in training with his first guide dog, Vince. Todd was in the third and final week of training, having received his guide dog on the first day of the program. Vince, a Labrador cross breed, was present at the interview. Todd reported that Vince was a very sociable dog and was with the family the whole time and enjoyed being near them. Todd felt confident that Vince had been well behaved at these times, especially with small children around. Todd reported that he felt Vince was a good match for him, as Todd stated he was quite short, and a bigger dog would have been difficult to handle.

Todd’s training had been going well according to Todd, and he felt he had a good bond with the guide dog and the family accepted Vince. There had been a few issues as Todd had young children and when they came home from school and had been eating snacks, they dropped crumbs all over the house which Vince found and ate. In addition, when walking, Vince had taken to sniffing and this had been corrected with a new piece of equipment, called a ‘gentle leader’ which assisted in controlling Vince’s head movements and which Todd found very useful, but the application of it did cause him some concern about Vince’s welfare as he had to wear it often. “pretty much like 99% of the time I have it on, the dog is now a completely different dog”.

Todd frequently reported to illustrate his anxiety, that he was nervous about the arrival of the guide dog as he had never had dogs before and felt he hadn't known what to expect of the guide dog and how it should act, especially around other dogs. This issue had resolved by Todd taking Vince to the dog park and seeing how other dogs interacted with Vince. Todd felt he was much better at handling these situations now. In addition, Todd felt he had accepted Vince and his behaviours and felt emotionally connected to Vince to the point where he had let Vince lick him, where previously he hated the smell and the feeling of dog saliva; "you know not the taste but you know the sense of having the dog wet me, it doesn't bother me now as my dog is a big lickable dog". Todd felt that his life had changed, and he had a new lifestyle now. Vince had made such inroads into the dynamics of the family that Todd had been talking with his partner about getting another dog as a family pet for Vince to play with.

Todd felt that acquiring and training with Vince had been a good decision. He no longer bumped into things and felt that if his vision did deteriorate that he would have additional skills now in working with a guide dog that would help him maintain his independence. He acknowledged that he had travelled further than ever in previous times and had even gone to a large shopping centre with the guide dog, where he really appreciated Vince's help. Todd recognised that his life had changed significantly and that now people had, through the presence of Vince, been made more aware of his vision impairment and made more offers of help when he needed it.

There had been a few people ask to pat Vince, but Todd had to say no which he was concerned about as he felt it metaphorically shut the door on talking with them. Todd felt this was a missed opportunity to expand his social contacts as refusal to pat the guide dog generally also ended the conversation. One area of concern for Todd had been Vince's



toileting routine which had changed since Todd returned to work and Todd had been anxious to keep to as strict a schedule as possible to avoid toileting accidents. Todd felt that having Vince had greatly increased his overall confidence and improved his independence and confidence in travelling independently. Having Vince had also reduced his anxiety about bumping into obstacles. Todd felt that Vince was an adored member of the family, and his children had a special bond with him, although dropping food that Vince found was an ongoing issue. This change in his children's attitude to Vince made Todd very happy, especially as his youngest child was frightened of the guide dog at first but now had an inseparable bond.

Todd felt relief that the process of having Vince was straightforward as he was nervous about it being harder prior to the guide dog's arrival. The issues he had encountered such as sniffing and the food scavenging were being overcome and he had found a degree of commitment to succeed in the training by increasing his control over the guide dog and not giving any leniency which he was pleased with. At the time of the second (training) interview, Todd's BDI score was five (indicating these ups and downs are considered normal).

At the time of the third interview Todd had completed training with Vince and had qualified for six months and was working the guide dog independently. Todd has still been developing an understanding of working with a guide dog and had been very concerned that he had done the wrong thing a few weeks prior by giving Vince a bone, against the advice the GDMI and the policies of the school. This had a catastrophic effect on Vince's bowel movements which took some time to settle and affected his work: the guide dog had to toilet frequently, even when working which caused Todd some anxiety and was out of character for Vince. Todd felt that the experience of having Vince was dynamic; "it's certainly a life changing thing, you know taking him to work every day. I have never had a dog before, having to feed him every

night and walking and all those things”. Todd felt that the whole process had gone smoothly and had been going well. Problems like Vince having stolen the children’s toys and playing with them and finding new ways of securing the garbage had been and were being overcome and dealt with positivity and Todd felt the experience was generally a positive, good one. Todd felt that as his children grew up his vigilance in keeping an eye on Vince would correspondingly reduce.

Todd felt some concern and anxiety that he was not spending enough time with Vince. When he got home from work Todd felt that if he sat down and wanted to relax after work, he was letting Vince down if he didn’t pay him 100% attention. Todd reported that his lack of quality time with Vince was a low point and he felt that “our relationship will build overtime, not just from walking but from playing in the backyard”. Todd reported that he enjoyed spending time patting and grooming Vince and saw this as bonding and paying attention to Vince time. Todd felt that Vince was happy and calm around most people, except the dog wash man who Vince remembered always gave him a treat. Todd felt if he reacted quickly, he could control Vince before he got too excited. Todd felt that Vince’s exuberance was due to the fact he wanted to be part of things. Todd was very reflective of the training he had received and was cognisant of the instruction given to him in relation to interaction with members of the public and the difficulties this could create if people become over familiar with the guide dog. To this Todd felt compelled to curtail Vince’s excitability in meeting new people, particularly the dog wash man in order to maintain a level of control of this behaviour where Vince had clear boundaries of acceptable interaction.

Todd reported that he felt very happy about the bond he had with Vince and was proud that people said how healthy Vince looked. Todd felt that Vince was a well behaved and calm guide dog and customer’s comments made him feel good about Vince. Todd felt that the

whole experience of having Vince was positive. “I have another companion and he gives me the confidence with how well he does, because I have not lost my sight completely yet so I have the confidence that he’ll be able to lead me where I need to and around things”. At the time of Todd’s third interview, the BDI score was two, which again indicated these ups and downs are considered normal.

At the time of the fourth interview Todd had been working with Vince for over a year and Todd felt the partnership was going very well. Todd felt that his confidence and independence had improved dramatically with having Vince and that his social skills and ability to be more socially active had also improved. Todd felt that Vince was now a member of the family and that the dynamics of his house had changed since the arrival of Vince. “well, my kids interact with Vince. They absolutely adore him. My partner wasn’t really much of a dog lover before but since having him here they are more to loving dogs”. Todd’s family were very supportive of him applying for a guide dog, his partner particularly was worried about him being out when it got dark and his vision failed, and he felt this was a motivating factor which made him feel good about getting Vince.

Todd felt his confidence had improved and that he was able to answer questions about having a guide dog with complete strangers where before he would never engage in conversation with them. “I’m definitely more confident out and about, and because I’m out, people asked me questions and I’ve become more comfortable chatting with people and being more social. Normally if I was out and about, I wouldn’t just go up to someone, but if they come up and talk about Vince then I will have to chat”.

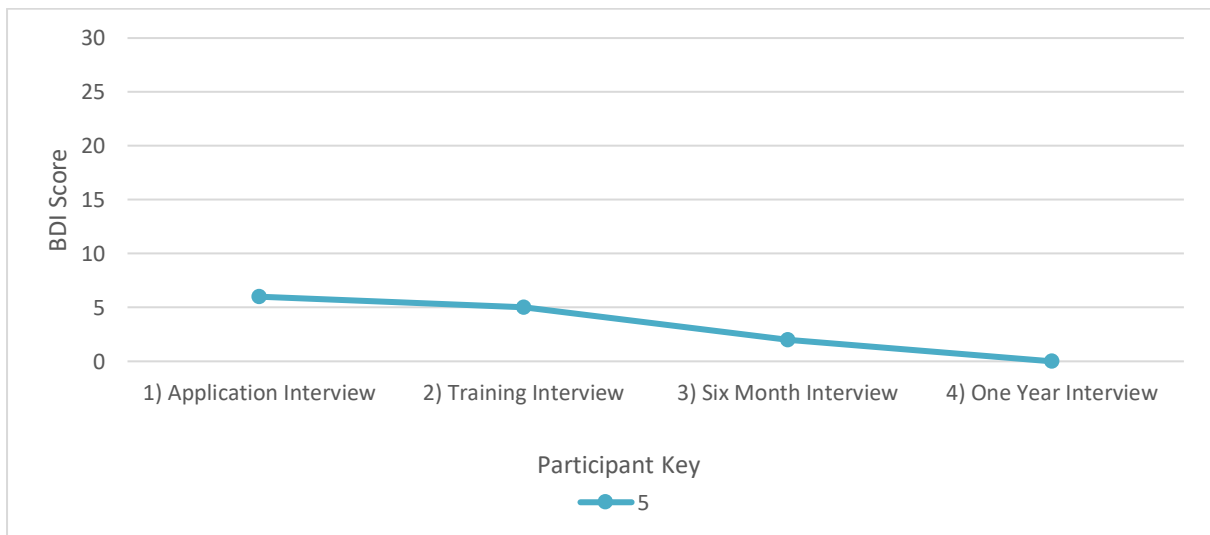
Todd felt that as his vision was almost certainly going to deteriorate that having Vince was going to be of more value in maintaining his independence. He felt sad and anxious about

how much vision he would lose and that there would be things he would not be able to do.

“the scariest part of it for me is not being able to see my kids when they grow into adults, or even normal things like watching tv in general. I feel that Vince is going to do his job for me, no worries”.

**Figure 4.5**

*Longitudinal BDI Scores for Participant Five - "Todd"*



**Table 4.5***Longitudinal self-reported emotions and feelings for Participant Five - "Todd"*

<b>Emotion/feeling</b>	<b>Milestone 1</b>	<b>Milestone 2</b>	<b>Milestone 3</b>	<b>Milestone 4</b>
+Acceptance	√			
+Acceptance (by others)				√
+Acceptance (of self)				√
+Anxiety	√			√
-Anxiety				
+Apprehension	√			
+Companionship			√	√
+Comfort				√
+Confidence		√	√	√
+Enjoyment				√
+Frustration	√			√
+Grief	√			
+Happiness	√			
+Hopeful	√			
+Independence				√
+Loneliness	√			
+Motivation	√			
+Security		√	√	√

\*Note re: prefixes: "+" indicates feeling/emotion reported; "-" indicates a reduction in feeling/emotion reported.

Todd's BDI score at the time of the fourth interview was zero, which indicated these ups and downs are considered normal. Todd's BDI scores across the longitudinal study all remained within the range of ups and downs that are considered normal, however experienced a slight reduction in his already low scores (see figure 4.5 above for a longitudinal summary of Todd's BDI scores across the four milestone interviews). A more detailed discussion of the BDI scores across the longitudinal time frame has been presented in the thematic analysis of depression in section 6.2. See also table 4.5 above for a longitudinal summary of Todd's self-reported emotions and feelings across the four milestone interviews.

#### **4.7 Participant six – "Gwen"**

Gwen, a 55-year-old woman, lived with her partner in a three-bedroom family home and had adult children. The eldest child lived close by. An issue of concern for Gwen was her child's

religious beliefs which might allow her potential guide dog into their house. Gwen stated that her child was a devout Muslim and that in Islamic religious belief and culture there is an implied fatwah of Muslims not being able to be in contact with dogs, particularly the mucous membranes of dogs or saliva, which is considered 'haram' or forbidden. She felt this cultural void could be overcome with pragmatic planning on where and how her guide dog would be in contact with her child, if it were in contact at all.

Gwen participated in a range of activities including adult academic study, work with other blind and vision impaired people on a voluntary basis and was employed in the area of vision impairment. Gwen was very worried and apprehensive that she might become so anxious and fearful, resulting in her being housebound and socially isolated should she lose her vision completely.

Gwen was in good physical health, apart from her vision impairment. She had some residual vision and used it very effectively in maintaining her mobility skills. Gwen reported that she had lost her vision from the age of three, but it took a catastrophic bleed in her eye to render her legally blind in her thirties. Thus, she had no useful vision in her right eye and poor vision in her left. Gwen had recently lost a parent to cancer and her sibling, who had a vision impairment as well, had recently had a similar bleed. Gwen had good mobility using a long cane as her preferred mobility aid and had good orientation but found travel difficult in new or complex environments. Gwen reported that she had a fear of travelling into unknown areas and this fear stemmed from several bad experiences, including a fear of crowds, which had taken all her confidence in independent travel.

Gwen had experience with animals in the past, having owned dogs. Gwen felt that the loss of family members and her sibling's recent vision problems had caused her depression to

resurface. She reported that the issue of blindness could not be discussed with her family as they got too upset about it. Gwen reported she had suffered with depression at various points during her life and this was one of her motivations for working with other people who had vision impairments or were blind. This had also been a reason why Gwen had refused a guide dog when it was first offered six months previously, as she felt she was not in a good enough frame of mind to do the training, having told the school. “So I’m just not ready, I’m not going to be able to cope. I want to be able to do when I’m in the right frame of mind”.

Gwen applied for a guide dog to assist her in maintaining her independence and mobility. In addition, for Gwen, a guide dog would mean travelling to places where previously she had been frightened to go. Her fear had led her to worry about her personal safety and she had concerns that someone might break into her house and having the guide dog would be a deterrent. As Gwen stated; “I know the guide dog probably wouldn’t attack them but it’s just having somebody else there as well”.

A number of Gwen’s friends had guide dogs, which was significant, as they shared their lived experience with her and encouraged her to pursue her guide dog application. Gwen felt that if she had a guide dog, she would be prepared to accept more risk in travelling independently whilst improving her mobility skills. These improved skills would increase confidence in attempting to negotiate the environment, which up to now created a high degree of anxiety at the prospect of attempting for Gwen. Situations like crossing roads caused Gwen immense fear, anxiety and frustration and she felt that with a guide dog she would challenge herself to make these crossings. Gwen’s children and partner had been a source of encouragement. Gwen felt that her partner would feel safer with Gwen having a guide dog and being out without them present. Gwen felt that a guide dog would also assist in lowering her stress levels; “it’s about everything, ‘cause if you’ve got a mate to go out with even if it’s a dog, it

doesn't matter, it's still somebody". Gwen completed a Beck Depression Inventory (BDI) as part of the interview process and her score using the BDI score was 15. The scoring system for the BDI indicated she was experiencing a mild mood disturbance (see appendix five for BDI questionnaire and scoring).

The second interview was conducted while Gwen was currently in her final week of a three-week course of training with her first guide dog, Ginny. Ginny, a Labrador, was present at the interview. Gwen's partner was present during the interview and her guide dog was on its bed the whole time. Ginny was, according to Gwen, matched to Gwen based on several parameters such as Gwen's preferential walking speed, her height, weight, personality as well as her mobility requirements and social needs for a guide dog.

Gwen reported the guide dog had arrived and was settling in. Gwen had some concerns and anxieties about Ginny coming and had a plethora of questions for the trainer. Gwen felt her lifestyle was so diverse that she needed assurance from the trainer:

We needed a dog that would cope with that without having a nervous breakdown, because the dog needs to be able to go on trains and trams and planes and be able to deal with not just having a set routine everyday so it will be me ringing the trainers and saying we are about to jump this hurdle how do we do it?

Gwen felt that her eyesight at the moment had been stable enough to be of some assistance to Ginny while the guide dog learnt about her, although she felt there would be a time when she would not have enough eyesight to be of any help, and whilst accepting of this, she felt anxious about the impending change in her vision. She felt she had a fear of some environments and suffered from anxiety attacks due to traumatic stress disorder associated



with agoraphobia in built up areas with crowds. In addition, her difficulty with moving objects, glare and her fuzzy vision had made independent travel very difficult and stressful. This fear of going outdoors had meant she had withdrawn and had not travelled independently for some time. Gwen had plans of continuing with her academic studies and working, and this would mean lots of travel for which she felt the only solution was to have a guide dog.

Gwen had grown up with a hatred of the white cane and to this end had tried most of her adult life to be independent and not rely on any help. Gwen had a fear of travelling in complex environments and felt fatigued and stressed when travelling independently in new places, particularly crowded ones. Whilst training with Ginny in the city, Gwen had to work in a very busy area, and this event assisted in her bond with the guide dog and she felt her confidence and self-assurance build with Ginny. In an area that would have previously caused Gwen anxiety bordering on panic, she had to work with Ginny, particularly with people blocking her access:

I just went, and I thought holy hell, look at you, that would take me 5-10 minutes before I took a step and the trainer said find the way and the dog just went this way and the person moved and I was like, I am sold.

Gwen reported that even when challenged to work with Ginny in areas where she would have normally used her vision, she shut her eyes and worked Ginny, confident in the guide dog's skills. She felt that the resulting success had been a huge confidence builder, even in places where she would have not been comfortable using her white cane. At the time of the second interview, it is noteworthy to observe that Gwen's BDI score has reduced, from 15

(indicating a mild mood disturbance) at the application interview to 0 (indicating these ups and downs are considered normal).

At the time of the third interview Gwen had completed training with Ginny and had qualified for six months and had been working the guide dog independently. Ginny was present in the interview and had been placed on her bed once with a firm command to stay. Gwen felt that Ginny had settled in but that she had to be firm and set boundaries in order to get the best working relationship outcomes and results from Ginny. Gwen felt she had a good bond with Ginny and a clear understanding of her abilities, shortcomings, and needs; “as I was saying (after placing dog on bed) she is a high maintenance dog and she does struggle with her inner puppy, but it’s a balance thing”. Gwen felt that she had enforced strict boundaries that gave her the room to negotiate between acceptable guide dog behaviour and acceptable working guide dog behaviour without coercion or punishment.

Gwen felt even with the degree of preparation and effort she had committed to the success of her training that she hadn’t realised how much responsibility she had taken on with accepting Ginny and had reached a point recently where she was stressed and anxious to the degree, she had thought seriously about giving Ginny back. However, she had worked through these feelings, had changed handling and control techniques, and this had been a turning point in addition to having positively rediscovered her independence through mobility with Ginny. “but yeah, I didn’t think I could do all that travel etc alone with just a cane, and she’s done 8 flights with me now interstate and we’ve had no problems at all”. Gwen felt her agoraphobia had been an issue in an airport recently and that Ginny had dissipated her anxiety by Gwen asking Ginny to find a way through the crowd. Ginny worked through the crowd effortlessly, reinforcing the correctness of Gwen’s difficult decision and consternation in what she felt was procrastination over three years in delaying her application for a guide dog. “this is why

you go through the difficult bits because you get moments like this where it is so much worthwhile”.

Gwen felt that the companionship of having Ginny had a positive impact on her stress levels and general wellbeing. She felt that the bond had developed over the past three months because Ginny had accepted the fact that this was her home for life now, which included developing her relationship with Gwen’s partner and visitors to the home without exceeding the boundaries set by Gwen. There had been a few issues with people wanting to pat Ginny, but Gwen had dealt with these, and had noticed that children were better informed than adults about not patting guide dogs. She reported that having Ginny had meant such an increase in confidence that she could tackle challenges that previously she may have avoided, and on those times when she was stressed or anxious about the environment, Ginny came to the front and led her through them.

Gwen felt the bond was so strong now that there were few obstacles to overcome, and she could continue with her plans to live as full a life as possible with Ginny as her inseparable companion and friend. “Me and my shadow! Ha-ha she follows me 24/7. She sleeps in the same room because she doesn’t want to be away”. Interestingly, Gwen’s BDI score had remained low (a score of one) at the time of the third interview, which indicated these ups and downs are considered normal.

At the time of the fourth interview Gwen had been working with Ginny for one year and in that time had several changes in her life. Gwen had moved to a new house, was studying at Ph.D. level, worked and travelled a great deal with both pursuits. Gwen felt that she had a very strong bond with Ginny and that there was a strong connection with the guide dog which left her feeling that “you are infected with every nuance and move and idiosyncrasy”. The

difficulties experienced in the first few months of having the guide dog were now balanced by the positive feelings about the guide dog, her independence and ability to explore new environments with confidence. So much so that Gwen feels that there was more than a partnership; that the guide dog was a part of her.

These feelings of positive growth in their relationship gave Gwen feelings of increased self-worth and self-esteem as well as happiness at the way Ginny had impacted on all aspects of her life, in particular at home and in the workplace where Gwen felt that Ginny played a part in her social acceptance and created a catalyst for communication and understanding. Gwen stated that her previous health conditions of PTSD, depression and agoraphobia had all significantly reduced, “with no flare ups” since having Ginny and this in turn has had a positive impact on her outlook and gave her courage. Gwen stated that in an effort to inspire her to meet new challenges the dog’s head goes up as if to say “I’m ready for it mum! The super cape in on, let’s go”.

Gwen felt she owed it to the guide dog not to hand her back, even after the initial difficulties, as she felt their bond was so strong now that the guide dog deserved the opportunity to work as a guide which she felt the guide dog lived for. This feeling has developed into a commitment to continue to work Ginny until Ginny retires, where she will be given to her partner as a pet. In addition, Gwen had feelings of interdependence on the guide dog and its role. Gwen felt sad at the prospect of needing Ginny more and more as she loses her sight completely but conversely felt more confident in the guide dog every day.

This positivity influenced Gwen’s health, she stated her fitness had improved, her exercise tolerance increased, and her weight had dropped by 9 kg. Gwen felt she had to work through

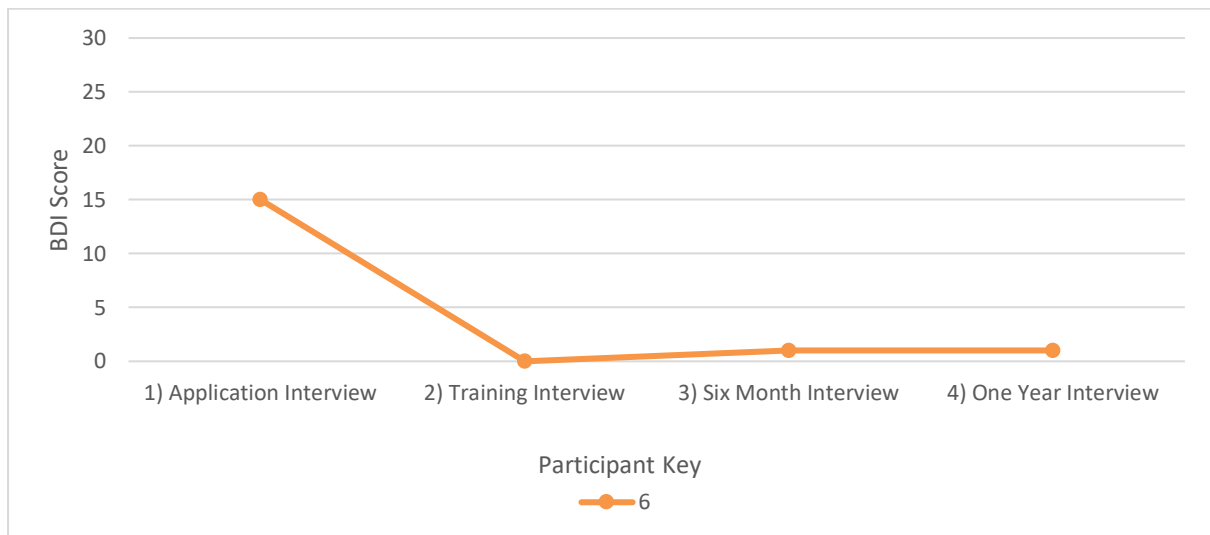
having a guide dog that was on “public display” and felt she had a role to play in educating the public about how to interact with a guide dog, this education also helped in her workplace and study environment and had created opportunities to meet new people and build new relationships.

Gwen has no children of her own (the adult children are her partners) but felt that having a guide dog was like having a baby and that Ginny acted like a child sometimes, which elicited strong maternal caring and supportive feelings from Gwen. “She’s my baby in a lot of ways, my substitute”. Gwen saw Ginny as a companion and friend, someone she could talk to, especially if she was not feeling confident in a new environment or situation, this relationship worked where Ginny was stressed too, and Gwen felt she understood the reasons for this and felt the need to help Ginny overcome these anxieties through support.

Gwen felt that her life had changed significantly since having a guide dog and more so that the future had guide dog mobility integral to her remaining independent and retaining her sense of self. “To me now, a guide dog is a part of life, it’s what the next 40 years will hold for me, as a series of guide dogs come through in different shapes and forms”.

**Figure 4.6**

*Longitudinal BDI Scores for Participant Six - "Gwen"*



**Table 4.6**

*Longitudinal self-reported emotions and feelings for Participant Six - "Gwen"*

Emotion/feeling	Milestone 1	Milestone 2	Milestone 3	Milestone 4
+Acceptance	√			
+Acceptance (of self)				√
+Accomplishment				√
+Anxiety	√			√
-Anxiety		√	√	√
+Apprehension	√			
+Companionship		√	√	√
+Confidence		√	√	√
-Confidence	√			
+Depression	√			
-Depression				√
+Empathy				√
+Enjoyment				
+Frustration	√		√	√
+Grief	√			
+Hopeful	√			
+Independence			√	
+Loneliness	√			
+Motivation	√			√
+Protective				√
+Sadness	√			
+Security			√	√
+Trust				√

\*Note re: prefixes: "+" indicates feeling/emotion reported; "-" indicates a reduction in feeling/emotion reported.

At the time of the fourth interview, Gwen's BDI score was one, indicating these ups and downs are considered normal. Of continuing interest is the fact that after having scored in the mild mood disturbance range on her initial (application interview), Gwen had sustained a consistently lower BDI score since the second interview, when she commenced training with her guide dog. See figure 4.6 above for a longitudinal summary of Gwen's BDI scores across the four milestone interviews. A more detailed discussion of the BDI scores across the longitudinal time frame has been presented in the thematic analysis of depression in section 6.2. See also table 4.6 above for a longitudinal summary of Gwen's self-reported emotions and feelings across the four milestone interviews.

#### **4.8 Summary**

The chapter explored the narratives offered by the participants formed by their experiences over the four milestones leading to working with their guide dogs. Consistent with a theoretical perspective of phenomenology, the data revealed a rich texture of emotions within the milestones and offered understanding relating to the lived experience of guide dog mobility for these participants. For these six participants, the narratives gave depth to issues surrounding their blindness or vision impairment, dealing with the practical aspects of mobility, and negotiating the environment before and after having their guide dog. In addition, in the latter interviews reveal issues that developed from guide dogs that were not working well with the participants, which was demonstrated by their increasing anxieties and in some cases, such as Stan, their fears lead to withdrawal of the guide dog and the end of their partnership.

## **Chapter 5 – Thematic Analysis Part A): Self-Reported Emotions and Feelings at Key Milestones of the Longitudinal Process of Guide Dog Ownership**

### **5.1 Overview**

To gain a greater understanding of the emotions and feelings experienced throughout the process of applying for, training and ultimately working with a guide dog, a thematic analysis has been conducted that examines self-reported emotions and feelings experienced by participants in the main study throughout this longitudinal process, using data gleaned from the transcribed participant interviews. Emotional and feeling-related themes have been analysed and presented in two ways. Firstly, this chapter has presented emotional and feeling-related themes according to individual stages of the longitudinal process so that service providers, in particular, may gain a greater understanding of the emotional needs of guide dog owners at individual key milestones of guide dog ownership. In addition, the themes will generate new knowledge and opportunities for further research across the field of blindness and vision impairment. Whilst a total of 33 emotions and feelings were identified in the interview transcripts throughout the process of thematic analysis, this was ultimately reduced to a total of 25 for discussion in this thesis. The rationale for this was that any emotions and feelings that were reported by no more than one participant at any one of the four key milestones was not considered significant and were thus excluded from further analysis. Secondly, chapter six has presented the key emotional and feeling-related themes that are reported to have fluctuated significantly across the key milestones of applying for, training and ultimately working with a guide dog, so that the reader may understand the capacity for a guide dog to improve the emotional wellbeing of guide dog owners.

The thematic analysis at the key milestones of guide dog ownership was as much a part of the markers of passage for each of the participants as it was for the service provider to have



points of reference and action. Each milestone gave rise to new emotional and feeling-related experiences and learning. The emotions and feelings identified and reported at each of the four key milestones; application, training, six-months and finally twelve months post-training has been summarized in table 5.1 below. These have been ordered according to how many participants from the sample reported this emotion or feeling, commencing with those most frequently reported across all four milestones.

**Table 5.1**

*Summary of the emotional and feeling-related themes identified at key milestones of the longitudinal study*

Milestone	1) Application	2) Training	3) Six months post training	4) Twelve months post training
Emotional themes identified	Anxiety	Anxiety	Anxiety	Anxiety
	Confidence	Confidence	Confidence	Confidence
	Frustration	Frustration	Frustration	Frustration
	---	Companionship	Companionship	Companionship
	Depression	Depression	---	Depression
	---	Independence	Independence	Independence
	---	Security	Security	Security
	Grief	Grief	---	---
	Happiness	---	---	Happiness
	Loneliness	Loneliness	---	---
	Motivation	---	---	Motivation
	---	---	Protective	Protective
	---	---	---	Acceptance (by others)
	---	---	---	Acceptance (of self)
	---	---	---	Accomplishment
	---	---	---	Comfort
	---	---	---	Empathy
	---	---	---	Enjoyment
	---	---	---	Gratitude
	---	---	---	Trust
	Acceptance	---	---	
	Apprehension	---	---	
	Discontentment	---	---	
Hopeful	---	---		
Sadness	---	---		

A detailed discussion of the thematic analysis of self-reported emotions and feelings by the six main study participants has been provided below. Definitions of the emotions reported by participants throughout this research has been provided in appendix two.

## **5.2 Application for a guide dog**

It was important to firstly provide details about the application for a guide dog process because this has bearing on the results in relation to the participant's emotions and feelings at the time of application. The application process for a guide dog involves several telephone conversations with guide dog service administration staff prior to being referred to a technical staff member such as a guide dog mobility instructor (GDMI). The GDMI then makes an appointment to conduct a formal application interview, which is usually done in person. This process can take several weeks from the initial phone call as the service gathers ancillary information via documentation such as a confidentiality agreement, self-declaration medical form and general information regarding the applicant's reasoning for the application for guide dog mobility (RSB, 2015). When the application process begins in earnest, the person who is blind or vision impaired is formally interviewed by the GDMI. The interview questions probe into the applicant's motivation for guide dog mobility, their functional vision, and their emotional state to be able to provide support for the guide dogs' wellbeing and welfare, including suitable accommodation. There are questions about their extended family and friend networks, employment and aspirations for increasing any or all of these when and if they are successful in their application. If unsuccessful, there are other signposting options offered to them and if totally unsuitable applicants and the service have an often-difficult conversation as to the reasons why, including explanation of the appeals process (RSB, 2015). Participants were awaiting the outcome of their application for guide dog mobility at the time of this first key milestone interview, and as such a decision about the outcome of their application was pending.

The thematic analysis of self-reported emotions and feelings by the six participants at the point of applying for guide dog mobility are summarized below. These have been ordered according to how many participants from the sample reported this emotion or feeling, commencing with those most frequently reported. Quotes from participants were presented to demonstrate the themes.

### **5.2.1 Application theme #1 – hopeful.**

The most common emotion or feeling that arose from the six participants during their application interviews was one of hope, for the opportunity and experiences that a working relationship with a guide dog brought to their lives. All participants reported feelings of hope, that when successful with the application process, resulted in a guide dog offered to them that improved feelings of personal safety, increase independence in daily life (particularly with mobility), and result in the development of companionship with their guide dog. All six participants had expressed some level of concern about personal safety with their current mobility, including feeling vulnerable and at risk, and expressed hope that the guide dog would address these issues for them.

Hopes for companionship with their prospective guide dog was reported by all participants during the application interview. In particular, Max expressed;

...and I also will need a companion... At the moment I live just to live. When I have a guide dog, I will live because he is going to be my buddy, my partner. Or she is. And it'll give me a purpose, to carry on.

