Section 1

SETTING THE CONTEXT
Chapter 1

INTRODUCTION

1.1. Embarking on a research journey: reasons and intentions

This thesis represents the story of an academic and personal journey of deepening understanding. In this research I have used a grounded theory methodology and a symbolic interactionist theoretical framework to explore the everyday lives of adults with acquired deafblindness.¹

Throughout this thesis, the term deafblind is used to refer to a range of combined hearing and vision impairments rather than total loss of hearing and vision (DeafBlind Association Victoria, 2005c). Functional definitions of deafblindness are most frequently used in the literature and these emphasise the everyday consequences of combined hearing and vision loss. The recently accepted definition used by the Australian DeafBlind Council, for example, states:

Deafblindness is described as a unique and isolating sensory disability resulting from the combination of both a hearing and vision loss or impairment which significantly affects communication, socialisation, mobility and daily living (Segrave, 2004, p. 20).

With a single sensory impairment of hearing or vision, the remaining sense is often used to compensate. With combined hearing and vision impairment this compensation is not possible to the same extent or at all. In regard to deafblindness, the expression “one plus one equals three” is sometimes used to acknowledge that the

¹ Throughout this thesis deafblindness is written as one word to indicate that it is a unique combination of two impairments. Neither the hearing nor the vision impairment can be considered separately or as more important than the other. Sometimes when the term deafblind is written as a title, such as in relation to political organisations or community events, both the D and B are capitalised, though there is no consistent international usage according to the Australian DeafBlind Council (Personal communication, J. Finch, 09/08/05).
effects of combined impairment are more than additive (e.g., Jansbol, 1999b; Moller, 2003).

This research evolved from a personal concern regarding the seeming social invisibility of adults who are deafblind. Adults with deafblindness appeared to be relatively poorly understood by me and by other professionals, in comparison to those with single sensory impairment, or deafblind children for example. My concern about the social invisibility of adults who are deafblind was a simmering one, emerging over time and with reflection. While it was present at the initiation of the research, it was a concern I found difficult to understand until much later in the research process. I knew it to be a concern beyond my professional socialisation as an occupational therapist, hence I felt uncertain how to frame or articulate it.

My concern and understanding deepened through listening to participants’ experiences and through becoming committed to a social relational view of disability. During the first 6–12 months of data collection, the issues participants raised challenged me to recognise that both the research and my interest were evolving. I had begun from an interest in how adults who are deafblind conducted themselves in daily life, how they got on with other people, and how being deafblind impacted on their sense of who they were. My initial desire to seek some understanding of the experience of deafblindness transformed into a need to understand how participants continued to compose their lives in the context of becoming deafblind. Participants’ accounts were more about disabling experiences and living in the world when one is “different”, rather than about deafblindness per se. This realisation directed me to the disability studies and research literature, initiating a passion to understand disability as social relational, context-specific and socially constructed in nature.

The United Kingdom (UK) strong social model of disability provided a language and perspective through which to better articulate the pervading sense of concern. According to the UK social model, people with impairments are oppressed and disabled by the socio-cultural and structural organisation of society (Oliver, 1990; 2

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2 Occupational therapy is a profession which focuses to a large extent on functional performance of occupational roles and tasks, that is, the functional management of impairment.
1996a; Thomas, 1999a). This perception differs from a traditional individualised medical conceptualisation of disability, where disability is considered inherent to the experience of impairment (Oliver, 1990). The social model at first appeared to be a refreshing and powerful tool in thinking about disability, as it related to participants.

Then again, I found the predominance of a historical materialist interpretation of the social model in the literature alienating. This was particularly so as I was interested in a starting point embedded in people’s experiences, rather than an analysis of structural material forces. I was also unconvinced by the extreme perspective that proponents of the social model appeared to take and, like many feminist and postmodernist critics, I found the dualistic thinking often evident in presentations of the social model discomforting, such as the construction of impairment as separate from disability, and the personal as separate from the public/political. Thus I became aligned with a broader social relational understanding of disability popular in the Nordic countries, rather than a strong social model perspective.

A social relational understanding of disability emphasises that disability emerges between the person and the environmental context (Gustavsson, 2004; Tossebro, 2004). Rather than disability being created by impairment per se (as in a medical model) or by society (as in a strong social model), in a social relational understanding disability is a relationship relative to the environment. For the purposes of my work, this perspective complemented the use of a symbolic interactionist theoretical framework, where reality and meaning are understood to be socially constructed from symbols and interaction, and where individuals are active participants in creating meaning in a situation (Blumer, 1969). In adopting a social relational approach to understanding disability I am not advocating the view of strong social modellists who claim that disability is only socially created and is not related to impairment or personal experience. Rather, I am suggesting that individuals, their impairment, and their physical and social environment all interact to construct and give meaning to the experience of disability.
However, I did, and do, feel there is a strong possibility that people who are deafblind are vulnerable to disablism as it is understood in the social model perspective, that is, oppression and exclusion. Through my clinical experiences I had known that adults with deafblindness did not have a presence in clinical service systems relevant to the impairments they experienced. In medical or rehabilitation research their perspectives had been largely ignored in preference to the voices of significant others or professional experts (e.g., Harland & Cuskelly, 2000; Petroff, 2001). At the outset of the research, adults who are deafblind did not appear to have a voice in the disability studies literature, though some individuals with single sensory impairment had established one (e.g., French, 1993a, 1993b, 1993c, 1999; Corker, 1998, 1999, 2001; Corker & French, 1999).

Nevertheless, a growth in anecdotal literature and life story accounts across conference forums, journal publications, and an expanding e-mail chat group community can be seen among people who are deafblind. This suggests not only that they desire a voice but that they are making their voices heard. There is talk of wanting to improve awareness of deafblindness. When people who are deafblind talk of improving awareness, what is it they actually seek: a shared dialogue, engagement with others, a space to be, perhaps?

As an occupational therapist with recent clinical experience in the field of vision impairment and blindness, I had had surprisingly little exposure to people who are deafblind. It was through professional social networks external to the blindness organisation where I worked that I first became aware of adults experiencing deafblindness. There was at that time in New South Wales a total lack of services specifically for adults who are deafblind. Therefore my interest in the area could not be developed clinically, and remained largely unexplored until the commencement of postgraduate research studies.

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3 Midway through the project a specific DeafBlind Service was established within the Royal Blind Society of New South Wales. Initially the funding and scope of services were limited to adults with communication skills living within a particular geographic area of Sydney. In early 2005 the scope of services expanded geographically to cover the entire state, although no new funding for staff was received.
At the outset of my PhD research, and to the frustration of supervisors, I had little idea of what I wished to study. I had no hypotheses. I had only an interest in deafblindness as a unique multiple-impairment experience, a sense of pervading concern about the social invisibility of people experiencing deafblindness, and a strong desire to be open to possibilities and not to preconceive or direct the voices of participants. Thus I identified strongly with a qualitative research paradigm, specifically a grounded theory methodological research design. As one of the founders of grounded theory suggested (Glaser, 1978; 1992), this research approach allows understanding of both “problems” and “social processes” in the lives of participants to emerge through engaging in the research process itself.

For me, grounded theory provided a means of directly accessing the concerns and experiences of people who are deafblind, without dictating or imposing an agenda. I did not commence fieldwork assuming to know about deafblindness or the problems which may exist for people who are deafblind, though the literature suggested a few. In fact, I was extremely conscious of my relative outsider position. I had never known personally or worked professionally with anyone who was deafblind or whom I had recognised as deafblind.4 I was unfamiliar with the alternative communication systems or etiquette of their world and knew that I found the concept of deafblindness confronting on a personal level. I felt strongly there was no way I could presume to know anything about deafblindness despite having worked as a professional in a related, similar but different, field of disability.

Rather, I launched into fieldwork for the study reported in this thesis as the curious novice, wanting to gain insights from the participants, the experts. I sought a familiarity with the world as people who are deafblind experienced it, in order to theoretically conceptualise “what is happening” in their lives. My sense of concern led me to believe that the lives of people who are deafblind were probably greatly misunderstood. Both early contacts with participants and introductory readings of the disability studies literature challenged me to consider their lives beyond the

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4 On reflection, I believe that as a service provider in a blindness organisation I was socialised to “see” (and deal with as a priority) issues relevant to blindness. As a result of this I failed to recognise the significance of multiple impairments or health conditions, assuming blindness to be the primary identity or issue of concern for my clients.
immediate effects of the impairment. I felt strongly that unless I made the commitment to engage people who are deafblind directly in research and shared dialogue I could never hope to understand their lives.

While I was uncertain how adults who are deafblind should or could be accessed for participation in a research project, I was fortunate to attend the biannual Australian National DeafBlind Conference during the early stages of my candidature (July 2002). This was an excursion I only later understood as one of my "pre-fieldwork experiences", that is, fieldwork prior to the recognition that data collection had begun. In attending this conference my primary goal was to make deafblind adults aware of my interest to engage them in research. On a personal level, I wished to use the opportunity to test my anxiety level interacting with people who are deafblind.

At the conference I was introduced to the perception of "different-ness" among people who experience deafblindness. Most notable were comments made by some about themselves and others who were deafblind. Individual experiences were defined with distinction: individuals appeared to consider their situation and experience of deafblindness to be distinct or unique, particularly in terms of the nature of deafblindness and the type of communication utilised.

Early interviews which followed drew attention to a related but separate issue: the experience of "becoming deafblind". Those most prepared to discuss their experiences spoke about the difficulties of becoming deafblind, their inability to fit in anywhere, and the sense of marginalisation with which they lived. Largely because of these initial impressions I made a decision to focus on and further sample individuals who had not always been deafblind.

Initially, then, the aim of this research was to gain a theoretical understanding of "what is happening" in the lives of adults experiencing deafblindness. Influenced by the symbolic interactionist methodological framework I wished to explore deafblindness as it was experienced in the everyday lives and social interactions of participants; then examine how such an understanding contributed to contemporary disability theory. Through the qualitative research process, the purpose of the
research became to understand and theoretically conceptualise how adults who become deafblind engage in the social process that we all share of finding our place in the world.

As readers of the research I welcome you as fellow advocates for the voices of people who are deafblind. This research represents a beginning: the start of the involvement of persons with deafblindness in a broader academic discourse on disability. You are now engaged in this development, providing their experiences and perspectives with an avenue and context through which to be heard.

1.2. Orientation to the structure of the thesis

This thesis is divided into three sections. The first section, “Setting the context”, includes three chapters, the first of which is this introductory chapter. This chapter is followed by two literature review chapters on disability theory and deafblindness respectively.

Chapter 2, “Understanding disability”, orients the reader to the social relational approach to disability. This approach is distinguished from the “strong” social model perspective which has dominated disability studies in the UK. Debates in understanding disability influenced by the work of post-modernist and feminist writers are presented. These developments appear to support a more “relational” approach to the study of disability. The chapter concludes by demonstrating how a symbolic interactionist methodological strategy, informed by a social relational understanding of disability, facilitates a holistic approach to studying the everyday experiences of adults who become deafblind.

Chapter 3, “What is known about the lives of adults who are deafblind?”, is divided into three subsections and begins by orienting the reader to deafblindness in the Australian context. The variable nature of policies and services throughout the
different states and territories is highlighted, as is the importance of the largely volunteer-run advocacy organisations for people who are deafblind.

The chapter then introduces the reader to two separate sources of knowledge about the lives of adults who are deafblind. Firstly, themes analysed from a growing number of personal accounts are presented. Although limited, these personal accounts demonstrate the richness and complexity of the everyday lives of people who are deafblind, and depict the spaces they have created for themselves to share. Secondly, the professional literature is reviewed and thematically described. Research in the area of adults who are deafblind has been limited to small qualitative studies focused on the functional effects of the impairment, or larger quantitative surveys which describe characteristics of people who are deafblind.

The second section of the thesis, “(My) Ways of thinking and doing research”, includes four separate chapters. Chapter 4, “Realities, agents and interaction”, outlines the social constructionist epistemological assumptions brought to the research. Symbolic interactionism as the theoretical framework underlying the methodological strategy is described. Grounded theory as a methodology is explained, participant observation and interviews as methods are introduced, and ethical issues of fieldwork are presented.

Chapter 5, “Observing and engaging”, details the principles of grounded theory as they have been operationalised in this study and describes the data collection processes undertaken. Three participant observation components of the research are (a) participant as observer in a deafblind social group; (b) observer as participant in a deafblind e-mail list group; and (c) observer as participant during interviews. Two interview components of the research are (a) e-mail conversations with two deafblind adults and (b) face to face in-depth interviews with six adults.

Chapter 6, “Journeying together: Participants and researcher”, provides profiles of the eight participants involved in the research interviews, whose stories and willingness to share their experiences provided the foundation for this thesis. This chapter also
introduces the researcher as the “research instrument” and contains some reflections on my journey as researcher.

Chapter 7, “Data management and analysis”, is the final chapter in this section of the thesis. Here the process of managing and working on data is described in an attempt to make the research process explicit. Issues of quality in qualitative research are considered, with description of how I attempted to address matters of trustworthiness.

The third section of the thesis is entitled “Understanding deafblindness: Findings and reflections”. This section includes six chapters, five results chapters and a final conclusion chapter. The first four results chapters each represent one of four concept categories identified through the research and follow a similar format.

Chapter 8, “Doing things differently”, describes how the individual who becomes deafblind has to find new ways of doing tasks and interacting with others. The individual experiences a changing self, seeks professional help, develops communication strategies and appreciates new perceptions. Each of these subcategories is explained and demonstrated through the use of participant narratives. Factors which impact on how “doing things differently” plays out in individuals’ lives are presented prior to the concept being discussed in relation to the literature.

Chapter 9, “Managing support relationships”, explains how when individuals become deafblind they often require the support of other people, either as an interface in communicating socially or as a means of accessing information about their environment. Individuals often do things together with other people, and come to have expectations of how others should interact with them. They seek to protect support relationships and to establish webs of support across multiple contexts. Each of these subcategories is explained and demonstrated through the use of participant narratives. Factors which impact on how “managing support relationships” plays out in individuals’ lives are presented, and the concept is subsequently discussed in relation to the literature.
Chapter 10, “Surviving others’ perceptions”, explains how individuals who become deafblind often notice the presence of others as different to themselves and feel emotionally vulnerable to others’ views and judgments. Individuals who become deafblind experience the presence of others through direct interactions or indirectly when interacting with the environment generally. They seek to use psycho-emotional strategies of resistance or surrender to “survive others’ perceptions”. These strategies include fuelling, dismissing, empathising and opting out. Each of these subcategories is explained and demonstrated through the use of participant narratives. Factors which impact on how “surviving others’ perceptions” plays out in individuals’ lives are presented, and the concept is subsequently discussed in relation to the literature.

Chapter 11, “Presenting sides of self”, explains how individuals who become deafblind strategically present different sides of themselves in different social situations. This is an attempt by deafblind individuals to impact on how others may support them in “managing support relationships”, or to decrease their sense of alienation in “surviving others’ perceptions”. Strategies for presenting sides of self oscillate within an intention continuum between revealing and concealing, and include confronting, guarding, conforming, disengaging, and putting on a front. Each of these subcategories is explained and demonstrated through the use of participant narratives. Factors which impact on how “presenting sides of self” plays out in individuals’ lives are presented, and the concept is subsequently discussed in relation to the literature.

The aim of Chapter 12, the fifth results chapter, is to explain how the concepts outlined in the preceding four chapters interrelate as strategies of a larger social process which I have named “negotiating a place in a hostile world”. I argue that people who become deafblind actively negotiate a place by working interactively to achieve recognised belonging from a position of interactional powerlessness. The contribution of this research in relation to existing literature is discussed.

The final chapter of the thesis, “Conclusion” offers my reflection on the research experience, discusses the strength and scope of the study, and considers some future implications of this study.
Chapter 2
UNDERSTANDING DISABILITY

This chapter of the literature review introduces different ways of understanding disability. A social relational perspective popular in the Nordic countries has been used as a theoretical lens throughout this research and therefore is explained first. Second, the social model perspective dominant in the UK over the last 30 years is outlined and positioned as a “strong” social approach to disability. Third, an analysis of recent trends and critiques of the social model perspective within disability studies is presented. The aim of this chapter is to demonstrate that my adoption of a social relational approach in this research was a debated and informed decision based on consideration of multiple perspectives and recent trends within the field.

2.1. Disability as social relational

Disability has traditionally been understood through a bio-medical framework (Tossebro & Kittelsaa, 2004) or in terms of an individual model (Oliver, 1996a). It has been seen as impairment in the physical, sensory or intellectual body, and considered intrinsic to the individual, a biological abnormality to be viewed as unfortunate or tragic. From this perspective, disability has been thought best managed by medical intervention, individual treatment or attempts at cure. Despite criticism of the individual model as reductive, de-humanising and de-politicising (e.g., Oliver, 1990, 1996a; Williams, 1996), it continues to be a pervasive discourse today, particularly in rehabilitative sciences where some argue that the concept of “normality” remains the basis for intervention (e.g., Barnes, 2003; Oliver, 1990, 1996a; Thomas, 2002).

For over 30 years the individual bio-medical model of disability has been challenged for not taking account of the environment (Tossebro & Kittelsaa, 2004). There has emerged a family of ideas in disability studies and politics that represents an
“environmental turn” in debates about disability (Tossebro, 2004, p. 3). In the Nordic countries (Denmark, Finland, Norway, Iceland, Sweden), for instance, disability is conceptualised theoretically as a relationship between the individual and the environment, and this is reflected in Scandinavian political understanding as well. As one example, in Norway disability is defined as a mis-match or gap between the person’s capabilities and the functional demands of the environment (Tossebro & Kittelsaa, 2004; Tossebro, 2004). An international example can be seen in the World Health Organization’s recent review of the International Classification of Impairment, Disability and Handicap (ICIDH). The newly developed classification (ICF), although criticised by some for maintaining disability as a health rather than political concern (e.g., Barnes, 2003), has been endorsed by Disabled Peoples’ International (Mulcahy, 2005). It defines disability as the outcome of interaction between a person with an impairment, the environment, and attitudinal barriers, and reduces the causal links between impairment and disablement (Thomas, 2002).

Broadly speaking, the family of ideas represented by the environmental turn in the Nordic countries is based around a “social relational” approach, which is distinct from the individual bio-medical approach. The Nordic approach focuses on appreciating the complexity of disability as emerging from the interaction between individual and society. The social relational understanding of disability refers basically to a process of disablement rather than to a population of individuals (Tossebro & Kittelsaa, 2004).

Traustadottir and Kristiansen (2004) have explained that the way disability is understood in Nordic countries is closely related to fundamental ideas about citizenship and equality which have been longstanding principles of the Nordic welfare states. Tossebro (2004) and colleagues (e.g., Gustavsson, Tossebro & Traustadottir, 2005) have summarised the main characteristics of the social relational approach as follows:–

1. Disability is seen as person–environment mismatch or poor fit. Disability occurs because the individual does not have capacities within the typical range and because the environment is not adapted to the whole range of human existence.
2. Disability is situational or contextual. Whether a specific impairment is disabling or not depends on the situation in which the individual is interacting.

3. Disability is relative. Social construction of disability takes place both in the relationship between the individual and the environment and in relations between individuals.

The social relational perspective popularly applied in Nordic countries has been relatively inaccessible to the international disability studies community until recently, with few Nordic research works available in English or other languages (Gustavsson, Tossebro & Traustadottir, 2005). The Nordic Network on Disability Research (NNDR) which commenced in 1997 has facilitated the growth and integration of an interdisciplinary network of disability researchers within the region (Traustadottir & Kristiansen, 2004). Three subsequent developments have encouraged international collaborations and helped to disseminate the Nordic relational perspective more internationally. These are (a) the NNDR’s biannual conferences where English is the official language; (b) publication of an English language Scandinavian Journal of Disability Research since 1999 (Gustavsson, Tossebro & Traustadottir, 2005); and (c) the launch of an English language book series from 2004.

Gustavsson, Tossebro and Traustadottir (2005) have suggested that the trend within disability research over the last 10 years has involved interest in a broad range of issues and use of a variety of approaches. Other authors have similarly noted a diversity of individual and social approaches to studying disability over the years (e.g., Pfeiffer, 2001, 2002; Priestley, 1998). Gustavsson (2004), in his assessment of the “theoretical temperature” of disability research, reported a growth in non-theoretical perspectives, including “the reformer’s perspective”, as well as a newer “experience-near perspective” (p. 56). Beyond this, he identified three different theoretical perspectives: (a) individual and contextual essentialism, linked to the individual and social model respectively (Soder 1999, cited in Gustavsson, 2004, p. 59); (b) “second generation” constructionist perspectives both linguistic and cultural; and (c) relative interactionist perspectives. He concluded, none too positively, that essentialist theoretical perspectives in particular could introduce a new kind of
“strait–jacket” and the “risk of circular reasoning” in disability research (Gustavsson, pp. 60, 67).

