

# **Working in the dark— what contributes to and supports the employment of people who go blind in midlife?**

---

**Bruce Blackshaw**

**A thesis submitted in fulfilment of the requirements  
for the degree of Master of Education (Research)  
University of Technology Sydney  
2014**

# Certificate of original authorship

---

I certify that the work in this thesis has not previously been for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Student:

Production Note:  
Signature removed prior to publication.

Date: 16 October 2014

# Acknowledgements

---

I would like to thank my primary supervisor Dr Tony Holland for his support and guidance during the period of this study. His comments and understanding during the various machinations of the thesis and the research itself has been invaluable.

I would also like to acknowledge and thank Emeritus Professor David Boud for his groundwork and the underlining themes of the research.

I also acknowledge the assistance of the various blindness associations referred to in this thesis, and I note that this thesis was copyedited for conventions of language, spelling and grammar by Suzanne Egging at Textwork editing. Without participants there would be no research or research outcomes therefore I would like to thank all of the participants who responded to requests for interviews and the openness of their replies and personal situations. Their honesty and openness allowed for a more informed vision of the issues of the participants.

My biggest and greatest supporter of any work or activity that I undertake is my wife. Therefore, I must acknowledge and thank my wife, Sylvia, for her undying, unfailing and total support for my research and my journey from my loss of vision to the thesis completion.

# Abstract

---

This study investigated and analysed the conditions that can assist individuals who lose vision in midlife regain or retain employment post blindness. Australia Bureau of Statistics figures reveal that in 2012 the overall employment rate of disabled individuals was approximately 54%, compared with 94% for non-disabled individuals. This figures mirror international rates. Vision Australia estimates that individuals who are blind or who have low vision and want to work have an employment rate below 42%.

Through qualitative research methods employing case study methodologies, and using semi-structured interviews the study revealed commonalities among individuals who lost their vision midlife and were employed. Participants' ages ranged from 30 to 64. The participants came from five states in Australia. The theoretical framework of social assumptions, along with the lack of awareness of disabled individuals and in particular blind individuals, was investigated. Through the ethnographical lens of the author from sudden vision loss to the re-establishment of himself provides a context of the emotional and personal aspects of midlife vision loss.

The major findings were the identification of three factors that participants described as impacting on their return to employment post blindness. These were the presence of multiple support networks, the availability of relevant vocational and non-vocational education and the need to deal with the lack of community awareness of the abilities of individuals who are blind.

Participants suggested that individuals who lose vision in midlife generally have no understanding of blindness and the changes it will require them to make in their lives. Vision loss typically requires individuals to reinvent themselves and actively seek to participate in new communities that were unknown to them before they lost their vision.

Participants agreed that midlife vision loss creates unexpected hurdles for those who want to work. Analysis of their responses indicated the need for support to help the individual to reassess their career and develop an action plan, formal or informal, along with the need to gain new skills to increase their employability in their new career direction. Participants' narratives also showed that individuals have to learn ways to manage social stereotypes about disabled people, particularly the blind,

including the need to re-educate the people they encounter in seeking and carrying out employment.

The study concludes by presenting recommendations and strategies to increase the employment rates of individuals who lose vision in midlife.

*Keywords:* midlife blindness, employment, disability, blindness,

# Contents

---

<b>ACKNOWLEDGEMENTS</b> .....	<b>III</b>
<b>ABSTRACT</b> .....	<b>IV</b>
<b>CONTENTS</b> .....	<b>7</b>
<b>FIGURES</b> .....	<b>12</b>
<b>TABLES</b> .....	<b>12</b>
<b>CHAPTER ONE INTRODUCTION</b> .....	<b>13</b>
Introduction.....	13
The origin and focus of the study.....	13
Background: definitions of blindness and disability .....	14
Blindness as a social construct .....	16
Economic aspects of blindness.....	21
The rights of the disabled and self-advocacy .....	21
The study .....	23
Research question .....	24
Justification and significance of the study .....	25
Contribution to knowledge .....	26
Research objectives and scope .....	27
<b>CHAPTER TWO DEFINITIONS, LITERATURE REVIEW AND FRAMEWORK</b> .....	<b>28</b>
Chapter Two Sections .....	29
1. Definitions relating to blindness.....	29
Definitions of blindness .....	29
Visual Acuity & Field of view .....	29
Handicap Severity levels .....	29
2. Statistics, policies & Acts .....	29
Worldwide disability statistics .....	29
Cost of disability .....	29
Disability Discrimination Act .....	29
NDIS .....	29
Employment factors .....	29
Career Stages in midlife .....	29
Blindness & Employment rates .....	29
Specialist employment agencies .....	29
Employment assistance.....	29
Summary & Discussion.....	29
3. Existing Research .....	29
Introduction.....	29
Social construct .....	29
Classifications.....	29

Support frameworks .....	29
Mentors, sponsors & significant others .....	29
Education & employment.....	29
Education & employment.....	29
Discussion.....	29
4. Theoretical propositions & questions .....	29
Section One -. Definitions relating to blindness .....	30
Definitions of Blindness .....	30
Section Two - Disability statistics, Acts and public policies.....	35
Worldwide disability statistics .....	35
Cost of disability.....	36
Disability Support Pension (DSP) and poverty levels .....	36
Disability Discrimination Act.....	37
National Disability Insurance Scheme (NDIS).....	38
Employment factors .....	38
Career stages and midlife.....	39
Blindness and employment rates.....	41
Specialist employment agencies.....	42
Government assistance to employers.....	42
Summary.....	43
Discussion.....	45
Section 3 - Existing Research.....	45
Introduction .....	45
Disability as a social construct.....	46
Classifications .....	47
Support frameworks .....	47
Employment support frameworks.....	48
Mentors, sponsors and significant others .....	48
Relationship between education and employment.....	49
Discussion.....	50
Section 4 - Theoretical propositions and questions.....	51
<b>CHAPTER THREE METHODOLOGY.....</b>	<b>53</b>
Introduction.....	53
Case study methodology .....	54
Different lens .....	57
Auto-ethnographic lens.....	57
Selection of participants for the case study.....	59
Participant criteria.....	60
Recruitment plan.....	60
Recruitment methods.....	61
Recruitment method 1: email and word of mouth.....	61
Recruitment method 2: blindness associations .....	62
Recruitment method 3: disabled radio interview .....	62
Participant interviews .....	63
Identification of potential participants.....	64



Participants.....	65
Ethical considerations .....	65
Informed consent.....	65
Confidentiality.....	66
Interview strategies .....	67
Interview preamble.....	69
Interview technique .....	69
Semi-structured interviews.....	71
Developing the interview guide.....	72
Initial interview guide .....	72
The final interview guide.....	73
Pilot testing.....	73
Interview preparation.....	73
The interviews .....	74
The interview process.....	74
Individual participant profiles .....	75
Concluding remarks .....	80
<b>CHAPTER FOUR DATA ANALYSIS.....</b>	<b>81</b>
Introduction.....	81
Interview progress.....	84
Thematic coding and analysis bias within disability studies.....	85
Qualitative analysis process.....	85
Data analysis .....	86
Familiarisation .....	86
Identifying thematic frameworks .....	88
Indexing.....	90
Charting.....	91
Mapping and interpretation .....	92
Multiple software use.....	93
Data collection and transcription hardware.....	93
Participant data .....	94
Chapter summary.....	96
<b>CHAPTER FIVE FINDINGS AND DISCUSSION OF THE PARTICIPANT</b>	
<b>INTERVIEW DATA .....</b>	<b>97</b>
Introduction.....	97
Discontinued themes.....	99
Transport .....	99
Financial situation .....	101
Blindness associations .....	105
Medical condition and level of handicap.....	107
Summary .....	108
Support networks .....	109
Emotional networks.....	109
The journey .....	110
The journey begins.....	112

Psychologist, counselling and therapy groups .....	116
Family support networks .....	118
Summary of emotional support networks .....	120
Employer and co-worker support networks .....	121
Summary .....	127
Training and technology .....	128
Holistic training needs assessment .....	130
Employment service: participant perspective .....	131
Employment service: provider perspectives .....	133
Challenges facing those seeking employment .....	134
Adaptive technologies .....	136
Training needs .....	138
Summary .....	145
Awareness and discrimination .....	149
Discrimination .....	150
Participants' views on discrimination .....	152
Awareness .....	154
General society .....	155
Significant others .....	156
Awareness and co-workers .....	156
Self-awareness .....	158
Summary .....	159
Contextualising themes .....	160
Affordance and engagement .....	160
Affordances and engagement framework .....	162
Bounded agency framework .....	163
Chapter summary .....	165
<b>CHAPTER SIX CONCLUSION AND EVALUATION.....</b>	<b>168</b>
Conclusions of the study .....	168
Addressing sub-questions of the study .....	172
Summary of the sub-questions .....	186
Evaluation of the research .....	190
Limitations of the study .....	190
Strengths of the study .....	191
The participant–researcher relationship .....	191
Implications for future research .....	191
<b>REFERENCES .....</b>	<b>194</b>
<b>APPENDICES .....</b>	<b>205</b>
<b>APPENDIX A PREPARATORY RESEARCH TOOLS .....</b>	<b>206</b>
A1. Proposed interview schedule .....	206
A2. Interview script .....	207
A3. Interview preamble and questions .....	207
A4. Questionnaire .....	210
<b>APPENDIX B CONSENT FORM.....</b>	<b>211</b>

Participant consent form.....	211
<b>APPENDIX C DATA COLLECTION TOOLS.....</b>	<b>213</b>
C1. Interview guide .....	213
C2. Email exchanges with participants.....	214
<b>APPENDIX D DATA ANALYSIS TOOLS.....</b>	<b>223</b>
D1. Phase one codebook .....	223
D2. Phase three codebook.....	231
D3. Data visualisation—code applications greater than five times.....	235
<b>APPENDIX E AUTOBIOGRAPHICAL OBSERVATIONS.....</b>	<b>237</b>

---

# Figures

---

Figure 2.1: Map of the field of view .....	32
Table 2 Participant demographics .....	79
Figure 4.1: Typical quantitative research phases.....	83
Figure 4.2: Typical qualitative research phases .....	86
Figure 4.3: States of origin for research participants.....	96
Figure 5.1 Comparison of average weekly earnings across industry sectors .....	103
Figure 5.2: Employment supply and demand .....	134
Figure 5.3: The Vision Australia logo explained. ....	138
Figure 6.1: Links and relationships between the individual and communities.....	188

# Tables

---

Table 2.1: Vision classifications (Spriggs 2007).....	31
Table 2.2: Severity levels .....	33
Table 2.3 Comparison of payments to blind people in relation to the estimated poverty line .....	37
Table 5.1: Accessible sydney buses.....	100
Table 5.2: Interviewee qualifications attained post blindness .....	141
Table 6.1: Disability prevalence by age range.....	169

## Chapter one

# Introduction

---

### **Introduction**

In this chapter, I present the study's aims and goals, including a brief explanation of the origins of and impetus for the study. The chapter opens with a general overview of blindness and its effects worldwide. I then introduce the relevant constructs, definitions and perceptions of blindness and outline the economic aspects of blindness. I introduce the issues of self-advocacy and the rights of the disabled. The chapter then outlines the study's methodology and its main and subsidiary questions. In the final section of the chapter I outline the significance of the research and its contribution to knowledge.

### **The origin and focus of the study**

The impetus for this research lies in my own experience of living with midlife vision loss. I lost my vision in mid-2010. This research was sparked by my gradual realisation that a high proportion of blind people are unemployed after vision loss and my belief that we need to better understand the issues blind people have to face. This research investigates the situations and experiences of people who have lost their vision when

they are between 30 and 60 years of age and who have gained employment after their vision loss. The research focuses on the employment and training requirements of individuals who experience midlife blindness. The research describes how individuals interpret and perceive their vision loss and explores their understandings of their needs and experiences in gaining employment.

### **Background: definitions of blindness and disability**

The World Health Organization (WHO), estimates in various fact sheets that in 2010 there were 44 million blind people worldwide (World Health Organization 2012b, p. 1). The social losses and the socio-economic impact of rehabilitation, treatment and loss of production are incalculable (Crewe, J. et al. 2012).

To protect the rights of people with disabilities the WHO has formulated the *Convention on the Rights of Persons with Disabilities*. The Convention outlines “the civil, cultural, political, social and economic rights of people with disabilities” (World Health Organisation 2014). The convention explains that disabled people should be entitled to education, employment, health and freedom from discrimination. This charter has been accepted across the world and various countries have legislated for the rights of the disabled, e.g. the *Australian Anti-discrimination Act 1997* (Basser, L.A. & Jones, M. 2002). However, such legislative rules may not

alter peoples' perceptions of people with disabilities. The WHO and a recent World Bank research report suggest that perceptions, attitudes and discriminatory practices "can only be solved by solid evidence, good science, and sound scholarship" (Bickenbach, J. 2011, p. 658). This study investigates these social constructs towards individuals who go blind in mid life and the resulting employment opportunities for them.

The typical perception of blindness, is of a person who experiences total loss of sight or who has no light awareness (Guide Dogs , N.A. 2012). However, in Australia the blindness community classifies blindness into three categories: vision impaired, legally blind and totally blind (Vision Australia 2012b). The WHO uses four classifications of vision: normal vision, moderate visual impairment, severe visual impairment and blindness (World Health Organization 2012b). I discuss these classification systems further in chapter two.

Blindness is defined in terms of either a person's (in)ability to see objects at standard distances and/or their visibility within a field of view. Two groups that are easily identifiable are the totally blind (who have no vision at all) and those who have a visual impairment. The group that does not fit into either category is the 'legally blind'. The definition of legally blind is that such a person has a degree of vision and light awareness, yet cannot function as an individual with normal vision. Many of these people

are in a borderline zone of blindness (Omansky, B. 2011). The confusion is that they are defined as blind yet still have limited vision (Kivelä, T. 2010), although not enough to be considered fully functional. Research suggests that each classification brings with it its own expectations and problems (Bell, E.C. & Mino, N.M. 2013; Omansky, B. 2011; Worth, N. 2013).

Across the world the definitions and categorisations of blindness are similar. In Australia, the United Kingdom and many other countries blindness begins with a Snellen vision score of 6/60. Normal vision is 60/60. This will be explained in more detail in chapter two. The 6/60 visual acuity rating is used in government policy to determine eligibility for welfare concessions, services and payments (Vision Australia 2012b).

### **Blindness as a social construct**

Blindness is a widely misunderstood and poorly defined condition.

Historically, blindness has been conceived of within medical and social models. These models will be explained in chapter two. The myths and uncertainties around blindness were summed up as follows by the psychoanalyst A. Robert Blank in 1957:

Society is strongly ambivalent towards the blind, about whom the sighted have contradictory and paradoxical beliefs. The blind are both saints and sinners, pariahs and prophets. Most blind persons have lived with this dichotomy of beliefs, which dates back to ancient times. Thus, one finds that folk beliefs are divided into two groups. On the negative



side of this dichotomy are the beliefs that blind people are either helpless and pathetic or evil and contagious and probably deserve their fate. On the more positive side are the beliefs that blind people have special or even magical abilities, special powers of perception, and deserve special attention. Blank, cited in Wagner-Lampl, A. and Oliver, G.W. (1994

Disability models have progressed since the 1970's, with researchers shifting away from definitions of disability in terms of the medical model and what has been called the 'personal tragedy perspective'. Instead, we have seen the emergence of a 'social model of disability', in which disability is interpreted as "the way in which physical, cultural and social environments exclude or disadvantage certain categories of individual, namely individuals labeled 'disabled'" (Davis, J.M. 2000, p. 194).

When we interpret blindness as a socially constructed condition, we recognise that visually impaired individuals self-classify according to the extent of the social restrictions on them or, as Oliver and Barnes put it, "the emphasis shifts to how far, and in what ways, society restricts their opportunities to participate in mainstream economic and social activities rendering them more or less dependent." (Oliver, M. & Barnes, C. 2010, p. 548).

These social constructions around blindness, the limitations and restrictions that non-blind people unwittingly apply to blind people—are present in the workplace in the attitudes and actions of employers and co-

workers, governments and the general population. These constructs and expectations, whether they be correct or not, can, and do cause disabled people to view social actions as discriminatory or at the very least stigmatising (Benoit, C. et al. 2012).

Discrimination and stigmatisation issues were some of the driving forces that moved the WHO to create the *Convention for Disabled People*. The convention for disabled people created the guidelines to protect the rights of disabled people toward the “equal enjoyment of the human rights and fundamental freedoms of people with disabilities and prompt respect for their inherent dignity” (World Health Organisation 2014, p. 1). The notion of stigmatisation draws on sociologist Erving Goffman’s use of the concept to explain social exclusion. Goffman (1963, 3) wrote that stigma “spoils identities”, disqualifying individuals “from full social acceptance” and reducing them “from a whole and usual person to a tainted, discounted one”. The stigmatisation of disabled individuals based on their physical or psychological differences builds or assists to build towards a social construct of disabled individuals as a disabled group or community.

Goffman suggested that stigmas are commonly organised into three main types: tribal stigmas are based on race or other identity categories, behavioural stigmas are rooted in deviant conduct, and bodily stigmas are linked to observable deformities (Goffman 1963). As Benoit et al. point out:

Groups of people who share characteristics with those who deviate ethno-culturally, behaviorally, or physically from dominant norms and values are subject to prejudice that results in social exclusion from society's main resources, such as housing, education and participation in the labour force. (Link, 2001 as cited in Benoit, C. et al. 2012)

Prejudice and social exclusion are factors that may impact on an individual's ability to gain employment. For the purposes of this study discrimination and stigmatisation will be called discrimination.

According to Anderson discrimination can be both real (actual) and unreal (imagined). Imagined discrimination may arise when the emotional state of the newly blind person leads them to perceive discrimination around them (Anderson, N. 2011). The emotions experienced due to vision loss and the need for ongoing counselling and rehabilitation are all issues that must be considered in any discussion of vision loss (Thurston, M., McLeod, J. & Thurston, A. 2013).

The loss of vision is a major emotional hurdle to overcome. Many people become depressed and need counselling (Hodge, S. et al. 2013). In recognition of this, various counselling services are provided across the world (Hodge, S. et al. 2013; Omede Andrew, A. & Tenimu, S. 2013; Thurston, M., McLeod, J. & Thurston, A. 2013). Hodge states that counselling helps those who have lost vision to "normalize their experiences by talking to an impartial listener" and that this can help them

“to accept and adapt to the physical, emotional and social changes in their lives resulting from their visual impairment” (Hodge, S. et al. 2013, p. 5). In Hodge et. al’s study, participants had a mean age of 65, an age demographic where there is a higher rate of age-related macular degeneration (AMD) than in the sample I have studied. In my study the age range of 30 to 60 is different, the participants’ journey from fully sighted to the world of blindness is not lessened by age or gender (Hodge et al, 2013).

The emotional issues triggered by vision loss have to be overcome before an individual can return to employment, if a person is to be able to work effectively in the workplace. This study indirectly looks at the emotional issues that arise from the diagnosis of blindness and the chilling feeling people experience when they hear the ophthalmologist say “You are blind” or “You are functionally blind and hence legally blind”. While the emotional issues may reduce over time, the individual must undertake a journey of rehabilitation in order to return to employment.

Research has explored the newly blind person’s process of accepting their blindness as part of their rehabilitation. The continuum from the sighted world to that of the blind world is often termed the “blindness journey” (Omansky, B. 2011). This metaphor captures the fact that the transition is an ongoing evolution for the individual. Every

individual has differing needs at differing stages of their rehabilitation.

Many people who are blind attempt to act as if fully sighted. It takes some time to accept their blindness and ultimately adopt the use of a white cane or a guide dog (Goodwyn, M., Bell, E.C. & Singletary, C. 2009; Matti, A. et al. 2011).

### **Economic aspects of blindness**

The economic impact of blindness cannot be calculated on a worldwide basis. It is estimated that there are approximately 300,000 visually impaired or blind people in Australia (Vision Australia 2012a). The number of legally blind individuals in Australia is approximately 32,900 or 0.15% of the population.(Crewe, J. et al. 2012). Including loss of wellbeing, direct health costs and indirect costs, Taylor suggests that “vision disorders cost Australia an estimated A\$9.85 billion in 2004”(Taylor, H.R., Pezzullo, M.I. & Keeffe, J.E. 2006, p. 272). Worldwide it is estimated that vision impairment cost \$3 trillion in 2010, of which approximately \$2.3 trillion was in direct health costs. These figures are expected to increase by 20% by 2020 (Gordois, A. et al. 2012). This increase is due to the expected continued worldwide ageing populations.

### **The rights of the disabled and self-advocacy**

An individual who has lived a fully sighted life and then loses vision later in life has no lived experience of vision loss. Generally newly blinded

individuals do not know about the rights of disabled people. There are eight general principles under the convention of rights of the disabled as outlined below.

“There are eight guiding principles that underlie the Convention and each one of its specific articles:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- b. Non-discrimination
- c. Full and effective participation and inclusion in society
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e. Equality of opportunity
- f. Accessibility
- g. Equality between men and women
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities” (World Health Organization 2015, p. 1)

The newly diagnosed individual commonly has low confidence and limited advocacy skills to be able to access, understand and implement these rights (DeMario, N. 1992; Goodwyn, M., Bell, E.C. & Singletary, C. 2009). In countries around the world that have implemented the WHO *Convention for the Disabled* with its implied rights, the question has been raised as to whether individuals with disabilities are in fact able to exercise these rights.(Benoit, C. et al. 2012). Once an individual gains the knowledge of their rights under the WHO convention, they then have to advocate for the rights to be implemented.

## **The study**

This study investigates the employment aspects confronting people who lose vision in midlife, reporting on their experiences and accounts of their life journeys and of their eventual return to the workforce or the methods they used to maintain their employment. The study is a qualitative study employing semi-structured interviews with participants who satisfied the research criteria. The semi-structured interviews are supported by my auto-ethnographic reflections on my experiences of the impact of the diagnosis and the journey to newfound employment domains. My auto ethnographic account begins with the chilling and life changing impact of the ophthalmologist's diagnosis that I was now blind.

In chapter two I review published studies relevant to my research project. In chapter three I detail the principles behind the semi-structured interview techniques and explain the development of the interviews and the application of the auto-ethnographical lens. This chapter also outlines the data sources, selection criteria, data collection process and principles. In chapter four I provide an overview of the data analysis, coding and sub-coding systems used. The findings based on interviews with the case study participants are presented in chapter five. In chapter six I discuss the conclusions and suggest further research in this area.

### **Research question**

Both the newly blind person and for the people they interact with may experience extremely negative expectations (my expectations early on were that my world had ended). Loss of sight, the social construction of blindness, negative expectations, discrimination, the need for emotional support and vocational rehabilitation combine to create a complex network of concepts that this study explores. Questions that arise include: What factors assist and/or hinder employment after sight loss? How do people gain competitive employment after vision loss? What roles do different types of education and training have in the re-employment process? Who assists the individual most to gain employment after vision loss? These questions can be formulated as one principal research question, with three subsidiary questions. The principal research question is:

- What contributes to and supports the employment of people who go blind in midlife?

The subsidiary questions that arise from this principal question are:

- What roles do education and training play in assisting people who experience midlife vision loss to gain employment?
- How do support frameworks contribute to the employment of people who have midlife blindness?



- In what ways do people who have midlife blindness perceive employment discrimination by society, employers and co-workers?

### **Justification and significance of the study**

Visually impaired people are subjected to many pressures. These include the challenges around the ability to communicate, mobility problems, problems with access to education and to meaningful and complete employment that uses the educational levels they have attained (Boerner, K., Wang, S.-W. & Cimarolli, V. 2006; Crudden, A. 2002). Employment can provide financial independence, a better standard of living and improved physical and mental health. It can also give individuals increased confidence, expanding their social network and social skills, as well as providing opportunities to develop a career by gaining new work skills and knowledge. (Ewing, I. 2011). As mentioned above, statistics show that blind people have a higher rate of unemployment and/or underemployment than the general population (Vision Australia 2012a).

The substantial existing research into blind people and employment includes studies of school leavers and of the perspectives of employers (DeMario, N. 1992; West, S. & Sommer, A. 2001; Wolffe, K. 1999). Research has explored the support and medical requirements of the legally blind and visually impaired elderly (Cavanaugh, B. & Rogers, P. 2002; Lee, I.S. & Park, S.K. 2008). Studies have investigated aspects of overall blindness and employment trends (Bell, E. 2010; Boerner, K., Wang, S.-W. & Cimarolli, V.

2006). However, research into midlife blindness and its effects on employment have been limited and have been conducted those who are not themselves visually impaired or blind.

Research into midlife blindness and employment from an 'insider's' viewpoint, as in this study, can add to our knowledge in this field by allowing a dual perspective on the topic. On the one hand, this study investigates employability from the outside, through interviews and analysis with participants who have experienced midlife blindness. Complementing this, the study also explores midlife blindness from the inside, through a case study of my own experiences of the journey from being fully sighted to being legally blind.

### **Contribution to knowledge**

A person who acquires a visual impairment later in life does not initially understand the enormity of changes they will have to undergo. Becoming visually impaired after living a life without impairment brings hurdles and barriers. These hurdles and barriers can be the personal aspects of life and everyday living that need to be addressed. They can also be the impact of social constructs of the blind, i.e. discrimination. There has been limited research into the employment barriers that midlife blindness brings. This research begins to fill that gap.

## **Research objectives and scope**

The research explores the employment issues faced by people who have lost vision in midlife. The study is conducted through the lens of participants' lived experiences to gain rich insights into their interpretations of their situations and experiences. The objective of the research is to better understand the employment issues that confront individuals who lose vision in midlife. The study's overall aims are:

1. to describe the barriers to employment for individuals who lose vision in midlife
2. to identify some of the supporting factors that assist such individuals to gain employment.

The scope of the research is limited to that of people who have lost vision between the ages of 30 and 60, gained employment after their loss of vision and who have only one impairment, i.e. blindness. The research describes the participants' experiences and their perceptions of the phenomenon of midlife blindness. In the next chapter I review published research relevant to the research topic.

## Chapter two

# Definitions, literature review and framework

---

This chapter is presented in four sections Section One definitions; Section Two Statistics, policies & Acts, Section Three, existing research, and Section Four, the theoretical framework of the study. The definitions are necessary to allow for a deeper understanding of the issues that are always in the background for the blindness community. The various disability statistics, policies and acts are presented to give the reader a holistic view of the underlying issues. The review of existing research establishes the gap in knowledge about midlife blindness and employment. The description of the theoretical framework outlines the approach that underpins this study. The following table presents the sections and how they relate to each other.

<b>Chapter Two Sections</b>		
1. Definitions relating to blindness	Definitions of blindness	Visual Acuity & Field of view
		Handicap Severity levels
2. Statistics, policies & Acts	Worldwide disability statistics	Cost of disability
	Disability Discrimination Act	
	NDIS	
	Employment factors	Career Stages in midlife
		Blindness & Employment rates
		Specialist employment agencies
		Employment assistance
		Summary & Discussion
3. Existing Research	Introduction	
	Social construct	
	Classifications	
	Support frameworks	Mentors, sponsors & significant others
		Education & employment
		Education & employment
	Discussion	
4. Theoretical propositions & questions		

## **Section One - . Definitions relating to blindness**

### **Definitions of Blindness**

Physical and sensory impairments can be of varying degrees of severity. The World Health Organisation (WHO) defines different levels of blindness (World Health Organization 2012b, p. 580), as explained in the following sections.

The WHO standard states that blindness is defined by measuring a person's visual acuity as well as their field of vision. The combination of acuity and field of vision determine an individual's functional vision. A person may be classified as either blind or legally blind, with a third classification of low vision.

### ***Visual acuity***

Visual acuity is the ability to read and detect objects at varying distances. It is measured using vision charts. The top line of the chart displays a very large letter, which the average person would be able to see at a distance of 60 metres. However, a person who is legally blind may only be able to see the same letter at six metres.

Normal vision means that an individual can read the top line at the correct distance from the chart. The vision of a normal person is described by the expression 60/60.

Legally blind people are those whose visual acuity is 6/60 or worse in the better eye. This means that the legally blind person can see an object at the distance of six metres compared with the normal sighted person who could see the same object at

60 metres. This effectively means that the legally blind person can only read the top line on a vision chart (Vision Australia 2012b). Using this method of measurement, an individual's vision level can be described as 6/12 or 6/24 etc. This is not a fraction or ratio but a comparison of visible distance. Table 2.1 summarises the standard descriptions of categories of blindness.

<b>Definition</b>	<b>Description</b>
<b>Totally Blind</b>	Legally blind, with no usable residual vision. Totally blind is defined as having visual acuity of less than 3/60 or no usable sight.
<b>Partial Blindness</b>	Legally blind, but with some usable residual vision. Legally blind or partially blind means having visual acuity of less than 6/60 and have some usable sight.
<b>Low Vision</b>	Vision impaired such that glasses cannot correct. Visually impaired or low vision means having visual acuity of less than 6/24

**Table 2.1: Vision Classifications (Spriggs, R. 2007)**

### **Field of view**

When people look straight ahead, they can normally detect objects to either side and above or below the direction in which they are looking. The measurement of visual field, or field of view, captures the extent of a person's vision by measuring the angle a person can see from the focal, center point of the vision. In normal sighted people, this is measured as 170°. This means a person with normal sight can see 170°, measured up or down, left or right. To be classified as legally blind, the field of vision must be less than 10° (Vision Australia 2012b).

Field of vision is measured using a light box of intermittent LED lights that produce a map of the eye, showing dark and light areas or non-visible and visible areas. The greater the white areas, the greater the field of vision. Figure 2.1 below shows the map of an eye with less than 10° field of vision. The dark areas are areas of no vision. If this were the individual's better eye the person would be diagnosed as being functionally blind.

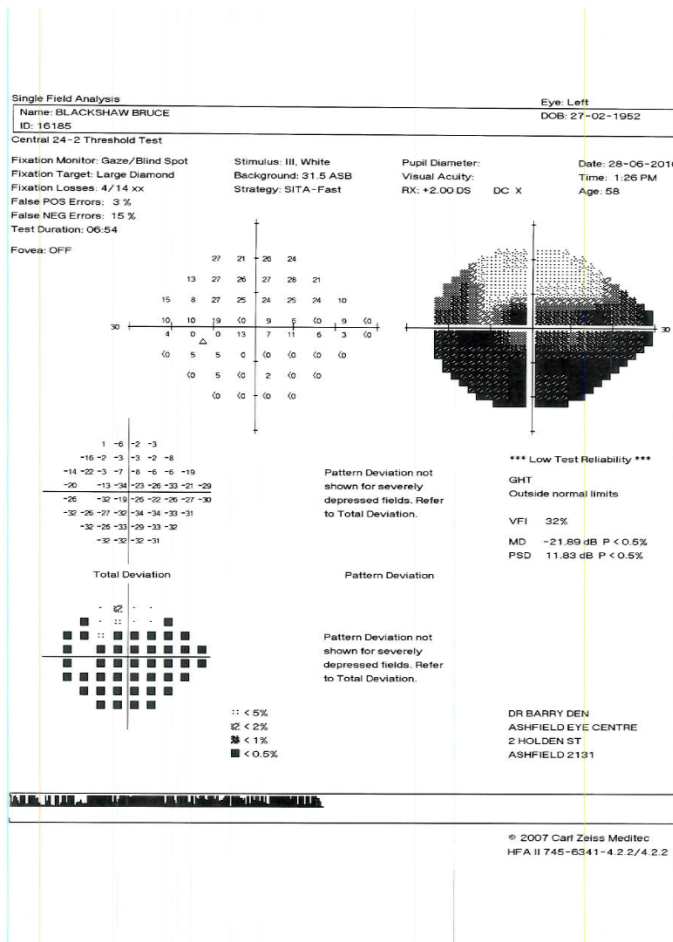


Figure 2.1: Map of the field of view

Functional blindness refers to a reduction in the individual's ability to function in performing some or all of their everyday tasks.(DiNuzzo, A.R. et al. 2001).



**Handicap severity levels**

Table 2.2 summarises the Australian Government's descriptions of the four levels of severity of handicap: profound, severe, moderate and mild. These levels are based on an assessment of a person's ability to independently perform specified tasks of self-care, mobility and verbal communication, or the amount of help required.

(Australian Bureau of Statistics 2000).

<b>Severity Level</b>	<b>Description</b>
<b>Profound</b>	Personal help or supervision always required.
<b>Severe</b>	Personal help or supervision sometimes required.
<b>Moderate</b>	No personal help or supervision required, but the person has difficulty in performing one or more of the tasks.
<b>Mild</b>	No personal help or supervision required and no difficulty in performing any of the tasks, but the person uses an aid, or cannot use public transport, walk 200 metres, walk up and down stairs without a handrail, or easily pick up an object from the floor.

**Table 2.2: Severity Levels**

*Source: ABS Website 2000*

These severity levels determine individuals' requirements for aid is also considered when classifying the individuals level of blindness or low vision.

**Midlife blindness goals**

Post midlife blindness individuals have to readdress many issues and create new goals and reappraise their future directions. Boerner & Wang suggest two methods

people use to achieve their goals (Boerner, K. & Wang, S.-w. 2012). The first is depends on tenacious determination and effort; the other depends on the ability or the willingness to re-address, adjust and modify their goals and be more realistic about what they can achieve. The methods of adjustment or coping strategies that an individual might use to maintain current goals include making more of a personal effort; changing one's methods of operations; using adaptive technologies and aids; and asking and accepting help from other people. On the other hand people can readjust their aspirations to cope with the new situations they may encounter. They can relieve some psychological stress by re-evaluating the importance of previously held views and by looking more closely at the current situation. Taking a positive view on events is another method of reducing pressure (Boerner, K., Wang, S.-W. & Cimarolli, V. 2006).

However, the strategies people who have a midlife vision loss use to help them achieve their goals have not been well researched. Many factors play a part in the employability of blind people. Some factors are personal or internal factors, as partly noted above. External social or community factors that affect the employment of blind people include general unemployment rates, educational levels required by employers, the cost of living and associated support systems, assistance available from family and friends, an individual's level of social inclusion or exclusion, the location in which one lives, accessibility to transport and employment, the ability to

be mobile and access to print. (Crudden, A. 2002) The loss of vision during midlife can, and does, affect the employability of people as demonstrated by high unemployment statistics (Australian Bureau of Statistics 2012a).

## **Section Two - Disability statistics, Acts and public policies**

### **Worldwide disability statistics**

Statistics show that blindness and other disabilities are increasing in Australia and internationally as the population ages (Australian Bureau of Statistics 2012a; West, S. & Sommer, A. 2001; World Health Organization 2012b). As stated earlier the unemployment rate for individuals who are blind is 54% much higher than non-disabled individuals who have an unemployment rate of approximately 6%.

The most common cause of blindness in the world is cataracts (World Health Organization 2012b). Cataracts are relatively inexpensive to remedy and recovery rates are typically high (World Health Organization 2012b). The major cause of blindness in people over 55 is macular degeneration. (West, S. & Sommer, A. 2001) Other causes of blindness are glaucoma, diabetic retinopathy retinitis pigmentosa. (Vision Australia 2012b)

People who are diagnosed blind or legally blind have an impairment that is irreversible (except in the case of cataracts) and so have to learn to deal with the challenges of the impairment. An individual's impairment also impacts on their family, community, society, government, employers and fellow workers. Many of the challenges blind people face are not obvious to other people. What are simple tasks

for sighted people can be major challenges for the blind, for example crossing the road, catching a bus or train, navigating around obstacles, reading print materials (Vision Australia 2012b).

### **Cost of disability**

Disability is a major cost for the Australian Government and governments around the world. The annual cost of the Disability Support Pension (DSP) to the Australian government is \$13.8 billion or 18.6% of the social services budget for individuals (FaHCSIA 2011). This cost will continue to increase as the number of people with disabilities increases. In 2012, the prevalence of disability in Australia remained steady at 18.5%, compared with last detailed disability survey which was conducted in 2009. The 2009 survey found that the number of people with a sensory and speech disability was 458,000. There were over 1,500,000 people with a physical disability, and a further 700,000 with intellectual, head injury and psychological disabilities. Blind people accounted for approximately 434,000 (0.4%) of the Australian workforce or approximately 10% of all disabled people. (Ewing, I. 2011, p. 9). Additional costs beyond the pension include medical expenses and community adjustments (Taylor, H.R., Pezzullo, M.I. & Keefe, J.E. 2006).

### **Disability Support Pension (DSP) and poverty levels**

According to the latest figures, Australia's minimum wage is \$16.87 per hour or \$640.90 per 38 hour week (before tax) (Fair Work Australia 2014). The Melbourne Institute of Applied Economic and Social Research states that in the March quarter

2014 the poverty line is \$680.25 per week for a couple comprising two adults, one of whom is working; for singles it is \$508.52 (Melbourne University, I.o.A.E.a.S.R. 2014). The overwhelming majority of unemployed blind and visually impaired people rely on the DSP (Blind), which is a maximum of \$383 for singles and \$288.70 each for couples per week. This payment places blind and visually impaired people below the Melbourne Institute's estimated poverty line. One mitigating point is that the DSP (Blind) is non-asset or means tested and so earnings from employment do not affect DSP payments. Table 2.3 below combines the various payments to more clearly compare them.