Feelings of hope for this outcome of canine companionship were also evident in Bill's interview, where he humorously remarked "...someone I could talk to, that won't backchat me. It'd be a companion and a friend, yeah..." Almost all of the of participants reported not only feelings of hope in having companionship with their guide dog, but that working with a guide dog yielded a positive impact on their interaction and relationships with others too. Some participants rationalised that the presence of the guide dog acted as a catalyst for initiating interaction, created a social conduit with other people in the community. As Todd reported;

Because a lot of people like dogs, and they'd probably come up and pat the thing. Pat him or her and maybe ask questions and things like that. What's his name? I'd probably feel a bit more comfortable with that.

The theme of hopefulness extended to anticipation about other areas of life that the guide dog improved for participants, including hope for an increase in confidence with aspects of daily life, and improved self-esteem. Bill reported feelings of hope that having a guide dog improved his confidence in himself (i.e. self-esteem) and in daily life, due to expectations that the guide dog increased independence and participation in daily life. As Bill reports; "*But it'd get me places, we'd go together, we'd go to places. To virtually start again, start my life off again.*"

Todd emphasized how his guide dog increased his confidence with a range of daily activities, including with mobility;

...especially when you're getting out and about it obviously builds confidence once I'm used to it and it's used to me, going around bins or going around trees, or

whatever. Or certain objects, things like that, or walking at night, or places that I'm not even aware of. Certainly, it will build confidence there, knowing that the dog's got used to me, and I'm used to the dog. So, it will certainly build my confidence and my independence in that way.

Similar feelings were iterated by Stan, when he spoke prospectively about hopes of how the dog increased his confidence with navigating potential risks when mobilising in the community;

...it's mobility in unfamiliar environments.... if I end up working back in town, you walk along a footpath and one day Telecom's got a hole dug, I don't know that, you know. But the dog will help me know that. But that's really important.

Bill reflected on how he had seen a guide dog improve self-confidence and self-esteem with other guide dog owners he associated with, which had influenced his own realised hopes for improved self-confidence with guide dog mobility;

... it (guide dog) gives them self-assurance I suppose. Independence instead of ring up and say mum can you come and pick me up, or something like this.... But I've noticed a couple in Western Australia, it's made a lot of difference to them.... To me it'd be wonderful. It would.

Finally, the majority of participants also expressed feelings of hope that working with their guide dog would enhance their emotional and physical wellbeing. More than half of the participants discussed their hopes for a variety of improved health measures, such as the

opportunity for more physical exercise and a focus to detract from their own personal anxiety and worries. Bill expressed hopes that his guide dog will;

Take my mind off what's going on. Take my mind off a lot of my worries.

Something, I've got a companion there, I say right, let's go, take my mind off my other thoughts, other worries. I've got someone to look after, instead of worrying about how the others are getting looked after.

Max concurred on the hopes he had for his guide dog for his emotional wellbeing "the emotional support will grow when I get to know the thing. And I don't readily attach myself. I've lost too many things in my life that meant something to me".

Feelings of hopefulness that participants reported during the process of applying for a guide dog have been explored and identified as the highest reported emotion or feeling at this milestone of the research study. The theme of hopefulness has been revisited when presenting the results from the fourth and final milestone of 12 months post training, exploring whether these opportunities and experiences that participants hope to achieve through a working relationship with a guide dog, were ultimately fulfilled.

### **5.2.2 Application theme #2 – frustration.**

The next most common emotion or feeling reported by participants during their application interviews was that of frustration. All participants expressed frustration due to difficulties encountered with daily life and accessing different environments, caused by their vision impairment. Stan expressed the daily challenges of living with vision impairment which trigger his frustration:

Can't go out to a shop and buy things like other people. Can't just walk up to, you know, a shop somewhere you're looking at signs, can't look at bus signs. I bump into things all the time, even things around my own home. Yeah, I mean, it affects my life all day, every day. There's rarely a time when it doesn't.

The frustration of a life with limitation and unfulfilled aspirations was amidst the discussion during Todd's application interview, where he reported:

I sort of do get frustrated if I trip over something, or if I can't see at night. Or that sort of thing. I one daydream of being able to drive a car or something like that, coz that's been one of my dreams since I was a kid. That sort of does, doesn't make me upset, but it's in the back of my mind where I wish I could do that.

Another source of self-reported frustration was one that was closely related to the decision to pursue guide dog mobility, that being difficulty with the use of, and public response to the white cane. More than half of the participants expressed these feelings and responses as a source of frustration, such as Todd who expressed this as a reason for his unwillingness to utilise his white cane:

I remember one time when I did a mobility lesson with it, people were looking a bit. Obviously, people who are very vision impaired or blind wouldn't even know, but when you see people looking at you, bit embarrassing... but I think I would feel a lot more comfortable with the dog than with the cane.



Gwen conveyed greater frustration in difficulty and limitations experienced when using the white cane:

The cane doesn't always pick up the potholes that you might fall down... Whereas the dog, the dog wouldn't lead you on that road. So that's probably a lot more beneficial... It's when you go out with your cane, is worse. People get abusive, you know. If you crash into someone or whatever.

While most participants reported feelings of frustration due to the current difficulties of living with sight loss or use of current mobility aids, half of the participants reported additional frustration with navigating the process of applying for and acquiring a guide dog. Bill summarised his feelings about the process of application thus far "It's a killer waiting for everything. And waiting for a dog is killer... it is frustrating, it is. Not hearing anything, you know... But I'll get there... But it's just the frustration of waiting and not hearing anything".

Some participants (less than half) reported their feelings of frustration with respect to the breakdown of relationships and ongoing challenges with family, friends and members of their community. For these participants, the breakdown of relationships and challenges arising from this further motivated the pursuit of guide dog mobility, not only in achieving independence and reducing reliance on friends and family with whom there is conflict but in creating a relationship with the guide dog that encompassed companionship. Max portrayed his feeling of frustration in the way he felt others perceived and treated him, due to his vision impairment;

It affects me to the point, whereby people treat me like a fool. They also treat you as if you're deaf. People tend to talk louder when you can't see... I wasn't always blind, I do know what vision is like.

Frustration has emerged as a significant theme reported by participants, coinciding with the timing of applying for guide dog mobility. Of note is that while the majority of these appear to have served as a driver for pursuing a guide dog, one source of self-reported frustration was due to the actual process of navigating an application for acquiring a guide dog. Regardless, sources of frustration are relevant and valid, and important for the service provider of the future to address in this process.

### **5.2.3 Application theme #3 – grief.**

Feelings of grief was the next most common emotion or feeling reported by guide dog owners who participated in the study. All participants reported having experienced grief and loss, either presently or previously, due to reduced independence and autonomy with mobility. They reported having perceived a greater reliance on other people and mobility aids, and a loss of opportunity to participate in daily life. Aspects of daily life identified as impacted and significant to the individual, varied amongst participants. Bob spoke of his grief surrounding the loss of his driver's licence as a result of his progressive sight loss:

When I lost my car licence, that was the worst day of my life you know, I used to get around a lot with the car, so you know the government took it away, I had too many accidents. The last one I had, I side swiped a semi-trailer and cut the car in half, and they said that's it.

Gwen described the way her sight loss affected simple, daily tasks. Of particular note was the grief she experienced in her loss of independence with choosing her clothes for the day:

Everyday things are really hard. Clothes are worst... if I go down to colours like black, dark blue, purple, or any dark colours, navy, that's it, I can't work that out. I have to get someone to help me with my clothing and stuff, because I can't tell which colour is which colour or anything. So, it makes life very very hard... just everyday stuff that used to be easy, and we take for granted, is very hard.

Stan is one of the majority of participants who reported feelings of grief and trauma in relation to his lived experience of progressively losing sight over a period of time:

It sort of went in stages. And so, for example, it's hard when you find out that you can't play footy anymore, that was a fairly hard thing to take. And not being able to drive anymore. But yeah, what tends to happen is, you notice something, and you think, I could see that once. And so it has been pretty traumatic.

Grief associated with loss of sight, independence, and opportunity to participate in meaningful activities is a significant emotion or feeling experienced by participants at the first milestone, according to self-report. This is something that participants were contending with as they navigated their application for a guide dog, which had a marked impact on their emotional wellbeing at this early stage of the journey toward guide dog mobility.

#### **5.2.4 Application theme #4 – acceptance.**

Feelings of acceptance toward both the experience of vision impairment, as well as following the necessary process in applying for and training with a guide dog was another common

emotion or feeling reported by participants at the stage of applying for their guide dog. All participants reported feelings of acceptance toward their experience of vision impairment, however participants reported their acceptance of this phenomena in various ways. Max described his acceptance of experiencing vision impairment, in the context of how he responded when confronted about his blindness when performing music in a club; "...and he said but you're very blind! Yeah, stick me behind the keyboard and find out! That type of thing, the stick disappears, the glasses come off..... you've got to correct them all the time". Max also reported feelings of acceptance about his vision impairment when discussing how he approached asking a woman out on a date "I meet a lady, and I go, would you like to go on a blind date? She goes, I've never been on one. The stick comes out, I say, well here you go love, you've got a blind date!"

Gwen reported not only how she had felt a sense of acceptance about her vision impairment, but also emphasised the importance of acceptance for managing her depression and living a full life:

It's a very very bad situation. But you do accept it, after a while... I tell my old friends this now, because I've gone through it... I say to them, you've got to accept it first. Once you can accept it, yes you will have your depressed days, and even, I think if I still have it in 20 years I'll still be in that state, but I said you've got to get out, and you've got to do something. You cannot sit at home, you've got to get out amongst people, because that is the most important thing.

Feelings of acceptance toward the necessary process involved with applying for and then training with a guide dog was another theme that emerged, with more than half of the

participants reporting this. Stan expressed his understanding of this process, and his acceptance that this could take some time for the service to find him a guide dog that will be a suitable match for his needs:

I'm not going to worry too much about it. If they ring me up one day and say we've got a potential dog, would you like to meet the dog, then good, I'd be more than happy to do that.... It's probably good that I'm doing it now, because you know, it could take a long time before a dog's available, a suitable dog.

Acceptance of both the experience of vision impairment, and the process one must follow in order to obtain a guide dog has emerged as a significant emotion or feeling experienced throughout the process of applying for a guide dog. It is evident according to self-report, that the participants of this study had experienced feelings of acceptance with respect to their vision impairment, which had in part led to their decision to apply for guide dog mobility. As previously described frustration in the application process was a significant emotional state, acceptance too was part of the emotional consequences of applying for guide dog mobility. It was evident from the findings in this study that while feeling both acceptance and frustration may appear in conflict with one another, they may in fact coexist. Indeed, all the participants of this study reported feeling frustrated due to the difficulties they encountered with daily life caused by vision impairment, but at the same time accepted that vision impairment was a part of their life at that point in time. This was indeed an interesting paradigm to identify and reflect upon, as emotional and feeling-related experiences at this first (application) milestone are explored in detail.

### **5.2.5 Application theme #5 – anxiety.**

Participants described sources for feelings of anxiety during the stage of applying for guide dog mobility. The majority of participants expressed feeling worried or anxious about applying for, training and then working with a guide dog, as a primary mobility aid. Sometimes this anxiety was related to uncertainty. For example, Max highlighted how the process of waiting to hear from the Royal Society for the Blind (guide dog service) regarding when a suitable guide dog was available, was worrying:

It is important to me. But whether I'm going to get one, or whether I don't get one, I don't know what the situation is. I'll just sit here and wait for that... Yes, I could. I could say I really don't know what's going on. Because they don't say anything, they don't talk to you. Which is a little bit of a worry... the communication between them and us is not the best. You know, because we don't know... I just sit now and just wait. That's all. It's a waiting game. I'll wait.

Bill reported feeling anxious about how the presence of his guide dog may have impacted negatively on an already difficult relationship with his ex-partner, whom he had ongoing contact with for gaining access to their young son:

But I don't know what reactions going to be for my dog to meet her dog... And what reaction he's going to get. Is she going to come along and say you can't bring him here, you got to take him home or leave him home? That's what I'm maybe up against. I don't know. I'll have to face that.

Todd also reported feeling anxious about what impact the presence of the guide dog might have had when accessing a range of areas of the community:

It plays on my mind a little a bit... Because there are places that I go, for example, sporting venues, just even going to the park or on a bus. It's going to be interesting taking the dog around and seeing what people say. You know, oh, you can't bring that dog in here. That worries me a bit.

Another source of anxiety reported by half of the participants was regarding their own personal safety, in particular with mobility and community access, due to their vision impairment. This was relative to how these participants reported not having the means to travel more independently outside of well-known environments, as they did not perceive feeling safe to do with their current mobility aids. Gwen described her anxiety about accessing unfamiliar places, and her concern for the way people who are blind or vision impaired were treated if using a white cane:

I don't go places that I'm not familiar with... because I'm scared. And my friend, he's actually been bashed at the train station, twice now because he had his white cane... there is people out there, that if you do have a cane, they will do stuff like that, coz they know you got eye problems.

Todd's expressed anxiety for his personal safety stemmed more from his concerns about tripping or falling, when at work or mobilising around the community; "I seem to be tripping over things or running into things a lot more than I used to... I think I'm going to hit something or fall down something, do serious bodily harm or something like that". Todd expressed feelings of hope that pursuing guide dog mobility would alleviate the fears and anxieties he held in relation to falling. This was because the guide dog would not only guide

him around potential fall hazards, but also offer him some stability in movement due to the size and spatial dimensions of the guide dog.

Anxiety surrounding the process of acquiring and integrating a guide dog into all areas of daily life is a significant emotion or feeling reported by participants of this research study, however this anxiety, even when relative to factors about the prospect of having a guide dog, did not prevent participants from proceeding with their application.

#### **5.2.6 Application theme #6 – loneliness.**

All participants reported experiencing loneliness during the application process of the study. Loneliness was reported as directly related to the impact of blindness and vision impairment on a variety of aspects of their daily lives. For many of the participants, interaction with family, friends or even care workers was a key factor in addressing the recurrent theme of loneliness. Bob explained how the presence of someone routinely visiting and providing support alleviates some of his loneliness; however the periods when there is no-one present rekindles these feelings of loneliness:

I still do all my own cooking and washing, she just does the floors and the vacuum cleaning that's all, she does this for an hour but I pay her an extra 30 minutes to have a cup of tea with me, just for a chat and some company... also I get a bit lonely at night especially weekends because no one comes and visits.

The theme of loneliness is also evident in Max's expression of feelings as a result of his perceived lack of human companionship; "Yes, I am lonely... but I have not yet found anybody, lady-wise, that I could say, well, how about we go and sit on the beach... I haven't been there for a long long time".



For some participants, the hope of alleviation from their state of loneliness was compounded by their expectation that the guide dog was a panacea for such episodes and provide the comfort and company to address the emotions experienced by states of loneliness. Bill explains his desire to create a bond of companionship and friendship with his guide dog when he got one, which would act as a compensatory mechanism if he loses more sight and becomes lonely in that process. As Bill reported; “If I have a dog then the dog can help me. Then if I do lose a bit more, then I have my friend.”

It is evident that all participants were experiencing feelings of loneliness at milestone one, due to their reported experiences of isolation occurring secondary to blindness and vision impairment. What was evident however, was that the experience of loneliness had acted as a motivator for many in applying for guide dog mobility, in the hopes that acquiring a guide dog might have improved this area of their emotional wellbeing.

#### **5.2.7 Application theme #7 – motivation.**

Motivation is one of the generic assessment criteria in the process of applying for guide dog mobility and is recognised as such by the International Guide Dog Federation (IGDF) in their current standards (IGDF, 2016). It is therefore noteworthy that all of the participants in this study have reported feeling motivated to action change in their life by applying for guide dog mobility, so they may achieve increased independence and participation goals in life, such as employment and engaging in physical exercise.

For many of the participants in the study, motivation was a feeling that factored into their decision making about applying for a guide dog. For Stan, the decision to apply for a guide dog was based on his motivation to find employment, and that having a guide dog would

make him a more appealing candidate to potential employers. A Stan explained; “I’m not sure that I’m the ideal candidate for a dog. But if I don’t press on then I might find it impossible to get the sort of employment that I want.” In addition, Stan’s acceptance of his vision impairment and associated self-image was a crucial motivator for applying for a guide dog, which he states as being “Pride. I never wanted to be a person with a white cane, a dog’s more acceptable. I can accept that... I’d rather stay home than go out with a white cane.”

Independence and increased mobility were identified as primary motivators for participants in this study in their decision to apply for guide dog mobility. Bill had made his application with a view to improving his social interaction, playing sport and improving his health through exercise. He states that:

I volunteer, I was volunteering for Blind Welfare, I was volunteering for the council, yeah. I still play sport... I’ll walk every day... To take my mind off of things. And just to get, keep active instead of just sitting around here... Just walking my pace and with my cane, and yeah. It’s just, got to keep active, keep your mind active.

#### **5.2.8 Application theme #8 – apprehension.**

For almost all participants, there was an introspective self-analysis of need that creates apprehension in pursuing the application for a guide dog. For Stan this was demonstrated in his concerns that a guide dog may not reach its full working potential if placed with him in his current situation, suggesting that he may have been depriving a more worthy applicant of a guide dog when one becomes available. As Stan states:

I'm still, to be honest, a little bit apprehensive about doing it... And it's just a question of if and when a dog comes up, and if the situation that I'm in actually still lends itself to having a dog. I don't want to have a dog that won't be used. You know, they'll lose their skills if they're not used... I do wonder whether there's people that could use it more than me...

Gwen reported feelings of apprehension relative to whether she felt "ready" to undertake the training for guide dog mobility, given recent changes in her family dynamics and the stress this had caused:

I'm not ready at the moment, my daughter's just left home, she's caused me a bit of grief as well... But later on, when my nerves are better and I feel that I could cope and be trained with the dog, yes I will do it.

For the majority of participants, the decision to apply for a guide dog raised feelings of apprehension that in turn saw some prolong their decision to apply and created feelings of uncertainty about what decision they would make if and when a guide dog was made available to them.

### **5.2.9 Application theme #9 – confidence.**

More than half of the participants in the study reported feelings of lowered confidence in self and throughout their daily activities due to the impacts of blindness and vision impairment. Interestingly, this finding corresponds with the reports of a high proportion of participants who expressed feelings of hope that having a guide dog would have increased their confidence in daily life, as previously noted in section 5.2.1.

The circumstances in which lowered confidence was reported varied amongst participants. Gwen expressed feeling a loss of confidence in unfamiliar places, such as when she was on a train for a recent trip interstate. Gwen at the time of first interview stated that she had hoped that by having a guide dog in the future, she could address these experiences and feelings of lowered confidence by using her guide dog to travel in unfamiliar places, especially as she continued to want to travel for both leisure and for work. As Gwen reported;

I went on the train up to Darwin, by myself... And when I got on the train, I was alright during the day because we had a cabin, and the man across from me had a bright shirt on, so I went by his shirt. Anyway, night-time came, and I needed to go to the toilet twice. I couldn't find my room, and I was absolutely, really really, upset about it. I cried and cried, and I thought, should I go and try and get help, what should I do? In the end I knocked on that, coz they told me to knock on the door of this person, the conductor, I knocked on the door. But it shook me, for two days, I was shaken about it.

Max reported feelings of lowered self confidence in the social setting, particularly when encountering people who he was not familiar with, "I find it difficult because people treat you like you are absolutely a fool. And I don't particularly like that... I'm very wary of people. Basically, because I cannot see them".

According to self-report by the majority of participants at milestone one, there was a link between feelings of lowered confidence due to the impacts of blindness and vision impairment, as well as expressed feelings of hope that having a guide dog would increase their confidence in daily life. As Stan speculates how he might feel once working with a guide dog "perhaps a little bit more confident. Yeah, probably a little more confident." Thus,

indicating a perceived increased confidence as part of the experience of owning and working with a guide dog, by most participants in this research.

#### **5.2.10 Application theme #10 – depression.**

Depression was an emotion or feeling of interest identified in the analysis of the study, with more than half of participants reporting this in some way throughout their application interviews. The elements of depression experienced by the participants in the study reflected the impact of blindness and vision impairment on their daily lives, including lowered mood, and the additional impact of relationships that were unsuccessful in their lives. This was potentially why relationships of an unconditional nature were so much a part of the application for a guide dog.

When asked whether he felt that a guide dog would make a difference to the existing relationships he had with family and friends, Bill reported feeling hurt and disillusioned. He felt that some of the difficulties he had experienced with previous family dynamics were in part due to his inability to be independent or remove himself from conflicting situations due to his vision impairment. Bill felt that with a guide dog he would be able to leave when he wanted if he saw his family again and that they would see the relationship he had with his guide dog as a positive one. As Bill states;

I have 5 elderly children; I don't even see them. I have 11 to 12 grandchildren I don't even see. I have a lot of friends that I made over the years, I don't even see. Because of what happened... Now I have a 9-month-old son. And that's hard. People say oh, that's hard, I say I know it's hard. You cry? No, I can't cry. I've finished crying. People say how's your daughter go, I don't know. We have no communication. She could be dead for all I know. I don't know. No grandchildren ring up, grandpa this or grandpa that. Or

dad this or dad that. And then I have 4 brothers and 3 sisters. 1, 2, 3, 4, 5. I have not seen 5 members for nearly 4 years... So, I have no contact with family in any way. Yeah, I'm hurt always. And then I had to give a lot of things away, because of the breakup. Hurt again.

Gwen discussed her experience of clinical depression, as a result of adjusting to life following vision impairment:

It does give me depression, every now and then I do go through depression, and have bad thoughts sometimes, and bad things... I just used to stay at home and not go out. So, it got to the stage where I thought, I don't want to buy clothes... I'm sorry, I get upset with this... and I didn't want to buy clothes, didn't want to buy things for the house, because I thought I wouldn't be able to see them... It's not just losing your sight, it's lots of things, there's the depression side, you lose your independence when you lose your car, it's getting out and about safely.

For more than half of the participants in this study who reported feelings of depression at the stage of applying for a guide dog, it would appear that a number of the causation factors could potentially be improved through acquiring a guide dog. For Gwen in particular, feelings of depression were reported to fluctuate throughout various stages of experiencing vision impairment. It was therefore important to observe fluctuations in depression across the four key milestones in this study and ascertain the influence of the guide dog in this process.

#### **5.2.11 Application theme #11 – happiness.**

The emotional state of happiness was identified by half of the participants at milestone one, which was relative to the prospect of having a guide dog. Bill stated that he was happy:

Happy! Happy. Get me out more. I'd be wrapped, I would. Someone sitting with me at night, and I could pat it and talk to it, and it's not going to... No, something or someone to look after. As a friend and a pal. Yep. So I'm looking forward to it, I am. I am, I'm looking forward to it, even if it takes another 6 months, I'll still look forward to it. No matter where I am.

Participants who reported these feelings of happiness did so as they associated the success in their application with a future of increased mobility and independence through working with a guide dog. Bill's report of happiness was expressed with regard to being in a relationship with his prospective guide dog, perceiving the dog as a confidante and companion. This stands in contrast to the proportion of the participant group (more than half) which reported feelings of depression at the application milestone. Furthermore, this elicits the question of how an individual may experience feelings of both happiness and depression simultaneously, as this appeared to be the case for some participants within this study, according to self-report.

#### **5.2.12 Application theme #12 – sadness.**

Sadness was expressed by half of the participants who associated these feelings with their experience of vision impairment and their perceptions of themselves as people who are blind or vision impaired. This concept the person with blindness or vision impairment has of themselves as a person with disability and therefore vulnerable, can have a direct impact of feelings of wellbeing and confidence.

For Max, feelings of sadness were associated with a degree of loss in his life "I've lost too many things in my life that meant something to me". Max feels that having a guide dog in his

life will provide a buffer for some of the loss he has experienced, and some of the emotional difficulties he has undergone, not least of all was his emotional adjustment to his deteriorating vision. Blindness and vision impairment impacts on the rites of passage through to adulthood, with accepted social conventions that are unable to be achieved or maintained because of their vision impairment have perceived catastrophic results. Gwen reports “And that’s what gets you down. Like when they took my licence, of course that was a big thing in my life, that I couldn’t drive any more. Took all my independence”.

Experiences such as coping with the everyday challenges were cause for sadness in Gwen’s life, as she explains “I do find everyday life just hard”. Some of these events were reported to cause stress and result in sadness, which led to Gwen seeking support and help with her feelings of sadness. Gwen explains:

So things like that as well just get me down. And because I already have bad nerves, because I’ve had a few breakdowns and ended up in hospital, I get probably more upset about things like that than what a normal person would. Somebody else might laugh it off, but I don’t laugh it off.

For the participants in the study, sadness was intertwined in other emotions such as frustration, depression and anxiety. Sadness due to blindness and vision impairment was deeply connected to frustrations about being unable to do things for themselves, their self-image and inevitably feelings of self-devaluation and low self-worth.

### **5.2.13 Application theme #13 – discontentment.**

A relatively small percentage (less than half) of all participants reported current experiences of feelings and emotions of discontentment. These were described as the result of breakdown



of relationships and ongoing challenges with interactions with family, friends and members of their community.

While Max openly describes himself as “lonely”, he proceeds to express his feelings of discontentment with his perceived lack of interpersonal relationships, and the way people have treated him:

I haven't got much of a social life. So loneliness is the biggest problem... Because I have no family or relatives as such. So I've had to do it by myself... I've come to the end of my time with people. I've seen what they can do, I've seen what they do. I've also witnessed how they can actually go out and really really set out to destroy someone completely. It is not a very pleasant thing to witness. Broken marriage is one of them, been there, done that.

It is evident that several themes expressed by participants with respect to their interpersonal relationships are those of a challenging nature, including frustration, loneliness, depression, sadness, and now discontentment. These were and more so, are, all valid and important for the service provider to be fully aware of when working with a person who is blind or vision impaired, more specifically to understand this lack in satisfaction with respect to the individual's social circumstances and the potential for a guide dog to address this unmet need. The emotional needs of the applicant for guide dog mobility are fundamental to the measurements offered for success in creating working partnerships and can influence the methodology offered in assessment, training and ongoing support. For the service provider, the ability to support the potential guide dog owner through the application, training and working with their dog journey is one that can require specialised skills and training. These include a heightened awareness of arising issues in the partnership and the impact of

emotional responses, not only on the efficiency of the partnership but on the wellbeing and welfare of the guide dog owner and guide dog, as independent and sentient entities.

### **5.3 Training with a guide dog**

For many prospective guide dog owners, the process of training to work with their guide dog is an arduous journey. The process challenges many factors associated with their blindness or low vision, as well as their emotional state of readiness for the formal training process necessary to qualify with their guide dog. For the participants of this study, their formal training involved a three-week program of universal foundation instruction as well as targeted (destination-specific) training, tailored according to the expressed and agreed upon needs in consultation with each participant and their instructor.

Training had both applied practical and theoretical components to educate participants in aspects of the guide dog's behaviors, skills and wellbeing. Such knowledge was critical to provide support, wellbeing and meet the emotional needs of the guide dog in this early stage of the working partnership. The thematic analysis of self-reported emotions and feelings by all of the participants of the main study at the point of training with their guide dog are summarized below.

#### **5.3.1 Training theme #1 – confidence.**

All of the participants who were now in training, expressed an increased level of confidence in using the guide dog and how that confidence had impact on their abilities to travel more independently and to stretch their knowledge of their environment with new destinations and new activities. Max stated that his confidence was improved based on his ability to now go to places that were new to him:

I took the dog, and I took it where I have never been, that way (points East) going, all the way, all over the place, find the lamp find the pole, this and that, at the bus stop find the seat, boom boom boom this dog is great.

Bill felt that his confidence had improved to the point where he could reduce some of his previous diligence in observing the terrain, safe in the knowledge the dog could negotiate it: “you know it leads me, takes me for walks, takes me here, takes me there. I don’t have to look at the ground, while I am walking, I can look straight ahead”.

Todd had similar experiences to Bill in so much that he was more confident in the knowledge that he would not be colliding with the environment. Even at night, Todd reported how he could safely rely on his guide dog to manoeuvre around obstacles that he had no ability to see, and in some cases did not know they were there: “It’s certainly giving me a lot more confidence especially with walking out and about knowing with like objects, and things like that, whether it’s a tree or bins or whatever I feel a lot more confident moving around objects...”

It is clear from self-report, that all the participants were in a process of learning new skills in working in a partnership with their new guide dog during this training stage. This development of a new skills set and the initial experience of commencing a working relationship with their guide dog correlated with an increase in the participant’s confidence in a range of daily living activities, in particular with respect to their mobility.

### **5.3.2 Training theme #2 – anxiety.**

Participants reported experiences of increased anxiety during the training stage as they begun working with the dog, as well as instances where their anxiety had been reduced by the

presence of their guide dog. Almost all of the participants reported a reduction in their anxiety, and feelings of ease when mobilizing with and being close to the guide dog. Max reported his acknowledgement of the impact his guide dog had on his emotional state; “but yeah, the difference is amazing, I am more relaxed too...” Bill’s experience concurred with this notion of the guide dog having as a calming effect, as he reported how working with his guide dog had helped to divert his thinking away from some of the long-term issues he had with the break-down of family relationships. As Bill reported; “...but you know the dog has been a great help, it helps to take my mind of a few things, like with the dog it’s like lets go for a walk, we sometimes go like three times a day”.

Whilst nearly all participants experienced a reduction in anxiety when mobilising with and being close to the guide dog, a smaller proportion (less than half) of the participants reported feeling anxious about the training process. Bill reported anxiety about the potential for negative public feedback in situations where he needed to be firm with managing the guide dog’s behaviours while training in public. As Bill illustrated:

They do they have their opinions, you know a couple of times I will be frightened, that someone’s going to get a call, then I am going to get a call, where they say look you have been ill treating the dog on the road.

Bob felt that the theoretical components of the training was cause for concern and created some anxieties, but on the whole was a positive experience. He commented that “It’s good but the exams are very stressful (laughs)”. This including some anxiety about the duration and intensity of the training program which had made him very tired. “They reckon the training is very strenuous and it has been, like every day for the last three weeks, but I am getting used to it”.

Less than half of the participants had some anxiety related feelings about the behaviours exhibited by the guide dogs in their early training period and how they were managing this. Bill had a friend whom the dog met but was excitable, requiring Bill to restrain the dog. This created some anxiety about the potential meeting of the friend again at his home, as Bill reported “The dog eventually relaxed but he wasn’t too happy with it, you know I would like to take the dog up to his house but no, but yeah I am worried, yeah you know”.

Todd found managing the guide dog’s behaviours and toileting routine created some anxiety. Toileting a guide dog and managing distractive behaviours is addressed early on in training. For Todd, the difficulties he was experiencing with fulfilling these expectations had created some anxiety as he felt he would be judged on this by the training staff. As Todd reported:

The dog has tested me... the whole toileting and taking the dog to work. I had to sort of push the dog a bit, like when the dog sort of stopped in the middle of the footpath, I was like look keep going, and sort of forced the dog to keep moving along before we got to work, and then the sniffing sort of thing, and that’s been a challenge... One of the things the instructors said was don’t let the dog, basically win, or you know don’t give the dog any leniency basically you be in control, if the dog makes a mistake... you get the dog to go back and do it again properly or if the dog sniffs, correct the dog and all that.

Anxiety was a major theme that arose from the training interviews with the participants, including both indicators of reduced anxiety as well as some areas where anxiety had spiked throughout the training process. The experience of training with the guide dog is the first

phase of life with the guide dog and for many new guide dog owners, including the participants of this study, it can be a reality check about their decision to own a guide dog.

### **5.3.3 Training theme #3 – companionship.**

The third most frequently reported theme across the study sample was one of companionship; more than half of the participants stated that they had experienced feelings of bonding and tenderness with the guide dog, and as such were valuing the benefits of companionship that owning a guide dog brings with it. Bill explained that one of the reasons he felt this companionship was because he perceives he can talk freely and openly with his guide dog without fear or contradiction or reprisal. Bill states "...yeah, yeah, someone's that not back answering me, throwing things at me, whatever, whatever".