2.2. The UK social model: A “strong” social approach

The UK social model of disability was pioneered by the Union of the Physically Impaired Against Segregation (UPIAS), and formalised by writers such as Finkelstein (1980) and Oliver (1990). It has been termed “the big idea” of the British disability movement (Hasler, 1993, cited in Shakespeare & Watson, 2001, p. 9).

The UK social model distinguishes between the impairments that people have and the oppression they experience, and importantly, defines disability as social oppression (Shakespeare & Watson, 2001). According to the social model, the inability of people with impairments to undertake social activities is a consequence of the erection of barriers by non-disabled people. As Thomas (1999a, 2002) explained, in this model disability is not the impairment or restrictions caused by the impairment. Rather, disability is the outcome of social arrangements and practices that work to exclude or disadvantage people with impairments (see also Oliver, 1996a). In the definitions used within the UK social model, as indicated below, the distinction between impairment and disability appears absolute.

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

Thus we define impairment as lacking part or all of a limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream social activities.

Shakespeare and Watson (2001) note the social model has been critical to the British disability movement for two reasons. First, it facilitated identification of a political strategy of barrier removal. Second, it challenged the bio-medical model where disability was seen in relation to problems of the body. In doing so, the social model altered the way disabled people saw themselves, removing blame from their individual bodies and identifying the problem of disability and therefore the responsibility as external, in society. It facilitated the collective action of disabled people, allowing them to develop a new social movement (Campbell & Oliver, 1996; Oliver, 1996a). As Campbell (2002) has noted, many disabled people, recognising their situation as social oppression, were able to break away from their “self appointed guardians” (p. 472), the charity and statutory bodies who spoke on their behalf.

Few would disagree that the social model has assisted politicisation of the social and spatial environment, drawing attention to ways in which “dominant ableist norms and practices” have worked to exclude people with impairments from the mainstream (Paterson & Hughes, 1999, p. 597). However, the extent to which it has achieved widespread impact in the general community is questionable. As some social modellists note, there remains much to be accomplished, because governments determine social policy in a system of representative democracy, and disabled people continue to encounter obstacles in attempting to influence the political process (Barnes & Mercer, 2001; Oliver, 1996a). Despite growing criticism of the social model from within disability studies, many social modellists (e.g., Barton, 1996, 2001; Coles, 2001; Oliver, 1996a; Shakespeare & Watson, 1997) have expressed commitment to it, and consider it a tool with the power to influence support services, policy, and the empowerment of disabled people.

Both Tossebro (2004) and Shakespeare (2004) have referred to the UK social model as a “strong” version of a social relational approach to disability because it emphasises the role of the environment in the causation process. Within the UK social model disability is understood not as a person-environment relationship but as something caused solely by the environment (Tossebro & Kittelsaa, 2004). British
social modellist, Oliver (1990), has distinguished himself as a social creationist rather than social constructionist. In doing so, he has argued that disability is created by society, and has encouraged the popularisation of a simplified version of the social model: that all restrictions are socially opposed (Thomas, 2004b). This strong position has led the social model perspective to be described by some Nordic disability writers as “contextual essentialism” (Soder, 1999 cited in Gustavsson, 2004, p. 59). That is, rather than addressing the interaction of individual and environment, the strong social model focuses only on the context/environment as essentially disabling.

Many debates and critiques have developed within UK disability studies (e.g., Corker, 1998; Corker & French, 1999; Finkelstein & French, 1993; Morris, 1991; 1992; Paterson & Hughes, 1999; Shakespeare, 1994; Shakespeare & Watson, 2001; Thomas, 1999a; Wendell, 1996). These critiques have been directed toward the impairment-disability dualism, the focus on structural barriers, the bracketing of personal experience and the marginalisation of different groups by the disability movement. These critiques appear to emphasise a social constructionist (as opposed to creationist) approach, and to suggest that a broader “relational” social perspective may be usefully applied in future disability research.

2.3. Growing critique of the strong social model

2.3.1. False dichotomy between impairment and disability

The separation of impairment and disability in the strong social model, while perhaps of value in establishing the radical politics of disability, has been criticised by a growing number of disability writers who argue there is little value persisting with the dualism this separation represents (e.g., Butler & Bowlby, 1997; Corker, 1998, 1999, 2001; Corker & French, 1999; Hughes & Paterson, 1997; Paterson & Hughes 1997; Schriempf, 2001; Shakespeare & Watson, 2001).
Few traditional social modellists have considered impairment in their discussions of disability. One early and notable exception is the work of Abberley (1987), who emphasised the social origins of impairment. A further example is in more recent work from Thomas (1999a), who introduces the idea of impairment effects while maintaining a historical materialist framework. Through this tendency to ignore impairment, the majority of social modellists have implied that impairment is of no importance in understanding disability as it is simply biological. Oliver (1996a, 1996b) for example, emphasised that in the social model disability is wholly and exclusively social. He wrote:

Disablement is nothing to do with the body. It is a consequence of social oppression … Impairment is … a description of the physical body (Oliver, 1996a, p. 35).

Traditional social modellists have resisted suggestions to bring impairment into conceptualisations of disability, though some have conceded a social model of impairment could possibly operate alongside the social model of disability (e.g., Oliver, 1996b). In resisting the inclusion of impairment, they have been concerned about the risk of attention being diverted from external barriers (e.g., Oliver, 1996a). In addition, many are fearful of letting the individual or medical model “in the back door” (Thomas, 2004a, p. 32). Such a concern has been thoughtfully countered. For example, Crow (1996) suggested that letting impairment in allows disabled people to redefine impairment in terms of their own experience. She argued that this is preferable to surrendering impairment to the biological arena of medical professionals and their powerfully negative discourse. Crow (1996), Morris (1991) and Thomas (1999a, 2001) have all emphasised that impairment is important in disabled people’s everyday lives and therefore should be important to disability theory.

Some have suggested that, through ignoring impairment, the social model has failed to counter the dominant personal tragedy perspective. Rather it has merely sidetracked the issue by focusing on disability alone (Swain & French, 2000). Swain and French (2000) argued that unless an “affirmative model” of disability is established, the social model leaves open the possibility that “even in an ideal world
of full civil rights and participative citizenship for disabled people, an impairment could be seen to be a personal tragedy” (p. 571).

Feminists’ insistence on the relevance of impairment has highlighted important impairment-related differences among disabled people, and encouraged attention to the social nature of impairment (Thomas, 2001). Work by Corker, for example, highlighted information and communication as areas of disablism for d/Deaf persons (Corker, 1998; Thomas & Corker, 2002). Corker (1999) stressed the importance of looking between disability and impairment, arguing that disability is produced in the relationship between impairment and oppression.

Interesting work by Paterson and Hughes (1999) highlighted the complex social nature of impairment as it is experienced in the “intercorporeal” social cultural space, that is, between (rather than within) social bodies. They argued that disabling socio-spatial environments produce a vivid but unwanted consciousness of one’s impaired body. Like Corker (1998; Thomas & Corker, 2002), Paterson and Hughes (1999) suggested that communication is an area where disablism emerges. They noted that people with speech impairment are excluded not because of their impairment. Rather, they are excluded because the conventions and norms of communication, particularly in relation to pace, are hostile to those who possess different bodies and function differently in social interaction.

Interactionists following a social constructionist and postmodernist epistemology (e.g., Corker & French, 1999; Schriempf, 2001; Shakespeare & Watson, 2001) opposed the dichotomy of impairment and disability. They claimed that everything is “always already” social. By this they meant that the words people use and discourse people develop to represent impairment are socially and culturally determined. As Shakespeare & Watson (2001, p. 18) asked, “where does impairment end and disability start?” Both are culturally and discursively constructed and, according to these authors, there cannot be biology prior to discourse (Shakespeare & Watson, 2001; Traustadottir & Kristiansen, 2004).

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5 d/Deaf is used to refer to people who identify with the Deaf Culture, as well as those who have a condition of deafness or hearing impairment but do not identify as culturally Deaf.
In a postmodern manner, Shakespeare (2004; see also French 1993a) declared that the utopian goal or implication of the strong social model – that there is a possibility of a world without disablement – is problematic because of the interrelationship of disablement and impairment. He wrote:

The problem is that environments are built for entire societies, and often it is a case that removing barriers for some means imposing them for others … different people have different requirements, bringing us back to the individual’s impairments, and their own ways of dealing with these, and their individual interaction with the landscape (Shakespeare, 2004, p.15)

Shakespeare (2004) concluded that in considering impairment and disability it is vital to think of them as a continuum, “it is not a case of either/or but of both/and” (p. 17).

2.3.2. Privileged emphasis on the structural

Early activists and academics (e.g., Campbell & Oliver, 1996; Finkelstein, 1980; Oliver, 1990) applied a predominantly historical materialist perspective to understanding disability. This perspective emphasised that the origins of disability lie in the social relations of the capitalist system of commodity production (Thomas, 2002). Efforts were focused on fighting for the rights of disabled people in terms of equal access to education, employment and independent living. Physical barriers and disabling built environments of local communities became a focus of political campaigning (Campbell & Oliver, 1996).

This emphasis on structural issues has since been described as neglecting the cultural and experiential dimensions of disabled people’s lives (e.g., Shakespeare, 1994). In particular, feminists have asserted that it reflects patriarchal interests (e.g., Morris, 1991; Thomas, 1999a; Thomas & Corker, 2002; Wendell, 2001). Additionally, it could be questioned whether a Marxist interpretation of disability can have the same application in postmodern society, where the organisation of labour has undergone considerable change (e.g., Thomas, 1999a, 2002). Access to technology and better awareness of universal design in building structures has arguably increased independence and physical access for disabled people in the workforce and other life
areas, altering their social position relative to life’s material necessities (French, 1993b; Roulstone, 1993, 1998; Thomas, 2001).

Exclusion and oppression can be experienced in different ways, not only through physical structural barriers. Some of these alternative forms of exclusion are being revealed through distancing from purely materialist approaches. Hughes (2002) for example, argued that people with impairments can be culturally excluded in postmodern society. Lacking economic capital, they become “flawed consumers” and are excluded from what has become a “culture of consumption” (Bauman, 1998, cited in Hughes, 2002, p. 580).

Thomas (1999a) claimed that in prioritising structural barriers the social model has focused on restrictions to doing, when in fact disablism operates at more subtle levels: people with impairments are not only restricted in doing, but also restricted in being. There are social barriers “closely bound up with socio-cultural processes which generate negative attitudes” (p. 47) about impairment, that erect restrictions within disabled people and place limits on their psycho-emotional well-being.

French (1993c, 1999), discussing her own experience of vision impairment, has alluded to these psycho-emotional issues. She reported that other peoples’ responses to her impairment caused her to deny aspects of herself or to behave in ways detrimental to herself. Further, the socio-cultural context by way of others’ attitudes, particularly in relation to notions of normality and independence, are problematic and can be a form of oppression (French, 1993a, 1993b, 1993c, 1999; see also Oliver, 1990; Smith, 2001). French (1999) noted that as a vision-impaired person she could not always be as fast as sighted people. Expectations around pace in interaction can create unequal relationships, making it difficult for her to meet her own needs without curtailing those of other people. In addition, the variable and complex nature of partial sight caused her to constantly feel that others were judging her as a fraud, for example, if she crossed the road with a white stick, yet pulled out a book to read on the train.
In these ways, both feminist writers and authors from interactionist or postmodernist positions have argued for greater consideration of socio-cultural disablism and for critical examination of the cultural representation and participation of people with impairments (e.g., Corker, 1999; Corker & French, 1999; Hughes, 1999, 2002; Shakespeare, 1994; Shakespeare & Watson, 2001).

2.3.3. The personal is political

In another critique, feminist disability writers have emphasised that there is a need to consider the personal and experiential dimensions of disability. They believe the personal is political, rather than something that should remain sidelined as private or individual troubles (Crow, 1996; Morris, 1991, 1992; Thomas, 1999a). Thus, narratives of personal experience are proposed to offer a route to understanding socio-structural and psycho-emotional issues (Thomas, 1999a, 1999b). Similarly, it has been noted that to ignore personal aspects of individual’s lives is to risk alienating them from the disability movement (French, 1993a; Thomas, 2001). Crow (1996) for example wrote, “when personal experience no longer matches current explanations, then it is time to question afresh” (p. 56).

For feminist writers there is power in considering the personal as political with regard to disability. To do so has allowed, for example, a re-conceptualisation of psychological or psycho-emotional issues, revealing their relationship to disablism rather than confining them, as the medical perspective does, to individual psychology or failure to adjust (e.g., Finkelstein & French, 1993; Thomas, 1999a).

Oliver (1996b) wrote of his difficulty socialising at a party while in a wheelchair, highlighting the distinction he considered necessary between the personal and political. Thomas (2001) however, successfully re-framed this account, demonstrating the incident in fact to be an example of disablism because both the forms of interaction used at the party and the physical location of the party took little or no account of him as a physically impaired man. Thomas, I believe, successfully illustrated that acknowledging the personal as part of disability can bring new understanding of experience and exclusion.
2.3.4. Marginalisation of different groups

Critique of the social model has deemed it inadequate when applied to specific impairment groups, such as those with intellectual disability, the Deaf, and those with vision impairment (Corker, 1998; French 1993a; Goodley, 2001; Morris 1991; Thomas, 1999a, Wendell, 1996). It has been argued that in relation to these groups the problems experienced are difficult, if not impossible, to solve by social manipulation alone. In addition, the social model has been criticised for marginalising groups based on sexuality, ethnicity, age or gender because it focuses on disability as distinct from other aspects of identity (Shakespeare & Watson, 2001; Thomas, 1999a).

French (1993a) outlined a number of problems she encountered as a vision-impaired person which were difficult to solve by social means. For example, she was not able to recognise people, became blinded when the sun came out, and was not able to read non-verbal cues in interaction. French (1993a) explained that such difficulties impinged upon her life “far more than indecipherable notices or lack of beeper crossings” (p. 17). In addition, Corker (1998; Corker & French 1999) suggested that d/Deaf people were marginalised because their oppression was mediated by discourse, language and communication, all issues that were sidelined in a social model that focused on material and structural barriers. Wendell (2001) further asserted that by distancing from the medical model perspective and not considering impairment and personal experience, social modellists’ had marginalised people with non-static impairments. This author has pointed out that impairment can be changeable and episodic rather than static, and many disabled people are not necessarily healthy.

The distinction between the impaired and non-impaired which the social model tends to emphasise has also been critiqued. Some have suggested this division cannot be sustained on the basis that one group is oppressed and the other the oppressor, because non-disabled people can also be oppressed (e.g., through poverty, racism, sexism), and furthermore oppressed people can also be oppressors (e.g., Humphrey, 2000; Swain & French, 2000).
Some authors have argued that non-impaired people are not so different from impaired people. Shakespeare and Watson (2001), for example, emphasised commonality rather than difference, suggesting it may be more meaningful to consider everyone as impaired, since “no-one’s body works perfectly, or consistently, or eternally” (p. 24). As Tregaskis (2002) noted in her account of the social model story, the impaired and non-impaired often need to work together to counter disability:

A concentration on disabled people’s experience, and by implication on the differences between disabled and non-disabled people may well have been justified in the early days of developing the social model theory and with it a proud disabled identity. However, the logic and practical expediency of continuing to use such an oppositional analysis in a changing political climate in which disabled people are increasingly making connections with non-disabled people as a precursor to influencing organisational changes … may be questioned (p. 467).

Many of the above debates and critiques are centred on the strong stance of the UK social model and appear to be calling for moderation and broad-mindedness in future approaches in disability research. While many writers have debated and supported the need to revise the strong social model and its dualistic foundations, only Thomas (1999a) has clearly documented an alternative framework.

Thomas (1999a) proposed an extended social relational understanding of disability which included structural and psycho-emotional dimensions of disability as well as impairment effects. Thomas describes this way of understanding disability as both essentialist and constructionist in its underpinnings. It is an attempt to counter weaknesses in the strong social model approach such as the failure to acknowledge the body and impairment, and the personal experience of oppression (Reeve, 2002; Thomas, 1999a, 2002). Thomas (2004) acknowledged that, initially at least, there were social relational underpinnings in what has become the UK strong social model. It is important to note, however, as Tossebro (2004) has done, that Thomas used the phrase “social relational” differently from authors coming from a Nordic perspective,
in that she continued to emphasise power relations as a critical component of social relationships.

2.4. Synopsis

The debates ongoing within the field of disability research are unlikely to be resolved easily as they reflect age-old dilemmas about individual–society and agency–structure which, according to Craib (1992; see also Oliver, 1996a), have permeated sociology since its conception. Shakespeare (2004) captured the dilemma well in his reflections on the nature of disability study:

Is it about studying disabling barriers, or studying the experiences of disabled people? Some argue that the latter takes research back to the bad old days of top down and unaccountable social science. But of course, the effect of disabling barriers is the restricted life chances of disabled people. In order to document exclusion, hearing the voices and demonstrating the impoverishment of people with impairment is vital. Structures impact on the lives of agents, as both Karl Marx and Anthony Giddens would remind us (p. 12)

For me, as a beginning disability researcher struggling to locate my position, the mass of perspectives in disability research was initially overwhelming. The concept of disability as social relational has been a helpful tool for understanding how the many voices referred to above interact within a wider body of knowledge and represent in varying ways the environmental turn in understanding disability.

The Nordic social relational approach to understanding disability has emphasised that disability is a process. Disability is social relational, in that it emerges in the space between individuals and their environmental contexts. I believe it is an approach which is sufficiently broad to avoid the risk of circular reasoning that Gustavsson (2004, p. 60) alluded to in essentialist approaches. In applying the social relational approach, I believe that disability is relative to the environment and other persons, but I do not specifically foreground issues of power as Thomas does (e.g., 1999a, 2004).
I do not think that disability can be considered distinct from impairment. In this research I have chosen to explore the experiences of people who become deafblind, a specific type of impairment. This immediately reveals that I believe impairment to be part of the situated understanding of disability that cannot be meaningfully ignored. As a biological component it is part of the social and cannot be meaningfully separated.

In addition, I have chosen to begin my research from the individual accounts and experiences of people who become deafblind. This suggests an alliance with feminist perspectives, a belief in the importance of personal experience and the personal as political. It also reveals one of the problems I (and others) have perceived in the strong UK social model: by starting from disabling barriers, this model appears to imply that people with impairments are passive recipients of disablism; it fails “to address bodily agency” (Paterson & Hughes, 1999, p. 597).

With regard to Gustavsson’s (2004) framework of contemporary theoretical perspectives in disability research, the approach taken in this study could be considered relative interactionist, with an emphasis on a multi-level understanding and empirical sensitivity. This approach demands a certain level of openness towards what is going on, a belief that empirical discoveries should guide the researcher in decisions about analytical focus, and a belief it is impossible to understand the processes producing disability, exclusion and discrimination without studying people’s lives and the interaction between individuals and their contexts.

In this spirit, this research applies a symbolic interactionist theoretical framework to underpin its methodological decisions and interpretative understanding.6 I believe, in a postmodern environment of “both/and” thinking, that this forms the most appropriate starting point from which to explore the situation of adults who become deafblind. Symbolic interactionism, informed by a social relational understanding of disability, facilitates understanding of broader contextual issues and of the way these interact with individual experiences.

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6 See Chapter 4 for more information on this framework and approach to research.
Importantly, the use of symbolic interactionism supports conceptualising the individual with impairment as an active co-constructor of meaning in their environment. As the researcher this conceptualisation was important to me both in the process of conducting the research and in constructing the thesis as a textual product. The importance of this approach is noted in the context of the historical neglect of individuals with deafblindness in research, their relative social invisibility in rehabilitation and general community spaces, and their frequent construction in the professional literature as passive recipients of intervention.

The next chapter of the literature review focuses on deafblindness and what is already known about the lives of adults who are deafblind.
Chapter 3
WHAT IS KNOWN ABOUT THE LIVES OF ADULTS WHO ARE DEAFBLIND?

In reviewing literature relevant to the lives of adults with deafblindness I found two separate sources of information: personal accounts from individuals themselves and professional research and literature resources.

In designing this study I was informed by a symbolic interactionist theoretical framework and a social relational understanding of disability. Thus the agency of individuals and their relationship with the environment and other people is emphasised. I therefore considered the perceptions and experiences of adults who are deafblind themselves to be of high importance. For this reason, the anecdotal literature of adults who are deafblind has been reviewed alongside the professional literature. In this chapter, a brief introduction to deafblindness in an Australian context is provided, prior to a thematic presentation of the anecdotal literature and thematic discussion of the professional literature and empirical research.