Payment Source	Singles per 38 hr week	Couples
<b>Poverty Line (Melbourne Institute's estimate)</b>	\$508.52	\$680.25
<b>Minimum wage (Fair Work Australia)</b>	\$640.90	\$1281.80 (both working)
<b>Disability Support Pension (Blind)</b>	\$383.00 (maximum)	\$577.40 (maximum combined)

**Table 1.3 Comparison of payments to blind people in relation to the estimated poverty line**

### **Disability Discrimination Act**

The *Disability Discrimination Act 1992* (DDA) aims to protect people with a disability being discriminated against. In 2004 the Productivity Commission changed the DDA to further protect the equality of opportunity for people with a disability. In addition to legislative protection, since 2009 employment support has been provided through the *National Disability Agreement* (NDA). The 2012 *Vision Australia Employment Report*

reported that discrimination or negative attitudes towards people who are blind or who have low vision had risen to 44% as opposed to 30% in 2007 (Vision Australia 2012a).

### **National Disability Insurance Scheme (NDIS)**

The most recent development in government provisions for the disabled is the introduction of the National Disability Insurance Scheme (NDIS). The NDIS is a 'person-centred' scheme: it changes the model from one where professionals provide the services they believe the disabled need to one where the disabled person decides on the services they need. The NDIS is set to be trialed during 2013–2015 in selected regions across Australia. This will be a major change in service provision to the disabled. There are still many issues to be resolved before the NDIS is rolled out nationally and the scheme is likely to evolve in response.

### **Employment factors**

Research into the employment of blind individuals has identified several aspects that appear to contribute to their employment success (Goodwyn, M., Bell, E.C. & Singletary, C. 2009). Goodwyn et al. stated that individual attitudes, motivation and desire to succeed were major factors in success. Common traits identified among successfully employed individuals who had experienced vision loss later in life were intelligence, a strong work ethic and a desire to be independent. These characteristics were attributed to family support and/or upbringing. (Crudden, A. 2002; Young, C.E. 1995).

However, there is no guarantee that individuals with these attributes will achieve gainful employment. Society has a major role to play in the rehabilitation of individuals who lose vision in midlife. The attitudes of employers and co-workers are also likely to be significant but have yet to be investigated, as does the impact of co-worker and employer attitudes once a blind person is employed in their workplace.

At the launch of the *Vision Australia 2012 Report* one employer spoke of his experiences of employing a person with vision impairment. He recounted how his perceptions had changed when it became clear that the worker was able to complete all set tasks to a higher standard than the employer had expected.

However, focusing on the individual's traits and background does not fully recognise the impact of external factors and influences on the employment prospects of blind people. Many of the employability challenges that affect individuals who go blind in midlife relate to organisational issues of mobility and transport and to overcoming discriminatory opinions that they have not previously experienced—or that they may even have shared themselves prior to becoming blind.

### **Career stages and midlife**

Both disabled and non-disabled people face different pressures across their working lives. Researchers generally identify three basic stages in a person's working life: the

initial or career creation period; the consolidation of career period; and the preparation for retirement period (Boerner, K., Wang, S.-W. & Cimarolli, V. 2006). These three stages can also be referred to as post-school, midlife, and pre-retirement. The midlife period is a period of many changes and is typically stressful as well as fulfilling. Boerner states that the stresses can include the consolidation and maintenance of one's career, the pressures of family and relationships, the upheaval of children moving out of the family home and various other dimensions of change (Boerner, K., Wang, S.-W. & Cimarolli, V. 2006).

Blindness during midlife drastically affects the individual's ability to consolidate and maintain their career and their relationships with family and others. Boerner states that several studies (Cavanaugh, B. & Rogers, P. 2002; Crudden, A. 2002; Crudden, A. et al. 1998b; Goodwyn, M., Bell, E.C. & Singletary, C. 2009) have indicated that people with visual loss during midlife develop mental health and well-being problems at a higher rate than in the general population that these could be attributed to the loss of vision at this critical period of adulthood. Boerner also suggests that people with midlife vision loss did not achieve the common goals of employment progression and planning for their future (Boerner, 2006).

In this study I define the midlife period as being from 30 to 60 years of age. This definition recognises that a person is likely to have gained their employment skills in initial employment between 18 and 25 years of age, and that they will then



have honed those skills between 25 and 29 years of age. It would be expected that post-30 year old employees would be progressing within their employment fields, increasing their skills and experience. Many people may not seek promotional positions but they continue to build networks and credibility due to their increased familiarity and ability in the workplace.

### **Blindness and employment rates**

Unlike people who have vision impairment for their entire life, midlife blindness is a unique crisis. Not only do individuals who lose vision in midlife have to adjust to the mental and physical aspects of their new world, they also have to rediscover themselves and retrain for everyday life. Then, when they have gained competence and confidence in these areas, they have to look at how to support themselves and their families. The statistics indicate suggest that this is a challenge. In the *Vision Australia's Employment Report 2012* the overall blind employment rate is 42% (Vision Australia 2012a).

Employment and the benefits of employment impact on many aspects of people's lives. Employment generally increases the well-being, overall happiness, health and quality-of-life for the majority of individuals of working age (Australian Bureau of Statistics 2012a). Employment for disabled people, as a whole, is more difficult and more challenging than for those who are referred to as "normal". The Australian Bureau of Statistics states that 94.8% of non-disabled people are employed as opposed to 54% of disabled people (Australian Bureau of Statistics 2012a).

Statistics from around the world suggest that disabled people typically live in poverty due to their inability to gain and retain employment.(Goertz, Y.H.H. et al. 2010).

### **Specialist employment agencies**

Specialist employment agencies, private providers, blindness associations and government departments prepare blind individuals to be work ready, typically through numerous training courses. A case manager guides the individual through any necessary training. The case manager then sources employers and matches individuals with employment opportunities. This will be discussed in depth later in the study.

### **Government assistance to employers**

The use of assistive and adaptive technologies allows blind people to undertake employment tasks that many consider they cannot perform. The Australian Government provides assistance to employers of people with a disability (Spriggs, R. 2007). This assistance covers reasonable adjustments to the workplace to allow for the employee to perform the tasks of the job.

Employers also are entitled to wage subsidies. These are designed to overcome the levels of disabilities the person has and hence the reduced work performance. These assistance packages are designed to overcome any or at least many of the barriers that employers may consider when employing blind and visually impaired people. The system has not resulted in dramatic increases in the

employment of blind people. There appears to be covert discrimination from employers towards people who are blind, as indicated by the participants in the Vision Australia 2012 employment survey. (Vision Australia 2012a).

### **Summary**

Blind individuals have historically been stereotyped into particular employment roles. At the turn of the 20<sup>th</sup> century the blind were in institutions and were taught to make baskets and brooms (Baker, R.K. 1989). Even through to the mid-20<sup>th</sup> century the blind were confined to menial repetitive tasks. It is only since the late 20<sup>th</sup> century and early this century that blind people have been able to move into more challenging and varied employment (Bell, E. 2010).

Technology has helped to change the employment situation for disabled people, including for the blind. In particular, the use of adaptive and assistive technologies has broadened employment opportunities for the blind. Advances in computer software have allowed for the everyday use of specialist screen readers such as JAWS (Job Access With Sound) or inbuilt accessible technologies as in the case of the Apple computer platforms (Brassai, S.T., Bakó, L. & Losonczi, L. 2011; Guercio, A. et al. 2011) . There is also an expanding use of screen magnification that

allows people who are legally blind to read. These technologies allow blind people to be more productive in the workforce and hence more employable.

Although the Australian Government has legislated to protect people with a disability from discrimination, the rates of unemployment are high for all people with disabilities. Common factors across all disabled people include mobility and transport issues that can be overcome through training for the blind individual. Other factors such as the inability to read print can be lessened by use of adaptive technologies. The DSP (Blind) is not means or asset tested and so it is not a disadvantage to a blind person to be employed.

The studies that have indicated personal traits as the overarching reasons for employment fall short by failing to consider the social factors that may impact on employability. The Vision Australia employment reports outline workplace discrimination once a person is employed but we know little about the discrimination blind people face prior to employment.

Society has deeply held perceptions of what people with disabilities can do and most of these perceptions are wrong (Wolffe, K. 1999). Given the lack of research into social factors that impact on the employment of those who go blind in midlife, I believe there is a need for a study like mine.

This section has defined blindness and its categories. It has explained that legally blind people have some useable sight,. The totally blind can also undertake meaningful employment with suitable workplace modifications.

## **Discussion**

Perceptions of disabled people's employment abilities are socially constructed and may be wrong (Barnes, C. 1999, p. 580). Some studies suggest that certain personal traits will equip blind individuals to gain employment (Crudden, A. 2002; Grow, S.J.L. & Daye, P. 2005) but this is not supported by the unemployment rates of blind individuals. There are support systems in place such as the DSP (Blind), workplace adjustments, and improved building and transport systems yet the employment rates are still relatively low. There is a need to determine what factors are at play and how they can assist employment of the blind.

In the next section I outline how disabled movements over the past 50 years have improved the employability possibilities for disabled individuals.

## **Section 3 - Existing Research**

### **Introduction**

Various social movements have campaigned to allow individuals with disabilities to have a greater voice in their own direction and destiny. The following literature review outlines areas of blindness research, social movements and associated issues.

### **Disability as a social construct**

Theorists like Morris (2001) argue that disablement is a social construct that has placed individuals into a collective of *inferior* individuals, thereby allowing trained and typically non-disabled professionals to dictate what is best for the disabled (Morris, J. 2001). Disabled individuals have been challenging this view and achieving growing influence since the 1960s. With the formation of disabled groups have come declarations that “disablement is a social construction” and that “the classification should be referred to as impairment” (Linton, S. 1998).

Classifications based on self-care and a person’s mobility are used by the Australian Government to determine the severity of an individual’s disability. This is a classification system that lends itself to that of Shakespeare’s more recent notions that a person may have impairments and not be disabled (Shakespeare, T. & Watson, N. 2001). Both Shakespeare and Morris (Morris, J. 2001; Shakespeare, T. 1993) argue that disability is a social construct that leads to the disabled being labelled and discriminated against. Society has constructed many norms that the Disabled People’s Movement has challenged. These challenges have achieved many advances for disabled individuals. The United Nations Charter for the disabled has mandated for various rights of the disabled (World Health Organization 2012a), The UN charter is a direct result of the disability movement’s activities and arguments over many years against the models of disability.

Disability models have progressed from the 1970s, with researchers moving the definitions of disability away from the medical model and the personal tragedy views to a 'social model of disability'. In this model disability is conceived as stemming from "the way in which physical, cultural and social environments exclude or disadvantage certain categories of individual, namely individuals labelled 'disabled'" (Davis, J.M. 2000, p. 194). These social constructionist models of disability help to explain why disabled individuals are treated as 'stigmatised' members of society.

### **Classifications**

Disability is generally divided into the categories physical, mental or sensory. Various models and social movements have arisen to attempt to reduce the compartmentalisation of individuals due to their disability.

Many researchers (Brisenden, S. 1986; Crudden, A. 2002; Ferguson, P.M. & Nusbaum, E. 2012; Shakespeare, T. & Watson, N. 2001) have argued that individuals should be allowed to determine their own needs rather than be institutionalised. In the 20<sup>th</sup> century institutions were closed and people with disabilities were allowed to integrate into the general population, yet in many cases they were simply moved from a formal institution to an informal one (Department of Social Services 2012).

### **Support frameworks**

When an individual loses usable vision the consequences are felt not only by the individual, but also by family members, friends and society as a whole. Studies have

suggested that the families and friends of blind individuals are a major factor in the rehabilitation of the blind (Goodwyn, M., Bell, E.C. & Singletary, C. 2009). Social constructs are also ingredients in the emotional wellbeing of individuals who lose vision in midlife (Shakespeare, T. & Watson, N. 2001). The way society views the blind individual and the barriers that are presented to them result in an increase or decrease in feelings of self-worth and impact on the individual's ability to achieve employment goals (Shakespeare, T. 1993)

### **Employment support frameworks**

While, like other disabled people, the vast majority of blind individuals aspire to become employed within businesses and corporations, a number seek self-employment. Often this is because they have been unable to source paid employment (Crudden, A. 2002). In order that individuals succeed in paid employment support frameworks have to be in place. Support within paid employment can take the form of co-workers, supervisors and managers who can contribute to the success in many ways. Both formal and informal employment support can assist the blind individual to participate in employment (Imo, K.O.C. 2013).

### **Mentors, sponsors and significant others**

Individuals who are members of minorities often experience "intergroup bias" which undermines diversity in corporations (Imo, K.O.C. 2013). Awareness of this intergroup bias has prompted major corporations to create sponsorship and



mentoring relationships to improve diversity within corporations (Imo, K.O.C. 2013). In comparison with sponsorship, mentoring “can be explained as a nurturing process in which a less experienced or less skilled person is being served by the more experienced or more skilled person.” (Rutti, R.M., Helms, M.M. & Rose, L.C. 2013; Suk-Hyang, L. et al. 2006). Mentoring can be a guidance relationship between a mentor and a protégé, while in sponsorship the sponsor supports the career advancement of the protégé (Cao, J. & Yang, Y.-C. 2013). Mentoring and sponsorship can both be formal or informal with formal programs typically designed to meet organisational objectives. Examples of the various formats mentoring can take include supervisory and team support and team skills and knowledge sharing—also termed networking—and virtual mentoring via online systems of self evaluations (Cao, J. & Yang, Y.-C. 2013)

### **Relationship between education and employment**

According to the *Vision Australia Employment Report 2012*, approximately 75% of blind and visually impaired people with tertiary level education were employed. The report states that this demonstrates the strong relationship between education and employment. This compared with approximately 50% with tertiary education and employed in 2007 (Vision Australia 2012a).

Educational levels have been shown to increase employment rates and salaries received (Bell, E.C. & Mino, N.M. 2013; Vision Australia 2012a). Data from a US research project by Bell and Mino (Bell, E.C. & Mino, N.M. 2013) states that there are

significant differences in employment status of blind individuals based on the levels of educational attainment. Table 2.4 below demonstrates four educational levels, employment rates and annual salary. The table is based on a survey of over 4000 blind respondents in the United States.

<b>Educational levels</b>	<b>Employment rate</b>	<b>Annual salary (\$US)</b>
	F(4, 576) = 13.09, p < .01, RS = .08	F(4, 296) = 12.23, p < .01, RS = .14
<b>High school diploma or less</b>	36%	\$31,500
<b>Baccalaureate Degree</b>	59%	\$42,300
<b>Master's Degree</b>	65%	\$48,200
<b>Law or Doctoral Degree</b>	80%	\$66,900

**Table 2.4: Educational attainment of blind people in the United States**

Source: (Bell, E.C. & Mino, N.M. 2013), based on available statistics

## Discussion

Some researchers have identified personal traits as possible explanations for successful employment (Barnes, C. 1999; Bell, E. 2010; Crudden, A. et al. 1998b).

However, such claims fail to investigate the impact of social factors on employment.

The *Vision Australia Employment Report 2012* identified workplace discrimination (Vision Australia 2012a) as a factor. Discrimination has been challenged by various disabled movements over the years.

Over the past 50 years the disabled movement's challenges to discrimination have contributed to change in many aspects of employment (Morris, J. 2001).

However, the statistics indicate that there are still areas of concern, given that the blind population of Australia is more at risk of unemployment than the rest of society.

The employment rates of blind people appear to be improved by the attainment of higher educational qualifications. An individual with a doctoral level degree is more than twice as likely to be employed (36%-80%) and will earn twice the salary (\$31,500-\$66,900) compared to an individual with high school or lower educational qualifications.

Informal training and learning can also complement formal education. Mentoring and sponsorships can assist individuals to both gain and improve employment. The mentoring role can be taken by friends and co-workers although this is an area where research is required. Further, there is a specific need to research the needs of individuals who go blind in midlife to better understand the support systems they need to find full and gainful employment.

#### **Section 4 - Theoretical propositions and questions**

The overall research question is: What supports and contributes to the employment of people who go blind in midlife? This broad question implies subsidiary questions about the necessary support frameworks, the relationship between training and employment and the false and/or negative social perceptions and expectations that blind people must deal with to gain employment. These negative perceptions

include the belief that if an individual is blind, they are not capable of undertaking or understanding complex tasks.

Other issues that relate to the conceptual framework are the internal and external barriers that the newly blind individual has to deal with before they can actively seek employment and the extent to which their employability may be heightened due to their previously acquired skills and work ethic. The study also explores the role of co-workers, managers and employers in the employment of blind individuals.

## Chapter three

# Methodology

---

### **Introduction**

This chapter describes the methods used by the study to investigate the research aims. It gives the rationale for using case studies, and outlines the participant selection plans and processes. The chapter examines the semi-structured qualitative interview methods of data collection.

The challenges at the beginning of this research were to devise methods to find people who fitted the criteria, and to attract them to participate in the study. Because the research required participants to be blind, paper-based advertising would have been undesirable and mostly unworkable. This chapter details the recruitment process and outcomes.

Originally I planned to collect the research data through Sydney-based, face-to-face, semi-structured interviews, but I had to change these plans very quickly. My revised methods are outlined in this chapter. The original concept of face-to-face interviews was changed because of geographical constraints. Participants were screened by a set of criterion.

The criterion of participant selection was that they had to be legally blind or blind; aged between 30 and 64 at time of vision loss; were employed pre vision loss and gained employment post vision loss and only had one disability.

### **Case study methodology**

This research uses a case study methodology. The case study methodology as described and used by Stake (Stake, R.E. 1978) was founded on social constructivism, as he based his on the belief that 'knowledge is constructed rather than discovered' (Denzin, N.K. & Lincoln, Y.S. 2000, p. 442). This methodology allows the researcher to collect and acknowledge multiple and even contradictory views of what is happening (Denzin, N.K. & Lincoln, Y.S. 2000). The present study of midlife blindness and employment looked at the complexity, particularity and the multiple realities of the people in the case studies used.

Yin (2009) states that the use of case studies is a way of collecting and presenting detailed information on small groups or single participants. Case studies are a form of empirical inquiry in which the focus is on a contemporary phenomenon within real-life contexts. The use of case studies allows the researcher to investigate how people experience the complex dimensions of their lived realities.

This research investigated the employment of people who are blind. It focused on the numerous issues of midlife blindness, such as the perspectives of

discrimination; access and independence; and employment direction and training requirements.

Two lenses were used to examine the data collected within each of the case studies. The first was to see midlife vision loss through the eyes of the researcher himself. In other words, I used an auto-ethnographic approach to capture my lived experience, describing how vision loss affected my employability. The second lens was that of the participants. The study gathered data on their personal and social experiences of visual impairment, and on how the impairment affected their employment opportunities and their interpretations of their experiences.

Case studies can take various forms, and can address different aims and researcher goals (Yin, R.K. 2009). Yin suggests that there are three forms of case studies—descriptive, explanatory and exploratory. *Descriptive* case studies are intended to describe a phenomenon. *Explanatory* case studies are intended to investigate and explain the characteristics of phenomenon in more depth, and *exploratory* case studies are applied to explore entirely new fields of research (Yin, R.K. 2009). This study employed the Explanatory case study style.

Stake (in Denzin, N.K. & Lincoln, Y.S. 2000) states that a case study can be intrinsic or instrumental in its intent, or both. By “intrinsic”, Stake means that the focus in these case studies is on better understanding the uniqueness and complexity of a case. By understanding, Stake means searching for the complexities that

intertwines between all aspects of life and attempting to get inside the mind of the subject in each case, empathetically recreating their thoughts, feelings and motivations (Stake in Denzin, N.K. & Lincoln, Y.S. 2000). Case studies of *intrinsic* intent focus on the individual, while the *instrumental* studies use case study data to look at larger issues. (Stake in Denzin, N.K. & Lincoln, Y.S. 2000).

Because each person has different experiences, and interprets them individually, it is necessary to use multiple case studies. The aim of multiple case studies is to replicate findings across cases (Yin, R.K. 2009). Stake's "intrinsic" research, a term I use in this research, is comparable with Yin's "descriptive" form. The complexities of each person's situation and requirements mean that the research needs to use an intrinsic approach.

The overall issue for the research is the employment of people who go blind in midlife, so a number of people who have experienced vision loss in midlife needed to be interviewed. As background, other stakeholders were also interviewed to generate a broader picture of the employment situations that the case studies face. Each interviewee therefore became a participant within the overall research into blind employment. The research used participants of intrinsic interest to allow for "thick" description (Ponterotto, J.G. 2006) of the participants' interpretations and draw on their collective experiences. My auto-ethnographic methods were also used as part of the case study approach.



### **Different lens**

The research explored the experiences of participants (including myself) through interviews and by using auto-ethnographic based reflection. The interviews were designed to include 8 to 16 participants who were selected to meet the criteria set out below. (Through my autobiographical reflections, presented principally in Appendix E, I narrate my own experiences and comment on connections between my experiences and those of the study participants.)

### **Auto-ethnographic lens**

In parallel with the qualitative interviews, I did an auto-ethnographic investigation of my journey from the onset of my midlife blindness until the conclusion of the research thesis. Presented in Appendix E, my personal investigation gives the reader a first-hand insight into the complexities of overcoming midlife vision loss, through the lived experiences of my expedition from the fully sighted world to that of the blindness community and my interpretations of my experiences. In my journey I detail the many changes I had to go through to adapt socially to my vision loss. The auto-ethnographic reflections are written in the first person.

There are various forms of auto-ethnography, such as analytic auto-ethnography and evocative or emotional auto-ethnography. To be meaningful, analytic auto-ethnography, according to Anderson (2006), must meet five conditions. The auto-ethnographic researcher must:

1. have 'complete member' researcher status

2. display analytic reflexivity
3. make the researcher's self visible through narrative
4. dialogue with informants beyond the self
5. demonstrate commitment to theoretical analysis.

As a person who is legally blind and as the researcher, I satisfy the first requirement as a complete member. I engage in analytic reflexivity through my reflections which make me aware of situations I have experienced. I am visible within the study dialogues. I used the case study method to interview various participants. I undertook analysis of the data, developing findings which the reader can use as a basis for generalisations. The interviews sparked memories of my past that I could use in my own journey of discovery, description and analysis, one of the basic characteristics of auto-ethnographic work, as Michael Schwalbe explains:

Every insight was both a doorway and a mirror—a way to see into their experience and a way to look back at mine. This mutual informativity is one of the most appealing features of auto-ethnographic work. However, it is not enough for the researcher to engage in reflexive social analysis and self-analysis. Auto-ethnography requires that the researcher be visible, active, and reflexively engaged in the text. (Schwalbe in (Anderson, L. 2006, p. 383).

Schwalbe and Anderson attempt to sum up the auto-ethnographic principles of research (Anderson, L. 2006). Within my study, I was extremely 'visible' to all the participants and observers, as I am a legally blind person who self-identifies with the blindness community and uses a white cane. These factors made me identifiable and

observable within the research, both during the interviews and during the subsequent reporting of the findings.

Together the interviews and the auto-ethnographic reflections were to be used to explain issues that relate to blindness and employment. The following section details the method of selecting participants for the research.

### **Selection of participants for the case study**

The initial recruitment plan involved advertising for participants with the three major blindness associations—Vision Australia, Guide Dogs and Blind Citizens Australia—to get wide coverage. (It was assumed that the three associations between them had email lists which covered a large proportion of people who were blind and employed.) These associations were to email their clients a copy of the research outline, and ask for potential participants to respond directly to me.

Those on the email lists were typically computer-literate and could read emails with the use of adaptive technology such as JAWS (Job Access With Speech), Zoomtext or similar screen-reading software technology. JAWS is a commonly used screen reader for those in the blindness and low-vision communities.

To be selected, individuals would have to be currently in an ongoing position, and have been in the workforce for at least 10 to 12 years, in a position where promotion would be a possibility. This meant that the lower age of participants would be 30. As most people retire at about 65, the cut-off age was set at 64.

Many people have multiple disabilities. Because this creates numerous effects on their employability, participants were limited to those having only one disabling feature, i.e. blindness. A participant had to be legally blind or totally blind, as in the definition in chapter two. This limited the available pool of participants. I considered the inclusion of visually impaired people, but although the potential pool of participants would have been greater, the added complexity of vision impairment would have made the study unmanageable with the resources available.

It was anticipated that equal numbers of male and female participants would be recruited, and that there would be two people from each division of the age range, giving a total of 16 participants. The expectations was that each decade in the range 30–60 years would be evenly represented, and that participants would be divided into the decade in which the vision loss occurred.

### **Participant criteria**

- age of vision loss: 30s, 40s, 50s and 60s
- have only a single disability i.e. blind (<3/60) or legally blind (<6/60)
- have gained or retained employment after vision loss.

### **Recruitment plan**

Vision Australia, Guide Dogs (NSW/ACT) and Blind Citizens Australia were approached to advertise the research through their client email systems. Contact was also made with the disabled radio station to organise a segment about the research. A radio interview increased coverage of the request for participants.

## **Recruitment methods**

### **Recruitment method 1: email and word of mouth**

As a person who had recently joined the blindness community I had very limited contacts, no public profile and no influence within the blindness communities or various associations.

To recruit participants the plan was to make early contact with people within the blindness communities to gain acceptance and publicity. I had joined Vision Australia, Guide Dogs (ACT/NSW) and Blind Citizens Australia—Vision Australia mainly for support and initial guidance after vision loss, Guide Dogs for mobility training, and Blind Citizens Australia for advocacy. From my observation, this combination of association memberships is typical of that of most blind people.

I attended a disability conference at Sydney University on 13–14 June 2012 entitled 'Research Rights: Disability Inclusion Change'. At this conference Dr Sally French from the UK Open University spoke about inclusive research and her experiences as a visually impaired person growing up in England. At the conference I spoke to an attendee from Western Australia. He described his methods of dealing with vision loss and what he did before losing his sight. I spoke to him about my situation and what I was doing at the University of Technology Sydney. (Although he fitted the criteria for my research, because of this contact with him before ethics approval, he was not included in the research.)

In January 2013, this WA contact forwarded an email explaining my research and request to people he believed would be interested in the research, through a Blind Citizens Australia email distribution list. This email brought five replies—two from NSW, and one each from WA, SA and Qld. One of these did not fit the criteria. A thank you email was sent and no further contact was made with that respondent.

### **Recruitment method 2: blindness associations**

I made representations to various blindness associations for support in advertising the research details and calling for participants. I sent emails via the Retinitis pigmentosa Association (now Retina Australia), Blind Citizens Australia and various Vision Australia distribution lists.

### **Recruitment method 3: disabled radio interview**

Unfortunately, the take-up rate from the previous two methods was very low—only five or six definite responses—so I looked for another recruitment method. A radio network for disabled people operates in most states of Australia, 2RPH and 3RPH. The stations support the disabled in many ways with information services, newspaper readings and so on. I spoke to the disabled radio network in Adelaide and an interview was arranged. The interview was planned and programmed for five to seven minutes; it lasted for 12 minutes.

Still needing more participants, I approached other smaller associations such as the Retina Pigmentation Association and the blind workers union. I received a few

new expressions of interest although many of them did not match the criteria in many fields and were therefore unsuitable.

I made an exception for one person who was included in the research even though one element of his background did not fit the criteria. The respondent was 28 when he lost his vision, two years short of the minimum age of the study. He was working in a medical field when he lost vision. Post-blindness he returned to university and undertook further and non-aligned professional training. He then worked for 20 years as a public advocate and lawyer. He is now undertaking a PhD in law. Due to his advanced skills both pre- and post-blindness I decided to include him in the research.

### **Participant interviews**

I interviewed participants to document their experiences and to examine their individual perspectives and their employment challenges.

I planned to interview each participant once and for 45 to 60 minutes. The plan was to interview participants mainly face-to-face where possible or via Skype or telephone if a participant lived in a distant location. Interviews were digitally recorded on two devices and then transcribed in order to categorise information into a coding scheme, initially using the Dedoose software platform. I used two recording devices to ensure no data was lost if one recording device failed. Once I had successfully transcribed an interview, I then destroyed the non-transcribed copy. The

transcribed copy was saved in two separate locations. The anticipated duration of the interviews was designed to produce comprehensive sets of transcribed information.

I then read and re-read the transcripts in an inductive, repetitive process to produce categories and sub-categories for information analysis in the context of the research objectives: a) employment barriers of people who lose vision in midlife and b) the supporting factors that assist people to gain employment. Statements were split into thematic and case subunits, analysed and summarised.

### **Identification of potential participants**

I initially expected that there would be many respondents to the expressions of interest as many people belong to the blindness associations named above.

However, the response rate using the various contact methods detailed above did not reach the numbers anticipated.

The expression of interest did result in an unanticipated reply from participants in five states across Australia. The population of the study that was originally envisaged for the research was 8 to 16 participants, spread across four age groups. The eventual total was 11 participants from WA, SA, Victoria, Queensland and NSW. All those who responded and satisfied the criteria were included in the research.



### **Participants**

There were two major age groups of vision loss—30s and 40s. There was close to a 50–50 gender balance and (as outlined later) the post-visual loss employment was generally in a new employment area.

### **Ethical considerations**

The UTS Human Research Ethics Committee approved the study. The measures outlined below were put into place to ensure that consent was obtained from each participant, along with suitable procedures to ensure anonymity of all participants according to UTS University guidelines.

### **Informed consent**

When a person replied with an expressions of interest, I sent an email which contained an information sheet and an informed consent form as required by the UTS Ethics committee. The information sheet outlined the research aims, goals and potential methodologies in greater detail than in the original call for expressions of interest. The informed consent form and the information sheet also gave contact details for the researcher and the principal supervisor. Some respondents asked minor questions and I responded with explanations. Some people from interstate wanted to know what UTS stood for (University of Technology) while others were interested in what they would need to do with technology. This arose from email conversations where I had stated that Skype would be used. The respondents thought they would have to set up video links. When I explained that the Skype was

from my end and that at their end they would be on their landline or mobile phone, the respondents were very happy to learn that they did not have to set up technology for the interviews.

As the participants were blind or legally blind, not all could physically sign the informed consent form and/or read the informed consent form. On the initial reply to expression of interest, I presented options for the participants to have contact in their preferred methods, i.e. Braille, large font, audio, standard text or electronic text. No requests were made for Braille, audio or large text format. The preferred format was email. The participants could then use their screen readers, typically JAWS, to read the forms. The majority of participants signed the form; two sent an email of acceptance.

Before the commencement of each interview, there were discussions regarding the interview content and structure and each participant was asked if they gave their consent verbally and/or in writing. The majority gave both a signed informed consent form and the verbal agreement to conditions regarding the interview and the research.

### **Confidentiality**

The participants were drawn from across Australia, in varying numbers for different states. Although the confidentiality of the participants was an ethical consideration in presenting the findings, it was considered that the participants would not know

each other. Nevertheless, all of the participants were given a code name that represented an overview of their particularity and their story. All information has been de-identified as much as possible to reduce any possibility of identification of the participants.

It was decided that in any quotations from interviews the participant would only be identified by a code name. The code name and real names have been stored in separate locations following UTS ethics requirements. This decision does not have any real impact on the findings or the outcomes of the research. As an example there are four participants in NSW, one from the southern region of the state, one from the north of the state and two from the Sydney Basin. It is highly unlikely that any of them would know each other or each other's stories.

### **Interview strategies**

I had originally envisaged face-to-face interviews at a convenient and safe location such as the Sydney offices of Vision Australia Enfield or Caringbah, because I had assumed that most participants would live in Sydney. I changed this when the majority of respondents to the initial call from the Blind Citizens Australia email were from outside the Sydney metropolitan area. I then decided that interviews would be by telephone rather than face-to-face. I researched suitable recording and communication software to determine the best way to collect the data. One criterion of the selection of the recording methods was that interviews should be conducted using Skype to reduce the costs of long-distance telephone calls. I purchased Skype

and call recorder software, and downloaded and installed it onto the main computer to record interviews. I undertook test interviews to perfect software operation and procedures.

Initial appointments were made with the two Sydney-based respondents and I interviewed them in April–May 2013. These first interviews were used to determine the accuracy and relevance of the interview questions. After the first two interviews, I re-examined and adjusted the questions for future interviews. I also modified the interview techniques from the initial open-ended question list and a semi-structured interview style to a more conversational interview technique, as outlined in the following section.

In designing the research, I considered four possible interview methods: structured interviews, semi-structured interviews, unstructured interviews and conversational interviews. Each of these methods has particular problems and advantages. Initially I decided to use open-ended questions in a semi-structured interviewing style that would allow the participants to re-live and explore their particular journey from fully sighted employment to that of semi or total blindness and into blind employment. The following sections outline the initial and subsequent data-gathering methods.

There was one non-participant interview with Vision Australia national employment service manager. The interview was conducted via telephone and was a scoping interview to gain a service providers perspective.

### **Interview preamble**

At the beginning of each interview I gave brief background about myself so that participants understood my position in the research. The following is the typical opening dialogue I used when starting the interviews:

I am Bruce Blackshaw. I had a bleed at the back of my eye three years ago which left me legally blind with a condition called Non-arteritic Anterior Ischaemic Optic Neuropathy (NAION) which is basically a smoky, foggy, patchy, blotchy vision. I cannot read normal print, I cannot make out detail and faces for example I cannot see my fingernails on my hands. I am legally blind with a Snellen reading of 1/60 in my right eye and 6/60 in my left eye. When I went blind I was working as a TAFE NSW Head teacher in engineering. My left eye had bled in late December 2009 and my right eye in June 2010. On each occasion there were no warnings or signs that the first one would happen or that I could expect the second one to happen.

One day I was tremendously busy the next day I was sitting in my backyard twiddling my thumbs.

I went through the emotional rollercoaster of sudden vision loss and the realisation that it was irreversible. I accepted the situation after a period of time and then wanted to know how I may be able to help others, hence the research project.

### **Interview technique**

As mentioned earlier, I initially planned for semi-structured interviews, with a set list of open-ended questions I would ask of each participant. This method of

interviewing was used in the first two face-to-face interviews. I realised that this method was unsuitable for the information and data required by the study. After the initial two face-to-face interviews, I reviewed the interview process was reviewed and restructured the interview techniques to better suit the needs of each participant. The aim was to tailor the basic questions of the research to suit individual participants' needs to recall their experiences (Trier-Bieniek, A. 2012). Scott (Scott, S. 2004) states that people are typically shy and not freely forthcoming with their inner personal details of their experiences. Scott suggests that regular contact be made to reduce the shyness. One approach that he suggests is that of a combination of contact styles, i.e. emails, discussion boards etc. and semi-structured interviews. People then tend to open up, discussing more personal issues. Following this approach, I emailed the respondents keeping them informed of the progress and processes, and providing background information about the research and about me.

As Oakley writes, "The goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical" (Oakley 2008 as cited in Trier-Bieniek, A. 2012, p. 222). Moreover, the tone of the words used to describe those interviewed as participants rather than as subjects or respondents indicates the negation of hierarchy, and places the participant as an equal within the interview (Trier-Bieniek, A. 2012).

The interviews were conducted with the understanding that a person who has developed midlife blindness has experienced a major trauma. Although many of the participants knew that blindness was inevitable, many wanted to believe they would be spared, i.e. they would be healed, or, as a few participants suggested, that science will find a cure for them. This is a direct link to the medical model of disability mentioned in the literature review. Participants knew that I was also legally blind and, except for the fact that I was conducting the research, they thought of me as an equal.

Scott's views on telephone interviewing were that the majority of the telephone interviews should be conducted in the safety and comfort of the participant's homes because it would allow participants to be more open than would otherwise be the case in unfamiliar surroundings. However, home-based interviews were not possible in my study. I opened each interview by reflecting on my own experiences of sudden vision loss and being diagnosed as legally blind.

### **Semi-structured interviews**

Semi-structured interviews were used to collect data. The initial questions were open-ended ones that allowed participants to provide their lived experiences and draw out their own circumstances. I then used a semi-natural conversational format with the participants. Unfortunately, because all participants were blind and the majority of interviews were by the telephone, neither I nor the participants were able

to gauge one another through non-verbal communication clues, so a good listening approach worked best.

Questions were designed to be open-ended and thought-provoking ones that allowed the participants to elaborate to the extent that they felt comfortable. The interviews evolved from dot point questions to a more holistic initial question and gentle prodding and realignment as the participant's story unfolded. The basic questions were grouped into various classifications (see Appendix C1).

### **Developing the interview guide**

As explained above, semi-structured interviewing was used to allow for flexibility within the interview. I developed an interview guide that would generate thoughts and responses from the participants. The guide was designed along the lines of the study's aims in exploring the factors that moulded and influenced the participant's particular situation and their subsequent employment opportunities. The interview guide appears in Appendix C1.

### **Initial interview guide**

The overall objectives of the study required that the interviews allowed participants to describe their journey from the acceptance of blindness to their employment status. As the participants were predominately reflecting on their history and using their memory, the recollection was not linear. Participants sometimes jumped forward and backward in response to various clues that they remembered during the interview.



Because I had designed the initial interview guide on the incorrect assumption that most participants would be Sydney-based and interviewed face to face, I had to slightly modify it for the telephone interviews.

### **The final interview guide**

The final interview guide included the initial guide as dot points only. Each interview evolved from a semi-structured interviewing opening to a more conversational continuation. I had introduced the participants to the research through previous e-mails, information sheets and initial discussions. I then encouraged participants to detail in their own way and in their own words their journeys along the path to employment.

### **Pilot testing**

Although there was no planned pilot testing the first two Sydney-based interviews were used to test the questions and the interview techniques. These interviews demonstrated that the interview questions were relevant but the method of interviewing had to change. The interview technique was then changed, as already described, to make the interviews more conversational.