Interestingly, Todd explained how the feelings of companionship he developed with his new guide dog was also observed in members of his immediate family. Todd commented: "my daughter and wife absolutely adore the dog, the kids adore the dog". Gwen states that she is in love with her guide dog and has a sense of gratitude for her efforts which has created this bond, she states "I sort of naturally scratched the ear and said you're doing really good, thank you for that, the dogs still figuring out who the hell I was, but it's a real friendship there, so you don't feel like you're doing it on your own, and even just in that, so when I came home I said to my partner, I think I am really in love with this one".

For many of the participants in the training period of their relationship with their guide dog companionship was a key element in developing the bond that would improve their working partnership and establish a work ethic.

#### **5.3.4 Training theme #4 – frustration.**

During the training stage, less than half of all participants reported the experience of frustration during this period of adjustment, requiring the development of working practices and a bond with their guide dog. Bill stated that he had some early issues in working with the dog but felt he had them mastered:

Initially when I took the lead and the dog, nearly tips me over, so I got a little ticked off about that, but I was so pleased to have the dog, and I was pleased to show the dog off to my friends, and ahh, but, it is ahh, other than the fact, the dog loses it from time to time, but that's all good, because when the dogs off that harness it's just a pup, and soon as gets that harness on it's a totally different dog.

Bob described frustration with his guide dog being disobedient during the training, and referred to the high expectations he had, based on how he was committed to managing the behaviour of his previous pet dogs. Bob commented “yeah it wants to play, it's like this, then all of a sudden it just wants to play, out in the field the dog is very disobedient”.

Stan had some initial issues with his guide dog being homed on his rural property, which caused him frustration regarding the difficulty in controlling or limiting the negative behaviour of his guide dog. Stan explained:

Everything was going quite well except for the fact on Monday the dog started to jump fences, and you just can't have that out here (participant lives in rural area), because of the sheep, if the dog gets in and kills sheep which we don't want happening.

One participant in the sample group also reported feelings of frustration in relation to the ongoing conflict he was experiencing due to broken family relationships. Bob explained his frustration and concern that bringing the guide dog to his ex-partner's house when he visited their son could trigger further conflict between them. He stated that:

I can't take the dog there (ex-house), because she would probably kill the dog, plus I don't know if she would let me in the bloody house, I am not you know (long pause). So I just haven't bothered her, she hasn't said anything so, no one's told her that I have a dog".

The early time period from commencement of training triggered feelings of frustration for some participants who were coming to terms with the balance of establishing a working relationship with their guide dog, and navigating how to overcome certain challenges encountered when integrating the guide dog into their homes, relationships and routines.

### **5.3.5 Training theme #5 – security.**

Less than half of the participants stated that they had experienced an increase in feelings of security since commencing the training with their guide dog. According to self-report, it does not appear that this proportion of participants feel safer in terms of protection by the guide dog taking aggressive action in their defense, but more so that having the guide dog with them when they were travelling might have been seen as a deterrent to any would be attackers.



Max, for example had an experience at the bank where he stated the guide dog did demonstrate some protective behaviors, or at least showed enough concern as to alert Max to the potential jeopardy of the situation and for him to take action. He states:

Because the dogs protective of me, I mean because I had to go to the teller machine... now Marion (suburb) is not a very safe place, now I don't look over my shoulders very much, because thank god my hearing is very very astute, and I can feel anything coming from behind I know where ever it is... there's a bloke behind me and I am standing pulling \$20 out, this fella was within 3 paces of me, this dog here sits in front of me on the machine, soon as this fella approached me because I could feel it in the harness, I thought what the hell is going on here, so I stopped using the machine, right between me and him the dog went back of mate, so I patted the dog on the head not knowing what was going on, and the dog wasn't going to let up... I stood there and didn't do nothing and then this bloke finally opened his gob and said something like 'are you going to use that machine mate' and I said if you back off I probably will because I said my dog doesn't like you, you are too close for comfort and I do not know, then the guy mumbles something about the dog, and I said yeah back off, then the security guard came over 'morning sir how are you is everything alright' I said I am fine, is said to him, and he said are you having a bit of a problem, and I said my dog doesn't feel very comfortable at the moment, and he said no your right we spotted this bloke, he did it apparently at the other side of the shopping centre... but yeah the dog wasn't happy, it was very, very astute.

Todd also expressed his increased feelings of security in having the guide dog with him, particularly when he was travelling home in the evening after dark. He stated that not only does to guide dog add to his feelings of confidence but also feelings of security:

Especially like when I get home at night, it's like 6:30 now cause of day light savings it gets dark, and in the dark, and even though the bus drops just up the road there, um you know the dog still leads me home.

All of the participants had reported during the application interview milestone that they felt hopeful that a guide dog would aid in addressing their concerns for personal safety.

Participants had reported that security was an issue and at times in their lives had felt vulnerable or unsafe particularly due to their sight loss or blindness. For many people having a disability creates feelings of vulnerability and risk. The interesting association is that a third of participants reported during the training milestone that having a guide dog improved this feeling of increased personal security, even when guide dog mobility instructors (GDMIs) go to great lengths to explain that guide dogs are not trained to offer protection through aggression. It appeared that for some of the participants that the physical presence of the guide dog beside them offers some confidence in their state of security and that the fact the dog was physically a presence to be noted by would be attackers and served as a deterrent.

### **5.3.6 Training theme #6 – loneliness.**

One of the participants reported feelings of loneliness at some level during the training milestone, however that the presence of his guide dog had gone some way to reducing that feeling of loneliness. He states:

But yeah I got very lonely, I lost my wife, a few years ago now and I have never been able to replace her, not that I am looking, it would be nice to be able to go to lunch, instead of by yourself all the time, or being what people would say the third cog on the wheel, you, your always like, you know always by yourself, and yeah now I have the

dog, It has it pretty good it couldn't care less, it sits under the table, and there you go...

I don't feel as lonely as I used to.

Loneliness can be a common experience for many people who are blind or vision impaired, usually associated with the isolation experienced when mobility is compromised and reduced (Brunes, Hansen & Heir, 2019; Grow et al., 2015; Osaba et al., 2019). Furthermore, relationships breakdown and fracture as they do in other relationships, but for many people who have sight loss or are blind these relationships may play an important part in maintaining independence and mobility in order to keep that contact established.

### **5.3.7 Training theme #7 – depression.**

One of the participants touched on how even at this early stage of building a working relationship with his guide dog in the training milestone, that the guide dog had gone some way to reducing his feelings of depression. As Max reported "I am not depressed... The dog has made a hell of a difference, and I don't, as I said, I don't get depressed, I have my ways and means of dealing with that"

The definition of depression in this study suggested that many of the participants have experienced this emotion or feeling at some point in the journey. As emotional state is a factor in assessing the suitability of guide dog mobility for a person who applies that is blind or vision impaired applies, the question is how would that impact on the decision to approve an applicant with a known history or diagnosis of depression? For some providers of guide dog mobility services, applicants with underlying mental health issues, particularly depression, may be assessed as unsuitable for guide dog mobility and their application is declined (IGDF, 2016). This may well be on the grounds that the service provider regards

training with a guide dog as an arduous task for people who are blind or vision impaired, and if the applicant is not in a state of sound mental health or wellbeing at the time of application, this process may not be deemed in their best interests to pursue until their mental health is being treated by the necessary health professionals. This may create for many providers of guide dog services, an enduring and complex series of questions, as the proposed secondary role of a guide dog in improving the emotional well-being of clients is not yet fully evidenced in the literature, something that this research aims to contribute to.

#### **5.3.8 Training theme #8 – independence.**

Feelings of increased independence in a range of daily activities, including mobility, was reported by one of the participants in the early stage of training with his guide dog. Max offered a scenario of his recent experience in navigating public transport to attend a meeting during a training session with his guide dog. Max used this to help illustrate how he had felt a greater sense of independence travelling with his guide dog on the bus, comparing this to his reliance on someone driving him to these appointments in previous times. As Max reported:

On Monday, we had a meeting with the RSB, next to me here the dog never even moved, didn't bother about nobody, then the dog went on the bus with me, because you know they pick me up usually and I used to use the cane, but I said you nah, I will make my own way in by bus, the dog travels, travels on the bus sits there, like I am...

Independence is a word familiar in the guide dog industry as it is usually synonymous with mobility. For the participants, independence had a much broader definition and training with the guide dog was pivotal to meeting that objective with their guide dog.

### **5.3.9 Training theme #9 – grief.**

One of the participants described a loss of his previous mobility aid, the long cane. For some participants, other mobility aids had a significant comfort factor associated with their use.

The long cane is an aid that requires the full attention of its user and subsequent errors are resolved by using the long cane as a probe or investigative tool to solve the problem (Blasch, Wiener & Welsh, 1997). Bob experienced a sense of grief and loss of this ability to problem solve as he transferred some of those problem resolution tasks to his guide dog and felt that by the guide dog taking on the responsibility, he was absolved from the process, relegated to the role of passenger. Bob reported his feelings of grief in losing the comfort he felt in using the familiar, long cane. This also suggests that relying on his own initiative and skills was now being shared, and in some situations, reliant on the skills of the guide dog was a process of giving up some of his own self-reliance. As Bob explains:

I still sort of miss the cane, now I really have to rely on the dog. When I first started practicing we would do it without the dog then would go back to the car and get the dog, we went up to Coles and went across the tram rail today, so I am still sort of getting used to the dog you know I was more comfortable with the cane, you know it may take about six months or something, but I manage o.k. with dog...

A routine phenomenon during the training of a person who has low vision or blindness with a guide dog is this transitional period of the perception of giving up their previous skills and knowledge to take on a new skills base in working with the guide dog. For some people this is a welcome addition to their arsenal of skills but for some like Bob, there is a sense of grief in the transition and even a sense of loss.

#### **5.4 Six months post training with a guide dog**

Following an intense training program where the participants have been given instruction in how to work with their guide dog, address any issues that arose from the training that might have been detrimental to the ongoing success of the partnership, and provided orientation to preferred destinations and objectives, all contact thereafter was regarded as non-routine.

Issues such as toileting on walks, anti-social behaviour (e.g. barking when visitors come to the door), weight gain in the guide dog, or even as severe an issue as poor or deteriorating work ethic and compromised safety, or a breakdown in establishing a bond, were dealt with outside the remit of the training program in order to recognise the participant status as a qualified guide dog owner, which through their qualification in South Australia grants them access rights with their guide dog.

This is the case until six months-post qualification where a scheduled “aftercare” visit was provided to ensure the partnership was on track and working to a safe and effective standard. A standard set by the IGDF as a benchmark for all member schools. For many guide dog owners, undergoing the experience of a six-month review of their working practices can be a harrowing one. This is often due to how the guide dog owner perceives this review of their progress in working with their guide dog as being based on a “pass” or “fail”. In most cases, a review of the working partnership with a guide dog and their guide dog owner results in identifying the need for some remedial work to rectify the issues, however the worst case scenario is the potential for the work to be of such a poor unsafe standard as to warrant withdrawal of the guide dog under the terms set out in the guide dog owners agreement signed on completion of training. This scenario creates a huge amount of pressure on the client to perform well on the day and could create exam tension between the guide dog owner and the guide dog and in some cases between the guide dog owner and the guide dog mobility instructor (GDMI). For the participants in the study, the service provider’s six

months aftercare visit presented a milestone by which to connect and conduct the third in the series of interviews to report on how the partnership was developing and how the participant's emotions and feelings had travelled the journey between training and the six months review. They all agreed to participate to be interviewed immediately following their six months aftercare visit from a GDMI.

#### **5.4.1 Six months-post training theme #1 – companionship.**

By six months into their relationship with their guide dog, almost all of the participants reported their understandings of the depth of bond and quality of relationship they now had with their guide dog, which involved feelings of companionship. Misdemeanors in performance as a guide dog were now being explained in terms of how each were thinking at the time and if there was a miscommunication rather than a blatant breach of the training principles. The time spent not working was, for most of the participants, time spent with a friend or companion as well as their working dog. Max explains the “mateship” he now shared with his guide dog; “...now as I go around with Holly, wherever I go she goes, because she is my mate... Oh yeah, she is my life”.

Bill returned his dog to the RSB guide dog service at six months for a short period for retraining due to some guiding work difficulties he was experiencing, as well as taking some time for a recurrent shoulder injury to heal. Even though he knew the guide dog would be returning, his feelings were very much a loss of the companionship his dog offered, “...oh yeah, because I lost me mate”.

However, Gwen appeared to have established a very firm bond based on the expectations of companionship from her guide dog and has used this relationship to establish some working expectations that were not taught to her in the training program. As Gwen reported, this type

of companionship supported the development of her working relationship with the guide dog by taking the relationship to the next level of shared learning:

Oh yeah for sure. The longer I continue to have her the bigger that understanding, and bond will be. We have a bit of sign language too, because I teach, I can't tell her off in class so accidentally she has learnt to sit and stay and lay with my hand movements which are great.

Gwen has an incredibly strong bond with her guide dog, as she reports they have become inseparable "me and my shadow! Ha-ha she follows me 24/7. She sleeps in the same room because she doesn't want to be away". They have an established work pattern that meets both of their needs and the sense of companionship based on this work and play ethic appeared to be working, according to Gwen. As she states, "If I've had a hard day's work, I have a glass of wine if she has, she gets her chew toy and maybe a little peanut butter. She also likes the beach we go about twice a week".

For most of the participants, companionship was a key element in the success of their relationship with their guide dog. This friendship based on companionship was in their opinion reciprocated in terms of work ethic in the guide dog as well as being part of a special bond that only they shared even though there were other people on the periphery of this relationship.

#### **5.4.2 Six months-post training theme #2 – anxiety.**

Less than half of the participants described instances where they had experienced some anxiety whilst working with and managing their guide dog, while a more than half had reported experiencing a reduction in their anxiety, due to the presence of their guide dog. For



those who experienced an ease in their anxiety, it appeared that the presence of their guide dog, and their perceived confidence in the guide dog's skills were attributing factors. When Max was asked by the interviewer whether the stresses he reported in relation to his environment (i.e. pre-existing conflict with neighbors and other relationships in his life) were improved by the presence of his guide dog, Max responded adamantly "Oh, a hell of a lot!". Gwen reported feeling calmer, with reduced anxiety linked to a pre-existing mental health condition when recently travelling through an airport with her guide dog:

I have a bit of agoraphobia and I don't cope well with crowds... clearly people were coming just off a flight and there was just this wall of people coming at us and I stressed shall we say and I just didn't want to know about it and then I remembered I had Ginny and told her to find the steps and find the way and she just went through the crowd and thought oh yeah, this is good! This is why you go through the difficult bits because you get moments like this where it is so much worthwhile.

Less than half of the participants reported experiencing new feelings of anxiety since commencing their working relationship with their guide dog, due to negative behaviours demonstrated by the guide dog and how they managed these. Bill experienced some handling issues with his guide dog that created some anxieties for him and some second thoughts about continuing with the training. He states "Oh, struggling a bit... 75% of the time she was doing what she was supposed to do but another 25% she wasn't able, or she wouldn't do it... I had to go her way she wouldn't go mine". Bill explains that the handling issues meant he could not work his dog in the places he needed to go and this caused him anxiety; "I was stressing out as well because I couldn't take her where I wanted to go you know".

Not an uncommon theme that caused anxiety for guide dog owners is the feeling and emotional turmoil of deciding whether or not to return their guide dog. This is predominantly due to handling problems they are experiencing and difficulties in communicating those feelings with their GDMI. Gwen states “I think you don’t realise how much you’re taking on board until you’re sort of in it. I mean I had one occasion where I really didn’t think I could do it and really seriously considered sending her back”.

At the time where participants had been working with their guide dogs for six months following successful completion of their training, it is evident that a greater proportion (more than half) had experienced a reduction in anxiety due to the presence of their guide dog, than the small minority who had developed feelings of anxiety due to challenging behaviours exhibited by the guide dog. For some like Bob however, the solution was to return his guide dog for a period of time to reposition himself emotionally and physically so that he could have her back and gain the full benefit of her work.

#### **5.4.3 Six months-post training theme #3 – frustration.**

For some (less than half) of the participants, the apparently constant interaction with the public or even family who wanted to pat the dog, especially when this is an acknowledged refusal point when the guide dog is in harness was reported as a serious cause of frustration. Bob was very protective of his guide dog, a role he took very seriously:

As I said, I’m also very protective of her, which is my job I have to protect her because there are some people that are total numb nuts and they don’t understand that a working dog is exactly what it is, a working dog.

For some guide dog organisations, the utilisation of more unusual breeds for guide dog stock can also add to the difficulties guide dog owners experience in public. Public perception may well paint the guide dog as a particular breed of working dog such as the Labrador Retriever, Golden Retriever or German Shepherd, other breeds outside this mainstay may well be subject to scrutiny or in some cases, derision. Bob states he has sometimes become upset when people try to pat his guide dog:

Well a lot of people, because he is so cute, they want to pat him and then he gets all confused. And I have to say 'Excuse me, please do not touch this dog, this dog is working'. There should be something on his harness to say, DO NOT TOUCH. A lot of people do not realise that you can't pat a dog when he is in his harness. Even talk to him... That upsets me a little bit.

Strategies and interventions to manage unwarranted public attention of guide dogs who are working with their guide dog owners are an ongoing challenge for guide dog organisations to consider. If public awareness around how to interact with guide dogs and their owners could be improved, then this could potentially improve the emotional wellbeing and community access of guide dog owners in the future. Education programs offered by service providers have valuable reach in providing insight into the expectations of the public when interacting with a guide dog owner and their guide dog, and this messaging appears to resonate strongly with younger people and in particular school children (IGDF, 2011).

#### **5.4.4 Six months-post training theme #4 – security.**

For less than half of the participants, the sense of security in owning a guide dog was enough to recognise the emotional value of working with their guide dog. For Gwen the security of having a guide dog was important to her in order to plan for her eventual complete sight loss.

She illustrates, “I feel the dog is really coming at the right time, to sort of work together and get to know each other and trust each other maybe before I lose it completely”.

Todd states that he felt safe when his guide dog was in close proximity to him. He says “Yeah, he is either out here in the room close to us. But just having him near, I feel safe and confident he will do the right thing”. Security as a theme was not only relating to the role of the guide dog in negotiating the environment and performing tasks such as safe and effective road crossings, but also the presence of the guide dog as a dog offers some sense of comfort when travelling by themselves and often in areas unfamiliar to them. Interestingly, a by-product of having a guide dog appeared to be the ability to explore previously unfamiliar areas.

#### **5.4.5 Six months-post training theme #5 – confidence.**

Some (less than half) of the participants expressed feelings of confidence when they were travelling with their guide dog as well as confidence in the work and tasks the guide dog could undertake. In the training period of working with their guide dog, this experience was new and novel and for many, a justification in applying for their guide dog in the first place. Bill described a positive experience early in his training, when he went shopping with his carer, which he stated was due to the presence of the dog, which in turn increased his feelings of confidence being in what would often be for him a challenging environment, even with his carer:

Yesterday at the supermarket, my cleaning lady took me shopping because my sister was sick, and I was out of everything. That was the first time she had been in a supermarket with a dog and she said Fred behaved himself very well. I said find left, and he found his left and his right. He’s really good at that and finds the ramp.

Todd reported that his recognition of the guide dog's orientation and mobility skills give him confidence when travelling in more dynamic environments, which he previously would have been apprehensive about falling or tripping due to obstacles he was no longer able to see. As Todd explained "I have confidence that he'll be able to lead me where I need to go and around things".

From the experiences described by Todd and Bill, it is evident that the guide dog not only has the potential to increase feelings of confidence in the guide dog owner, but subsequently lead to increased access within the community, including more dynamic spaces, which in itself may lead to other emotional and physical wellbeing outcomes for the owner.

#### **5.4.6 Six months-post training theme #6 – independence.**

One participant reported having experienced an increased feeling of independence in the early stages of working with their guide dog. Gwen described how her life has changed and that "...there has been a lot more exercise, doing things independent travel which is all the reasons why I took her on board". She also recognised that some elements of her commute before having her guide dog were difficult and stressful "...but yeah I didn't think I could do all that travel etc alone with just a cane, and she's done eight flights with me now interstate and we've had no problems at all". It is evident that for Gwen, that feelings of independence had led to her perceived increase in self-efficacy and ease with several key areas in her life, including physical exercise and travel.

#### **5.4.7 Six months-post training theme #7 – protective.**

Protective is an emotional experience characterized by caring for and feeling nurturing of another living being. Although he recognised his guide dog as a highly skilled and capable

living being, Max reported feeling protective of his guide dog, and the extreme degree he was prepared to go in order to protect it. As Max reported:

I think I'm as protective of her as she is of me, I think that... but yes she's very very protective and I am as protective of her. Anybody comes anywhere near this dog or tries to hurt it, I will kill 'em. I got nothing to lose. I'll just bang... gone.

In Max's case, it was a mutually protective relationship that he perceived sharing with his guide dog. His compulsion to feel protective of his guide dog, were reported as relative to the fact he felt protected by his guide dog.

### **5.5 Twelve months post training with a guide dog**

Twelve months post qualification is a milestone for guide dog owners in their journey with their guide dog. The distance travelled between their training program, their six months review and their current position is measured in a number of contacts with the guide dog mobility instructor (GDMI) to provide what is termed post class support, and this point which is now called aftercare or routine follow up. The post class support is generally regarded as providing support to the new graduate guide dog owner on issues that are still seen as partnership establishment concerns (RSB, 2017). The twelve-month aftercare visit is generally considered to be supporting the established guide dog partnership and their activities, possibly adding new routes to destinations or working on public transport. Very much though, the marking of the rite of passage from new graduate guide dog owner to established guide dog owner. The provision of these services is mandated by The IGDF as part of the organisation's commitment to membership and is accredited every four years to ensure standards are met and maintained (IGDF, 2016).

For the guide dog owner, the twelve-month aftercare visit from their GDMI is an opportunity to reflect and consider how far they have come in this unique relationship. There are objectives that would have to have been met in terms of safety and working expectations set by the organisation through the GDMI and there would have been personal objectives and destinations set by the guide dog owner as part of a program agreement with the GDMI and guide dog organisation to ensure the partnership is sound and working well.

For many guide dog owners, this point in the working life with their guide dog is the precursor to how they should expect the next seven to eight years to unfold in terms of working expectations. The next major milestone being to prepare for retirement of the guide dog at approximately eight to nine years of age. This is of course if the plan is on track and there are no issues that need attention or that might negatively influence the success of the partnership necessitating early withdrawal of the guide dog and the ending of the partnership. Issues from either party such as health concerns, breakdown in the working relationship or life changes can all have a direct impact on the guide dog partnership from here on.

Guide dog owners often state that at this point in the relationship, they feel they have a deeper understanding of their guide dog and that their guide dog has a deeper understanding of them (Whitmarsh, 2005). There is a bond now that is stronger based on shared experience, often more than one event that could have been perceived as dangerous where the guide dog has made a good decision and protected the guide dog owner and where the personality of the guide dog has shone through and endeared itself to the guide dog owner, or not.

#### **5.5.1 Twelve months-post training theme #1 – security.**

For all of the participants, the emotional state of feeling safe in the presence of their guide dog, and secure in its working capabilities was a strong influence in measuring their success

12 months on from qualification. Max stated the following with respect to the difference he now felt when making road crossings with his guide dog:

I repeat this until such time that he can safely make the crossing; it's amazing! I don't always try and test her to see if this will work, but when we need to, I know I can make this crossing; together we can do this safely.

Bill also reported how feeling more secure in his daily life was a key component in working with his guide dog:

I think, well I'm going to lose my sight one day, but I don't know when. Or, I could fall over and knock myself out on the footpath, and she gets away from me, but she'll know exactly where to go to get home. This is why her company and her help... it's marvellous.

With feelings of being safe and secure, comes the necessity to build trust that the guide dog is capable of doing the role it has been trained for, and also trust the guide dog owner will invest in that relationship to bring out it's potential. As Gwen states, this sometimes takes a significant event or experience to cement that feeling of being safe:

Yeah, I think with everything you do that's a significant moment, like the first time you go in an aeroplane or a catamaran, or the first time she doesn't step out when I ask her to and then a car goes whizzing past, the first time she doesn't slam you into a wall you believe is there but quite obviously not... All those things obviously build that trust.



Gwen also highlighted an integral aspect of having a guide dog in terms of the ripple effect of being safe. That family and friends have the emotional need to be confident in the guide dog's abilities to keep their loved ones safe as well. As Gwen states:

I know that if I leave the house, I can come home safe, and I think that is the thing for Kevin as well, that since Ginny has come on board, he feels much better about me going out and doing what I do, because he knows I have Ginny and we get each other out of trouble! It goes both ways, so he feels much better about that as well, which is important.

The bond between guide dog owner and guide dog is pivotal to the relationship, and fundamental to that relationship is feeling safe and secure in the skills and capabilities of the guide dog. Skills and capabilities of the guide dog that may increase feelings of security on the guide dog owner include the ability to avoid danger such as traffic, and also to problem solve when there is threat and to work in partnership with the guide dog owner to find safe solutions. This can be simulated to some degree in training but is reinforced in the day to day world of travelling without sight. All participants reported feeling a degree of this safe, secure working relationship with their guide dog at 12 months post qualification.

#### **5.5.2 Twelve months-post training theme #2 – confidence.**

At 12 months on from qualification, almost all of the participants felt they had increased confidence in working with their guide dog and were confident in exploring environments that prior to having their guide dog they may have been reluctant or hesitant to tackle. For some participants, finding home was a measure of the confidence they had in their abilities and their guide dog. Todd illustrated this in reporting:

Definitely a lot more confident. During the day, I can see quite a bit, especially if its good light then I can see most objects like trees and things. If I was walking home from the shops say, and it was getting dark, I can say to Vince 'find home' and he'll just continue walking, and he will find the way to our house; he knows which driveway to turn into, even without me telling him 'find left' or 'find right'. I find being out and about with him, I feel confident in his ability to guide me where I need to go.

Services such as public transport for Bob were a daunting prospect but necessary for him to meet commitments relating to his health. He had to work on building his confidence and skills, and recognising that his guide dog, once instructed as to how to board, became a very capable bus traveller. As Bob reported:

It took me a while to get used to getting him on to the bus. Because he will find the step and then wait for me. I then find the step and get up near the bus driver, I then let go of the handle, hold him on the leash and tell him 'behind'. This is because there's not enough room between the seats. I then tell him 'find a seat', but the trouble is he finds a seat with somebody sitting on it! (Laughs). It took me a lot of practice to get confidence with this; (instructor's name) took me a couple of times on the bus, and eventually I went by myself. I got the confidence now, but it took a fair while to get used to that.

Stan felt that the presence of his guide dog gave him confidence in busy environments as he could move through them safely and efficiently with some socially cognisant onus on the people around him to make room for him and his guide dog. Stan states:

I think where I really noticed the benefit was when I could walk down the mall or into Myers or something with the dog, and it was like Moses parting the Red Sea! I thought this is where the use really comes in; people see a fairly large guy with a fairly large dog, and they just step aside. He helps me so much in that way, I had confidence to get around. You have to know where you are going, but the dog makes it possible.

Gwen acknowledged that with increased confidence for her came improved self-esteem, and that everyday challenges she would have previously avoided, were now perceived as surmountable. Gwen comments about her confidence “Yeah, a lot better. I think because you feel capable of doing stuff and confident that your self-esteem goes up and all those good endorphins get released and what have you”.

For one of the participants, working with their guide dog had improved their confidence with social interaction out in the community. As Todd illustrates:

I’m out, people have asked me questions and I’ve become more comfortable chatting with people and being more social. Normally, if I was out and about, I wouldn’t just go up to someone, but if they come up and talk to me about Vince, then I will have a chat.

Having increased feelings of confidence since the commencement of working with their guide dog was reported by the majority of participants as a key factor in measuring the working capacity and success this provided for them, as a primary mobility aid. For some, these feelings of increased confidence opened up new opportunities and environments for them that previously would have created anxiety or been avoided all together.

### **5.5.3 Twelve months-post training theme #3 – companionship.**

For almost all participants, the relationship with their guide dog had created a strong bond and feelings of companionship that now saw their guide dog as very much an integral part of their lives. Max observed this phenomenon by explaining how he applied for a guide dog following a conversation with his doctor:

He then responded by asking if I had thought about a guide dog? I said ‘well, yes I have!’ He then explained he would write the letter; he didn’t need to but he was very supportive of me having a guide dog, not just because of the support this would give my mobility; but for the companionship the dog would provide as well. This has been excellent; probably the best part of having the dog is the companionship.

Gwen states she has an inseparable bond with her guide dog. This transcended a number of levels whereby giving her dog characteristics that would be attributed to humans, such as the right of reply to some of the questions she asks of her dog, she attributed human behaviours, language, speech and responses to her guide dog’s interaction with her. Gwen demonstrated this as she reports:

We’ve bonded; she’s going nowhere! There’s a thing I read when I was doing my dissertation for my Honours year on sympathetic trust. It talks about kids, but I see this happening with Ginny and me as well, sympathetic trust is all about having this connection with each other where basically you are infected with every nuance and move and idiosyncrasy, so you feel that you are actually joined at the hip, like you share some sort of skin together in some ways. It is probably one of the strongest bonds I’ve ever had, with her.

Gwen also illustrates another aspect of the emotional connection with a guide dog in so much that it was a shared experience and other members of the family or extended circle of friends also had a bond with the guide dog that was real and measurable. This extended bond was often influential and a consideration in the success of a partnership between the guide dog and guide dog owner. Gwen explains:

I didn't go to Wollongong recently when Kevin went to visit his father, and I said hello on the phone and I asked 'are you missing me?' and he said 'no, I want the dog to be here!' I went, thanks a lot! I'll put her on the plane tomorrow for you then will I? So everybody has just taken her onboard and um, deal with her, she's become a part of the family.

Developing a bond with their guide dog was a milestone in the early part of the participant's training, in part to connect them with their guide dog but also to set the tempo for the working relationship. The rationale for this is so that the guide dog owner and guide dog are reliant on each other at various times in the mobility journey which spills over into everyday life with their guide dog.

#### **5.5.4 Twelve months-post training theme #4 – motivation.**

More than half of the participants also noted in explaining their emotional connection with their guide dog and some of the feelings of wellbeing are due to an increased activity in their lifestyle and a sense of improved health. These participants described these increased feelings of motivation toward leading an active lifestyle were due to the presence of the guide dog, and the need to exercise it as well as travel to more destinations than they might have prior to having the guide dog. Bob explains one of the motivating factors he felt enthused about

working with his guide dog was to increase his fitness and hopefully this would lead a more active lifestyle:

That's why it's great working with a guide dog; it keeps your mind and body more active, compared to if you didn't have one. It's the difference between getting out and catching a bus or going to the shops, rather than just staying home.

Gwen also agrees that having her guide dog has changed her lifestyle pattern for the better, as she reports:

She certainly has changed my exercise regime, to say the least! I'm a lot healthier physically. Emotionally, I just feel a lot more stable. I have a history of endogenous depression, and I have PTSD and none of that has flared up at all, even with being sick.

There is an element of fitness that is necessary to undertake a guide dog training program and for some of the participants this part of the training was arduous and tiring. 12 months further on, the motivation to develop and maintain a level of fitness was present and necessary for meeting the needs of their guide dog but also improved their independence and mobility.