3.1. The Australian context

Australia is a geographically dispersed country divided into five states and two territories. Each state or territory has its own government operating in relationship with the Commonwealth (federal) government. There are two sectors generally involved in the welfare of people with disabilities: the disability services sector (people under 65 years) and the aged care services sector (Australian Institute of Health and Welfare, 2003). The Commonwealth State and Territory Disability Agreement (CSTDA) provides the structure to disability policy funding and services in Australia, dictating that some disability concerns are the responsibility of the Commonwealth while others fall to state level governments (Commonwealth
Department of Family and Disability Services, 2004). Supports and services available to adults who are deafblind therefore vary depending on geographical location.

At a federal level there has been little recognition of deafblindness by way of government funding or service provision, and accurate data do not exist on the prevalence of deafblindness (ACROD, 1993; Steer, 2002, 2003; Ward, 1996). Ward (1994) used a population extrapolation method (10:100, 000) to make a conservative estimate of 1500 expected deafblind people under the age of 65 throughout Australia. Consistent with this population extrapolation method, the majority of people experiencing deafblindness (approximately 500) are thought to be located in the state of New South Wales (Ward, 1994).

The majority of the states in Australia have a DeafBlind Association and/or a representative member on the Australian DeafBlind Council (ADBC). The majority of these organisations are volunteer-run, without government funding or support. For example, the ADBC, set up following the National Conference in 1993, is a network for individuals who are deafblind and other interested parties such as families, support people and service organisations (Australian DeafBlind Council, 2003). The ADBC is financed by subscriptions from members and does not receive ongoing government funding.

The ADBC has had some small success in campaigning for better recognition of problems faced by people who are deafblind. For example, small grants have been secured to conduct research into their needs, first in 1994 (Ward, 1994, 1995, 1996) and more recently in 2005 (report not yet released) (personal communication, J. Finch, 14/05/05). The ADBC was also involved in a National Deafblindness Forum in 2001, where 40 agency and special interest group representatives, as well as public officials, gathered to discuss the situation of people who are deafblind across the nation (Steer, 2002, 2003). Using the eight areas of human service provision outlined by the CSTDA, the forum concluded that “no state or territory comes close to meeting the needs of its citizens who are deafblind” in any area (Steer, 2002*). This

* An asterisk indicates that the quote is taken from an electronic source where no page numbers are available.
was consistent with past research efforts that have highlighted variation and unmet service needs across the different states (e.g., ACROD, 1993; Forman, 1992; Ward, 1994). The outcome of the forum was a list of recommendations presented to the National Disability Advisory Committee. Regrettably, no action has since been taken to act on those recommendations or to improve the situation for people who are deafblind.

A recent government-supported development in Australia with implications for people who are deafblind, though not specifically designed for them, is the provision of medical interpreting support for people who are Deaf (Australian Association of the Deaf, 2004). However, as Barrey-Grassick (1998) noted, with no accredited training courses specific to deafblind interpreting there is a high probability that an interpreter for the Deaf would not have experience in deafblindness. It is only since 1998 that a postgraduate program has been available to professionals working in deafblindness through Renwick College Winter School; however, this focuses primarily on children’s education needs rather than adult concerns (Steer, 1998).

The most developed services in relation to people who are deafblind are located in the state of Victoria (Finch, 1999), and include educational services, single sensory impairment rehabilitation services, employment agencies specialising in sensory impairment, and a well developed support organisation specific to people who are deafblind: Deafblind Association Victoria. In addition, emphasis within Victoria has been placed on interagency communication (Finch, 1999) and research has been conducted specific to the needs of people with Usher Syndrome7 (Forman, 1992).

The Deafblind Association Victoria was formed in 1967 as a self-help group by families who had children with deafblindness. It represents the interests of people with multiple disability including deafblindness, and provides community support,

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7 Usher syndrome is an autosomal recessive genetic condition characterised by hearing impairment from birth and the vision impairment retinitis pigmentosa (Guest, n.d.; Kimberling & Moller, 2003). There are three types, with types 1 and 2 being more common. In Usher syndrome type 1 a person is usually born profoundly deaf, has poor balance and develops retinitis pigmentosa. In Usher syndrome type 2 a person is born with hearing loss and later develops retinitis pigmentosa. In retinitis pigmentosa the retina of the eye degenerates and loses the ability to transmit messages to the brain. Symptoms include difficulty seeing in dark places or at night, loss of peripheral vision creating tunnel vision, and difficulty with light adaptation (Kilsby, 1997).
accommodation and respite (Deafblind Association Victoria, 2005a; Finch, 1999). Finance is provided through the state government and fundraising efforts. Services are comprehensive, including computer training, music therapy, case management, communication support and medical interpreting, psychological services, recreation, respite, hydrotherapy and day services (Deafblind Association Victoria, 2005b).

In the state of New South Wales, however, there is a history of fragmented service provision, with single impairment rehabilitation organisations (e.g., the Royal Blind Society and Deaf Society), educational facilities, and one small-scale accommodation service (Finch, 1999). It is only since 2003, as a result of advocacy work by the New South Wales voluntary DeafBlind Association, that services specifically designed to cater for adults who are deafblind have developed (personal communication, J. Bidenko, 28/9/03). As a new department within the Royal Blind Society, the DeafBlind Service is staffed by the equivalent of two full-time workers. It provides communication, information access and living skills training, as well as emotional support (Lalich, 2004).

In brief, the structure of government in Australia creates variability in the services and policies across the different states and territories for people who are deafblind, as demonstrated by contrasting Victoria and New South Wales. Typically, little government recognition by way of funding is available to people who are deafblind. DeafBlind Associations at state/territory and national levels are predominantly volunteer-run, and have played an important role in the advocacy and self-organisation of people who are deafblind.
3.2. Individual voices of adults who are deafblind

Published biographical accounts and a growing collection of personal stories are available from individuals who are deafblind. Conference forums and, to a lesser extent, community journals are important avenues for adults to share, first-hand, advice and experiences.

For this section of the literature review I accessed individual stories of people who are deafblind and read accounts and opinions of the lives of Helen Keller and Alice Bettridge. These were famous women in their respective countries, the United States and Australia, who experienced deafblindness from early in their lives.

This personal literature has some limitations in presenting a comprehensive view of deafblindness. Firstly, it is comprised of individual accounts that are not theoretically informed or scientifically researched and may not have general application. Secondly, this literature contains only stories of particular members of the deafblind community, most of whom like the participants in this research have not experienced early onset deafblindness. These are the voices of individuals who are articulate and well-connected and who have the resources to attend national and international events and who are often involved in advocacy work.

That said this literature is valuable for a number of reasons. First, the personal stories, and the contexts in which they have been shared, are demonstrative of the spaces people who are deafblind have created for themselves. The creation of these spaces indicates their agency, desire to come together, and achievement in doing so with regularity. Second, through analysing the common themes raised among the personal stories of adults, the richness and complexity of their everyday lives is revealed, and this needs to be acknowledged in any study on deafblindness. I believe that these complexities have not yet been adequately embraced by researchers, and cannot continue to be ignored in trying to understand disability as social relational in the lives of people who are deafblind. Third, these personal accounts, although not
studied in detail prior to data collection, formed a valuable source of constant comparison during fieldwork as is typical in grounded theory research (Glaser, 1978). Six themes analysed from the personal accounts literature are discussed here.

3.2.1. Just like everyone else

Many personal stories have been structured around normal life events emphasising, at times deliberately, that it is possible to engage in typical life activities despite being deafblind. Such stories reflect the desire of adults to be recognised as citizens of the world, just like everybody else (e.g., Brioso, 2003; Doran, 2003; Lawson, 2002; Wright, Tarrant, Staughton, Ireland, Pontelandolpho & Jeffrey, 1993).

People who are deafblind have spoken about getting an education, finding employment, forming relationships, and getting married (Coker & Sauerburger, 1995; Fukushima, 2001; Geason, 1999; Gribs, Dougherty & duPre, 1995; Riedel, 1999; Shapiro 1999; Sypula, 1997). For example, in Mitchell’s (2001*) account of an interview with the Smithdas’, a married couple who are both deafblind, two seemingly ordinary people are presented. The Smithdas’ discuss their tertiary qualifications, hobbies (gardening, tinkering with the stock market and old cars, cooking, exercising), and their relationship (described as “it was love at first bump”). Through this account and others like it, people who are deafblind communicate their ordinariness; they seek to be seen as capable adults attaining typical life roles rather than as victims of a tragic disability.

Being just like everyone else, adults who are deafblind have stressed their right to full participation in the community (e.g., Bohrman & McNamara, 2002; Hicks, 2000; Vinterhoj, 1995) and their desire to feel “oneness with their fellow beings” (Scahill, 1995, p. 6). Ripley (2002) for example emphasised that as a deafblind person he remains a member of society:

People say it’s a hearing world or a sighted person’s world. They’re wrong.
That implies ownership. The world doesn’t belong to hearing or sighted

* An asterisk indicates that the quote is taken from an electronic source where no page numbers are available.
people – it belongs to everyone. It’s just that the world has been geared more to people with hearing and sight. This is my world too. I live in this world, pp.162-3).

3.2.2. Using strategies to live differently

A dominant topic in anecdotal accounts is sharing the ways in which adults live differently. Individuals speak of adaptations they have made to daily living activities (communication in particular) through use of assistive equipment and environmental modifications (e.g., Belanich, Smithdas, Stoffel, Stoffel & Zarate, 1997; Bryce & McMinn, 2002; Ferguson, 2002; Jeffrey, 1995; Jones, 1997; Lawson, 2002; Malcolm, 1998; Mitchell, 2001; Reyes, 2001; Ripley, 2002; Shapiro, 1999; Stiefel, 1991; Sturley, 2003). For example, Gribs, an 87 year old woman born deaf and becoming blind over 50 years, described relying on various assistive devices to live alone, such as a vibrating sensor for the doorbell, a TTY and phone, and a Braille printer (Gribs et al., 1995).

A second aspect of living differently discussed by adults is experiencing the world in different ways through use of their other senses (Coker & Sauerburger, 1995; Geason, 1999; Gilbert, 1993; Kleege, 2000; Malloy, 2001; 2003; Ripley, 2002). Kleege (2000), for example, described Helen Keller’s second and less known book, The world I live in, (1908), as a “detailed phenomenology of her everyday sensory experiences” (p. 324). Rather than discussing her perception as a lack of hearing or vision, Keller instead described a heightened awareness of taste, smell and touch. Other adults have similarly written about using smell or touch to identify people or engage in activities (e.g., Coker & Sauerburger, 1995; Geason, 1999).

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8 TTY is a teletypewriter that allows a person to send and receive text messages over the telephone network. People with no hearing can conduct text-to-text conversations with other TTY users or conduct text to voice calls using the National Relay Service. TTY’s come in different forms, usually combining phone and TTY features, some with printers, adapted with large screens, or Braille output (Telstra, n.d.).

9 Braille is a system of raised dots used to represent letters, words and numbers. Non-electronic and electronic aids are available with options to translate Braille into print text, and print into Braille (DeafBlind Association Victoria, 2005c).
Ripley (2002) emphasised that his functioning at a different level without hearing and sight was not a tragic or lacking experience, just an alternative perception:

My world is not sad because I cannot hear the birds singing; my world is not sad because I cannot see the curtains that match the lounge suite covers – my world becomes alive when I get to feel a small warm bird in my hands or feel the intricate design of the curtains – as well as the smell of the fabric spray …
Same world, different reality (p. 163).

3.2.3. Dealing with uncertainty and change
A further theme in adults’ stories is the need to adapt to changes in vision and hearing, and the emotional challenge of facing an uncertain future (Lawson, 2002; Ripley, 1995; 2002; Stiefel, 1991; Sturley, 2003; Wright et al., 1993). Clark (2004), for example, explained that becoming deafblind involved not a single adjustment but “a succession of adjustments” (p. 7).

Some adults talk about having to redefine independence in their lives and make sacrifices in practical terms, such as giving up driving or learning Braille (e.g., Pessin, 1995; Ripley, 2002; Stiefel, 1991; Sturley, 2003). Others refer to the emotional aspects of adapting, describing wanting to stay home for security, becoming isolated, experiencing depression and thinking of suicide (e.g., Belanich et al., 1997; Lawson, 2002; Stiefel, 1991; Tunison, 1998; Wright et al., 1993).

Change can be a feature of location: individuals must adjust to their vision or hearing loss in different situations. For example, a Japanese deafblind man, Kadokawa (2002), described developing different strategies for mobilising in New York as compared to Japan, not because of physiological changes to his vision/hearing, but due to different features within the two environments.
3.2.4. Fighting for ourselves

Deafblind adults have spoken of difficulty getting educated, navigating services and finding affordable support such as interpreters (Belanich et al., 1997; Harland, 1992; 1993; Lawson, 2002; Talbot-Williams, 1996). Lawson (2002), for example, recalled attending rehabilitation training within a blindness organisation where she found no ongoing support afterwards, no access to the community and no technology. Hicks (2000) and Van Deventer (2001) have argued that the inadequacy of single sensory services is one reason why a deafblind community is necessary in addition to single sensory groups.

People who are deafblind have been advocating for themselves and the support they desire over many years. The earliest known attempt at self-organisation was in 1928, when the National League of Support of DeafBlind People was established in the UK (Reyes, 2001). Today this is DeafBlind UK, a national charity (run by a board composed of individuals who are themselves deafblind) providing a range of support services to adults and carers (Hicks, 2000; Reyes, 2001).

Further self-advocacy efforts can be seen in articles, such as one by McNamara (1999) where she implores organisations to support the participation of deafblind people in meetings. McNamara described frustrating personal experiences such as attending meetings where communication rules were not established or where the pace of proceedings prohibited her full participation.

3.2.5. Requiring support

Personal accounts of adults emphasise three important types of support in their lives: support of other groups, support of individuals and support of each other.

Reyes (2001) argued that the tendency of professionals to prioritise congenital deafblindness has left those with acquired deafblindness to create their own organisations. He acknowledged this occurred largely with the support of other sensory impairment groups, particularly blindness organisations. Ohlson (2001), in discussing the newly formed World Federation of the DeafBlind, similarly drew attention to the importance of cooperating with other groups such as professional
groups (e.g., DeafBlind International) and single impairment groups (e.g., the World Blind Union and the World Federation of the Deaf). He argued these are well established groups that can assist in making the demands of the deafblind carry more weight (Ohlson, 2001).

Interdependence between people who are deafblind and other individuals has also been emphasised in the personal literature. Adults report that they rely on family, volunteers and professionals (e.g., Belanich et al., 1997; Fukushima, 2001; Harland, 1992; Kadokawa, 2003; McNamara, 2000; Roderick, 1993, cited in Seahill, 1995, p. 7). According to Ripley (2002) people who are deafblind need others to nurture them, interpret and guide them. He argued supporters become the deafblind person’s links to the community. The role of supporters is often emphasised in adult’s stories, for example, Keller’s teacher and friend Annie Sullivan remains a famous part of her life accounts (Crow, 2000; Herrmann, 1998; Kleege, 2000).

Through individual accounts the need for trade-offs when relying on other people has been noted as problematic. Crow (2000) argued that Keller’s reliance on the goodwill of others left her vulnerable because if access to solutions was controlled by others, so too were her choices. Ripley (1995) similarly noted that cooperating with others without feeling ones’ independence being lost was a great challenge.

Another aspect of needing support is discussed in relation to deafblind individuals gaining support from sharing their experiences together (Anderson, 1994; Hartmen, 1993; Kadokawa, 2002; Lawson, 2002; Roult & Miner, 1993; Wright et al., 1993). Within the deafblind community there is growing recognition that adults who are deafblind can be valuable supports to youth who are deafblind (Benton & McNamara, 2002; Malloy, 2000). For example, the American Association of the DeafBlind (AADB) recently established a mentoring project with a deafblind woman as director (Benton & McNamara, 2002).

Some adults reported that prior to meeting others they felt isolated and believed themselves to be the only deafblind person in their country, because of the lack of information available to them (e.g., Kadokawa, 2002; Reyes 2001). Tunison (1998), a
woman with Usher Syndrome type 1, explained that connecting with other adults helped her deal with her deafblindness. Hartmen (1993) advised being with others who experience similar impairment provides security that is important in adjustment. Tarrant (Wright et al., 1993) similarly noted that meeting others with Usher Syndrome improved his future. Clark (2004, p. 7) suggested that greater opportunities for people who are deafblind to come together may prevent them being “ambivalent about their identity”.

3.2.6. Sharing the world is not easy

Crow (2000) noted that as an adult, Keller’s views as a socialist and activist were largely disregarded by others. She was not taken seriously and instead was perceived by the public to be a puppet for Annie, her teacher and friend. Keller’s impairments were used to discredit her, as though their nature and her reliance on others kept her from forming her own views (Crow, 2000; Herrmann, 1998; Kleege, 2000). This is demonstrative of a recurring theme within the stories of adults who are deafblind: the struggle of sharing the world with others’ attitudes and ignorance.

The personal accounts of people who are deafblind suggest that others’ behaviour and attitudes can be difficult to deal with (Cielens, 1995; Clark, 2004; Doran, 2003; Fukushima, 2001; Gilbert, 1993; Kadokawa, 2002; Marcous, 1998; Pessin, 1995; Reed & Dwek, 2003; Reyes, 2001; Roult & Miner, 1993; Stiefel, 1991; Talbot-Williams, 1996). Clark (2004) noted adapting to change is made difficult by hearing-sighted people encouraging one to cling to whatever vision and hearing is left. Other adults have spoken of encountering impatience and forgetfulness (Roult & Miner, 1993), embarrassment (Talbot-Williams, 1996) and confusion (Kadokawa, 2002). Cielens (1995) suspects that the discomfort of hearing-sighted persons is related to a general fear of the unusual.

At the “CHARGE and Usher Syndrome in Europe” conference (CAUSE), held in March 2003, individuals with Usher Syndrome reported that other people do not understand their lifestyle and see them as “ill with symptoms” (Reed & Dwek,
2003"). According to one woman, when people feel bad for her, or think her brave it makes her angry (Pessin, 1995). Doran (2003*, see also Gilbert, 1993; Hicks, 2000) recalled people made her feel “so abnormal” by praying for her when she was diagnosed. She stated outright: “It is not just living with the disability and its symptoms, but it is also living with public perception [that you have to adapt to], public perception has affected my coping”.

Both Doran (2003) and Marcous (1998) have suggested it is important to educate and improve understanding among the general public. Marcous (1998) expressed a desire to teach about issues of stigma, oppression and power dynamics. For other people who are deafblind, however, it appears preferable not to draw attention to themselves and not to confront others’ assumptions (Pessin, 1995; Reed & Dwek, 2003).

Personal accounts illustrate that people who are deafblind feel they are defined by their impairments and believe others see them to be tragic victims. Reyes (2001*) stressed that there is a need to end the stereotype that deafblindness is “almost the end of everything”, noting, however, that the nature of the combined impairment is complex, making it difficult for able-bodied people to grasp. Some (Belanich et al., 1997; Stiefel, 1991) have explained that public knowledge is simplistic: people see a white cane and expect the individual using it to be totally blind. Fukushima (2001) claimed that public understanding of the need for communication support for adults who are deafblind is particularly poor. Significantly, he pointed out that often adults who are deafblind are independent with regard to activities of self care, making the impact of deafblindness not tangible in the way that difficulties associated with physical impairment might be (Fukushima, 2001).

In summary, through their personal accounts, people who are deafblind see themselves first and foremost as people just like everyone else, though they acknowledge and value their need to live differently and have support. People who are deafblind live with uncertainty and must adapt to changes in their lives while

* An asterisk indicates that the quote is taken from an electronic source where no page numbers are available.
fighting for the services they need. As a minority, they appear to be in the difficult position of sharing the world with ignorant others who hold strong but ill-informed views about their lives and their abilities.

3.3. The professional literature and empirical research

This section of the literature review presents themes synthesised from the professional literature and empirical research. First, the strategy used to conduct the review is outlined, challenges experienced in locating information are noted, and the limited nature of the information found is critiqued.

Information was located through two primary strategies. First, I conducted catalogue and database searches through traditional professional library resources, using “deafblind”, “adult”, or “Usher Syndrome”\textsuperscript{10} as keywords. The tools included databases such as Medline, Cinahl, Science Direct, Psych Info, Proquest, Health and Society, Ageline, Family and Society Studies Worldwide, Social Science, ERIC, Expanded Academic, Women’s Resources International and Sociofile. Second, I conducted broader internet-based searches using common search engines like Google. I located and searched information from national deafblind organisation websites such as the Deafblind Association (Victoria), the DeafBlind Association NSW, and the Australian DeafBlind Council. I also gathered information from the websites of international organisations, such as SENSE UK, DeafBlind UK, DeafBlind International, the Nordic Staff Training Centre for Deafblind Services (NUD), The World Federation of the DeafBlind (WFDb), the American Association of the DeafBlind (AADB), the Helen Keller National Center for Deaf-blind Youths and Adults, The National Technical Assistance Consortium for Children and Young adults who are DeafBlind (NTAC) and DeafBlind Link Clearinghouse. Through these websites I followed links related to publications, research or newsletters and sought information that could provide insight into the lives of adults with acquired deafblindness.

