

Becoming deafblind: Negotiating a place in a hostile world

Julie Schneider
B. App. Sc. (Occupational therapy) Hons

February 2006

A thesis submitted in fulfilment of the requirements
for the degree of Doctor of Philosophy (PhD)

Faculty of Health Sciences
University of Sydney

Abstract

This study addresses the situation of adults who become deafblind. To date, their everyday lives have received little attention in the research literature. Of the few studies conducted many involve surveys, the findings of which present the characteristics of people who are deafblind such as their rates of employment, need for support, or use of equipment. There are also a small number of qualitative studies that have explored the effects of having a dual sensory impairment, and particularly in relation to communication and psycho-social wellbeing.

Important as these research efforts have been, there is little empirical information available about the everyday lives of people who become deafblind and their concerns, nor any systematic attempt to theorise their experiences. There are however many personal anecdotes typically presented at conferences or through community publications and newsletters.

This project aimed to redress the gap in the literature by developing a theoretical framework to explain the everyday experiences of adults who become deafblind. In doing so, it built upon the research and anecdotal literature with an overall purpose of presenting, through rigorous research, the experiences of adults who become deafblind and to do so within the broader discourse on disability and disablism. The study was informed by the social relational understanding of disability developed within the Nordic countries. Grounded theory was the method of choice to examine the lives of adults who become deafblind from their own perspective.

Participant observation was employed through direct engagement in shared experiences with adults who have become deafblind both at a social group and via an e-mail list group. Multiple in-depth interviews were undertaken both face-to-face and by e-mail with a smaller group of eight participants.

The core finding from this study is that people who become deafblind are rendered interactionally powerless in a society predicated on seeing and hearing. The powerlessness that they experience comes from having this dual impairment in a world in which being able to see and hear are expected both in the physical and the social environment. The inability of people who become deafblind to ‘know and be’ in the world in the same way as others results in them feeling, and experiencing interactional powerlessness. In response, people who become deafblind actively engage in trying to minimise or remove their powerlessness. They do this by working to negotiate a place in this hostile world. They adopt four interrelated strategies, namely, doing things differently, managing support relationships, surviving others’ perceptions and presenting sides of self.

This study, with its central tenet that interactional powerlessness drives ongoing attempts to negotiate a place makes a theoretical contribution to understanding the experience of becoming deafblind. The findings support the concept of disability as social relational. Disability is not the same as the sensory impairment, rather it is expressed in the organisation of personal relations in society which render some more powerful than others and in this case, some less powerful due to their inability to use the natural means of communication of hearing and sight. Moreover, the study findings propose that professionals working with people with this dual sensory impairment must endeavour to reduce their part in the hostile world by providing information about options and support available; recognising the complexity of these adults support requirements; and considering the link between psycho-emotional issues and disablism. Further research is needed to understand empirically and theoretically the relative contribution of personal relationships vis a vis organisational or structural relationships in disabling people who become deafblind.

Acknowledgements

I acknowledge the financial support provided by the Australian Postgraduate Award Industry (APAI) scholarship, particularly the financial contribution by the Centre for Developmental Disability Studies and the Royal Rehabilitation Centre Sydney as Industry Partners.

I thank all my friends from the DeafBlind Association NSW, particularly Janne and Tony, who have only ever been welcoming and supportive of my interest and participation.

Thank you also to Di, moderator of the deafblind e-mail list, who supported my involvement on the list and the circulation of information regarding this study.

I thank all the participants in the research – especially the interview participants who kept allowing me back into their lives, trusting me with their intimate thoughts and feelings. I engage with the world differently because of you. I am forever grateful to each of you for expanding my mind and challenging my taken-for-granted ways of being, knowing, and doing.

Thank you to all those individuals who responded to pleas for assistance and who supported my search for information on deafblindness: Mike Steer and Leonie Cheetham at Renwick College; helpful staff at DB link; staff at Sense UK; representatives from the World Federation of the DeafBlind (WFDB); and in particular, John Finch at Australian DeafBlind Council (ADBC).