### **Interview preparation**

In preparing for the interviews, I sent each participant an email asking them some demographic questions such as age, marital status, region in which they lived and eye condition. I filed the responses and re-read them just prior to the interview so that I had some basic idea about the person. This allowed me to open the interview

by reviewing the participant's demographics. This enabled me to create a more comfortable environment for the participant and convey the feeling that I knew the participant. The following section outlines the basic demographics of each of the participants, with some background on previous employment and eye conditions.

### **The interviews**

I conducted all 11 of the interviews. Eight interviews were conducted by telephone to the participant's home; one was at the participant's workplace by mobile phone; one was at Vision Australia's Enfield Office; and one was in a café in a Sydney suburb.

As mentioned, digital recordings were made of the interviews using either an iPhone and a digital recorder or the iPhone and the iMac computer. Although it is typical of interviewers to take handwritten notes as the interview progresses, I did not do this as I am legally blind and cannot see enough to write. I recorded short notes after the interviews.

### **The interview process**

In opening the interviews I outlined my experiences post-blindness with depression, my necessary retraining for my new life, and how I adapted to that new life. This took approximately five minutes on average. I then asked participants to reflect on their experiences of vision loss and how they regained or maintained their employment. I asked questions in the order that the participants related their experiences. In many cases I did not have to ask the questions from the pre-prepared

questions, as many of the participants raised the questions before they were asked. This allowed the participants to relate their experiences in their own way and in their own order. Some related chronological events, while others used milestones that were not in order but were significant to them. In the process of reflecting on their needs, participants outlined some areas that would not have been as easily accessed if I had employed a structured or even semi-structured set of questions. I had originally planned for the interviews to be between 30 and 45 minutes. The actual average duration of the interviews was just over an hour, with the longest running for over an hour and a half.

### **Individual participant profiles**

The individual participants have code names that reflect their story or personal profiles. The code names do not identify the person (in line with UTS HREC requirements). Brief descriptions are given below for each participant—Blind Chef, Freeman, Gearbox, Schoolie, CPA Farmer, Reflex, Fighter, Volunteer, Lone Ranger, Miss Positive, and Builder.

**1. Blind Chef** is a male living in a suburb of Sydney. His eye condition is Retinitis pigmentosa (RP). He was diagnosed in 2005 when he was in his late 40s. Prior to diagnosis he had no knowledge of RP and was fully sighted. He was employed in hospitality and managed restaurants in New York City. Blind Chef lost his vision over a comparatively short period in the USA, where welfare assistance is different from that in Australia. He had no knowledge of workplace assistance and

modifications either in the USA or in Australia. He attempted to continue working in the business he had been in for 17 years, albeit as an office worker rather than a maitre d'. He eventually realised that he could not continue and left the business. He felt that the business did not attempt to support him past his own endeavours.

Blind Chef subsequently went to university and graduated with a Masters degree. He is currently undertaking a doctorate at a major Sydney university. Blind Chef works fulltime as a disability policy advisor for a client consumer company.

**2. Freeman** is a male living in an outer Sydney suburb and is legally blind. His eye condition is Retinitis pigmentosa (RP). He was diagnosed at 43 years of age and was in his late 50s in 2013. He was mainly self-employed before his vision loss. Since his vision loss he has been employed at TAFENSW and on other freelance projects. Before his vision loss, Freeman had been used to working short-term contracts and moving around for employment. He continued to have this expectation after his vision loss. Freeman has some usable vision with the assistance of glasses but requires sighted guides when travelling to unfamiliar locations. Freeman contacted the researcher after reading the Blind Citizens Australia email about the research. He was eager to be part of the research and wanted to participate before UTS ethics approval. This was not permitted. Freeman has RP and has noticed that his sight is deteriorating more quickly in the past 12 months than in the past few years.

**3. Gearbox** is a male who lives in a major regional city. He had the support of his wife and family. He went blind progressively over a long period of time. He had to leave his original trade and move to a non-aligned trades area where he stayed for approximately 12 years. When he was declared blind he undertook training at a specialist training centre away from his home city. He returned and took up a position not related to that training and stayed at that same job for the next 25 years until he was totally blind and could no longer work. He had to retire before 60 years of age. Gearbox suffered from RP.

**4. Schoolie** is a female who lives in northern NSW. She was a classroom teacher who was moving towards a school principalship when her vision declined. She undertook a doctoral degree after her vision loss and was subsequently medically retired from her teaching career. She then used her various skills in many different employment situations. On many occasions she did not inform the employer of her blindness until after she was employed. She became blind when she was in her early 40s. She suffers from a rare eye condition.

**5. Fighter** is a female who lives in rural South Australia. She is a divorced person who moved close to her employment so that she could walk to work. She lost her vision in her 40s and has mobility via the use of a guide dog. She fought the establishment and maintained her employment against substantial efforts to remove

her. Her efforts to maintain her employment demonstrate her will to retain employment against the odds. She suffers from a rare eye condition.

**6. CPA Farmer** is a male who lives in a Brisbane suburb. He lost his vision gradually while living in Victoria. In his early 50s he moved to Queensland and expected that finding employment would be fairly easy. He soon learned that the combination of age and disability did not assist his endeavours. He was a professional in his home state and found it difficult to gain permanent positions.

**7. Reflex** lost her vision while out of the workforce raising her children. She found it difficult finding employment and eventually became self-employed as a reflexologist. Her experiences with travel and employment highlight the efforts she had to make.

**8. Volunteer** is a woman who lost her vision in her 40s. She did not have a supportive family and had difficulty adjusting to blindness. She worked for various organisations and volunteered in between employment situations. This she hoped would assist her in gaining fulltime employment. However, she was only able to secure short-term roles, not permanent full-time employment.

**9. Lone Ranger** was diagnosed with RP and at 28 was legally blind. His previous career was as a medical practitioner. After vision loss he undertook a law degree and worked for the next 20 years as an advocate and lawyer in various positions. In 2012 he returned to university studies and is undertaking a PhD in law.

**10. Miss Positive** is a woman who lost vision in her 40s. She had a very active pre-blindness career. She had to resign the career she had before she was blind and find new employment. She works effectively in her new career and often describes herself as non-blind and wants to be treated as if she is not blind.

**11. Builder** is a man in his early 30s who has RP. He has been diagnosed as legally blind. He is continually negotiating with his employer to modify his duties so that he can prolong his employment options. He is married with small children. He is constantly re-inventing himself to prolong his employment in the building industry.

	Participant	Gender	Age	State	Eye Condition
1	Blind Chef	Male	45-50	NSW	RP
2	Freeman	Male	40-45	NSW	RP
3	Gearbox	Male	30-35	NSW	RP
4	Schoolie	Female	45-50	NSW	Other
5	Fighter	Female	40-45	SA	Other
6	CPA Farmer	Male	45-50	QLD	RP
7	Reflex	Female	40-45	WA	Other
8	Volunteer	Female	40-45	VIC	Other
9	Lone Ranger	Male	28	QLD	Other
10	Miss	Female	40-45	QLD	RP
11	Builder	Male	30-35	QLD	RP

**Table 2 Participant demographics**

### **Concluding remarks**

This chapter has outlined the methods that were employed in this study. The underlying theories of Yin and Stake were detailed and compared as part of the research style. The participant criterion and selection processes were detailed along with the unexpected changes that had to be made when the interviews were organised. The participant profiles were presented to provide a broad overview of the participants. The methods of interview and recording were outlined and the changing methods of transcription were described. The transcriptions were then used in data analysis.

The following chapter details the data analysis of the research data.



## Chapter four

# Data analysis

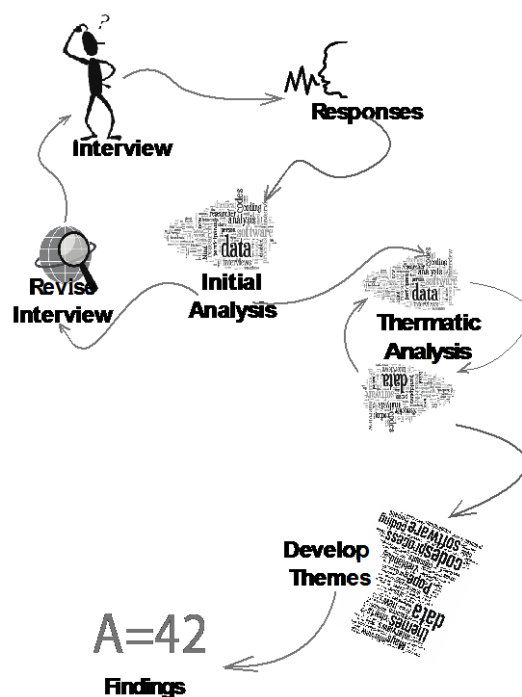
---

### Introduction

In this chapter I explain how I analysed the data, the underlying principles and theories I employed to summarise the outcomes and finally demographics of the participants in the study. As Pope et al. point out:

Data analysis can either be analysed inductively—that is, obtained gradually from the data—or deductively—that is, with a theoretical framework as the background. (Pope, C., van Royen, P. & Baker, R. 2002, p. 149)

The following figure outlines the data collection and analysis phases. The start of the



cycle begins with the interview and responses that are then analysed. The future interviews modified and the cycle continues with the interviews ever evolving. At the same time thematic coding is undertaken to develop themes and concepts to arrive at the study finds. The following chapter explains this in detail.

In the analysis phase of the research the data was inductively investigated, with no predetermined theoretical framework. Hence it was the data that led me to collect statements and then the group them into themes, consistent with the methodology of grounded/descriptive theory (Sandelowski, M. 2000).

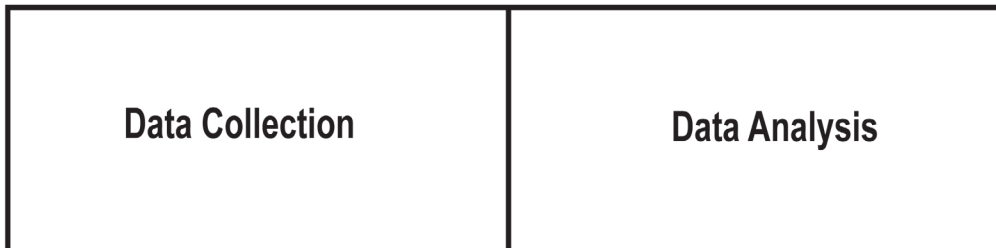
At the beginning of any qualitative research project the major emphasis is on data collection, with some limited analysis carried out. By contrast, in quantitative research there is typically a distinct data collection and data analysis phase (Pope, C., Ziebland, S. & Mays, N. 2006) (see Figure 4.1 below). Commencing with the first interview and the subsequent data gathering, I began to decipher and attempt to become familiar with what the participants were saying. As Sandelowski points out, like any form of inquiry:

research ... entails description, and all description entails interpretation.

Descriptions always depend on the perceptions, inclinations, sensitivities, and sensibilities of the describer. (Sandelowski, M. 2000, p. 335).

As the participants answered my questions and elaborated on the topics as they remembered them, I began to modify my approach to data collection. In a semi-structured interview, hearing the responses and asking the next question or

prompting requires a constant interpretation and understanding of what has been said (Sandelowski, M. 2010).



**Figure 4.1: Typical quantitative research phases**

*Source: Pope, Ziebland & Mays 2006, p. 65*

Qualitative descriptive grounded theory research covers a broad range of approaches and styles. Each research project develops its own research methodology and data analysis techniques and approaches (Sandelowski, M. 2010). Unlike traditional qualitative descriptive studies, grounded theory looks past the 'surface' meaning of the words participants say and delves into the meaning of what has been said during the interviews (Sandelowski, M. 2000).

Grounded theory principles are qualitative in nature and evolve during the progress of the research study with each interview adding new aspects and clues to direct and navigate future interviews (Corbin, J.M. & Strauss, A. 1990). Corbin and Strauss detail data collection and analysis as

"Data Collection and Analysis are Interrelated Processes. In grounded theory, the analysis begins as soon as the first bit of data is collected. By contrast, many

qualitative researchers collect much of their data prior to beginning systematic analysis.” (Corbin, J.M. & Strauss, A. 1990, p. 6)

During the transcription of the interviews I gradually became increasingly familiar with the data gradually as I listened over and over again to participants’ responses, tones and concepts. Basic themes emerged over many interviews that allowed me to take an initial position in the coding of the data. The basic canon of grounded theory is the constant comparison of words, tones and phrases. The constant comparison allows the analyst to reduce the data, as semi-structured interviews produce copious pages of rich data (Corbin, J.M. & Strauss, A. 1990; Hutchison, A.J., Johnston, L. & Breckon, J. 2011).

The data was analysed using the techniques outlined below with the application of the software programs Dedoose and NVivo10. The following sections discuss the techniques used and the analytical processes employed.

### **Interview progress**

I commenced the interviews in March 2013 and continued through to October 2013. The time between the first and the last interview allowed me to develop and modify not only my interview style but also the basic formation of initial codes. These codes became the basis of the thematic analysis I used and were subsequently modified during the ongoing coding process. I took care to consider any bias in thematic coding and subsequent analysis.

### **Thematic coding and analysis bias within disability studies**

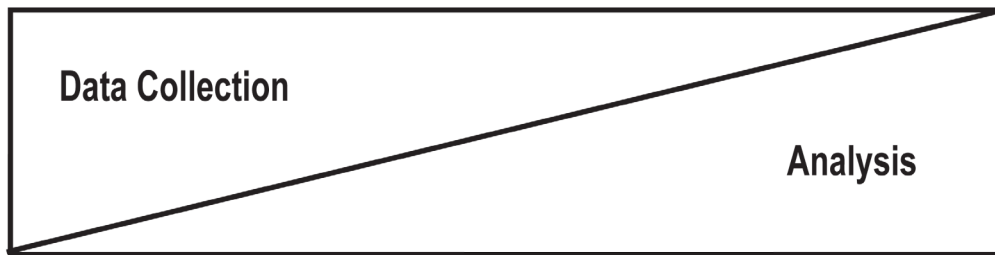
I developed the thematic codes with consideration of potential bias towards people with disabilities. The generalised labels and hence codes that emerged were from the perspective of a person who is blind. I took efforts to reduce the possibility of “ableism” (Eckhardt, E. & Anastas, J. 2007, p. 235). Ableism is the belief that all participants in the study are able-bodied and hence that the answers would be from the perspective of a non-disabled person (Eckhardt, E. & Anastas, J. 2007). Ableism implies that interviews are conducted with a non-disabled lens, anticipating answers from a non-disabled stance. However, as I am a legally blind person (i.e. myself a disabled person). Being disabled allowed me to conduct the interviews from the disabled stance i.e. an insider researcher.

There are many instances where disabled people do not feel disabled (Watson, N. 2002) because they have adjusted to the norms of their worlds. I do not feel blind. I have normalised my world and I accept and understand the need to adapt to the sighted world as well as to the world of blindness. The two worlds are one, yet are far apart due to the increasing ability to visualise the world thanks to technology. A blind person has to cope within both worlds.

### **Qualitative analysis process**

The process of qualitative analysis is an ongoing one where the initial stage of the research is predominantly data collection, after which data analysis is initiated. As the research progresses the analysis grows in importance and data collection

reduces. This relationship is shown in Figure 4.2 below, a modification of Pope et al.'s comparison between quantitative and qualitative research presented earlier in Figure 4.1 (Pope, C., Ziebland, S. & Mays, N. 2006, p. 65).



**Figure 4.2: Typical qualitative research phases**  
 Source: Modified from Pope, Ziebland & Mays 2006, p. 65

### **Data analysis**

Pope et al suggest that there are five steps in data analysis: familiarization; identifying thematic frameworks; indexing; charting and mapping; and interpretation (Pope, C., Ziebland, S. & Mays, N. 2000). The following sections explain how I approached each step of data analysis.

### **Familiarisation**

The first step, familiarisation, refers to:

immersion in the raw data by listening to tapes, reading transcripts, studying notes and so on, in order to list key ideas and recurrent themes. (Pope, C., Ziebland, S. & Mays, N. 2000).

To familiarise myself with the data, as soon as I had completed an interview I began to transcribe the digital recording. During transcription I developed a feel for the emerging trends and themes. While transcribing the second and subsequent

interviews I was also coding previous interviews. The new transcriptions subsequently created new codes. I paid special attention to the tones and intent of the participants' voices in an effort to capture the essence of the conversation, i.e. its conversational validity. I listened to the digital recordings repeatedly to be able to transcribe the words and capture the content of the interview.

The literature about analysis then recommends a quick reading of the transcriptions (Corbin, J.M. & Strauss, A. 1990; Pope, C., van Royen, P. & Baker, R. 2002; Pope, C., Ziebland, S. & Mays, N. 2000). As I am legally blind this approach was not possible and complete coding was undertaken from the beginning. As one interview was coded I began coding the next. As new codes emerged the previous interview was recoded in line with the new codes. This coding scheme began to create a framework or tree of codes that developed around themes and labels. In other words, the analysis took shape as thematic coding.

Transcription was a slow and tedious process due to my blindness. After transcribing the first three interviews by listening and typing what was spoken, I experimented with dictation software which allowed me to listen to the interview in one ear and repeat what was said into the software. This process increased the speed of transcription. It was further sped up with the use of specialist transcription software, f5. The f5 software allowed for a better approach to the transcription process by allowing me to stop and restart at a predetermined time before the last

stoppage. It also placed time stamps in the transcripts whenever a new paragraph or topic was created.

A Computer Assisted/Aided Qualitative Data Analysis Software (CAQDAS) package called Dedoose was used. The Dedoose program is a web based data analysis program that uses Graphical User Interface (GUI) technologies to code the interviews. The coding can be conducted on written transcripts, audio recordings, video, pictures and many other forms of artifacts.

Using the capabilities of the Dedoose software package, the newest raw digital recordings of the interviews were loaded into the program and coded directly. The written transcripts were then transcribed at a later date. This then allowed for an improved coding timeline and allowed more time to consider the emerging concepts. The emerging concepts are presented in Appendix D.

Towards the end of October 2013 I incorporated NVivo10 software into the research. This allowed me to generate word trees from the transcribed interviews. These visualisations or charts will be discussed further below.

### **Identifying thematic frameworks**

Pope, Ziebland and Mays describe the step of next step, identification, as follows:

Identifying all the key issues, concepts, and themes by which the data can be examined and referenced. This is carried out by drawing on a priori issues and questions derived from the aims and objectives of the study as well as issues raised by the respondents themselves and views or experiences that recur in the data. The



end product of this stage is a detailed index of the data, which labels the data into manageable chunks for subsequent retrieval and exploration. (Pope, C., Ziebland, S. & Mays, N. 2000)

Using the software to code both the transcribed interviews and digital recordings generated new concepts and themes as the interviews continued. As a new theme emerged a new code was created. Some codes were generated and later moved to become sub-codes of other codes that appeared to be more comprehensive.

Other codes were deleted, as I realised they were not a theme but a consequence of blindness. Codes that were deleted were determined by their relationship to employment, for example mobility aids such as ultrasonic hand held devices, long canes, ID canes or guide dogs. Mobility aids were originally thought of as a factor in the ability to commute to and from the place of employment. However, this was subsequently deleted as the mobility aids did not have any significant impact on, or determine if, a person was employed or not. Other codes were also deemed redundant. The reasons for making themes redundant will be detailed in the next chapter.

The next phase of the analysis was to 'chunk' the codes and sub-codes into manageable categories. The key issues were identified. I labelled all issues and statements by the participants, whether they were relevant or not. These ideas and statements were all taken into account in order to interrogate robustly the data and not omit possibly significant details (Pope, C., Ziebland, S. & Mays, N. 2000).

The initial coding of the interviews resulted in 89 thematic codes and sub-codes (see Appendix D). The codes were created as each new theme emerged in each interview. They were collapsed and deleted as the coding process continued.

### **Indexing**

The next step, indexing, is described as follows:

applying the thematic framework or index systematically to all the data in textual form by annotating the transcripts with numerical codes from the index, usually supported by short text descriptors to elaborate the index heading. Single passages of text can often encompass a large number of different themes, each of which has to be recorded, usually in the margin of the transcript. (Pope, C., Ziebland, S. & Mays, N. 2000)

This step, although important to Pope *et al*, was designed for a period when computer-aided research software was not as capable as it now is, nor able to interact with other software packages. That is, data can now be coded in Dedoose or NVivo and other similar software packages and results downloaded as spreadsheet files that can be read by applications like MS-Excel, Numbers etc. The data can then be manipulated in the spreadsheet, graphs and visualisations produced and then loaded into a word processing program such as MS-Word, Pages etc.

This indexing step can also be incorporated within the coding system by allocating numerical values and descriptions to the codes, completed when coding.

Following initial thematic coding I downloaded the code tree as an MS-Excel file and grouped it into nominal themes. This process reduced the code tree from 89

to 17 themes. Using the code application chart codes that had fewer than five occurrences were deleted (see Appendix D).

The table of 17 labels was then regrouped, like themes joined and codes collapsed into larger contextual themes. This produced four basic areas (see Appendix D). One area contained the themes that were not considered significant to the research. The first grouping is training and technology; the second is supporting frameworks and the last is awareness and discrimination. These groupings will be discussed in the next chapter.

### **Charting**

Once indexing is complete, the next stage is charting:

Rearranging the data according to the appropriate part of the thematic framework to which they relate, and forming charts. For example, there is likely to be a chart for each key subject area or theme with entries for several respondents. Unlike simple cut and paste methods that group verbatim text, the charts contain distilled summaries of views and experiences. Thus the charting process involves a considerable amount of abstraction and synthesis. (Pope, C., Ziebland, S. & Mays, N. 2000).

The charting process is an analytical tool consisting of current software that can ask various logical questions. As Pope *et al* were formulating their analytical steps pre-2000, the software available was limited and this step was much more difficult than with today's software packages (Pope, C., Ziebland, S. & Mays, N. 2000). Charting is now referred to as 'data visualisation'. The data visualisations can be produced by

using various methods such as word clouds and word trees. In my study, as the codes were refined I could instantly produce various charts using the software packages.

Both the software programs Dedoose and NVivo10 have basic data visualisations available in the form of common research charts. Each program also allows for custom charts to be produced or the data can be downloaded to a spreadsheet and manipulated as required.

I generated many of the standard charts to view the data in these different ways. These charts assisted in the process of modifying the codes based on factors such as frequency per interview, total number of times mentioned etc. This was the commencement of the mapping and interpretation phase.

### **Mapping and interpretation**

The last stage of the analytical process is mapping and interpretation:

Using the charts to define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to providing explanations for the findings. The process of mapping and interpretation is influenced by the original research objectives as well as by the themes that have emerged from the data themselves. (Pope, C., Ziebland, S. & Mays, N. 2000)

This final stage in the five-step process involved reviewing the data visualisations, word clouds and word trees to refine and refresh the key concepts that were developed during the coding and indexing process. The key concepts were re-

interrogated to discover links between them. This stage was also useful for determining possible future research projects that could expand knowledge in these areas.

### **Multiple software use**

As mentioned earlier I used two software programs: Dedoose® and NVivo10®. I did this as firstly I had never used any coding software systems previously and had no concept of their capabilities and possible outcomes. Secondly, having had no training of either of the software systems, when I conducted the initial coding using Dedoose I was unsure if my techniques were appropriate or correct.

### **Data collection and transcription hardware**

As described in chapter three, I used two recording devices to collect data at each interview. I did this as I had in the past unintentionally erased recordings by pressing incorrect buttons on digital equipment. Due to my blindness I often cannot see LED or LCD displays and so I do not know when the recording device has stopped. Sometimes I have thought that I was stopping the device when in fact I was deleting the recording of a meeting or interview that had just conducted. I therefore employed technology and equipment that acknowledged my limitations, including computers with large screens and projection systems along with an iPhone with voice-over. The following is a list of equipment used

- Face-to-face interviews were recorded via iPhone 4S iTalk app and a Sony handheld digital voice recorder.

- Interstate and intrastate interviews were recorded using software on iPhone with 4S iTalk app and Skype with call recorder software to record interviews.
- Transcription was undertaken using f5 transcription software and the use of Dragon dictate for Mac 2 and later version 3 software.
- Initial data interrogation was via Dedoose software package.
- Secondary data interrogation used NVivo10 software.
- Computer hardware used
  - Dedoose 27" iMac 3.4 Ghz Intel core i7, 16GB OSX system.
  - NVivo 27" Windows 8 based computer

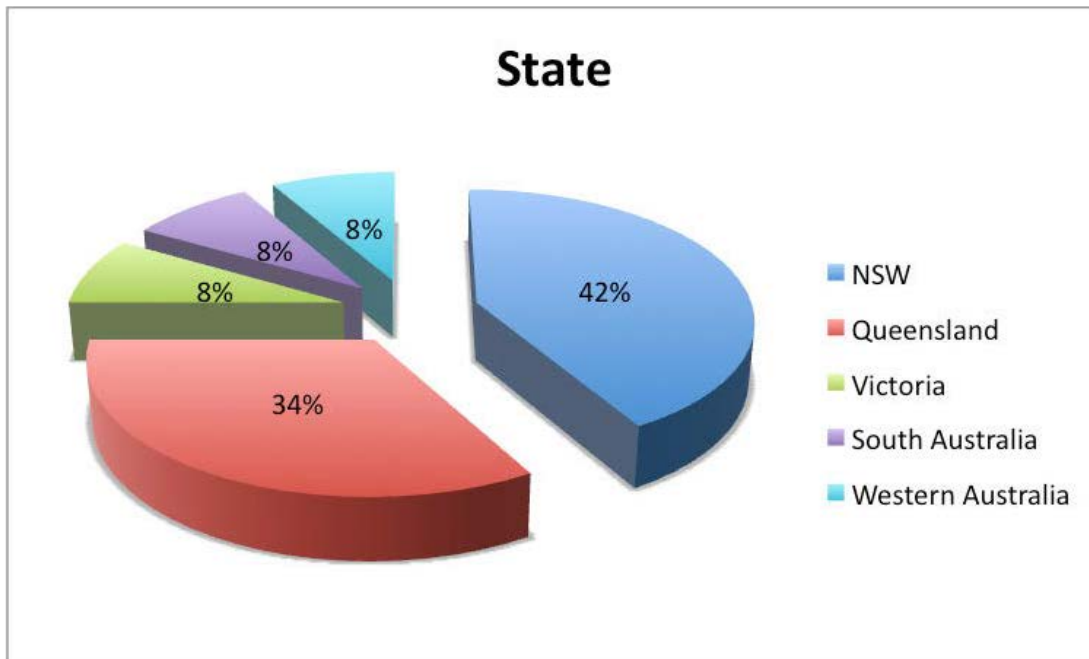
### **Participant data**

As stated previously 11 participants were interviewed for this study. The number of people interviewed was dependent on replies to an expression of interest set out via various e-mail methods including but not limited to BCA, Vision Australia employment services, Vision Australia's tertiary education officer, Vision Australia's local client networks and word-of-mouth referrals.

I interviewed and recorded all the participants either face-to-face or by Skype. I transcribed a direct copy of the telephone conversation and then de-identified each interview to protect the participants' identities. Each of the participants was given a code name that reflected the story depicted during the interview.

The demographic profile of the participant group is 6 males, 5 females, with 9 living with their spouse and/or children. The proportion of people living in

metropolitan areas of major capital cities is 6 with a spread of participants across Australian states: 4 in New South Wales, 3 Queensland and 1 in Western Australia, Victoria and South Australia. The majority of the participants lost their vision in a period greater than 18 months with 1 losing vision between 6 and 17 months and 2 losing vision in less than 6 months. The majority of the participants (6) suffered a degenerative eye disease, principally RP. The post-vision loss employment categories were 3 in both professional and administration roles, with 2 self-employed and 9% working in manual trades areas. The average interview time was 61 minutes. The majority of the participants (6) had lost their vision in the 30-year age group; 2 had lost vision in the 40-year group. There were no participants who had lost vision in their 50s or 60s other than myself. I lost vision in my late 50s. However my data was not included in the participants' data (French, S. & Swain, J. 1997). As an insider researcher (French, S. & Swain, J. 1997) I am working with the data rather than being part of the data.



*Figure 4.3: States of origin for research participants*

### **Chapter summary**

In this chapter I have described the principles and techniques used to explore the research questions. The chapter covered the concepts of validity and audibility of the data, analysis and theme development, following the five-step analysis model proposed by Pope et al (Pope, C., Ziebland, S. & Mays, N. 2000). The following chapter presents and discusses the findings derived from the various data analysis processes.



# Findings and discussion of the participant interview data

---

## **Introduction**

This chapter presents the findings of my research. The chapter first presents accounts of each of the clusters of themes which, although often discussed in the literature about the employability of the blind, in fact emerged to be of little relevance to the participants in this research: transport, financial situation, blindness associations and medical condition. The second part presents the findings in the areas of training and technology, supporting network and awareness and discrimination. On the following page there is a map of the chapter, There are five distinct themes groupings represented by the map Discounted themes, support networks, training & technology, awareness & discrimination and affordances and bounded agency

**Section One - Discounted themes**

Transport, Finance, Blindness  
Associations, medical conditions

**Section Two – Support Networks**

Emotional Journeys, Counseling  
& Therapy, Family & Friends,

**Section Three – Training &  
Technology**

Training & Assessment, Employment  
Service providers, Job seeking issues,  
Adaptive Technologies

**Section Four – Awareness &  
Discrimination**

Awareness & Discrimination,  
Participants views, Declaring  
Blindness, Awareness

**Section Five – Affordances &  
Bounded Agency**

Affordances and bounded agency

## **Discontinued themes**

Concepts and themes that were considered out of the scope or not significant for this research are discussed below, to show why they were judged to be either out of the scope or not significant.

### **Transport**

This section details the availability of buses, trains and taxis in the Sydney transport system. Sydney is the country's largest and most populous city in Australia, with a population estimated at over 3.8 million people (Digital Atlas 2013). In 2012 66% of Australia's population resided in greater capital cities (Australian Bureau of Statistics 2012b; Digital Atlas 2013). The attitudes and situations of participants living in Sydney are therefore taken as representative of the attitudes and situations for participants in other capital cities across Australian.

In prior research concerning individuals with vision impairment, transport was considered a relevant factor for a number of researchers (Bell, E. 2010; Crudden, A. et al. 1998b; Goertz, Y.H.H. et al. 2010; Young, C.E. 1995). These researchers suggested that poor access or lack of transport is a limiting factor in the employment of disabled people and hence the blind. I therefore included the topic of transport in the initial interview questions. My view was that society should accept that transport be accessible and available to all members of society.

In October and November 2013, I investigated the Sydney bus network timetables. I examined the Sydney Buses website (<http://www.sydneybuses.info>) to

determine the availability of accessible buses, frequency of buses on selected routes, and changes in the number of accessible buses within the Sydney buses fleet according to the organisation’s annual reports over a number of years (Rowley P 2010, 2011, 2012). I noted a substantial increase of accessible buses from 45% in 2008 to 72% in 2011.

STA annual report	total buses	accessible	percentage
2008–09	2027	913	45%
2009–10	2163	1266	59%
2010–11	2252	1499	67%
2011–12	2209	1596	72%

**Table 5.1: Accessible Sydney buses**  
 Source: Sydney Buses Annual Reports 2008 to 2012

A similar investigation of the Sydney urban railway network for accessibility of stations and platforms yielded similar improvements of access for the disabled (Berejiklian, G. & Gay, D. 2012). The railway network has increased accessibility from the 2007 levels of 32% to what is predicted to be 52% in 2015.

**The decision**

None of the participants I interviewed considered that they had more transport issues than any other person, abled or disabled. Social acceptance of policies such as the *Transport NSW Disabled Plan Transport for NSW Disability Action Plan 2012 – 2017* (Transport for NSW 2013) is an indication that transport will continue to improve for

disabled people. My experiences of excellent service from many modes of public transport (see Appendix E) are in line with participants' statements.

Although transport is not further considered in this research, people who live in remote areas are likely to have issues with the accessibility of transport services compared with those provided in capital cities. Services are provided in proportion to population. Many country towns and cities have no rail services, and rely solely on bus networks. Some rural towns and villages have no transport systems at all. When I raised this issue of transport with the two participants who lived outside major cities, neither participant considered transport a relevant issue. I believe they simply accepted the limitations on the transport available in their regions.

### **Financial situation**

The financial situation of all participants was a sensitive area. All of the participants were receiving the Disabled Support Pension – Blind. A number of the participants had been self-employed or employed part-time before the onset of blindness. Annual salaries, pre and post blindness, with the support of this pension, generally matched pre-blindness salaries. This pension is not considered as income by the Australia Taxation system until a person reaches the aged pension age. It is then treated as income and is counted toward the tax-free freehold of \$18,000.

The major financial concern for participants was that of permanent employment. The majority of the participants were working part time, self-employed or on short to medium-term contracts.

A number of participants undertook university studies after vision loss and had important roles in the workforce.

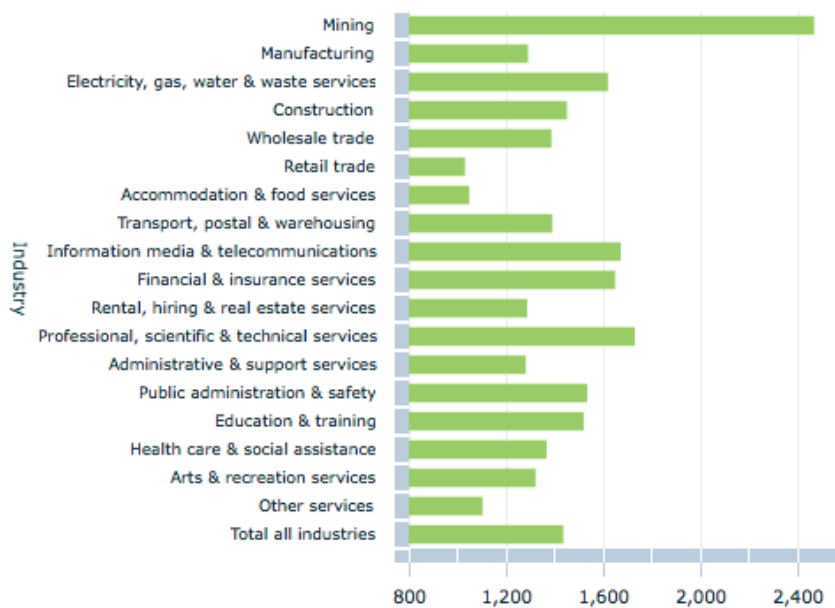
Salary range, I earn more now than before I was blind because I worked in the US. Salaries are lower there. I cannot compare between the US and here. Wages are better in Australia. (Blind Chef)

Although Blind Chef compared wages in the US and Australia, his position in the US was as a *maître d'* in restaurants, and his Australian occupation is as a national public policy adviser, so no valid comparison can be undertaken.

Another participant stated that the Disabled Support Pension – Blind assisted him to maintain his family's financial situation. After vision loss he had to change career from a building industry worker to that of a production worker in an automotive transmission assembly factory.

Typically building workers earn more than process workers on a production line. The average weekly wage for all persons in the construction industry in November 2013 was \$1487.80, compared with \$1332.70 in the manufacturing industry of (see figure 5.1, below) (Australian Bureau of Statistics 2014).

**Average Weekly Ordinary Time Earnings, Full Time Adults by Industry, Original, Nov 2013**



**Figure 5.1 Comparison of average weekly earnings across industry sectors**

Source: ABS 2014 Average weekly earnings

Gearbox stated that the wage differences between his building employment and that within the assembly factory were supplemented with the Disabled Support Pension DSP (Blind):

When I first left the building game the difference between [name of company] and the building game in pay ... it was a little less in the factory as to what I was getting on the building site. But I got the blind pension [DSP] that wasn't means tested and made up the differences and took me a little bit above what I had earned in the building game. I was actually very lucky to be on a good wicket. Otherwise I would have had to just gone onto the DSP. My family would have suffered because of that. (Gearbox)

Other participants had sponsors who either created positions for them or moved them around within a company to maintain their employment. This was the case for Builder, CPA Farmer and Fighter:

Our general manager who is the overall boss, I have had three good conversations with him and the last one was not with him but with the 2IC to him ... he pulled me aside and said, I just want to have a talk to you about your health and where to [from here].

This is where I opened a conversation about, OK, I am very interested in finding a niche role that is going to allow me to do work for the next five years. The response that came out of that was that the manager, the GM, is trying to find a role to you for the next 15 to 20 years. (Builder)

Although the company was a large multinational company, it was trying to maintain Builder's employment and hence his financial arrangements. Other employers similarly looked for ways to keep participants:

So midway through the 18 weeks, about the 10 week period, one of the senior guys said, we are going to keep you on, we do not have a position but we will do what we have to do to keep you [...] Then they gave me a three-month contract but without a position. I was just in there doing different stuff [...] But obviously they had me on some sort of bypass just to hold me. (CPA Farmer)

### ***The decision***

The motivation for exploring the theme of financial situations was to investigate whether employment changes due to vision loss reduced or increased a person's earning potential. Participants were largely happy to be employed and with the



assistance of the Disabled Support Pension generally maintained their financial situations.

The concerns of the participants are similar to those other employees would have. Many companies regularly employ people on short-term contracts and make positions redundant. This instability in employment makes for uncertainty within workforces (Dickerson, A. & Green, F. 2012; Shildrick, T. et al. 2012).

Although finance was not considered further in this research, the participants are those who were employed or were self-employed. The experiences of those who cannot gain employment and survive only on the Disabled Support Pension – Blind may cast a different perspective.