\textsuperscript{10} Usher syndrome is considered the most common cause of adult deafblindness (Barrett, 1992; Moller, 2003).
In searching for information about adults it became apparent that the majority of the available literature focuses on congenital deafblindness and the education and communication challenges of children who are deafblind. There is some evidence that the predominantly child-focused literature is extending to consider adulthood experiences. Many research projects or service programs are funded through education yet designed to meet the needs of children up to age 21 or 22 years (e.g., Programs for Deaf-Blind Children and Adults, 2004). This encourages attention to young adulthood issues, and education professionals have begun to explore contexts beyond the family and school such as: transition planning (e.g., Everson, 1995; Stuart & Smith, 2002), post-school options or outcomes (e.g., Petroff, 2001), employment (Everson, Burwell & Killan, 1995; Griffin & Lowry, 1989; Heller, Allgood, Ware, Arnold & Castelle, 1996; Kappen, 1991; McGinnity, 1985), post-secondary education (Bourquin, 1994) and recreation participation (Lieberman, 1996, 2002; Lieberman & Houston-Wilson, 1999). Some research has explored the experiences of congenitally deafblind persons as adults, though typically not from the adults’ own perspectives. Rather, the perspectives of parents (e.g., Petroff, 2001) or siblings (e.g., Harland & Cuskelly, 2000) have been sought, or research is based on observation of behaviour only (e.g., Romer & Schoenberg, 1991).

I found the literature regarding adults widely dispersed and difficult to locate. For example, while there is a web-based information clearinghouse for children and youth (DB-LINK), there is no equivalent on-line resource focusing on adults or acquired deafblindness. To my knowledge, no articles related to deafblindness have appeared in general disability studies journals. Occasionally, single sensory impairment journals (e.g., Journal of Visual Impairment and Blindness) or general rehabilitation journals (e.g., American Rehabilitation, Journal of Vocational Rehabilitation) feature articles relating to deafblindness. Reports are often shared among deafblind community publications, such as Talking Sense or Deaf-blind Perspectives which are non-peer reviewed publications. However, these reports are typically brief, making it difficult to assess their quality. Many studies lack theoretical or methodological detail and use what Reiman (1993) refers to as “overgeneralising terminology” (p. 3). That is, sometimes authors fail to specify which group of people who are deafblind they are referring to. Therefore, in the following literature review I have at times drawn on
information which may not be specific to adults with acquired deafblindness. Additionally, information and research are often shared at deafblind-specific conferences where unfortunately proceedings are not always available. For instance, no proceedings were kept prior to 2004 for the Acquired DeafBlindness Network seminars in Europe (personal communication, G. Roulstone, 15/06/05). Considering the dispersed nature of literature it is possible that the review presented in this thesis is not exhaustive.

Much of the professional literature has been directed toward sharing knowledge and building expertise. As Bullis and Bull (1986) noted in an earlier literature review regarding adolescents and adults with deafblindness, the majority of resources are non-research based. Rather, much of what is known about deafblindness is based on useful accounts written by experienced professionals (e.g., Sauerburger, 1993; Smith, 1994; Snider, 1994). A preoccupation with professional development has created large amounts of literature describing “practice models” such as models of assessment (e.g., Cavedon & Bass, 2000; Prain, 2000), communication training (e.g., Barrey-Grassick, 2000, 2002), behaviour modification (e.g., Sisson, Hersen & Van Hasselt, 1993; Sisson, Van Hasselt & Hersen, 1993) and service programs (e.g., Bourquin, Mascia & Rusenski, 2002; Feille, 1995; Mezack, 1995; Rocchio, 1995).

McGinnity (1997) observed that adult services focus on particular aspects of adults’ lives rather than on developing an individual to their full potential. Literature on adults mimics this trend, focusing on particular fragments of individuals’ lives and typically emphasising the functional impact of the condition. For example, there are works specific to orientation or mobility (Bourquin, 1996; Cioffi, 1995, 2002; Franklin & Bourquin, 2000; Lolli & Sauerburger, 1997; Sauerburger, 1993, 1997), technology or equipment development and use (e.g. Belanich, 1995; Hinton, 1989; Jaffe, 1994; Osborn & Gaeth, 1993), communication training (e.g., Godfrey & Costello, 1995; Prain, 2000), and counselling needs (Adler, 1987; Anderson, 1976; Cumpston-Bird, 1993).

Research typically is descriptive, undertaken with the purpose of informing practical services or political advocacy, and takes two forms. The first form is surveys that
describe quantitatively features of the deafblind community. The second form includes smaller qualitative and case-study-based designs that concentrate on describing the functional effects of deafblindness, most frequently in relation to communication. The experiences of adults who are deafblind often seem to be obscured by the research designs used, such as closed response surveys or focused observational analysis of communication exchanges. As a result, literature and research inform about deafblindness as a challenge to professionals, yet overlook an “insider” understanding of the everyday social lives of adults. Seven themes analysed from the professional literature are detailed below.

3.3.1. Diversity of conditions and identities

Deafblindness can be experienced differently and to varying degrees by different individuals. It might exist alone or in combination with additional impairments. One or both impairments can be acquired gradually or suddenly, or be present from birth. There is not one condition that can be described as the main cause of deafblindness: up to 70 known causes are reported to have been identified (Alsop, 2002; Bidenko & James, 1999), with as many as 30 syndromes thought to cause acquired deafblindness (Kimberling & Moller, 2003). In addition, many personal, environmental, communication and family factors are considered to affect an individual’s experience of deafblindness (Ward, 1996). Therefore great heterogeneity exists among people who are deafblind, and an individualised approach to service provision is considered imperative (e.g., Everson, 1995; McInnes, 1999).

The literature distinguishes between those with congenital deafblindness\(^1\) and those with acquired deafblindness. In the case of the latter, further categorisations are made regarding the order of impairment onset, creating three different groups (e.g., Aiken, 2000; Alsop, 2002; Godfrey & Costello, 1995; Hersh & Johnson, 2003; Lewis, 1998; Ward, 1996). First are those who are congenitally deaf and adventitiously blind, born deaf or hearing impaired and later acquiring blindness or vision impairment. The most common aetiology is Usher Syndrome (Aiken, 2000; Guest, n.d.; Kimberling & Moller, 2003). Second are those who are congenitally blind and adventitiously deaf,

\(^1\) Congenital deafblindness typically refers to those who experience both impairment of vision and hearing from birth or early in the developmental period.
born blind or vision impaired and later acquiring deafness or hearing impairment (e.g., Aiken, 2000; Everson & McNulty, 1995; Lewis, 1998). Third are those who are adventitiously deafblind, born with hearing and vision and later losing both through accident, illness or old age (Aiken, 2000; Alsop, 2002; Lewis, 1998).

There is support for the notion that diversity within the deafblind community creates a mixture of identities; many people do not necessarily consider themselves to be “deafblind”. A CAUSE research survey of 67 people with Usher Syndrome across Europe found that participants identified differently (Kilsby, 2003). Those with Usher Syndrome type 1 considered themselves “Deaf”, identifying with Deaf culture. As vision impairment advanced they tended to describe themselves as “Usher”, but not deafblind. Those with Usher Syndrome type 2 regarded themselves as part of the hearing world. As vision impairment worsened they described themselves as “hard of hearing and vision impaired”, more so than “Usher” or “deafblind”. Similarly, in a purposive survey sample of 73 deafblind people in Australia aged over 16, only 42% considered deafblindness their primary disability, while 25% identified deafness (Prendergast, 1996).

A qualitative study by Barnett (2001) identified that people do not typically describe themselves as deafblind for fear of misleading others about the nature of their loss. In e-mail interviews with 10 individuals with acquired deafblindness, Barnett (2001) found that unlike those in the Deaf culture, participants did not see deafblindness as a positive cultural label, rather as a negative disability label.

3.3.2. Living with isolation

The professional literature suggests that people who are deafblind live with various levels of isolation and that in fact isolation may be “an unavoidable reality” in their lives (Yoken, 1979, p. 157). Deafblindness has been referred to as “the most isolating condition” (Barrett, 1992, p. 393), and people who are deafblind are thought to “hunger for human companionship” (Smith, 1994, p. 28). Isolation is identified in three ways: isolation from information in the environment, isolation from the peer group and isolation from others who are deafblind.
Approximately 90% of information humans receive about the world is thought to come through vision and hearing (Deafblind Association Victoria, 2005c). A person with deafblindness can experience the world only through residual hearing and vision and by use of touch, smell and taste (Deafblind Association Victoria, 2005c). Deafblindness has been described as a disability of access (Alsop, Blaha & Kloos, 2000, cited in Alsop, 2002, p. 1), and the professional literature suggests that deafblind individuals’ experience of the world is narrow, effectively extending only as far as their fingertips (Miles, 2000, 2002).

Those with hearing and sight are able to learn incidentally, while those who are deafblind need to be strategically provided with information readily available to others (Aiken, 2000; Huebner, Prickell, Rafalowski Welch & Joffee, 1995; Lolli & Sauerburger, 1997). As a result, people who are deafblind are considered at risk of isolation from the world around them and are thought to participate best through direct experience and interaction (Barrey-Grassick, 2004; McLetchie & Riggio, 2002). Belanich (1995, p. 15) emphasised that in this “information age” people who are deafblind are at “serious disadvantage when it comes to accessing information”.

However, research has shown that individuals who are deafblind are not totally isolated from their surroundings. Rather, they use different methods to detect, localise and identify events and objects around them. Two studies have reported on how adults with acquired deafblindness compensate for lack of sensory information about their environment (Borg, Ronnberg, Neovius & Kjellander, 1999; Ronnberg, Samelsson & Borg, 2002). Both found discovery rather than localisation of persons and events to be most important. They reported that participants used residual vision, smell, airflow and residual hearing as sources of information, whereas use of vibratory and tactile information was unexpectedly low.

In earlier seminars on Usher Syndrome (e.g., Vernon, 1976), and in more recent research studies (e.g., Miner, 1995, 1997) the issue of isolation from one’s peers has been noted. Miner (1995, 1997, 1998, 1999; Roult & Miner, 1993), an experienced social worker in the area of Usher Syndrome, noted that as teenagers many people with Usher Syndrome type 1 start isolating themselves. On the basis of interviews
with 39 people, Miner (1995) reported that participants often lost friends in the Deaf community as decreasing vision affected their communication and mobility. In a later report on interviews with 32 people with Usher Syndrome type 2, Miner reported that both those from Deaf culture and those with hearing-sighted peers experienced marginalisation from their identity group (Miner, 1997, 1999; Vernon, 1976). Sauerburger (1993) suggested that the tedious and intimate nature of communication, fear of deafblindness by peers, and withdrawal on the part of the deafblind person who is reluctant to risk rejection are factors contributing to their isolation.

Isolation also extends to lack of opportunity for contact with others who are deafblind. For example, Barnett (2001) found isolation to be a factor in individuals’ choice of communication. Some participants did not try to learn sign language because they had no one to practise with. Typically, participants relied on people outside the deafblind experience, such as professionals, guides and family, who did not have signing skills. Similarly, Miner (1998, 1999) deplored the fact people with Usher Syndrome often grow up without meeting others with the condition. Instead they receive an underlying message that what is happening to them is “awful”, that significant others cannot bear to expose them to it, or that other people with Usher Syndrome “have nothing to offer” (Miner, 1998, p. 9). She argued that professionals need to recognise people with Usher Syndrome as the real experts and facilitate their coming together.

Few studies report on patterns of connection between deafblind adults. Perhaps to some degree because of the nature of sampling, individuals involved in research may be more likely to report contact with others. For example, of 17 people identified by the Royal Blind Society (RBS), the majority (n = 12) belonged to support groups for the blind or deafblind (Strategy & Planning Department RBS, 1996).

3.3.3. Psycho-emotional vulnerability

The idea that people who become deafblind should grieve their loss and access counselling is a commonly expressed view in the professional literature (Adler, 1987; Cumpston-Bird, 1993; Miner, 1995, 1997, 1999; Scott, 1998; Sherlock, 2000; Tedder, 1987; Vernon, 1976). Some authors have suggested, however, that
professionals’ interest in psycho-emotional coping may be related to their own discomfort with the idea of living with deafblindness (e.g., Anderson, 1976; Miner, 1999; Scott, 1998).

In two separate interview studies with people who have Usher Syndrome type 1 and 2, Miner (1995, 1997) used a life cycle approach to describe the psycho-social implications of Usher Syndrome at various life stages. Her research emphasised the constant need for adaptation throughout the life cycle due to the progressive nature of Usher Syndrome (see also Ronnberg & Borg, 2001; Tedder, 1987).

Importantly, Miner’s research (1995, 1997) highlighted the fact that psycho-emotional concerns emerge not as some intrinsic component of deafblindness but in relation to social roles and environments. Adler (1987) similarly acknowledged that acceptance and psycho-social coping could be impacted by the attitudes of those close to the individual, and influenced by wider societal acceptance and accessibility. Miner (1995) suggested loss of roles to be an important psycho-social issue. For example, people with Usher Syndrome may not feel they can become parents due to the risk of children also having the condition. In addition they may no longer be able to drive or read. Miner (1995) wrote, “The world becomes smaller and smaller, and their isolation, lack of stimulation, and grief are overwhelming” (p. 293). In particular, young adulthood was a time of concern as participants had fears about making choices while facing an uncertain future (Miner, 1995, 1997). Depression and suicidal ideation were reported by many in both studies. However, several persons with mental health problems were ignored by professionals, who assumed that those symptoms were “normal” for people who are deafblind (Miner, 1997, p. 586).

There is some indication that people who are deafblind may experience psychiatric problems. Case studies have been reported including one documenting a psychotic illness in a 50-year-old man with Usher Syndrome type 1 (Hess-Rover, Crichton, Byrne & Holland, 1999) and another documenting psychiatric treatment of a deafblind woman with a high rate of self injurious behaviour (Luiselli, 1991). Thirty years ago, Rainer (1976) provided statistics that 11 out of 200 patients admitted to a Mental Health Program over a 12 year period had Usher Syndrome. The majority
(10) showed improvement on medication and many (8) were successfully rehabilitated through the Helen Keller National Center.

3.3.4. Communicating differently

People who are deafblind find it difficult to communicate in auditory and visual forms, and often use touch uniquely to communicate, explore the environment, and access information (Barnett, 2001). Not surprisingly, communication issues dominate the professional literature. Many guidelines have been published outlining what to consider when communicating with a person who is deafblind (e.g., Barrey-Grassick, 1998; Jolley, 2002; Kilsby, 1997; Morgan, 1998; Petronio, 1988; Sauerburger, 1993; Smith, 1994; Snider, 1994). Petronio (1988), for example, made useful suggestions for interpreters based on interviews with 10 deafblind college students and observations of interpreting situations. She emphasised the importance of establishing signing preference, considering sign modifications, and providing the deafblind person with visual information. This latter element has become a distinct feature of deafblind interpreting and is considered essential to allow them equal participation in a social setting (e.g., Jolley, 2002).

Researchers have identified diversity in the communication methods of people who are deafblind. In surveys of adults, sign language and speech were found more common than tactual methods such as hand over hand, hand over hand is tactual sign language where the receiver places both hands over the hands of a person who is communicating using Auslan or Signed-English and receives the signed information through touch rather than vision (DeafBlind Association Victoria, 2005c)., finger spelling or Signed-English (e.g., Burton, 1990; Prendergast, 1996; Sense, 2005; Strategy & Planning Department RBS, 1996). The majority of survey respondents reported they were able to read using large print, Braille, or normal print.

12 Hand over hand is tactual sign language where the receiver places both hands over the hands of a person who is communicating using Auslan or Signed-English and receives the signed information through touch rather than vision (DeafBlind Association Victoria, 2005c).

13 Finger spelling is the spelling of individual sign letters rather than full words. It is similar to the two-handed manual alphabet used in Auslan and Signed English but is modified with information given on the palm and fingers of the person who is deafblind (DeafBlind Association Victoria, 2005c).

14 Signed-English is sign language which directly represents spoken English. This gestural language has all the grammatical markers and structures of the English language (DeafBlind Association Victoria, 2005c).
Aside from survey studies documenting communication methods, there has been exploration via interviews of how Deaf people cope as they lose vision. Reed and Floyd (1998) reported that participants became tired, had difficulty with lip reading, and experienced confusion in communication, typically finding sign language too fast.

A second interest has been exploring how language structure varies between tactile and visual modes of sign language, through observation or video-recording of communication exchanges (e.g., Frankel, 2002; Quinto-Pozos, 2002; for useful reviews see Fuglesang & Mortensen, 1997; Mortensen, 1999). Researchers have reported evidence that in tactual exchanges deafblind people use different feedback channels (e.g., finger taps and hand squeezes), show changes in signing space and greater use of Signed-English and finger spelling compared with visual sign language (e.g., Frankel, 2002; Quinto-Pozos, 2002; Mesch, 1994, cited in Fuglesang & Mortensen, 1997, pp. 5-6).

A third area of interest has been observation and self-reports of the speed and accuracy of tactile methods of communication (e.g., Fuglesang & Mortensen, 1997; Reed, Delborne, Durlach & Fischer, 1995). Similar levels of accuracy have been found in tactual sign language (hand over hand) and manual alphabet (finger spelling) users, with both methods proving slower than speech. However, questionnaires conducted with 78 persons through the Acquired DeafBlindness Network in Europe (Fuglesang & Mortensen, 1997) revealed that over 70% of respondents considered their communication methods accurate and fast enough.

3.3.5. Benefits of equipment and technology

Many authors have suggested that computers and other assistive equipment can reduce isolation and improve functional independence for people who are deafblind (e.g., Belanich, 1995; Hersh & Johnson, 2003; Jaun, 2003; Moller, 2003; Noonan, 1997; Sasse, 1997; Tarrant, Hocter & Telfeson, 2002; Trentini, 2000; Ward, 1996). For example, some people have received benefits from cochlear implant technology (e.g., Aplin, 1993) or hearing aids (e.g., Burton, 1990; Prendergast, 1996; Sense, 2005).
In terms of assistive equipment, a variety of possibilities ranging in sophistication are presented in the literature. People who are deafblind may be able to use a computer with magnification or Braille, devices like closed circuit televisions,\(^{15}\) scanners,\(^{16}\) vibrating object sensors to assist mobility, vibrating alarm clocks, vibrating liquid levels, or Braille printers (e.g., Belanich, 1995; Bryce & McMinn; Hinton, 1989; Hersh & Johnson, 2003; Lolli & Sauerburger, 1997; Mandy, 2002; Sauerburger, 1993; Ward, 1996).

The results of studies of assistive technology use are mixed. In recent research into the leisure preferences of 51 adults who are deafblind, only 29% used computers while many more (57%) indicated a desire to (Lieberman & Stuart, 2002). In Australian survey research only small numbers of participants have indicated computer use (Prendergast, 1996; Strategy & Planning Department RBS, 1996). In the broader CAUSE survey, Kilsby (2003) reported equipment provision to be inadequate, with only the more affordable equipment items (e.g., alarm clocks rather than vibrating pagers or Braille-adapted computers) likely to be used by people with Usher Syndrome.

Sense, a charity supporting people who are deafblind in the UK, recently conducted a large survey on technology use. While the majority (79%) of 326 respondents reported that they made use of assistive technology, 45% reported difficulty in doing so (Sense, 2005). Expense of items, difficulty keeping up with new developments, and the trend toward smaller technology were concerns noted by participants. In addition to difficulty using assistive technology, 59% of participants highlighted difficulties using common household equipment such as cookers and washing machines. A former survey of technological needs in the United States similarly found that the majority of respondents used multiple technology devices, though only

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\(^{15}\) Closed circuit televisions are known as CCTVs. They contain a camera that when placed over printed material magnifies it up to 50 times on a television monitor.

\(^{16}\) Scanners allow printed material to be scanned into a computer and stored in computerised form. Information can then be converted to speech by optical character recognition software and speech synthesiser, or viewed through magnification software, or converted to Braille if the computer is suitably adapted.
a minority used computers (Gilden, Fowle, Jampolsky & Simon, 1994). Gilden et al. suggested that getting information to deafblind people about what is available may be a barrier to more widespread computer use.

Jaun (2003) and others (e.g., Gafga, 1997; Hersh & Johnson, 2003; Sense, 2005) have cautioned that while technology can open up opportunities for people who are deafblind it can also create new dependencies. Commonly available technologies are not typically user-friendly for people without hearing and vision, making coordination between providers and special needs users necessary to ensure that technological developments do not further exclude people who are deafblind (Gafga, 1997; Hersh & Johnson, 2003; Hinton, 1989; Sense, 2005).