#### **5.5.5 Twelve months-post training theme #5 – frustration.**

Frustration continued to be a common theme throughout the participant's life, encountering numerous challenges and barriers due to their blindness and vision impairment, as well as difficult life experiences. Half of all participants reported experiencing feelings of frustration as a result of interactions and responses from the public perceived as negative, due to the presence of their guide dog. Examples of the way members of the public may respond to a

guide dog which is perceived as negative by the guide dog owner may include instances of active discrimination such as refusal to enter a restaurant or taxi with their guide dog present, or unwanted questioning of a personal nature when present with a guide dog. This experience of being under scrutiny and observable based on the presence of a guide dog, which was conversely an aid to overcome limitations of the disability, was one that Gwen stated created a dichotomy for her. The feelings of freedom and independence countered by the increased spotlight she finds herself under in public can detract from the pleasure of owning a guide dog. Gwen stated that her frustration was very real:

Yeah, on occasion. If you've had a long day, like anybody, sometimes the last thing you want is another conversation or another *'yes, I've had her for 12 months, yes she's 3 years old, yes she's a Labrador'*, and you've said it 40,000 times and you just don't want to do it another time. Quite often people will think that it's your role as well, rather than asking if they can have a talk, they will just launch straight into it. That's why sometimes on the trains, trams and busses I will put the earplugs in even if I'm not listening to anything. But, I have had people come along and pull the ear bud out of my ear and say *'can I ask you a question?'* I say *'um, I'm in the middle of something and...'* They reply *'Oh, but I just want to ask you something...'* So, there is a lack of boundaries sometimes with people, um, so you have to be really mindful of that".

Gwen also experienced frustration when people do not respect her request to not touch her guide dog:

Often other people will ask *'well why can't you?'* I say *'well, it's a bit like driving a car and text messaging at the same time'*. If she's got a choice of not concentrating on not

slamming me into a pole or not pulling me down a flight of stairs, or concentrating on the pat, if I was her I'd be concentrating on the pat. So that's how I often explain that one. I think that's what you have to come up with, is these analogies, because I had a guy who once brought a little white dog along and Ginny went a bit silly because little white dogs are her weakness, and he said *'isn't she trained not to do that?'* I said well, are married men trained not to look at other women?' Then his partner came out and he didn't say anything else! So, you have to have this stock station of things!

Gwen also commented on her experience in another city she was visiting and trying to get a taxi, Gwen states; "Melbourne was my worst experience with discrimination. Um, two taxis and an IGA (Supermarket chain) wouldn't accept us in there. So, you've got that barrier as well, and I was too tired to deal with it".

Todd reported frustration in circumstances where people had interacted with his guide dog, which presented a distraction while it was supposed to be working. As Todd described:

Oh yeah. Depending on how congested it is on the bus. Even with people on a bus, they will either try and pat him on the way through or say hello and he can get a bit distracted; that's a bit challenging.

Feelings of frustration for the participants had several triggers. As they increased their independence and mobility the opportunity to interact with the public is increased and with that increase is the potential for more frustration from people not respecting their work with their guide dog, or more worryingly active discrimination by public transport operators such as taxis not letting them in the taxi because they have their guide dog with them. In many countries there are education programs for public transport drivers and operators to



demonstrate the public access rights of guide dog owners including their use of taxis and other forms of public transport. For guide dog owners to assimilate into the concept and participation in a universal access to public transport, global education programs for drivers and operators needs to be mandatory and in situ to ensure compliance and commitment to access for all. (Almon, 2001)

One of the participants felt that there was a poor public awareness of people who were blind or vision impaired and even though blindness organisations provided a lot of education there was still a gap in knowledge and understanding. As Bob reports:

One day, I was out with the cane and a young chap was walking in front of me; zigzagging all over the place, trying to be funny. I don't think he knew I had a bit of sight, so I swiped the cane out in front of me and tripped him up. 'Oh, sorry I didn't see you!' I said to him. People can be a nuisance sometimes like that; just a bit cheeky thinking that he can zigzag in front of me, that I'm a blind man and can't see him. People seem to think that if you're blind, then you can't see anything.

One of the participants reported ongoing feelings of frustration with life daily, which had commenced prior to receiving their guide dog and almost entirely due to the limitations they had because of their vision impairment or blindness. Bob reports his frustration as he recalls meaningful daily activities he was once able to complete independently, but is now unable due to his degree of vision impairment:

Yes, exactly! It makes it hard to live with I can tell you that! Especially because I wasn't born like that, so it wasn't always that bad. I used to drive a car, I was a

machinist, and I was a press-operator and dye-setter. I could find the measurements; I could still see them with my glasses.

Participants' daily battle with their vision impairment or blindness creates feelings of frustration for them and complexities and hardship in performing sometimes the simplest of tasks such as putting a key in a lock or finding the right bus. The relief experienced in working with their guide dog on known routes to established destinations for some was a reduction in this frustration and anxiety, and in some respects, recaptured and recovered some of the feelings of loss and disempowerment experienced when their sight began to deteriorate. For Bob, the ability to travel independently with his guide dog was a pivotal moment in his acceptance of his vision impairment and addressed some of the frustrations he had previously experienced.

#### **5.5.6 Twelve months-post training theme #6 – acceptance (by others).**

There are many factors to be considered for guide dog owners when interacting with the public. The inability to see people's face and gauge facial responses makes this interaction often complex and difficult. For half of the participants, they felt more accepted, welcomed and at ease in the presence of others, when accompanied by their guide dog. Max illustrated how he felt others had a greater awareness of his vision impairment and were more willing to offer him assistance, since he had begun taking his guide dog on community outings:

It's comforting to know that people are a little more cognisant of my vision because I've got the dog in harness and as I said, I went to Smith Street the other day which entailed catching five buses. These all involved walking to different places getting off at one location and getting on at another. Bless them, I got a little confused, and its usually ladies, bless them, that came up and ask what bus I wanted to catch.

Gwen described one instance involving an individual in her workplace, whose cultural beliefs presented a challenge to accepting her with her guide dog. However, Gwen described a positive outcome being achieved whereby approaching the situation with a degree of cultural sensitivity led to a mutual appreciation and respect for one another, and ultimately feeling accepted by this colleague. As Gwen describes:

We've had a couple of cultural clashes in there, but we've got around that now so that's ok. You just need to be aware of it, particularly with the Islamic students, but I talked with one student who has just started their PhD there and he said that he understands the rules and regulations, and we occasionally have a coffee now. You just have to be respectful of that.

Half of the participants felt that having a guide dog offered opportunity for greater acceptance by members of the public, when compared to how they felt the public responded when utilising other mobility aids in the community, such as the long cane. It was perceived that having the guide dog also created neutral ground on which they could share conversation and build a social conduit, creating the chance to educate but also to seek or be offered assistance without discomfort for either the member of the public or the guide dog owner.

#### **5.5.7 Twelve months-post training theme #7 – independence.**

Half of the participants felt that having their guide dog with them increased their sense of independence and the freedoms that accompany that independence. This included being able to travel, negotiate the environment, and plan or make decisions about where they wanted to go without involving anyone else.

Stan describes his feeling of independence as he reported “oh absolutely! ...in town, as soon as you step off the bus it’s like, it enabled you to do what you needed to do and be independent”. Bob stated that his newfound independence meant he had an opportunity to do things the way he wanted to “... makes me happier that I have something I can rely on. I feel I have a way forward and do the things I want to do”. Todd’s experience of feeling more independent appeared to correlate also with increased feelings of confidence, as he reported:

Definitely, when I’m going out an about by myself; If I’ve got Fred with me then I feel more confident and more independent in that way. I know that if there are things I can’t see, then I’ll be ok with him.

Independence is a term much used in the guide dog industry and is generally related to the ability to travel and have independent mobility, however the measurement of independence for these participants goes beyond this definition. Indeed, it extends into areas where they have gained or regained control of some aspects of their lives that not having vision has made difficult and, in some cases, impossible without their guide dog.

#### **5.5.8 Twelve months-post training theme #8 – anxiety.**

By 12 months-post the successful completion of training with their guide dog, participants reported situations where they had felt both a reduction and an increase in their anxiety levels, due to different circumstances relevant to the working relationship with their guide dog. For half of the participants, the reduction of anxiety in working with and simply being close to their guide dog was a benefit that was measurable. The underlying need to have their guide dog was reflected by Bill who had an epiphany when one day he was stressed when his vision failed him and he was using his cane and states “From that day on, I thought ‘great!’

It's only the odd day now that I say '*I'm not going to take Ruby with me*', but then my eyes play-up! So I can't do without her".

Bob states that his guide dog made clear and accurate decisions when he needed them in relations to directions and this in turn reduces the anxiety he experiences when he is away from home. Bob comments that:

Oh yeah, because he can find 'left' better than my sister can! She will tell me to go left and then says 'no! Your other left!' Not with Fred, as so as I tell him to 'go left', off he goes! He's really good with directions.

Gwen reported that because her vision is unpredictable and can give her false readings that having her guide dog forge ahead in environments where this happens reduces her anxiety. Gwen states:

One of the great glories of my eyesight these days is that if I'm in a shopping centre where they have tiles or patterns on the floor, like the city arcade, um, that rises up and becomes a vertical wall sometimes, so I feel like I'm going to slam into that, and that's where I rely a lot on Ginny these days, because if she doesn't slow down, then I know there's not a wall there, although I do feel like I'm going to walk into one someday!

Half of the participant group reported they felt an increase in their anxiety at times due to concerns about the impact of difficult behaviours demonstrated by their guide dog. The anxiety and stress reported could be relative to trying to resolve the behaviour or the

perceptions of others about their ability to handle and work with their guide dog. Max recalls how he felt when his guide dog began refusing to move forward on request:

I thought she had a problem like hip-dysplasia or something because she didn't want to move. Anyway, (instructor's name) wasn't available, so they had (other instructor's name) come out and I took him for a walk with us, and Ginny would stop at various places. He just put it down to 'bloody mindedness!' I was being a bit too easy with her, and she was stretching from time to time, giving indications that she didn't want to move, and I thought this meant pain. Nothing to do with pain!... Anyway, we've gotten over that, I just needed to be more assertive, for want of a better word I was just too gentle with her.

Gwen also had problems with the working ethos of her guide dog in the first twelve months:

I think I went to (instructor's name) with a 'shopping list' at one stage with some things that weren't going right! We then worked through them one at a time and came up with a different method for going down steps, because she was really pulling me, and I felt I was going to go head-over-heels down the steps. Now, we go down steps with no issue, so that's fine! We just use the 'Ginny technique' instead of the 'guide dog technique!'

Gwen also raised an interesting observation that some of her guide dog's anti-social behaviour was a cause for her anxiety. This is behaviour that occurs when the dog is not in harness and technically "not working". Gwen stated:

One of the big problems when I was in Cairns last year, is that every time someone would walk past my door she would bark! Scared the bejeezus out of everyone, including the room service lady with a glass of wine! So we have a technique for that now, if she barks we've got this room that is the 'dog house', she goes in there and has to have a 'time-out'. In hotel rooms, she goes in the bathroom. She knows pretty quickly, you only have to do it a couple of times before she knows *'oh that's right, I'm not supposed to bark!'*

Todd had similar experience of social behaviour becoming an issue for his guide dog that needed attention, as he reported:

Oh yeah definitely. I suppose too with all Labradors that they are sort of like rubbish bins in a way! If they see a food, they will just go for it! I've noticed when the kids used to go outside, he would go up and try to take food from them. Especially little Mary; because she's so tiny, she's not the sort to put her hand up and keep the food away. Vince would go up and sort of just take it, but then she'll get upset! I've noticed more recently that when she has food near him; he may go up to her, but he doesn't really take it off her.

Half of all participants reported that negative working behaviours in their guide dogs created stress and anxiety and needed to be addressed with the GDMI to find solutions as quickly as possible. However poor social behaviours such as barking or scavenging for food also was unwanted and created anxiety. The first 12 months of guide dog ownership saw these issues and concerns materialise and require intervention. Once resolved there is a sense of return to status quo and accomplishment in fixing the problem. Moreover, anxiety had a direct impact on the efficiency of working with a guide dog and for the participants who were able to

reduce their anxiety through the performance and relationship with their guide dog the effect was tangible to them.

#### **5.5.9 Twelve months-post training theme #9 – depression.**

Less than half of the participants felt that having their guide dog had led to a reduction in their feelings of depression. This reduction was due to the feelings associated with success in completing their training and also revelling in the working capabilities and relationship they had now developed 12 months post qualification with their guide dog.

Gwen commented that her guide dog has the role of a “therapist” on occasion, and this reduces her feelings of depression by allowing her to refocus. Gwen states:

...so there's that side of it too, that companion when you are out and about. And she's a counsellor; she's good at listening. Then she will lie down and groan and go '*oh, I've heard this all before! I don't get paid \$150 an hour for this*' she says! She just likes to be loved, you know, and she earns it.

Less than half of the participants felt that their guide dog had a positive influence on the previous depressive state. These participants reported how owning a guide dog was in part a catalyst for the change in feelings they were experiencing to the positive, due to the strength of the relationship, the bond established between them and the freedom of mobility owning a guide dog offered them.

Although a small percentage (less than half) of the participants reported a reduction in depressive emotions, with no continuation of symptoms experienced since working with their guide dog, continuing and ongoing feelings of depression was an experience reported by one



of the participants. For Bob, this was discussed in relation to his sight loss, and in particular with relation to his functional vision, meaning his ability to see with the residual vision he had left. Bob's reported depression and frustration in relation to not having enjoyment from watching television, something he longed to do, demonstrated how there are some areas of a guide dog owner's life that the guide dog is not able to have impact on. Bob illustrated this as he reported:

Oh, just over a year ago. At night, it gets very quiet and boring here, I can't watch TV much. I bought a big 57-inch plasma; but I can only see a bit of movement and that's it! I thought I might be able to see the bigger screen; that this might help. I like watching the garden programs, and they say things like 'what a beautiful flower!' I thought, 'I just wish I could see that!' You do get depressed a bit; wondering 'why can't I see that now?'

For many years in the guide dog field, total blindness was the prerequisite for application for a guide dog. The presence of residual and functional vision can be, for some applicants, a useful legacy of their sight loss to assist in working with their guide dog and serve as a parameter of consideration for the matching of them with a particular guide dog.

Nevertheless, there are some life experiences that are permanently lost or changed once a person loses their sight, something that the introduction of a guide dog is unable to address. For some, this ongoing loss of meaningful experiences manifests in feelings of depression and low affect due to the parameters of their life that remain permanently changed due to blindness or vision impairment.

### **5.5.10 Twelve months-post training theme #10 – enjoyment.**

Less than half of the participants reported having experienced an increase in social interaction since commencing work with their guide dog, and how this gave them feelings of pleasure and enjoyment.

Todd reported having made friends with a volunteer of the RSB who assisted him with transport during his guide dog training. This friend invited Todd to a regular quiz evening, where Todd proceeded to develop a whole network of friendships. As Todd explains, he had enjoyed this experience of developing a new social network:

Before the training, I just took life like normal. But, when the training happened, because it was all the way up at the city, I had to be picked up early. That's actually how I met one of my friends; you know how I said before how I go to quiz? Well, that person that I met during training first brought me along to quiz; he would pick me up a couple of days during the week and then drop me home again. He and I were talking, and he mentioned this quiz stuff to me, and I was very interested. He lives nearby... He mentioned the quiz and I said, 'I'd love to go to that!' Ever since then, we've become best friends! He was one of the volunteers, and you know I've met his friends and I've come to have more of a social life outside of home and that now, because of that whole guide dog thing.

Stan makes note of how he enjoys the way he has experienced his guide dog as a social conduit and attractor of the opposite sex to conversations with him. As Stan conveyed:

The dog would be a conversation starter. You would get onto the bus; if ever you were looking to 'pick-up', the dog would have been just fantastic for that! The

number of females that started conversations with me because they wanted to talk about the dog! So yeah, and these were people I didn't know.

For some participants (less than half), they relished the opportunity to engage with people in the relative safety of conversations about their guide dog, including their appearance, skills and working partnership with the owner. For half of the participants, it was reported that this increased interaction with people in the community can be a cause of frustration, especially if the interaction with others is perceived as unwanted or uninvited. As was addressed in section 5.5.5, some of these frustrations were due to members of the public overstepping the cordial conversation with participants to seize the opportunity to try and touch the guide dog, necessitating being told not to by the guide dog owner. In other instances, the frustration was relative to the frequency social contacts in a day that can impede progress and make them run late.

#### **5.5.11 Twelve months-post training theme #11 – comfort.**

For a small number of the participants (less than half), a definite preference in being identified as blind or vision impaired by the presence of their guide dog rather than their long cane was reported. This was due to their greater feelings of comfort in the connotations that the label of a guide dog had for them.

Both Todd and Stan very clearly defined feelings of embarrassment that accompanied their mobility using the long cane that was not evident when they worked with his guide dog. As Todd reflected:

I did train with a cane; I probably should have used it more, but I think with that I felt quite embarrassed. You know, everyone is looking at you, but with Vince, I can walk

him and I won't feel embarrassed, because you know lots of people love dogs, and then you get praised more than 'deadly stares', you know what I mean?

Stan reported feeling comfortable with the label of a guide dog, and that pride caused him to view the long cane in a negative way. As Stan explains:

I've got a cane, but I'm probably too proud to use it! I have to admit that, I know pride is a failing, but yeah, basically if you have a cane or a dog, you're hanging a big sign on yourself saying 'I'm blind'. Now, I don't mind that, because people tend to help you if they know it. If they don't know you're blind and you just bump into them they just think 'what's wrong with that person?' But, I could deal much better if that sign was a dog rather than a cane.

Using the long cane is often the precursor to training with a guide dog, so most guide dog owners will have some experience in using both and may subsequently reflect on the differences both mobility aids offer. For less than half of the participants in this study, the difference was the chasm between appearing vulnerable and exposed due to their sight loss and the safety and comfort experienced using a guide dog. The long cane may be described as an obstacle detection device in so much it is designed to give you feedback by contact with the environment. The guide dog is trained, where possible to avoid obstacles and negotiate the environment without collision or contact with it.

#### **5.5.12 Twelve months-post training theme #12 – trust.**

Some of the participants in this study felt there was feelings of trust that now existed between themselves and their guide dog, by the time they had been working with their guide dog for 12 months following completion of their training program. These participants felt this was

part of the working relationship, but also part of the broader relationships based on companionship and friendship and extending into the lives of the people around them who saw the participant and their guide dog as together. Bob explains his feelings of trust toward his guide dog in the way he is trained to keep him safe in manoeuvring through the environment avoiding obstacles that Bob could not see and creating a working partnership based on trust to continue avoiding these hazards:

Oh yeah, because when I'm out walking with Fred, and we are coming up to some big overhanging branches, I will tell Fred to 'find the way'. He then guides me around the branches, so I won't get hurt. He could get underneath it, but I can't, and he knows this.

Gwen commented that her relationship with her guide dog is built on trust:

Yeah, I think with everything you do that's a significant moment, like the first time you go in an aeroplane or a catamaran, or the first time she doesn't step out when I ask her to and then a car goes whizzing past, the first time she doesn't slam you into a wall you believe is there but quite obviously not... All those things obviously build that trust.

Less than half of the participants noted that trust was an important component of their relationship with their guide dog and that trust came in many forms. The trust formed from the guide dog keeping the guide dog owner safe, trust in finding destinations, trust in forming bonds and sometimes trust established from the shared experience and history between them.

### **5.5.13 Twelve months-post training theme #13 – empathy.**

It was reported that guide dog ownership had resulted in an increase in feelings of empathy for less than half of the participants in the study. For guide dog owners like Max, he felt that the shift within himself was one of improvement, He felt that creating an environment where he had to meet the emotional and physical needs of his guide dog had enabled him to open his thinking to understand and share experiences of others, as he reported “you’re not going to believe this, because everything I’ve said is contrary. I’m not quite so self-centred as I used to be! Because now I have somebody else to think about”.

Gwen acknowledges her concerns for the impact it would have on her guide dog’s happiness and wellbeing in the case she was no longer able to work, as she reports “So I can’t really imagine her not being a guide dog, that’s probably part of it too, is letting her down in that regard”.

It can be postulated that along with an intense bond, a relationship based on companionship and shared work and pleasure experiences that some level of empathy with the guide dog is inevitable for a number of guide dog owners. For less than half of the participants in this study, they were able to demonstrate insight into the thoughts and feelings they had about their guide dog and identify how an increase in feelings of empathy was something they welcomed as a positive change in their lives.

### **5.5.14 Twelve months-post training theme #14 – acceptance (of self).**

The small number of participants (less than half) that reported feelings of acceptance regarding their level of vision impairment, also expressed a belief that the relationship they were creating with their guide dog would augment the sight loss and still allow them a level of independence with what they felt was a well-established relationship. Todd went so far as

to recognise his feelings of acceptance regarding his continually deteriorating sight as a motivator to apply for guide dog mobility. Todd recognised the benefit of obtaining a guide dog prior to losing his vision altogether, as he reported:

I suppose, well who knows when my sight is going to deteriorate more? So I thought if I get used to a guide dog now, and he gets used to me now, then it's going to be easier down the track. When I did training with him, one of the other guys with me had worse sight than I did. I asked (instructor's name) 'I wonder how people go with no sight at all, trying to get used to the guide dog?' I thought that if I waited that long, it would have been more of a challenge.

Todd's feelings of acceptance regarding his degenerative vision impairment was also evident in the way he expressed his intention to meet some of his life goals before he inevitably loses his sight completely. Todd comments,

As far as objects and things like that in general. I mean, doctors say that I've got less than 20% left. But I'm still just trying to do as much as I can before it goes, it's just hard to say when that is going to be; it could be any time. It could be another 20 years, who knows?

For some, the difficulty in accepting vision impairment was what can only be described as PTSD type symptoms where the experience at each phase of progressive sight loss triggers a response to the trauma of the original feelings associated with the initial loss of vision. As many people with vision impairment or who eventually become blind find, there is a "death by a thousand cuts" phenomenon of gradual sight loss that takes its toll on the journey. For a smaller proportion (less than half) of the participants in this study however, feelings of

acceptance toward their vision impairment appeared to have played a part in their decision to apply for guide dog mobility, as they responded proactively to achieve greater independence in experiencing loss of a fundamental sensory modality.

#### **5.5.15 Twelve months-post training theme #15 –protective.**

The guide dog is not trained to be protective of the owner in other than reducing risk, such as making road crossings. Interestingly, a small proportion of participants in this study (less than half) reported feelings of protectiveness toward their guide dog, based on an acknowledgement that the guide dog had needs and vulnerabilities which they as a guide dog owner committed and served to address. Max explains his feelings of protectiveness relating to a sense of being needed by his guide dog. Max describes “yeah, it makes me feel as though I’m ‘needed’, if that’s the right word? You know, she can’t feed or care for herself; she needs me to do that”.

Gwen also recognised these protective feelings and based it on the recognition that her guide dog was an animal, which carried with it a degree of vulnerability and a degree of responsibility toward this animal. As Gwen explains:

She (guide dog) can’t speak as such, so therefore my job is also to protect her and to figure out what she needs, so there’s this interdependence between us. She’s got her ways of letting me know what she needs, and she’s able to communicate and she’s a very good self-advocate; I just have to figure out the language!

The bond between guide dog owner and guide dog can vary in its intensity based on the foundations and strength of the emotional connection. For some guide dog owners, the relationship is a working one and can seem to the observer as perfunctory. For some guide



dog owner's, the relationship is deeply loving, mutually protective and very much a partnership beyond the working expectations.

#### **5.5.16 Twelve months-post training theme #16 – gratitude.**

For some guide dog owners, there is an overwhelming sense of gratitude to the organisation and those who have been involved in caring for and training their guide dog in the early days. Less than half of the participants explained that they had their feelings of gratitude toward the service provider and their staff for receiving a guide dog to work with. Bob expressed his gratitude in recognising the efforts of his GDMI and volunteers who supported the training and raising of his guide dog. As Bob explains:

I think it would be a lot of work for (instructor's name) and the other instructors; to teach the dogs these things. It's amazing! I think it would be very hard for the puppy workers to give the dogs back to RSB after training them”.

Stan explained feelings of gratitude for the guide dog he received from the RSB, especially as his friends admired this skilled, beautiful animal he had been allocated to work with. As Stan describes “I was lucky to be given this big, beautiful dog! I'd take him over to the pub, and we'd take him to the footy, we watch a bit of the footy over at Mount Barker, so we'd take the dog”. The multiple facets of gratitude elicit different feelings for the participants and for some who engage with their training organisation in such activities as public speaking or fundraising, there is a feeling of contributing to the process and the financial cost that is both rewarding and an expression of gratitude.

**5.5.17 Twelve months-post training theme #17 – accomplishment.**

It is an arbitrary milestone in the life of a guide dog partnership when 12 months post qualification is reached. There is the feeling of no longer being a novice guide dog owner and the feelings that there is a bond and clear understanding of the workings and intricacies of the partnership. Some guide dog owners will however testify that just when they feel they have a routine and what they feel is a handle on the dynamics, the guide dog can, without notice throw that theory and confidence into disarray with one or more changes to the status quo. For a small proportion (less than half) of the participants in this study, they expressed feelings of accomplishment as they acknowledged having completed training and their first year of working with their guide dog. When Bob was asked if he would reapply and train with a successor dog, he reported “yes, I certainly would. The outcome has been worthwhile; the hard work was worth it”.

Gwen remarks that her journey was not altogether smooth towards guide dog mobility but that with perseverance she had accomplished her goals and been able to set new ones, one year on from qualification. Gwen acknowledged these feelings of accomplishment were significant in her experience of guide dog mobility, so much so that she would recommend the journey to anyone who has a vision impairment or who is blind who is contemplating application. Gwen explains:

Then again, I wouldn't have got Ginny, and when it all happened, it happened really fast which was probably good. I think that for me worked, that 'rollercoaster ride', because you didn't really have time to think about what you were doing until you had done it. I think those info sessions are good, I know a couple of people who are contemplating going through that, and I would encourage them to go.... To hear that it's not easy, it's a lot of hard work that first 12 months, and I've had a lot of guide

dog handlers tell me the first 12 months can be hell. I would agree! It is a hellish journey, but in that time, there are moments that you get that just reinforce that the decision is right.

Gwen also notes that the accomplishment of succeeding to 12 months post qualification had been a journey for both her and her guide dog, and that without the two of them working together, this milestone may never have been reached. Gwen states,

Yes, it's probably a big thing for me because 3 months after I got her I really contemplated that I couldn't do it. I really thought would I have to give her back. I really just couldn't handle some stuff that was going on with her, and I talked with (instructor's name) and I talked through a few things and sorted it out, and it gave me a bigger understanding of Ginny and how she works and how I need to work with that rather than against that. Since then it's like *'you're not having her back! Just not going to happen!'* And it's probably what has motivated me in the last 12 months or so. I really work hard with her, to bring her right up to that top level of being a guide dog with me, so that we weren't at risk. We've educated each other, she's told me a few times that she knows how to do things that I never knew she knew how to do, like finding the fridge in the supermarket, and I never knew she could do that".

Some guide dog owners feel that 12 months post-training with their guide dog is a milestone, and some say that it is the end of the "honeymoon period" of the relationship. This signals that issues and concerns have been addressed and resolved as well as patterns and expectations of performance established, such as route destinations, social behaviour and working protocols. There is generally within this year, periods of adjustment and challenge where guide dog owner and guide dog create a working platform based on a bond, training

and skills development. There are some partnerships that do not stand the test of this arbitrary time frame and for those guide dog owners this can leave feelings of failure and disappointment that may see them not apply for another guide dog in the future.

#### **5.5.18 Twelve months-post training theme #18 – happiness.**

Feelings of increased happiness since acquiring and working with their guide dog was reported by one of the participants. Specific reasons were explained across a number of areas, however Bob emphasised how the dependability of his guide dog was a key attributing factor to his increased happiness. Bob explains this as he describes “I reckon it has; makes me happier that I have something I can rely on. I feel I have a way forward and do the things I want to do”. The increased feelings of happiness experienced by Bob was solely due to the relationship he was sharing with his guide dog, and the work that the guide dog consistently carried out to keep him safe, allowing Bob to enjoy his mobility and independence.

### **5.6 Summary**

The thematic analysis undertaken in chapter five has delved into the lived experiences of the participants across the key milestones of applying for, training and working with a guide dog at six months and twelve months after their qualification. For some of the participants, the application process was a crucial moment in identifying themselves as a person with a vision impairment or who was blind as the preliminary work in applying and training with a guide dog marks the participant, due to the iconic and functional nature of the guide dog as a person who is blind or vision impaired. Many of the emotional experiences that participants reported at the application stage were indeed factors which motivated or contributed to the decision of applying for guide dog mobility, some of which were impacting negatively on the participant’s emotional and physical wellbeing (e.g. frustration with difficulties encountered with daily life and accessing different environments due to blindness and vision impairment).

Throughout this chapter, it is apparent that the four milestones become key points of reference to identify shift and change in the participants' emotional wellbeing and a measuring point to mark progress and regression from the fixed point of application.

Throughout thematic analysis of emotional and feeling-related themes across the four key milestones, it was identified that some of these themes were reported to have fluctuated (i.e. increased or decreased) more significantly than others. Chapter six sought to further expand this understanding of the impact of a guide dog on the emotional wellbeing of guide dog owners, by isolating these specific emotional and feeling-related themes, and examining them in greater detail.

## **Chapter 6 – Thematic Analysis Part b) Key Self-Reported Emotions and Feelings Across the Entire Longitudinal Process of Guide Dog Ownership**

### **6.1 Overview**

Chapter five has presented the findings of this study, by summarising the specific emotions and feelings participants reported experiencing at each of the four key milestones. This chapter (six) will now explore seven of those key emotions and feelings in greater detail, including the fluctuations in these emotional states as reported by participants across the longitudinal period. The emotions and feelings that were selected for more in-depth thematic analysis in this section were depression, anxiety, frustration, confidence, independence, security and companionship. To isolate which key emotions and feelings would be explored in greater detail, the researcher reflected qualitatively on the significance of emotional and feeling-related experiences as described by the participants, as well as how many and how often these were described as having fluctuated in some way (i.e. increased or decreased) across the milestones of this study. As previously mentioned in section 5.1, any emotions or feelings that were reported by no more than one participant at any one of the four key milestones was not considered significant and were thus excluded from further analysis. It is important to note however, that the seven key emotions and feelings which will now be explored in greater detail were not necessarily identified at each of the four key milestones, nor by all the participants, however their experience was reported as relatively significant and profound at the milestones in which they did emerge.

### **6.2 Theme 1 – Depression**

The relationship between blindness and vision impairment, and the increased incidence of depression was acknowledged in the existing literature (Kivett, 1979; Nollett et al., 2019; Nyman et al., 2012; Rees et al., 2013). As such, the emotional theme of depression was

purposefully selected for examination in this study, using both thematic analysis of the self-reported emotions discussed throughout participant interviews, and the Beck Depression Inventory (BDI). The BDI was selected for implementation throughout this study, to achieve a quantified measure of the impact of guide dog ownership on the incidence and severity of depression. BDI scores were calculated and presented longitudinally, to provide a quantitative measure of depressive symptoms across the four key milestones. These scores run concurrently with the self-reported feelings of depression, which were discussed during participant interviews.

For the participants in this study, depression was identified as a significant feature of the emotional journey experienced by guide dog owners. At the application stage (milestone one), more than half of the participants reported feelings of depression due to challenges in their daily lives attributed to blindness and vision impairment, as well as the breakdown in relationships with others. At this stage, BDI scores largely indicated an elevated level of depressed mood, where nearly all participants ranged from a mild mood disturbance to a moderate level of depression. For Bill, his BDI score was 30, which indicated he was experiencing a moderate state of depression at the time of his application interview. His feelings of depression were reported in the way he expressed a loss of interest in previously enjoyed activities. Bill explained his recent withdrawal from his valued sporting activities, even those which were specific to people living with blindness or low vision:

I've given carpet bowls away, used to run the blind carpet bowls, used to run that, but I've given that away. I used to run Wednesday night blind welfare carpet bowls, gave that away. I joined lawn bowls last year and played for the first nationals, I've given that away. I've given regular 10 pin bowling away.