I am extremely grateful to both my supervisors, Gwynnyth Llewellyn and Trevor Parmenter, who, despite our initial ignorance on the topic, encouraged my interest in deafblindness. You have enabled me to make this PhD passionately my own.

Gwynnyth, you have been a wonderful mentor for this laborious journey. You have been constant, patient, responsive and critical and for that I thank you. If I had to entitle our journey together I would probably call it “Lessons in the grey(ness of) matter”. Not only have you helped me appreciate the ambiguity of a world of multiple realities, you have supported me to stretch (and better understand) my own mind.

Trevor, as my associate supervisor you have allowed me access to your many years wisdom on the art of research work. Your support, feedback and expertise throughout this process, and particularly toward the end, have been greatly valued.

To my very dear friends, Heidi and Ruth, an enormous and heartfelt thank you for punishing your fresh brains by scrutinising the final draft.

To my partner in life, Andrew, very special thanks, hugs and kisses. Without your tolerance, neck massages and unfailing positive encouragement, I would never have maintained the courage to keep going. Together we share in this achievement.

To my PhD buddies, Marg, Gabe, and especially Rach, without you all I would have collapsed long ago! Thank you for all the therapeutic conversations, emergency coffees, and for sharing the ups and downs of the research journey with me. Rach and Marg, I can think of no better companions to cross the finish line beside.

Table of Contents

Section 1

SETTING THE CONTEXT

CHAPTER 1

INTRODUCTION

- 1.1. EMBARKING ON A RESEARCH JOURNEY: REASONS AND INTENTIONS..... 2
- 1.2. ORIENTATION TO THE STRUCTURE OF THE THESIS 8

CHAPTER 2

UNDERSTANDING DISABILITY

- 2.1. DISABILITY AS SOCIAL RELATIONAL..... 12
- 2.2. THE UK SOCIAL MODEL: A “STRONG” SOCIAL APPROACH..... 15
- 2.3. GROWING CRITIQUE OF THE STRONG SOCIAL MODEL 17
 - 2.3.1. *False dichotomy between impairment and disability*..... 17
 - 2.3.2. *Privileged emphasis on the structural* 20
 - 2.3.3. *The personal is political*..... 22
 - 2.3.4. *Marginalisation of different groups*..... 23
- 2.4. SYNOPSIS 25

CHAPTER 3

WHAT IS KNOWN ABOUT THE LIVES OF ADULTS WHO ARE DEAFBLIND?

- 3.1. THE AUSTRALIAN CONTEXT 28
- 3.2. INDIVIDUAL VOICES OF ADULTS WHO ARE DEAFBLIND 32
 - 3.2.1. *Just like everyone else*..... 33
 - 3.2.2. *Using strategies to live differently* 34
 - 3.2.3. *Dealing with uncertainty and change* 35
 - 3.2.4. *Fighting for ourselves* 36
 - 3.2.5. *Requiring support* 36
 - 3.2.6. *Sharing the world is not easy*..... 38
- 3.3. THE PROFESSIONAL LITERATURE AND EMPIRICAL RESEARCH 40
 - 3.3.1. *Diversity of conditions and identities*..... 43
 - 3.3.2. *Living with isolation*..... 44
 - 3.3.3. *Psycho-emotional vulnerability* 46
 - 3.3.4. *Communicating differently*..... 48
 - 3.3.5. *Benefits of equipment and technology*..... 49
 - 3.3.6. *Restricted participation in the community*..... 51
 - 3.3.7. *Living with dependency*..... 52

Section 2

(MY) WAYS OF THINKING AND DOING RESEARCH

CHAPTER 4

REALITIES, AGENTS AND INTERACTION

4.1. EPISTEMOLOGICAL ISSUES.....	56
4.2. SYMBOLIC INTERACTIONISM	58
4.3. GROUNDED THEORY METHODOLOGY	60
4.4. PRACTICAL STRATEGIES OF FIELDWORK.....	63
4.5. ETHICAL CONSIDERATIONS IN FIELDWORK	66
4.6. SYNOPSIS	68