3.3.6. Restricted participation in the community

The professional literature provides advice on guiding or training people who are deafblind in regard to mobility (e.g., Franklin & Bourquin, 2000; Kilsby, 1997; Lolli & Sauerburger, 1997; Sauerburger, 1993, 1997; Smith, 1994; Snider, 1994). Aspects of orientation and mobility typically emphasised include instructor communication with the person who is deafblind, facilitating communication with the public, extra care for street crossings, and increased emphasis on the use of remaining senses (e.g., Armstrong, 1995; Bourquin 1996; Franklin & Bourquin, 2000; Lolli & Sauerburger, 1997; Sauerburger, 1993, 1997).

Survey research has shown that people who are deafblind find community activities difficult to participate in and/or require assistance to mobilise in the community (e.g., Burton, 1990; Prendergast, 1996; Strategy and Planning Department RBS, 1996). Prendergast (1996), for example, reported that the activities considered most difficult by the majority of 73 survey respondents included shopping, communication and transport use. In a smaller Australian study (Strategy & Planning Department RBS, 1996) of 17 adults, almost half (n = 8) reported the need for a guide to accompany them when out and the majority (n = 14) indicated difficulty crossing roads.

There is little information regarding the extent to which people who are deafblind participate in education and employment in the community. Survey findings report
employment rates ranging from as low as 8% (Sense, 2005) up to 50% (Lieberman & Stuart, 2002). Professional anecdotes suggest that people with Usher Syndrome, while often intellectually able with good qualifications, are commonly under-employed or retire early when sight loss creates difficulties (Guest & Ellis, 1998).

In a report entitled “European guidelines on combating the social exclusion of deafblind people” Simms (n.d) indicated that people who are deafblind experienced low employment rates throughout Europe. While the number of adults interviewed as background to the report was not made clear, Simms reported that 50% of participants from Portugal (12% from Italy and 10% from the UK) believed they were refused a job, or felt forced to leave a job (50% from Portugal, and 37% from Italy) because of their impairments.

3.3.7. Living with dependency

Survey studies have indicated that large numbers of people who are deafblind live in private homes in the community (e.g., Sense, 2005) and depend on assistance from family and friends over long periods of time (e.g., Burton, 1990; DeafBlind UK, 2004a; Kilsby, 2003; Prendergast, 1996).

A survey conducted in Northern Ireland found high levels of dependency among a predominately older sample in which 75% of 42 respondents were over age 60 (DeafBlind UK, 2004a). More than half of the participants had carers who were family members, while only 22% had carers provided through social services. Support was provided for cleaning, shopping, communication, transport, information, and personal care. Similarly, Kilsby (2003) reported high levels of support required among 67 respondents of the CAUSE survey. The majority of support was received from family or friends, or less commonly, volunteers and professionals. Again, in the Australian survey (Prendergast, 1996), while respondents indicated that support was provided from multiple sources, family support was reported most commonly. Although support was received for a range of practical care tasks, many respondents wanted and did not receive support for transport and companionship.
Need for one-to-one support for adults who are deafblind is acknowledged by professionals yet inconsistently recognised by governments, and the availability of formal support services varies internationally. Simms (n.d.) noted that in the UK, 100% of those involved in survey interviews had access to a paid communicator-guide to assist with mobility, information and communication. In Portugal, however, where no such service was mandated, no participants had access to such support, and in Italy only 50% did. In other countries such as Denmark, innovative support programs including the provision of “social interpreting” beyond the traditional educational and work contexts have been piloted (Jansbol, 1999a).

Very little research has been conducted regarding the nature of support relationships beyond descriptive statistics about the source of support or the duties performed. When asked if they felt receiving support from a family member placed stress on their relationships, approximately 40% of participants in the CAUSE survey answered in the affirmative (Kilsby, 2003). In interview surveys with 52 adults and 28 carers in Greater Manchester, Burton (1990) noted that 50% of carers reported problems of relationship with the person they were supporting. Romer and Schoenberg (1991) drew attention to domination issues in support relationships. In a descriptive study of communication behaviour between staff and deafblind “mentally retarded” group home residents, they reported that communication was dominated by staff and was directive, with the aim of behavioural compliance.

In sum, the main emphasis of the professional literature has been on the functional effects of the combined impairment. Deafblindness is recognised as an isolating condition, restricting adults’ participation in the community. Adults who are deafblind are thought vulnerable to psycho-emotional problems and are known to depend on other people for support with practical tasks and communication. Adults who are deafblind communicate differently and could, and sometimes do, benefit from equipment and technology.

The following chapter begins Section 2 of the thesis, “(My) ways of thinking and doing research”, where the methodological philosophies and actions applied in this research are described in four chapters. In Chapter 4, the social constructionist
epistemological assumptions and symbolic interactionist theoretical framework are explained. Grounded theory is described and fieldwork methods introduced prior to an outline of ethical considerations. Chapter 5 details the processes of fieldwork as experienced through participant observation and interviews. Chapter 6 introduces the participants and researcher and describes the journey undertaken. Chapter 7 provides a detailed summation of the data management and analysis procedures used in developing the theoretical framework of negotiating a place.
Section 2

(MY)
WAYS OF THINKING AND DOING RESEARCH
4.1. Epistemological issues

According to Crotty (1998) and others (de Laine, 1997; Taylor & Bogdan, 1998), decisions a researcher makes regarding theoretical approaches and research methods are informed not only by pragmatic concerns but also by the researcher’s philosophical beliefs about the social world. I came to use symbolic interactionism as a theoretical perspective, grounded theory as a methodology, and participant observation and interviews as methods in this research by considering my beliefs about the nature of existence/reality, and how reality can be known (Crotty, 1998; de Laine, 1997).

In conducting this research I subscribed to a social constructionist epistemology, based on a combined realist and relativist ontology (Crotty, 1998). Thus, I believe reality is a complex world of lived experience, “constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, 1998, p. 42). Meaning emerges only when consciousness engages with objects of the world. Objects do not have inherent meaning but neither is meaning created just in our minds, independent of objects. Rather, meaning is constructed in the interaction of object and subject. Individuals do not merely discover a given reality, but actually construct a reality for themselves through the active process of interpretation and in the choice of action undertaken in interaction. This means that individuals are active in constructing their own reality. Thus there are multiple realities rather than one true reality, because meanings may be constructed differently by different people. It is important to note, however, that individuals act from an already embedded position within a pre-established “world of meaning” which can inform and blind their interpretations of reality (Crotty, 1998, pp. 53-4).
This social constructionist epistemological position contrasts with a positivist approach that seeks facts or causes apart from the subjective states of individuals. Positivist thinking has its roots in the study of inanimate objects, and is concerned with pursuit of a single external reality, based on an objectivist epistemology (Crotty, 1998). I concur with Guba and Lincoln’s (1994) assessment that such an approach is inappropriate for the exploration of personal experience, where I believe multiple realities, active construction of meanings, and the social context in which people act all need to be acknowledged.

Given these epistemological underpinnings, I brought a number of assumptions to this research, including:

- Deafblindness is a diverse human experience rather than an objective reality experienced by all people in the same way. Individuality of experience needs to be embraced rather than seen as a source of error in research.

- Individuals who become deafblind bring their own perspectives and meanings to their experience. These are historically and contextually based, embedded in the pre-existing systems of meaning active in their social world. Therefore it is important to take a naturalistic approach to research, which allows access to an individual’s naturally occurring everyday life contexts. Equally it is important to pay attention to the “sedimentation” (Crotty, 1998, p. 59) or layers of meaning that form the individual’s context (de Laine, 1997; Denzin & Lincoln, 1994; Lincoln, 1992).

- People who become deafblind are active in creating a reality for themselves and are experts on their own reality. Individuals who take part in research are thus active participants in the research process rather than passive subjects.

- Through close acquaintance and interaction it is possible to learn about the world of people who become deafblind. However, this understanding is necessarily a partial one, gained from an interpretive process, constructed from one’s position as the researcher.
4.2. Symbolic interactionism

The theoretical perspective underlying the methodology adopted in this research was symbolic interactionism, which is consistent with a social constructionist epistemological position. Symbolic interactionism is a theory of human conduct and group life focused on the acting individual, perceiving the individual as determining rather than determined (Blumer, 1969). Symbolic interactionism emphasises the social construction of reality from symbols and interaction, and individuals as active participants in creating meaning. It is based on the following three premises:

1. Humans act toward things on the basis of meanings they have for them.
2. Meaning is derived from the social interactions people have with each other. Meanings are social products which grow “out of the ways in which other persons act toward the person with regard to the thing” (Blumer, 1969, p. 4).
3. Individuals manage and change meanings through an interpretive process. That is, human beings have to interpret the world in order to act.

Central concepts of symbolic interactionism include the self, the world, and action. The self is active. It is constructed through interaction, by viewing oneself from the position of others. Individuals can recognise themselves as various objects (e.g., woman, student, partner) and can act toward themselves on the basis of these perceptions (Blumer, 1969). Thus, the way people who become deafblind see themselves and act is socially constructed from how they recognise themselves through the views they understand others to have of them.

Worlds or environments of individuals are composed of objects that individuals recognise and know. These objects are anything that can be indicated or referred to, and can be physical, social, or abstract (Blumer, 1969). Each person’s world has its own objects which may or may not be shared with other people. Therefore people who become deafblind may be living side by side with others yet be living in “different worlds” (Blumer, 1969, p. 11).

Individuals must interpret the world in order to act (Blumer, 1969). Society consists of persons acting with one another, that is, taking account of what each other is
doing and engaging in non-symbolic and symbolic interaction (Blumer, 1969). Joint action refers to a collective form of action accomplished through individuals fitting their courses of action together (Blumer 1969). It is always designed and conducted in complex dynamic social contexts. Therefore observation and interpretation in such contexts is considered important in researching the empirical world.

Blumer (1969) noted that in the symbolic interactionist approach, social life should be studied through first-hand observation, through exploration followed by theoretical inspection. According to Blumer, reality is the “world of everyday experience” as it is known through individual perception (p. 35). It must be understood by developing close acquaintance with the sphere of social life under study and the different worlds of individuals involved. As a researcher I understand myself to be an outsider to the worlds of people who become deafblind, and that there are “levels of happening that are hidden” (Blumer, 1969, p. 39) to all participants in this research, including me. Understanding gained through a study such as this is necessarily partial and situated.

Symbolic interactionism is associated with the University of Chicago and over the years has been popularly applied as both a theoretical perspective and a methodological strategy in relation to understanding disability. Work by Goffman on stigma and the management of spoiled identity (1963) emerged from the Chicago School in the 1960’s. This work has been influential in medical sociology in particular, encouraging attention to issues like biographical disruption (Bury, 1982) and loss of self (Charmaz, 1983) bought about by the effects of chronic illness

17 Applying a social relational understanding of disability, this study sought to explore the everyday lives of adults who become deafblind in a broader way than simply focusing on individual adaptation to impairment or changes in self perception. In light of this, detailed discussion of applied symbolic interactionist literature focused on identity issues was not the intention of this thesis and was considered beyond the scope of this thesis. Such work is predominantly located within the field of the sociology of chronic illness and disability, which Thomas (1999a, p. 146-153) explains has a different understanding (from that adopted within disability studies) of both disability and experience.
Goffman (1963) highlighted three different types of stigma, one being abominations of the body. He “drew a stark picture of strained relations” (Gill, 2001, p. 355) between impaired and non-impaired people. He emphasised that those with “discredited” or “discreditable” stigmas had to ward off devaluation caused by their classification as less than normal (Goffman, 1963). However, within disability studies, his work has been criticised for representing disabled people as passive victims of devaluation (Thomas, 1999a). In addition, Goffman (1963) focused on only one strategy, that of trying to “pass” as normal, and failed to critique the behaviour of the so called “normals” (Wan, 2003). This narrow focus does not sit well within disability studies, and as Wan (2003, p. 283) has noted, there has been a shift from a focus on “spoiled identity” to a critique of the “identity spoilers”.

4.3. Grounded theory methodology

Grounded theory is consistent with the symbolic interactionist theoretical framework and social constructivist epistemological position adopted in this research. Firstly, grounded theory seeks to develop theory from data. While the process involves both induction and deduction, induction is given priority (Strauss & Corbin, 1990), reflecting belief in the expertise of the participants: it is the participants’ interpretations and constructions of their realities that are the focus of concern, not categories imposed by the researcher. Secondly, individual differences are embraced as opportunities for better developing variation in the theory (Strauss & Corbin, 1990), indicating a respect for the multiple realities of participants. Finally, grounded theorists consider that people act for reasons rather than causes (Glaser & Strauss, 1967; Minichiello, Aroni, Timewell & Alexander, 1995), and value interpretive explanation as a means of explaining processes by which people interpret and construct their own reality.

Grounded theorists search for social processes present in human interaction, aiming to understand how a group of people define their reality via these interactions
Glaser and Strauss (1967) suggested that grounded theory can proceed at either substantive or formal levels. Substantive theory is developed from and for an empirical area of study. Formal theory extends on this, comparing a number of substantive cases to develop theory for a conceptual area of sociological inquiry. In this research the task set was to develop a substantive level theory of the everyday experiences of people who become deafblind.

The approach to grounded theory taken in this research drew on a combination of advice from Glaser and Strauss’ (1967) original presentation of the method, as well as their subsequent publications (e.g., Corbin & Strauss, 1990; Glaser, 1969, 1978, 1992, 1996, 1998; Glaser & Strauss, 1967; Kendall, 1999; Melia, 1996; Strauss &
Corbin, 1994, 1998). Glaser and Strauss have grown apart amidst some controversy, and their later writings reflect differing views on the application of grounded theory. Glaser (e.g., 1992) has remained critical of Strauss and Corbin’s (1990) increasingly complex set of operations and procedures intended to guide the researcher through the process of developing grounded theory. Strauss and Corbin (1990, 1998) introduced a paradigm approach to coding involving axial coding, which Glaser believed diverted attention from data to procedures, encouraging looking for data (forcing) rather than looking at data (emergence) (e.g., Annells, 1997a; Glaser, 1992; Seale, 1999; Strauss & Corbin, 1990, 1998).

In my application of the grounded theory methodology I attempted to use suggestions by both Glaser and Strauss as a means to an end; as tools to assist me to think theoretically about data. I disagree with Glaser’s resistance to the paradigm approach and also with his assertion that grounded theory is merely a method and is neither constructionist nor objectivist (1992, 2002). Like Charmaz (1990, 2000), I consider the way I apply grounded theory to be informed by the social constructionist epistemological underpinnings I brought to the research. That is, I appreciate that the collecting of data, the development of ideas emerging from the data, and the analytical procedures undertaken with data have not been researcher-independent. In this way, as the researcher, I became the research instrument and all interpretations were developed through me. Figure 4.1 is an attempt to represent the dialectic between data and researcher as I experienced it.

As indicated by Figure 4.1, in this research I do not attempt to account for the reality “out there” for people with deafblindness. Rather, I construct an interpretive account of recounted experiences, interpreted from a particular positionality. This thesis essentially communicates the partial understanding I have gained as a researcher in a particular historical and social context, undertaking the research in a particular way, and bringing my background and frames of reference to my understanding. The perceptions of participants as expressed by their words and observed in their actions constitute data. In recounting their experiences, participants engaged in an interpretive activity. I then re-interpreted their accounts in my immediate response to them, and in thinking and working on the data later.
Observational data was usually interpreted only through my own lens, except if I asked participants to reflect on their own behaviour.

Figure 4.1 Different aspects of the research process interacting to develop a thesis

4.4. Practical strategies of fieldwork

According to Crotty (1998) and Savage (2000), a hierarchically interdependent relationship is formed between epistemology, theoretical perspective, methodology, and research methods. Figure 4.2 indicates how each level informs the next throughout the research process. In Figure 4.2 the relationship between the basic elements is indicated in red, while the corresponding choices made in this research are indicated in yellow. As suggested by the figure, the chosen methods of participant observation and interviews were informed by underlying epistemology, theoretical perspective, and methodology already discussed.
Participant observation and interview methods allowed me to focus on the interactive (processes, activities and acts) and the interpretive (definitions, perspectives, meanings) aspects of deafblind individuals’ daily lives (Grills, 1998). Principles identified as valuable were the importance of immersion and extended time in the field to develop rapport with participants and gatekeepers, my own communication skills, and knowledge of the specific culture. Following Wolcott (1995), fieldwork was defined as the time I spent in the field: participating, observing and interviewing. It was experienced as a wholehearted commitment, characterised by my personal and emotional involvement to achieve some level of understanding.

Below and in subsequent chapters, the fieldwork strategies are somewhat artificially divided into participant observation and interview components. In reality, both types of data collection strategies overlapped in fieldwork. That is, observations were involved in interviews, and informal discussions were shared during periods of participant observation. They are separated in the thesis for ease of presentation only.
Participant observation, as an aspect of fieldwork, has been defined as regular participation in the naturally occurring activities of the social groupings being studied (Emerson, 1981). It facilitates the discovery of subjective meanings of group participants. Fieldwork repositions the researcher “in such a way as to allow for questioning that would otherwise not be available” (Grills, 1998, p. 10). It involves going to the action and knowing the world of the other through direct involvement with it. This occurs by pursuing “an intimate familiarity with the ‘world of the other’ through getting close to dilemmas, frustrations, routines, relationships, and risks that are part of everyday life” (Grills, 1998, p.4). Research data collection components 1A, 1B, and 1C detailed in the following chapter allowed my intimate re-positioning from what was initially an “outsider” position to what became an “alongside” position.

Using participant observation in a symbolic interactionist study allowed me to consider important aspects of interaction that are potentially neglected, as de Laine (1997) suggested, if only interviews are conducted. Although language is an important aspect of symbolic interaction, I also considered dimensions of appearance, spatiality, and experiential perception to be important. Use of participant observation in addition to interviews allowed me to derive knowledge from multiple contexts, through multiple senses and interpretations, adding to the complexity of understanding gained (Savage, 2000). In this research I valued my role as the research instrument, and recognised meaning was co-constructed between myself and participants. Thus, my subjective experiences were valued as data, acting alongside and informing the collection of observational and interview data.

In-depth or unstructured interviews are those where both the question and answer categories are not pre-determined, and social interaction is relied upon to generate knowledge and elicit information (de Laine, 1997). Ramos (1989) described in-depth interviews as shared experiences where researchers and participants join to create a context of conversational intimacy in which participants feel comfortable telling their story (cited in Corbin & Morse, 2003, p. 338). The researcher is
perceived as active and reflexive in the process of data generation, though not central (Mason, 2002).

In-depth interviewing provides a means through which to access and understand individuals’ private interpretations of social reality (Minichiello et al., 1995; Patton, 1990), by inviting talk about topics conceived by the participant (Ezzy, 2002; Kaufman, 1994; Patton, 1990). In-depth interviews usually take the form of repeated face-to-face encounters between researcher and participants, and are characterised by an interview process that is conversational rather than interrogative (Taylor & Bogdan, 1984, cited in Minichiello et al., 1995, p. 68). Interview data collection components 2A and 2B are detailed in the following chapter.

4.5. Ethical considerations in fieldwork

Ethical approval to conduct the research was received from the University of Sydney Human Ethics Committee late in 2002 (see Appendix 1). Ethical approval was renewed each year on the basis of progress reports provided to the same Committee (Appendix 2 & Appendix 3). Print copies of Participant Information sheets and Participant Consent forms are provided in Appendix 4 and Appendix 5.

Five main ethical considerations were considered in designing and implementing this research, all of which are alluded to in subsequent method discussions. However, to be clear, they are summarised below.

The voluntary nature of participation and the individual’s right to withdraw at any time were communicated in person and documented in information supplied to participants. Each person was given a choice of whether to participate in one or more of the data collection components used in this research. Participation was therefore negotiated throughout different phases of the research and not assumed to continue from previous contacts. For example, each time an interview was requested, participants were asked if they would be happy to continue participation by attending another interview. In cases where access to potential participants was
sought via other organisational bodies such as the DeafBlind Association or the e-mail list, I emphasised that the research was independent and that those organisations would not be privy to who was participating.

Participant information sheets and informed consent agreements were made available in whatever format a potential participant required. This included Braille, large print, electronic, and in-person exchange via an interpreter. Written informed consent, including Braille, was gathered where possible. Verbal consent or electronic consent was also considered sufficient if written consent was not appropriate to the participant.

All efforts were taken to ensure that the requirements of participants were met in the best possible way to maximise their participation in the research process. For example, when the use of an interpreter was required for one participant, I asked him to nominate a preferred interpreter. When he did not specify one, I arranged a professionally accredited interpreter at no cost to him, and informed him who it was before proceeding with arrangements. In this instance, where an interpreter was used, care was taken to adhere to the national guidelines for interpreting (Barrey-Grassick, 1998), such as ensuring that 10-minute rest breaks were taken every 50 minutes. Additionally, in cases where e-mail was a participant’s preferred communication medium, this was embraced. For example, following the interpreter-assisted interview this participant declined further face-to-face interviews but was happy to have some clarifying e-mail exchanges, so this is what we did.