### **Blindness associations**

Blindness associations—the various Guide Dog associations in each state, Vision Australia and Blind Citizens Australia—exist to assist blind people and people who have low vision. Each blindness association has broadly distinct areas of operation, i.e. mobility, advocacy, and whole-of-life.

Guide Dogs generally specialise in mobility. Their mission is “to enhance the independence and safe mobility of people who are blind or vision impaired” (Guide Dogs , N.A. 2012).

Blind Citizens Australia deals mainly with policy development and advocacy issues of people with low vision and those who are blind. It is a national body with state-based subsidiaries and states its mission as follows:

Our mission is to achieve equity and equality by our empowerment, by promoting positive community attitudes, and by striving for high quality and accessible services which meet our needs. (Blind Citizens Australia 2014)

Vision Australia is a holistic association which provides services “from the cradle to the grave”, i.e. they provide services for children, adolescents, adults and seniors. The services range from orientation and mobility training (use of white canes, how to catch buses and taxis, how to get around at home and in the community etc) to Braille training to employment services and much more. It spells out its role as follows:

Vision Australia is a partnership between people who are blind, sighted or have low vision. We are united by our passion that people who are blind or have low vision will have access to and fully participate in every part of life they choose. (Vision Australia 2012b)

Most participants knew about either Vision Australia or Guide Dogs, but only a few knew about Blind Citizens Australia. My experiences with the various blindness associations reflect those of participants (see Appendix E).

### ***The decision***

Participants did not generally highlight issues with the associations, which are generally viewed as enabling people to progress in their life as independent people and to seek work if they want it.

Although the blindness associations were not further considered in this research, their roles could be the topic for future research. The degree of duplication between state and national associations could link into the evolving National Disability Insurance Scheme and could inform public policy on funding models for blindness associations.

### **Medical condition and level of handicap**

Medical conditions and levels of handicap play a significant role in people's employability. The participant selection criteria in this study—that participants have only one disability, i.e. blindness—reduced participants' consideration of medical issues.

The participants did not highlight medical conditions other than blindness as a concern. The participants thought that the issue of medical conditions and levels of handicap was more one of the need for non-disabled people to show understanding and awareness. In some cases this became a form of discrimination. This is dealt with below, in the 'Awareness and discrimination' section of this chapter.

Retraining for the participants and education of co-workers was of greater concern than the level of blindness a person had.

## **Summary**

Although areas of transport, financial situations, blindness associations and medical conditions are not discussed in depth in this research, each of these areas could constitute a complete research project of its own. While my participants did not regard transport as a major factor impacting on their employability, published literature suggests that transport can be a major factor in employment for all people, not just blind people. Through various policies governments are attempting to improve transport for the disabled as a whole. Most state governments have a long-term commitment to improvements to transport systems for disabled passengers and hold regular reviews to monitor the operational effectiveness and to continually improve practices.

Transport strategies are similar in most states of Australia. The variety of transport services—their availability, flexibility and diversity—is proportional to the population of the region. Reflex is a resident of Perth, WA, and spoke about assistance and public transport services similar to those available to CPA Farmer, who lives in Brisbane, or to me in Sydney. This demonstrates the commitment around the country to improving transport for residents as a whole and also for the disabled.

Although the financial situations of the participants in this research showed generally good remuneration through their employment, supported with the assistance of the Disabled Support Pension – Blind, blind people are not generally

progressing beyond basic levels of income. Blindness associations do advocate on behalf of blind people for equal salary and conditions and offer other services for the blind (Blind Citizens Australia 2014; Vision Australia 2014).

Blindness associations help people to become work-ready through mobility training, 'soft skills' training (communication, etiquette and workplace relationship skills), and emotional support. They are a factor within the re-employment cycle but, as detailed later in this chapter, there are more important social and personal needs for people who lose vision in midlife. Blindness associations deal with various vision-related conditions although many people have multiple medical conditions and are catered for by multiple organisations.

There are many support networks for this study's participants in personal spheres, at workplaces and from government bodies.

### **Support networks**

This section presents various formal and informal networks that assist people to re-enter the workforce after losing vision.

### **Emotional networks**

Before any person who loses vision considers re-entering the workforce an emotional journey has to commence. This emotional journey has no ending, just various stages, all with different emotional needs (Omansky, B. 2011).

### **The journey**

This section discusses aspects of the various participants' emotional journeys and their coping methods. The rollercoaster of emotions participants go through and the various personal observations and reactions to personal and social constructs of blindness are also discussed.

Blind people must work in a society that has preconceived notions about blind people's needs and abilities. This is reflected in the workforce where perceived abilities and competence of a blind person limit their employment prospects (Boerner, K., Wang, S.-W. & Cimarolli, V. 2006; Royal National Institute for the Blind 2012).

An emotional readiness to re-enter the workforce was a major factor in the employment progression for all participants. With the loss of a sense in midlife, trauma and feelings of loss must be overcome prior to attempting to re-enter the workforce (Krausz, S.L. 1980). Until people are emotionally ready to re-enter the workforce there is no possibility of a person being able to effectively contribute in the workforce. With the initial trauma and emotional rollercoaster that everyone has experienced comes the need for psychological assistance (Omansky, B. 2011; Watson, N. 2002).

The following quotes demonstrate the emotional hurdles that the participants had to overcome:

Well, I did have a cane, a white cane and I had white cane training. I had problems using the cane. Like emotional problems not logistical problems or physical problems. I was not emotionally ready to tell the world that I needed a cane so I would carry the cane under my arm and when things got really difficult then I would use it. I remember that I would always fold it up when I got to the block and street that I lived on [laughs]. It took a long time for me to go home, all the way home or to leave my apartment with the cane. (Blind Chef)

Freeman had to overcome his rebellious feelings prior to the acceptance of blindness.

In this next extract he describes feeling guilty because he had not reflected on his rebellion and what it meant to him and people who surrounded him:

Freeman: I was pretty hard on my wife initially in as much as I became what I would refer to as belligerently independent. So, she wouldn't know where I was. I would be out to ridiculous hours and so I think that the wife was incredibly supportive and understanding.

Researcher: So with your *belligerent independence* was that a form of emotional release for yourself because of the blindness?

Freeman: It was definitely about the blindness. It was me (pause) it was me, it is my version of denial. It's not denial it is not me saying I don't have this issue. I really needed serious time out in the world figuring out what that hell it meant in my life. I went to South America by myself for three months ... Not on my own of course you just don't do that. And rode mountain bikes around there. That the belligerent independence was when I was not communicating particularly with my wife about where I was, what I was doing. It was like, don't curtail what I can do. And because I am blind I really need to get out and do this, I don't know, I know what it is meant to be Go out finding out what I

should be doing and doing it and I actually needed to create some separation, [pause]. I'm feeling a little bit guilty about this now.

One participant decided that she needed to overcome her issues and get back into the workforce:

I stayed at home for a while but had a mortgage, had bills to pay, I am 51 and decided I'm going to get back out into the workforce and try and organize a job and help pay the bills and things like that so I did. (Miss Positive)

The following section outlines the emotional journeys that the participants experienced and how they overcame their issues to be ready to re-enter the workforce or, in some cases, stay in their current employment.

### **The journey begins**

The journey from the sighted world to that of the blindness world is one that can come extremely slowly or can be devastatingly fast. The length of the journey does not diminish the amount of anxiety, confusion, or emotional pain that people experience along the way (Goodwyn, M., Bell, E.C. & Singletary, C. 2009).

Participants told of their personal journeys from the sighted world to the blindness world and how they overcame that. Many wanted to believe that there was a possibility of a medical remedy for their blindness. They all knew that blindness is irreversible and permanent but wanted to believe otherwise. Some wanted to believe that the blindness was not happening until the inevitable happened. Others knew they would be blind in a short time and took various courses of action to attempt to overcome their new disability and increase their employability.



All of the participants experienced emotional struggles. Whether these struggles led to other issues was a personal consequence of their emotional stability and maturity:

I mean it is a very frustrating thing, you just have to do the honours. No use sitting around feeling sorry for yourself, you'll be sitting there on your own. So you just gotta pick yourself up and work things through. (Reflex)

Reflex's frustration with her blindness could for other be reason to give up hope and confidence, as Volunteer indicated:

So that was for about four or five years I could still use public transport and go to the shops and that sort of thing. But then when I lost the last bit of vision I guess that was it. I just started to give up. I lost all confidence. (Volunteer)

Schoolie was attempting to come to terms with her blindness and gain some employment when she was told not to work. She now was not allowed to work and her emotions were still fragile:

I was not game to do anything and I was still in a state of trauma. (Schoolie)

### ***My journey begins***

My own speedy passage from the fully employed and fully sighted world to the realisation that I was blind and would have to accept the label of disabled was extremely traumatic. Coupled with the labelling was the thought that I would soon be unemployed. This demonstrates the emotional state that most people encounter when they lose vision, whether the loss is rapid or gradual. The loss is not accepted as pending and inevitable until it happens. People hope desperately for cures:

For me who had, you know this dark cloud of RP [Retinitis pigmentosa] hanging over your shoulders since I've been a young boy, that one negative that does come with it is that you do just put your head in the sand, and the white cane for me, it has been a big hurdle ... It was very good to go through and do and confronting that first of all the fear of hang on, white cane—acknowledging that you'd need it in certain situations. (Builder)

While their vision loss was inevitable, many participants hoped that a magic cure would be found. However, with current medical technologies there are no cures: blindness is irreversible and permanent. This hope of a cure reflects the medical model of blindness that was outlined in chapter two (Morris, J. 2001).

As part of the emotional journey, some people ignore the slow and gradual onset of blindness:

I started to look for what's available out there. I started researching is there any cures, and I don't believe the medical science approach to things necessarily, so I was looking at what were the alternative possibilities and so on. And I was actually believing what I was being told, that there wasn't a cure. (Freeman)

The hope that a personal cure will be found is still there even though the participants have irreversible blindness:

In the back of my mind I still think that they will find a cure, and maybe even give me back some of my vision, if not all. At least they give me some ability to recognize people and read again and you know see better than I can now. (Reflex)

Although only one person spoke openly about contemplating suicide, from my experience most people with loss of vision have a period where they think about committing suicide, such is the depth of depression experienced and the need for emotional support networks:

Well I had strong, strong good parents who basically would never let go and were always there for me. So I think that's very important when I was told on 14 January 1985 that yes you probably won't get your vision back. The next day they learnt that I would have to take insulin for the rest of my life ... thinking it might get better in six months' time. OK I might give it six months' time and then kill myself by giving myself an over-injection of insulin. But that didn't happen. My parents were good and strong and after six months' time they said OK time is up it's time to do something rather than listen to talking books and going to Aussie Rules once a week or something like that. You've got to do something. So go and re-educate and get on with your life. They were positive parents. (Lone Ranger)

Lone Ranger mentions his family's emotional support, his thoughts of suicide, his semi-depressed state for six months, the hope of a cure, and remembering the exact date of the diagnosis of blindness. The Lone Ranger lost his vision in two weeks. As will be seen, other participants also talked about their need for formal and informal emotional support networks. Whereas Lone Ranger thought of suicide, Builder sought formal support from psychologists, Miss Positive felt the need to ask her husband to leave her, and Freeman had to run away and undertake wild and outlandish adventures to try and find himself.

The emotional issues and hopes of cures fade but are always there. Many people often require counselling and psychological assistance to reduce or manage their emotional issues.

### **Psychologist, counselling and therapy groups**

Many participants discussed various forms of coping with the emotional issues relating to their blindness, and described how they moved forward toward their employment goals (Boerner, K. & Wang, S.-w. 2012).

Builder stated that he went to a psychologist because he did not want any of his emotions to affect his family life. He had been attending a private psychologist for a number of years (a psychologist dealing with the whole person, not necessarily only with a person who was gradually going blind). It was not until he went to Guide Dogs (Qld) for mobility training that he spoke to a specialist psychologist who he said “hit the nail on the head” with his topics. He remarked that this psychologist helped him with blindness-related issues, and the private psychologist helps him in his general life:

Mobility to me is taking that step to say well how do you keep that mobility? and making the decision to go through the [mobility] course and then through that, there was counselling with Guide Dogs.

I think I had four sessions with one of the Guide Dogs guys [counsellor] and that was pretty good because I think it was tailored to suit vision impairment more than the counsellor that I see personally, brilliant guy and very, very good guy to talk to. What I found from the Guide Dogs fellow was that he hit the

money; he hit the spot. He knew a lot of the challenges that we were going through almost as if you are talking on a similar sort of level. So I think that was pretty positive. (Builder)

On the other hand CPA Farmer did not have any counselling, as he wanted to work it out for himself. Here he speaks about losing his driving licence when initially diagnosed as legally blind. His coping method was to see himself as better off than others and as one who could still do things as well as everyone else:

I'll tell you another one, I attended an off-site conference, we travelled in an office car with someone else when we got back, because of the pillars the parking in the car park is difficult, the pillars are concrete pillars that supports the floor above you and this female person said look I'm stuck here I can't get in, I can't reverse the car. There was a pillar to the left and there was a car to the right and whatever else. And I said "Just give me a go, I reckon I could do this." And she said no "You are blind. " I said "Give me a go I reckon I can do it." And when you have enough vision, you still rely on your senses, you know the driving skills and whatever else. And, I got the car in for her! Well it nearly blew her backwards. And here is a fully sighted person couldn't do it. (CPA Farmer)

Other participants used similar comparisons between their pre vision loss personal abilities and their post vision loss abilities. This comparison of abilities serves to normalise their vision loss and to reassure themselves that others are worse off than they are. This is one way of coping with the trauma of vision loss. The use of professional assistance from psychologists and facilitated self-help groups is also a

coping method (Krausz, S.L. 1980). I was also resistant to seeing a psychologist but after a period of time thought that a visit might help (see Appendix E).

### **Family support networks**

Families can be another support system that assists a person's emotional state with vision loss. In contrast to programs like Vision Australia's Quality Living Group, family support is informal and ad hoc. Some of the participants had positive family support whereas others did not:

I suppose more particularly, my husband said now you've gone blind that is it, you cannot go to work anymore. And [pause] last year I suggested, having more, or actually I started to do it, go back and have some more white cane training. So I could at least go for a walk up and down the street, around the block, or down to the shops to buy an ice cream. Just something and I didn't get any encouragement from him whatsoever.

He said, No it's too dangerous, you'll fall over, you will get knocked over crossing the road.

And I had an O&M [Orientation & Mobility] come out from Vision Australia. [...] I probably did that for a couple of months and then I just because I was just negative and I had to find the cane, and one thing and another and I thought I would try it again ... but I never did. (Volunteer)

One participant said his wife was extremely supportive and allowed him to work out his own issues although his mother attempted to overcompensate and wanted to feel the pain of vision loss. This form of overreaction by families, although it is

meant to be supportive, sometimes is another person's coping method for their loved one's vision loss:

Probably if there was something that was frustrating it was around wanting to be sympathetic and almost wanting to be more helpful than and when I necessarily wanted. I was pretty hard on my wife initially in as much as I became what I would refer to as *belligerently independent*. So, she wouldn't know where I was. I would be out to ridiculous hours and so I think that the wife was incredibly supportive and understanding and has ... In a way, we lived our lives and raised our kids, we have been ones to allow mistakes to be made, allow people to hurt themselves and you know fall over and hurt themselves, scratch knees etc and she has been very, very good at doing that. But I think they have been by-and-large supportive and helpful without being too much. The most difficult relationship was with my, particularly my mother, who wanted to take the blame for it. And you know, woe is me. If someone is going to be woe is me, then that should be me. (Freeman)

Many of the participants stated that their spouses supported them in many areas of life and were their emotional springboards:

I said to Robert that when I got diagnosed with this [blindness] I think you should leave me. He said why? I said well I don't wanna be a burden to you when I am in complete darkness. He said "I didn't marry you just cause you could see!" He said you know "you are more of a person than that". (Miss Positive)

Other forms of support are not as obvious but just as important. Support from family takes all forms, from mobility assistance to an understanding that a person may look

the same to the outside world and not look blind, whatever that is supposed to look like.

Coping with being blind is a part of the emotional journey and many mistakes are made along the way. The reactions of the families towards these mistakes are another piece of the maze. The following quote outlines how indirect support when mistakes are made can aid a person's passage along the emotional journey:

One of the funniest stories, I used to love doing a lot of cooking. I still try to do cooking and stuff like that and the house stuff but one night I cooked spaghetti Bolognese. I used to have big storage bottles before my sight loss. And rather than using corn flour to thicken it I used custard powder. So I took one bite, and I said to my husband, I think you should add more chilli sauce. My husband said that everything was all right; I just got dessert and mains together tonight. But you've got to laugh at those little sort of things. (Miss Positive)

The emotional needs of the situation include allowing time to find yourself, as in the case of Freeman, or strong support from parents, and understanding from families.

### **Summary of emotional support networks**

Loss of vision is a major issue. Whether it is sudden and unexpected, as in my case, or slow and dreaded as in many of the participants' cases, the emotions are similar and have to be overcome before employment can be sought

Family and friends play a major role in the emotional repair work a person needs. These roles are both ad hoc and informal, yet are as important as any structured support system.



Counselling and group therapy programs like the Vision Australia Quality Living Group programs and Guide Dogs Mobility and Orientation training coupled with counselling appear to help individuals to overcome their emotional issues, but other support also appears to be needed.

### **Employer and co-worker support networks**

Support networks of employers and co-workers are also necessary to support a person in gaining or retaining employment. Co-workers can assist, as in the case of Fighter's friend who advocated for her to maintain her employment. Co-workers also assisted when one gave Blind Chef the lead to gain a position. Employers can be positive towards a person who has lost vision and make meaningful workplace modifications to assist a person's employment; or employers can be negative, making token efforts to assist a person which in fact result in coercing a person to leave an employer. Volunteer reflected on a negative employer who did not want to assist her and did not help her in any way. She stated the following:

I was in the fortunate position of being the accounts clerk and so I got all the invoices and I knew that the employer wasn't going to the employer's chamber of commerce.

So I rang them (Chamber of Commerce) up and said we had an employee. This is when I was still working.

I said we've got an employee that is (pause) that has a health situation. She has been off for weeks and when she comes back to work 3 days a week ... so what would we do. And he said, "Just make sure you keep in touch with her. You

know, give her all the literature so that you can say that, you know, if she has to leave it is her decision. Not yours.” And that is exactly what they did not do. You know. I didn’t expect them to do it but I thought well, that’s what should they be doing. (Volunteer)

Other employers do not recognise the abilities of blind people and what skills they have and so do not employ people with disabilities. Lone Ranger was a qualified lawyer but was not employed as he was blind:

In fact, there was a family court judge who said, no I don’t want to take you as an associate because you are blind. (Lone Ranger)

Similarly, co-workers can be positive or negative. Typically the negative co-workers can seem discriminatory to the blind person. Fighter had a team of co-workers who resented her being there and put hurdles in her way, not recognising her work performances. She also felt isolated by not being given wage rises:

Anyway, they finally got through to putting the clerical and admin staff onto an ASO2 level and there would be one person who would not be moved up onto ASO2 level and that was me because I just answered [indignant tone] the phone! [laughs] and that came from my team leader. And if I had of been much younger, in the workplace, I would have taken that to discrimination. And sorted it out but I couldn’t be fagged at that stage. (Fighter)

Employers with negative attitudes towards people who are blind became covert following the introduction of the *Anti-Discrimination Act 1992*. The Act outlaws discrimination against a person on many grounds, one of which is physical or sensory disabilities. Before the introduction of the Act employers could openly state

that they did not employ blind people. After its introduction, in some instances employers would offer positions where the job description stated that a driving licence was required and/or a car was offered as part of the salary package, even though a person could perform the required duties with the use of public transport. Freeman had a head teacher who decided that Freeman was a risk to students as he was blind, without undertaking a risk assessment of Freeman's blindness.

Many participants spoke in detail about the reactions of employers when told that the applicant was blind. The time chosen to declare a person's blindness directly affected the employer's reaction. Often, when an applicant declared blindness in an application, no replies would be received.

Not declaring blindness in an application often resulted in granting of interviews. Subsequently the declaration of blindness at the commencement of the interview created a situation where "the interviewer's eyes glazed over" (Miss Positive) with no possibility of employment from the point of declaration.

Declaration of blindness at the completion of the interview was thought to allow for interviewers to at least hear about the skills and abilities of applicants. This may or may not have had a different outcome as employment decisions and discriminating factors are now covert and not stated in terms of a person's disability. None of the participants said they had not declared their blindness in the application or during the interview while hoping to be offered a position, and then declared it

later. Research suggests that blind applicants have a better chance of getting employed if they declared blindness or a disability early in an interview or at least before the acceptance of a position (Dalgin, R.S. & Bellini, J. 2008). It could be argued that these practices by employers are discriminatory, although this chapter later raises the question of whether it is discrimination or a lack of awareness of the abilities of the blind person, especially that of a person who has lost vision after have established a career in their sighted working life.

Employers who are supportive about employment of blind people may also look at ways of retaining them by various methods, such as creating positions for them, moving a person around within a company, or modifying the duties of a person to better use the skills and abilities that the person has. For example, Builder had many changes of position to enable him to retain employment; Fighter changed roles to become a blind proofreader using adaptive technologies; and CPA Farmer had positions created for him to allow him to be retained in the company.

Supportive co-workers are similar to supportive employers. Co-workers can include managers, supervisors and colleagues. Their support includes co-worker advocacy and representation; assisting in introducing meaningful duties; and better utilising a person's skills. Participants outlined the assistance of co-workers who knew the power of self-advocacy and coached participants on the self-advocacy skills required and the background to the issues.

In Fighter's case, she used these self-advocacy skills to represent herself, managing to retain her employment while under considerable pressure to resign. While her self-advocacy meant she retained her position, it also led to her being moved from position to position without utilising her skills. During these redirections her movements created animosity with colleagues as they were moved to accommodate her. She was given little work that suited her skills and felt under-utilised. After a period of time co-workers realised her adaptive technology could be used to assist in proofreading documents, by using screen readers to verbalise the text and listening to what was written. Her workload and self-esteem increased as her co-workers realised that she had skills that they thought were not available to a blind person.

Reflex, Builder, Blind Chef and CPA Farmer experienced managers who recognised their skills and abilities, either creating positions for them or coaching them into new careers and positions. This support from co-workers prompted the notion of the role of the 'significant other' in the maintaining of employment.

CPA Farmer, who was older and more experienced than the people who were interviewing and employing him, outlined the significance of key people at work by saying:

CPA Farmer: I think the blindness definitely would have been an issue and *company* would never have opened up to bringing in blind people just on a voluntary basis unless a person in *company* pushed it. And this particular person

had prior employment somewhere else and she has a social conscience and seen how given the opportunity how people can develop their own abilities and bring good things to organisations. She has been one pushing this and without her I don't think *company* would have employed anybody with a disability.

Researcher: With a disability, not just blindness?

CPA Farmer: Yes, with a disability not just blindness. Absolutely.

Across all of the participants a significant other, or others, played a major role whether positive or negative. In all cases there was a person who influenced their employment future. The positively significant others recognised that the person had skills and abilities that the company could use, or saw injustices being carried out and assisted the person to overcome them. The negatively significant others attempted to have the participants resign by various methods or gave no support or encouragement to the person. Some participants reported the stereotyping practiced by co-workers who believed they could not perform tasks because they were blind. Many of the participants signaled that they had help from others i.e. Gearbox has the CES officer who help gain him a position on the assembly line; Blind Chef has a manager a blindness association who assisted him at another organisation to gain the type of employment he was searching for; Fighter had a co-worker who taught her how to advocate and advised her on many issues that assisted her to maintain her position; Builder had the General Manager of his multi national company to plan his future into the future; CPA Farmer had support of the upper management in his last position who invented positions for him; Reflex had a manager who assisted her

into her self employment. This represents a huge assistance to the participants, that of significant others. Wherever a significant other was assisting them they gained employment whereas in the case of volunteer and her lack of significant others never gained fulltime employment or self employment. This is an area of interest that could be a future study area.

### **Summary**

This section has presented the personal journeys from fully sightedness to blindness, reflecting on the support networks such as psychologists and therapy groups that are necessary to allow a person to overcome vision loss. Blindness associations were also considered, with their roles within the support networks to help re-integrate people back into meaningful and rewarding employment. The major roles of families, employers and co-workers in the emotional stability of people who lose vision are important in their rehabilitation.

Each person has to deal with midlife vision loss in his or her own way. Some ignore the slow and relentless onset of blindness, hoping that it will go away or not happen at all; some confront blindness and work towards the unknown future of blindness, attempting to ready themselves for its inevitable and growing shadows. Others jump from a world which is fully sighted into the world of blindness overnight or in a comparatively short time.

Without both formal and informal support, it appears that a person who has lost vision in midlife would not be able to move towards gaining fulfilling employment. These support networks are a major factor in the re-employment processes. Another major factor is the need for training in various areas, such as the use of technologies to allow blind people to explore new career choices and the particular training requirements for the new career directions.

The following section considers training and technological factors in the progress towards employment, and presents the views of employment providers (employment services) and participants' reflections. The need for holistic assessment to determine the training needs of a person is investigated and the subsequent training needs, both formal and informal, are presented.

### **Training and technology**

Once the emotional aspects have been explored and a possible journey plotted and commenced, there is a need to reassess a person's abilities in the light of his/her blindness. One issue is the ability of a person to be independent. This could include the ability to travel to and from a place of employment, the ability to read, and the many soft skills that are needed in a workplace. Soft skills include workplace communication, workplace ethics and the ability to work with others in teams, whether formally or informally. Possession of these skills also impacts on perspectives of awareness, discrimination and stigmatisation. What may be a



common expression, for example “Look over there”, or “Did you see that?” can be misinterpreted as a form of discrimination if the soft skills have not been developed.

Holistic assessment of appropriate employment options must be undertaken with realistic expectations as DeMario observed:

Many successful individuals with visual impairments had a high school diploma; positive attitudes about work and about themselves; realistic vocational goals; and good orientation and mobility, communication, and social skills. (DeMario, N. 1992)

DeMario’s research conducted in 1992 produced similar results to the findings of the *Vision Australia Employment Report 2012*. The higher one’s educational level, the more employable one is (DeMario, N. 1992; Vision Australia 2012a). Employment outcomes can also be achieved as a result of work history, whether it is full-time or casual temporary work.

In a vocational rehabilitation study, Yonghong & Martz (2010) noted that one way of returning to work may be to consider temporary work while undertaking vocational education. Furthermore, they suggested that short-term employment can demonstrate work experience and increase a person’s confidence, and might eventually become a permanent position (Yonghong\_Jade. X & Martz. E 2010).

The learning that is required transforms a person from the sighted community to the blindness community and so become a member of numerous communities.

TL [transformational learning] theory can be seen as a theory of learning that is addressed precisely to the experience of individuals whose participation in a social

practice has been disrupted, a form of learning that occurs in a social space conceptually “outside” a community of practice. Mezirow (2000) charted this space with his phases of meaning perspective transformation that begin in a disorienting dilemma, self-examination, and “critical assessment of assumptions,” and end with development of “competence and self-confidence in new roles and relationships” and reintegration into the social world (p. 22). The first phases have been briefly discussed and it has been suggested that they are descriptive of an outbound trajectory. (Hodge, S. 2014, p. 173)

Adult learning theories of transformational learning and practice-based learning are said to be complementary (Hodge, S. 2014). Work placements and work experience based on the research findings could therefore assist newly blind people to learn the social practices within particular work communities. The outbound trajectory of leaving the sighted world and the inbound trajectory of entering the blind world are similar to the change when a master craftsperson leaves his or her ‘tools’ to take up a management position in a related field: the individual leaves the craft circle and must join a new fraternity. This leaving and joining are similar to the experience of a person who has to retrain for their new world and the new career. Transformation learning and communities of practice are two huge areas that have not been explored in this study.

### **Holistic training needs assessment**

My research did not ask who was best suited to conduct a holistic training needs assessment, the blind person him/herself or a professionally trained assessor. A

training needs assessment would typically require the person to determine desired employment outcomes and then list the skills needed to reach that outcome. The skills could be formal training at private providers, TAFE or university, or informal skills such as interview and resume writing skills with the help of employment service providers.

The participants generally determined their own futures, while professional employment officers at various employment service providers guided some of the participants toward employment. Below I present the perspectives of participants on the private providers.

### **Employment service: participant perspective**

Many of the participants stated that the employment service providers they had used in the past were “at best useless”, stating that they were ill-prepared, ill-informed and looked only for quick and easy placements. Two of the participants reflected that before the Commonwealth Employment Services became Centrelink, it had employment officers who cared and looked after the clients, and went what they described as “out of their way” to assist them

High staff turnovers at both Centrelink and among private providers causes their clients some issues:

I find that the RBS (Royal Blind Society) staff has gone down the gurgler now that they have a lot of rapid turnover of staff down there. You have a good one [employment officer] that may be a really, really good employment officer and then they are gone.

About six months after I got my workplace modifications, i.e. a wireless headset, I was having a problem with it and I rang up to speak to her and of course she had gone. The new girl, she didn't know anything about the case and she didn't know, she didn't have much idea at all. (Fighter)

The current Centrelink Offices and private employment service providers were said to have high staff turnovers and to employ people who were not as dedicated. As one participant stated "You get what you pay for!" This was reflected in comments from a number of participants e.g. Miss Positive, Volunteer and Blind Chef.

I went to CRS [Commonwealth Rehabilitation Service] and my experience there was horrendous. They had no idea how to deal with someone who was blind. They had a computer that they said had the software on but the computer did not work.

There was an office of computers for people to work on and also a meeting room where you could sit around and read newspapers. Then there was another little room attached to that which had an exercise bike and other exercise equipment and that's where the computer was stuck. It was in the corner and that is the computer with the software for the blind people.

The software actually didn't work, then after a month of complaining that I was going there for no reason, as I couldn't use the computer, the software got sorted out. It turned out that that computer wasn't connected to the internet. So I couldn't go online to look for work and in three months they took me on one job interview and that was a volunteer position.

It was all very much ticking boxes, and having another client on their roster.

They were completely incapable of providing me service. I think that there is a big area there that could be changed (Blind Chef)

A number of participants stated that the employment services would suggest training courses to get the participants off their books and park them for six months. They suggested that they learned unusable skills to allow for the service provider as they were often placed in the “too hard” basket.

The majority of the participants who had used an employment service had found their own employment after ceasing to be a client of the employment providers and so had not had a satisfactory service or result from the providers..

### **Employment service: provider perspectives**

As a follow-up to the statements made by the participants I made contact with the Vision Australia national employment service manager to gain a current insight as to what the private providers believed their roles were and their perspectives.

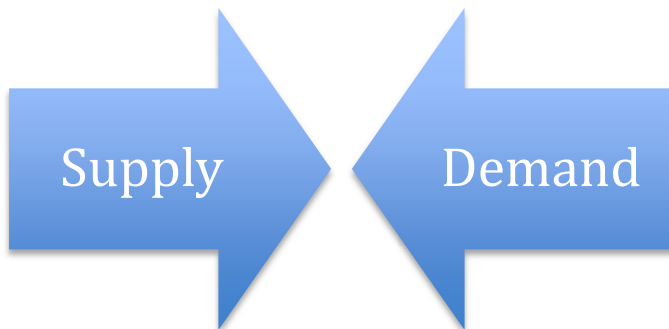
### ***Vision Australia's employment service perspective***

The manager summarised the situation as follows: employment providers can be generalised or specialist. Both face similar challenges gaining employment for clients. Specialists providers provide services for specific clients, for example disabled employment services. The issue is that all disabilities have differing needs and one specialist disabilities employment service provider cannot have all the skills or contacts for all the disabilities.

For all employment service providers there are two components: job seekers and employers. The job seekers are very dependent on skills and personal attributes, and are affected by the number of employment service clients (the ‘supply side’).

The employers are the demand side of the equation, lobbying for education, confidence, what clients don’t know, and soft skills such as workplace communication:

Vandergoot (1982) suggested that work readiness is determined by an interaction of personal attributes and the environment. Personal attributes include skills, behaviors, and psychological traits of the individual. Environmental factors include labor market conditions, attitudes of employers, and inappropriate or inadequate vocational and educational training. Individuals with disabilities traditionally have been unemployed or underemployed in the workforce. (DeMario, N. 1992)



**Figure 5.2: Employment supply and demand**

### **Challenges facing those seeking employment**

The Employment Services Manager of Vision Australia told me that blind job seekers generally highlighted the following challenges: the lack of suitable skills for the tasks

required, limited or no training, and lack of soft skills—personal attributes, confidence and communication.

The service provider payment scheme has recently changed to overcome some of the common complaints that my participants made. There are now proportional payments to service providers on placement and at the milestones of 26 and 52 weeks in a position. This requires service providers to better job match rather than parking a person in a job for three months, getting paid by the government and not creating a relationship with the employer.

The employers generally want disclosure of the person's blindness and the particular person's levels of disability:

I went through an interview process which lasted for about two hours. And got to the point of, look we think you got the job what sort of car do you want?

I said well is a car necessary, and I said you know it is yours it is in the package.

I said look I don't drive.

Well the director handling it went off his nut. He said we have wasted two hours here and you tell me that you don't drive a car.

I said but that did not impact on the ability to do the job. It is just a car issue. I don't drive but I can do a lot of things and I can get to many places without having to drive myself in a car. He did not buy that he just shut things down very quickly.

So that told me something and I still do not disclose disability until the end.

Because once you do at the start people's perceptions, they put up shutters and automatically assume that you can't [do the job].

That instance proved to me that you are as good as the next person it is just the very last part of one small criteria, or aspect of the job. So yeah there's just one, I think it is in a lot more instances. (CPA Farmer)

Many participants spoke about the disclosure issue. Miss Positive described her strategy of getting to an interview and declaring her disability at the end of the interview to maximize her opportunities.

Although the statements from the participants did not align with those of the employment provider, none of the participants had used Vision Australia Employment services. They had used the Commonwealth Employment Scheme and Commonwealth Rehabilitation Services Australia, and found the services extremely poor. Often they had then found their own employment.

### **Adaptive technologies**

A major aspect of employment is the ability to access the written word. Advances in technology allow the blind to use computers and other devices to work in areas once inaccessible to them. Devices available range from screen readers that are additions to computers, to inbuilt software that allows for both screen reading and magnification of the screen.

The following is an example of how adaptive technologies can be used to allow access to the written word and hence facilitate employment in industry.

Computer Numerical Control (CNC) machines are used in various industries across the world. CNC machines are extremely accurate; lathes and mills can create



accuracies of 0.001 mm repeatedly. The machines are controlled by computers and are coded with a combination of words and numbers.

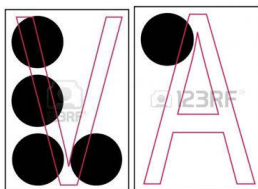
Lighthouse for the Blind—a company formed to assist the blind—has converted its CNC machines so that blind people can operate them. CNC machines have a computerised control system that uses touch screen displays to allow the operator to operate the machine, a control that is designed for visual management. The control was adapted to allow JAWS to operate as a screen reader, allowing a blind operator to hear what was on the screen and what they were typing into the computer, with added speakers so that the operator can hear JAWS. An oversized keyboard allows an operator to have large keys or Braille keys (Okuma America Corporation 2010).

Adapting the CNC machine for use by the blind is an example of changes that are possible if employers are willing to be open to workplace modifications, not only of processes, but also of plant and equipment.

Although Braille was invented by Louis Braille (1809–53) and is not an adaptive technology as such, it has been modernised, not by changing the system, but by using computers to create the Braille dots on a regenerating Braille board. Braille is a universal system that has been adapted to all languages across the world and can be used for music. Braille is a code using cells of six dots that have 63 combinations. The dots are in a cell that has two columns and three rows with each

combination having differing characteristics. The upper left dot on its own, for example, can be the letter “A” or the number “1”, depending on the context in which it was used. There are three levels of Braille for faster reading of large volumes of work. A Braille book is a huge tome due to the thickness of the paper and the spacing of the lines (Royal Blind Asylum and School, T. 2014).

I have learnt basic Braille, finding it useful in lifts and signs that are difficult to read, but find it extremely difficult to learn at the age of 59. There are also special Braille typewriters that have only six keys that produce the Braille dots. I did not understand the Vision Australia logo until after learning Braille, because the dots look like a capital L and a dot, as shown in Figure 5.3.



**Figure 5.3: The Vision Australia logo explained.**

### **Training needs**

A person who loses vision in midlife needs to reassess their employment futures.

Some will attempt to maintain their current position and adapt it to suit their changes of skills and abilities. A few participants spoke of how they decided to continue at the existing employer’s, and modify their duties. One had a continual battle with their supervisors; another had the support of his managers who helped

move him to positions more consistent with his vision loss; and yet another was retained without a position; others had to change employment status post retraining.

Once the decision either to maintain current employment or to leave and seek a new career has been made by either party, an assessment of the person has to be undertaken. A decision to stay will involve discussions with the current employer as to possible workplace modifications and necessary retraining for the new position.

If a new career has to be commenced, an assessment of the possible career options is needed. This assessment needs to determine what the person would like to do and create an audit of the person's skills and abilities, to see whether the person can successfully function within the new career and what training would be necessary. As mentioned earlier, employment service providers have structured approaches to the assessment process to help a person determine their needs.

All of the participants who changed careers used the employment service to determine what they needed to do to reach their goals. In this area the service providers appeared to assist the participants.