At the time of the second milestone (training), one of the participants had reported a reduction in his feelings of depression due to the commencement of training and working with the guide dog. Max was vehement that he was not feeling depressed, and that “the dog has made a hell (emphasized this word) of a difference!” Interestingly, while Max states he was not feeling depressed, his BDI score of 16 indicates the presence of symptoms for a mild mood disturbance.

There was no clear evidence of self-reported feelings of depression during the third milestone interviews (six months post-qualification with their guide dogs). However, the majority of BDI scores had reduced since the application and training milestones, ranging from normal fluctuations in mood to only a mild mood disturbance.

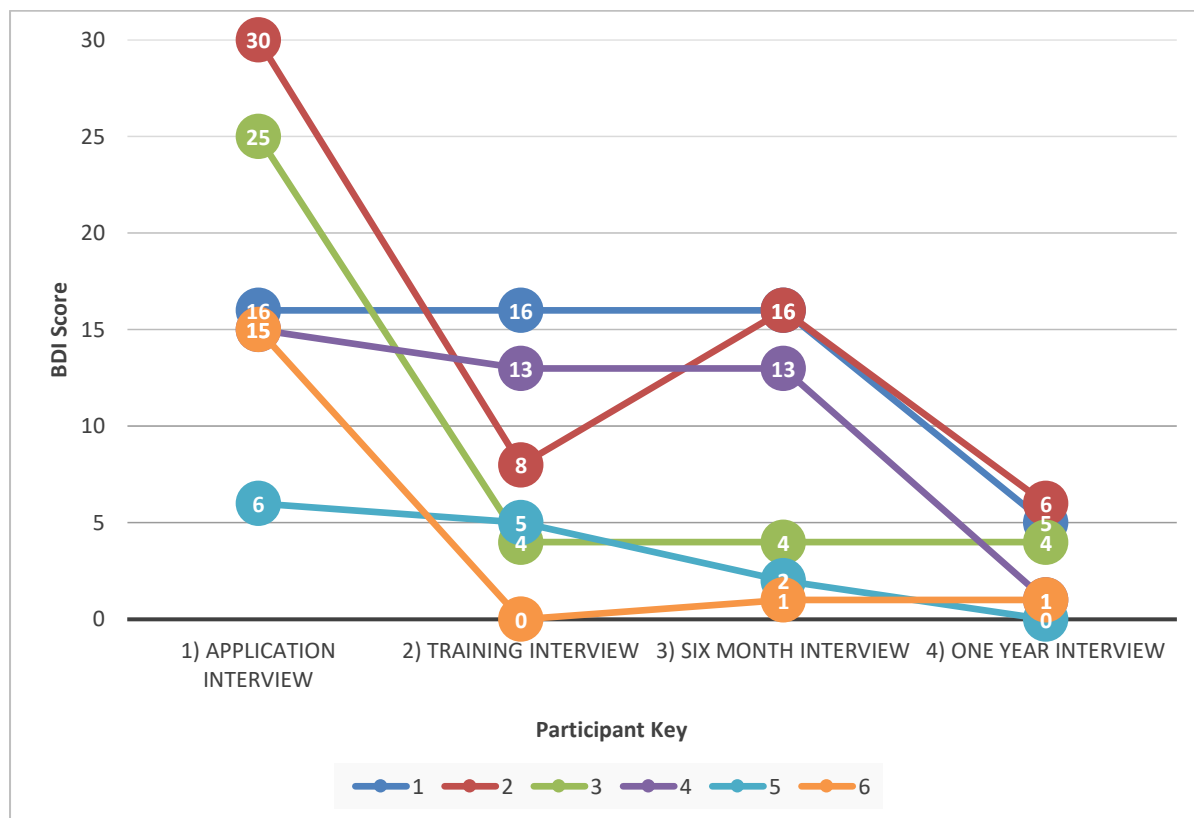
By the time of the fourth milestone interviews (twelve months post-qualification), one participant reported having some persistent feelings of depression due to the impact of his vision impairment, while nearly half of the participants reported a reduction in their feelings of depression due to working with their guide dogs. Bill expressed that he was feeling less depressed since he received his guide dog and that this was in part due to the bond and relationship that had formed between them. Bill says:

How do I say? Well, she is my eyes. We are great partners, great friends. She is a loveable dog. Um, she listens 99% of the time, and then the 1% she wants to do it her way, or thinks *'I've had enough of our way, I'll do it my way!'* I won't get into the other part, as I've been told-off several times by other women (laughs)!



**Figure 6.1**

*Longitudinal BDI Scores Summary for All Main Study Participants*



KEY	
Total Score	Levels of Depression Indicated
1-10	These ups and downs are considered normal
11-16	Mild Mood Disturbance
17-20	Borderline Clinical Depression
21-30	Moderate Depression
31-40	Severe Depression
>40	Extreme Depression

Interestingly, the BDI scores for all participants demonstrated a marked reduction in symptoms of depressed mood when compared with scores from the first (application) milestone. At the fourth milestone, all participant scores indicated normal fluctuations in mood (see figure 6.1). The utilisation of both self-report and a quantified measure of incidence and severity of depression (BDI) has supported the researcher to capture a more holistic and accurate measure of depressed mood and feelings. It was evident that there were occasions where participants did not report feelings of increased or decreased depression,

however the BDI had enabled participants a structured system whereby symptoms of depressed mood (e.g. changes in appetite, sleep, self-esteem and satisfaction in daily life) could be identified and reported. This differentiation between a participant's BDI score and the emotions and feelings they report to have experienced indicated that some participants lack the necessary skills to accurately recognise their emotional experiences and appropriately communicate these to the interviewer. The structure and scoring of the BDI did not require this degree of emotional awareness and expressive communication skills in order to identify depressed mood, and thus served to identify fluctuations in the participant's emotional experiences and state in a more rigorous way.

### **6.3 Theme 2 – Anxiety**

Anxiety was a theme reported by participants as having been experienced in varying degrees and pertaining to their experience of applying for guide dog mobility, training and ultimately working with a guide dog. At the first milestone of guide dog application, an increase in feelings of anxiety was reported by the majority of participants, in relation to the impending acquisition of a guide dog. For some participants, they felt anxious about the potential changes to their lifestyle or challenges they may face when mobilising in the community with a guide dog. For Stan, he expressed a degree of anxiety as he ruminated whether his current circumstances were truly deserving of a guide dog. As Stan explained:

Um, because I think there may be other people more deserving. I'm not working, I'm spending most of my days around home... and so I'm not sure that I'm the ideal candidate for a dog. But if I don't press on then I might find it impossible to get the sort of employment that I want.

As participants progressed onto training and through milestone two with their guide dog, the majority expressed that they felt a reduction in anxiety when mobilising with and being close to their guide dog. Gwen, who had expressed her challenges with post-traumatic-stress disorder, reported her experience of feeling her anxiety ease when talking to her guide dog during the training process; “because it’s quite calming to do that, to have that conversation with the dog...” Interestingly, a small minority of participants reported an increase in anxiety regarding the experience of the training process they were undergoing with their guide dog. A further larger majority of participants reported increased anxiety about negative or concerning behaviours their guide dog exhibited, and their abilities to manage these.

Once participants had successfully completed training and had been working with their guide dog in the community setting for approximately six months (third milestone), anxiety levels were reported to have changed again. At this milestone, a slightly lesser number of participants still maintained they felt a reduction in anxiety when mobilising with and being close to their guide dog. A small minority of participants reported increased anxiety about negative or concerning behaviours their guide dog exhibited, as was the case during the previous training milestone. Stan explained feelings of anxiety when he learned his guide dog had begun jumping the neighbour’s fence. When questioned by the interviewer if this was causing him stress and anxiety, Stan concurred that it was and described the source of his anxiety as “there are people around here with sheep, including myself, and we can’t have him jump fences because if he gets caught in with sheep he might get shot or kill the sheep”.

At the final milestone where participants had been working with their guide dog for a period of 12 months post-training, it was interesting to observe that an equal proportion of participants reported increased and reduced anxiety, relative to different experiences of working and living with their guide dog. Half of the participants expressed ongoing feelings

of anxiety relative to negative or concerning behaviours their guide dog exhibited, while half of the participants maintained the stance that their anxiety was eased or reduced by the mere presence of their guide dog, and moreover when they were mobilising with their guide dog out in the community. Although there was ultimately a slightly higher frequency of anxiety reported (total of 14 occasions reported by participants) than a reduction in anxiety (total of 12 occasions reported) across this longitudinal study, it is important to acknowledge that the level of anxiety reported at the first milestone by the majority of participants had ultimately reduced to half of the participants by the final milestone.

#### **6.4 Theme 3 – Frustration**

The participants reported that frustration, in many variances, was a theme that they felt across the four milestones in applying for, training with and working with a guide dog. The key factors that contributed to their frustration varied across all four milestones.

All of the participants reported at first milestone, that being the application process, that they were frustrated with their daily life due to their blindness and vision impairment. These feelings ranged from a failure in recognising loved ones and people they were familiar with, through to activities of daily living that were made more complex due to their sight loss. Bill explained his frustration of living with a vision impairment as “I’d rather have lost a leg or lost an arm or lost my hearing instead of my sight. And that virtually killed me because I couldn’t do what I was doing before”. One of the most frustrating impacts of blindness and vision impairment for some of the participants was their inability to drive, which to most felt like a loss of privilege, and a failure to secure and maintain a recognised rite of passage into adulthood. Stan explains the impact of not being able to drive with respect to his freedom to move beyond his own home, as he described “I don’t drive, and my wife is at work, so I’m basically pretty much imprisoned here from Monday to Friday”.

Another source of frustration which was reported by the majority of participants was that related to their use of and the public's response to the white cane. Bill illustrated his frustration about the practical challenges and response to using his white cane during his application interview, where he postulated greater success in working with a guide dog if his application became successful, which it did. As Bill reports:

The cane, I can't do without the cane, but sometimes it's a hindrance. You know, you've got to fold it up, put it in your back pocket or bag. Then some people shun you, too. A lot of people are ignorant of the white cane. I think with the dog, the dog has got a bit of control. I think with the dog, it will get me around a bit more.

At the time of milestone one, the application process, frustration was also reported by half of the participants due to the process of applying for a guide dog and with respect to difficulty experienced in relationships and interaction with others by the minority of participants.

At milestone two, the training process, a small minority of participants were in the process of commencing a working relationship with their guide dog. During this time, a small percentage of participants reported frustration in relation to adjusting to living and working with a guide dog, as the participant and guide dog were both settling into a new home life and daily routine. Bill reported his feelings of frustration about the amount of time required to groom and clean up after his dog, as he stated:

This is what I hate cleaning the unit of this hair, I brush the dog take outside, but still two to two and a half hours to clean, I put the dog outside vacuum the floor vacuum the bed wash the floors.

At the time of training (milestone two), one participant also expressed frustration in relation to the stress associated with broken relationships and difficult interaction with others.

When participants were interviewed at the point of reaching six months post-qualification with their guide dogs at milestone three, the six months post qualification, a small proportion of reported feelings of frustration due to concerns about ways the public had responded to their guide dog, including interactions resulting from the presence of the guide dog, perceived as negative by the participant. Gwen explained how her frustration is triggered by members of the public touching her dog without first gaining her consent to do so, which distracted her guide dog from its work and even presented a safety risk. Gwen described her experiences:

Yeah you do, Kids are better than adults, they must learn it at school. It's like they know not to touch. Adults I've had troubles with, they say 'I know I'm not meant to pat her' and persist and Ginny doesn't like it and she backs away because she knows it's not meant to happen. I sort of just gently say can you please stop she is working and a few times I've had to be assertive and tell someone off because we were almost about to cross a busy road and someone did it and it took me 15 minutes to calm her down. Someone at a function once fed her a hot dog... you know oh my god!

At milestone four, twelve months post-qualification, the proportion of participants who reported frustration relating to interactions they had experienced with members of the public regarding their guide dog had increased. It appeared that this cohort of participants had experienced a number of problematic interactions resulting from the presence of the guide dog that either impaired the guide dog's ability to remain focused on their work or was upsetting for the participant. As Bob explained "yeah, it's frustrating sometimes; they really

do need to advertise that people can't touch the dog when it's in a harness. Even to have this written on the harness would be great". Todd had similar frustrating encounters to report, regarding unsolicited interactions with his guide dog:

Depending on how congested it is on the bus. Even with people on a bus, they will either try and pat him on the way through or say hello and he can get a bit distracted; that's a bit challenging.

At the fourth milestone, twelve months post-qualification, other sources of frustration reported by one of the participants included poor public awareness of the needs of a person with blindness and vision impairment, in addition to their ongoing difficulties with daily life. It was interesting to observe that although participants did not specifically report an improvement in areas of daily living they previously found frustrating, that the number of participants reporting frustration with aspects of daily life had reduced significantly since the first milestone. At the time of the first milestone (application for a guide dog), all participants reported feelings of frustration with aspects of their daily living because of their vision impairment, whereby only one participant expressed frustration for this reason at the fourth and final milestone.

There were many sources of frustration reported across the longitudinal study which indicated that a guide dog itself can be the epicentre of frustration for the participant, either directly through its behaviour or indirectly through the attention it attracts. However, inferences were made that the support provided by the intervention of a guide dog may have had a role to play in reducing frustration in participant's lives by improving challenges with daily living due to their blindness and vision impairment.

### **6.5 Theme 4 – Confidence**

Confidence was a common theme, discussed in some way across all four milestone interviews in this study. At the first milestone (application), this ranged from feeling hopeful that working with a guide dog would increase their confidence in interacting with the public, confidence to explore and access new destinations, and perhaps even achieve an improved their self-confidence. Stan was one of the majority of participants who reported feeling hopeful that their guide dog would increase their feelings of confidence in daily life, which was a great source of motivation in his decision to apply for guide dog mobility. As Stan explains his reasons: “you know, confidence, companionship, that sort of thing”.

Also, at the first milestone, more than half of the participants reported both a lack of confidence in themselves (i.e. self-esteem) and in their daily activities and hoped that working with a guide dog might serve to improve their confidence levels. Gwen explained that her application for a guide dog was motivated by her wish to improve her self-esteem and confidence that having a vision impairment has robbed her of, “but if I had the choice to go to town or go to Melbourne or not go, I wouldn’t. I wouldn’t stay down there, I’d stay around here. But having said that, if I had a dog then I would”. For some of the participants, the corroboration and encouragement from their family or friends had an impact on their decision-making process in applying for a guide dog. For Stan it was his wife who gave him the support he needed to pursue the application. “Oh yeah, she would like to make it easier for me to get around, and for me to be, I guess, less dependent on her. I don’t think she minds helping me, but she just thinks that it would be good for my own self-esteem”.

During the training process (milestone two), all of the participants reported that their feelings of confidence had increased due to the training they were receiving and the working relationship they were forming with their guide dog. Bob, when asked if the



training, which he commented was difficult, had any impact on how he felt stated that it had increased his confidence “Yeah more confidence in myself”. For Gwen the building of the relationship with her guide dog in training was the preface to setting more challenging goals, goals she felt she would not have attempted to set if she did not undertake the training or have her guide dog. Gwen comments, “I think that’s another side of it, so yeah for me I know there’s a lot of work involved, um but bring it on, bring it on”.

The increased feelings of confidence had reduced from all to less than half of the participants at milestone three (six months after they had qualified with their guide dog). This indicated that the first few months following the completion of training presented a number of challenges for new guide dog owners, as they proceeded to apply the learning achieved from training with their guide dog, without the constant presence of a GDMI to support with troubleshooting any uncertainties in the moment these are experienced. Max was flippant about his relationship with his guide dog but acknowledged the impact her had on his confidence and wellbeing, whilst recognising that there were some behavioural issues with his guide dog that needed to be addressed. Max said “I still got to get used to a female telling me what to do and what not to do and she tries but other than that, she’s made a big difference and I think it’s all positive, the only negative side to her is that she is very possessive”. Todd felt that the working partnership he had established with his dog gave him increased confidence and was confident that if his sight deteriorated further, he would retain to the current level of confidence he had in his guide dog to continue to work with his guide dog safely and effectively. He commented that “I have not lost my sight completely yet, so I have confidence that he’ll be able to lead me where I need to go and around things”.

At milestone four (twelve months after qualification with their guide dog), an increase in feelings of confidence was observed, from less than half at milestone three to almost all participants at milestone four reported feeling more confident with mobility due to working with their guide dog. Bob stated that a previous obstacle to his independence was an inability to be confident in using public transport, particularly buses. He stated that with the training he received and the confidence he had in the skills and abilities of his guide dog, this obstacle to his independence was now greatly reduced. He stated “Oh yeah, I feel much more confident now. I only ever catch the bus from here to the city, or here to the hills”. One participant also reported increased feelings of confidence in social interaction with the public since owning and working with his guide dog.

For the participants, confidence was multifactorial. It was reflected in their feelings of confidence in the skills and attributes of their guide dog from the application process, where they wished to improve their confidence levels, to the final interview at twelve months post qualification, where they felt more confident in the way they worked with their guide dog, explored new and sometimes challenging environments, and interacted with others. More so, the participants felt that having improved confidence augmented their self-esteem and made them feel better about themselves and their daily lives. They felt that obstacles in their mobility were now potentially able to be overcome and that having a guide dog was an integral aspect of accepting the challenge.

## **6.6 Theme 5 – Independence**

All the participants were feeling hopeful that following their application for a guide dog which was milestone one, they would have increased independence and autonomy with daily life, in particular mobility. Max explained feeling hopeful for the ways in which his guide

dog would increase independence through mobilising in places he was currently unable to access on his own. As Max explains “practically, of course I’ll have more mobility with it. Which is very important. That is really important. I can go places where I now can’t. Or where I won’t. Practically it will make a big difference”. For all participants, this ability to make their own decisions about when and where they went was a key factor in determining how independent they felt in the context of their daily lives.

One of the participants had begun to feel an increase in independence at milestone two, which was nearing the end of his training period with his guide dog, where working protocols and expectations were being consolidated. Max explained his feelings of independence through a freedom of movement throughout his community environment, that when using his guide dog, he identified he is no longer reliant on other people to guide and keep him safe. Max also recognised that in being released from supervision by the ceremonial signing off on his period of training, his independence was now achieved and notarised by this rite of passage. As Max explained:

And then one day (instructors name) took me off by myself... boom went into some shopping centre... in out all over the place, sat down had a cup of tea, bang good as gold, then ahh, (instructors name) came along to sign the dog up and all of that, and he said geez textbook, where ready to go somewhere else, I took the dog, and I took it where I have never been...

One of the participants felt an increase in their independence at milestone three, which was six months following qualification with their guide dog. Gwen commented that one of her goals in the application process and in training with her guide dog was to increase her independence to the point where she could undertake studies that would require a great deal

of increased mobility and travel to places she had never been before. She felt that “oh yes, it’s been good. One of my aims to having a guide dog was to help me do my PhD and there is a lot of travel involved in that”.

The fourth milestone, at twelve-month post qualification, half of the participants experienced an increase in their feeling of independence, which was facilitated by their guide dog and the level of training they had received. Max reiterated that he was always an independent person but felt there was a significant recognition of that independence via the presence, working capabilities and proficiency he demonstrated in using his guide dog. Max comments:

Oh, yes. I was always independent as I’ve mentioned and I still get out most days, it’s comforting to know that people are a little more cognisant of my vision because I’ve got the dog in harness and as I said, I went to Smith Street the other day which entailed catching 5 buses.

Stan recognised the independence his guide dog had provided him in both the present and his potential future using a guide dog, with his aspirations of working in the nearest town to his remote farm property. Stan stated:

Oh, it presents a challenge and to be honest, I need the dog, especially if I’m going to work in town. I was in town yesterday with my wife, and I said to her ‘I just can’t walk around in here on my own anymore, it’s just too hard’”.

Half of the participants across the four milestones experienced increased feelings of independence working with the guide dog, by the time they had been working with their guide dog for twelve months. For some, it was a progression from their existing states of

independence and for others it was a newfound independence that brought promise of greater exploration and discovery of life with their guide dog unattainable with their sight loss and previous levels of independence. For many of the participants, the training with their guide dog had been arduous and challenging the motivation they had expressed in the application. However, on completion of the training, the independence this offered was worth the effort and the challenges.

### **6.7 Theme 6 – Security**

The first milestone of the application process for a guide dog saw all the participants express feelings of hope that their acquisition of a guide dog would improve their feelings of security and being safe. At this time, half of all participants explicitly reported concern for their personal safety, as they felt a distinct lack of security particularly with their mobility and community access, due to their vision impairment. Bill stated he had feared doing some of the practical mobility activities that allowed him to maintain his independence, such as crossing roads and that the act of crossing the road created fear and anxiety for him and compromised his personal security. Bob said:

Sometimes it is hard to do things, I used to cross the road without traffic lights, but it's gotten that bad now, I just can't stand there and study the traffic coming along. Because some of the cars blend in with the road, and I can't see them.

Gwen had several valid reasons for applying for a guide dog but a recurring theme for her was the concern about her personal safety and security. Gwen explains:

That's what it's about. It's not about the companion. It's about the dog and the safety issues. That's the biggest thing that I would say it would be for. Coz like I said, if I

had a dog, I know that I would go out more. And feel safer, and maybe go to Adelaide City or something, but the way I am now, no I don't.

At milestone two (training), some of the participants reported feeling safer, with increased feelings of security, and that this was more pronounced as they improved their mobility and access to their communities since the commencement of training with the guide dog. Bob stated that he feels safer crossing roads but due to previous experiences where he has been in danger from oncoming cars remains vigilant. Bob comments:

Yeah, yeah, see when we cross the roads, I am sort of very careful because I have to feel sort of, because the dog wants to keep going where the ramp or the curb is, because with the cane I could sort of walk and feel with it, its still (pause) I just have to get used to it that's all.

Half of the participants continued to report improvements in personal safety and feeling more secure at milestone three, the six months post qualification. At this stage, these participants reported that having a guide dog had improved their ability to access new and unfamiliar places with a higher degree of safety and security. This led to increased feelings of confidence and independence based on their skills development, their relationship with their guide dog and the capabilities of the guide dog to deal with situations that previously may have caused them concern or anxiety. Gwen reports that even though guide dogs are not trained, nor are they encouraged to be protective of their owners, her guide dog had demonstrated this behaviour and as a result she felt more safe and secure in the protective qualities of her guide dog to fend off danger and alert her to that potential. Gwen states:

I think she's very protective of me, there's been two incidences where I've had a guy on the train who have been menacing and she's come out of her relaxed stated like she is now and sat up and started baring her teeth and growling and I've got her to calm down. But I'm not going to tell her not to do that because it makes me feel better. I just can't imagine her not being a guide dog she is just thriving.

Todd explained his feelings of greater security in community mobility has come from his guide dog being able to assist him in safely manoeuvring obstacles and thus reducing his frequency of falls. As Todd described how his guide dog had prevented injury in less familiar environments:

Cause I found myself ah, I suppose injuring myself a bit cause especially like places I haven't been or even places I know like Coles there's a lot of poles and seats that are sort of so (measures height with hand) high because I can't sort of see, due to my tunnel vision, ah, I had tripped over a couple of times, brushed a tree or whatever, having the dog has prevented that.

At milestone four (twelve months post qualification), all participants reported improved feelings of safety and security in accessing public areas, as well as negotiating both familiar and unfamiliar environments with their guide dog. Participants explained how the very presence of the guide dog and the skills it possessed and demonstrated were strong factors attributing to the increased feelings of security. Bob remembered vividly the feelings of safety and security he experienced when working with his guide dog when in a potentially volatile and confrontational situation. In conclusion, Bob commented "Oh yeah, I feel much safer with Ginny than with the cane". Gwen recognised that the safety and security she experienced is a convergence of factors that centred around her relationship with her guide

dog, her family and friends and the security in knowing she had support from the organisation if there were issues or concerns that arose. Gwen explains her feelings:

Now, I sort of wondered why I didn't do it any earlier. I mean, I wouldn't have got Ginny, timing would have been different as I was living in a different state at the time. I think what's helped is that it is about her and I, it is about the relationship she has with (Kevin) and my family and friends and stuff, but it's also the back-up system with RSB. I'm not just saying that to 'suck-up' Chris! (Laughs) I know that if we get stuck, I can make a phone call, and that's huge. So that gives you the security that whatever you've got to do, whatever's happening that you can talk it through. They may not know the answer, like with the Catamaran, but you can do it".

In milestone four all the participants stated that working with their guide dog, developing their relationship and honing their own skills in how to work with their guide dog left them feeling safer and more secure in the variety of environments and situations they found themselves day to day with their guide dog. This feeling of security was particularly true when accessing new or unfamiliar, often complex environments and where the combination of their skills and the guide dog skills were instrumental in negotiating the environment safely, efficiently and effectively. As in previous cross-sectional themes, the feelings of security and safety allowed for increased feelings of wellbeing and self-esteem, sometimes after initial doubt but always improved on resolution.

### **6.8 Theme 7 – Companionship**

At the first milestone (application for a guide dog), all the participants reported feeling hopeful that they would experience increased feelings of companionship with their guide dog, once they had begun training and working together. Gwen explained how she envisaged



having a bond with her future guide dog, and how the relationship shared would extend beyond the expectations of a working dog, to deeper feelings of companionship and “mateship”. As Gwen described:

I think you got to have that bond with the dog, and knowing the dog's there...

Because you're with someone, and even if it's not a person, it doesn't matter, it makes no difference. It's the dog as a human being, you look at it that way, as a human being, you look at it as your mate. And I know people say they're only working dogs, but us blind people don't look at it like that.

By the time participants had commenced training with their guide dog and a GDMI (milestone two), more than half of all participants reported experiencing feelings of companionship and tenderness with the guide dog they had begun working with. Bob reports his acknowledgement in the early stages of a strong bond and feelings of companionship with his guide dog, and relishes in the time they spend together. Bob explains that “Oh yeah it's been good having a dog around for sure, you know the dog comes outside with me, the dog's a good gardener, the dog sort of lays there and watches me”.

At milestone three (six-months following the completion of training with their guide dog), nearly all the participants reported feelings of companionship, tenderness and a bond developing with their guide dog. Todd reported his recognition of this companionship with his guide dog, which also elicited greater feelings of confidence in the support his canine companion brought to him “Oh, definitely. I have another companion and he gives me the confidence with how well he does”.

At milestone four (twelve-months following the completion of training with their guide dog), the same high proportion of participants reporting feelings of companionship, tenderness and a bond developing with their guide dog was maintained. Bill explained the magnitude to which he felt the companionship with his guide dog had reached, as he shared “she’s a big part of my life now. We’ve bonded well”. Todd explained the bond and feelings of companionship he had developed with his guide dog was different to that he experienced with previous pets. As Todd explained:

I’ve never actually had a dog before, only cats. What I find with Vince I suppose is that he’s the one I’ve bonded with the most. He listens to me, he’s very playful and he also helps me out and about.

When describing their feelings of companionship, it was interesting to see participants often associating this with several other encompassing terms, such as friendship and mateship. It appeared that these were seen as anthropomorphic qualities, associated with trust, loyalty, respect and a provision of company for the participant. These qualities that the participant sought after in the relationship with their guide dog, were, in most cases, offered by the participant toward the dog in a mutually beneficial way. In this way, both guide dog owner and guide dog were able to mutually benefit from the experience of companionship, in the context of a trusting, working partnership.

## **6.9 Summary**

The second stage of thematic analysis undertaken in chapter six sought to immerse the reader in the lived experiences of the participants, by examining seven of the emotional and feeling-related themes that were most frequently reported to have fluctuated in some way across the four key milestones. By examining these emotions and feelings in isolation, a greater

understanding of the impact the guide dog had in facilitating or hindering emotional wellbeing across the longitudinal time frame of guide dog ownership has been achieved. Depression was the only theme which involved the utilisation of both qualitative self-report and a quantified measure of symptoms for depression; the BDI. The innovative use of these mixed methods of data collection for depression facilitated a more comprehensive method of inquiry, as the BDI enabled identification of the intensity and frequency of depressed symptoms in circumstances where participants did not report having consciously identified an increase or decrease in depressed feelings. Data gathered and analysed from both the BDI and self-report indicated that overall, participants experienced a reduction in symptoms and feelings of depression, from the point of applying for a guide dog to when they had then been working with their guide dog for a period of twelve months. At the time of the fourth (final) milestone, BDI scores indicated normal fluctuations in mood, and nearly half of the participants consciously reported a reduction in their feelings of depression due to working with their guide dogs.

When examining the thematic analysis of self-reported emotions of frustration and anxiety, it has been recognised that the guide dog served a role in both increasing and decreasing these across the longitudinal time frame. Of importance, was that the value of the guide dog in addressing challenges with daily living due to vision impairment contributed to improving feelings of confidence, independence, security and companionship. This was to the degree that participants largely recognised that any frustration or anxiety caused by their guide dog was outweighed by the benefits to their emotional wellbeing and quality of life.

The four milestones in this study were key points of reference in the journey to guide dog mobility: facilitating identification of shifts and changes in the participants' emotional wellbeing and a measuring point to mark progress and regression from the fixed point of

application. In chapter seven, the discussion has centred on the experience of the participants on their journey to being twelve months post qualification with their guide dog, with reference to the literature and methodology used in this study to set the scene and establish the foundation and impact of the results. The achieved outcome of such discussion has been to further elaborate on the findings of this study, determining whether the guide does in fact serve a secondary role of contributing to improved emotional wellbeing, and implications of this new information for guide dog service providers.

## **Chapter 7 – Discussion**

### **7.1 Overview**

This chapter will illuminate the key findings of this study through in-depth discussion and further linkages with the theoretical perspectives and literature discussed in earlier chapters (two and three). This discussion has sought to elicit new understanding with relation to the research question; how does the guide dog impact upon the emotional wellbeing of the guide dog owner, across the longitudinal process of applying for, training and ultimately working with a guide dog? Firstly, the factors impacting on the emotions and feelings of guide dog owners have been discussed, acknowledging how the experience of blindness and vision impairment, guide dog mobility, and factors that are not specific to those who have vision impairment, all influenced emotional wellbeing of the participants in this study. Finally, a greater understanding of motivations for pursuing guide dog mobility and ideal characteristics that supported participants' success in the process of application, training and working with a guide dog has been explored. No previous study has explored this experience longitudinally, and it was intended that this discussion would assist in obtaining a greater understanding of factors that may facilitate or hinder success with guide dog mobility, and how guide dog service providers may seek to deliver meaningful services that address the emotional wellbeing needs of guide dog owners.

### **7.2 Factors impacting on emotions and feelings of guide dog owners**

The range of emotions and feelings reported by participants was complex and varied, sometimes difficult to express and often all-consuming in the relationship with their guide dogs. There were also a wide range of pre-existing emotions and feelings, that in conducting this research, were impossible to exclude and many of the feelings and emotions expressed in the data were deeply rooted in the individual character of each participant.

This section sought to address the factors that were found to impact on the emotional experiences of guide dog owners in this study, commencing with an overview of those factors that the lived experience of vision impairment or blindness had on the emotions and feelings experienced by participants, followed by factors that the experience of working with a guide dog had on these. Finally, the impact of external and/or other factors that are not specific to a person who is blind or vision impaired on emotions and feelings have been identified and discussed.

### **7.2.1 The impact of blindness and vision impairment on emotions and feelings of guide dog owners.**

The lived experience of blindness and vision impairment, as well as the wide-reaching impact this had on daily life was identified as triggering a range of emotional experiences for participants of this study. It was pertinent at this stage of the study to reflect back to the definition of emotional wellbeing provided in chapter one, which acknowledged hedonic theories of happiness and pleasure as contributors to wellbeing, whilst acknowledging that negative affective states, such as depression and anxiety, lower wellbeing (Delle Fave et al., 2011; Ryan & Deci, 2001; Ryff, 1989; Waterman, 1993).