To ensure safety, interviews were undertaken at a location of the participant’s choosing, which was most commonly the participants’ home. This was anticipated, given the mobility challenges faced by people who are deafblind in unfamiliar environments. Participants were invited to have another person present if desired, though none chose to do so.

For confidentiality, all data were coded from the time a participant agreed to participate in the research. The majority of interviews were audio-recorded with the
participant’s permission. To ensure identifying information could not be inadvertently witnessed by others, identifying information was erased on transcription, as recommended by Sullivan (n.d.). On one interview occasion I underestimated the length of the meeting and ran out of tapes. Notes were taken in that instance. In another interview, the participant involved needed to go shopping so we abandoned tapes, which were impractical while out in the community, and instead fieldnotes were taken upon return. For e-mail participants, identifying information was removed as text was copied from the e-mail program to a word-processing program. The e-mail was then deleted from the e-mail mailbox. Each participant agreed to a pseudonym for the thesis report and any research documentation. Files/transcripts were stored in a locked file cabinet to ensure privacy. Electronic records of data, including fieldwork journals, transcripts and appointment schedules, were collated within password-protected computer files.

4.6. Synopsis

This chapter introduced the theoretical underpinnings of the research in which a social constructionist epistemology was embraced. Symbolic interactionism as a theoretical perspective guided a methodological focus on the self as active, the existence of different worlds consisting of objects (given meaning through interactions) and joint actions.

Grounded theory was chosen as a methodology and provided a framework for exploring social processes in human interaction. Grounded theory emphasises the importance of exploring everyday situations to develop theory about a substantive area. Participant observation and interviews were the methods of choice to facilitate the process of grounded theory.

The ethical issues that guided the conduct of fieldwork included care taken to establish voluntary participation, adaptations to support participants’ requirements, action to ensure participants’ safety and steps taken to establish and maintain confidentiality.
The following chapter explains the guiding principles of grounded theory methodology operationalised throughout this research. Also the practical processes undertaken to engage in participant observation and in-depth interviews are explained.
5.1. Procedural principles underlying grounded theory

In this chapter I describe the key components of grounded theory identified from the literature, and how I adhered to them in my application of the methodology (see Annells, 1997a, 1997b; Creswell, 1998; Glaser 1992; Glaser & Strauss, 1967; Grbich, 1999a, 1999b; Smith & Biley, 1997; Strauss & Corbin, 1990, 1998).

5.1.1. Theoretical sensitivity

This term refers to the researcher’s familiarity with the research topic and context, which provides the local awareness to recognise and name concepts. Theoretical sensitivity can stem from professional and personal experience, the literature and the analytic process, as well as knowledge of possible coding families.

To gain theoretical sensitivity I engaged in a number of activities I called “pre-fieldwork experiences”. Prior to commencing the PhD I attended a four-day information course coordinated through the DeafBlind Association and the Royal Institute for Deaf and Blind Children in NSW. This course provided an opportunity to meet people who were deafblind and learn about different communication methods. From there my research interest in the area of deafblindness developed.

Once I commenced my candidature I engaged in various activities to enhance my theoretical sensitivity. Firstly, as mentioned in Chapter 1, I attended the July 2002 National DeafBlind conference during the early stages of my candidature. Here I became aware of the concepts of different-ness and learning and living through experience.

Prior to data collection I attempted to conduct a focused literature review on deafblindness and found very little literature through the usual professional
databases (July – October 2002). Most literature focused on education and was restricted to ideas around communication development in congenitally deafblind children. In addition there were medical articles outlining types of Syndromes or genetic research. I became conscious of two dominant discourses. The first, a medical discourse, situates deafblindness as an abnormality of the auditory and visual body systems and seeks to manage it through medical investigation, prevention, cure or restoration. The second, which might be called a professional discourse, understands deafblindness as an educational and functional challenge, and seeks to enhance the abilities of the individual by making up for the negative impact of the condition on development and function through specialist intervention.

The dominance of these discourses motivated me to persist with designing research focused on the perspectives of adults with deafblindness. The voices of these people formed a third and less dominant discourse in the literature, which I explored more fully during the research rather than at the beginning. Another event strengthened my resolve. In August 2002 I met with a professional recommended as an expert in the area of sensory disability. We discussed the idea of conducting qualitative research with adults who become deafblind. Despite some involvement with the deafblind community, he advised against doing research with them for fear I would “get nothing from them”. Rather, he recommended I explore the perspectives of professionals working in the area. This attitude emphasised the dominance of professional discourse, and suggested that the voices of adults with deafblindness were not necessarily recognised as valid. In hindsight, this was an introduction to the concept of perceptions of others.

I began to focus on methodological issues, enrolling in a qualitative research elective at the University of Sydney from August – November 2002. This introduced me to concepts of epistemology, theory, and methods. I was exposed to examples of qualitative research, theoretical debates in the literature, and conceptual thinking. I decided to apply a grounded theory methodology and read both instructive literature (Becker, 1993; Charmaz, 2000; Dey, 1999; Glaser, 1978, 1992, 1998; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1994, 1998) and

As part of the course requirements I conducted a pilot interview with a deafblind man, to build my qualitative research skills. This interview experience alerted my interest to issues such as transition, identity, and self presentation. In addition, concepts of isolation and aloneness, different-ness, interaction and communication, feeling limited and dealing with change were identified.

Hoping for more opportunity to mix with people who were deafblind, I attended a communication workshop in September 2002. However, this was a professional conference where I was introduced to professional perspectives and the importance placed on the distance senses in the development of communication. Throughout the workshop, the importance of direct experience, information clarity (the distinction between sensation and perception), and communication as “shared experience” rather than simply language, were emphasised. I also had the opportunity to be blindfolded and ear-plugged, becoming “deafblind” for a short while. In this experience I became very self-conscious, and concepts of privacy, vulnerability, touch and consistency emerged for me.

I attended a tactile finger spelling course in November 2002 and was disappointed to find the instructor to be the only attendee to be deafblind. The remaining participants were education professionals, from diverse geographical areas, who had contact with perhaps a single student with deafblindness. This directed my attention to the small numbers of people who are deafblind and the practicalities of accessing them. I enjoyed watching the process of the training as it was conducted through the use of interpreters, but had no opportunity to interact directly with the deafblind teacher. The concept of inter-linkers, communication, community and invisibility were observed.

In the same month I attended a monthly meeting of the DeafBlind Association, requesting their support for this research and permission to use their social group
for fieldwork. Here I observed deafblind persons interacting as a group. Many concepts were raised, including dependence, filtering of information, pace, influence, and equipment. Volunteer interpreters ran late and some members missed out on information which had to be filtered down by inexperienced volunteers. The pace of proceedings was noticeably slow, and some non-deafblind members, meant to be facilitating the participation of the deafblind people, were clearly impatient. Despite the slow pace, interpreters struggled to transmit information and became flustered. A number of different equipment items were in use, and much organisation had gone into the logistics of setting up the room. The voluntary nature of the supporters was noted, and discussions about funding, or lack thereof, were dominant.

In December 2002 I travelled interstate to visit a computer training centre for people who are deafblind. I observed and attempted interaction with a few service users, who were independently operating computers to access information, e-mail with others and convert printed items to Braille. I also spent time with the staff person who was positive about the potential of computers to allow access to the broader world. She commented that a number of users had become angered when they realised how much information they had been missing previously. She also stressed the importance of the way the centre was run in terms of the autonomy given to users, who had their own key and could come and go as they please. During the same trip I visited a service provider at a local blindness organisation. She spoke about people who are deafblind living in an “inward world”, and perceived them to be “demanding” in the way they interacted. Various concepts were noted, including accessibility, independence, control, equipment, the perceptions of others’, missing out, and the inward world. This experience importantly pointed to the potential for e-mail data collection methods.

5.1.2. Theoretical sampling

The practice of seeking additional material driven by the need to enhance exploration of concepts being identified in the data is known as theoretical sampling. It can be applied prospectively or retrospectively, and both methods were applied in this study. In prospective theoretical sampling, new contacts believed to
be able to contribute data to assist ideas are sought. In retrospective theoretical sampling the existing data are reviewed to fill gaps in theoretical understanding or add to concept development.

When I had recruited and conducted initial interviews with only two participants, the concept of dealing with a changing self was coming strongly to the fore. On the basis of this, I made the decision to focus on recruiting participants who were “becoming” deafblind. I began prospective theoretical sampling on this basis, being interested in the notion of impairment as a dynamic phenomenon. As a result of this decision, in April 2003 I made contact with the Deaf Society and conducted a presentation at an Usher Syndrome workshop there. I had the opportunity to observe the resource intensity of supporting people with Usher Syndrome to interact on a group level, and the varied communication modes used. Following my presentation people made comments about challenges they experienced, such as learning about their diagnosis, dealing with changing senses, navigating service systems, and securing an advocate or supporter to assist them. Through the group I was able to recruit one further participant. I then presented an invitation to participate over the Australian wide e-mail list and specified that I sought participants who had not always been deafblind. I openly encouraged people who would be interested in communicating via e-mail. Through this action I recruited a further two participants. Later in the research process I made direct invitations to individuals recommended by those already involved, or whom I had met through fieldwork experiences and observed to be potentially helpful to my better understanding concepts in the data. For example, I recruited two participants on the basis of further exploring variation in concepts of independence, doing things differently, and presenting self.

I often went back to the data in a retrospective way in the process of developing concepts. This action included not only re-sampling interview data, but comparing data across the different sources. For example, I used concepts developed from interviews to theoretically guide re-coding of participant observation data. This practice allowed a deeper understanding of concepts to be gained. One example, as I attempted to better understand being and doing in relation to isolation, is presented
in Box 5.1. In interviews, participants spoke about a sense of abandonment and often being left alone, which I coded as isolation. Through my observations, I came to understand that unless a person was doing something with the person who was deafblind it was not possible for them to be perceived as being with them: there was a spatial dimension to isolation.

**Box 5.1. Example of memo and cross data source sampling**

I have been thinking about space – social spaces and the meaning of space. Open space is fearful and close space preferable for people who are deafblind, and being with the person becomes the doing. You can’t really be with the individual and not be doing or acting on/with that person. If you are just sitting back in a neighbouring chair you are not being with them, you are part of an ill-defined open space. If you are interacting with them you are touching them, or communicating directly with them or somehow “doing”, so that being with becomes doing with. What you do together (i.e. activities) is not so important, because the real value is in the doing to/being with – that becomes the shared experience if you like.

In my hearing-sighted world a lot of being with is about doing things other than being with. Just last night I was talking with my husband and preparing a meal. But because of the intensity of communication with people who are deafblind, there is so much action involved there is not room for doing (something else) and being with the person. Even with speech users there is much effort to go into the proximity, tone, controlling background distractions, confirmation/feedback etc. I think this balance is always a problem because you can’t just be with the person. For example at the social outings, things need doing and there are others in the group to be with. That is why deafblind people talk to me about being left alone and abandoned. They are not literally being left alone – but there may not be anyone doing to/being with them. Instead the person previously with them is doing other things and they become part of an ill-defined space because the deafblind person can no longer experience that person as still there with them.

It is not that people are deliberately abandoning the deafblind person, but they cannot be with them AND do things that they need to be doing to facilitate the group. It is a challenge for companions to manage the need to get things done and the individual’s need to have them with them.

*(Extract from memo journal 25th September, 2003)*

5.1.3. **Coding, comparison, memos and categories**

*Conceptual and theoretical coding* refers to the task of classifying and naming data segments. Strauss and Corbin (1998) distinguished three types of coding, whereas Glaser (1978) took a more general view toward the process. According to Strauss and Corbin, open coding is the process of fracturing the data into small segments
Axial coding is an intensive analysis of one category, where connections between a category and its subcategories are developed. Selective coding is the process of validating the relationship between a core category and other categories. These three processes were adhered to in dealing with data and are demonstrated in more detail in Chapter 7.

*Constant comparison* refers to the ongoing process of systematically comparing and contrasting data segments with each other and with an emerging category. This assists in the identification of concepts, properties and dimensions, and was the technique used across all data sources throughout this research.

*Memo writing* is the process whereby the researcher writes to him/herself about ideas regarding the evolving theory, including ideas about emerging categories, properties, dimensions and relationships. The above memo extract around the concept of abandonment and isolation as a spatial experience provides an example of how I “talked to myself” about concepts emerging from analysis in journal writing and fieldnotes. I also kept narrative reflections on each interview encounter with participants, which became a useful adjunct to memos.

In grounded theory a *category* is the unit of information analysed. It is composed of events, happening and instances in the data. Four concept categories were developed from the data using constant comparison of data chunks. For example, “surviving others’ perceptions” was one category, reflected in instances in the data where participants reported experiencing the presence of others, and where this had the effect of making them feel different or marginal. That is, when an event had a negative impact on the deafblind person, no matter what emotional strategy they applied to manage it, it was coded as “surviving others’ perceptions”. If interaction with other people was experienced positively, it was coded as another concept category, “managing support relationships”.

In the latter stages of analysis in grounded theory a concept is selected as the central idea in the theory and regarded as “core”. All other concepts are examined in relation to that core category and it accounts for most of the variation in the
problem/process. The concept of “negotiating a place in a hostile world” became core because it captured the meaning of the four concept categories and their interrelationships. In considering all the concept categories as mini-processes, I understood that they all represented the individuals’ attempts to access the world alongside others, to negotiate a place. The core category embraced underlying concepts of the concept categories: agency, interactivity, interactional powerlessness, and recognised belonging.

5.1.4. Theoretical saturation

The ideal endpoint of data collection and analysis is theoretical saturation, where new information no longer adds to the understanding of a category. Once I had re-shaped data into different code chunks and re-examined codes across the different data sources (for variation, properties and dimensions), it became easier to identify patterns in participants’ experiences.

During interviews and participant observations I attempted to gather new information in relation to concepts already identified. When participants began to repeat incidents and I began to see repetition in the group outings, I decided the data were becoming saturated. I withdrew from the field once concept categories were identified, and persisted with retrospective theoretical sampling to build further on the concepts and their relationships. I acknowledge that additional time dedicated to data collection could possibly have contributed greater understanding regarding variation. However, my decision to withdraw from the field was necessarily influenced by the nature of this research: because it was undertaken as a PhD study time was constrained by length of candidature and scholarship.
5.2. Participant observation research components

I engaged in three types of participant observation. First, I became involved in a social group for people who are deafblind. Second, I was part of an e-mail list group for people who are deafblind. Third, I had the opportunity to observe participants while conducting interviews. Each component is detailed below in terms of finding a location, gaining access and maintaining rapport, taking a role, and exiting the field. Information regarding fieldnotes is not addressed in this section as it is detailed in Chapter 7.

5.2.1. Component 1A: Deafblind social group

A location is a social situation where a researcher can participate and observe naturally occurring interactions of the people under study. The choice of location is guided by pragmatic concerns as well as research interests. Spradley (1980) advised that a social situation or location can be identified by three primary elements: a place, actors, and activities.

As part of my fieldwork experience I joined a deafblind social group organised by the Deaf Blind Association that was open to adults experiencing deafblindness. Up to 10 members and their volunteer companions regularly attended a day or weekend outing on a monthly basis. At times personal commitments interfered with my attendance, but in total 15 activities were used as fieldwork opportunities over an 18 month period. Examples of activities included:

- Christmas harbour cruise (November 2002)
- Disability surfing day (February 2003)
- Visit to aquarium (March 2003)
- Wine-tasting weekend away (April 2003)
- Fire safety education seminar (May 2003)
- DeafBlindness Awareness week activities including stall in public park and masquerade ball (June, 2003)
- Conference dinner outing (July 2003)
- Swimming day (August 2003)
 ➢ Theme park outing (October 2003)
 ➢ Christmas dinner dance (November 2003)
 ➢ Train and bus museum visit (March 2004)
 ➢ Celebration of opening of the DeafBlind Association office (April 2004)
 ➢ Island adventure weekend away (April 2004)
 ➢ Ferry ride and markets day trip (May 2004)

Having identified this group I had to gain access and manage relationships. As advised by Berg (1989, p. 59), I directed attention to gatekeepers, those with authority to allow me in, as well as the actors in the social setting, referred to as participants in this thesis. I recognised that my ability to access participants and move in the field would be influenced by how others understood my intentions. I was also aware that gaining entry and maintaining rapport would be a constant activity, critical for the duration of the research, not only in the beginning moments (Grills, 1998; Mason, 2002; Wolcott, 1995).

Permission for me to join the group was granted by the DeafBlind Association Board members at a meeting in November 2002. All members present were informed of my role as a research student and the aims of the research before voting on whether to accept me into the group. Throughout the research I was careful to maintain rapport with the organisers of the group and the volunteers on whom it depended, as well as spending time interacting with members.

I sought a role or position in the setting to facilitate interactions with deafblind people and complement the setting and my attributes. Many authors have described possible researcher roles that exist along a continuum from detached to involved, described by terms such as total researcher, observer as participant, participant as observer, and total participant (Emerson, 1981; Russell, 1999; Spradley, 1980). As recommended by Grills (1998) and Wolcott (1995), in taking a role I had to be reflexive, as “every social location we occupy brings with it a mixture of insight and blindness” (Grills, 1998, p. 10). At the social group I took the position of participant as observer. I tried to become familiar and involved in the setting, and to
have a distinct role besides that of researcher (Russell, 1999). I became a volunteer helper in the group.

Early fieldwork experiences revealed that observation alone would contribute little to understanding insider perspectives. As a novice in deafblind communication, it was difficult for me to accurately follow interactions taking place between different members. However, I was able to use my initial impressions and learning as valuable experiential data. I came to appreciate that interaction with people who are deafblind requires a level of intimacy and intensity that is different from the ordinary communications of everyday life. The level of intensity required precluded me from attending to other activities occurring in the group while I was interactively engaged. Thus fieldnotes became dominated by accounts of direct interactions rather than observations of the group happenings.

The volunteer helper role enabled me to become closely acquainted with individuals who were deafblind. It was also a role where novice communication skills were not negatively viewed, and the general precept of “having a go” permitted a variety of interaction opportunities. I was limited only by my self-consciousness: concern that perhaps I would not always understand what a deafblind person was trying to tell me. As a volunteer helper I was able to demonstrate usefulness, for instance by becoming involved in organisational activities and helping with transport.

I could actively engage in communicating with participants as a helper guide or communicator interpreter, or I could tend to background tasks and watch elements of interaction. Using these options I was able to gain an understanding of the social and physical contexts of people who are deafblind. Even when unable to engage in “talk” with particular members, I often had to physically interact with them in activities such as eating and drinking, going to the bathroom and getting around. These opportunities bought their own valuable contributions, facilitating deepening understanding without necessarily relying on language skills.

As anticipated, my level of participation increased as my skills and comfort improved, and as members of the group became more familiar with me. Throughout
the research I completed three Auslan\textsuperscript{18} community courses to develop beginner level interaction skills. Through immersion and many humorous failures my tactile finger spelling improved, though sometimes individual variation continued to challenge my receptive abilities.

The group provided the opportunity to observe deafblind adults interacting with each other, their companions (not all of whom were hearing-sighted), and the broader community, in diverse physical and social environments. Secondly, the group provided a context from which to locate participants for the interview component of the study. Thirdly, participant observation experiences provided topics that were explored further in interviews. Finally, the group provided “hands on” experience which guided me in how to conduct myself around people who are deafblind. For example, I became sensitive to the importance of pace and allowing extra time, providing information about the environment rather than just communications, and taking care to be hygienic and not smell unpleasant or have cold hands when interacting so intimately.

After some 18 months of involvement in the group I began to withdraw, attending only sporadic activities and no longer treating these as fieldwork. I explained to organisers of the group that the amount of theoretical work remaining in my PhD would minimise the likelihood of my continuing as a regular volunteer. I continue to pay a membership and receive a newsletter about the activities, so while I have largely withdrawn from the setting I have not yet detached emotionally (Berg, 1989).

5.2.2. Component 1B: Deafblind e-mail list

When visiting the computer training facility I was made aware that up to 40 deafblind individuals Australia-wide and some professionals participate in a national e-mail list group. Additionally, one interview participant suggested the list to me as a means of exploring what deafblind people talk about amongst themselves.

\textsuperscript{18} Sign language used by the Australian Deaf Community. Auslan is a gestural language which has its own rules about sign/word order (DeafBlind Association Victoria, 2005c).
In April 2003 I sought permission was from the list moderator to join. Through discussions with the moderator I clarified that the purpose of my joining was limited to becoming sensitised to issues raised by people who are deafblind and circulating information regarding the research.

It is important to note that permission to join the list was not equivalent to permission to utilise information within the list as data. In the literature there is some question surrounding issues of ownership for material pasted publicly on e-mail lists (e.g., Hardin, 2003; Mann & Stewart, 2000). Some argue that it is public information and can be used by anyone for any purpose. Others perceive it to belong to either the person posting or the system operator (Mann & Stewart, 2000). For this research, in collaboration with the moderator, and through discussions with participants who were also list members, I decided to respect information shared on the list as the property of the individual posting it.