CHAPTER 5

OBSERVING AND ENGAGING

5.1. PROCEDURAL PRINCIPLES UNDERLYING GROUNDED THEORY	70
5.1.1. <i>Theoretical sensitivity</i>	70
5.1.2. <i>Theoretical sampling</i>	73
5.1.3. <i>Coding, comparison, memos and categories</i>	75
5.1.4. <i>Theoretical saturation</i>	77
5.2. PARTICIPANT OBSERVATION RESEARCH COMPONENTS	78
5.2.1. <i>Component 1A: Deafblind social group</i>	78
5.2.2. <i>Component 1B: Deafblind e-mail list</i>	81
5.2.3. <i>Component 1C: Observations during interviews</i>	83
5.3. IN-DEPTH INTERVIEW RESEARCH COMPONENTS.....	84
5.3.1. <i>Component 2A: Face-to-face in-depth interviews with six adults.</i>	84
5.3.2. <i>Component 2B: E-mail conversations with two adults.</i>	87
5.4. SYNOPSIS	88

CHAPTER 6

JOURNEYING TOGETHER: PARTICIPANTS AND RESEARCHER

6.1. PARTICIPANT PROFILES	90
6.2. THE RESEARCHER'S PROFILE AND POSITION	97
6.3. REFLECTIONS ON A RESEARCHER'S JOURNEY	98
6.4. SYNOPSIS	101

CHAPTER 7

DATA MANAGEMENT AND ANALYSIS

7.1. INERTIA, INCUBATION AND DOING THE ITTY BITTY	102
7.2. MANAGEMENT OF PARTICIPANT OBSERVATION DATA	105
7.3. MANAGEMENT OF INTERVIEW DATA.....	107
7.4. ISSUES OF QUALITY	114
7.5. SYNOPSIS AND ORIENTATION TO SECTION THREE	116

Section 3

UNDERSTANDING DEAFBLINDNESS:

FINDINGS AND REFLECTIONS

CHAPTER 8

DOING THINGS DIFFERENTLY

8.1. INTRODUCTION.....	118
8.2. EXPERIENCING A CHANGING SELF	120
8.3. SEEKING PROFESSIONAL HELP	121
8.4. DEVELOPING COMMUNICATION STRATEGIES	122
8.5. APPRECIATING NEW PERCEPTIONS.....	124
8.6. FACTORS IMPACTING ON DOING THINGS DIFFERENTLY	125
8.7. DISCUSSION.....	131

CHAPTER 9

MANAGING SUPPORT RELATIONSHIPS

9.1. INTRODUCTION.....	134
9.2. DOING THINGS TOGETHER	136
9.3. HAVING EXPECTATIONS OF OTHERS.....	138
9.4. PROTECTING THE RELATIONSHIP	140
9.5. ESTABLISHING WEBS OF SUPPORT.....	141
9.6. FACTORS IMPACTING ON MANAGING SUPPORT RELATIONSHIPS	144
9.7. DISCUSSION.....	148

CHAPTER 10

SURVIVING OTHERS' PERCEPTIONS

10.1. INTRODUCTION.....	151
10.2. EXPERIENCING THE PRESENCE OF OTHERS	153
10.3. MAINTAINING A THRESHOLD OF TOLERANCE	154
10.4. EXPERIENCING SELF AS DIFFERENT/MARGINAL	157
10.5. FACTORS IMPACTING ON SURVIVING THE PERCEPTIONS OF OTHERS.....	158
10.6. DISCUSSION.....	162

CHAPTER 11

PRESENTING SIDES OF SELF

11.1. INTRODUCTION.....	164
11.2. BALANCING REVEALING AND CONCEALING.....	166
11.2.1. <i>Putting on a front</i>	166
11.2.2. <i>Disengaging</i>	166
11.2.3. <i>Conforming</i>	168