At the point of applying for a guide dog (milestone one), the vast majority of emotions and feelings reported were relevant to the participant's experience of vision impairment (e.g. frustration, depression, loneliness and sadness). The literature supports this by acknowledging an increased incidence of depressive symptoms, lowered confidence and emotional distress on those who are blind or vision impaired (Marques-Brocksopp, 2011; Nyman et al., 2012). The literature also acknowledges an increased incidence of anxiety and fear relative to a diagnosis of blindness or vision impairment, and the impact this has on daily

life (Alma et al., 2011; Cimarolli et al., 2017). Of interest is that the findings from this study did not identify a theme of anxiety relating to the impact of vision impairment more specifically, rather themes regarding the presence of or a reduction in anxiety were relative to the acquisition, training and working with their guide dog (see section 7.2.2). If anxiety was a predisposing factor in relation to their vision impairment, this was not expressed by the participants at any point in the study. There are numerous reasons as to why anxiety due to the lived experience of vision impairment was not identified as an emotional or feeling-related theme in this study. One possible reason is that participants were awaiting the outcome of their application for a guide dog at the time of the first interview, and thus their discussion and expression of anxiety was more focused on a degree of anxiety regarding the acquisition of a guide dog and the practical implications this would have on their lives. Not all participants disclosed the origins and pathology relating their vision impairment. For those participants that had experienced a loss of vision some time prior to the interview taking place, then it could be considered a potential factor that they had developed strategies and coping mechanisms and were therefore less anxious about the impact of their vision impairment.

Although the first (application) milestone noted an abundance of reported emotions and feelings relative to negative affective states surrounding the lived experiences of vision impairment, it is interesting to acknowledge that all the participants reported feeling hopeful that applying to work with a guide dog would serve to improve their emotional state and wellbeing. Participants reported they felt the acquisition of a guide dog would support in achieving this by addressing key issues relating to their experience of vision impairment, such as a lack of independence, companionship and personal safety. Subsequently, all participants reported feeling motivated to action change in their life by applying for and training to work with a guide dog, as they were feeling hopeful for what the guide dog would

achieve for them, such as improved mobility, wellbeing and achieve various participation goals in life, such as obtaining employment. A strong theme of hopefulness also emerged during the first (application) milestone, as most participants expressed feelings of hope that their guide dog would improve their confidence, independence, safety, and companionship with the guide dog. These findings demonstrated a clear alignment with a theoretical perspective of phenomenology, as a change in feelings of motivation and hope were influenced by certain elements within the lived experience of blindness and vision impairment that participants of this study had particularly attended to. Smith and Osborn (2015, p. 41) acknowledged the interpretative element of IPA in their own research, which esteemed participants as “sense-making organisms”, whereby the elements an individual attended to within a lived experience of pain in turn influenced the meaning and feelings (e.g. confusion, loss, threat) they identified through a lived experience of chronic pain. The participants of this study reported attending to the element of loss with respect to their independence, autonomy and opportunity throughout the lived experience of vision impairment. This in turn influenced their decision to pursue guide dog mobility and submit their application to the RSB. Indeed, the lens of IPA has enabled the researcher to develop a more comprehensive understanding of the emotional wellbeing of guide dog owners. Congruent to this, Finlay (2011) and Pietkiewicz and Smith (2014) identified that the role of research for both the researcher and participant is transformative, by witnessing the events and giving voice to participant’s lived experiences. In the case of this study, this transformative process was observed through identifying the emotions and feelings that stemmed from experiencing vision impairment and subsequently led to the decision to pursue an application for guide dog mobility.



### **7.2.2 The impact of the guide dog on emotions and feelings of guide dog owners.**

In examining more specifically, the impact of the guide dog on participants' emotions and feelings, this allowed the researcher to address the main purpose of this study. The introduction of the guide dog into participants' lives was found to have elicited a range of emotions and feelings, each being relative to the experience of training, working and living with their guide dog. One of the limitations in the current literature identified from the systematic literature review (see section 2.5.4) was a lack of longitudinal data, as existing studies only collected participant data at a single point in time thus impacting on the credibility of their findings (Miner, 2001; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008; Steffens & Bergler, 1998).

This study addressed a gap in the research by utilising a longitudinal design, and through examining the thematic analysis of self-reported emotions and feelings, it was evident that the impact of the guide dog on emotions and feelings was temporal. This meant that emotional experiences fluctuated across each of the four milestones and were relative to the stage of the guide dog partnership that participants were at when engaging in their interviews. When seeking to identify changes in participant's emotional wellbeing across this longitudinal time frame, it was important to recognise how the balance between self-reported emotions and feelings that were attributed to negative affective states and positive affective state varied at each of the four milestones. At the application stage (milestone one), three of the six emotions and feelings reported (50%) that were relevant to the guide dog were associated with a negative affective state (i.e. anxiety, frustration and apprehension) while the other three (50%) were associated with a more positive affect (i.e. hopeful, acceptance, happiness). At the second milestone, participants were undergoing an intensive period of training with their guide dog which elicited a much higher proportion of emotions and feelings associated with a negative affective state (75% of the emotions and feelings reported that were relevant

to the guide dog). Some of these emotions and feelings (including anxiety and frustration) were associated with managing difficult behaviours exhibited by the dog. At the time of the second interview, one of the participants had returned his guide dog to the school, as he felt the tendency to jump fences on his rural property put the dog in danger. The existing literature demonstrates how the way a guide dog behaves, when on and off duty, has a significant impact on the guide dog owner, and their relationship with the guide dog (Craigon et al., 2017; Fallani, Prato Previde & Valsecchi, 2007; York & Whiteside, 2018). There can be many reasons for returning a guide dog to the school that trained it, however the most common are a breakdown in the guide dog's work and social behaviour (Craigon et al., 2017; Fallani, Prato Previde & Valsecchi, 2007; York & Whiteside, 2018).

Once participants had qualified with their guide dog (milestones three and four), the vast majority of emotions and feelings reported that were relevant to the guide dog (14 out of 16 or 87.5%) were associated with a positive affective state. One of the few emotions and feelings reported that were associated with a negative affective state was anxiety, which was largely related to concerns about managing ongoing difficulties with the guide dog's social and working behaviour. By the time of the fourth milestone interview, two of the participants had returned their first guide dog to the school due mutual agreement that the guide dog's behavioural issues made returning them to work with the participants irreconcilable and had already completed training with their replacement guide dogs. At the time of the fourth interview, both participants reported increased satisfaction with their replacement guide dogs, feeling more confident in travelling safely and independently with their canine partner.

The findings of this study imply that more positive emotions and feelings were experienced as the participants progressed through the journey. The reason being is that participants had overcome some of the challenges associated with their intensive training period with support

from the school for ongoing management of any concerns with guide dog behaviour and began to experience the emotional and practical benefits of guide dog ownership. This view is supported by the findings from the previous studies (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008) which identified a degree of improved emotional and social wellbeing for the guide dog owner once they were at the stage of working with their guide dog. The limitation of the evidence produced by these previous studies (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008) is that they only collected data at a single point in time, when guide dog owners had already been working with their guide dog, and therefore cannot provide data regarding emotional experiences at the earlier stages of applying for or training with their guide dog.

When examining thematic analysis based on self-reported emotions across the longitudinal period of applying for, training and working with their guide dog, it was evident that this experience elicits a range of emotions and feelings in participants. Indeed, the emotional wellbeing of participants was challenged during the application process and by the presence of the guide dog in the early stages of training, when participants reported higher frequency of frustration, anxiety and apprehension. These findings demonstrate that guide dog owners have additional support needs at this time in the longitudinal process of guide dog mobility. However, the findings of this study largely supported the literature reviewed in chapter two, whereby guide dog ownership was ultimately identified as having a greater degree of benefit rather than disadvantage on the emotional wellbeing of guide dog owners (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008).

### **7.2.3 The impact of external/other factors on emotions and feelings of guide dog owners.**

While both the lived experience of vision impairment and the introduction of the guide dog into participants' lives have been acknowledged as having a significant impact on the emotional wellbeing of participants, there were also other life events that had an influence on the emotions and feelings reported. One of the key assumptions that underpins a theoretical perspective of phenomenology, is that elements that appear within a person's experiences and the meaning these have to a person is unique to each individual (Smith, 2018a). It was therefore important to acknowledge elements unique to each participant's lived experience, so that the researcher could extrapolate which of the participant's emotions and feelings were relative to the guide dog, and those associated with other life experiences not specific to blindness or vision impairment. This was achieved through application of a phenomenological perspective when undertaking thematic analysis. Through this, the researcher yielded a qualitative narrative of how these emotional experiences were described by individual participants, as well as the elements that participants reported as relative to these emotions and feelings.

Some life events were not necessarily unique to people with vision impairment and could also be experienced by people without vision loss. These included: difficulties such as relationship breakdown, loss of family members (i.e. death of a spouse), and difficult interactions with other people in their life. These events and aspects relative to the participant's social environment in this study were associated with negative affective states such as increased feelings of frustration, depression, loneliness, and discontentment.

Unlike factors addressed in sections 7.2.1 and 7.2.2, these unique social environmental factors were not necessarily related to the experience of vision impairment or working with a

guide dog, meaning they were not disability-specific and were therefore not exclusive to the participants of this study (Nyman et al., 2012). One's social environment has the capacity to either strengthen or hinder emotional wellbeing, regardless of whether a person is living with a disability such as blindness or vision impairment (Ravesloot et al., 2011). Notably, the guide dog was recognised by most participants, at the fourth milestone, as increasing feelings of companionship toward the guide dog. Therefore, this may have had a positive influence on emotional wellbeing by addressing the participant's need for social and emotional support. Interestingly, thematic analysis did not identify any emotional and feeling-related experiences relative to the social environment contributing to a positive affective state. The identification of these unique factors relative to the participants own social environment was facilitated by a theoretical perspective of phenomenology, as it is idiographic in its dedication to investigate the experience of each participant in detail, prior to developing more general claims about phenomenon (Smith & Osborn, 2015).

### **7.3 Understanding the applicant for guide dog mobility**

In the introduction chapter (see section 1.4), the potential contributions of this study to the profession of guide dog mobility were highlighted. In particular, the fourth aim of this study sought to reflect on the wider significance of emotional wellbeing in framing and informing the work of organisations supporting those who are blind or vision impaired. This section has now synthesised and summarised key findings that are relative to gaining a greater understanding of guide dog applicants and how to deliver meaningful services that address their holistic wellbeing needs. Firstly, a discussion was presented regarding motivations for pursuing guide dog mobility that were identified throughout the process of semi-structured interviews at milestone one (application) and subsequent thematic analysis. This motivation is important in the discussion as demonstrated applicants for guide dog mobility have many rationales for their application. This relevance to their application is reflected in their

emotional state which, as the findings have demonstrated, can fluctuate between the milestones of applying for, training and working with a guide dog. In particular, some of the participants found the application process challenging, as it required validation of their vision impairment and raised feelings of stigma or worthiness in the pursuit of guide dog mobility. Then, a reflection of the ideal characteristics of a guide dog applicant that encouraged success with guide dog mobility was presented, based on the fluctuations in emotions and feelings, and relative circumstances across the longitudinal inquiry, identified within this study's sample group.

### **7.3.1 Motivations for pursuing guide dog mobility.**

At milestone one (application), it was apparent that there was a strong theme of hope. Seven different prospective outcomes of guide dog mobility that participants reported feeling hopeful they would achieve were conveyed at the point of applying for guide dog mobility (please see section 5.2.1). It was apparent that a key motivation for pursuing guide dog mobility was linked to the strong theme of hope; for what the guide dog would enable them to achieve and the impact this would have on the quality of their daily lives at a macro level, as well as the ability to access a range of environments in their world. Some of the ways in which participants anticipated or hoped their guide dog may improve their lives were congruent with the identified role of a guide dog, as evidenced in the existing literature. These included hopes that the guide dog would increase independence and autonomy with daily life, in particular with mobility, and increase feelings of personal safety (Gravrok et al., 2018; IGDF, 2011). Other aspirations that participants reported as hoping their guide dog would achieve for them are emerging in the current literature, but perhaps less established. These included feeling hopeful that they would develop a companionship with their new guide dog, and experience improved self-confidence (Banham, 2000; Sanders, 2000; Whitmarsh, 2005). It is important then, for guide dog service providers to be realistic in the

creation of hope and expectation for prospective guide dog owners. To this end, honest and frank discussion should be a key element of the application process, in outlining not only the positives of guide dog mobility, but the limitations as well. Furthermore, the engagement of prospective guide dog owners in these collaborative discussions should support with clearly setting program objectives and goals for the provision of their services.

In addition to feelings of hope, feeling motivated to action change in their life was also acknowledged by participants in their study as relative to their reasons for pursuing guide dog mobility. An understanding of the significance of these emotions and feelings of hope and motivation, and their link to prompting the participant's decision to pursue an application for guide dog mobility was and is of relevance to guide dog service providers, as this informs them of the applicant's expectations and whether these are relevant, realistic and are able to be fulfilled through guide dog mobility alone.

There needs to be a concerted effort and commitment to developing the skills, especially in the GDMI, focusing on an understanding of hope and motivation in relation to emotional wellbeing. Acquisition of this skill set would support a practice standard for discerning between the aspirational and the realistic, contributing to honest preliminary discussions with prospective guide dog owners about the suitability of guide dog mobility, meeting their expectations and dealing with applications who are unsuccessful in a supportive manner.

### **7.3.2 Ideal characteristics of an applicant that will encourage success with guide dog mobility.**

In the previous section, a reflection of the participant's motivations for guide dog mobility was presented, including the implications this has for service providers in ensuring appropriate skills development for their staff and effective communication procedures with

prospective guide dog owners. This section will now seek to discuss the findings of this study in relation to certain characteristics and capabilities of the participants that enhanced their emotional wellbeing, and in turn encouraged their success when applying for, training and working with a guide dog. Such knowledge may be utilised for enhancing client service pathways, development of application criteria and provision of appropriate supports to enhance holistic wellbeing of applicants throughout training and working with their guide dogs. Below, three key characteristics that guide dog owners in this study presented with that appeared to support their success in applying for, training and working with their guide dog will be presented. These three are by no means conclusive of those characteristics that may support success with guide dog mobility; however, were identified as most prevalent throughout thematic analysis (see chapters five and six) in this study and may be indicators for guide dog service providers to consider when designing their processes for individuals applying for and receiving guide dog mobility services.

**7.3.2.1 Emotional buoyancy and resilience.** As cited earlier in this chapter (see section 7.2.2), many emotions and feelings reported by participants in the earlier stages of applying for and training with their guide dog were associated with negative affective states (e.g. frustration, anxiety and apprehension). This infers that the emotional wellbeing of participants was challenged during these peak times of fluctuating emotions and feelings, which may have implications for an acceptance and resilience of these emotionally vulnerable periods. Applicants who are more emotionally labile or have pre-existing conditions which impact on their mental health may therefore require further investigation prior to approval of a guide dog, or additional supports at key stages in the subsequent process of training and working with a guide dog. In the case of this study, one of the participants (Gwen), had disclosed that she had been diagnosed with post-traumatic stress disorder (PTSD), depression and agoraphobia. While Gwen reported at the third and fourth



milestone interviews that the emotional symptoms of her mental illness had significantly reduced since working with her guide dog, she did report feelings of anxiety, fear and frustration regarding personal safety and mobility in the community at the first (application) milestone. It is important for guide dog organisations to recognise that without providing the appropriate supports to people applying for guide dog mobility, in particular for those who may lack the necessary emotional buoyancy and resilience, that these individuals may not go on to successfully qualify from training and maintain their guide dog mobility in the long term. Moreover, the concern remains that the failure to qualify or maintain guide dog mobility is likely to have a negative impact on the emotional wellbeing of the guide dog owner.

Resilience can be described as one's ability to adapt positively and overcome adversity in the presence of difficult circumstances (Barnard, 1994; Luthar, Cicchetti, & Becker, 2000; Pinquart & Pfeiffer, 2012). There is some evidence to support a positive correlation between resilience and improved emotional well-being in people who are blind or vision impaired. For example, studies by Butler et al. (2018) and Dahlbeck and Lightsey (2008) found that high levels of resilience in people who are blind or vision impaired were associated with increased self-esteem, improved wellbeing and low levels of anxiety. Nyman et al. (2012) found that two key factors which facilitated emotional well-being in people who were blind or vision impaired included an acceptance of their vision impairment, and a positive attitude.

Participants of their study reported improved well-being and demonstrated high resilience when they reflected on how their conscious choice to maintain a positive attitude supported them to manage negative emotions and experiences (Nyman et al. 2012). Nyman et al. (2012) also identified how factors within the person's social environment, such as the presence of a supportive network of family and friends, also influenced the emotional well-being and resilience of people who were blind or vision impaired. Some of the participants in the study

reported negative emotional experiences (e.g. frustration, discontentment, depression) with regard to relationship breakdown and ongoing conflict with family and friends. It was evident that the lack of a supportive social network had a detrimental impact on the emotional wellbeing and resilience of those participants, as they reported continued conflict and difficulty with these relationships across the longitudinal study.

Phenomenology has supported the recognition of each participant as an individual case, acknowledging that each will attend to and make sense of different elements that are unique to their own lived experience of vision impairment and guide dog ownership (Charlick et al. 2016). This perspective supports the recognition that the participant's resilience or ability to overcome adversity was impacted by how they attended to and made sense of difficult circumstances that were unique to their individual lived experience (Barnard, 1994; Luthar, Cicchetti, & Becker, 2000; Pinquart & Pfeiffer, 2012).

**7.3.2.2 Capacity for flexible thinking to participate in problem solving.** In chapter six (see section 6.3 and 6.4), anxiety and frustration were two of the seven most frequently reported emotions and feelings across the longitudinal process of applying for, training and working with a guide dog. Several of the reasons that participants gave as to why they were experiencing these emotions and feelings, were relative to the experience of working with their guide dog and the guide dog service provider. For example, half of the participants reported feeling frustrated about the process they undertook to apply for a guide dog. Furthermore, half of all participants also reported feeling anxious about negative behaviours demonstrated by their guide dog, and how they could manage these. In order to progress beyond the challenging circumstances at hand and proceed with guide dog mobility, participants were required to work in partnership with their guide dog mobility instructor

(GDMI) to manage these negative affective states and their behavioural responses, think flexibly and participate in problem solving.

Effective problem-solving skills are recognised as an ideal characteristic of guide dog owners, particularly in the management of their guide dog. Craigon et al. (2017) highlighted the importance of problem-solving capabilities in guide dog owners, through their study on guide dog owners' perspectives on their guide dog's behaviours. Findings of the study report that guide dog owners experienced frustration regarding a range of problematic behaviours exhibited by their dog, including pulling on the harness, distraction and toileting issues (Craigon et al., 2017). Guide dog owners also reported difficulties in managing problem behaviour by their guide dogs, such as distraction and scavenging for food while working (Lloyd et al., 2016). Studies by Craigon et al. (2017) and Lloyd et al. (2016) concluded that further research is needed to understand what characteristics of both guide dogs and guide dog owners will encourage success in their working partnership. The preliminary findings from these studies, however, infer that effective problem-solving skills are a desirable strength in guide dog owners that correlates with increased success with guide dog mobility (Craigon et al., 2017; Lloyd et al., 2016).

**7.3.2.3 Motivation to establish a relationship with their guide dog.** At milestone one (application), all participants reported feelings of loneliness due to the impacts of vision impairment and blindness and were feeling hopeful that having a guide dog would increase feelings of companionship with the dog. Interestingly, at the fourth milestone (12 months post qualification), none of the participants reported feelings of loneliness and almost all participants reported achieving these feelings of companionship and a strong bond with their guide dog. These findings are congruent with studies by Steffens and Bergler (1998) and Wiggett-Barnard and Steel (2008), which also identified that the majority of participants

reported a strong companionship with their guide dog, that reduced feelings of being alone and loneliness. Of interest is that the majority of participant's in Whitmarsh's (2008) study reported, in retrospect, that their motivations for applying for a guide dog were led by their desire to achieve increased independence and safety with mobility. Only a minority of these participants had recognised companionship as a motivating factor when initially choosing to pursue guide dog mobility (Whitmarsh, 2018). These findings, both from this study and the previous research (Steffens & Bergler, 1998; Whitmarsh, 2018) support that the role of a guide dog is still primarily recognised as providing safe and independent mobility, whilst recognition of their secondary role of contributing to improved emotional wellbeing is still emerging.

The findings from this longitudinal study and studies preceding this (e.g. Steffens and Bergler, 1998; Wiggett-Barnard and Steel, 2008) provide evidence to support the notion that guide dogs have the potential to contribute to improved emotional wellbeing for people who are blind or vision impaired, through addressing feelings of loneliness with the provision of companionship. Whitmarsh (2018) suggested that guide dogs may still be more widely recognised for their primary purpose of improved mobility, and that secondary benefits, such as companionship with the dog, may not be fully recognised until the person starts training and working with the guide dog. Thus, a need to recognising these more holistic benefits of guide dog mobility at the point of application is implied, so that the secondary benefits of guide dog mobility, such as companionship with the guide dog, may be made explicit for the purpose of guide dog referral.

#### **7.4 Summary**

The illumination of the key findings undertaken in chapter six has incorporated the methodology and literature discussed in chapters two and three. This synthesis of the data

enabled the researcher to delve more extensively into the phenomena being investigated and elicit new understanding regarding the emotions and feelings that guide dog owners experience when applying for, training and ultimately working with their guide dog. New understanding regarding not only the emotions and feelings reported across the longitudinal study, but factors that have elicited these emotions and feelings has been established. The influence of experiencing vision loss, working with their guide dog and external factors not specific to a person who is blind or vision impaired all had a role to play in this. A deeper understanding of guide dog applicants and how to deliver meaningful services that address their holistic wellbeing needs has also been discussed, so that guide dog service providers may have a greater understanding of motivations for pursuing guide dog mobility, and ideal characteristics of a guide dog applicant that will encourage success in the process. This understanding has the potential to influence the practice of guide dog organisations and the professionals working with people applying for and working with guide dogs; supporting the emotional needs of guide dog owners in conjunction with the technical education of how to effectively work with their guide dog. This in turn will create a greater opportunity to establish wellbeing benchmarks and a focus on the client's needs for the delivery of services. Chapter eight has now followed and concluded this study, by revisiting the aims, proposing recommendations for future research, and acknowledging the specific contribution to new knowledge that this study has achieved.

## Chapter 8 – Conclusion

### 8.1 Overview

This study has sought to gain an in depth understanding of the emotions and feelings experienced by guide dog owners who are blind or vision impaired as they go through the process of applying for, training and ultimately working with their guide dog. Thematic analysis of the four key milestone (semi-structured) interviews with Beck Depression Inventory (BDI) questionnaires has resulted in uncovering a stratum of rich data regarding the lived experience of the six participants who generously gave of their time and allowed the researcher to travel with them on their longitudinal journey to guide dog mobility. In the introductory chapter (see section 1.1), the researcher referenced that there was currently an unprecedented increase in the incidence of blindness and vision impairment worldwide (United Nations, 2017; World Health Organisation, 2017; World Health Organisation, 2018). This increase in incidence adds stress to existing health care services, at an economic, health and welfare-based state level, and for the individual has a direct the impact on their daily living and wellbeing (Vision 2020 Australia, 2016). Given the need to address independence with daily living activities (especially with mobility) and emotional wellbeing for an increasing number of individuals experiencing blindness and vision impairment, this study proposed the timely investigation into whether guide dog mobility offers a possible solution by addressing not only a primary role of providing safe mobility, but possibly in serving a secondary role of contributing to improved emotional well-being (Sanders, 2000).

Although the issue of addressing the needs of a growing population of people who are blind or vision impaired is a global issue, the findings of this study, which utilised a small sample of six participants living in South Australia, must be interpreted in context. The value of gaining an in-depth understanding of the lived experience of the six guide dog owners across

a longitudinal time frame bears weight in understanding the potential advantages and disadvantages of guide dog mobility, and the way in which this affects the emotional wellbeing for those who are blind or vision impaired. This chapter has sought to conclude this study by revisiting the objective and aims, and how these were achieved. Then, offer recommendations for improving this study design and informing the direction of future research will be discussed. Finally, there will have been an outline regarding how the findings of this study may contribute to addressing gaps in the existing literature, and more specifically to inform the guide dog mobility profession; to improve systems and service delivery to guide dog mobility applicants.

## **8.2 Revisiting Aims and Scope of the Study**

At the outset of this study (see section 1.3), a clear purpose and research question was established, that being to explore the impact of a guide dog on the emotional wellbeing of guide dog owners. In order to allow the reader to immerse themselves in the lived emotional and feeling-related experiences of these six participants who took part in this study, the researcher sought to address three broad aims which guided the implementation of this study and the way in which data were gathered and processed. This section has discussed how each of these three aims were addressed, and briefly mention what new learning was gained in this process.

### **8.2.1 Aim #1 - To explore whether and how the guide dog contributes to emotional wellbeing.**

The first aim of this study sought to gather, synthesise and present evidence from the existing literature and that which was gathered throughout this study to determine whether a guide dog serves more than one key function for the guide dog owner. Traditionally, guide dog mobility has served a principal function in the provision of safe and more dynamic mobility

to people who are blind or vision impaired (Gravrok et al., 2018). As discussed in chapter one (see sections 1.2.1 and 1.2.4), for people living with the experience of blindness or vision impairment there was a recognised impact on their emotional wellbeing, with increased anxiety, a lack of confidence and reduced independence with mobility and other aspects of daily life (Cimarolli et al., 2017; Nyman et al., 2012).

Data yielded from both a systematic literature review (see chapter two) and the current longitudinal study contributed to addressing this first aim of the study. The two key themes that emerged from the systematic literature review indicated firstly that guide dog mobility is associated with social and emotional benefits for the guide dog owner (see section 2.5.1.1), and secondly that guide dog mobility can be associated with negative responses from and interactions with the public that are perceived as undesirable by the guide dog owner (see section 2.5.1.2). The challenges faced by guide dog owners when encountering undesirable public responses toward their guide dog is also recognised in the existing literature (Lloyd, 2008; McManus, Good & Young, 2021). While the findings of this systematic literature review ultimately supported the notion that guide dog mobility ultimately yielded a greater degree of emotional and social benefit than disadvantage for the guide dog owner, the existing literature was recognised as limited in methodological rigour. It was determined that further research was needed that examined the temporal aspects of emotional wellbeing for guide dog owners, using a longitudinal and mixed methods design, to investigate the frequency, intensity and significance of emotional experiences of guide dog owners (Miner, 2001; Steffens & Bergler, 1998; Whitmarsh, 2005; Wiggett-Barnard & Steel, 2008).

This longitudinal, mixed methods study has explored the range of emotional experiences that were elicited through the introduction of a guide dog into the participant's lives; emotions and feelings that are associated with both positive and negative affective states. In the earlier



stages of applying for and training with a guide dog, there was a higher proportion of emotions and feelings reported that one would associate with a negative affect (e.g. frustration, anxiety and apprehension). However, by the time participants had been working with their guide dog for 12 months, they reported substantially higher incidence of emotions and feelings associated with a more positive affect. This was largely due to the fact that the value of the guide dog in addressing challenges with daily living due to blindness or vision impairment contributed to improving feelings of confidence, independence, security and companionship. This was to the degree that participants essentially recognised that any frustration or anxiety caused by their guide dog was outweighed by the benefits to their emotional wellbeing and quality of life. Whilst acknowledging the factors that challenged participant's emotional wellbeing in the earlier stages of the study, which may necessitate the need for greater support mechanisms at this time, the findings of this study provided evidence to support how the guide dog definitively served a secondary role of contributing to improved emotional wellbeing of their guide dog owners.

### **8.2.2 Aim #2 - To investigate whether depression has a significant impact on emotional wellbeing.**

The second aim of this study has involved the use of both qualitative self-report and the quantitative Beck Depression Inventory (BDI) tool, to investigate whether depression had a significant impact on emotional wellbeing for participants across the longitudinal process of applying for, training, and ultimately working with a guide dog. There is an acknowledged link between depression and vision impairment identified in the literature, (Kivett, 1979; Nollett et al., 2019; Nyman et al., 2012; Rees et al., 2013) creating a rationale for the use of depression as an emotional theme within the study. Quantitative data provided by the BDI, as well as the qualitative thematic analysis of self-reported emotions and feelings from participant interviews gave a rich yield of data. BDI scores were collated, analysed and

presented longitudinally, in order to gain a quantitative measure of depressive symptoms across the four key milestones. The presence of some differentiation between a participant's BDI score and self-reported emotions was recognised and indicated that some of the participants may have lacked the necessary skills to accurately identify their emotional experiences and report these to the interviewer (see section 6.2). The combination of both data collection tools was a strength of this study that supported in capturing a more holistic and accurate measure of depressed mood and feelings,

In conclusion, depression has been clearly identified as having a significant impact on emotional wellbeing for participants in this study, in particular when applying for their guide dog (milestone one). At the commencement of the main study (milestone one), more than half of the participants reported feeling depressed, due to either challenges in their daily lives attributed to their vision impairment, or a breakdown in relationships. At this same stage (milestone one), the BDI scores largely indicated an elevated level of depressed mood, where nearly all participants ranged from a mild mood disturbance to a moderate level of depression. The presence of depression was again recognised for some participants at emotionally vulnerable periods throughout the longitudinal period of training and in the first six months of working with their guide dog. As the study progressed to the fourth milestone more than half of the participants reported a significant reduction in their depression but one reported an increase which he attributed to a deteriorating in his vision and associated impact on his wellbeing. Interestingly, the BDI scores at this time (fourth milestone) indicated normal fluctuations in mood, whereby significant symptoms of depression were not present (see figure 6.1). This reduction in participant's BDI scores and self-reported emotions and feelings from the point of application, to working with the guide dog for twelve months post-qualification supports the recognition of the less-established secondary role of the guide dog in contributing to improved emotional wellbeing.

**8.2.3 Aim #3 – To specify the temporality of emotional wellbeing across the longitudinal process.**

The third aim of this study required the collection of data that would allow the researcher to explore the impact of time on the emotional and feeling-related experiences reported by participants, in order to draw comparisons between different stages of the longitudinal journey. Identifying any fluctuations in emotional states and wellbeing across the process of applying for training and working with a guide dog served by helping to acknowledge periods of emotional vulnerability in this process, and what factors influenced emotional and feeling-related experiences of guide dog owners in this study.

Changes in emotional wellbeing were ascertained by identifying emotional and feeling-related experiences of individual participants in case study format (see chapter four); looking at the range and intensity of all self-reported emotions and feelings experienced across the longitudinal process, including their BDI scores. Thematic analysis of participants self-reported emotions and feelings provided valuable insight into the emotional and feeling-related experiences of the participant group as a collective, whereby themes were collated and summarized at each of the four key milestones (see chapter five), as well as an exploration of the seven themes that were reported most frequently as having fluctuated (i.e., increased or decreased) in some way across the entire duration of the longitudinal study (see chapter six). The substantial changes observed in these key (seven) themes of depression, anxiety, frustration, confidence, independence, security and companionship demonstrated fluctuations in emotional wellbeing across the longitudinal process of applying for, training and working with a guide dog. This information aided in ascertaining to what degree the introduction of a guide dog impacted on emotional wellbeing of participants in this study, and what role other factors (such as the lived experience of vision impairment as well as other factors not specific

to a person who is blind or vision impaired) had on influencing participant's emotional and feeling-related states.