The participants undertook various levels of retraining; some undertook Certificate 3 level training courses and others undertook Masters degrees, summarised in Table 5.2 below. Others attended the service provider's employment courses for preparation of resumes and interview skills. Many of the participants had

not been in the competitive recruitment process in many years, and certainly not as blind applicants. Again the service provider here was said to be effective in this area:

Look, prior to going there (Vision Australia Employment service) I thought that if I detailed everything I did in my past it's like casting the net somewhere out there and the fish will fall into the net and you will get the job. Well I very quickly realised what you did in the past, they are only interested in what you can do. Or what you're capable of doing, and as long as there is no risk attached and that you don't bring baggage or you're not risk impacting upon the business. (CPA Farmer)

<b>participant</b>	<b>qualification attained post blindness</b>
<b>Blind Chef</b>	Masters degree Studying for Doctor of Philosophy
<b>Gearbox</b>	Basic metals trade training
<b>CPA Farmer</b>	Employment provider training
<b>Reflex</b>	Certificate 3 Reflexology
<b>Lone Ranger</b>	Law degree Studying for Doctor of Philosophy (law)
<b>Schoolie</b>	Doctor of Philosophy
<b>Miss Positive</b>	Studying for Bachelor's degree

**Table 5.2: Interviewee qualifications attained post blindness**

The employment service providers conducted training courses that were not nationally accredited within the vocational education system. Many of these course are in-house, designed to meet the specific goals of a particular service provider. Participants do not receive certificates on completion. Typical training provided by the providers was for resume writing, interview skills and the soft skills required by the employers.

The experiences of participants undertaking study were similar whether they were at TAFE or university. Both types of institutions have policies and procedures about the provision of training for the disabled. For example, the University of Technology Sydney, Notre Dame University and TAFE all have Disability Action

Plans (UTS 2010; Notre Dame University 2014; TAFE NSW 2014). These policies set out what should occur and the organisations' approach to disabled students, although the policies and procedures may not always be implemented in practice.

The learning experiences were similar for a participant who studied both at university in Queensland and at the University of Oxford in England. In Australia the university allowed him extra exam time with an amanuensis provided after experimenting with taping his verbal responses. At that time, approximately 20 years ago, readings and course materials were not supplied in his preferred formats such as Braille or tape recordings. Another participant who attended the University of Sydney a few years later stated that a few resources were provided in soft copy that could be read using rudimentary screen readers. Screen reading technology and the availability of soft copies of articles has increased dramatically over the past 10 years. The increase in technology has allowed for both improved learning success for the blind and also employment success.

Fighter was underemployed, only answering telephones, when she was given access to JAWS 8 that allowed her to increase her productivity and job satisfaction:

I started to get minutes for meetings. I would not attend the meetings but I would transcribe the minutes from a dictaphone etc and a bit more variety of work, more useful work than that, then what I was doing.

I started doing appointment bookings so I would be doing all the bookings. I would be doing the bookings for local child and health youth clinics; I would be responsible for bookings for the annual bone density test for [name of city].

My job at that stage became really, really rewarding. I'd be given a request and a health professional might say I've written this. Because at this stage the girls were doing their own reports, and the girls would say I've written this report, would you proof it for me? Because they had recognised that JAWS was really good proving [*proofing the reports*] because it read what was there not what you thought was there. JAWS was really good at picking up inaccuracies and proofing and I was given a lot more interesting jobs like this. (Fighter)

Builder had progressive issues with his vision and computer screens and software that were overcome with computer software and hardware:

So having gone through all that the reading vision was my next challenge and I suppose the pressures in the eye [...] And what I have found with the pressures under reasonable control my reading of white paper ... became more challenging and I actually, again as you do in these silly situations, you dig your head in the sand and you just ignore it and ignore it and ignore.

On my computer I was basically, as you do with Windows, [changing] text size. You change a couple of colours, and very subtly, week by week and month-by-month you change colours on your workstations so that it works for you.

My computer played up—it was about a year after I lost my driver's [*licence*], ... my computer was playing up so I gave it to one of the IT guys and he gave it back to me. He had reformatted it as well, basically he had saved all my information and he brought the computer back and he had rebooted and reloaded all the software. By doing that he had obviously sped up the computer

and got rid of rubbish and so on in the computer system and so I got the computer back.

I would have spent about four hours just squinting at the screen ... trying to read the screen and getting yourself to that point of saying f\* it! I needed help after four hours of almost nearly hitting your head against the wall ... I went home ... the next day one of the IT guys came and sat down. He inverted all the colours on the computer screen through windows. So having done that exercise, I went oh shit, I can actually I can read this computer screen a lot easier than I was before with the white screen. So merging the colours certainly made a big difference.

So that went on for about a year and I have only in the last six or seven months, I went through job access and I put in I've got magnifier now on the desk so that I am steering very much away from reading paper.

I am set up now with one of these magnifiers which is connected to a big 24" screen. You have two screens and basically the magnifier works if you put a piece of paper underneath it pulls up on the screen and inverts the colours to give you them black-and-white in a high contrast then you can magnify it. Then I can use both of them as an actual computer screen as well. With Magic® software which is a Zoomtext® style, but it works on the two screens. So they only implemented that about six or seven months ago.

Just the ability to keep doing what you're doing now is working and in my mind. I suppose if I look at eyesight and being quite realistic, I have probably got another three or maybe four years working in that sort of arrangement and then I am very well aware of it ... If I had said oh f\*, you have to just adjust and if there is one thing that I have learnt, you have to start adjusting progressively and not put your head in the sand which [*is*] when it all comes crashing down.



It's like when you fall off the edge of the cliff, so my next stage is I'm much more receptive to finding new and improved technologies that help. So at the moment I'm still using my vision for reading. It is on a high contrast-magnifying sort of arrangement. My next phase is that OK that's working for me in the next three years, but where to next? (Builder)

During my first three years of blindness I have had experiences at both TAFE and university. In Appendix E I outline my personal experiences of how institutions approached me as a person with a disability and how they were similar yet different in many ways.

### **Summary**

In this section I have discussed the concept of training and education, and the need for a training needs assessment or audit of a person's skills and abilities, to identify each person's "training gaps".

Training is essential to allow a person to progress from a previous career into a new uncharted career (Grow, S.J.L. & Daye, P. 2005). Choice of courses and training depends on what gaps in knowledge are identified. Some basic training in soft skills areas may seem unproductive to participants who have previous work skills but as participants suggested, resume writing and interview skills change when you have not been in competitive recruitment processes for some time. There is also the added complication for employers of being blind.

Competitive recruitment processes differ from organisation to organisation and within the different sectors such as public and private, and the various public

sector organisations differ, for example TAFE and universities. Applications and procedures change, as CPA Farmer describes:

When I look back on it I put down too much stuff. When I went out to Brisbane City Council and it was through Vision Australia I think originally, so I rang them up and said look I am going nowhere, I went down and had a talk to them and they hooked me up with Brisbane City Council for an administration role. And I got in there and am sitting in front of the panel. They asked me so many things and one of the things they asked was, so what are your qualifications? I just happened to say I well I was a certified practising accountant (CPA), as a matter-of-fact, Fellow CPA.

I should never have said that. Things just shut down straight away because it came out after that as totally overqualified, would not be happy, you know people you're working with would not be comfortable because of your qualifications etc.

Which was bullshit because all I was after was a job, somewhere to go, I'm not interested in climbing the ladder again. I am just interested in survival and to put food on the table and look after the family. You couldn't convey.

They then told me to cut out the qualifications and just put in what, in fact just put in what is required you know for each position. (CPA Farmer)

CPA Farmer had a job that started as a three-week appointment and lasted for 13 months. He found himself looking for employment and the process with a smaller private company emerged. CPA Farmer explained the process below:

That just coincided with the start of the GFC. They started to lay off people and I knew I was in danger as well. So luckily locally a job came up in a warehouse for a mature person. I rang up and they said when can you start?

I said I'm prepared to start tomorrow if you like, literally.

He came to my workplace and interviewed me and said start tomorrow. Again he was the same age group.

He said, I am comfortable with what you have told me. I will check you out, blah, blah, blah. I gave my notice to my employer which was normally two weeks and I said look this company has offered me a job in these circumstances.

The boss said leave today [laughs]. (CPA Farmer)

Some issues relating to blindness and employment can be reduced by workplace modifications and changes (Hartnett, H.P. et al. 2011). Various workplace modifications and an openness to change (such as that demonstrated by the conversion of a touch screen on a CNC machine to allow blind people to operate complex pieces of machinery) can assist the blind to be meaningfully employed.

Strategies that assist the blind in access to workplaces also help. Many building codes have changed, or are changing, to allow access for the disabled (City of Canterbury 2014). Signage is essential for people to locate various rooms and buildings, and the inclusion of large print and Braille assists people to access buildings independently (Legge, G.E. et al. 2013). All of these skills have to be learned and individual training programs have to be developed in consultation with employment providers.

The research participants' divergent views of private employment providers and the users of the services demonstrated the need for a person-centred approach to employment. Recent changes to payment methods to private employment providers

have ensured that the job matching of people to employment positions was determined on a long-term placement basis rather than on simply payment for an initial placement. Many participants reported that their private employment providers were not fully aware of their personal needs, and that participants were less than happy with their support.

I had so much hardship with Centrelink and employment agencies, I just gave up and tried myself. (Miss Positive)

Blind Chef attempted to gain employment by searching the internet for positions for three months and used an employment agency to help him with less than positive results:

It was not through going online and filling in job applications or a job agency. I had been involved with a vocational training centre that hadn't been very useful and I was on the phone with my caseworker from the vocational service.

The person from Guide Dogs, who had come to interview me about getting a guide dog, arrived and she had to wait while I was talking to my caseworker. She overheard the conversation. Essentially I was telling the caseworker that she was wasting my time and how that I was not going to come there anymore. That it wasn't working out and that they hadn't got me a position, they hadn't been able to provide the access to the software I needed to use so it was a waste of time for me to go into the office but they wanted me to do two days per week and they had found me one position and got me one interview. It turned out to be a volunteer position for one day a week. And I didn't get it either. (Blind Chef)

Awareness and discrimination are intertwined in public perceptions of the visually impaired. Where there is awareness, discrimination is reduced, and vice-versa (Moore, D. & Nettelbeck, T. 2013; Vaughan, G. & Hansen, C. 2004). My research findings on the need for education and training for people who lose vision in midlife was presented at the 17th Australian Vocational Education and Training Research Association International Conference in 2014 (Blackshaw 2014). The next section discusses understanding and awareness of the complex nature of blindness that reduces workplace differences and hence helps decrease discrimination.

### **Awareness and discrimination**

The initial emotions of vision loss tend to colour how newly blind people hear what others say. Sometimes everyday comments are interpreted as implying discrimination, when in fact that was not the speaker's intention. For example, people will say things such as "Did you see that?" or "Have a look at this". This is not intended as a discriminatory statement, only a statement within everyday speech, but for a distraught newly blind person, such comments can seem intentionally hurtful.

Often people believe, as I once did, that blind people have no light perception at all. Five% of blind people have no light perception, but 95% have some degree of it (as discussed in chapter two). People overcompensate for the perceived total blindness of others when the blind person may not need as much assistance as is being offered (Siebers, T. 2004). This is highlighted by the views of volunteer's

husband when “My husband said now you’ve gone blind that is it, you cannot go to work anymore”. (Volunteer)

Freeman’s degenerating eye condition was affecting his sight and hence his apparent safety:

The Head Teacher in one of the sections that I was working in told me that I was a danger to my students. Because I couldn’t see.

It came to a point that I had to let them know that I had vision issues and they decided I should not be there, possibly getting him in trouble. That is really what it is all about. And I thought yeah I really should fight this. Take it to the unions or somewhere.

It would have done a lot of fighting bureaucracy and fighting for rights in different situations. And I just went I am over it, I don’t care, I am walking away, and so I walked away from there I was really pissed, really pissed with what they’ve done and said. (Freeman)

Some people create situations where their lack of attention to the needs of others causes others to believe that they are discriminating whereas they are merely negligent of a person’s needs. In this section I present the views of participants about awareness and discrimination. For an auto ethnographical reflection of a case of lack of awareness in an educational setting, see my description of ‘George’ in Appendix E.

### **Discrimination**

Participants raised discrimination in many of the interviews. Some participants saw discrimination as a factor in employment and in their relationships with co-workers.

Other participants did not see any discrimination. Analysis of what was said and the intent of the underlying statements that were seen as discrimination by some participants suggests that participants seemed to misunderstand comments that were not necessarily meant as discriminatory. Thus they were misusing the term 'discrimination' term. However, there were definite discriminatory practices from some managers and co-workers, although more often the perceived discrimination could have been a lack of care and awareness for the blind person.

There were varying views on discrimination amongst the participants, but overwhelmingly discrimination was not seen as a major factor. There was an acceptance that discrimination does exist, albeit hidden or disguised, but it was not the major issue for the majority:

No, [discrimination] is not in my vocabulary I guess I come across it but and I thought about it at times but I think what is the use. It didn't impact on me greatly. I suppose that it did remind me was that people can't help themselves. It is THERE. But if you can see outside the square, if you fully abled people come across some form of discrimination now and again in their lives so, whilst you have a disability or some sort of handicap I don't see a reason to raise the discrimination thing. (CPA Farmer)

Builder did not see discrimination as an issue. Mostly people have their own agendas for promotion and not on discrimination, he explained. On the other hand Lone Range described a situations whereby discrimination was open and clear:

Interviewer: You have had no real issues with any sort of discrimination at work or from anywhere else?

Builder: No. I have been positive. I have had a couple of occasions where I have said some people's management style for example because of where I am sitting in a role there are certain things you can't do. There are certain things you find yourself becoming less efficient on (due to the onset of blindness) and that are what it is. I don't think it is discrimination it is just people pushing their way in a corporate environment will generally pull people in that they know are going to be the best for the job and that is tough. (Builder)

Lone Ranger: When I had a job, they hired me but didn't really know what to do with me. So I would be doing research for the partners rather than giving me my own files. And the minute there was a downturn in the economy they fired me. But other firms would not even think of having somebody who was blind.

Interviewer: And what did they say, they couldn't obviously come out and say they would not maybe because you are blind.

Lone Ranger: Well I didn't say anything. But actually I could at that time because it was prior to the Queensland *Anti-Discrimination Act* of 1992. The *Disability Discrimination Act* was 1993. So yes they could actually at that time say that I don't want you, you are blind. In fact, there was a family court judge who said, no I don't want to take you as an associate because you are blind ... Now it still happens, they simply would not say it. (Lone Ranger)

### **Participants' views on discrimination**

There were instances of open discrimination such as that experienced by CPA

Farmer who, while at an interview for a logistical position, was told that he had the job and that he should select the type of car that would be supplied. He had not disclosed that he was legally blind and did not possess a driver's licence. When he



explained to the interviewing committee that he was blind and that he could use public transport as effectively as a private car he was instantly rejected for the job, with the interviewer becoming hostile about the non-disclosure. The interviewer stated that the position required a person to have a driving licence and so was not discriminatory. It is unsure if the participant wanted to believe he could perform the duties as well as a person who could drive to locations. It seemed that the position was a warehouse-based position and hence the majority of the time was at the warehouse.

Fighter experienced many forms of what she termed “discrimination” that may have been a combination of discrimination and a lack of awareness from her co-workers. Her immediate supervisors and middle managers discriminated against her, yet her upper managers were open-minded as to her skills and abilities and modified her position description to allow her to use the skills she had to offer.

Lone Ranger experienced overt discrimination in the legal profession prior to the *Anti-Discrimination Act 1992*. He was openly told that the Law Office did not hire blind people. Blind Chef suggested that he experienced discrimination due to age and lack of experience in a new career. Schoolie hid her blindness from potential employers for fear that she would not be employed. She developed strategies to hide her blindness, such as mailing her stories to the editor. She used skills she had developed during her teaching years and at university. She also learned new skills in

basic assistive technology to be able to produce her stories for the editors of the papers she worked for. She worked freelance and off-site so the employers did not need to know of her blindness. Volunteer's husband told her that now she was blind she could not go outside as it was too dangerous and hence she could not work, as she was now blind. Was this discrimination by her husband or was this a result of his lack of awareness of the abilities of blind people?

By contrast, Freeman did not experience any discrimination. He expected his work environment would change regularly and many positions would be short term. Builder also had not experienced discrimination or any activity that appeared to be discrimination. He thought it was more about people not understanding, suggesting it was not necessarily ignorance but merely they were unaware of the issues confronting people who are blind

### **Awareness**

A lack of awareness is more likely to be a foundation of how people react toward blind people. Many statements that might be seen as relating to discrimination can also be seen differently. Many people do not understand blindness and do not understand that people have skills and abilities even if they cannot see. Openness towards the skills and abilities of a blind person, and modifying the position descriptions and duties, would allow for greater use of their skills.

Fighter had a period where her co-workers and line managers placed her in the stereotypical role of switchboard operator who could not do anything else. This changed when co-workers from another area recognised that she used screen readers to proof her documents. Her duties changed as more people realised she could do more than switchboard operation and she became a more valued member of the workplace. This is a classic example of a person who has the skills to be more productive and therefore increase their own personal workplace value, yet was deemed to be unable to be a productive member of the workplace.

### **General society**

A lack of awareness about blindness by general members of society is a major factor. Many people do not have regular contact with or exposure to people with disabilities, especially with people who are blind. Often people still believe that disabled people could be better served in institutions rather than being part of the general populace (Department of Social Services 2012). Many people who in the past would have been institutionalised are now “shut up” in boarding houses and homes rather than experiencing the freedom that was expected from the closure of the institutions (Department of Social Services 2012).

As CPA Farmer suggested, society as a whole does not understand that blind people are individuals and they are all different, having varying levels of vision:

Leading you by the hand and that is the other thing they see a lot of the time people with a dog, perhaps a cane or perhaps a person leading them by the

hand and automatically it is that they are not independent. Now I think that independence is not well sold by the industry, by the blindness industry. Because we are often treated, and seen as a group. You know the function that we seem to be herded into a group mentality where we have one sighted leader leading us as a number of people. And I think that seems to be part of the perception. (CPA Farmer)

### **Significant others**

As stated earlier, significant others have a major role in the employment of blind people. Significant others are aware that although the employee is blind, they still have skills that the company can and should use. In the case of CPA Farmer, he was retained when others were being retrenched. CPA Farmer also wanted to educate and increase awareness with co-workers, because doing so increased awareness with his managers who in turn became his mentors. Builder had a significant other in his general manager, who was aware that he was skilful in the field and sought to retain him in the office within the company.

### **Awareness and co-workers**

Co-workers have numerous opportunities to assist others in the workforce. Their influence can be positive or detrimental. Fighter experienced many occasions where the co-workers either absent-mindedly or as an act of discrimination changed settings on screen reading software. They were repeatedly asked not to change the settings.

Builder had worked with a person for a number of years and had told the co-worker of his vision issues, yet when Builder walked into a support pole in the site-office, the co-worker did not understand or did not want to understand that Builder could not readily see the column.

I did not know how to fight discrimination at that stage, and people's attitudes. A couple of things to sort of highlight people's attitudes, I would have my desktop set up so that, you know I could put my hands here and I knew the phone was there and my Braille machine was there and I knew how to easily locate things on my desktop without knocking things off the desk and all of that. You would go off for morning tea break and while they [the relieving people] were there the person who was relieving the switchboard duties, I would come back and everything would have been changed. And I had a huge struggle to get through to not just my team leader but the people who were relieving me, how difficult this made my working environment. Not that I wanted to be treated with kid gloves or anything like that but when I came back from morning tea, I did not want to have to search all over the desktop to find the phone. (Fighter)

Moving workplace setups was also experienced by Gearbox on his station on the production line. Gearbox put a more positive approach to it than did Fighter:

I was doing a sighted person's job all the time I was there. I learnt by feel in the early days when my peripheral vision was reasonable. Everything was there and you didn't have to look around for everything so was always in the same place every day. I made sure of that. There was a couple of times where a couple of scallywags would try and trick you and shift things around a little bit. You got that anyway. (Gearbox)

The typical reactions to people's blindness was that unless you overtly demonstrated total blindness co-workers and society did not understand the various levels of blindness:

Two weeks ago somehow I must have put my make up on a bit heavy on one side and I walked in and she turned around and she said, Miss Positive, we are blind this morning or something when you put your make up on? Not even realizing that I was blind. Then she screamed in embarrassment because she had forgotten that I have a vision impairment which is I think is wonderful because you know I don't claim a disability at all sort of thing I just want to be one of the team." (Miss Positive)

### **Self-awareness**

Although the research literature concentrates on others being aware or non-discriminatory towards the blind, blind people also have a responsibility in heightening awareness and discrimination within the workplace as well as in the broader community.

As CPA Farmer suggested, blind people need to make others aware of their blindness to allow people to understand and help. Builder would not use a long cane due to his embarrassment about being blind. Blind Chef would fold his cane up a block away from his home and attempt to walk home hugging the walls:

I had white cane training I had problems using the cane, like emotional problems, not logistical problems or physical problems. I was not emotionally ready to tell the world that I needed a cane so I would carry the cane under my arm and when things got really difficult, and then I would use it. I would

always fold it [white cane] up when I got to the block and street that I lived on.

*Laugh* It took a long time for me to go home, all the way home or to leave my apartment with the [white] cane. (Blind Chef)

Using the long cane or other mobility aides is an admission that the person is blind.

In many cases people do not want to admit to themselves—let alone to others—that they are blind as they do not wish to be classified and treated according to the ‘blind person’ stereotype. The diagnosis of blindness can trigger emotions of embarrassment and shame in the newly blind person. The white cane is a universal symbol and signal to the world that a person is blind or has low vision. But this reluctance to acknowledge their condition can cause serious difficulties. My research suggests that blind people have to be aware of their blindness, accept it and make it a part of them so that they are people first and then a person who just happens to be blind—for example, Fred who is a university lecturer and who happens to be blind, rather than Blind Fred the university lecturer:

### **Summary**

This section has presented participants’ attitudes towards discrimination and awareness. The concept of discrimination is that of assumptions, positive or negative, of people’s abilities or inabilities. Disabled people are discriminated against when they are treated less fairly than a person who is not disabled (Australian Human Rights Commission 2014). Although the participants did recognise disability discrimination towards them in various forms, they managed to

overcome the discrimination and sought to take an educational approach to increase other people's awareness. The participants mostly saw the positive aspects of society and did not allow discrimination to restrict their employment outcomes any more than the physical limitations imposed by the blindness itself.

## **Contextualising themes**

### **Affordance and engagement**

Researchers refer to community involvement as a form of “engagement”, i.e. the degree by which individuals engage with what is afforded them (Billett, S. 2001a, 2001b; Gibson, J. 1982). “Affordance” is refers to the degree to which an individual, or animal in the a wider definition by Stoffregen (2004), is invited to participate.

Various groups inside and outside the workplaces afford participation on numerous levels to employees and job seekers alike. Subsequently, this layering of affordance governs the learning and employment of people. Using the network outlined by Billett (2001b), the layers of affordances are divided between aspects of the relationships of groups and individuals (Billett, S. 2001b). Participants are encouraged or inhibited due to various factors such as whether the person is a job seeker or an established employee, full or part-time employment, the nature of his/her goals (be they personal or vocational) and membership of groups such as unions, middle management cliques and upper managers associations (Billett, S. 2001b):



Therefore, participation in work activities is not afforded in similar ways to all who work in the workplace and participation in work activities can be the bases of competition and exclusion between competing interests. (Billett, S. 2001b, p. 210)

Billett also states that all work practices are not afforded equally and evenly.

Furthermore, he states that inclusion is based upon on various factors, i.e.

perceptions of a person's competencies, race and gender, status of work and employment, workplace demarcations, personal relations, workplace cliques and affiliations (Billett, S. 2001b). The concept of Billett's "competition and exclusion"

based on perceptions is another factor blind people have to overcome:

This aspect of the definition sometimes can be confusing because we often think of meaning as being related to "things I care about." Within the ecological approach, it is critical to distinguish "what I can do" from "what I want to do." The former refers to affordances, the ecological account of meaning. The latter refers to intentions or goals (cf Shaw, 2001). Affordances that relate to an animal's goals may be greatly desired. (Stoffregen, T.A. 2004, p. 82)

Zhao, researching social media interaction design, investigates affordances with the subjective-objective dichotomy. Zhao claims that Hartson's (2003) work "expands the affordance concept and identifies four types of affordance, including physical affordance, cognitive affordance, sensory affordance, and functional affordance" (Zhao, Y. et al. 2013). Zhao explains these types as follows:

The physical affordance is a feature that actually supports or facilitates physical actions; the cognitive affordance is a feature that supports thinking or learning; the sensory affordance is a feature that supports or facilitates users in sensing; and the

functional affordance is one level higher than the physical affordance, and it is a feature supporting physical action for some functional purpose. (Zhao, Y. et al. 2013, p. 292)

### **Affordances and engagement framework**

Participant perspectives can be located in Hartson's framework of affordances and engagements (Hartson, R. 2003).

Affordances can be any action in a given environment, so it follows that there are various situations and roles that can be both positive and negative. The affordances framework includes the roles played by significant others including, in the case of one participant (Fighter), a lack of positive roles. Where significant others offered assistance in various ways, each participant who was afforded assistance accepted it and became gainfully employed.

Another section of the framework is that of discrimination, albeit positive or negative. Those who did not accept discrimination, Builder and CPA Farmer, saw opportunities rather than discrimination, and were both supported by significant others in positive ways. Others witnessed negative discrimination and overcame this.

Participants also were afforded counselling and even career changes, or the possibility of changing careers, by using the efforts of blindness associations, personal networks and significant others.

It appears that where positive affordances of support were offered participants accepted and excelled with the assistance of others. When the

discrimination was positive, employment was gained or continued, and conversely, where discrimination was negative, employment was short-term or voluntary in nature.

Where participants became a part of the community, this could also lead to or assist the blind person to 're-invent' themselves, as an act undertaken by an individual to engage with the wider world. These engagements are often person-dependent, e.g. some participants elected to engage with psychologists, some did not divulge their eye conditions when applying for positions, and yet others adopted other strategies to assist in engaging with the workplace.

### **Bounded agency framework**

Affordances are actions in environments, and engagement is the levels of acceptance of the offers afforded to them. The concept of bounded agency is the degree of agency individuals can have or are able to exercise within boundaries, including their reshaping of those boundaries, so each person has to continually create and renew their boundaries.

As an example, pre-vision loss, Blind Chef was a *maître d'hôtel* and was bounded by his location and skills. He suffered vision loss that changed his situation. He returned to Australia and determined that his new career goal was to be in public policy. His immediate goals were to be employed and retrain in public policy. He gained call centre work and retraining at university. He then volunteered at a

blindness association, where he was mentored by a significant other who guided Blind Chef to his first role in public policy and then moved onto a national public policy position. Blind Chef created and recreated his goals and continually changed his boundaries and was active in his future career goals. This changing of boundaries and the acceptance of offers of assistance was a feature for many of the participants.

The ability of older people to gain employment is limited, and as Blind Chef describes below, being granted an interview is difficult in itself. Being blind adds to the age issues and creates misconceptions of a person's abilities and skills:

I actually enrolled in a Masters program, a coursework program in Public Policy. I spent three months trying to get a part time job while I was going to uni. I never worked so hard in my life as those three months. I got up every day and I got on the computer and I search and searched and searched and filled out applications and sent off resumes and I got a couple of job interviews with recruitment agencies I got one with a bank and the Blind issue was a really big issue ... The HR person as soon as he saw me with my cane he made it very apparent that I was not going to get the job. (Blind Chef)

So I think the bigger hurdle is getting a job, once you have a job you know my history of work and my retraining has stood me in good stead but I think that getting past that perception what a blind person is capable of doing in the workplace is a really, really big hurdle. That's my experience anyway. (Blind Chef)

Blind Chef outlined the need for affordance and acceptance by the interviewers and employers towards the blind employee. His situation highlights discrimination

issues or possibly the lack of awareness disguised as risk assessments and workplace health and safety issues:

Another example was I applied for a job with NSW Electoral Commission.

Again it was in a call centre and the reason he told me I couldn't get the job was that it was upstairs on the second floor and there was no elevator.

I said I can take stairs, and they said yes but there is a risk involved and the insurance blah, blah, blah. And it was ridiculous. So I see that as the number one problem hurdle barrier for people who are blind. (Blind Chef)

### **Chapter summary**

This chapter has introduced, linked and conceptualised various themes. The chapter presented various themed sections. The first theme section was the discounted themes that discounted transport and financial issues along with the issues relating to specialist associations and medical conditions.

Then the support network section followed. The section presented the many support networks that assisted people to overcome their emotional and physical issues. Emotional aspects of vision loss require support networks that can be provided by institutional organisations and blindness associations, or through work-based networks, which can be informal and ad hoc or formal and employer-supported. No one single kind will necessarily help blind people find employment.

This was followed by section Three - training and retraining needs of people who had lost vision in midlife. Training is aligned to psychological and counselling needs, as they are both required progressively. Ongoing training will be expensive to governments due to the limited numbers of blind students and their small numbers in mainstream classes; there is a need for special considerations within these mainstream classes. *Training*, both formal and informal, is required by the majority of people who go blind in midlife. Training needs have to be determined after a person chooses their employment direction. The training programs may be as simple as updating interviewing skills, or may extend to the use of adaptive technologies or formal career changing training. Training and employment assessment cannot be undertaken until the newly blinded person has overcome the emotional aspects.

The next section introduced awareness and discrimination and how the participants related to the difficulties that arise. *Awareness* was viewed as either discrimination or the perceptions of historical inabilities of blind people to perform necessary tasks at work. The workplace accommodations that can be incorporated to allow a blind person to undertake meaningful employment have dramatically advanced in the past 20 years. These advances allow blind people to be employed if given opportunities and the necessary training.

The themes presented were drawn together within the concepts of affordances and engagement in the final section of the chapter, where the participants were afforded agency and engagement to gain and maintain employment post blindness.

The entire community has to contribute to allowing blind people to continue to be employed and hence have a more productive and meaningful life.

In the following chapter I offer concluding remarks on the research, its limitations, and possible future research suggestions.

## Conclusion and evaluation

---

This chapter is presented in two sections. The first section presents the conclusions of the study based on the analysis of the participants' experiences. The second section presents an analysis of the research strengths and weaknesses, and suggests possible future directions for research.

### **Conclusions of the study**

The fact that people who are blind and want employment have an unemployment rate of more than 45%, and the fact that I lost my vision in June 2010 provided the major impetus for this research. Many people diagnosed as blind, whether it is total blindness or legal blindness, have not previously had any experience of vision loss and hence they enter a new world, a world of isolation and often with no social inclusion (Royal National Institute for the Blind 2012; 2012a).

It is often the case that "the workplace provides the majority of a one's social interactions outside of the home" (Royal National Institute for the Blind 2012).

Employment not only has social and income benefits, it also has health benefits (Grow, S.J.L. & Daye, P. 2005). Being employed creates benefits to individuals and society and hence increased health benefits, as outlined by the ABS:



Many people with disability engage in work and make a valuable contribution to society. Employment can provide financial independence, a better standard of living and improved physical and mental health. Entering employment can provide individuals with increased confidence, expanding their social network and social skills as well as opportunities to develop a career by gaining new work skills and knowledge. (Australian Bureau of Statistics 2012a, p. 1)

The world's population is living longer (Economics, A. 2001; Stanciu, M. & Stoica, A.-M. 2014). As the population ages the prevalence of disability increases (Australian Bureau of Statistics 2012b). Table 6.1 below, compiled from the ABS report on Disability, Ageing and Carers, shows the percentages of overall disabilities in Australia in 2009 (Ewing, I. 2011).

<b>age range</b>	<b>disability prevalence (%)</b>
<b>15–24</b>	6.6%
<b>25–34</b>	8.6%
<b>35–44</b>	14%
<b>45–54</b>	18%
<b>55–64</b>	38%

**Table 6.1: Disability prevalence by age range**

Source: ABS 4430.0 – Disability, Ageing and Carers, Australia: Summary of Findings, 2012

Blindness as a disability also increases proportionally with age, resulting in the loss of employment noted by the Vision Australia employment report (Vision Australia 2012a) and negative impacts of vision loss on wellbeing (Ewing, I. 2011). Increasingly

people are losing vision later in life, and finding themselves either unemployed or underemployed (West, S. & Sommer, A. 2001).

My research aimed to gain insight into this from the perspective of those who have experienced vision loss. The purposes of the study were to determine what assisted people who lose vision in midlife to gain employment, and to ascertain the factors that support their employment. The major question of the study was, “What are the factors that support and contribute to the employment of people who lose vision in midlife?”

Subsequent questions that were investigated are:

- What roles do education and training play in assisting people who have midlife vision loss to gain employment?
- How do support networks contribute to the employment of people who have midlife blindness?
- In what ways do people who have midlife blindness perceive employment discrimination by society, employers and co-workers?

**Chapter one Introduction** set out the reasons for the research and its contribution to knowledge, i.e. the contributing factors that assist people who lose vision in midlife to gain or maintain employment.

**Chapter two Literature review** presented the results of literature searches, and the many explanations given in existing research for high unemployment of the blind (Royal National Institute for the Blind 2012). The chapter also detailed the

different levels of blindness, and how these varying levels affect employment prospects (Anderson, N. 2011; Australian Bureau of Statistics 2012a; Vision Australia 2012a). The ontological and epistemological aspects of employment of people with disabilities and more specifically blind people were presented through a review of historical models of disabilities such as the medical and social models (Bell, E.C. & Mino, N.M. 2013; DeMario, N. 1992; Guide Dogs , N.A. 2012; Vision Australia 2012b, 2014). The construct of blindness and its effects on employability was presented (Morris, J. 2001; Shakespeare, T. 1993; Shakespeare, T. & Watson, N. 2001)

**Chapter three Methodology** discussed my reasons for using case study and auto ethnographic research methods (Bell, E. 2010; Bell, E.C. & Mino, N.M. 2013; Boerner, K., Wang, S.-W. & Cimarolli, V. 2006). The reasons for using both face-to-face and telephone interviews were presented (Anderson, L. 2006; Denzin, N.K. & Lincoln, Y.S. 2000; Richardson, L. 2000; Yin, R.K. 2009). The chapter also presented the criteria for participant selection, the selection plan and selection methods. The ethical considerations were presented and finally the demographics of the 11 participants were presented.

**Chapter four Data analysis** explained the systems of analysis and the software programs used to code the interviews to develop thematic codes from the data collected, using a grounded theory perspective (Eckhardt, E. & Anastas, J. 2007;

Flyvbjerg, B. 2006; Scott, S. 2004). The thematic codes were tabulated, mapped and interpreted to develop specific frameworks of inquiry.

**Chapter five Findings and Discussion** presented accounts of participants' experiences within each of the themes. The themes were deemed to be significant or not significant, based on the results of the data analysis and interpretations derived from the mappings and charting during the analysis.

### **Addressing sub-questions of the study**

In chapter five I proposed that three major factors affected and supported the participants in their returning to employment: awareness of blind people's abilities, training needs analyses for people who lose vision in midlife, and the need for multiple support networks. These factors were then conceptualised as various forms of affordances, engagement, and agency (Corbin, J.M. & Strauss, A. 1990; Denzin, N.K. & Lincoln, Y.S. 2000; Pope, C., Ziebland, S. & Mays, N. 2006) whereby people who have lost vision need to be given employment opportunities to gain and maintain employment, and need to be able to accept these opportunities.

### ***Sub-question 1: Education and training***

**What roles do education and training play in assisting people who have midlife vision loss to gain employment?**

Based on the research findings, the need for training and retraining appears to be an episodic continuum of nonlinear and 'just in time' learning sequences that are

determined by the individual. This nonlinear and episodic learning is demonstrated by Reflex's account of her journey to establish her own employment:

I was very lucky in that I got into a mentoring program through the Association for the Blind in WA and a large mining company. I wanted to see how much multi-tasking was involved in administration work, which was my area of employment prior to stopping to have a family and where I believe I have the best skills.

My studies just prior to the mentorship had been in the natural therapies area, and whilst with my Mentor, I was persuaded to look at working within the company in reflexology... I am still there more than seven years later working on a contract basis, self-employed, but doing regular hours and being paid directly by the staff, not the company. (Reflex)

All of the participants stated that they had to undergo various educational programs and/or training to gain employment. Whether the training was formal or informal, it resulted in the participants acquiring new skills that made them more employable.

Based on the research findings, education and training appears to be an essential ingredient in the search for employment. This is consistent with previous findings by reports that stated that higher levels of education and greater educational attainment assist blind people to gain employment (Billett, S. 2001a). The amount and type of vocational and rehabilitation training is dependent on the individual's desired career direction. The findings suggest that employment service providers have a role to play in the training component of the individual's pre-employment.

The research suggests employment service providers have a role in assisting individuals in a chosen career direction, or advising them of alternatives that better suit their abilities. The research presented the notion that decisions of career direction should be determined in two ways. One way is the individual's desired career path, and the other way is by conducting a skills gap analysis and producing a training needs program. Participants spoke about poor training needs assessments as well as limited resources, job placements and overall training plans.

Blind Chef spoke about the resources provided to him that were ineffective, and included damaged equipment totally unsuited to his needs. He also spoke about gaining employment, not through the original employment provider, but through a casual meeting with another organisation. Miss Positive spoke of poor results with employment agencies and how she left them and searched for work on her own. The lack of relevant individual training needs assessments was highlighted when CPA Farmer was told to take a general job readiness course that included personal hygiene and other non-related vocational training.