11.2.4. <i>Guarding</i>	169
11.2.5. <i>Confronting</i>	170
11.3. FACTORS IMPACTING ON PRESENTING SIDES OF SELF.....	171
11.4. DISCUSSION.....	177

CHAPTER 12

NEGOTIATING A PLACE IN A HOSTILE WORLD

12.1. NEGOTIATING IN THE CONTEXT OF INTERACTIONAL POWERLESSNESS.....	180
12.2. NEGOTIATING A PLACE IN A HOSTILE WORLD: AN ILLUSTRATIVE CASE	183
12.3. CONTRIBUTION.....	185

CHAPTER 13

CONCLUSION

13.1. PERSONAL REFLECTIONS	190
13.2. STRENGTHS AND SCOPE OF THE RESEARCH.....	191
13.3 CHALLENGES FOR THE FUTURE.....	193
13.3.1. <i>Some practical implications</i>	193
13.3.2. <i>Research directions</i>	195

REFERENCES

REFERENCES	198
------------	-----

APPENDICES

APPENDIX 1: NOTIFICATION OF ETHICAL APPROVAL	223
APPENDIX 2: ETHICAL APPROVAL RENEWAL NOTIFICATION FOR 2004	225
APPENDIX 3: ETHICAL APPROVAL RENEWAL NOTIFICATION FOR 2005	226
APPENDIX 4: PARTICIPANT INFORMATION SHEET	227
APPENDIX 5: PARTICIPANT CONSENT FORM	229

LIST OF FIGURES

FIGURE 4.1	DIFFERENT ASPECTS OF THE RESEARCH PROCESS	63
FIGURE 4.2	FOUR RESEARCH ELEMENTS AS CONCEPTUALISED BY CROTTY (1998).....	64
FIGURE 8.1	CONCEPTUAL CATEGORY: “DOING THINGS DIFFERENTLY”	119
FIGURE 8.2	PERSONAL AND ENVIRONMENTAL FACTORS THAT IMPACT ON DOING THINGS DIFFERENTLY	129
FIGURE 9.1	CONCEPTUAL CATEGORY: “MANAGING SUPPORT RELATIONSHIPS”	135
FIGURE 9.2	PERSONAL AND ENVIRONMENTAL FACTORS THAT IMPACT ON MANAGING SUPPORT RELATIONSHIPS.....	147
FIGURE 10.1	CONCEPTUAL CATEGORY: “SURVIVING OTHERS’ PERCEPTIONS”	152
FIGURE 10.2	PERSONAL FACTORS THAT IMPACT ON SURVIVING THE PERCEPTIONS OF OTHERS	161
FIGURE 11.1	CONCEPTUAL CATEGORY: “PRESENTING SIDES OF SELF”	165
FIGURE 11.2	PERSONAL AND ENVIRONMENTAL FACTORS THAT IMPACT ON PRESENTING SIDES OF SELF.....	176
FIGURE 12.1	NEGOTIATING: INTERRELATIONSHIPS BETWEEN CATEGORIES AND SUBCATEGORIES.	182

LIST OF TABLES

TABLE 7A	GROUNDING INTERVIEW GUIDE (EXAMPLES FROM GARRY).....	109
TABLE 7B	EXAMPLE OF CODE CLUSTERING PROCESS	110
TABLE 7C	EXAMPLE OF CONCEPT CLUSTER TABLES DEVELOPED ACROSS CASES	111
TABLE 7D	EXAMPLE OF CODE LIST TALLY SHEET	113
TABLE 7E	ORDERING OF LIKE CODES	114

LIST OF BOXES

BOX 5.1.	EXAMPLE OF MEMO AND CROSS DATA SOURCE SAMPLING	75
BOX 5.2	EXCERPT FROM REFLECTIVE JOURNAL	85
BOX 7.1	EXCERPT FROM FIELDNOTES (GROUP OUTINGS)	105