Emotionally vulnerable periods were identified in particular at the application (one) and training (two) milestones, where participants reported a greater proportion of emotional experiences associated with negative affective states (e.g. frustration, grief, anxiety and apprehension). At the application milestone (one), all the participants reported feelings of frustration due to difficulties encountered with daily life due to their vision impairment, and feelings of grief due to reduced independence with their mobility. The majority of participants reported a degree of anxiety regarding both their personal safety and the process they were undertaking in applying for their guide dog, and potentially moving forward to training and working with a guide dog. Loneliness, depression and apprehension were other themes identified at this time. When commencing training with their guide dog (milestone two), applicants reported different emotional and feeling-related experiences, some of which indicated a more positive affect, such as increased confidence in using the guide dog to travel more independently, and others were still relating to negative affective states (e.g. frustration and anxiety due to the period of adjustment in working with their guide dog). By the time participants had been working with their guide dogs in the six and 12 month (third and fourth) milestones, new themes were emerging that reflected a stronger association with improved emotional wellbeing, such as companionship with their guide dog, increased confidence and a reduction in anxiety and depression. Consistent with a theoretical framework of interpretative phenomenological analysis (IPA), this longitudinal study design has allowed for the emergence of an appreciation for the temporality of emotional wellbeing of guide dog owners (Apostolescu, 2019; Arnett, 2017). This has been achieved by identifying how the emotions and feelings reported are associated with the elements that

participants attend to or “bracket” (Smith & Osborn, 2015) at different stages of applying for, training, and ultimately working with a guide dog.

**8.2.4 Aim #4 - To reflect on the wider significance of emotional wellbeing in framing and informing the work of organisations.**

This aim sought to synthesise the new data gained from participants regarding their emotional experiences and propose how this may be utilised to enhance service delivery by organisations who support people that are blind or vision impaired, in particular to address emotional wellbeing needs. Chapter seven (see section 7.3) sought to present findings from this study in a way that would provide a greater understanding of guide dog applicants and how to deliver meaningful services that address their holistic wellbeing needs. In particular, the motivations participants expressed for pursuing guide dog mobility were reported on, as well as specific characteristics of a guide dog applicant that would support them to succeed with guide dog mobility in both the short and long term.

Throughout the process of thematic analysis, a strong theme of hope emerged at the first (application) milestone. At this time, participants reflected on what they hoped a guide dog would enable them to achieve and the impact this would have on improving their lives by addressing unmet needs and challenges they faced. Some of these hopes were congruent with the recognised primary role of a guide dog, such as increasing independence with daily life, in particular with mobility, and feelings of personal safety (Gravrok et al., 2018; IGDF 2011). Other hopes and aspirations reported by participants at the first (application) milestone reflected the less established secondary role of a guide dog for improving wellbeing, including opportunity to develop a companionship with their new guide dog, and experience improved self-confidence (Banham, 2000; Sanders, 2000; Whitmarsh, 2005). By developing a greater understanding for the motivations of applicants for guide dog mobility, guide dog

service providers may then work to understand the practical and emotional needs of their potential clients and work collaboratively to support these throughout the longitudinal journey toward guide dog mobility. This may well involve signposting or referring guide dog owners to other multidisciplinary services who are more appropriately skilled to address their emotional wellbeing needs, such as counselling, psychology or social work disciplines.

When reflecting on the thematic analysis of emotional and feeling-related experiences and demands that participants reported throughout the longitudinal process of applying for, training and working with a guide dog, a number of strengths emerged that were associated with increased success with guide dog mobility. These (three) strengths were not conclusive, however were identified as most prevalent throughout thematic analysis. These included an emotional buoyancy and resilience to manage emotionally vulnerable periods, the capacity to think flexibly and problem solve, and a strong motivation to build a relationship with their guide dog. Guide dog service providers may utilise this understanding of the ideal characteristics and capabilities for guide dog mobility applicants, to develop informed application criteria and consider strategies to support enhanced wellbeing of applicants throughout training and working with their guide dogs.

### **8.3 Recommendations**

As this study has now drawn to a conclusion, it is important to reflect upon the steps taken in the pursuit to understand the lived, emotional and feeling-related experiences of guide dog owners across the two-and-a-half-year journey of applying for, training and working with their guide dog. Reflecting upon the process and methodology applied to guide inquiry allows the researcher to scrutinise the steps taken and make recommendations that guide future investigation into the emotional wellbeing of guide dog owners. This section will therefore

address ways in which the current study design may be improved, and what direction future research should undertake in order to further build on the knowledge yielded through undertaking this study.

### **8.3.1 Improving the study design.**

In order to consider ways in which the study design could be improved to enhance the process of inquiry, it is important to demonstrate transparency about the limitations inherent within the chosen methodology and how this influences the way that findings may be applied to practice, such as generalisation to populations out with this study's sample group. These limitations were outlined in chapter three (see section 3.7), where the study's methodology was discussed and justified. Throughout implementation of this study, a number of ways in which the study design itself could be improved for the purpose of addressing limitations to support a more rigorous approach to inquiry were identified. These will now be discussed, with respect to the original limitations addressed in section 3.7 which include a heavy reliance on self-reported outcome measures, and the utilization of quantitative measures without an effective control measure in place.

*8.3.1.1 Reliance on self-reported outcome measures.* The inherent risk of relying so heavily on data collection methods which assumes that all participants have an adequate level of emotional literacy and expressive communication skills (including both verbal and non-verbal cuing) to accurately convey their emotions and feelings at various points in time is evident within this study design. Whilst both the existing literature and the researcher recognise this potential vulnerability within the methodology, such as the increased risk this places on resulting in reporting bias and reliability of results yielded, very little exists with respect to an alternative to self-reported measurement with regard to one's emotional and

feeling-related experiences (Cheng & Clark, 2017; Kendrick et al., 2016; Pilkonis et al., 2011; Smith, Cano & Browne, 2019).

Throughout the implementation of this study, the researcher observed how the use of a quantitative tool (BDI Questionnaire) sought to reduce the risk of potential bias and strengthen reliability of results when measuring participant's emotional experiences of depression. The reason for this is that the semi-structured interviews alone relied heavily on a participant's capacity to sufficiently report and describe their feelings and emotions, whilst the BDI questionnaire examined whether the participant had experienced symptoms of depression, thus reducing risks presented by participants who may have lacked in emotional literacy and expressive communication skills. In order to support increased reliability of results for measuring participant's emotional experiences, measures to improve the study design could involve a screening tool for the recruitment process to ensure that participants demonstrate a baseline level of communicational and emotional literacy skills. Another recommendation for improving reliability of results could be to maintain a mixed method longitudinal approach to inquiry (QUAL-Quant), which incorporates the use of additional standardized quantitative questionnaires for measuring symptoms of other emotions and feelings (e.g. anxiety, frustration, confidence). The rationale for this is to strengthen the reliability of self-report, by capturing both direct report of emotions, as well as more concrete symptoms that indicate emotional experiences so that more in-depth understanding of the frequency, intensity and significance of all emotions and feelings reported can be yielded.

**8.3.1.2 Use of quantitative measures with lack of controls.** The lack of a control measure within the study design impacted on the ability of the researcher to report with complete certainty that fluctuations in the emotional and feeling-related experiences of participants were solely due to the introduction of a guide dog in their lives. One measure that



was adopted to address this within the thematic analysis, was to identify the trigger of the emotion or feeling being reported so that a rationale for these was identified and proposed, for example, feeling increased confidence with mobility due to training and starting to work with the guide dog. Again however, this provides reliance on the capacity for participants to acutely recognise and accurately report on these triggers, which again poses a risk for ensuring reliability in the results. One measure that could be considered for improving the study design would be to include a control group, such as a sample of individuals who were undergoing training for the use of a different mobility aid (e.g. long cane). A similar longitudinal study could run concurrently with the present study, and involve data collection at the four key milestones, whereby investigating the emotional and feeling-related experiences of white cane users as they undergo the process of applying for, training and subsequently using a long cane in daily life.

### **8.3.2 Direction of future research.**

Having considered ways in which the present study design could be improved, it is now important to consider the direction that future research should proceed with in order to build on the findings yielded in this study. The following are opportunities for future research to commit to obtaining a greater understanding the emotional experiences of people who are blind or vision impaired, the relationship these people share with their guide dog and the role of guide dog mobility in providing both safe mobility and improved emotional wellbeing:

- For future longitudinal studies on the emotional wellbeing of guide dog owners to commence their investigation with a solid foundation of participant measurements. These measurements can be applied to offer benchmarking, not only for specifics such as degree of sight loss, levels of independent mobility, but also of prior to investigation states of emotional well-being and health. Using a theoretical model such as “The Five Stages of Sight Loss” to define the stages of blindness (Thurston, Thurston & McLeod, 2010) could

give insight into the positionality of the participants in future studies as to their readiness, or non-readiness for guide dog mobility and give greater explanation of the process of acquiring sight loss and its relationship to the emotions and feelings experienced by participants.

- A longitudinal study that provides follow-up to explore the impact on the emotional wellbeing of guide dog owners at the time where the working partnership with their guide dog ends (i.e. when the dog is withdrawn, retired or dies). Such a study could serve as a foundation for exploring this transition period and the potential trauma experienced by guide dog owners (Lloyd et al., 2021; Whelan, 2017), so that service providers are better informed to meet the emotional needs of the guide dog owner at this time.
- A study to investigate the emotional impact in the relationship between the guide dog owner, and their immediate family and social networks, in supporting or not supporting the decision to pursue guide dog mobility.
- An exploration of the potential incidence of Post-Traumatic Stress Disorder (PTSD) in people who are blind or vision impaired due to an accumulative trauma of sudden sight loss, or progressive sight loss due to a degenerative condition. Some studies investigating the relationship between PTSD and vision impairment exist (Goodrich et al., 2014; Stevelink et al., 2015; Trachtman, 2010; Van der Ham et al, 2021), however these do not investigate symptoms of PTSD in guide dog owners. Subsequent research focusing on the impact of the guide dog on potentially ameliorating symptoms of PTSD in people who are blind or vision impaired, would further contribute to the evidence from this study regarding the secondary role of the guide dog in contributing to improved emotional wellbeing,
- Research to investigate whether the presence of a guide dog has an emotional impact on the guide dog owner's perceived identity as a guide dog owner. This research should investigate whether the use of a guide dog correlates with a greater sense of social stature, or rather contributes to perceived stigma in being identified as a person who is blind or

vision impaired, and the impact this perception has on the guide dog owner's emotional wellbeing.

#### **8.4 Contributions to knowledge**

It is timely as this study draws to a conclusion, that the data which has been yielded throughout the process of implementing this longitudinal study be recognised for its contributions to the developing knowledge base regarding guide dog mobility and the emotional wellbeing of guide dog owners. This section will therefore discuss what gaps in the existing literature have been addressed through the findings within this study, and how these findings may be utilised by guide dog mobility service providers, to improve the delivery of appropriate and timely services to applicants for guide dog mobility.

##### **8.4.1 Addressing gaps in the literature.**

As the systematic literature review outlined in chapter two found, there was and still is a dearth of current and methodologically sound literature available to support a conceptualisation of the emotional needs of people who are blind or vision impaired, and the impact guide dog mobility has on their emotional wellbeing over time. This study has served to address some of the gaps identified throughout undertaking the systematic literature review (see chapter two). Firstly, the existing literature was largely limited in focus, because it only collected participant data at a single point in time. This means that findings of these studies may not accurately represent change in emotional wellbeing over time, or more permanent change as a result of introducing the guide dog. This study addressed such a gap in the literature by applying an innovative longitudinal design in gathering participant data across four key milestones, which captured fluctuations in emotional wellbeing and findings which supported greater confidence in the notion that the guide dog ultimately yielded greater emotional benefits for the participants.

The second gap in the existing literature which this study served to address was to utilise a mixed methods approach, employing a quantitative measure to strengthen qualitative inquiry (QUAL-Quant) by identifying both the type and frequency of emotions and feelings reported through the process of thematic analysis. Approximately half of the existing literature identified in the systematic literature review (see section 2.5.4) was found to lack in the quantification of emotional and feeling-related experiences of guide dog owners, which indicates a substantial gap in understanding the frequency, intensity and significance of the emotional and feeling-related experiences reported by guide dog owners. The mixed methods approach undertaken for this study enabled some quantified measures to be achieved, which included an understanding of both the type and frequency of emotions and feelings reported via undertaking a thematic analysis, and the intensity of depressive symptoms reported at each of the four milestones via use of the BDI questionnaire.

#### **8.4.2 Contributing to the profession of guide dog mobility.**

This study has endeavored to expand on the knowledge of the psychosocial impact of blindness and vision impairment, by developing a greater comprehension of emotional states of people who apply for, train with and work with a guide dog. This knowledge could be used by service providers to trigger further thinking and recognition of the value in the relationship between a guide dog owner and their guide dog, as one that is based on both the working efficiencies of providing safe and effective mobility, as well as enhancing emotional wellbeing.

For guide dog service providers, it is hoped this study will add some discussion to the curriculum for the education of not only of GDMIs but all staff who work with people who are blind or vision impaired and seek guide dog mobility as their primary objective for

contacting the organisation. This study has outlined the emotional factors that contribute not only to the pursuit of guide dog mobility, but also impact on the success of the relationship with the guide dog, the GDMI and inevitably with the guide dog service.

For the people who are blind or vision impaired and would seek out a guide dog as their preferred mobility aid, this study may offer some recognition that the guide dog service and the staff within it are committed to understanding them not only as applicants and clients, but as people. For people who have lived the experience of vision impairment and are determined to change their circumstances by pursuing guide dog mobility, they must recognise all the emotions, feelings and conditions that are attached to that decision before they are able to make an informed decision about their application. This includes preparing for the complex application process, the intensive training, the highs and lows of working with a guide dog, and a commitment to maintaining standards and accepting advice to improve the partnership and maintain the health and wellbeing of the guide dog.

For collegiate members of the ancillary professionals to the world of guide dog mobility, such as Orientation and Mobility Specialists, and Occupational Therapists working with people who are blind or vision impaired, teachers of the blind or vision impaired, or readers with a special interest, it is hoped this study provides some insight in the complexity and myriad of emotional considerations and decisions surrounding the guide dog and its relationship with all who provide and use them.

For the guide dog, even with all its impressive skills of which reading is not one, this study acknowledges that their role is more than just mobility, more than just providing safety in travel, and more than just finding destinations. The guide dog is the physical and social connection, and emotional conduit to the world for people who are blind or vision impaired,

particularly over time. In those times when the guide dog is not performing all of these highly skilled roles, it is the educator of GDMIs who train them, the technical staff who support them, the volunteers who raise and care for them, and additionally for the guide dog owner at an emotional level, as Bill emphatically stated; “a confidante, a friend and companion”.

## **8.5 Summary**

The purpose of this study was to identify the emotions and feelings experienced by guide dog owners who are blind or vision impaired as they go through the process of applying for, training and ultimately working with their guide dog; to identify any changes in emotional wellbeing throughout this longitudinal process. The ultimate discovery for the participants in this study, is that emotional wellbeing was tested and tried throughout their experience of vision impairment, applying for and training with their guide dog. While being mindful of this emotionally charged experience, involving a considerable proportion of emotions and feelings associated with negative affective states in the earlier stages of applying for and training with a guide dog (e.g. frustration, anxiety and apprehension), participants were reporting a substantially higher proportion of emotions and feelings associated with a positive affect (e.g. confidence, independence and companionship) by the time they had been working with their guide dog for 12 months.

Even though the research question, as an open-ended question, queries what emotions and feelings are experienced by guide dog owners in the application, training and working of their guide dogs, we draw this study to a conclusion by asking did the guide dog ultimately have a positive impact on the emotional wellbeing of guide dog owners? For the participants of this study, the answer is yes.



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## Appendix 1 – Thesis glossary

### A

**Aftercare** – *see Follow up*

**Applicant:** A person, who is blind or vision impaired, who has applied to be trained with a guide dog.

### B

**Behaviour:** Anything an individual does, given certain conditions, which can be observed or measured.

**Behaviour Analysis:** The study of the functional relations between behaviour and environmental events.

### C

**Classical Conditioning:** Involuntary association. A neutral stimulus (NS) becomes a conditioned stimulus (CS) if it is paired a number of times with an unconditioned stimulus. Example is Pavlov's dogs, after a number of pairings of a bell (NS) with the presence of food (US), the dogs began to salivate to the sound of a bell, now a conditioned stimulus.

**Client:** A person, who is blind or vision impaired who has sought out and is being provided with services by a guide dog organisation. These services could be the provision of a guide dog or aftercare/follow up services.

**Corrected vision:** What a person can see with the addition of refraction and opticals (e.g. spectacles, contact lenses, monocular aids, binocular aids).

## **E**

**Evidence based learning:** Learning practices based on the available scientific evidence, rather than tradition, personal judgement or other influences.

**Extinction:** The process of decreasing behaviour by permanently removing all reinforcement.

## **F**

**Follow up (Aftercare)** - A service supplied to a client to assist them with their guide dog.

These follow up or aftercare services could be telephonic or in the form of a visit. The client may benefit from follow up or aftercare services to assist them any aspect of guide dog ownership.

## **G**

**General Practitioner (GP):** A medical doctor, often the first point of contact for individuals with concerns regarding their health. GPs provide treatment, education and onward referrals for the management of acute and chronic illness across the lifespan.

**Guide Dog Mobility Instructor (GDMI):** A technical professional who can show evidence that they have achieved the outcomes of the IGDFs GDMI curriculum and the IGDFs Standards related to GDMI education.

**Guide Dog Trainer (GDT):** A technical professional who can show evidence that they have achieved the outcomes of the IGDFs curriculum and the IGDFs Standards related to GDT education. A GDT trains dogs from intake age until the dog is at a class ready standard.

**Guide Dog Owner (GDO)** a person who is blind or vision impaired who has applied for, trained with, works with or has previously owned a guide dog.

## H

**Haptic Information:** A sensory modality utilises a person's sense of touch and is a key factor in the use of the harness when working and communicating with a guide dog.

## I

**Intake age:** The age that formal training begins. This age differs between organisations but may not be before 12 months.

## N

**Negative punishment:** The removal (subtraction) of a stimulus immediately following a behaviour, which decreases the strength of the behaviour.

**Negative reinforcement:** The removal (subtraction) of a stimulus immediately following a behaviour, which increases the future strength of the behaviour; also known as escape/avoidance training.

## O

**Operant Conditioning:** Voluntary behaviour; behaviour that occurs at some frequency and is increased or decreased as a function of consequences.

**Orientation and Mobility Instructor (OMI)** a professional trained and educated in the provision of mobility services and mobility aids to people who are blind or vision impaired.

## **P**

**Positive punishment:** The presentation (addition) of a stimulus immediately following a behaviour, which decreases the future strength of the behaviour. Also known as correction.

**Positive reinforcement:** The presentation (addition) of a stimulus immediately following a behaviour, which increases the future strength of the behaviour. Also known as reward training.

**Punishment.** The process by which a consequence decreases the strength of the behaviour it follows.

## **R**

**Reinforcement:** The process by which a consequence increases the strength of the behaviour it follows.

**Repossession (Withdrawal):** When a guide dog is removed from a client.

**Retirement:** When a guide dog retires or ceases working as a guide. This could be for several reasons relevant to the guide dog or client.

**U**

**Uncorrected vision:** What a person can see in the absence of refraction and opticals (e.g. spectacles, contact lenses, monocular aids, binocular aids).

**W**

**Withdrawal** – *see Repossession.*



## **Appendix 2 – Definition of emotional themes**

***Acceptance (of self)*** – the emotion experienced when an individual acknowledges a situation or limitation within their lives, and as a result, modifies their values and expectations to adjust to the change (Kaur & Tan, 2018; Zhang et al., 2014).

***Acceptance (by others)*** – a positive state of emotion experienced where a person is feeling accepted and welcomed in a social environment, resulting in the feeling of ease and enjoyment when spending time in the presence of others (Stanoeva & Stoyanova, 2012; Jasini, De Leersnyder & Mesquita, 2018).

***Accomplishment*** – an emotional state associated with feelings of competency, success and achievement, often associated with the experience of overcoming a challenge or achieving a desired outcome (Fives, Hamman & Olivarez, 2007; Kokkinos, 2007).

***Anxiety*** – an emotional state resulting from a non-specific threat, associated with feelings of tension and worry, intrusive thought processes, and physiological symptoms including elevated heartrate, shortness of breath and sweating (American Psychological Association, 2020; Cisler & Koster, 2010).

***Apprehension*** – feelings of reluctance and the need to approach a situation or event with caution, and alertness, due to a suspected outcome being something unpleasant or disastrous (Cambridge University Press, 2020; Choi, 2016).

**Companionship** – feelings of closeness, care and comfort with another person or living being, due to the intimate interpersonal relationship that you share (Beck & Katcher, 1996; Holbrook et al., 2001).

**Comfort(able)** – as an emotion, comfort is associated with feelings of psychological ease and a perceived absence of suffering, which can be related to the presence of certain thoughts, people, animals, objects or environments (Coelho & Dahlman, 2002; Tutton & Seers, 2003).

**Confidence** – feelings of assurance and certainty regarding a certain ordering of things, how a situation will eventuate, or of one's own capabilities (Centre for Confidence and Wellbeing, 2020; Haavardsholm & Naden, 2009).

**Depression** – a persistent state of altered mood reflecting a low affect and loss of pleasure in previously enjoyed activities. Altered mood can occur with or without reason, and is accompanied by a range of cognitive (e.g. thoughts of self-reproach), behavioural (social avoidance, changes in activity levels) and physical (changes in appetite, sleep and libido) symptoms (Beck & Alford, 2009; National Institute for Health and Care Excellence, 2020; World Health Organisation, 2010).

**Discontentment** – feeling a lack in satisfaction with regard to an individual's circumstances, such as social, financial, physical or cultural (Mahdi et al., 2020; Merriam-Webster Inc., 2020).

**Empathy** – an emotional state felt where an individual observes the emotional state of another, and in striving to comprehend their lived experience and perspective, shares their feelings and emotional state. These feelings the individual experiences are often characterised

by compassion and tenderness as they consider the perspective of another and share in experiencing their emotional state (Decety & Lamm, 2006; Sucksmith et al., 2012).

**Enjoyment** – an emotional experience, characterized by feelings of pleasure, relating to the possession or experience of something that is perceived as either beneficial or pleasant to the individual (Boudreau, MacIntyre & Dewaele, 2018; Csikszentmihalyi, 2008).

**Frustration** – feelings experienced when present challenges impair one's ability to move closer toward a meaningful and presumably attainable goal. Frustration occurs not just when a challenge is encountered, rather when the individual senses a lack of control over these present challenges (Meindl et al., 2019; Anderson & Bushman, 2002; Pekrun, 2006).

**Gratitude** – An emotional state characterized by feelings of appreciation, due to a cognitive awareness and value of the possessions, resources and interpersonal relationships one has. An individual may also experience gratitude where another being has demonstrated kindness or a generous act toward them, in particular during a time of vulnerability or hardship (Kini et al., 2016; Solaka, 2016; Tsang, 2006).

**Grief** – an acute and overwhelming feeling of bereavement, resulting from a devastating and permanent end to an emotional bond. The source of this bond can vary greatly, ranging from another person, an animal, a place or personal skill/attribute (Abi-Hashem, 1999; Parker, Paterson & Hadzi-Pavlovic, 2015).

**Happiness** – a positive emotional state, characterized by light, pleasant, relaxed and enjoyable feelings. This emotional state is commonly associated with high levels of satisfaction with regard to quality of life across domains, such as social, financial and

occupational (Diener, Kesebir & Tov, 2009; Hommerich & Klie, 2017; Van Cappellen, 2020; Vikan, 2017).

**Hope** – feelings of expectancy regarding an achievable future occurrence that one regards as positive and preferred (Roth & Hammelstein, 2007; Snyder, 2000).

**Independence** – feelings of flexibility, capability and freedom to act without the need for support, supervision or control by another. As an emotion, independence is often experienced where the individual perceives the presence of effective strategies and mechanisms that will enable them to overcome any barriers they may otherwise impede their ability to operate without the need for external supports or controls (Gignac & Cott, 1998; Salvador & Garcia, 2010).

**Loneliness** – an emotional state associated with feelings of distress and anguish resulting from an individual's perception that their social contacts and relationships are qualitatively and/or quantitatively less than the individual would desire them to be (De Jong Gierveld, Tilburg & Dykstra, 2018; Hawkley, 2007).

**Motivation** – the feeling of being intrinsically driven to take action, which is perceived as being of moderate to high challenge to an individual, due to the degree of reward or pleasure associated with the process and/or outcome achieved (Majnemer, 2011; Ryan & Deci, 2010).

**Protective** – the experience of feeling nurturing and caring toward another living being. This emotional state is often characterized by the perception of vulnerability or risk of being exposed to jeopardy for another living being, therefore is associated with the desire to take action that will protect them from harm (Mazzucchelli, 2009; Poretti, 2019).

***Sadness*** – an emotional state characterized by a low affect, feelings of sorrow and heaviness, usually the result from then individual experiencing a temporary but meaningful loss or failure to meet expectations (Parker, Paterson & Hadzi-Pavlovic, 2015; Vikan, 2017).

***Security*** – as an emotion, security is the feeling of being emotionally and physically safe, free from concern in the perceived absence of harm, vulnerability or threat (Ramsden, 2008; Yau, McKercher & Packer, 2004).

***Trust*** – a secure emotional state, whereby the individual experiences feelings of being sure about a person, situation or outcome, even in the absence of tangible proof. Where the target of an individual's trust is a living being, their feelings are often a result of their perceived reliability or virtuous qualities (Dunn & Schweitzer, 2005; McKnight & Chervany, 2001).

**Appendix 3 – Systematic review: an overview of the decision-making trail for inclusion of articles in the review**

<b>Database Search Summary</b>				
<b>Database</b>	<b>(1) Results (total)</b>	<b>(2) Results (after deleting duplicates)</b>	<b>(3) Results (title/abstract review and skim read)</b>	<b>(4) Results (thorough read of full text articles)</b>
Cochrane	5	5	0	0
Embase	96	56	11	0
Emcare	44	42	13	1
Informit	15	15	1	0
Medline	71	15	3	0
PsychINFO	476	415	31	2
Scopus	163	83	17	1
Web of Science	102	25	6	0
<b>TOTAL</b>	<b>972</b>	<b>656</b>	<b>82</b>	<b>4</b>

<b>(4) Results (thorough read of full-text articles)</b>					
<b>Author</b>	<b>Year</b>	<b>Title</b>	<b>Database(s)</b>	<b>Included or Excluded</b>	<b>Reason</b>
1. Lethbridge, E.M & Muldoon, C.A.	2018	Development of a mobility-related quality-of-life measure for individuals with vision impairments.	Emcare	excluded	Quality of life measurements for people with sight loss but no mention of Guide Dog owners.
2. Krawczyk M.	2017	Caring for patients with service dogs: Information for healthcare providers.	Emcare	excluded	Study investigating nursing care of people with service dogs in hospitals, not guide dog specific.

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3. Craigon P.J., Hobson-West P., England G.C.W., Whelan C., Lethbridge E. & Asher L.	2017	"She's a dog at the end of the day": Guide dog owners' perspectives on the behaviour of their guide dog.	Emcare	excluded	Study investigates the behaviours of the guide dog in social settings and owner's feeling about this.
4. Audrestch H.M., Whelan C.T., Grice D., Asher L., England G.C.W. & Freeman S.L.	2015	Recognizing the value of assistance dogs in society	Emcare	excluded	The article was not based on a research study and did not report specifically on the benefits of Guide Dog ownership (such as emotions experienced).
5. Vincent C., Gagnon D., Routhier F., Leblond J., Boucher P., Blanchet M., Martin-Lemoyne V., Tousignant M., Corriveau H. & Poissant L.	2015	Service dogs in the province of Quebec: Sociodemographic profile of users and the dogs' impact on functional ability.	Emcare	excluded	Study investigates socio demographics of assistance dog users but not guide dog owners specifically.
6. Parenti L., Foreman A., Meade B.J. & Wirth O.	2013	A revised taxonomy of assistance animals.	Emcare	excluded	Taxonomy of various roles for assistance dogs, not guide dog specific or addressing owner emotions.
7. Winkle M., Crowe T.K. & Hendrix I.	2012	Service dogs and people with physical disabilities partnerships: A systematic review.	Emcare	excluded	OT study looking at use of assistance dogs, not guide dog specific.
8. Godley C.A. & Gillard M.A.	2011	Assisting handlers following attacks on dog guides: Implications for dog guide teams.	Emcare	excluded	Focuses on trauma related to attacks on guide dogs not emotional responses to any other variable.
9. Rintala D.H., Matamoros R. & Seitz L.L.	2008	Effects of assistance dogs on persons with mobility or hearing impairments: A pilot study.	Emcare	excluded	Study looks at impact owning an assistance dog, not guide dog specific.
10. Wiggett-Barnard C. & Steel H.	2008	The experience of owning a guide dog.	Emcare	included	Reported on the emotional experience of owning a guide dog, according to self-report by a sample of guide dog owners.
11. Bergin B.	2005	Staying independent with canine help.	Emcare	excluded	Conducted by Assistance Dogs Santa Monica, California, USA (not specific to Guide Dogs).
12. Sachs-Ericsson N., Hansen N.K. & Fitzgerald S.	2002	Benefits of assistance dogs: A review.	Emcare	excluded	Study investigates benefits of assistance dog ownership, not guide dog specific or addresses emotional benefits in detail.

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13. Haymes S.A., Guest D.J., Heyes A.D. & Johnston A.W.	1996	The relationship of vision and psychological variables to the orientation and mobility of visually impaired persons.	Emcare	excluded	Refers to Orientation and Mobility training, nothing about guide dog use.
14. O'Leary M.	2005	A Young Man Blinded	Informit	excluded	Biographical experience of person with sight loss, no guide dogs.
15. Andreu, J.A.L. & Monleon, M.C.B.	2017	Adoption of assistance dogs as anxiolytics and positive stimulation during hospitalization.	Embase	excluded	Sample does not include those with low vision, rather Prolonged or repeated hospitalizations of paediatric patients with chronic disorders are associated with hospital aversion and high anxiety scores.
16. Schoenfeld-Tacher R., Hellyer P., Cheung L. & Kogan L.	2017	Public perceptions of service dogs, emotional support dogs, and therapy dogs	Embase	excluded	Study sample of general population, not dog guide users.
17. Scholtz S., Kobelt C., Schmelt A., Kretz F. & Auffarth G.	2014	A cold nose will show you the way: On the history of guide dogs for the blind.	Embase	excluded	On the basis that it is a literature review, does not measure impact on emotions as an outcome measure.
18. Kwong M.J. & Bartholomew K.	2011	"Not just a dog": an attachment perspective on relationships with assistance dogs	Embase	excluded	Sample includes people with a physical disability.
19. Friedmann E. & Son H.	2009	The Human-Companion Animal Bond: How Humans Benefit.	Embase	excluded	Relative to pet ownership and assistance animals (not guide dogs specifically).
20. Fallani G., Prato Previde E. & Valsecchi P.	2007	Behavioral and physiological responses of guide dogs to a situation of emotional distress.	Embase	excluded	Outcomes looking at the behavioural and physiological experiences of guide dogs in distressing situations.
21. Ng D.H.L., Chew R.Y.K., Seow-Choen F., Kua C.H. & Eong K.G.A.	2008	Opening our eyes to guide dogs for the blind in Singapore	Embase	excluded	No study sample, just a commentary on guide dog services around the world.
22. Wirth, K.E. & Rein, D.B.	2008	The economic costs and benefits of dog guides for the blind	Embase	excluded	Study investigates fiscal cost of a guide dog compared to providing other services.