The findings of the research suggest that individualised training assessment programs should be tailored toward a more personal assessment and not towards generic programs. The assessment program should determine the particular needs of an individual for gaining employment, and not employ a one-size-fits-all-program. Based on the research findings, there appears to be a need for urgent attention to

services offered for blind individuals by private providers. The current National Disability Insurance Scheme (NDIS) with its person-centred approach might address this issue.

The issues that arise from the NDIS are whether the newly blind individual knows what they want and how to achieve it. The NDIS has a personal 'supports' assessment built into the program. However, it is not strictly an employment assessment but more a personal support needs assessment (Bell, E.C. & Mino, N.M. 2013; Crudden, A. et al. 1998a). The NDIS is an evolving policy of the Australian Federal Government and will continue to change as more is known about how it really operates and how it affects all stakeholders. The NDIS will not attempt to determine the vocational educational needs of the blind, whereas an employment provider can assess an individual's skills and abilities.

Based on the research findings, vocational educational needs vary widely. The findings suggest that the breadth of needs of blind individuals is similar to that for non-disabled individuals attempting to change careers. Because needs vary so widely, they are difficult to define and classify. The broad categories based on the research findings could be i) adaptive technologies, ii) résumé and interview skills and iii) employment position skills.

There are specialist skills required by individuals who are blind that will assist their employment goals. Training in adaptive and assistive technologies increases the

productivity and employability of a blind individual (National Disability Insurance Agency 2014). The adaptive and assistive technologies vary from screen reading software (e.g. JAWS, Zoomtext and Apple OSX) to CCTV systems and computerised refreshing Braille boards. Specific career training for an individual's desired employment options is also required.

Although specialist training can be identified for the specialist positions, other factors hinder the blind individual from gaining employment. Two were mentioned by a number of participants—age discrimination and lack of experience in the role (these are not restricted to the disabled spectrum). Discrimination is discussed in sub-question 3 (below). The lack of experience is the same for all job seekers and, as mentioned in the previous chapter, can be overcome by part-time and casual work experience. Age discrimination is the same for all ageing individuals attempting to seek new employment. The gravity of the situation is that many individuals who go blind post 30 years of age and have to change careers have a combination of age, lack of experience post training and blindness, all making it more difficult to place the individual into employment. The individual becomes a member of a community of individuals who are attempting to enter new employment communities.

These new communities have their own norms and structures. The entry–exit dichotomy is a major factor of sight loss and employment. The entry into the new communities of practice is also the exiting from familiar communities of practice and



their normal ways of life, a transformational phase of their life and their employment, each of which is painful and individual to oneself (Cirson, N. 2013; Ryder, B. 1992). Hodges describes it like this:

This can be a painful time of alienation from familiar ways of being-in-the-world. Coming back to the suggestion that the assimilation of initial meaning perspectives corresponds to an “inbound” trajectory of membership of a large-scale social practice, Mezirow’s phases of disorienting dilemma, self-examination, and critical assessment of assumptions can be construed as describing the “outbound” trajectory identified by Wenger (1998). Explaining this kind of trajectory, Wenger (1998) says that “being on the way out” of a community of practice is associated with a special kind of learning, including “seeing the world and oneself in new ways” (p. 155). He also illustrates this kind of trajectory with reference to the end of childhood, echoing Mezirow’s own account of the origins of perspective transformation. (Hodge, S. 2014)

When the newly blind person’s life changes and they move from being a member of the sighted world to that of the blinded world, this constitutes a transformational learning experience that requires a continuum of training and retraining:

***Summary recommendations on training and employment***

The following recommendations are drawn from the findings of the research.

- Personalised training needs assessment for each individual should be developed by the employment service provider.
- Various levels of training need to be formally organised by the employment service provider based on the results of a training needs assessment.

- Work experience must become a standard practice in the re-employment process. Private providers would need to form relationships with various employers to organise work placements
- Employment providers should be audited biannually for their ability to provide specialist employment services.

***Sub question 2: Support networks***

**In what ways do support networks contribute toward the employment of people who have midlife blindness?**

The findings in chapter five demonstrate the need for multiple support networks that can provide emotional support and stabilisation after vision loss, on both personal and professional levels. Emotional stability is a requirement prior to re-entry into the workforce (Nyman, S.R., Gosney, M.A. & Victor, C.R. 2010). Once a person is emotionally stable, new networks within the workplace are required. My autobiographical observations in Appendix E support these findings.

Networks within workplaces are essential to the success of a person's re-entry to employment. They can be formal and employer-driven, or ad hoc and nonlinear. Builder, as outlined in earlier chapters, spoke about his manager and the network that was established by the manager's actions. Others spoke about significant others who assisted them to gain employment or at least guide them within the workplace. In the case of Fighter, she had a person who advocated for her and taught her how to advocate for herself. All participants mentioned some form of significant others assisting them in the workplace.

The research found that significant others—managers, family and co-workers—all contribute to the employment of people who have lost vision in midlife. Many terms—such as mentors, sponsors, patrons, or backers (Hodge, S. 2014)—are used for significant others. Their roles, based on the research, are essential in the employment of people who lose vision in midlife, and should be encouraged within the workplace community.

An individual who loses vision in midlife is thrust into a new complex community, that of blindness. The individual has to recreate him or herself in relation to a new identity and join new communities. The new identity commences with “self categorization” (Alvari, H., Hashemi, S. & Hamzeh, A. 2013), where an individual internalises the norms of the groups and communities that he or she identifies with (Cinoğlu, H. & Arıkan, Y. 2012). After vision loss the individual must develop a new meaning of self and new identities, possibly unwillingly, to successfully navigate the transition process of identity change (Stets, J.E. & Burke, P.J. 2000):

Once individuals have regenerated their identity and become members of various communities, they take on the norms and customs of the interrelated communities or communities of practice, which are formed for mutual benefits of the members and which create community empowerment. When individuals and their communities are empowered, they “gain greater control over their lives, acquire

rights, and reduce marginalization” (Cinoğlu, H. & Arıkan, Y. 2012). Furthermore, “empowerment represents a strengths-based, non-expert driven approach that emphasises the ability of people facing difficult life circumstances or community conditions to define and actively engage in solutions to the problems confronting them” (Peterson, N. 2014, p. 96).

Communities of practice “are everywhere and ... we are generally involved in a number of them ... In some groups we are core members, in others we are more at the margins”(Lave, J. & Wenger, E. 1998). Wenger’s model of communities of practice involved groups of individuals with common causes and interests (Wenger, E. 1998). Wenger suggested that communities of practice should have three components that evolve over time—a definition of what the community is about; a characteristic way of functioning, and the capability the group has produced (Wenger, E. 1998). In later works Wenger introduced the expert/novice concept in situated learning, a similar concept to the apprentice/master training system (Li, L.C. et al. 2009). Communities of practice have been further modified and redefined, as Li wrote:

Brown and Duguid also focused on the close relationships among working, learning, and innovating for workers, and stressed the importance of the social environment in advancing practitioners’ skills and knowledge in organizations. They encouraged interaction of workers across different communities within and outside of their own organisation, a concept known as ‘community-of-communities’.(Li, L.C. et al. 2009)

The “community of communities” concept can be used to identify teams, groups and networks both within and outside organisations (Li, L.C. et al. 2009). This community of communities is a way for knowledge exchange. Membership in each different community of practice allows an individual to learn a particular skill, task or increased ability in a new role. The use of communities of practice can also be via the internet in the use of social media such as Facebook or Chalkboards, or with media like electronic newsletters (Li, L.C. et al. 2009). Individuals who are members of multiple communities of practice over time recreate themselves and adhere to the social norms of each group as needed.

Once an individual has recreated himself or herself and their various identities within their various community of communities, a sense of empowerment allows them to invoke social justice for themselves and others (Peterson, N. 2014, p. 96).

Significant actors within communities, organisations and workplaces attempt to create social justice and change for various interrelated and unrelated communities (Brady, S.R. & O’Connor, M.K. 2014). Social justice could provide the basis of a support networks within the family or in larger organisations, for example, in the blindness community organisations such as Vision Australia or Guide Dogs. Social justice (Alvari, H., Hashemi, S. & Hamzeh, A. 2013), empowerment (Brady, S.R. & O’Connor, M.K. 2014) and identity (Peterson, N. 2014) theories all have impacts on an individual seeking to regain self and identity after vision loss, and on

their ability to join multiple communities, whether through a mentor–mentee relationship or as part of a large support community. Vision Australia, for example, provides support systems via a peer network. The peer network is a group of volunteers who are blind and have experienced vision loss, and who assist others to overcome issues and recreate their identities. One method used by Vision Australia is a buddy system, where a person becomes a peer and is available as a telephone contact to discuss their lived experiences of sight loss and reinventing themselves.

Support networks, communities or networks based on the research outcomes are required to help an individual progress from their previous sighted identities and communities toward a productive new identity and self.

***Summary recommendations on support networks***

- Encourage support networks at all levels
- Encourage buddy systems to assist individuals to recreate themselves
- Encourage individuals re-entering the workforce to seek significant others and support networks

***Sub-question 3: Discrimination and employment opportunities***

**In what ways do people who have midlife blindness perceive employment discrimination by society, employers and co-workers?**

Research participants outlined the need for employers and co-workers to be aware that—although blindness has limiting factors—many blind people can be an integral part of a productive workforce. There are typically many misunderstandings about the abilities of the blind. In chapter five, Blind Chef stated that the State Electoral

Office did not employ him as he would have had to walk up stairs and they considered that the risks were too great. CPA Farmer also discussed perceptions about the blind:

We are often treated and seen as a group. You know the function that we seem to be herded into a group mentality where we have one sighted leader leading us as a number of people. And I think that seems to be part of the perception.  
(CPA Farmer)

The majority of the participants were aware of discrimination and its inhibiting impact on gaining employment. However, they stated that the lack of awareness was a more significant reason than outright discrimination. As discussed in chapter two, public awareness and hence employer awareness of the abilities of the blind are social constructions and can be challenged. Various disability advocates (Morris, J. 2001; Shakespeare, T. 1993) discuss the cultural and social construct of blindness and disability, and resulting lack of awareness of the abilities of the blind.

This lack of awareness of the blind is also manifested as discrimination. Discrimination toward stigmatised people such as the disabled, or minority groups, can be organisational or interpersonal (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011). Discrimination has changed since the laws of discrimination were introduced, and has become less overt and more covert (Davis, J.M. 2000; Morris, J. 2001; Shakespeare, T. & Watson, N. 2001).

Literature indicates that the two main forms of discrimination—organisational and interpersonal—have effects on the workplace as well as on the individual who is being discriminated against (Australian Human Rights Commission 2014).

Organisational or formal discrimination is illegal, whereas interpersonal discrimination is not an illegal act (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011).

The various anti-discrimination Acts across the world may have reduced and limited formal discrimination, yet it still exists in a more covert manner. Reducing interpersonal discrimination depends more on personal intervention, and a mix of methods could be employed to do so (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011).

The literature outlines ways of reducing interpersonal discrimination against stigmatised individuals in the workplace. These include acknowledgement, disclosure, increased positivity and individualising information (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011). Acknowledgement, it is suggested, is the “bringing attention to, or acknowledging already apparent stigmas” (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011). Acknowledging the stigmatising features is said to reduce the tensions about how to interact with a stigmatised person. The breaking down of the tensions allows for a more open interaction between individuals.

The second suggested method is disclosure of the visible or nonvisible stigmas.



Disclosing in the workplace is related to positive workplace-related outcomes such as increased (i) job satisfaction, (ii) commitment to the organization, (iii) satisfaction with coworkers, (iv) engagement on the job, and (v) person–organization fit; and decreased (i) turnover intentions, (ii) anxiety on the job, (iii) role ambiguity, and (iv) psychological strain. (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011, p. 32)

The third way of reducing interpersonal discrimination against stigmatised individuals in the workplace is for disabled people—and in fact *all* people—to display increased positivity and agreeableness. Individuals who smile more, and who make efforts to be more friendly and more bubbly, generally encounter less interpersonal discrimination (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011, p. 33).

‘Individuating information’ involves an individual providing personal information that is more than the requirements of the workplace. Individuals are then individuated, which creating a counter-stereotypical identity and hence reducing discrimination (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011).

Each of these strategies can be employed separately or in combination with each other. The selection and application of each will depend on the individual’s nature and abilities. Many of the participants in this study displayed many of these strategies and these enabled them to seek and gain employment. Each participant had strategies they had developed and employed; their use is a major factor in overcoming discrimination. The majority of the participants did not see discrimination as a factor, yet expressed the belief that people did not understand

blindness and that the individual, whether they are blind or not, has abilities that can be employed.

### **Summary of the sub-questions**

Self, identity and empowerment are all factors that affect the progress of an individual towards employment. An individual has to be capable of joining communities post blindness and also needs to be afforded entry to the community by the population (Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011). A number of the participants displayed many of the strategies that were suggested by Ruggs et al. to overcome discrimination. The participants overall did not see the reactions of co-workers as discriminatory, but as being due to a general lack of awareness. The de-stigmatisation of individuals with disabilities (in this research meaning blindness) would lead to less discrimination. Participants such as Fighter used her ability to use technology to proof read documents accurately to de-stigmatise herself. She changed the co-workers' stereotypical notions of her as a blind woman who could not perform proof reading and transcription duties. With reasonable adjustments in the workplace she was able to increase her job satisfaction from a poor level, being allowed only to answer the telephone, to performing a multi-tasking role.

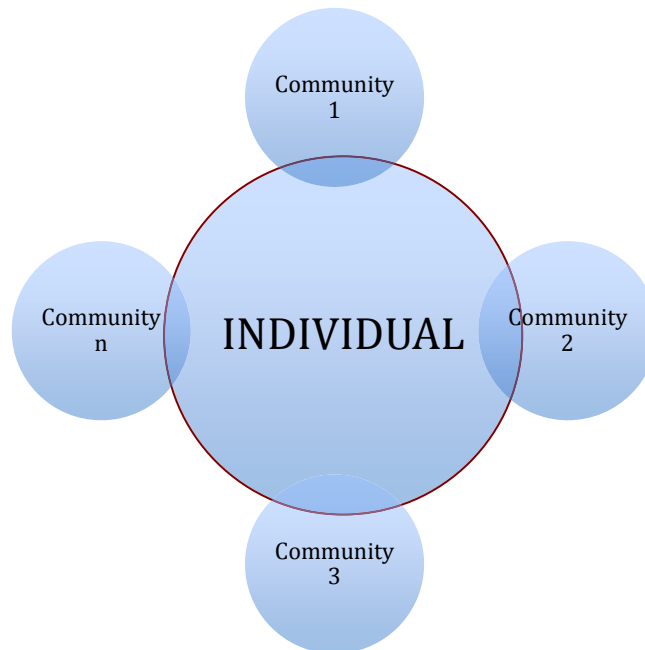
Builder and CPA Farmer had similar experiences. They had progressed from emotionally instability within themselves to create new identities within the new communities they joined. The participants demystified their blindness to the co-workers and employers to create a more open workplace.

The participants required training once they had commenced the journey to new identities. The training was not restricted to formal educational aspects. Many of the participants undertook tertiary level training to allow them to head towards their personal career goals.

An individual who has been employed for a number of years and who is cementing a career at the time when he or she loses sight is typically not familiar with the current competitive employment market and with its recruitment practices. CPA Farmer was one who required training in current recruitment methods. Training, whether it is formal accredited qualifications or non-accredited training, is a major factor underpinning the successful gaining of employment for the blind and their ability to enter new communities.

While training, self and identity are major factors in reinventing oneself and gaining employment, support networks are also an integral factor. Support networks or communities are interconnected by various threads and linkages (Billett, S. 2001a). Support communities can be small— mentor and mentee or family-related—or can consist of large complex organisations. Family support is not restricted to direct family members, but can include other individuals close to an affected individual. My research suggested that individuals who are rediscovering themselves require family support.

The world is made up of multiple communities, some small and some large. The individual is a member of multiple communities, each with different rules and norms. Each community is independent of each other yet, through the individual, the communities are linked to one another. This relationship is captured in Figure 7.1.



**Figure 6.1: Links and relationships between the individual and communities**

The links in figure 6.1 between the individual and innumerable (community n) intertwining networks or communities of practice is the same for all people whether they are blind or not. The significance is that the person who has lost vision in midlife has to rebuild many old networks and create new networks.

In Gearbox's case, he had to reinvent himself by changing vocations from the building industry to the metals production industry. He retrained and joined a new

employment community. He left one community and entered a new community. He also joined the overarching blindness community. The industrial community and the blindness community are not related except through Gearbox. He had to create his identity as a blind man and then as a production worker.

**Study question**

The major question of the study was “What are the factors that support and contribute to the employment of people who lose vision in midlife?”

The key findings are

- the contributions of education and training in making the person more employable
- the need for support networks and the part that significant others play.

Yet there is no one aspect that stands alone. Agency is a requirement for people to be accepted for their skills and abilities. These affordances are community wide and no one factor will by itself make possible the employment of people who go blind in midlife. A complex mix of all these aspects is needed to create an atmosphere favourable to the employment of people who are blind. Losing vision in midlife is an emotional and personal issue; support frameworks are required and retraining is essential for the person to be ready to participate in employment. Moreover, the critical factor has to be that blind people are accepted by the general population, and are offered every possibility to succeed in general life and employment.

Based on my participants' comments, it seems that employers generally do not acknowledge an individual's pre-blindness skills and abilities. A number of participants noted that disclosing blindness in a job application resulted in no reply from employers. Disclosure is suggested as a strategy to assist with employment but, as Miss Positive stated, the timing of the disclosure may affect the employment possibilities. Blind Chef stated that once an individual is employed the employer then tends to recognise their abilities and the person becomes a valued member of the workforce. Changes in employers' and the general population's awareness are required to overcome the stereotypical constructs of blindness.

The research found that there is a need for awareness programs directed at the general population and more importantly towards employers to raise awareness of the abilities of the blind. The general population needs to learn that there are varying degrees of blindness and that, with technology, blind people can perform tasks that previous generations would only dream of doing. Reasonable adjustments to workplaces and rethinking of employment tasks could allow employers to tap into the major market of unemployed blind people.

### **Evaluation of the research**

#### **Limitations of the study**

The limitations of the research are the inherent weaknesses of the selected methods i.e. case study interviews and auto-ethnographic reflection (Anderson, L. 2006; Eyal, K. & Dailey, R.M. 2012; Wall, S. 2008; Yin, R.K. 2009).

Auto ethnographic reflections do develop rich insights of a person's journey – in this case, my own – are also limited by personal bias and subjectivity. Because I am a member of the community under study, this also can affect the selection of participants, although a strict set of criteria was developed for participant selection.

### **Strengths of the study**

As an individual who has the lived experience of midlife blindness, I can empathise with the participants. The participants may have been able to be more open and honest with me because I am an “insider researcher”, that is, a member of the blindness community.

### **The participant–researcher relationship**

Prior to the replies from expression of interest emails, I did not know any of the participants. Our only relationship was that we were all blind or legally blind, and had used a blindness service provider in some way.

Participants were selected on the basis of the participant criteria developed before ethics approval. A larger pool of respondents could possibly have had a more even distribution across age demographics if the databases of the various blindness associations had been available, but privacy issues restricted the use of these databases.

### **Implications for future research**

This research has highlighted numerous areas where people who are blind can perform tasks in the workforce. Many people who lose their vision in midlife do not

return to the workforce. Research into the reasons why these people do not return to the workforce should be conducted.

It is traumatic for people who have lost vision to return to the workforce, but does the employer see any difference between a newly blinded person and someone who has been blind from birth? This area of research has merit for future research.

Another area that has merit for future research is the consideration of vocational retraining in existing workplaces or vocational training for people who lose vision and want a new career. The new career could be a complete contrast to their pre vision loss employment. Public policy may have to be realigned for people with disabilities to be able to retrain in smaller groups. Research in this area of retraining and public policy would benefit not only blind people but people who acquire any disability in midlife.

There are numerous blindness associations, some of which receive public funding and others which do not. Many associations duplicate the provision of services for the blind. The major associations duplicate services such as mobility and orientation services, advocacy services and employment services. Research into the possibility of streamlining the associations to reduce duplication of services would be useful. A research question that could be investigated is, "Does the duplication of blindness services create improved outcomes for the blind person?"



The Federal Government's new initiative of national funding for the disabled has shifted under the NDIS from bulk funding to a user choice system. This will mean that disabled people select their own provision of services. Further research is required as to the effect of the NDIS funding model, and whether the specialist blindness associations will be functional post NDIS.

# References

---

- Alvari, H., Hashemi, S. & Hamzeh, A. 2013, 'Discovering overlapping communities in social networks: A novel game-theoretic approach', *AI Communications*, vol. 26, no. 2, pp. 161-177.
- Anderson, L. 2006, 'Analytic autoethnography', vol. 35, no. 4, pp. 373-395, viewed Nov 2012, <<http://jce.sagepub.com/content/35/4/373%3E>.
- Anderson, N. 2011, 'Perceived job discrimination: Toward a model of applicant propensity to case initiation in selection', *International Journal of Selection and Assessment*, vol. 19, no. 3, pp. 229-244.
- Australian Bureau of Statistics 2000, *Disability and Disabling Conditions, 1998* Australian Bureau of Statistics, Canberra, ACT, viewed 27 February 2013, <<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4433.0Main+Features1998%3E>.
- Australian Bureau of Statistics 2012a, *Australian Social Trends, March Quarter 2012 - Disability and Work*, Australian Bureau of Statistics, Canberra, ACT, viewed Feb 2013, <<http://www.abs.gov.au/socialtrends%3E>.
- Australian Bureau of Statistics 2012b, *Population by Age and Sex, Regions of Australia, 2012* Australian Bureau of Statistics, Canberra, ACT, viewed Jan 2014, <<http://www.abs.gov.au/ausstats/abs@.nsf/Products/3235.0~2012~Main+Features~Main+Features?OpenDocument - PARALINK0>>.
- Australian Bureau of Statistics 2014, *Average Weekly Earnings, Australia, Nov 2013, 6302.0* - Australian Bureau of Statistics, Canberra, ACT, viewed June 2014, <<http://www.abs.gov.au/ausstats/abs@.nsf/Products/6302.0~Nov+2013~Main+Features~Industry+Earnings?OpenDocument%3E>.
- Australian Human Rights Commission 2014, *D.D.A. guide: What's it all about*, Australian Human Rights Commission, Pitt St, Sydney Australia, viewed Mar 2014, <<https://http://www.humanrights.gov.au/dda-guide-whats-it-all-about%3E>.
- Baker, R.K. 1989, *A quality of vision - A History of the ROYAL BLIND SOCIETY of New South Wales - 1880 to 1987*, Royal Blind Society of NSW, Sydney, Australia, viewed May 2012,, <<http://www.visionaustralia.org/info.aspx?page=645%3E>.
- Barnes, C. 1999, 'Disability Studies: new or not so new directions?', *Disability & Society*, vol. 14, no. 4, pp. 577-580.
- Basser, L.A. & Jones, M. 2002, *Disability Discrimination Act 1992 (CTH): A Three-Dimensional Approach to Operationalising Human Rights*, The, HeinOnline, viewed Sept 2013 2013, <<http://heinonline.org/HOL/LandingPage?handle=hein.journals/mulr26&div=20&id=&page=%3E>.
- Bell, E. 2010, *Competitive employment for consumers who are legally blind: a 10-year retrospective study*, Professional Development and Research Institute on Blindness, Louisiana Tech University, Woodard Hall, 100 Wisteria, Ruston, LA 71272.
- Bell, E.C. & Mino, N.M. 2013, *Blind and Visually Impaired Adult Rehabilitation and Employment Survey: Final Results*, Louisiana Tech University, Louisiana USA,

- viewed Sept 2013, <<http://www.pdrib.com/pages/reports-35-323-3-PB.php%3E>.
- Benoit, C., Jansson, M., Jansenberger, M. & Phillips, R. 2012, 'Disability stigmatization as a barrier to employment equity for legally-blind Canadians', *Disability & Society*, vol. 28, no. 7, pp. 970-983.
- Berejiklian, G. & Gay, D. 2012, *Transport for NSW Disability Action Plan 2012 - 2017*, NSW State Government, Sydney, viewed Jan 2014, <<http://www.transport.nsw.gov.au/content/transport-nsw-disability-action-plan-2012-2017%3E>.
- Bickenbach, J. 2011, 'The world report on disability', *Disability & Society*, vol. 26, no. 5, pp. 655-658.
- Billett, S. 2001a, 'Co-participation: affordance and engagement at work', *New directions for adult and continuing education*, vol. 2001, no. 92, pp. 63-72.
- Billett, S. 2001b, 'Learning through work: workplace affordances and individual engagement', *Journal of workplace learning*, vol. 13, no. 5, pp. 209-214.
- Blind Citizens Australia 2014, *Blind Citizens Australia*, Blind Citizens Australia, Melbourne, viewed Jan 2014, <**Error! Hyperlink reference not valid.**>
- Boerner, K. & Wang, S.-w. 2012, 'Goals with limited vision: a qualitative study of coping with vision-related goal interference in midlife', *Clinical Rehabilitation*, vol. 26, no. 1, pp. 81-93.
- Boerner, K., Wang, S.-W. & Cimarolli, V. 2006, 'The Impact of Functional Loss: Nature and Implications of Life Changes', vol. 11, no. 4, pp. 265-287, viewed June 2013, <<http://www.lib.uts.edu.au/sso/goto.php?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=20855338&site=ehost-live%3E>.
- Brady, S.R. & O'Connor, M.K. 2014, 'Understanding How Community Organizing Leads to Social Change: The Beginning Development of Formal Practice Theory', vol. 22, no. 1/2, pp. 210-228, viewed June 2014, <<https://http://www.lib.uts.edu.au/goto?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=96412162&site=ehost-live%3E>.
- Brassai, S.T., Bakó, L. & Losonczi, L. 2011, 'Assistive Technologies for Visually Impaired People', no. 3, pp. 39-50, viewed Jan 2014, <<https://http://www.lib.uts.edu.au/goto?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=79552239&site=ehost-live%3E>.
- Brisenden, S. 1986, 'Independent Living and the Medical Model of Disability', *Disability, Handicap & Society*, vol. 1, no. 2, pp. 173-178.
- Cao, J. & Yang, Y.-C. 2013, 'What are Mentoring and Sponsoring and How do they Impact Organizations?', viewed Feb 2014.
- Cavanaugh, B. & Rogers, P. 2002, 'Employment Patterns of Older Workers with Visual Impairments', *Journal of Visual Impairment & Blindness*, vol. 96, no. 9, p. 655.
- Cinoğlu, H. & Arıkan, Y. 2012, 'Self, identity and identity formation: From the perspectives of three major theories', vol. 9, no. 2, pp. 1114-1131, viewed July

- 2013,  
 <<https://http://www.lib.uts.edu.au/goto?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=90595934&site=ehost-live%3E>.
- Cirson, N. 2013, 'Through mine eyes: Technology helping the blind make their way through the day', *Independent Living*, vol. 29, no. 3, pp. 26-27.
- City of Canterbury 2014, *City of Canterbury Disability Access Committee*, Canterbury Council, Canterbury, NSW, viewed Jan 2013,  
 <<http://www.canterbury.nsw.gov.au/Community/Disability-Programs%3E>.
- Corbin, J.M. & Strauss, A. 1990, 'Grounded theory research: Procedures, canons, and evaluative criteria', vol. 13, no. 1, pp. 3-21, viewed Feb 2013.
- Crewe, J., Morgan, W.H., Morlet, N., Clark, A., Lam, G., Parsons, R., Mukhtar, A., Ng, J., Crowley, M. & Semmens, J. 2012, 'Prevalence of blindness in Western Australia: a population study using capture and recapture techniques', vol. 96, no. 4, pp. 478-481, viewed Jan 2013,  
 <<http://bjo.bmj.com.ezproxy.lib.uts.edu.au/content/96/4/478.short%3E>.
- Crudden, A. 2002, 'Employment after Vision loss: Results of a Collective Case Study.', *Journal of Visual Impairment & Blindness*, vol. Vol. 96, no. 9, p. 7.
- Crudden, A., McBroom, L.W., Skinner, A.L. & Moore, J.E. 1998a, *Comprehensive Examination of Barriers to Employment among Persons Who Are Blind or Visually Impaired.*, Reports - Research Mississippi State. Rehabilitation Research and Training Center, Mississippi State, USA.
- Crudden, A., McBroom, L.W., Skinner, A.L., Moore, J.E., Mississippi State Univ, M.S.R.R., Training Center on, B. & Low, V. 1998b, *Comprehensive Examination of Barriers to Employment among Persons Who Are Blind or Visually Impaired*, Mississippi State. Rehabilitation Research and Training Center, Mississippi State, USA.
- Dalgin, R.S. & Bellini, J. 2008, 'Invisible disability disclosure in an employment interview impact on employers' hiring decisions and views of employability', vol. 52, no. 1, pp. 6-15, viewed Nov 2013,  
 <<http://rcb.sagepub.com/content/52/1/6.abstract%3E>.
- Davis, J.M. 2000, 'Disability studies as ethnographic research and text: research strategies and roles for promoting social change?', vol. 15, no. 2, pp. 191-206, viewed Aug 2012,  
 <[http://www.tandfonline.com/doi/abs/10.1080/096875900256211.U\\_wWNkgu5fY](http://www.tandfonline.com/doi/abs/10.1080/096875900256211.U_wWNkgu5fY)>.
- DeMario, N. 1992, 'Skills needed for successful employment: A review of the literature', *Re:View*, vol. 24, no. 3, p. 115.
- Denzin, N.K. & Lincoln, Y.S. 2000, *The handbook of qualitative research* /|cNorman K. Denzin, Yvonna S. Lincoln editors,, 2nd edn, Sage Publications, Thousand Oaks, California.
- Department of Social Services 2012, *Shut out :|bthe experience of people with disabilities and their families in Australia : National Disability Strategy consultation report* /|cprepared by the National People with Disabilities and Carer Council., Australian

- Government, Canberra, ACT, viewed 21 June 2012 2012,  
 <<http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia?HTML%3E>.
- Dickerson, A. & Green, F. 2012, 'Fears and realisations of employment insecurity', vol. 19, no. 2, pp. 198-210, viewed Sept 2013,  
 <<http://www.sciencedirect.com/science/article/pii/S0927537111001114%3E>.
- Digital Atlas 2013, *Bonzle.com - Bonzle Digital Atlas of Australia*, Digital Atlas Pty Limited, viewed 8th January 2013, <<http://www.bonzle.com/c/a?a=f&sc=lg%3E>.
- DiNuzzo, A.R., Black, S.A., Lichtenstein, M.J. & Markides, K.S. 2001, 'Prevalance of functional blindness, visual impairment, and related functional deficits among elderly Mexican Americans', *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, vol. 56, no. 9, pp. M548-M551.
- Eckhardt, E. & Anastas, J. 2007, 'Research Methods with Disabled Populations', vol. 6, no. 1/2, pp. 233-249, viewed June 2012,  
 <<http://www.lib.uts.edu.au/sso/goto.php?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=25474190&site=ehost-live>
- Error! Hyperlink reference not valid..**
- Economics, A. 2001, *Population ageing and the economy*, Care, D.o.H.a.A., Department of Health and Aged Care, Canberra, Australian Capital Territory, viewed Aug 2014,  
 <<http://www.bicciab.org.au/d611b/sites/default/files/ACCESS ECONOMICS ageing demographic access economics.pdf%3E>.
- Ewing, I. 2011, *Disability, ageing and carers, australia: summary of findings*, Australian Bureau of Statistics,, Canberra, ACT,  
 <[http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/9C2B94626F0FAC62CA2577FA0011C431/\\$File/44300\\_2009.pdf%3E](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/9C2B94626F0FAC62CA2577FA0011C431/$File/44300_2009.pdf%3E).
- Eyal, K. & Dailey, R.M. 2012, 'Examining Relational Maintenance in Parasocial Relationships', *Mass Communication & Society*, vol. 15, no. 5, pp. 758-781.
- FaHCSIA 2011, *FaHCSIA - Facts and Figures October 2011*, Department of Social Services, Canberra, ACT, viewed 23 March 2012  
 <[http://www.fahcsia.gov.au/about/publicationsarticles/corp/fahcsia\\_facts\\_and\\_figures/Pages/default.aspx%3E](http://www.fahcsia.gov.au/about/publicationsarticles/corp/fahcsia_facts_and_figures/Pages/default.aspx%3E).
- Fair Work Australia 2014, *Minimum Wages*, Commonwealth of Australia, Canberra, ACT, viewed 2nd Sept 2014, <<http://www.fairwork.gov.au/about-us/policies-and-guides/fact-sheets/minimum-workplace-entitlements/minimum-wages%3E>.
- Ferguson, P.M. & Nusbaum, E. 2012, 'Disability Studies: What Is It and What Difference Does It Make?', *Research & Practice for Persons with Severe Disabilities*, vol. 37, no. 2, pp. 70-80.
- Flyvbjerg, B. 2006, 'Five misunderstandings about case-study research', vol. 12, no. 2, pp. 219-245, viewed Marc 2012,  
 <<http://qix.sagepub.com.ezproxy.lib.uts.edu.au/content/12/2/219.short%3E>.

- French, S. & Swain, J. 1997, 'Changing disability research: Participating and emancipatory research with disabled people', *Physiotherapy*, vol. 83, no. 1, pp. 26-32.
- Gibson, J. 1982, 'The concept of affordances in development: The renaissance of functionalism.', *The concept of development: The Minnesota symposia on child psychology*, vol. 5, pp. 67-82.
- Goertz, Y.H.H., Lierop, B.A.G.v., Houkes, I. & Nijhuis, F.J.N. 2010, 'CEU Article. Factors Related to the Employment of Visually Impaired Persons: A Systematic Literature Review', *Journal of Visual Impairment & Blindness*, vol. 104, no. 7, pp. 404-418.
- Goodwyn, M., Bell, E.C. & Singletary, C. 2009, *Factors that Contribute to the Success of Blind Adults*, Professional Development and Research Institute on Blindness at Louisiana Tech University, Louisiana Tech University, viewed 19 June 2012, <<http://www.pdrib.com/pages/researchreports.php%3E>.
- Gordois, A., Cutler, H., Pezzullo, L., Gordon, K., Cruess, A., Winyard, S., Hamilton, W. & Chua, K. 2012, 'An estimation of the worldwide economic and health burden of visual impairment', *Global public health*, vol. 7, no. 5, pp. 465-481.
- Grow, S.J.L. & Daye, P. 2005, *Barriers to Employment Identified by Blind and Vision-Impaired Persons in New Zealand*, Centre for Social Research and Evaluation at the Ministry of Social Development. NZ,, viewed 26 March 2012, <[http://www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj26/26-barriers-to-employment-identified-by-blind-and-vision-impaired-persons-pages173-185.html - top%3E](http://www.msd.govt.nz/about-msd-and-our-work/publications-resources/journals-and-magazines/social-policy-journal/spj26/26-barriers-to-employment-identified-by-blind-and-vision-impaired-persons-pages173-185.html-top%3E)>.
- Guercio, A., Stirbens, K.A., Williams, J. & Haiber, C. 2011, 'Addressing Challenges in Web Accessibility for the Blind and Visually Impaired', *International Journal of Distance Education Technologies*, vol. 9, no. 4, pp. 1-13.
- Guide Dogs , N.A. 2012, *Common Vision Impairments*, Guide Dogs NSW/ACT, Sydney, viewed 21 March 2013, <<http://guidedogs.com.au/education-and-resources/common-vision-impairments%3E>.
- Hartnett, H.P., Stuart, H., Thurman, H., Loy, B. & Batiste, L.C. 2011, 'Employers' perceptions of the benefits of workplace accommodations: Reasons to hire, retain and promote people with disabilities', *Journal of Vocational Rehabilitation*, vol. 34, no. 1, pp. 17-23.
- Hartson, R. 2003, 'Cognitive, physical, sensory, and functional affordances in interaction design', *Behaviour & Information Technology*, vol. 22, no. 5, pp. 315-338.
- Hodge, S. 2014, 'Transformative Learning as an "Inter-Practice" Phenomenon', *Adult Education Quarterly*, vol. 64, no. 2, pp. 165-181.
- Hodge, S., Barr, W., Bowen, L., Leeven, M. & Knox, P. 2013, 'Exploring the role of an emotional support and counselling service for people with visual impairments', vol. 31, no. 1, pp. 5-19, viewed July 2014, <<http://jvi.sagepub.com/content/31/1/5.short%3E>.