In this location I took a position as “observer as participant”, where I had some interaction with people in the location, but the main purpose was to gather data outside the list (Russell, 1999). For example, as three participants involved in interviews took part in the list talk regularly, I observed their interactions and used the information to cross-reference that from interviews or direct discussions.

When joining the list I posted an introductory e-mail, identifying myself and explaining my intentions. I took care to explicitly assure list members that I did not plan to use postings in reporting the research. Rather, if I was interested to use a particular posting I would seek permission directly from those involved in that exchange via an e-mail.

During the 18-month fieldwork period on the e-mail list I posted on another three occasions only: once to request participants and then on two occasions to provide and clarify information. Therefore I was not active in the list, mainly observing for the purposes outlined above.
I continue to be a quiet member of the e-mail list group, although I have ceased to keep records of the interactions or to use them deliberately to inform ideas related to the research.

5.2.3. Component 1C: Observations during interviews

Each interview experience provided an opportunity to observe and, to some extent, participate in the activities of participants in their homes and local community. These experiences, while not extensive, allowed me to observe in action views expressed by participants, to observe issues that may have been difficult for participants to express, to verify data from interviews, and to generate ideas to be addressed in future interviews. Observation during interviews was particularly helpful in relation to participants who did not participate in the deafblind social group or e-mail list.

In participant’s homes and communities, the position I took could be described again as “observer as participant”, because the intention was to gather data not by observation but by interview.

With the six face-to-face interview participants I had varying degrees of observer-as-participant opportunities. Sometimes I would observe participants’ interacting with other people such as family members, partners, people over the phone, food delivery services, visitors, and pets. I was able to observe participants interacting with their physical home environments and performing activities around the home such as food preparation or clothes hanging. In a few cases I also observed participants navigating external environments within their home yard, to the mailbox, or further into their local community streets and shops.

The two interview participants engaged in in-depth interviews over the e-mail (component 2B) were “observed” via the e-mail list interactions in hyperspace (component 1B above). Additionally one face-to-face meeting was held.
5.3. In-depth interview research components

Two fieldwork components comprised in-depth interviewing. First, I shared in-depth conversations face to face with six adults, and second, I shared repeated e-mail conversations with two adults.

5.3.1. Component 2A: Face-to-face in-depth interviews with six adults.

Participants were initially recruited via promotion of the research at functions involving adults who are deafblind, including the deafblind social group. This was a mixed purposeful sampling strategy (Patton, 1990). As explained earlier, theoretical sampling soon replaced purposeful sampling (Cutcliffe, 2000; Glaser & Strauss, 1967; Llewellyn, Sullivan & Minichiello, 1999).

The initial challenge was to ensure that interested people could have information about the research in the format they required. Three participants required large print copies of varying print size, one required Braille, and two requested Microsoft Word documents be sent as e-mail attachments. All but one of the participants had e-mail access, so e-mail became the primary way of communicating between interviews and when planning meetings. The participant without e-mail nominated a friend as a contact person and large print information was mailed through the post.

All but one participant were happy for interviews to be conducted at their home. This minimised the demands on participants for negotiating unfamiliar environments, and allowed meanings to be shared in the participant’s context. Of the 16 face-to-face interviews conducted, one was conducted at the participant’s partner’s home, and another in a neutral location at the participant’s request. In the latter case, arrangements were negotiated with a university library close to the participant’s home.

The in-depth interview strategy allowed participants to direct the conversation. Particularly in initial interviews I saw my role as establishing a safe context which allowed autonomy and freedom of expression for participants. I played an active
role by way of focused listening (Corbin & Morse, 2003; Mason, 2002). I allowed participants to begin their narrative wherever they desired, having learned from my pilot interview experience. On that occasion I had been nervous about trusting social interaction between the participant and me to create a conversational interview. Instead I started by asking him to describe current relationships in his life. He responded by saying he wanted to tell me about how life used to be before he made connections with other people who are deafblind. This was a lesson in trusting the participant to determine topics of importance.

Through my engaging with participants’ lives, the research interviews had an unanticipated emotional impact on me. While participants were living their lives already familiar with any challenges or unpleasantness involved, I was a naïve researcher and at times found their stories confronting. The excerpt in Box 5.2 is taken from my reflective journal and illustrates this.

**Box 5.2 Excerpt from reflective journal**

*The more sadness replaced excitement, particularly as I attempted to transcribe and listen again to what he had said. To think another person is living their life under these circumstances is very sobering. I can see why so many disability writers, like French and Oliver, become so passionate about “the cause”, about the limitations imposed on the lives of people with disabilities. It really does happen, and now it happens to people I know … When I started this research I began with an idealised conception of a process of discovery. I imagined I would find fascinating things, be able to get inside the lives of people who are deafblind and show them as people with valuable attributes, and things to teach … I really did not give much thought to the idea of discovering unpleasant things, or encountering strong negative feelings toward themselves or the world around them. I have a newfound respect for a process which can obviously be transformative. I am not “doing” research: in fact I think it might be doing me. (October 2002)*
When conducting interviews I drew from questioning strategies outlined by Minichiello et al. (1995) to facilitate participants’ talk. Sessions typically began by simply chatting and a topic would often emerge. In some instances I deliberately used storytelling questions such as “tell me about how you came to be involved in the deafblind social group?” Less deliberately, a funnelling approach could be seen in interviews where we would move from general to specific topics. For example, the starting topic might be communication and we would then work down to specific strategies the person used to present themselves at work.

I was careful to be open when participants asked questions of me, which they often did. For example, in one interview I was asked, “Tell me about yourself – where do you live? You married? What do you like to do? I find people don’t talk to me about themselves anymore and I miss that”. As interviews continued, I found participants had expectations of me as the researcher. They began to ask me about what other people were saying, and what I was thinking about their stories. For example, I was asked direct questions like, “Is things I am telling you different to other deafblind people because they don’t have physical disability? If you had to sum up deafblindness in Australia what would you say?” Also, as interviews continued, I felt more comfortable to raise topics identified from other sources, or to reintroduce old topics for further exploration, so the interviews became more interactive.

Initial interviews lasted between 1.5 to 3 hours. Subsequent interviews took place 3 – 10 months after initial interviews, in some cases lasting up to 7 hours. The complete series of interviews were conducted from October 2002 to January 2004. All but one participant chose to participate in multiple interviews.

In early 2004 I informed participants that I had collected a lot of information and may not require further interviews. I invited participants to express interest in receiving updates about the research and idea development. All participants wished to remain in touch and be informed of the progress of the research. Updates were sent every few months and were often reciprocated, with many participants responding and sharing their impressions and/or updating me about their lives.
5.3.2. Component 2B: E-mail conversations with two adults.

As part of the theoretical sampling strategy to involve people who had become deafblind, I circulated an e-mail through the deafblind e-mail list requesting participants for the research. Two people responded, expressing an interest to talk via e-mail. One participant requested to be sent information on the research and the consent form in Braille. The other participant required an electronic word document be e-mailed.

Computer mediated communication (CMC) as an interview mode in qualitative research is a relatively new phenomenon, and there are yet to be clear guidelines on the topic (Hardin, 2003; Mann & Stewart, 2000). I conceptualised CMC as merely an alternative medium to face-to-face opportunities for human relationships, and one that was essentially complementary.

Many issues were considered in adopting this method of data collection. Some advantages were the ability to cross time and space barriers (Mann & Stewart, 2000), and to allow individuals to participate from the comfort of their homes at their own pace. I also believed that e-mail data collection could possibly eliminate the need for interpreters and potentially remove environmental communication barriers by eliminating concerns about background noise interfering with cochlear implants or hearing aids. It could potentially also break down communication-mode-related discrepancy barriers, in that participants used equipment they needed at their end, and the information was retrieved by me as text. Interacting directly through the computer as an interface in such a manner I considered might eliminate my need to master a particular communication skill like finger-spelling.

However, a number of possible challenges were anticipated in using CMC, and further challenges emerged from the process. From observations of the e-mail list I noticed that some users had limited written English skills, at times creating confusion in messages. I considered there could still be a need for an interpreter to assist me to interpret what Auslan users might write. No Auslan users expressed an interest in participating in e-mail interviews, so this became a non-issue. With
consideration for variable typing skills and ease of computer use among individuals I deliberately chose e-mail rather than instant messaging.

Some unanticipated challenges involved maintaining an in-depth interview approach and dealing with participants’ concerns about trust and confidentiality. I found that with e-mail, depending on the participant, I had to be more direct in asking questions because we were without a shared context from which spontaneous conversation could arise. Some authors have suggested that men tend to use “report talk” rather than “rapport talk” (Tannen, 1991, cited in Mann & Stewart, 2000, p. 166). This appeared to be the case for one participant, who for many months rarely initiated topics or e-mails, which I found challenging. Upon our meeting in person, this participant told me he felt reassured and had found it difficult to feel trust for me through e-mail contact alone.

Throughout 2004, e-mail conversations became less regular, as few new concepts were being provided by our discussions. I informed both participants that I had collected a lot of information and may not require further interviews. As with participants of component 2A, I invited expressions of interest to receive updates about the research and development of ideas. Both participants wished to remain in touch and updates were sent every few months and were often reciprocated.

5.4. Synopsis

During fieldwork I adhered to various components of grounded theory. For example, I took action to enhance my theoretical sensitivity, and used both prospective and retrospective theoretical sampling techniques. I applied analysis procedures which embraced theoretical coding, constant comparison, memo writing and the identification of conceptual categories until repetition of data suggested theoretical saturation may have been reached.
Fieldwork consisted of both participant observation and in-depth interviewing. I took the role of participant as observer in a deafblind social group. Also I took the role of observer as participant in an e-mail list group and during interviews in the individual homes and local communities of participants. I also engaged in in-depth interviews face to face with six adults, and additionally by e-mail with two adults.

The following chapter of the thesis introduces the participants involved in both interview components. Their willingness to share their experiences provided the foundation for this thesis. The chapter also introduces the researcher as the “research instrument” and offers some reflections on the research journey as a transformative experience.
6.1. Participant profiles

Joseph
Joseph is a 50 year old male who lives in his own home in a suburban area of a large city. He is married and refers to himself as the carer for his wife who is blind and experiences ill-health.

Joseph has been vision-impaired since childhood, experiencing a condition known as retinitis pigmentosa, and later, cataracts. He had a slight hearing impairment as a child, but his hearing decreased steadily over his adult years, significantly so in the last nine years. His formal diagnosis is Usher Syndrome type 2, and although his parents had been informed earlier, he did not learn of this diagnosis until early adulthood. At the time of diagnosis he experienced his first episode of mental ill health. Now he has a diagnosed anxiety disorder.

Joseph works four days per week in a financial institution, holding tertiary qualifications in business. To communicate with others Joseph uses speech, e-mail, and some finger spelling. To understand others he uses hearing aids and requires close proximity and reduced background noise. Joseph also uses e-mail and has computer adaptations which enlarge font and improve the contrast of screen settings. To access printed material he uses a closed circuit television. He has attempted to learn Braille with limited success and much frustration.

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19 In retinitis pigmentosa the retina of the eye degenerates and loses the ability to transmit messages to the brain. Symptoms include difficulty seeing in dark places or at night, loss of peripheral vision creating tunnel vision, and difficulty with light adaptation (Kilsby, 1997).

20 Cataract is a partial or complete opacity of the lens of the eye leading to blindness (Dox, Melloni, Eisner & Melloni, 2002).
Throughout the research we communicated with speech and via e-mail. Three informal interviews were conducted over a 12-month period, totalling 10 hours of interaction. One interview was conducted at his partner’s unit prior to their marriage. The second and third interviews were conducted at Joseph’s home. Beyond the interview context, five participant observation experiences were shared, contributing approximately 23 hours of additional interaction.

**Isabel**

Isabel is a 51 year old woman who lives in a residential facility for the aged in a large city. She was born with cerebral palsy\(^{21}\) and vision impairment. By the age of nine she was blind and had to learn Braille. She experienced mild hearing loss as a child, but did not consider herself deafblind until she sustained a head injury that resulted in total loss of her hearing in her late 20s. After the accident her hearing returned but has since deteriorated to profound deafness.

Isabel has worked in sheltered workshops in the past, and now works in a voluntary capacity. She has lived both in group homes and independently in the community, prior to the deterioration of her physical abilities.

Isabel attended a segregated school for children with physical disabilities and left with the equivalent of 5\(^{th}\) grade education. She subsequently undertook a range of technical and further education (TAFE) courses as an adult, including creative writing and various Braille codes.

To communicate to others Isabel uses speech, Braille and e-mail, with the computer adapted with Braille and speech software. To understand speech Isabel uses a Tactaid,\(^{22}\) Tadoma,\(^{23}\) or hearing aids. To access printed material Isabel relies on

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\(^{21}\) Cerebral palsy (CP) is a permanent physical condition that affects movement. Movements can be unpredictable, muscles can be stiff or tight and in some cases people have shaky movements or tremors. People with CP may have seizures and other impairments affecting their speech, vision, hearing and/or intellect (Spastic Centre of NSW, n.d.).

\(^{22}\) The Tactaid is a device worn against her skin, through which Isabel interprets speech by detecting sound waves as vibration.
someone transcribing information to Braille or audio-cassette, or reading aloud to her.

Throughout the research we communicated via speech and the Tactaid. On some occasions we used Tadoma, for example when we went swimming together and Isabel was not able to wear the Tactaid. Three interviews were conducted over a nine-month period totalling eight hours. Beyond the interviews, 13 participant observation experiences were shared contributing approximately 80 hours of additional interaction.

Garry

Garry is a 46 year old man who lives in a large city with his wife, two teenage children, and mother-in-law.

As a child Garry had surgery to remove a tumour which resulted in significant vision impairment. His deafness was acquired as an adult in his 40s. He has a formal diagnosis of cerebral siderosis.24

Garry attended a segregated school for blind students and holds high school level educational qualifications. He previously worked in a sheltered workshop. He met his wife, who is also blind, at the workshop. Garry is unemployed and requires regular support due to deteriorating health. He is mobile with a frame and has poor balance. Respite care is undertaken daily to facilitate his participation in activities he enjoys.

Garry is a creative man who used to write music. When he lost his hearing, in the absence of music, he found poetry to be a useful mode of expression.

23 Tadoma is a method of receiving oral speech through tactile contact. The receiver places a hand on the speaker’s face, the thumb over the lips and the fingers spread on the upper neck, to allow interpretation of the lip/face movements and the vibration of the vocal cords (Hersh & Johnson, 2003).

24 Siderosis is the presence of iron dust or particles in tissue (Dox et al., 2002), and in Garry’s case it is cerebral, involving the cerebrum (brain).
To communicate to others, Garry uses speech, e-mail, Braille and finger spelling. To understand others, Garry uses a cochlear implant, Braille, e-mail (adapted with speech and Braille software), and some tactile finger spelling. To access printed material Garry relies on someone transcribing information into Braille, or someone reading aloud to him.

Throughout the research we communicated via e-mail over 9-12 months. One face-to-face meeting (5 hours) was conducted. We met for a meal and spent time walking around a park in his home city, in the company of his respite worker. We could only engage in limited communication on this occasion due to environmental noise interfering with the cochlear implant use. In addition to the above occasion, participant observation experiences were shared via the e-mail list group.

**Ralph**

Ralph is a 47 year old man who lives with his aging mother in a large city. He was born with congenital cataracts and as a result has been vision-impaired all his life. He experienced an unusual viral infection in 1997 which affected his hearing.

Ralph attended high school at a segregated school for blind students and completed grade 3-4 (equivalent of Year 9-10). He has held a range of jobs, starting in a sheltered workshop environment. Ralph is employed as a switchboard operator at an educational facility, and plans to change to part-time employment.

To communicate to others Ralph uses speech and computer/e-mail. To understand others he needs close proximity for hearing speech, or uses e-mail with large print. He finds hearing aids unsatisfactory and no longer chooses to wear any. To access printed material Ralph uses his magnifying glasses and good lighting.

Throughout the research we communicated via e-mail over 9-12 months. One face-to-face meeting was conducted over a three hour period, where we met for a drink at a pub. Beyond the face-to-face meeting, participant observation experiences were shared via the e-mail list group.

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25 Congenital cataract is opacity of the lens of the eye present from birth (Dox et al., 2002).
Glen

Glen is a 25 year old man who lives at home with his mother in a large city. He has been Deaf since birth and is the only member of his family to be so.

Glen attended a segregated school for the Deaf and completed year 12. He began experiencing vision problems from early high school age, and was formally diagnosed at age 15 with Usher Syndrome type 1. After school he attempted two technical and further education (TAFE) courses, successfully completing one. He is currently employed part-time in data entry.

To communicate to others Glen uses Auslan, which is his first language. He also writes English but doesn’t speak it. To understand others he requires Auslan at a close range, e-mail or large print English writing. To access printed material, Glen requires large print and good contrast, and sometimes uses a magnifier.

Throughout the research we communicated via Auslan with the assistance of an interpreter. We also communicated via e-mail. Only one formal interview was conducted for two hours as this was all Glen wished to attend. Several follow-up e-mails were exchanged. Beyond the interview, one participant observation experience was shared, totalling approximately one hour.

Sam

Sam is a 47 year old man who lives alone in a small city in his family home. He has been hearing-impaired since birth but this was not diagnosed until he was at school.

Sam attended a mainstream school and began experiencing vision impairment in high school. He was formally diagnosed with Usher Syndrome type 2 at the age of 16. Both his siblings also have the condition. Unlike his siblings, he has experienced additional visual complications and now has perception of light in a visual field of less than 10 degrees.
Sam has studied at university and worked for many years prior to his vision deteriorating. At the time of the research he worked in a voluntary capacity on deafblindness-related committees.

To communicate to others, Sam uses speech, Braille, and e-mail, with the computer adapted with Braille and speech outputs. He can also do some tactile finger spelling. To understand others, Sam uses hearing aids for speech, or Braille and e-mail. To access printed material Sam uses a scanner with voice output, or converts information to Braille using the computer and Braille keyboard or printer.

Throughout the research we communicated via speech, one-to-one in a quiet environment. Three interviews were conducted over a six month period (July – Dec 2003) totalling 10.5 hours. Beyond the interviews, seven participant observation experiences were shared contributing approximately 40 hours of additional interaction.

**Natalie**

Natalie is a 30 year old woman who recently purchased and moved into her own unit in a large city. Previously she lived with her parents. She has been vision-impaired since birth, first experiencing hearing impairment at the age of 16.

Natalie first attended a segregated school for blind children before being integrated into a mainstream school. She completed year 12 education and studied at a technical and further education (TAFE) college part-time while working full-time. Throughout the research she was employed full-time.

To communicate to others, Natalie uses speech, Braille, and e-mail, with the computer adapted with Braille and speech output. To understand others she uses hearing aids, Braille and e-mail. To access printed material Natalie prefers Braille, relies on others to read to her, or uses a scanner with voice output.

Throughout the research we communicated via speech in a quiet environment. Two informal interviews were conducted over a three-month period, totalling five hours.
Beyond the interviews one participant observation experience was shared, contributing approximately four hours of additional interaction.

Debbie
Debbie is a 42 year old woman and mother of three young adult children. She lives with her youngest son in rented accommodation in a small city. She grew up hearing and sighted, and first experienced hearing impairment approximately five years prior to the research. Debbie has been totally deaf for approximately three years. She has experienced deteriorating vision over the last four years. Recently she was formally diagnosed with a rare genetic condition mitochondrial myopathy.26

Debbie attended mainstream school and completed high school level education before becoming a nurse. She endured a difficult marriage and divorce, raising her three children alone. During the research Debbie was unemployed and receiving the Disability Support Benefit.

Debbie’s condition fluctuates and affects her ability to function in many ways, in addition to causing her deafblindness. For example, she experiences fatigue, pain, and mobility and speech difficulties.

To communicate to others Debbie uses speech, some tactile finger spelling and some Auslan sign. To understand others she requires large print writing, finger spelling, or Auslan. During the course of the research Debbie obtained a cochlear implant and was able to understand speech with it for our last interview together. Debbie is also hoping to learn to use the computer. To access printed material Debbie uses magnifying spectacles and aids, or relies on someone to summarise information in very large print.

Throughout the research we communicated with speech and a whiteboard with large print writing which she had to be very near to read. At times we used some signing, for example when sorting out possible outfits in her wardrobe, or when out, buying

26 Myopathy refers to any disease of the muscles; in Debbie’s case her muscle disease is caused by dysfunction in the mitochondrion responsible for energy supply to cells (Dox et al., 2002).
kebabs for lunch. Four interviews were conducted over a nine-month period, totalling 17.5 hours. The first three were conducted with large print on a whiteboard or computer screen. In the fourth interview, we communicated by speech with Debbie using the new cochlear implant. Beyond the interviews, three participant observation experiences were shared, contributing approximately 17.5 hours additional interaction.