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23. Robson, H.	1985	Dog guide and blind person: The matching process.	Embase	excluded	A discussion of the variations of temperament and physique exhibited by dog guides and potential masters that must be considered when they are paired.
24. Warnath, C. & Seyfarth, G.J.	1982	Guide dogs: mobility tool and social bridge to the sighted world.	Embase	excluded	Does not include outcome measures of the impact of Guide Dog use on client emotions.
25. Robson H.	1974	The practice of guide dog mobility in the United Kingdom.	Embase	excluded	Does not include outcome measures of the impact of Guide Dog use on client emotions.
26. Lloyd, J., Budge, C., La Grow, S. & Stafford, K.	2018	An Investigation of the Complexities of Successful and Unsuccessful Guide Dog Matching and Partnerships.	Medline	excluded	Study looking at matching process from the dog perspective mainly.
27. Meyer, D., Bhowmik, J., Islam, F.M.A. & Deverell, L.	2018	Profiling guide dog handlers to support guide dog matching decisions.	Medline	excluded	Study looking at matching from an orientation and mobility decision process.
28. Glenk L.M., Pribylova, L., Stetina, B.U., Demirel, S. & Weissenbacher, K.	2019	Perceptions on Health Benefits of Guide Dog Ownership in an Austrian Population of Blind People with and without a Guide Dog.	Medline	excluded	Looks at social wellbeing and quality of life for guide dog owners.
29. Gravrok, J., Howell, T., Bendrups, D. & Bennett, P.	2018	Adapting the traditional guide dog model to enable vision-impaired adolescents to thrive	Scopus	excluded	Thematic analysis reporting on physical, psychological and social benefits of guide dog ownership, can't be isolated reporting from kids and workers.
30. Bohan, D.B. & James, C.T.W.	2015	Mobility of a guide dog team in Singapore: A case study	Scopus	excluded	Study about development of guide dog services not pertaining to client experience.
31. Marquès-Brocksopp, L.	2015	How does a dog attack on a guide dog affect the wellbeing of a guide dog owner?	Scopus	excluded	Study investigates impact and trauma experienced by person with vision impairment following attack on their guide dog.
32. Rybarczyk, Y., de Seabra, J., Vernay, D., Rybarczyk, P. & Lebret, M.C.	2015	Towards an augmented assistance dog	Scopus	excluded	Development of a robotic device to mount on to the dog, not client related.

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33. Irvin, S.	2014	The healing role of assistance dogs: What these partnerships tell us about the human-animal bond	Scopus	excluded	Focus on assistance dog services, not a research article.
34. Gaunet, F. & Milliet, J.	2010	The relationship of visually impaired people with the guide dog: How could the use of dogs be further developed in France	Scopus	excluded	Not in English language.
35. Valsecchi, P., Previde, E.P., Accorsi, P.A. & Fallani, G.	2010	Development of the attachment bond in guide dogs	Scopus	excluded	Study investigating experience of dogs to attachment situations.
36. Duncan, S.L. & Allen, K.	2006	Service Animals and Their Roles in Enhancing Independence, Quality of Life, and Employment for People with Disabilities	Scopus	excluded	Book chapter predominantly exploring impact on employment roles for people with VI and physical/neurological disability (only study sample discussed was relative to those with neurological disability).
37. Fallani, G., Previde, E.P. & Valsecchi, P.	2006	Do disrupted early attachments affect the relationship between guide dogs and blind owners?	Scopus	excluded	Study focuses on dog attachment little or nothing to do with guide dog owners.
38. Anonymous	2005	Training and living with an assistance dog	Scopus	excluded	Referencing assistance dogs, not guide dogs.
39. Whitmarsh, L.	2005	The Benefits of Guide Dog Ownership	Scopus	included	Discussion and report of the emotional benefits of owning a guide dog, according to a sample of guide dog owners interviewed.
40. Hutchinson, R.	2000	Guide Dogs: New Mobility Service	Scopus	excluded	Article about the work of Guide Dogs UK.
41. Bonneau, L.J.	2000	Compensating for sight loss with a guide dog	Scopus	excluded	Article designed to inform nurses about how a guide dog is trained and their functional uses. Not relevant to the emotions experienced by Guide Dog users.
42. Riederle, G.	1999	The importance of the guide dog for the blind - Does the guide dog have a place in the next century?	Scopus	excluded	Does not report outcomes specifically on the emotions of GD users.

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43. Refson, K., Jackson, A.J., Dusoir, A.E. & Archer, D.B.	1999	The health and social status of guide dog owners and other visually impaired adults in Scotland	Scopus	excluded	Does not report specific emotions. The health and social circumstances of a random sample of 82 guide dog owners in Scotland were investigated in comparison with two other groups of visually impaired people (hospital low vision clinic patients and social services rehabilitation clients) as part of a research study on the ophthalmic and visual profile of guide dog owners.
44. Lane, D.R., McNicholas, J. & Collis, G.M.	1998	Dogs for the disabled: Benefits to recipients and welfare of the dog	Scopus	excluded	A study about assistance dogs for people with a broad range of disabilities, not guide dogs.
45. Kupfer, R.	1992	The guide dog in the life of blind persons - Experience, insights, considerations.	Scopus	excluded	Self-reporting from GD owner, outcomes does not involve emotions experienced, discusses difficulty with environment etc.
46. Hicks, J.R. & Weisman, C.J.	2015	Work or Play? An Exploration of the Relationships between People and their Service Dogs in Leisure Activities	Web of Science	excluded	Focus in leisure and assistance dogs, not guide dogs.
47. Crowe, T.K., Perea-Burns, S., Sedillo, J.S., Hendrix, I.C., Winkle, M. & Deitz, J.	2014	Effects of Partnerships Between People With Mobility Challenges and Service Dogs	Web of Science	excluded	Focus of study on mobility challenges for three women in wheelchairs.
48. Nicolau, H., Guerreiro, T. & Jorge, J.	2009	Designing Guides for Blind People	Web of Science	excluded	Study investigates mobility tools for people with sight loss.
49. Sanders, C.R.	2000	The impact of guide dogs on the identity of people with visual impairments	Web of Science	excluded	Discusses identity and some elements of the emotions associated with sight loss but only in relation to identity.
50. Refson, K., Jackson, A.J., Dusoir, A.E. & Archer, D.	1999	Ophthalmic and visual profile of guide dog owners in Scotland	Web of Science	excluded	Focus on demographics of sight loss through ophthalmology.

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51. Nicholson, J., Kempwheeler, S. & Griffiths, D.	1995	Distress arising from the end of a guide dog partnership	Web of Science	excluded	Study focuses on the distress arising from the end of a Guide Dog partnership, with no relevance to the emotions experienced throughout application, training and working with a guide dog.
52. Jau, J. & Hodgson, D.	2018	How interaction with animals can benefit mental health: A phenomenological study.	PsychINFO	excluded	Not guide dog focussed.
53. Mills, M.L.	2017	Invisible disabilities, visible Service Dogs: The discrimination of Service Dog handlers.	PsychINFO	excluded	Focusses on discrimination experienced by assistance dog owners.
54. Kemp, H.R., Jacobs, N. & Stewart, S.	2016	The lived experience of companion-animal loss: A systematic review of qualitative studies.	PsychINFO	excluded	Discusses experience of grief relating to companion dog loss.
55. Mongillo, P., Pitteri, E. & Marinelli, L.	2017	Sustained attention to the owner is enhanced in dogs trained for animal assisted interventions.	PsychINFO	excluded	Study focuses on relationship with dog and dog's attention to owner.
56. Hall, S.S., MacMichael, J., Turner, A. & Mills, D.S.	2017	A survey of the impact of owning a service dog on quality of life for individuals with physical and hearing disability: A pilot study.	PsychINFO	excluded	Not guide dog focussed.
57. Rehn, T. & Keeling, L.J.	2016	Measuring dog-owner relationships: Crossing boundaries between animal behaviour and human psychology.	PsychINFO	excluded	Focusses on the dog's experience.
58. Ng, Z., Albright, J., Fine, A.H., Peralta, J., Fine, A.H.	2015	Our ethical and moral responsibility: Ensuring the welfare of therapy animals.	PsychINFO	excluded	Focuses on welfare of assistance dogs, not emotions experienced by guide dog owners.
59. Tedeschi, P., Pearson, J.A., Bayly, D. & Fine, A.H.	2015	On call 24/7-The emerging roles of service and support animals.	PsychINFO	excluded	Study looks at roles for assistance dogs (not guide dogs specifically).
60. Silcox, D., Castillo, Y.A. & Reed, B.J.	2014	The human animal bond: Applications for rehabilitation professionals.	PsychINFO	excluded	Study focuses on human animal bond (not guide dogs).

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61. Woolf, A., Brown, A. & Mohiyeddini, C.	2013	Man's best friend: The therapeutic impact of emotional relationships with animals.	PsychINFO	excluded	Looks at animals more broadly, not guide dogs specifically.
62. Gaunet, F.	2012	Visually impaired people and the guide dog in France.	PsychINFO	excluded	Demographic of Guide Dog distribution in France.
63. Margrain, T.H., Nollett, C., Shearn, J., Stanford, M., Edwards, R.T., Ryan, B., Bunce, C., Casten, R., Hegel, M.T. & Smith, D.J.	2012	The Depression in Visual Impairment Trial.	PsychINFO	excluded	Great study but not about guide dog owners.
64. Koda, N., Kubo, M., Ishigami, T. & Furuhashi, H.	2011	Assessment of dog guides by users in Japan and suggestions for improvement.	PsychINFO	excluded	Matching assessments in Japan.
65. Hart, L.A. & Fine, A.H.	2010	Positive effects of animals for psychosocially vulnerable people: A turning point for delivery.	PsychINFO	excluded	Not guide dog focussed.
66. Kruger, K.A. & Serpell, J.A.	2010	Animal-assisted interventions in mental health: Definitions and theoretical foundations.	PsychINFO	excluded	Looks at of animal-assisted interventions broadly, not specific to guide dogs.
67. Nyman, S.R., Gosney, M.A. & Victor, C.R.	2010	Emotional well-being in people with sight loss: Lessons from the grey literature.	PsychINFO	excluded	Review of grey studies - no guide dogs.
68. Chur-Hansen, A.	2010	Grief and bereavement issues and the loss of a companion animal: People living with a companion animal, owners of livestock, and animal support workers.	PsychINFO	excluded	Looks at companion animals and livestock, not guide dogs.
69. Thurston, M.	2010	An inquiry into the emotional impact of sight loss and the counselling experiences and needs of blind and partially sighted people.	PsychINFO	excluded	Participants are not guide dog owners and have not previously applied for or worked with a guide dog.

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70. Serpell, J.A., Coppinger, R. & Fine, A.H.	2006	Welfare considerations in therapy and assistance animals.	PsychINFO	excluded	Regarding welfare considerations for assistance dogs.
71. Wenthold, N. & Savage, T.A.	2007	Ethical issues with service animals.	PsychINFO	excluded	Regarding ethical considerations with the use of service animals broadly, not relevant to the emotions experienced by guide dog users.
72. Collins, D.M., Fitzgerald, S.G., Sachs-Ericsson, N., Scherer, M., Cooper, R.A. & Boninger, M.L.	2006	Psychosocial well-being and community participation of service dog partners.	PsychINFO	excluded	Participants were those who had a physical disability, not a vision impairment.
73. Schneider, K.S.	2005	The Winding Valley of Grief: When a Dog Guide Retires or Dies.	PsychINFO	excluded	Practice report on internet searches on reports, no participants.
74. Deshen, S. & Deshen, H.	1989	On social aspects of the usage of guide-dogs and long-canes.	PsychINFO	excluded	Comparing people with sight loss and their dogs, and ways they use the dog compared to the way people use a long cane, not relevant to the emotions experienced by GD users.
75. McCutcheon, K.A. & Fleming, S.J.	2002	Grief resulting from euthanasia and natural death of companion animals.	PsychINFO	excluded	Grief related to companion animals.
76. Miner, R.	2001	The experience of living with and using a dog guide.	PsychINFO	included	Participants reported on their emotions surrounding living and working with a guide dog.
77. Naderi, S., Miklosi, A., Doka, A. & Csanyi, V.	2001	Co-operative interactions between blind persons and their dogs.	PsychINFO	excluded	Study focuses on working relationship and skills of guide dogs, not emotions of owners.
78. Milligan, K.	1999	Evaluation of potential dog guide users: The role of the orientation and mobility instructor.	PsychINFO	excluded	Study focuses on role of orientation and mobility training.
79. Fouladi, M.K., Moseley, M.J., Jones, H.S. & Tobin, M.J.	1998	Sleep disturbances among persons who are visually impaired: Survey of dog guide users.	PsychINFO	excluded	Outcome measures were the quality of sleep for guide dog users (not emotions).

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80. Steffens, M.C. & Bergler, R.	1998	Blind people and their dogs: An empirical study on changes in everyday life, in self-experience, and in communication.	PsychINFO	included	A study reporting on the changes in everyday life that guide dog owner experiences when working with their guide dog. One of the outcomes reported on is the positive impact that guide dog ownership had on the Guide dog owner's emotional wellbeing
81. Kenworthy, C.A.	1997	The emotional role and dynamics of play with pet dogs among blind and sighted adults: A multiple clinical case study.	PsychINFO	excluded	Study about people with sight loss and pet dogs.
82. Jackson, A.J., Murphy, P.J., Dusoir, T., Dusoir, H., Murdock, A. & Morrison, E.	1994	Ophthalmic, health and social profile of guide dog owners in Northern Ireland.	PsychINFO	excluded	Comparative between people using guide dogs and not using guide dogs (doesn't report on emotions).

## **Appendix 4 – Interview questions**

### #1) Application Interview Questions:

- Can you tell me a little bit about your vision?
- Does your vision loss affect your day to day activities?
- Can you tell me about why you have made the decision to apply for a Guide Dog?
- How do you think having a Guide Dog will make a difference in your life?
- How do you think having a Guide Dog will make you feel?
- The next series of questions are part of a scoring system for depression called a Beck Depression Inventory, if you are comfortable then we will proceed with these questions?

### #2) Training Interview Questions:

- Do you feel your vision loss has changed since your initial application for a Guide Dog?
- Do you feel there have been changes in your life since you made the decision to apply for a Guide Dog?
- How do you think your training with your Guide Dog is going?
- How do you think having a Guide Dog will make you feel?
- How have you been feeling since you began training with your Guide Dog?
- Do you feel you are bonding with your dog?
- Do you feel you have an understanding between you and your dog?
- How do you feel when your dog is near you?
- How do you feel when you are training with your dog?
- How do those closest to you feel about you with your dog?
- Do you feel there is a relationship between you and your dog?
- When you talk about your dog, how do you feel?



- The next series of questions are part of a scoring system for depression called a Beck Depression Inventory; if you are comfortable then we will proceed with these questions?

#3) Six Months Post Training Interview Questions:

- Do you feel your vision loss has changed since your initial application for a Guide Dog?
- Do you feel there have been changes in your life since you made the decision to apply for a Guide Dog and especially now you are qualified with the dog?
- How do you think the six months since you qualified with your Guide Dog have gone?
- How does having a Guide Dog make you feel?
- Have you experienced any difficulties with your dog since you qualified?
- How have you been feeling since you qualified with your Guide Dog?
- Have there been any particular high points you can remember since you qualified with your dog?
- Do you feel you have bonded or are still bonding with your dog?
- Do you feel you have an understanding between you and your dog?
- How do you feel when your dog is near you?
- How do you feel when you are out and about with your dog?
- How do those closest to you feel about you with your dog?
- Do you feel there is a relationship between you and your dog?
- When you talk about your dog, how do you feel?
- The next series of questions are part of a scoring system for depression called a Beck Depression Inventory; if you are comfortable then we will proceed with these questions?

#4) Twelve Months Post Training Interview Questions:

- How does the dog make you feel about yourself?

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- How would you feel if you could no longer keep your dog?
- Have your feelings changed about having a guide dog from the time you applied for the dog a year ago until now?
- What emotions would you use to describe the relationship between you and your dog?
- Has having the dog impacted on the relationships you share with family and friends, how does this make you feel?
- If you were to start the process again, knowing what you know today, how would you feel about applying again?
- Do you think your mobility and independence has changed since you've had the dog, how does this make you feel?
- Do you feel your level of social acceptance has changed since you got your dog?
- Do you think having the dog has changed you in any way?
- Do you feel you have a bond with the dog, can you describe it and how it makes you feel?
- Do you feel your reasons for applying for the guide dog been met?
- What do you feel is the most significant role the dog fulfils in your life?
- Do you travel to more places since you have had the dog?
- Has the dog served to meet any of your social/emotional needs? If so, please explain how.
- Do you feel your independence has changed since you have been working with your dog?
- Have your feelings of isolation changed since you received the dog?

**Appendix 5 – Beck Depression Inventory (BDI) questionnaire (Beck et al. 1961)**

Choose one statement from among the group of four statements in each question that best describes how you have been feeling during the **past few days**. Circle the number beside your choice.

**1**

- 0 – I do not feel sad.
- 1 – I feel sad.
- 2 – I am sad all the time and I can't snap out of it.
- 3 – I am so sad or unhappy that I can't stand it.

**2**

- 0 – I am not particularly discouraged about the future.
- 1 – I feel discouraged about the future.
- 2 – I feel I have nothing to look forward to.
- 3 – I feel that the future is hopeless and that things cannot improve.

**3**

- 0 – I do not feel like a failure.
- 1 – I feel like I have failed more than the average person.
- 2 – As I look back on my life, all I can see is failure.
- 3 – I feel I am a complete failure as a person.

**4**

- 0 – I get as much satisfaction out of things as I used to.
- 1 – I don't enjoy things the way I used to.
- 2 – I don't get any real satisfaction out of anything anymore.
- 3 – I am dissatisfied or bored with everything.

**5**

- 0 – I don't feel particularly guilty.
- 1 – I feel guilty a good part of the time.
- 2 – I feel quite guilty most of the time.
- 3 – I feel guilty all of the time.

**6**

- 0 – I don't feel I am being punished.
- 1 – I feel I may be punished.
- 2 – I expect to be punished.
- 3 – I feel I am being punished.

**7**

- 0 – I don't feel disappointed in myself.
- 1 – I am disappointed in myself.
- 2 – I am disgusted with myself.
- 3 – I hate myself.

**8**

- 0 – I don't feel I am any worse than anybody else.
- 1 - I am critical of myself for my weaknesses or mistakes.
- 2 – I blame myself all the time for my faults.
- 3 – I blame myself for everything bad that happens.

**9**

- 0 – I don't have any thoughts of killing myself.
- 1 – I have thoughts of killing myself, but I would not carry them out.
- 2 – I would like to kill myself.
- 3 – I would kill myself if I had the chance.

**10**

0 – I don't cry any more than usual.

1 – I cry more now than I used to.

2 – I cry all the time now.

3 – I used to be able to cry, but now I can't cry even though I want to.

**11**

0 – I am no more irritated by things than I ever am.

1 – I am slightly more irritated now than usual.

2 – I am quite annoyed or irritated a good deal of the time.

3 – I feel irritated all the time now.

**12**

0 – I have not lost interest in other people.

1 – I am less interested in other people than I used to be.

2 – I have lost most of my interest in other people.

3 – I have lost all of my interest in other people.

**13**

0 – I make decisions about as well as I ever could.

1 – I put off making decisions more than I used to.

2 – I have greater difficulty in making decisions than before.

3 – I can't make decisions at all anymore.

**14**

0 – I don't feel that I look any worse than I used to.

1 – I am worried that I am looking old or unattractive.

2 – I feel that there are permanent changes in my appearance that make me look unattractive.

3 – I believe that I look ugly.

**15**

- 0 – I can work about as well as before.
- 1 – It takes an extra effort to get started at doing something.
- 2- I have to push myself very hard to do anything.
- 3 – I can't do any work at all.

**16**

- 0 – I can sleep as well as usual.
- 1 – I don't sleep as well as I used to.
- 2 – I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
- 3 – I wake up several hours earlier than I used to and cannot get back to sleep.

**17**

- 0 – I don't get more tired than usual.
- 1 – I get tired more easily than I used to.
- 2 – I get tired from doing almost anything.
- 3 – I am too tired to do anything.

**18**

- 0 – My appetite is no worse than usual.
- 1 – My appetite is not as good as it used to be.
- 2 – My appetite is much worse now.
- 3 – I have no appetite at all anymore.

**19**

- 0 – I haven't lost much weight, if any, lately.
  - 1 – I have lost more than 5 kilograms.
  - 2 – I have lost more than 10 kilograms.
  - 3 – I have lost more than 15 kilograms.
- (Score 0 if you have been purposely trying to lose weight)

**20**

- 0 – I am no more worried about my health than usual.
- 1 – I am worried about physical problems such as aches and pains, or upset stomach, or constipation.
- 2 – I am very worried about physical problems, and it's hard to think of much else.
- 3 – I am so worried about my physical problems that I cannot think about anything else.

**21**

- 0 – I have not noticed any recent change in my interest in sex.
- 1 – I am less interested in sex than I used to be.
- 2 – I am much less interested in sex now.
- 3 – I have lost interest in sex completely.

**Total score =**

**Scoring**

- 1 – 10: These ups and downs are considered normal.
- 11-16: Mild mood disturbance.
- 17-20: Borderline clinical depression.
- 21-30: Moderate depression.
- 31-40: Severe depression.
- Over 40: Extreme depression.

**Appendix 6 – Extract from a participant’s annotated interview transcript (coded)**

And having spoken to a couple of my friends that have got the guide dogs, they’ve told me a few things that they wouldn’t . even have picked up. One of them was yesterday, I was talking to my friend who got my dog, she said she would have never picked this up, but a couple of men, that the dog can pick up that they don’t like. So when she takes the dog out, sometimes the dog will sniff people if they’re a friend. But there’s a couple that the dog won’t go near. So that tells her, that the dog doesn’t like them for some reason. And that’s one thing that I would have never picked up. But she actually told me that. So, I think for our independence and mobility and safety, I think the dog has all of that to cover, absolutely. Because we have the cane, but the cane doesn’t always pick up the potholes that you might fall down, or, you know what I mean? Whereas the dog, the dog wouldn’t lead you on that road. So that’s probably a lot more beneficial. Because, see, years ago I didn’t know nothing about guide dogs or anything. And I thought initially, I thought you had to be totally blind to have a dog, and you did have to be, but nowadays

Feeling hopeful that having a Guide Dog will increase feelings of personal safety

Feeling hopeful that having a Guide Dog will increase independence with daily life, in particular mobility



you don't have to be. They would rather train you with the dog while you have a little bit of sight, because that enables you to learn quicker. To get to know the dog and the dog get to know you, and it's a lot easier for training I believe, that's what I've been told anyway. So yeah, I definitely will be getting a dog, I'd just love it. But I've just lost my dad, my sister had cancer, my twin sister, coz she's got bad eyesight as well, the same sort of eye condition. And she had a massive haemorrhage in her opposite eye than mine, so we've both been through a lot of depression lately. So we, I'm just not ready, I'm not going to be able to cope. Because the two ladies, they said it is a very severe training program, and I want to be able to do it when I'm in the right frame of mind. So yes, that will be another thing in my near future. Because I like to go away to see my children and stuff too, and I know on the train that you can take the dog with you. Coz I've already spoken to the railways, and they've told me all that, that you can and all that sort of stuff.

Feelings of depression due to family/social situation and

Feelings of apprehension about acquiring a Guide Dog ("not ready" and concerned about not being "able to cope", needing to be in "the right frame of mind").

## Appendix 7 – Participant information sheet



*FACULTY OF MEDICINE*  
Department of Psychiatry

Chris Muldoon  
Eleanor Harrauld Building

Level four

THE UNIVERSITY OF ADELAIDE  
SA 5005

AUSTRALIA

### **A study exploring your journey with your guide dog**

#### **INFORMATION FOR PARTICIPANTS**

You know me as the Manager of the Royal Society of the Blind Guide Dog Services Manager. You may not know that I am also doing a PhD at the University of Adelaide.

In my research I am interested in what it is like to apply for a Guide Dog, to train with that dog, and to work with that dog as part of a team. I am really interested in your experiences – what is it like for you?

I am interested in your experiences generally, but also I am interested in your emotions – how you are feeling. Therefore, the interviewer will also ask if you would be willing to complete a questionnaire on depression. I am not interested in only depression though, I am interested in positive emotions too.

Because of my role as Manager, I have asked a Psychology student to help me, by asking them to conduct interviews for my study. I will not know what you have said - that is, you will not be identifiable – because she will transcribe the tape-recording (if you give permission for the interview to be taped) – and I she will remove your name and anything that identifies you from the transcript. I will never hear the tape. Your name will not be on

the depression questionnaire. However, because the number of people applying for a Guide Dog is small, there is a possibility I will recognise something in the interview that identifies you to me. But all steps will be taken to prevent that.

I would like you to be one of the people who the student interviews. I would like her to interview you four times: when you are applying for the dog, then later, when you have the dog, and then finally, after you and the dog have been working together for a while.

If you agree to participate, I will pass your case on to another RSB employee – I will not be involved in allocation of a dog to you, or in any decisions that might impact you in any way in relation to the Guide Dog Service.

If you agree to participate, your participation is voluntary – you can choose to discontinue at any time, without any negative consequences whatsoever.

I will write some papers based on the research, to enable me to submit a thesis for my PhD. You will not be identifiable in any of the papers or any presentations I give. I will give you a summary of the results in your preferred format (Braille, tape or large print), once they are ready, and I will also give you a transcript of the interview (via the student interviewer), if you would like one.

My supervisors are Professor Anna Chur-Hansen and Dr Susan Hazel. Anna is a Psychologist and Susan is a Veterinarian. If you would like to speak to either of them about this research, at any time, you can contact Anna on 8222 5785 (email [anna.churhansen@adelaide.edu.au](mailto:anna.churhansen@adelaide.edu.au)) and Susan on 8303 7828 (email [susan.hazel@adelaide.edu.au](mailto:susan.hazel@adelaide.edu.au)).

If you have any questions please do not hesitate to contact me on xyz.

I will pass your details on to the student interviewer, who will call you for a time to see you, if you wish to participate. If you decide not to, please let the student know when she calls.

With kind regards,

Chris Muldoon

**Appendix 8 – Participant consent form**



**FACULTY OF MEDICINE**  
Department of Psychiatry

Chris Muldoon  
Eleanor Harrauld Building

Level four

THE UNIVERSITY OF ADELAIDE  
SA 5005

AUSTRALIA

DATE

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

**STANDARD CONSENT FORM**

**FOR PEOPLE WHO ARE PARTICIPANTS IN A RESEARCH PROJECT**

1. I, ..... *(please print name)*

consent to take part in the research project entitled: ...

Your Journey with your guide dog, .....

2. I acknowledge that I have read the attached Information Sheet entitled:

A study exploring your journey with your guide dog

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the interviewer. My consent is given freely.

4. I understand the nature of the project and the need to collect information and agree to have interviews taped.

5. I understand that at the conclusion of the study I can have a transcript of interviews and the results of the study in my preferred format.

THE EMOTIONS AND FEELINGS EXPERIENCED BY GUIDE DOG OWNERS

- 6. Although I understand that the purpose of this research project is to improve the understanding of the journey, for blind and vision impaired people, towards choosing to use and using a guide dog, it has also been explained that my involvement may not be of any benefit to me.
- 7. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
- 8. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
- 9. I understand that I am free to withdraw from the project at any time and that this will not affect me in any way, now or in the future.
- 10. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

.....

*(signature)*

*(date)*

**WITNESS**

I have described to ..... *(name of subject)*

the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project: .....

Name: .....

.....

*(signature) (date)*

**Appendix 9 – Ethics approval from the University of Adelaide**



RESEARCH BRANCH  
OFFICE OF RESEARCH ETHICS, COMPLIANCE AND  
INTEGRITY

SABINE SCHREIBER  
SECRETARY  
HUMAN RESEARCH ETHICS COMMITTEE  
THE UNIVERSITY OF ADELAIDE  
SA 5005  
AUSTRALIA

TELEPHONE +61 8 8313 6028  
FACSIMILE +61 8 8313 7328  
email: [sabine.schreiber@adelaide.edu.au](mailto:sabine.schreiber@adelaide.edu.au)  
CRICOS Provider Number 00123M

18 December 2012

Professor A Chur-Hansen  
School of Medicine

Dear Professor Chur-Hansen

**PROJECT NO: H-227-2010**  
***An exploration of the emotional impact of acquiring a Guide Dog***

Thank you for your report on the above project. I write to advise you that I have endorsed renewal of ethical approval for the study on behalf of the Human Research Ethics Committee.

**The expiry date for this project is: 31 December 2015**

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

A handwritten signature in cursive script that reads 'S. Schreiber'.

*per* Dr John Semmler  
Acting Convenor  
Human Research Ethics Committee

**Appendix 10 – Ethics approval from Flinders University**

**MODIFICATION (No.2) APPROVAL NOTICE**

Project No.:

<b>8206</b>
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Project Title:

An exploration of the emotional impact of acquiring a Guide Dog
---

Principal Researcher:

Mr Christopher Muldoon
------------------------

Email:

<a href="mailto:christopher.muldoon@flinders.edu.au">christopher.muldoon@flinders.edu.au</a>
--

Modification  
Approval Date:

20 July 2020
--------------

Ethics Approval Expiry  
Date:

<b>31 October 2020</b>
------------------------

I am pleased to inform you that the modification request submitted for project 8206 on the 18 July 2020 has been reviewed and approved by the Chairperson. A summary of the approved modifications are listed below. Any additional information that may be required from you will be listed in the second table shown below called 'Additional Information Required'.

Approved Modifications	
Extension of ethics approval expiry date	*
Project title change	
Personnel change	
Research objectives change	
Research method change	
Participants – addition +/- change	
Consent process change	
Recruitment process change	
Research tools change	
Document / Information Changes	
Other (if yes, please specify)	

**Additional Information Required**

Noted on 04/06/21 from email to human.researchethics@flinders.edu.au  
human.researchethics@flinders.edu.au;

Hi Chris,

Thanks for reaching out – I am working the Ethics Officer role now, and hope I can help you out.

**As long as you have completed your data collection, and require no more participants, then the submission of your thesis doesn't affect your ethics. No, you do not need to reapply.**

Camilla

---

**Camilla Dorian (BSc) Hons**

Human and Animal Research Ethics Officer

*Research Ethics and Compliance*

Research Development and Support (DVCR)

Registry Building Basement

Flinders University

Sturt Road, Bedford Park, South Australia, 5042

GPO Box 2100, Adelaide, South Australia, 5001

**P:** +61 8 8201 2255

**E:** Camilla.dorian@flinders.edu.au

[www.flinders.edu.au/research/researcher-support/](http://www.flinders.edu.au/research/researcher-support/)

<https://staff.flinders.edu.au/research/integrity>



## RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

### 1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).*

### 2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)*; please be reminded that; an annual progress report must be submitted each year on the **26 November** (approval anniversary date) for the duration of the ethics approval using the report template attached.

**Please note** that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please either submit (1) a final report; or (2) an extension of time request (using the modification request form).

Next Report Due Date:

**26 November 2019**

Final Report Due Date:

**31 October 2020**

#### Student Projects

For student projects, the SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

### 3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, researchers and supervisors)
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the [Managing Your Ethics Approval SBREC web page](#). Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests must be submitted before ethics approval has expired for the project.

Change of Contact Details

If the contact details of researchers, listed in the approved application, change please notify the Committee so that the details can be updated in our system. A modification request is not required to change your contact details; but would be if a new researcher needs to be added on to the research / supervisory team.

#### 4. Adverse Events and/or Complaints

Researchers should advise the [Executive Officer](#) immediately on 08 8201-3116 or [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au) if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards

Andrea

---

**Andrea Mather**

Executive Officer, Flinders University Human Research Ethics Committee (FU HREC)  
Research Development and Support | [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au)  
P: (+61-8) 8201 3116 | [andrea.mather@flinders.edu.au](mailto:andrea.mather@flinders.edu.au)

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GPO Box 2100, Adelaide, South Australia, 5001

[http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics\\_home.cfm](http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm)

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