- Hutchison, A.J., Johnston, L. & Breckon, J. 2011, 'Grounded Theory-Based Research within Exercise Psychology: A Critical Review', *Qualitative Research in Psychology*, vol. 8, no. 3, pp. 247-272.
- Imo, K.O.C. 2013, 'Mentors ARE GOOD, Sponsors ARE BETTER', *Law Practice: The Business of Practicing Law*, vol. 39, no. 1, pp. 42-46.
- Kivelä, T. 2010, 'Blind, by definition – or should we prefer functional vision?', *Acta Ophthalmologica (1755375X)*, pp. 161-162, viewed May 2012, <<http://www.lib.uts.edu.au/sso/goto.php?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=48303790&site=ehost-live%3E>>.
- Krausz, S.L. 1980, 'Group psychotherapy with legally blind patients', *Clinical Social Work Journal*, vol. 8, no. 1, pp. 37-49.
- Lave, J. & Wenger, E. 1998, 'Communities of practice', *Retrieved June*, vol. 9, p. 2008.
- Lee, I.S. & Park, S.K. 2008, 'Employment Status and Predictors Among People with Visual Impairments in South Korea: Results of a National Survey', *Journal of Visual Impairment & Blindness*, vol. 102, no. 3, pp. 147-159.
- Legge, G.E., Beckmann, P.J., Tjan, B.S., Havey, G., Kramer, K., Rolkosky, D., Gage, R., Chen, M., Puchakayala, S. & Rangarajan, A. 2013, *Indoor Navigation by People with Visual Impairment Using a Digital Sign System*, Article, *PLoS ONE*, vol. 8, no 10, Public Library of Science, pp. 1-1 <<https://http://www.lib.uts.edu.au/goto?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=94478677&site=ehost-live%3E>>.
- Li, L.C., Grimshaw, J.M., Nielsen, C., Judd, M., Coyte, P.C. & Graham, I.D. 2009, 'Evolution of Wenger's concept of community of practice', *Implementation Science*, vol. 4, pp. 1-8.
- Linton, S. 1998, *Disability Studies/Not Disability Studies*, Article, Taylor & Francis Ltd., Abingdon, UK, viewed 4 April 2013, <<http://www.lib.uts.edu.au/sso/goto.php?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=14018635&site=ehost-live%3E>>.
- Matti, A., Pesudovs, K., Daly, A., Brown, M. & Chen, C. 2011, 'Access to low-vision rehabilitation services: barriers and enablers', vol. 94, no. 2, pp. 181-186, viewed 26 August 2013, <<http://onlinelibrary.wiley.com.ezproxy.lib.uts.edu.au/doi/10.1111/j.1444-0938.2010.00556.x/full%3E>>.
- Melbourne University, I.o.A.E.a.S.R. 2014, *Poverty lines: australia september 2014 March quarter*, University of Melbourne, Melbourne, viewed 2nd Sept 2014, <<https://melbourneinstitute.com/miaesr/publications/indicators/poverty-lines-australia.html>>.
- Moore, D. & Nettelbeck, T. 2013, 'Effects of short-term disability awareness training on attitudes of adolescent schoolboys toward persons with a disability', *Journal of Intellectual & Developmental Disability*, vol. 38, no. 3, pp. 223-231.
- Morris, J. 2001, 'Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights', *Hypatia*, vol. 16, no. 4, pp. 1-16.



- National Disability Insurance Agency 2014, *Planning and Assessment - Overview*, National Disability Insurance Agency, Canberra, viewed June 2014, <<http://www.ndis.gov.au/document/323%3E>.
- Nyman, S.R., Gosney, M.A. & Victor, C.R. 2010, 'Psychosocial impact of visual impairment in working-age adults', *British Journal of Ophthalmology*, vol. 94, no. 11, pp. 1427-1431.
- Okuma America Corporation 2010, *Real Productivity / Lighthouse for the Blind*, Okuma America Corporation,, Seattle, WA, USA, viewed April 2013 <<https://http://www.youtube.com/watch?v=I6mmEL6MyrQ%3E>.
- Oliver, M. & Barnes, C. 2010, 'Disability studies, disabled people and the struggle for inclusion', *British Journal of Sociology of Education*, vol. 31, no. 5, pp. 547-560 %@ 0142-5692.
- Omansky, B. 2011, *Borderlands of blindness*, First edn, Lynne Rienner Publishers, Boulder, Colorado, 80301.USA.
- Omede Andrew, A. & Tenimu, S. 2013, 'Counselling Persons with Visual Impairment for Effective Career Choice: Implication for National Development', *Journal of Emerging Trends in Educational Research and Policy Studies (JETERAPS)*, vol. 4, no. 2, pp. 345-349.
- Peterson, N. 2014, 'Empowerment Theory: Clarifying the Nature of Higher-Order Multidimensional Constructs', *American Journal of Community Psychology*, vol. 53, no. 1/2, pp. 96-108.
- Ponterotto, J.G. 2006, 'Brief note on the origins, evolution, and meaning of the qualitative research concept "thick description"', *The Qualitative Report*, vol. 11, no. 3, pp. 538-549.
- Pope, C., van Royen, P. & Baker, R. 2002, 'Qualitative methods in research on healthcare quality', vol. 11, no. 2, pp. 148-152, viewed Feb 2013.
- Pope, C., Ziebland, S. & Mays, N. 2000, *Qualitative research in health care: Analysing qualitative data*, BMJ Publishing Group Ltd, viewed Feb 2013.
- Pope, C., Ziebland, S. & Mays, N. 2006, 'Analysing qualitative data', vol. 3, viewed Aug 2013.
- Richardson, L. 2000, 'Evaluating ethnography', *Qualitative Inquiry*, vol. 6, no. 2, pp. 253-255.
- Rowley P 2010, *Annual Report 2009/2010 State Transport NSW*, State Transport Authority NSW, Sydney, viewed Dec 2013 <[http://www.statetransit.info/publications/STA\\_Annual\\_Report\\_2009-10.pdf%3E](http://www.statetransit.info/publications/STA_Annual_Report_2009-10.pdf%3E).
- Rowley P 2011, *Annual Report 2010/2011 State Transport NSW*, State Transport Authority NSW, Sydney, viewed Nov, 2013 <[http://www.statetransit.info/publications/STA\\_Annual\\_Report\\_2010-11.pdf%3E](http://www.statetransit.info/publications/STA_Annual_Report_2010-11.pdf%3E).

- Rowley P 2012, *Annual Report 2011/2012 State Transport NSW*, State Transport Authority NSW, Sydney, viewed Nov 2013  
<[http://www.statetransit.info/publications/STA Annual Report 2011 12-1.pdf%3E](http://www.statetransit.info/publications/STA_Annual_Report_2011_12-1.pdf%3E).
- Royal Blind Asylum and School, T. 2014, *Royal Blind Braille Week October 2013*, webpage, The Royal Blind Asylum and School, Gillespie Crescent, Edinburgh EH10 4HZ, viewed Feb 2014,  
<<http://www.nationalbrailleweek.org/page/braille-facts%3E>.
- Royal National Institute for the Blind 2012, *Sight loss UK 2012: the latest evidence* RNIB, London, England.
- Ruggs, E.N., Martinez, L.R. & Hebl, M.R. 2011, 'How Individuals and Organizations Can Reduce Interpersonal Discrimination', *Social & Personality Psychology Compass*, vol. 5, no. 1, pp. 29-42.
- Rutti, R.M., Helms, M.M. & Rose, L.C. 2013, 'Changing the lens: Viewing the mentoring relationship as relational structures in a social exchange framework', *Leadership & Organization Development Journal*, vol. 34, no. 5, pp. 446-468.
- Ryder, B. 1992, 'Implications for vocational success for visually impaired users of adaptive equipment. (Cover story)', *American Rehabilitation*, vol. 18, no. 4, p. 29.
- Sandelowski, M. 2000, 'Whatever happened to qualitative description?', *Research in Nursing & Health*, vol. 23, no. 4, pp. 334-340.
- Sandelowski, M. 2010, 'What's in a name? Qualitative description revisited', *Research in Nursing & Health*, vol. 33, no. 1, pp. 77-84.
- Scott, S. 2004, 'Researching shyness: a contradiction in terms?', vol. 4, no. 1, pp. 91-105, viewed Aug 2013,  
<<https://http://www.lib.uts.edu.au/goto?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=13089678&site=ehost-live%3E>.
- Shakespeare, T. 1993, 'Disabled people's self-organisation: a new social movement?', *Disability, Handicap & Society*, vol. 8, no. 3, pp. 249-264.
- Shakespeare, T. & Watson, N. 2001, 'The social model of disability: an outdated ideology?', vol. 2, pp. 9-28, viewed Mar 2012,  
<<http://www.emeraldinsight.com/doi/abs/10.1016/S1479-3547%2801%2980018-X%3E>.
- Schildrick, T., MacDonald, R., Webster, C. & Garthwaite, K. 2012, *Poverty and insecurity: life in low-pay, no-pay Britain*, Policy Press.
- Siebers, T. 2004, 'Disability as masquerade', *Literature and Medicine*, vol. 23, no. 1, pp. 1-22.
- Spriggs, R. 2007, 'Results and Observations from Research into Employment Levels in Australia', unpublished, Vision Australia.
- Stake, R.E. 1978, 'The case study method in social inquiry', *Educational researcher*, vol. 7, pp. 5-8.

- Stanciu, M. & Stoica, A.-M. 2014, 'World population – Accelerator or brake in development?', *Contemporary Readings in Law & Social Justice*, vol. 6, no. 1, pp. 527-536.
- Stets, J.E. & Burke, P.J. 2000, 'Identity theory and social identity theory', *Social psychology quarterly*, pp. 224-237.
- Stoffregen, T.A. 2004, 'Breadth and Limits of the Affordance Concept', *Ecological Psychology*, vol. 16, no. 1, pp. 79-85.
- Suk-Hyang, L., Theoharis, R., Fitzpatrick, M., Kyeong-Hwa, K., Liss, J.M., Nix-Williams, T., Griswold, D.E. & Walther-Thomas, C. 2006, 'Create Effective Mentoring Relationships: Strategies for Mentor and Mentee Success', *Intervention in School & Clinic*, vol. 41, no. 4, pp. 233-240.
- Taylor, H.R., Pezzullo, M.I. & Keeffe, J.E. 2006, 'The economic impact and cost of visual impairment in Australia', *British Journal of Ophthalmology*, vol. 90, no. 3, pp. 272-275.
- Thurston, M., McLeod, J. & Thurston, A. 2013, 'Counselling for sight loss: Using systematic case study research to build a client informed practice model', vol. 31, no. 2, pp. 102-122, viewed Nov 2013.
- Transport for NSW 2013, *Transport for NSW Disability Action Plan 2012 - 2017*, Transport for NSW, Chippendale NSW, viewed 13 Sept 2014, <<http://www.transport.nsw.gov.au/content/transport-nsw-disability-action-plan-2012-2017%3E>.
- Trier-Bieniek, A. 2012, 'Framing the telephone interview as a participant-centred tool for qualitative research: a methodological discussion', *Qualitative Research*, vol. 12, no. 6, pp. 630-644.
- Vaughan, G. & Hansen, C. 2004, 'Like Minds, Like Mine': a New Zealand project to counter the stigma and discrimination associated with mental illness', *Australasian Psychiatry*, vol. 12, no. 2, pp. 113-117.
- Vision Australia 2012a, *Vision Australia Employment Report 2012*, Vision Australia, Sydney.
- Vision Australia 2012b, *Vision Australia Eye Conditions*, Vision Australia, Sydney, viewed Sept 2012 <<http://www.visionaustralia.org.au/info.aspx?page=1136%3E>.
- Vision Australia 2014, *Living with Low Vision*, Vision Australia, Melbourne, Australia, viewed June 2014, <<http://www.visionaustralia.org/living-with-low-vision%3E>.
- Wagner-Lampl, A. & Oliver, G.W. 1994, *Folklore of blindness*, Article, American Foundation for the Blind, viewed Sept 2014 <<https://http://www.lib.uts.edu.au/goto?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=9502164095&site=ehost-live%3E>.
- Wall, S. 2008, 'An autoethnography on learning about autoethnography', vol. 5, no. 2, pp. 146-160, viewed Nov 2012,

- <http://ejournals.library.ualberta.ca/index.php/IJQM/article/viewArticle/4396%3E>.
- Watson, N. 2002, 'Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: identity and disability', vol. 17, no. 5, pp. 509-527, viewed Sept 2012,  
<http://www.lib.uts.edu.au/sso/goto.php?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=6998108&site=ehost-live%3E>.
- Wenger, E. 1998, 'Communities of practice: Learning as a social system', *Systems thinker*, vol. 9, no. 5, pp. 2-3.
- West, S. & Sommer, A. 2001, 'Prevention of blindness and priorities for the future', *Bulletin Of The World Health Organization*, vol. 79, no. 3, pp. 244-248.
- Wolffe, K. 1999, 'Responding to a Common Concern About Hiring People with Visual Impairments: Access to Print Information', *Journal of Visual Impairment & Blindness*, vol. 93, no. 2, p. 110.
- World Health Organisation 2014, *Convention on the Rights of Persons with Disabilities*, World Health Organization New York, viewed April 2014,  
<http://www.who.int/disabilities/media/news/unconvention/en/%3E>.
- World Health Organization 2012a, *UN Enable - Disability and the United nations*, Secretariat for the Convention on the Rights of Persons with Disabilities,, New York, NY 10017, viewed Oct 2012  
<http://www.un.org/disabilities/default.asp?id=161%3E>.
- World Health Organization 2012b, *Visual impairment and blindness, Fact Sheet No.282*, World Health Organization New York, viewed Sept 2013  
<http://www.who.int/mediacentre/factsheets/fs282/en/%3E>.
- World Health Organization 2015, *Guiding Principles of the Convention*, Enable, New York, viewed 22 Jan 2015 2015,  
<http://www.un.org/disabilities/default.asp?navid=16&pid=156%3E>.
- Worth, N. 2013, 'Visual Impairment in the City: Young People's Social Strategies for Independent Mobility', *Urban Studies*, vol. 50, no. 3, pp. 574-586.
- Yin, R.K. 2009, *Case study research : design and methods*, Thousand Oaks: Sage, California USA.
- Yonghong\_Jade. X & Martz. E 2010, 'Predictors of employment among individuals with disabilities: A Bayesian analysis of the Longitudinal Study of the Vocational Rehabilitation Services Program', *Journal of Vocational Rehabilitation*, vol. 32, no. 1, pp. 35-45.
- Young, C.E. 1995, 'A focus group on employment', *Journal of Visual Impairment & Blindness*, vol. 89, no. 1, p. 14.
- Zhao, Y., Liu, J., Tang, J. & Zhu, Q. 2013, 'Conceptualizing perceived affordances in social media interaction design', *Aslib Proceedings*, vol. 65, no. 3, pp. 289-303.

## Appendices

---

## Appendix A

# Preparatory research tools

---

### **A1. Proposed interview schedule**

#### ***1. Introductions***

Hello, my name is **Bruce Blackshaw** and I'm the researcher at the University of Technology, Sydney. Before going any further, let me first say thank you for agreeing to participate in this interview.

I am working on a research project called 'Employability of Blind Freddie'. The research is focused on the factors that support and contribute to employment of people who go blind in midlife.

"Before we get started there are a few other things I want to explain to you"

#### ***2. Informed consent (give time to read consent form)***

Talk specifically about how what they talk about here will be used

"To get a good understanding about midlife blindness I am talking to people like yourself who lost vision between the ages of 30 and 64. They will be in age groups of 30-40-50-60. So what you say here will not lead back to you but will be combined with what other people say - to produce a sort of composite story."

"Later on when we are writing papers and other types of documents about this research we might use some of your exact words - if this is the case we will use a fake name."

Explain recorder

The interview will be recorded using these digital devices so that we can capture all of your discussions - but you can ask me to turn the recorders off at any time during the interview- without having to give me an explanation. Why two recording devices? Just in case one fails for whatever reason.

Stopping

"You can stop the interview at any time - without needing to give a reason"

Ask if there are any questions

#### ***3. Get ethics form signed or verbally record agreement***

#### ***4. Turn on recorders***

#### ***5. Start the interview***

#### ***6. At the end thank the participant***

#### ***7. Turn off the recorders***

## **A2. Interview script**

### ***Recorded and emailed prior to interview***

Hello, my name is **Bruce Blackshaw** and I'm the researcher at the University of Technology, Sydney. Before going any further, let me first say thank you for agreeing to participate in this interview.

I am working on a research project called 'Employability of Blind Freddie'. The research is focused on the factors that support and contribute to employment of people who go blind in midlife.

Before we get started there are a few other things I want to explain to you

### ***Informed consent form***

To get a good understanding about midlife blindness I am talking to people like yourself who lost vision between the ages of 30 and 64. They will be in age groups of 30, 40, 50 and 60. So what you say here will not lead back to you but will be combined with what other people say - to produce a sort of composite story.

Later on when we are writing papers and other types of documents about this research we might use some of your exact words - if this is the case we will use a fake name.

The interview will be recorded using these digital devices, iPhone and digital recorder so that we can capture all of your discussions - but you can ask me to turn the recorders off at any time during the interview- without having to give me an explanation. Why two recording devices? Just in case one fails for whatever reason.

You can stop the interview at any time - without needing to give a reason.

***Do you have any questions?***

***Could you sign the ethics form or verbally agree to it?***

***Turn on recorders and start the interview***

## **A3. Interview preamble and questions**

### ***Interview preamble***

I am Bruce Blackshaw. I had a bleed at the back of my eye three years ago which left me legally blind with a condition called Non-arteritic Anterior Ischaemic Optic Neuropathy (NAION) which is basically a smoky, foggy, patchy, blotchy vision. I cannot read normal print, I cannot make out detail and faces for example I cannot see my fingernails on my hands. I am legally blind with a Snellen reading of 1/60 in my right eye and 6/60 in my left eye. When I went blind I was working as a TAFENSW Head teacher in engineering. My left eye and bleed in late December 2009 and my right eye in June 2010, on each occasion there were no warnings or signs that the first one would happen nor that you can expect the second one to happen.

One day I was tremendously busy the next day I was sitting in my backyard twiddling my thumbs.

I went through the emotional rollercoaster of sudden vision loss and the realisation that it was irreversible. I accepted the situation after a period of time and then wanted to know how I may be able to help others, hence the research project.

***Interview questions V1***

1. What is your eye condition?
2. How long ago did you lose your vision?
3. How did you lose your vision—rapid or slowly?
4. How old were you when you first knew that you were going to go blind?
5. How old were you when you lost your vision?
6. How has vision loss affected your mobility?
7. Could you tell me what has changed in your life since the onset of your vision loss?
8. How was your employment affected by your blindness?
  - Not at all affected
  - Had to reduce my hours
  - Had to temporarily cease work
  - Had to permanently cease work
  - Decided to retire early
  - Other
9. Since your blindness, how supportive has your employer been?
  - Extremely supportive
  - Very supportive
  - Somewhat supportive
  - Not too supportive
  - Not at all supportive
  - Not applicable - I'm self-employed
10. What were/would have been the best ways your employer was able to support you?
  - Supportive attitude
  - Extra time off
  - Flexible work hours
  - Kept my job open
  - Staff home visits
  - Staff newsletter/updates
  - Other
11. Are you...?
  - Male
  - Female
12. Where do you currently live?



- Western Australia
  - Northern Territory
  - Queensland
  - New South Wales
  - Australian Capital Territory
  - Victoria
  - Tasmania
  - South Australia
  - Elsewhere
13. Do you live in a...?
- Metropolitan area
  - Regional area
  - Rural area
14. What age were you when you lost your vision
- 40 to 49
  - 50 to 59
  - 60 to 69
  - 70 +
15. What is your marital status?
- Single
  - Married/Defacto
  - Separated/Divorced
  - Widowed
  - Other
16. Which of these best describes your living arrangements?
- Live alone with little support
  - Live alone with good support
  - Live with other(s) with little support
  - Live with other(s) with good support
  - Other
17. What was your annual household income before tax prior to vision loss?
- Less than \$30,000
  - \$30,000 to \$49,999
  - \$50,000 to \$69,999
  - \$70,000 to \$89,999
  - \$90,000 to \$109,999
  - \$110,000 to \$129,999
  - \$130,000 to \$149,999
  - \$150,000 or more

- Prefer not to say
18. What was your annual household income before tax AFTER vision loss?
- Less than \$30,000
  - \$30,000 to \$49,999
  - \$50,000 to \$69,999
  - \$70,000 to \$89,999
  - \$90,000 to \$109,999
  - \$110,000 to \$129,999
  - \$130,000 to \$149,999
  - \$150,000 or more
  - Prefer not to say
19. How have people's views of you changed since vision loss?
20. How have your friends reacted to your vision loss?
21. What type of work did you do before your vision loss?
22. How did your vision loss affect your employment?
23. What did you do to get back into the workforce?
- Training
  - Emotional support
  - Workplace changes
  - Barriers experienced
24. Have you used an employment service to gain employment?
25. How did the employment conditions change after you were employed?
26. How did co-workers accept you when you first commenced work versus six months later?

#### **A4. Questionnaire**

What was your position before you went blind?

How was your employment affected by your blindness?

Since your blindness how supportive was your employer?

## Appendix B

# Consent form

---

### Participant consent form



**Research title:** *Employability of Blind Freddie: What factors contribute to and supports people who go blind in midlife?*

Ethics Approval: UTS HREC REF No. 2012000557

I have read the attached information sheet and I have been given the opportunity to ask questions about the research and to receive further explanation about any risks involved. I understand that I may be asked to participate in an interview, and that the data generated from the interview may be analyzed and used for the study. Any interview conducted will be recorded and transcribed for ease of research and to ensure that the information gathered is accurate.

Consent can be via signatures in written or Braille formats or a recorded verbal agreement.

I understand that I can withdraw from the project at any time without giving a reason. In the event that this occurs, I agree to inform the researcher about whether or not my data can be analyzed or withdrawn.

The researcher will undertake:

- That any confidential information shared with the researcher or inadvertently obtained will remain confidential and will not be revealed to any person outside the research team.
- The data will not be used for any other purpose than the ones stated.
- Any transcripts produced will be anonymised in order to protect the identity of the participants.

All data gathered may be used in future studies and or publications

- Any research publications or reports produced will be similarly anonymised.
- All digital recordings and transcriptions produced will only accessible to members of the research team.
- All data will be electronically stored, and will be accessible only to members of the research team.

### ***Important note***

The disclosure of illegal activities cannot remain confidential

The researcher is legally required to disclose to the appropriate authority any such information

***Participant consent***

I understand both the project description attached and this consent form, and I give my consent to participate in the **Employability of Blind Freddie** research.

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Researchers' undertaking

I undertake to abide by the undertakings made in this consent form.

Name: Bruce Blackshaw \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

Mar\_2013—Standard and Recorded

## Appendix C

# Data collection tools

---

### **C1. Interview guide**

#### 1. Introductions

Hello, my name is **Bruce Blackshaw** and I'm the researcher at the University of Technology, Sydney. Before going any further, let me first say thank you for agreeing to participate in this interview.

I am working on a research project called 'Employability of Blind Freddie'. The research is focused on the factors that support and contribute to employment of people who go blind in midlife.

"Before we get started there are a few other things I want to explain to you"

Firstly your Informed consent. I sent you an informed consent form and an information sheet regarding the research.

To get a good understanding about midlife blindness I am talking to people like yourself who lost vision between the ages of 30 and 64. They will hopefully be in age groups of 30-40-50-60. What you say here will not lead back to you but will be combined with what other people say - to produce a sort of composite story.

Later on when I am writing papers and other types of documents about this research I might use some of your exact words - if this is the case I will use a fake name.

The interview will be recorded using two digital devices so that we can capture all of your discussions - but you can ask me to turn the recorders off at any time during the interview- without having to give me an explanation. Why two recording devices? Just in case one fails for whatever reason.

"You can stop the interview at any time - without needing to give a reason"

2. Do you have any questions.

3. Please sign the ethics form

Signed or verbally record agreement

4. Turn on recorders

5. Start the interview

6. At the end thank the participant

7. Turn off the recorders

#### ***Interview script (recorded and emailed prior to interview)***

Hello, my name is **Bruce Blackshaw** and I'm the researcher at the University of Technology, Sydney. Before going any further, let me first say thank you for agreeing to participate in this interview.

I am working on a research project called 'Employability of Blind Freddie'. The research is focused on the factors that support and contribute to employment of people who go blind in midlife.

Before we get started there are a few other things I want to explain to you

*Informed consent form*

To get a good understanding about midlife blindness I am talking to people like yourself who lost vision between the ages of 30 and 64. They will be in age groups of 30, 40, 50 and 60. So what you say here will not lead back to you but will be combined with what other people say - to produce a sort of composite story.

Later on when we are writing papers and other types of documents about this research we might use some of your exact words - if this is the case we will use a fake name.

The interview will be recorded using these digital devices, iPhone and digital recorder so that we can capture all of your discussions—but you can ask me to turn the recorders off at any time during the interview—without having to give me an explanation. Why two recording devices? Just in case one fails for whatever reason.

You can stop the interview at any time, without needing to give a reason.

*Do you have any questions?*

*Could you sign the ethics form or verbally agree to it.*

*Turn on recorders and start the interview*

## **C2. Email exchanges with participants**

### ***Emails with Jim***

Begin forwarded message:

From: Jim

Subject: RE: Research Request

Date: 29 January 2013 10:28:44 AM AEDT

To: Bruce Blackshaw <[\\_\\_\\_\\_@optusnet.com.au](mailto:____@optusnet.com.au)>

HI Bruce

Yes, I do remember our conversation.

I will pass your message around to a few people I have in mind and see how we go.

Sorry you haven't heard from BCA, I will chase that up. The BCA CEO did resign late last year and a new CEO has been employed, I can only guess your request has been lost in that change over.

Happy to help wherever I can.

Jim

-----Original Message-----

From: Bruce Blackshaw [mailto:██████████@optusnet.com.au]

Sent: Saturday, 26 January 2013 6:50 AM

To: JIM

Subject: Research Request

Jim

I think we met at a disability conference at Sydney University last year. At that time I mentioned to you my research and you said that you fitted the bill of my research. I am nearing my data gathering phase and require participants..

I am undertaking a Masters in Education by Research at UTS. I am in need of some participants to speak to for my research data-gathering phase. This is not through BCA just by word of mouth.

My research title is Employability of Blind Freddie: What contributes to and supports employment of people who go blind in midlife.

The people I am looking for are

- \* Males and females
- \* Are legally blind or blind (not low vision)
- \* Acquired vision loss after the age of 30
  - o Vision loss can be gradual or sudden
- \* Were employed at time of vision loss or had had a career prior to diagnosis
- \* Have only one disability i.e. vision loss
- \* Regained employment since vision loss

Ideally I would like people in differing age groups 30, 40, 50 and 60 when they went blind.

I have asked BCA to advertise my research but I have not had a reply to date. (probably Christmas New Year Periods)

I am currently working on my ethics application, which is a deed on its own. The ethics application ties me into many rules of protection for participants. No names or identifying features will ever be disclosed in my research. I would not contact any person until after the ethics has been approve probably mid March.

So, do you know anyone who fits the criteria and may be willing to talk to me?

I would like to talk to them via telephone first and then I would want to get their consent, talk to them and record our conversation all of which probably would take an hour.

If you know people who fit the bill could you ask them to contact me via email [██████████@optusnet.com.au](mailto:██████████@optusnet.com.au) or mobile ██████████

If you feel uncomfortable about any of this please just let me know and I will not contact you about this again.

Regards

Bruce

***Emails with Freeman***

Rang Freeman 11am Friday 12<sup>th</sup> April 2013 to arrange interview. Spoke to Freeman and he said he was legally blind with less than 10<sup>0</sup> peripheral vision and works with TAFENSW Outreach Thursday and Fridays. He said he works freelance at other areas.

Resolved to meet next week Tuesday or Wednesday afternoon or the following week. TA will call the night before to let me know time and location.

On 11/04/2013, at 3:33 PM, Bruce Blackshaw <[REDACTED]@optusnet.com.au> wrote:

Freeman,

I am just sending you a short note to explain why I appear so slow getting back to you.

First of all we had the Easter break and then I was hospitalised for over a week so I had an enforced break from the research. I have been recently diagnosed with MDS an early form of Leukaemia. I have been on Chemo and that has dropped my immune system, blood counts etc and hence my stay in hospital. I am getting better every day and so would like to start the interviews next week if possible.

I will call you tomorrow morning Friday 12th to arrange a day , time and place that suits you for an chat.

I look forward to meeting you.

Bruce

Begin forwarded message:

**From:** Freeman

**Subject:** RE: MATURE AGED BLINDNESS RESEARCH

**Date:** 23 March 2013 1:38:15 PM AEDT

**To:** Bruce Blackshaw <[REDACTED]@optusnet.com.au>

Hi Bruce,

I applaud your stand re the Blind Freddie title, whilst I get the Uni's need for the ethical navel gazing...I love the multi-layered meanings present. With a little luck it will empower a few who have been gifted with vision challenges to be a little less precious about how they engage with the world.

My preference would be a face-to-face interview at a time and place that's mutually convenient. To organise this you can phone me on the mobile number below. Generally I'm available on that number 9am-9pm Saturday-Wednesday (also Th and Fri during TAFE holidays). Leave a message if I miss you and I'll return your call.

Freeman

**From:** [REDACTED]@optusnet.com.au

**Date:** Fri, 22 Mar 2013 16:38:31 +1100

**Subject:** MATURE AGED BLINDNESS RESEARCH



Hello one and all,

After some reviews and changes requested by the Higher Research Ethics Committee (HREC) University of Technology Sydney I now have approval to proceed with the next phase of the research I.e. the interviews and data collection phase.

There has been a fair bit of discussion regarding the title of the research. The HREC requested eight modifications to my original ethics application of which I completely addressed seven. The first request was that I reconsider the project title (see attachment below). I have had to defend the title from many perspectives from an assortment of diverse elements of the university, the blindness associations, the blindness community and the community at large. The perspectives of the various groups were toward the use of the term “Blind Freddy”, a simple Australian saga of a fumbling English aristocrat who was hopeless and hapless as a policeman in the late 1800’s. Some views of the title were that the title was sexist as it only mentioned “Freddy and not Frederica”; which is ridiculous in an extreme. Others, who are blind, stated that they had no qualms about the term and used it at times but thought others may have some issues and still others said that the term has been used in a derogatory ways and as a put down to the blind. Other sections of the scholarly academy have called for the outlawing of the term. Blind Freddy has been used in many areas such as the Australian Stock exchange, the Federal Government and in popular songs.

I do understand and agree that people have been unkind and hurtful in the use of the term but there are many other ways that people are put down and demeaned such as by staring at a person with a white cane, or someone who wants to take care of a blind person as naturally you cannot look after yourself as you cannot see as well as them, so it figures to them, that you therefore cannot help yourself. Other forms of discriminatory practices are to assume that you must be deaf as well as blind and so on. Even the professionals within the blindness community often assume that they know what is best for a blind person as they, the professionals, are trained and so know more than you. There are multitudes of ways to demean and discriminate against a person. I preach to the converted though as you all would have experienced these practices and many, many more.

I believe that blind people in general can and do make a useful and purposeful contribution to society and to themselves in various ways. The research I am looking at is regarding the useful and complete employment of a person who experiences late onset of blindness. The research will also investigate ways to help people overcome their newfound blindness and explore any possible hindrances in the progression of the person to employment. My intentions are to increase the knowledge base regarding the difficulties faced by midlife blind people and enhance understandings of what the blind people experience on a day to day basis. This research in no way diminishes the problems people who have blindness from an early age endure all their lives. The research is specific to a target group and only can investigate that arena.

The title of the project has and will be critiqued positively and negatively; people will take up the cause just because and some will ignore it all together. But, if there is attention given to the issues due to a project title then great; if there are positive changes to attitudes due to a title great; If employers become aware of the

abilities of blind people then great; and if employment opportunities are enhanced sensational. After all the research is about employment of people who go blind in midlife, their experiences and stories of what was needed to gain employment after vision loss.

Thank you for volunteering to be part of the research. Attached is an information sheet and a consent form. For the research to commence please reply to this email with your first and second preferred day and time for an interview, your telephone number and I will call you. When I call you I will ask you to consent to the research and I will record your consent. If you would prefer Braille or large print format please email me your address and I will mail the format to you.

I look forward to speaking with you soon.

Kind regards and thank you once again.

Bruce

Ethics attachment - HREC outcome and comments

UTS HREC 2012000557—HOLLAND (for BLACKSHAW, PhD student)—  
“Employability of Blind Freddie: What contributes to, and supports employment of people who go blind in midlife?” [RMENet]

The Committee considered the above application and made the following comments:

1. Consideration should be given to changing the project title as this may be offensive to participants;

*Response*

Consideration of the title has been given as per this request. From the outset the title was developed to be a paradox of meanings regarding the usefulness of the blind and their employability and the negative perspectives of others regarding the blind peoples’ abilities. The title is still a working title and may change as the research progresses and more data is collected and analysed.

***WA Help 1***

Begin forwarded message:

From: Help 1

Subject: RE: Research Request

**Date:** 29 January 2013 10:28:44 AM AEDT

**To:** Bruce Blackshaw <[redacted]@optusnet.com.au>

Hi Bruce

Yes, I do remember our conversation.

I will pass your message around to a few people I have in mind and see how we go.

Sorry you haven't heard from BCA, I will chase that up. The BCA CEO did resign late last year and a new CEO has been employed, I can only guess your request has been lost in that change over.

Happy to help wherever I can.

Help 1

-----Original Message-----

From: Bruce Blackshaw [mailto: [REDACTED]@optusnet.com.au]

Sent: Saturday, 26 January 2013 6:50 AM

To: Help 1

Subject: Research Request

Help 1

I think we met at a disability conference at Sydney University last year. At that time I mentioned to you my research and you said that you fitted the bill of my research. I am nearing my data gathering phase and require participants..

I am undertaking a Masters in Education by Research at UTS. I am in need of some participants to speak to for my research data-gathering phase. This is not through BCA just by word of mouth.

My research title is Employability of Blind Freddie: What contributes to and supports employment of people who go blind in midlife.

The people I am looking for are

- \* Males and females
- \* Are legally blind or blind (not low vision)
- \* Acquired vision loss after the age of 30
  - o Vision loss can be gradual or sudden
- \* Were employed at time of vision loss or had had a career prior to diagnosis
- \* Have only one disability i.e. vision loss
- \* Regained employment since vision loss

Ideally I would like people in differing age groups 30, 40, 50 and 60 when they went blind.

I have asked BCA to advertise my research but I have not had a reply to date. (probably Christmas New Year Periods)

I am currently working on my ethics application, which is a deed on its own. The ethics application ties me into many rules of protection for participants. No names or identifying features will ever be disclosed in my research. I would not contact any person until after the ethics has been approved probably mid March.

So, do you know anyone who fits the criteria and may be willing to talk to me?

I would like to talk to them via telephone first and then I would want to get their consent, talk to them and record our conversation all of which probably would take an hour.

If you know people who fit the bill could you ask them to contact me via email [█@optusnet.com.au](mailto:█@optusnet.com.au) or mobile █

If you feel uncomfortable about any of this please just let me know and I will not contact you about this again.

Regards

Bruce

### **Freeman's Emails**

Rang TA 11am Friday 12<sup>th</sup> April 2013 to arrange interview. Spoke to TA and he said he was legally blind with less than 10<sup>0</sup> peripheral vision and works with TAFENSW Outreach Thursday and Fridays. He said he works freelance at other areas.

Resolved to meet next week Tuesday or Wednesday afternoon or the following week. TA will call the night before to let me know time and location.

**On 11/04/2013**, at 3:33 PM, Bruce Blackshaw <█@optusnet.com.au> wrote:

TA,

I am just sending you a short note to explain why I appear so slow getting back to you.

First of all we had the Easter break and then I was hospitalised for over a week so I had an enforced break from the research. I have been recently diagnosed with MDS an early form of Leukaemia. I have been on Chemo and that has dropped my immune system, blood counts etc and hence my stay in hospital. I am getting better every day and so would like to start the interviews next week if possible.

I will call you tomorrow morning Friday 12th to arrange a day , time and place that suits you for an chat.

I look forward to meeting you.

Bruce

Begin forwarded message:

From: TA

Subject: RE: MATURE AGED BLINDNESS RESEARCH

**Date:** 23 March 2013 1:38:15 PM AEDT

**To:** Bruce Blackshaw <█@optusnet.com.au>

Hi Bruce,

I applaud your stand re the Blind Freddie title, whilst I get the Uni's need for the ethical navel gazing...I love the multi-layered meanings present. With a little luck it will empower a few who have been gifted with vision challenges to be a little less precious about how they engage with the world.

My preference would be a face-to-face interview at a time and place that's mutually convenient. To organise this you can phone me on the mobile number below. Generally I'm available on that number 9am-9pm Saturday-Wednesday

(also Th and Fri during TAFE holidays). Leave a message if I miss you and I'll return your call.

TA

From: [REDACTED]@optusnet.com.au

Date: Fri, 22 Mar 2013 16:38:31 +1100

Subject: MATURE AGED BLINDNESS RESEARCH

Hello one and all,

After some reviews and changes requested by the Higher Research Ethics Committee (HREC) University of Technology Sydney I now have approval to proceed with the next phase of the research I.e. the interviews and data collection phase.

There has been a fair bit of discussion regarding the title of the research. The HREC requested eight modifications to my original ethics application of which I completely addressed seven. The first request was that I reconsider the project title (see attachment below). I have had to defend the title from many perspectives from an assortment of diverse elements of the university, the blindness associations, the blindness community and the community at large. The perspectives of the various groups were toward the use of the term "Blind Freddy", a simple Australian saga of a fumbling English aristocrat who was hopeless and hapless as a policeman in the late 1800's. Some views of the title were that the title was sexist as it only mentioned "Freddy and not Frederica"; which is ridiculous in an extreme. Others, who are blind, stated that they had no qualms about the term and used it at times but thought others may have some issues and still others said that the term has been used in a derogatory ways and as a put down to the blind. Other sections of the scholarly academy have called for the outlawing of the term. Blind Freddy has been used in many areas such as the Australian Stock exchange, the Federal Government and in popular songs.

I do understand and agree that people have been unkind and hurtful in the use of the term but there are many other ways that people are put down and demeaned such as by staring at a person with a white cane, or someone who wants to take care of a blind person as naturally you cannot look after yourself as you cannot see as well as them, so it figures to them, that you therefore cannot help yourself. Other forms of discriminatory practices are to assume that you must be deaf as well as blind and so on. Even the professionals within the blindness community often assume that they know what is best for a blind person as they, the professionals, are trained and so know more than you. There are multitudes of ways to demean and discriminate against a person. I preach to the converted though as you all would have experienced these practices and many, many more.

I believe that blind people in general can and do make a useful and purposeful contribution to society and to themselves in various ways. The research I am looking at is regarding the useful and complete employment of a person who experiences late onset of blindness. The research will also investigate ways to help people overcome their newfound blindness and explore any possible hindrances in the progression of the person to employment. My intentions are to increase the knowledge base regarding the difficulties faced by midlife blind

people and enhance understandings of what the blind people experience on a day to day basis. This research in no way diminishes the problems people who have blindness from an early age endure all their lives. The research is specific to a target group and only can investigate that arena.

The title of the project has and will be critiqued positively and negatively; people will take up the cause just because and some will ignore it all together. But, if there is attention given to the issues due to a project title then great; if there are positive changes to attitudes due to a title great; If employers become aware of the abilities of blind people then great; and if employment opportunities are enhanced sensational. After all the research is about employment of people who go blind in midlife, their experiences and stories of what was needed to gain employment after vision loss.

Thank you for volunteering to be part of the research. Attached is an information sheet and a consent form. For the research to commence please reply to this email with your first and second preferred day and time for an interview, your telephone number and I will call you. When I call you I will ask you to consent to the research and I will record your consent. If you would prefer Braille or large print format please email me your address and I will mail the format to you.

I look forward to speaking with you soon.

Kind regards and thank you once again.

Bruce

Ethics attachment - HREC outcome and comments

UTS HREC 2012000557—HOLLAND (for BLACKSHAW, PhD student)—  
“Employability of Blind Freddie: What contributes to, and supports employment of people who go blind in midlife?” [RMENet]

The Committee considered the above application and made the following comments:

1. Consideration should be given to changing the project title as this may be offensive to participants;

*Response*

Consideration of the title has been given as per this request. From the outset the title was developed to be a paradox of meanings regarding the usefulness of the blind and their employability and the negative perspectives of others regarding the blind peoples’ abilities. The title is still a working title and may change as the research progresses and more data is collected and analysis

## Appendix D

# Data analysis tools

---

### D1. Phase one codebook

Id	Parent Id	Depth	Title	Description	Weighted	Weight Minimum	Weight Maximum	Weight Default
1		0	TRANSPORT	Ability to use public transport independently., 0-3 Difficult, 4-6 Reasonable, 7-8 Good, 9-10 No more problems than sighted people.	TRUE	0	10	0
2	1	1	Personal Issues		FALSE			
3	1	1	Lack of Services		FALSE			
	1	1	Time Taken	0-4 hours each way	TRUE	0	4	3
			Support from Transport System	1 = Low, 2 = moderate, 3 = High	TRUE	0	3	0
5	1	1	LIMITING		TRUE	0	3	0
6		0	FACTORS		FALSE			

Id	Parent Id	Depth	Title	Description	Weighted	Weight Minimum	Weight Maximum	Weight Default
7	6	1	EMPLOYER	Discrimination by employer towards blind applicant	FALSE			
8	7	2	Bias		FALSE			
9	7	2	Ignorance		FALSE			
10	6	1	SOCIETAL	Discrimination due to societal values and norms 0-3 No self discrimination 4-7 Limited self discrimination 8-10 Self discrimination	FALSE			
11	6	1	SELF		TRUE	0	10	0
12	6	1	AGENCIES		FALSE			
13	12	2	CENTERLINK		FALSE			
14	12	2	EMPLOYMENT SERVICE		FALSE			
15	6	1	TECNHOLOGIES		FALSE			
16	15	2	ACCESSIBLE FORMAT		FALSE			
17	15	2	COMPUTER SOFTWARE		FALSE			
18		0	TRAINING		FALSE			
19	18	1	Retraining for new career		FALSE			



Id	Parent Id	Depth	Title	Description	Weighted	Weight Minimum	Weight Maximum	Weight Default
20	18	1	Upgrade training for pre vision loss career		FALSE			
21	18	1	On Going Training		FALSE			
22	18	1	Useless Training		FALSE			
23	18	1	No Training available		FALSE			
24	18	1	SELF DIRECTED STUDIES	Participant initiated studies	FALSE			
25		0	SOCIETAL EXPERIENCES		FALSE			
26	25	1	ACCEPTANCE LACK OF ORGANISATIONAL SUPPORT		FALSE			
27	25	1	KNOWLEDGE OF ABILITIES		FALSE			
28	25	1		Overall support that allows employment.	FALSE			
29		0	SUPPORTING FRAMEWORKS		FALSE			
30	29	1	NON FAMILY FRIEND		FALSE			
31	30	2		Can be Employment agencies or support officers	FALSE			
32	30	2	PROFESSIONAL		FALSE			

Id	Parent Id	Depth	Title	Description	Weighted	Weight Minimum	Weight Maximum	Weight Default
33	29	1	FAMILY	Family support that allows employment	FALSE			
34	33	2	SPOUCE		FALSE			
35	33	2	SIBLINGS		FALSE			
36	33	2	RELATIVES		FALSE			
37	29	1	AGENCIES		FALSE			
38	37	2	SPECIALIST EMPLOYMENT		FALSE			
39	37	2	CENTERLINK		FALSE			
40		0	USE OF TECHNOLOGY		FALSE			
41	40	1	ASSISTIVE TECHNOLOGIES	JAWES, SCREEN READERS ETC	FALSE			
42	40	1	COMPUTER TECHNOLOGIES		FALSE			
43	40	1	SPECIALIST SYSTEMS		FALSE			
44		0	PERSONAL ATTRIBUTES		FALSE			
45	44	1	Determination	The ways of moving forward – self-determination, and assisted determination	FALSE			
46	44	1	MOBILITY		FALSE			
47	46	2	GUIDE DOG		FALSE			

Id	Parent Id	Depth	Title	Description	Weighted	Weight Minimum	Weight Maximum	Weight Default
48	46	2	LONG CANE		FALSE			
49	46	2	NO AIDS		FALSE			
50	46	2	Difficulty in New Places		FALSE			
51	46	2	Change of Aid		FALSE			
52	46	2	FAMILY	Family drive to and from outings	FALSE			
53	46	2	TAXIS etc	Taxis and hire cars NOT PUBLIC TRANSPORT	FALSE			
54	44	1	PERSONAL ACCEPTANCE	Acceptance of personal situations and vision loss This relates to the levels of independence a person has achieved i.e choosing own care, directing own career	FALSE			
55	44	1	INDEPENDENCE DISCRIMINATI	paths	FALSE			
56		0	ON		FALSE			
57	56	1	Employer		FALSE			
58	56	1	Co-Workers		FALSE			

Id	Parent Id	Depth	Title	Description	Weighted	Weight Minimum	Weight Maximum	Weight Default
59	56	1	Family		FALSE			
60	56	1	Friends		FALSE			
61	56	1	AGE DISCRIMINATION		FALSE			
62		0	IMPORTANT QUOTES		FALSE			
63		0	Financial Situations Decreased		FALSE			
64	63	1	Earnings		FALSE			
65	63	1	Pension Top Up Increased		FALSE			
66	63	1	Earnings		FALSE			
67		0	Blindness Association Support		FALSE			
68	67	1	Guide Dogs	1-Low, 2- Mopderate, 3- High	TRUE	0	3	1
69	67	1	Blind Citizens Australia	1-Low, 2- Mopderate, 3- High	TRUE	0	3	1
70	67	1	Vision Australia	1-Low, 2- Mopderate, 3- High	TRUE	0	3	1
71	67	1	Others	1-Low, 2- Mopderate, 3- High	TRUE	0	3	1

Id	Parent Id	Depth	Title	Description	Weighted	Weight Minimum	Weight Maximum	Weight Default
72		0	Support Services		FALSE			
73	72	1	Positive		FALSE			
74	72	1	Negative		FALSE			
75		0	CAREER post vision loss		FALSE			
76	75	1	Changed		FALSE			
77	75	1	Same		FALSE			
78		0	Significant Others	People or organisations that helped with employment	FALSE			
79	78	1	Friends	Friends outside of work who helped	FALSE			
80	78	1	Co-Workers	Co-workers who assisted with employment issues	FALSE			
81	78	1	Agencies	Agencies who assisted with employment issues	FALSE			
82		0	Medical Condition		FALSE			
83		0	EMPLOYMENT DEMOGRAPHICS LARGE CORPORATION		FALSE			
84	83	1			FALSE			

Id	Parent Id	Depth	Title	Description	Weighted	Weight Minimum	Weight Maximum	Weight Default
85	83	1	BLINDNESS ASSOCIATION		FALSE			
86	83	1	SMALL EMPLOYER		FALSE			
87	83	1	SELF EMPLOYED		FALSE			
88		0	SOCIETY IGNORANCE	Ignorance of society, people or family towards who are blind	FALSE			
89		0	DECLARE BLINDNESS	Whether to declare that you are blind BEFORE interview in Application or never	FALSE			

## D2. Phase three codebook

CONTEXT		Cluster CHUNKS	Title
No	Description	No o Name	
1.	TRAINING & TECHNOLOGY	3 TRAINING  6 USE OF TECHNOLOGY	TRAINING Retraining for new career  Upgrade training for pre vision loss career Ongoing Training Useless Training No Training available SELF DIRECTED STUDIES USE OF TECHNOLOGY  ASSISTIVE TECHNOLOGIES  COMPUTER TECHNOLOGIES SPECIALIST SYSTEMS
2.	SUPPORTING FRAMEWORKS	5 SUPPORTING FRAMEWORKS	SUPPORTING FRAMEWORKS NON FAMILY FRIEND PROFESSIONAL FAMILY SPOUCE SIBLINGS RELATIVES AGENCIES SPECIALIST EMPLOYMENT CENTERLINK

CONTEXT	Cluster CHUNKS	Title
	<p>7 PERSONAL ATTRIBUTES</p> <p>1 2 Support Services</p> <p>1 3 Significant Others</p>	<p>PERSONAL ATTRIBUTES            Determination            MOBILITY            GUIDE DOG            LONG CANE            NO AIDS            Difficulty in New Places            Change of Aid            FAMILY            TAXIS etc            PERSONAL ACCEPTANCE            INDEPENDENCE</p> <p>Support Services            Positive            Negative            CAREER post vision loss            Changed            Same</p> <p>Significant Others            Friends            Co-Workers            Agencies</p>
<p>3. AWARENESS &amp; DISCRIMINATION</p>	<p>1 5 EMPLOYMENT DEMOGRAPHICS</p>	<p>EMPLOYMENT DEMOGRAPHICS            LARGE CORPORATION            BLINDNESS ASSOCIATION            SMALL EMPLOYER            SELF EMPLOYED</p>



CONTEXT	Cluster CHUNKS	Title
	1	
	6 SOCIETY IGNORANCE	SOCIETY IGNORANCE
	1	
	7 DECLARE BLINDNESS	DECLARE BLINDNESS
	8 DISCRIMINATION	DISCRIMINATION
		Employer
		Co-Workers
		Family
		Friends
		AGE DISCRIMINATION
	2 LIMITING FACTORS	LIMITING FACTORS
		EMPLOYER
		Bias
		Ignorance
		SOCIETAL
		SELF
		AGENCIES
		CENTERLINK
		EMPLOYMENT SERVICE
		TECNOLOGIES
		ACCESSIBLE FORMAT
		COMPUTER SOFTWARE
	4 SOCIETAL EXPERIENCES	SOCIETAL EXPERIENCES
		ACCEPTANCE
		LACK OF ORGANISATIONAL SUPPORT

CONTEXT	Cluster CHUNKS	Title
		KNOWLEDGE OF ABILITIES

<p>4. ISSUES CONSIDERED NOT SIGNIFICANT</p>	<p>14 Medical condition 1 TRANSPORT</p> <p>9 IMPORTANT QUOTES 1 0 Financial Situations</p> <p>1 1 Blindness Association Support</p>	<p>Medical condition TRANSPORT Personal Issues Lack of Services Time Taken</p> <p>Support from Transport System IMPORTANT QUOTES</p> <p>Financial Situations Decreased Earnings Pension Top Up Increased Earnings</p> <p>Blindness Association Support Guide Dogs Blind Citizens Australia Vision Australia Others</p>
---	---	--

### D3. Data visualisation—code applications greater than five times

VOLUNTEER.docx			1	1			1										1											1						12		
SCHOOLIE.rtf																																		12		
REFLEX.doc		16			1	1	6	2			13	14		5	1		6	6	1		7					7	6	3	12	4	6	7	1	5	5	147
MISS_POSITIVE.mp3			5		2																															38
LONERANGER.mp3					2																															7

GEARBOX.docx		1			2				3	7	7			1		5	4			1	1							2	2					1			1	52		
FREE MAN.docx						1	5				2	11				2	2	1	1			1						2		1						2	1			40
FIGHTER.mp3			4	8	1		3	3	1	2	2		1		1		1	1		1	2			1	3	4	2		1									1	52	
CPA FARMER.mp3				1		1	7	1		2	4			1	5	6	6	2		1	2	1	1	1	1	1	4	3	1						1	1	4	3	72	
BUILDER.mp3	7			1	2		3			2	4	6		1	3	1		2					7	4		1	4	1										2	53	
BLIND CHEF .docx		9					4	1	2	3	8		1	1		5	6	2		2	1	1				1	2	2	1	2	2	3	5	4	7	9	93			

# Autobiographical observations

---

### **Introduction**

In chapters of the thesis I present the findings from the coding and analysis of themes in the participant interview data. Through extracts and discussion I suggest that the events and dimensions of most impact on the employment prospects and experiences of my participants were: dealing with the emotional upheaval associated with their diagnosis; obtaining (or not) access to training; accessing useful (or not) support networks to help with employment and/or emotional needs. These dimensions were also critical in my own case. In this appendix I therefore supplement my case study participants' accounts with my autobiographical account.

### **Emotional challenges: the journey starts**

In June 2009 I had cataract operations. I had worn glasses from an early age and wanted to be glasses free. Cataract operations involve the removal of a person's lens by making an incision in the eye then removing the lens. The lens is then replaced with a new artificial lens. Using a combination of myopic (short sighted) and hyperopic (long sighted) lens to achieve a 60/60 vision. Prior to the incision in the eye, a needle is inserted into the back of the eye to inject a local anesthetic. The operation is conducted with a person who is awake and aware of what is happening. The incision is then closed over the new lens and a dressing is applied. There is little to no pain just a feeling of discomfort and anxiety. The result far outweighs the discomfort. Following my operations, I had 60/60 vision. The world was clear and clean.

Then, in December 2009, I had an episode in my left eye that left me visually impaired. Not knowing that any problem had happened to my eye I assumed that I just had blurry eyes. I accepted this for a few weeks until I decided to return to the ophthalmologist. The ophthalmologist conducted various tests and then explained to me that I had had a bleed at the back of the right eye that was irreversible and irreparable. There was shock and disbelief that this had happened with no warnings.

The ophthalmologist stated that the possibility of it happening again to the same eye was zero and only 10% that it could happen in the other eye. I accepted his diagnosis and return to work in the New Year.

Functioning very well with limited vision in my left eye and full vision in my right eye. I had a few changes at work but all was good. Then on the last Saturday in June 2010 I awoke to a cold, wet winter's morning. I stumbled around and made my way downstairs. The morning was dark and overcast, grey and miserable. I had sleep still in my eyes and could not focus too well. My vision did not get any better during Sunday; I put this down to winter and the cold.

On the last Monday in June 2010 I drove to work at 6 am as usual. My employment was as a Head Teacher of Fitting and Machining at TAFE NSW's Sydney Institute in Ultimo. I had planned a meeting with my teachers to explain what was needed during the mid-semester period, the expectations and directions for second semester. I had produced a PowerPoint display to go through it all. At the designated time all the fulltime teachers and around a quarter of the casual teachers assembled. During the presentation I could not see the screen or the computer keyboard, I could not focus, there seemed to be something wrong.

Being much more aware of eye conditions after my previous episodes I began worrying. After the presentation I rang my wife to tell her about the situation and that I felt I should see the ophthalmologist. My wife rang and got an appointment. I left work at lunchtime and drove to the ophthalmologist's rooms.

The ophthalmologist's rooms are in the Sydney suburb of Ashfield. Ashfield is 10 kilometres from the Sydney Institute along Parramatta Road. Parramatta Road is a busy road at the best of times.

At the ophthalmologist's rooms, the ophthalmologist administered some drops and looked into my eyes. He said I had a bleed behind my right eye and explained what had happened but had no answers as to why, or how bad it was. He prescribed a high dose course of steroids to try and reduce the swelling and any resultant long-term damage. There was a glimmer of hope that the eyes could repair themselves and my sight be restored.

The following Thursday, 1st July 2010, after taking the high doses of steroids and with the worry about the side effects of the drugs along with the concerns for my vision, my wife and I went to the ophthalmologist's rooms. The rooms are located on the ground floor of a multi storey building. To access the ground floor rooms there are nine steps from street level to the ground level. Those nine steps were like climbing a mountain. Once inside the rooms I had to wait what seemed like an eternity. Finally I was called in. The doctor put some drops in my eyes, glared through the magnifier, and uttered a few hmms and noises that were not very friendly. The anxiety grew with the continued peering into my eyes and the Google searches and the re-peering into my eyes. He then rang a colleague to confer about his diagnosis and possible effects. More noises and more looking into the eyes. Then he said that the damage was irreversible and he had to do some more tests. One test was the field of vision test, described in chapter three. The printout results showed mostly dark areas—again not good news.

The ophthalmologist looked into my eyes yet again. He then said that due to the bleeding in my right eye and my previous bleeding in my left eye, coupled with a limited field of vision that I was functionally and legally blind.

I said to him "Just give me some pills and fix it all up!"

He replied, "I am not a magician and no pills can fix this up. This is irreversible and permanent."

I did not know what to do or what to say. I was stunned, stupefied by his words.

He asked how I would function at work, I told him that I probably could not work in the TAFE workshops and so would need to reassess my employment. He then told me to come back in a week's time to see how things had progressed.

That was the extent of his counselling and pastoral care.

I walked out of the rooms. It was around 6:30 pm on a cold, dark and wet July evening. When I reached the top of the stairs all of my emotions erupted, I kept saying to my wife that I didn't want to be blind. I burst into tears not knowing what my future would hold, thinking that all was lost and there was no future for me. That last Monday in June 2010 was the very last day that I attended my employment. It ended abruptly, irreversibly and permanently.

The next day after being informed by the ophthalmologist that I was now blind I went to see my GP. I was still in total denial and shock about my new world and I was very scared.

My GP called me into her rooms. As usual everything was in its place and a place for everything, yet this time she was guiding me into her room so that I did not fall over anything. My wife had rung and told her about events of the previous day and arranged an emergency appointment. The GP spoke to me at length about the perils of blindness and what it would mean for me. Then the GP said, "You realise you are now disabled".

At that moment I felt like crying. My world as I knew it was gone. All of a sudden I had become a blind man. Worse still I had been labelled "disabled". I had no future. What could I do?

The GP went onto say that there were worse things in life. She recommended that I should go and see a psychologist. At that stage I was no more ready to see a psychologist than fly to the moon. It took me six months before I went to see a psychologist (described below). The GP did not know what was in front of me, the challenges and changes that had to be made. She was of little help except for her display of some limited understanding and empathy.

As a parting comment she said, "Well at least you won't have to see me grow old!" Not the best time to have a sense of humour.

Little did I really know what was in front of me, what I had to learn and re-learn. I had no idea of how I would have to change; how my emotions would react; how I would have to reinvent myself. Nor did I know what my new world looked like or what it had in store for me.

In the space of seven days I had been labelled legally blind and disabled. I did not want to be either, I just wanted to go back to being me but that was not possible. My journey had commenced.

### **Denial and frustration**

Many of my case study participants described their initial—and sometimes long-lasting—unwillingness to accept their new lives. My experience parallels this. My wife and I had pre-planned a trip to south-eastern USA well before my diagnosis and were to leave three weeks after my diagnosis. This was a trip lasting five weeks. We thought that it would be OK, I was strong and we could cope!

The trip included Orlando and the various Disney theme parks, Memphis and Graceland. New Orleans. Kennedy Space Centre, Las Vegas and Los Angeles. What could go wrong? I had had no training of any kind regarding blindness, no mobility training, no white cane, no counselling, just a self-belief that we could handle it.

I quickly learned that not being able to see was a huge hurdle to overcome. I had not been in this new world very long and here I was halfway around the world in a strange country with huge crowds and where everything is large.

My emotional journey became longer and wider as every aspect of life had changed. I became very angry at people speaking as they normally did with such simple things like “look at that” or “did you see that”.

The emotions grew with every new mishap, e.g. following the wrong wife is shops, the shape was right but not the right person; trying to walk with a bowl of soup, failed at that attempt; bumping into people, not knowing male toilets from female toilets and missing steps. These all heightened my emotional state. The five weeks were extremely difficult emotionally, and continually became worse as the time went on.

On returning to Australia I could not, or would not make contact with Vision Australia. I was in denial and thought that I could work through this on my own.

As time went on my emotional state was worsening. I was looking for some screws in my workshop. My workshop area is a large double brick workspace with 300 x 300mm tiled floors. There is internet access, TV, metal cupboards containing portable power tools, hand tools, various sized tins of leftover paints from previous painting duties the obligatory shadow board for frequently used hand tools and beer fridge. I dropped a screw. Not an unusual occurrence but for me an emotional one. I erupted and began to cry and feel sorry for myself. I could not see the screws in my hands. I could not see my hands properly and when I dropped the screw onto the floor I could not see my feet or the floor.

### **Turning to support networks**

Realising that I needed assistance or I would end up with a major depressive incident, I finally began to turn for support to some of the blindness organisations, as did many of my interview participants. My first step was to make contact with Vision Australia, where I arranged to be assessed in the Vision Australia Low Vision clinic for blindness levels.

That assessment day at Vision Australia was an intense day with multiple eye tests, information regarding adaptive technologies (I had never heard about adaptive technologies prior to that day), meetings with occupational therapists and a barrage of information, paperwork and mountains of information.

Towards the end of the day’s assessments I had a meeting with an Occupational Therapist who offered me a position in a Quality Living Group (QLG). I had no idea what a QLG did but I accepted it as I knew I needed help emotionally.

Vision Australia has an eight-week QLG program for people who have recently lost vision. The program is two hours per day, one day per week and deals with many issues relating to blindness and coping methods. There is a facilitator, a peer support and normally up to eight clients.

The facilitator is a trained facilitator employed by Vision Australia. These facilitators have multiple roles within Vision Australia. My facilitator was also an orientation and mobility trainer.

The peer support person is a volunteer who is blind and has gone through the emotional and societal issues that the clients were either starting to understand or just learning about.

The clients were male and female and from different situations ages and eye conditions.

I attended the QLG meetings where I began to realise that I was not the only person to go blind in midlife. The ‘but’ part of this was, it was the first time I had gone blind and it was all new to me. I hardly spoke at the meetings for the first three or four weeks.



The QLG meetings were held at the Vision Australia Enfield office. The QLG is run in one-hour sessions, two sessions per day. Each session is facilitated to guide the group through the various topics. There were topics like available services both with Vision Australia and government assistance and services, mobility services, understanding your personal eye conditions and what others had as well. One session was to be conducted by a psychologist and deal with the emotional issues related to loss of sight.

### **My blind psychologist**

While the Vision Australia support was giving me valuable new awareness, support and basic skills, I was still emotionally distraught by my new blindness. My GP was still suggesting that I visit a psychologist. Again I was in denial but eventually I made enquiries at Vision Australia for a psychologist who understood blindness related emotional issues.

An appointment was made to speak with a psychologist for my wife and myself. My wife was in as much of an emotional state then as I was.

On the appointment day I insisted on catching a bus to the Sydney suburb of Leichhardt. Leichhardt is approximately seven kilometres from my home and about a twenty-minute bus trip.

I knew that a bus route near my house went near to the rooms so I planned walking to the rooms unassisted. My wife wanted to drive me but I was determined to be independent and find my own way.

I caught the bus and got off where I thought was the best stop. I started walking in the general direction I thought I had to go. Whilst walking down an unknown street, unknown as I cannot read road signs. My wife rang me on my mobile and asked where I was. I told her I had no clues and should find her soon. I asked her to keep an eye out for me, ring me when she saw me and guide me to the rooms. I eventually found the rooms.

The psychologist's rooms were in a two-storey federation terrace building. A typical two-storey terrace, two sandstone steps lead to the short front patio. The typical design for the Leichhardt area.

The psychologist was a woman, not that that mattered. Her consulting room was on the second floor. I traversed a steep set of stairs. The psychologist spoke to my wife and me for approximately 45 minutes. She was astounded when told that I had caught a bus unescorted and had walked to the rooms on my own. My mobility skills at that time were very basic yet effective. I had not had much mobility training.

The psychologist suggested that I might need some further counselling into the future but not just yet. On the other hand she requested that my wife continue counselling due to her emotional situation at that time.

My emotional state was extreme when the ophthalmologist diagnosed irreversible and permanent blindness. Those words "functionally and legally blind" echoing in my head. My emotional state at that time was intensified when I was labelled "disabled". There was a slow but continual improvement of my emotional state from the time that we went to Orlando through the ensuing months and into the Vision Australia program.

On the second last week of the QLG sessions the theme was with a psychologist. The psychologist that I saw was the psychologist at the QLG meeting and asked if I minded telling the group that I had been to see her. I was fine with that; my emotional state was

getting better. From time to time my emotional state still erupts, my emotional journey continues to this day.

### **Taking up training**

A major step in my personal acceptance of my blindness and my readiness to initiate new directions was my decision to pursue training through university and TAFE study. In the next sections I describe the challenges, barriers and benefits of this stage in my journey.

### **University study**

Undertaking university studies for this research degree has allowed me to be more aware of the educational situations that exist for blind people. Along with the university studies I also enrolled at TAFE to learn to use digital screen-printing using dye sublimation systems with the intent of creating a small home-based business in this area.

During 2011 the concept of researching employment opportunities for those who lose vision in midlife took shape. I made approaches to a university lecturer about the university's policies towards people who have disabilities and especially blindness. Over a period of a few months and with the unpaid support of the lecturer I submitted my application and it was subsequently accepted. I am truly thankful to the lecturer for his support and guidance.

I was assigned two supervisors, one an outstanding academic and the other a newly conferred academic. The supervisors guided me through the initial stages of the research reformulating the question and direction of the research. As part of the research I was directed to attend various Doctoral/Masters classes and two Masters coursework classes.

The coursework classes had electronic readings that made it much simpler for me to access and read prior to classes. Student acceptance was varied as many had not met a blind person and did not know what to say or do. It was pretty impersonal for more than half of the year with students feeling more at ease toward the end of the spring semester. I recorded the sessions and listened to them after classes

During the various doctoral classes I realised that the lecturers did not understand that I was blind and the requirements of blindness. Everything was visual—handouts, PowerPoint etc. This form of instruction was difficult as many of the concepts that were being explained were missed. I requested that I record their sessions and all agreed that I could record their sessions. After eighteen months of attending classes and attempting to piece together the recordings with the written handouts at home I attended a series of lectures regarding publishing papers.

At home I read printed handouts in one of two ways. First I have a CCTV Projector that magnifies the page onto a LCD screen. I use a magnification of between 350-500 times depending on the print quality and format of the page. This then requires the movement from side to side under the camera to see small portions of text. The other is to scan the text into a word processor and magnify the screen or use the screen reader to read the text.

The publishing sessions required students to submit their proposed papers online so that others could read them and allow fellow students to critique them and report back at the next session. Only one person uploaded their paper prior to the session, the person was me. I made contact with the lecturer and said I could not attend as I cannot read papers in class time. The lecturer had fulfilled all of his requirements and attempted to have the students follow his instructions. No more papers were submitted. I decided that would not punish myself and did

not go to the final class in the series, as reading in class is impossible for me. The lecturer apologised later and asked what he could have done better to assist me.

This was the first time I had been directly asked if I needed extra support from a lecturer in 18 months.

The next series of lectures by that lecturer saw vast improvement as I was supplied with the entire lesson PowerPoint presentations, handouts as soft copy well prior to the classes commencing. This was such a great support for me as I knew what was on the screen as it was displayed to the other students.

### **George—a helping hand?**

The University Graduate School (UGS) at the University of Technology Sydney (UTS) has a service for students that allows for a senior academic who is independent of your faculty and relatively unknown to the post-graduate student to read their Doctoral Assessment (DA) papers prior to submission. This allows for an independent academic to read and comment on the paper and ideas.

I requested this service to be undertaken and a prominent academic offered to read and comment on my DA paper. The paper was at that stage nearing completion and standing at around 9,500 words of the required 10,000 words. This DA paper and a seminar presentation are the assessment tools to progress into stage two of the Masters/Doctoral program at UTS. I was attempting to be converted from Masters level to PhD. The paper was the tool that had to be assessed to allow for the transformation. Thus this paper was important to my goals and me. I subsequently learnt that conversion from M.Ed. to PhD had been reviewed and that this was not the usual process but I found this out long after this incident.

A prominent academic, 'George' (not real name), read the paper and had made comments on it using a PDF program called iAnnotate for the iPad or iPhone. The program allows for editing and addition of notes to the paper on screen to PDF files. The program then allows for the paper and the comments to be printed out in hardcopy for discussion, line by line. When George had completed his reading and subsequent comments he then arranged a meeting between us.

On the arranged day I arrived early to the appointment by at least 45 minutes expecting to sit and wait. George hurriedly printed off the hardcopy of the paper with all the notes and annotations on a separate page. George came in with the paper and his iPad to go through in detail every change that was suggested and to highlight the errors within the paper.

This is the process that is normal for the service that is offered. George had just finished reading about the experiences of the blind in a 9,500-word paper. George came to the meeting with a legally blind person and 80 plus pages of hardcopy print that could not be read.

The meeting had an expected duration of an hour but lasted around 25 minutes, as George could not show me the errors on hard copy. George did not know what to do except to say it was all printed off and I could read it at home. George emailed the file to me so that I could view it on my computer at home.

George had also conducted some workshops throughout the year and he asked me if I had attended any of the workshops. I said I had attended many of his workshops and learnt many things from them.

George then asked me how I managed to see the PowerPoints that he used. I explained that I couldn't see them. I listened in class, went home and located the PowerPoint online if available and then matched them together. Most academics do not talk through their slides and assume everyone can read them, which in my case I cannot, even if I sit in the front row.

This is not unusual for people who mean well to unconsciously demonstrate that they are not fully aware of people's situations. They do not know what to do, what actions are needed and the protocols to follow. George could have had the foresight to contact the 'Special Needs' or Disabled Unit for advice. George would have been advised to rethink his methods of feedback and would have been advised to look to alternatives to hardcopy for a legally blind person.

### **TAFE study**

At TAFE I undertook a digital printing course to learn how to design and produce merchandise such as Tee Shirts, cups, or any promotional products. I had to learn how to use the software and then the various pieces of equipment.

I approached the disabilities (blind) unit at TAFE. I went to the disabilities unit at Ultimo TAFE. The disabilities unit is on the fourth floor of a multistorey building. The building has four main entrances each of which take you to different areas. One entrance takes you to the library, another to student administration, the third to a computer access facility that is attached to the library and another that is the entrance to a lift area. As I had worked at Ultimo College for 25 years the location for me was easy but for someone attending for the first time it would be extremely difficult to firstly find the building and then to access the correct entrance. I knew that the disabilities unit was on the fourth floor but I had only been in that area of the college a handful of times and was not sure of the directions. I knew the room number I was looking for and thought that the area as being a disabilities unit would be well sign posted. It was not. I stumbled around the corridors for a long while before I found the co-ordinators room. The room was at the end of a corridor and had limited signage for a disability blind co-ordinator's room.

The disabilities blind co-ordinator is also blind. She told me of the assistance she could provide me with and asked if I would want to use a support person for in class support. She then asked me to fill in an enrolment form. I had no way of completing the form. From my years at TAFE and knowing that a customer service kiosk was close by I suggested to her that I have them fill in the form for me. I went to the kiosk and was the only person requesting assistance. I asked the customer service officer to assist me fill in the form as I was blind. She answered that she was too busy and she could not do it for me. I then thought that there was an issue brewing here and I looked around and saw no lines of people in fact not one other person had passed me in the fifteen minutes I had been in the area. I again asked her for assistance and again told her I could not see forms and hence could not fill it in. Having 25 years in the same location albeit a large institution you have the local knowledge and numerous contacts, it was only nine months since I had lost vision and many of the managers were still in their current positions. I asked her one more time and suggested that the college director would be interested that she would not assist me. At that stage another person came to the desk and he knew me. I had not seen him as I could not see that far. I did not recognise him. He asked the required details and completed the form for me.

The classes commenced in the screen printing area of the college with the teachers in the area very closely guiding me around the facility pointing out the dangerous equipment and the

areas I was not allowed in. I was not allowed in the areas for safety reasons as chemicals were stored and used in the area. The support person came along and we commenced classes. The teacher gave me all of the notes for the classes in soft copy so that I could read them on the computer. He supplied me with all the resources for the entire course so that I did not have to ask as we went along.

The support person supplied by the disabilities unit knew how to use the software but had no idea how to support my vision needs. After learning the very basic concepts of the software I requested that the support person be withdrawn because at that time she was not supporting my vision issues and barely my software needs.

### **The combined learning journey**

Between the two institutions there were similar issues of awareness towards the needs of the blind person. Some were hesitant to assist, some were hesitant to mix some were unaware of the needs of blind people. Two teachers went past their typical roles and became more supportive by being more aware of my issues and assisting the blind person with resources in the format that best suited me.

### **Transport—the challenge of getting around**

Although my interview participants had not considered transport to be a major barrier on their post-blindness employment, for me in the initial stages it was one of the most significant hurdles to overcome. From the time I commenced work until the time I became blind, a period of 41 years, I had not used public transport on a regular basis. I had heard how bad the system was, how dirty, unreliable and unsafe it was. However, once I became blind I needed to start using it.

After overcoming the emotional issues of vision loss, I began to want to be independent and to travel to various destinations on my own. Initially unsure how I would cope, I contacted Vision Australia's Orientation and Mobility (O&M) department to seek assistance. They gave me some basic instructions and offered one-on-one training. I decided to be adventurous and learn about the transport system. I had the belief that if I caught the wrong bus I would ask for help.

I did catch incorrect buses, I had buses pass me by and had to wait on some occasions 1½ hours for a bus that had a service interval of 30 minutes. I missed bus stops. Many times I got off the train or bus not knowing where I was. Trains arrived at a different platform than the one I was used to, which left me with no idea of how to navigate to my destination. I learned to use the Sydney buses website to plan complete trips using multi transport systems and, more importantly, after a time I learned how to plan for mishaps.

Overall I was pleasantly surprised that the Sydney transport system actually worked the way the Transport Minister's *Disability Plan 2012-2017* (Berejiklian & Gay 2012) said it would.

Stations have tactile markers, Braille signposts with many having lifts to platforms. The audio announcement system in trains and on platforms is informative and useful.

The buses are now working to timetables and are timed at various locations along their routes. There are smartphone applications that provide mobile timetabling with real time running, along with a live map of where the bus is along its route. These applications work with voiceover so that they are audible for blind people. The buses run on time or at the least real time updates allow people to know the current situation. There is a rollout of audio-visual

systems on the buses initially on the newer routes (Red Buses). The smartphone application integrates buses, trains and ferries so that you can plan a trip and independently travel to your destination. I was so impressed with the overall system that I wrote to the Buses depot managers to compliment the department on the services provided.

When I began studying at UTS, I learned to travel to UTS independently by government buses. To go to UTS I walk to a bus stop close to my home that has only one bus route except school buses. I can catch the bus knowing that it will be the bus I require. I do not have to guess the route number. I can hear the bus coming and see it when it turns around the roundabout about fifty metres from the bus stop.

My return trip from UTS is a different matter. UTS is on the edge of the Sydney CBD, at Broadway, and more than twenty bus routes that run directly by it. My vision is limited to seeing the bus at a distance of about 20 metres. I have no ability to see the route numbers. I have used a monocular to attempt to see the numbers but by the time I focus on the number the bus has passed or is very close to passing.

To be able to catch a bus I hold a sign in front of me with the bus number on it. I also have an iPhone app that allows me to know the time a bus will be arriving at the stop so I have a fairly good idea of when the bus should be arriving.

There are other people who assist and allow me to be independent. They take note of the sign and tell me when the bus is approaching but allow me to be independent. Many of the drivers stop because of the white cane and tell you the bus number; others ask you where you are getting off.

However, one unexpected challenge of being blind on public transport has been encounters with sometimes well-meaning people who believe that the white cane means a person cannot hear or has no intellect. On many occasions well-meaning people, believing that I do not know what I doing, want to take over. The general perception of blindness is of someone needing to be led by the hand when in reality many blind people want to be independent as much as they can.

Although using public transport was a major challenge in the initial stages of my blindness journey, it gradually became less of an issue. My experience is therefore similar to that of my interview participants: transport is not a major barrier to the employability of the person who goes blind in midlife. ■