### 6.2. The researcher’s profile and position

I am a 29 year old woman, married with no children. I grew up in a dairy farming family, the third of four daughters, and went to a small rural school. Following school I moved to Sydney to study occupational therapy at University. I successfully completed an Honours degree in 1997 before beginning occupational therapy practice.

I worked in a range of public health positions (aged care, rehabilitation, acute hospital) before becoming a Low Vision Advisor at the Royal Blind Society of NSW. Initially when working I did not miss academic thinking. Clinical practice required new learning, and changing jobs meant that new learning continued. Gradually, however, I began to notice feelings of frustration regarding the constraints of the system and the outcome focus of the clinical world.

In 2001 I received an invitation to attend an information session on postgraduate study at the University. As a result, I applied for and received an Australian Postgraduate Award Industry scholarship.²⁷ I enrolled in a PhD full-time though I continued to work part-time for the majority of my candidature. I became part of the Family Support and Services Project (FSSP) team, later the Australian Family and Disability Studies Research Collaboration (AFDSRC) at the University of Sydney. I also became involved with the industry partner, the Centre for Developmental Disability Studies (CDDS), as the Director became my Associate Supervisor.

²⁷ This is a tax-free scholarship funded through the government in contract with an industry partner, in my case, the Centre for Developmental Disability Studies.
Through both these environments I enjoyed the support of fellow researchers, most of whom were experienced. The University of Sydney postgraduate seminar series offered the opportunity to share work in progress and learn from the tales of others. Similarly, at CDDS we initiated a PhD group which became a motivating collaboration. Informally, regular coffee sessions shared with “PhD buddies” facilitated the growth of ideas, and permitted the unleashing of pained whines.

It is from within this context that I engaged in the research documented in this thesis. Although it felt like a lonesome journey undertaken with regular battles largely inside my own head, it was in fact a well supported and somewhat indulgent endeavour; at times agonising, but never regrettable.

6.3. Reflections on a Researcher’s Journey

Naïve beginnings: First encounters and emerging curiosities
24th March 2001

I nervously juggled the umbrella to the other arm and sought reassurance from the damp map clenched in my hand. This was the place. With growing anxiety I entered the building and perused the set-up.

There were a number of bodies scattered throughout the room, getting coffee or seated at tables. Some people were conversing animatedly in Auslan. Others were intimately seated head to head, intensely focused, hand in hand exchanging signals tactually. My apprehension rose. It seemed oddly unfair that I could stand here watching these people, and in a very human way, be passing judgment from observations, when they were not yet aware of my presence.
It was to be my first experience in meeting people who were deafblind. How could I ever hope to enter their world? I did not understand the etiquette or have knowledge on their rules of interaction or communication methods. I felt immediately uncomfortable and confronted. I knew I was staring but fascination overcame manners on this occasion. Here they were, alive and well. A group of people with impairments I could not imagine experiencing. I watched as one man tripped over a chair and felt powerless to offer assistance. He righted himself and groping for the table edge he continued around until he bumped into a person! They touched hands and the conversation began with a flurry of finger movements.

My gaze shifted and I located some others I recognised as staff – “normal people” – relief was instant. We established eye contact, waved and smiled. I made my way over and we spoke briefly before the session began.

People who are both deaf and blind – one or the other would be frightening in itself, but both together? This is mind-boggling for me. I am a very visual person, a lover of art, music, reading, bushwalking and sightseeing. In amazement I watched and wondered … How do these people experience the world? Do they feel oddly suspended in free space? Is the world empty to them or can they sense objects and visualise in their minds the environment in which they engage? Are they fearful of becoming confused or disorientated? Do they feel lonely or alone? Do they feel trapped inside themselves? How do they perceive they are received by others? Are they oddly free from negative characteristics such as our tendency to judge others on appearance/first impressions? Do they wonder what they are missing – do they feel they miss anything? How do they enter into the community? They have to struggle with white cane or dog or person guide in hand, they cannot don a cloak of competence or “pass as normal”. Do they feel displaced as people coming from different cultures may in a foreign country? Are they frustrated by communication difficulties? How do they meet others and who are their friends?
Incomplete endings: Appreciated rituals and comfortable familiarity
April 2004

I noticed Sally by herself on the log and approached her. Touching her arm I slid my hand to hers and signed HI using finger spelling. Using her hand to then gesture to myself, I signed, JULIE. She immediately felt for my left hand, touching my engagement and wedding bands before sliding her right arm firmly around my shoulders, patting my ponytail in confirmation, followed by a gentle squeeze.

Thinking we had established greeting I was ready to proceed to the business – I intended to ask if she wanted a drink while waiting for her turn on the swing. Before I got the opportunity, she pulled back from the embrace to sign HUSBAND’S NAME? Laughing, I finger spelt my response. Excitedly, gurgles coming from her throat, she signed BROTHER SAME! We hugged properly, embracing for an extended moment.

This had become our greeting ritual, firmly established at an outing last year when we discovered my husband and her brother shared a name (in one of my brave attempts at conversation). It now took at least 5 minutes to express our greetings in this way, often being the longest part of what were typically business exchanges dictated by my volunteer helper role at the gatherings. I smiled at the fact she refused to let it be shortened.

The ritual greeting now complete to her satisfaction, she moved back from the embrace and presented her palm for my signing. Using her hand to gesture toward her body, I then signed WANT DRINK? She indicated YES by repetitively brushing her closed fist against my palm in an up and down, top to bottom motion.

These journal entries are indicative of the remarkable shift I experienced throughout the research. It occurred gradually, and although each occasion was carefully and reflectively documented, it remains a difficult task to describe it adequately now as a transformative journey.
I moved from an outside observer, paralysed by uncertainty and unable to engage, to a subjective insider, where I was able to establish, feel, and enjoy real connections with deafblind individuals. It was of course a very gradual shift, facilitated by each experience in the field and every new conversation with participants. Through these fieldwork experiences, I came to reassess the presumed problematic nature of a deafblind life at an individual level. My discomfort, and the perception of unrelatedness of my life to theirs, dissolved. I came to understand and know them as people. My valued ways of doing and being were challenged and new ways embraced. I became more conscious of process and relationship rather than task.

Not surprisingly, the questions in my mind shifted. Once curious fascination about the individual experience of deafblindness – based on the assumption that it must be extraordinarily different from my own life – were replaced with new concerns. I began to ponder: Why can’t or how can society better embrace people who are deafblind, as persons not dissimilar to any other human in our shared community?

6.4. Synopsis

This chapter has introduced the eight participants who shared their experiences through in-depth face-to-face and e-mail interviews. These participants vary in terms of social situation, nature of impairments, and the type of communication required.

In addition, I have introduced myself as the “research instrument” and described the supportive context I studied within. Reflections on the research process as a transformative journey, facilitating new understanding and altering my position from “outside” to “alongside” people who are deafblind, have been provided.

The following chapter details data management procedures and analysis work in an attempt to make the research process explicit. Issues of quality in qualitative research are raised including how I have attempted to address matters of trustworthiness.
Chapter 7
DATA MANAGEMENT AND ANALYSIS

“There could be no more nurturing circumstances for the self-reflective
individual than in the mindwork that must accompany fieldwork”
(Wolcott, 1995, p. 233).

7.1. Inertia, incubation and doing the itty bitty

Huberman and Miles (1994) defined data management as the operations needed for
a systematic, coherent process of data collection, storage, and retrieval (p. 428). I
perceive data management to be part of the process of data analysis, as it is often
under the guise of “managing data” that one begins to reduce it and be sensitised to
themes and concepts. The manner in which one begins to organise data is informed
by and informs analytical thoughts about data.

In this research there were different and complementary data sources available,
offering both data and method triangulation\(^\text{28}\) to assist in the richness of
understanding gained (Denzin, 1989). Similar data management and analysis
procedures were applied to each data source.

Data analysis is defined by Minichiello et al. (1995) as a systematic process of
arranging information in order to search for ideas. Analysis is a process of inductive
reasoning, thinking and theorising (Taylor & Bogdan, 1998), and while it involves
mechanistic operations it is not merely a mechanical task. Data analysis involves
data reduction (summaries, coding, stories), data display (organised compressed
assembly of information) and conclusion drawing (drawing meaning from data)
(Huberman & Miles, 1994). As noted previously, analysis within the grounded
theory tradition is based on the notion of constant comparison, and examination of
material within cases and across cases (Huberman & Miles, 1994; Mason, 2002). It

\(^{28}\) Triangulation is the process of investigating the same issue in a variety of ways, for example using
different methods, groups or locations (Denzin, 1989; Minichiello, Fulton & Sullivan, 1999).
also involves comparison and examination within and across categories (Rubin & Rubin, 1995).

A number of authors (e.g., Brown & Sullivan, 1999; Minichiello et al., 1995) have recommended the use of different files in data management. Examples of such files include a transcript file detailing interview dialogue, a personal file containing a reflective account, an analytical file for documenting ideas, and topic files which bring together material from various sources on the same topic or concept.

In this research, I established transcript files and a reflective journal. The reflective journal contained both the personal file and analytical file elements described above. This was found easier than attempting to separate out analytical from reflective material, and allowed for a free-flowing approach to documenting the research process. As the journal enlarged I would sometimes review it, cutting and pasting sections pertaining to analysis of different categories into separate documents (called memos) for ease of reflection. Paper topic files were established in manila folders based on the code groups identified. These were beneficial for jotting down ideas and drawing diagrams while reflecting on code clusters and data incidents.

I experienced the process of analysis as a continuous cycle occurring throughout data collection (18-24 months) and beyond, during the thesis writing itself. The process involved three notable phases: inertia, incubation and doing the itty bitty.

Phases of inertia were those periods where I felt overwhelmed by the amount of data or paralysed by the diversity of experiences being revealed, and needed to pause. Inertia was most notable in the earlier stages of data collection when I was enthralled by participants’ stories and concerned by how to represent individual experience and maintain participants’ voices. Initially, inertia reflected a reluctance to dissect data and a concern for holistic appreciation of experiences. Inertia was related to my desire to have a better sense of what was important to participants prior to “acting on” the data. Like Whyte (1984), I felt that a period of orientation and indexing was required prior to aggressive coding. During this initial phase I
focused predominantly on developing within-case understanding, engaging in holistic data reduction and presentation (e.g., narrative summaries, code lists and memos for individual participants).

Incubation is the term I used to refer to long periods of reflection which accompanied my immersion in the transcripts or tapes and contributed to memos. Incubation describes my growing appreciation for the importance of allowing time for thoughtfulness about the data. Incubation occurred both purposefully and subconsciously, and was indicated by epiphanies. Purposefully, I would put aside hours of time to reflect, sitting somewhere comfortable with sketchbook and pencil in hand. Subconsciously, incubation seemed to occur during periods of rest. I would often wake up at night with ideas about data which needed to be jotted in a beside-the-bed notebook. At first I experienced incubation as frustrating inefficiency of thought. Gradually I came to celebrate it as a required process and an indication of deepening understanding.

Doing the itty bitty refers to the phase where I moved to more aggressive data coding, grouping and comparison. This occurred once I felt well oriented to data both within and across cases. It accompanied my growing appreciation for the interpretive nature of analysis, and my deepening respect for the notion of “researcher as research instrument”. This phase was both mechanistic and interpretive. Data were coded, re-coded and clustered. Constant comparison, consideration of properties and dimensions, and the use of data displays, diagramming and brainstorming were predominant activities I engaged in to consciously “act on” the data.

The pages following describe and give examples of data management and analysis processes used across both interview and participant observation data. These processes did not necessarily occur one after another in a linear fashion. Rather, they occurred in a simultaneous and iterative fashion, as I sought to grapple with holistic and detailed analytic concerns, move between subjectivity and objectivity, and engage in inductive and deductive thinking.
7.2. Management of participant observation data

After leaving the field of the deafblind social group, most commonly I immediately created a condensed account (Spradley, 1980) from memory. This was usually handwritten, or if I was fatigued, spoken into a tape recorder.

An expanded account was typed up in a computer file (Spradley, 1980). This was more detailed than the condensed account and formed the fieldwork journal (Grbich, 1999a). The format of fieldnotes was a narrative ethnographic account as described by Berg (1989). Experiences in the field were described with the detail that memory allowed, usually sequentially, and were not divided into different thematic headings, though codes were applied throughout. I embraced a first person experiential approach when writing fieldnotes. Care was taken to consider multiple elements of the field excursion such as space, people, activities, objects, events, and timing (Spradley, 1980). Drawings were made of settings and spatial relations. At the end of each expanded account I made a summary of key ideas/issues arising from the experience. The same format was applied when documenting happenings and observations taking place during interview sessions. A short example from a section of fieldnotes is provided in Box 7.1.

**Box 7.1 Excerpt from fieldnotes (group outings)**

As I helped unpack from the bus many boxes of Christmas decorations and gifts, the second bus arrived. There was a flurry of activity as people were quite literally “unloaded”, i.e. physically guided or assisted from the bus. This bus was much fuller, and seemed to contain more severely impaired people, some with mobility impairments and some without formal communication systems. I immediately tried to be of assistance but felt rather inhibited, knowing my signing skills were minimal.

I met Bob, an elderly man who has been deafblind since his childhood. I had heard of him and knew he had travelled the world with an interpreter. I also learned from others over the course of the day that he makes and sells cane baskets. I attempted to sign “hello I am Julie” and hoped he understood me. He was rather frail and the access to the boat was quite challenging for him, perhaps more so because I neglected to sign to describe where we were going e.g., narrow bit here, step up etc. Linda, a blind volunteer helped me walk him, and her signing was much better than mine. Another man also had to assist to get Bob up and over the ramp and down the step into the boat. INACCESSIBILITY OF ENVIRONMENTAL INFO/DEPENDENCY
I was in charge of seating Bob and we sat hand in hand. BEING WITH / TOUCH He tried to sign to me a few times, and all I could do was sign back “go slow I am learning” and my name. I felt very awkward. I found myself assuming he had minimal comprehension, just because we had difficulty communicating, even though I knew him to be an intelligent and well travelled man. I would use almost point form language when signing, perhaps also because of my slowness and desire to get the point out. We achieved some very basic communication, I was surprised when I signed to Bob did he want a biscuit/drink and he understood easily and responded. There was no way I could have had a detailed conversation with him however or establish a sense of rapport with the level of communication we shared. COMMUNICATION / OTHERS PERCEPTIONS

Other, more skilled interpreters, like Ashley, came along and chatted to him, signing for lengthy periods (10 - 20 mins), back and forth, possibly quite complex things though I could not follow. The main difficulty I found was in my interpreting from him. He actually signed on his own hand (not mine), and I simply could not follow him. I noticed there are quite a few individual variations to the signing that I had been taught. COMMUNICATION I was totally impressed with the interpreters, especially Ashley. She had been married the previous weekend and today wore her veil. She circulated around the boat chatting to the deafblind people and letting them feel her veil, and her wedding ring, answering their questions about the wedding. I thought that was very impressive, that she had thought of a way to share her experience. DOING THINGS DIFFERENTLY / TOGETHER / COMMUNICATION

(Extract from fieldnotes, November 2002)

Notes were made in participants’ files if they were present during fieldwork for ease of cross referencing. Topics or issues noted could then be compared to interview data or used to inform questioning.

With the e-mail list group, I read postings and conversations regularly, printed them out and filed them in chronological order in folders. I read the postings and conversations for themes, and to examine the functions of the list group, such as information sharing, news exchange, advice seeking, or support. A journal listing themes for each month was established on computer file, much like a topic index. Specific notes were made next to topics contributed to by interview participants. In participants’ files, a journal of themes/topics discussed by them was kept. These topics were compared to interview data or used to inform questioning.
7.3. Management of interview data

With face to face interviews, each interview was tape recorded whenever practicable. Immediately after interviews, a condensed account of the interview experience was recorded (Spradley, 1980). This included information regarding events, exchanges, topics, and personal reflections. An expanded account (Spradley, 1980) of the interview experience was typed and stored in an electronic reflective journal. This account included all of the above elements in more detailed form and, once complete, it replaced the condensed account. Given that in some instances interviews became whole day events, expanded accounts could be lengthy documents.

I listened to each entire interview tape and reflected upon it prior to transcription. The complete interview was then transcribed and formatted with a cover page detailing time, date, setting, topics, and special circumstances. Transcription was used as an opportunity to remove identifying information. Transcription was treated as an opportunity for thoughtfulness about the data and not merely as a mechanical task, as recommended by Rubin and Rubin (1995). Tapes were stored in locked file cabinets.

For computer mediated interviews these several initial steps of data management were reduced to only two. Immediately following an exchange with a participant, I would cut and paste data into a Microsoft Word document transcript file similar to face-to-face transcript files. All identifying information was removed and, instead of tape timings, dates and subject headings of e-mails were documented in the left hand column. My reflective journal was updated regularly with topical and methodological reflections on the research relationship and e-mail data collection process.

With all interview data I read and re-read the transcription or listened again to tapes. Transcripts and tapes were reviewed in this way to facilitate a number of reflections. For example, through this process I would:
• Jot down broad topics to guide further interviews
• Look for gaps in understanding
• Listen for recurring stories/themes and unusual ideas (Rubin & Rubin, 1995)
• Take note of language and maintain a list of striking concepts participants introduced (e.g., the black abyss is where I am falling into; foot in half the world, worlds within worlds, sides of self, sub-human being)
• Document and describe emerging ideas in memos (guided by questioning, e.g., What is going on here? What is it participants want people to understand about their experiences?).

Narrative summaries of complete interviews were compiled as a means of reducing data while maintaining a holistic within-case approach (Brown & Sullivan, 1999). In this way I reduced transcripts of 30-50 pages to 5-15 pages of narrative, permitting reflection on more manageable amounts of data. Mason (2002) suggested that such activities allow the researcher to look for the particular and holistic, gaining a sense of distinctiveness and allowing examination of social processes in context.

A “grounded” interview guide and summary was developed (a section from one is illustrated in Table 7A). In this process each participant’s series of interview transcripts were reviewed and broken down into topics, themes within topics, and concepts represented by themes. This activity corresponds to Strauss and Corbin’s (1998) notions of open coding and micro-analysis. The information was compiled into a table format and each data segment was referenced back to the original transcript. This enabled me to view each participant’s data more easily, across interview experiences. This process involved questioning the data as suggested by Glaser (1978, 1992), such as: What are these data a study of? What does this incident indicate? What is actually happening in the data?

Mason (2002) suggested that cross-sectional indexing of data allows a systematic overview which helps distance the researcher from the immediacy of striking
In this way, sorting and organising tasks assist the researcher to move beyond an impressionistic view of data.

### Table 7A Grounded interview guide (examples from Garry)

<table>
<thead>
<tr>
<th>Topics</th>
<th>Themes</th>
<th>Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Deafblind community</td>
<td>Went to blind school and thought of self as part of blind community [p.9]</td>
<td>Self</td>
</tr>
<tr>
<td></td>
<td>As hearing deteriorated communication was difficult and needed assistance from deafblind services, blind community does not supply such help. [p. 9 -10]</td>
<td>Not belonging</td>
</tr>
<tr>
<td></td>
<td>Feels part of DB community but physically restricted in terms of participation. [p.10]</td>
<td>Different-ness / support</td>
</tr>
<tr>
<td></td>
<td>Label fits because blind without hearing problems don’t understand and look down on combined impairment. [p.10; 12]</td>
<td>Different-ness</td>
</tr>
<tr>
<td></td>
<td>DB community as close, fewer people and need moral support. [p.11]</td>
<td>Nature of impairment</td>
</tr>
<tr>
<td></td>
<td>DB world 2 main types of people – Auslan culture (dominant) and those deafblind later. [p.17 -19]</td>
<td>Collective identity - doesn’t fit anywhere else / different-ness</td>
</tr>
<tr>
<td></td>
<td>Sheltered world – outrun by ushers [p.17; 21]. Have to learn to become one of them. Talk of outside world not welcome, seen as threat, boring. [p.17-19; p.21]</td>
<td>Brought together by marginalisation (similarity = collective identity)</td>
</tr>
<tr>
<td></td>
<td>DB community as prison, frustration of sheltered world. [p.17]</td>
<td>Segregation</td>
</tr>
<tr>
<td></td>
<td>At same time DB want to cross the line between the worlds for assistance – wanting the best from both worlds without commitment. [p. 18], closed community but at same time trying to show general community their importance [p. 18]</td>
<td>Different-ness within collective</td>
</tr>
<tr>
<td></td>
<td>Usher group just for Usher people = 2 world factor; Auslan or not Auslan; CI – these factors all segregating. [p.17; 21]. Those entering the DB community later seen as outsider with strange views [p.17; 24]</td>
<td>Self segregation</td>
</tr>
<tr>
<td></td>
<td>Slowness of finger spelling means communication simple. [p. 23]</td>
<td>Self interested</td>
</tr>
<tr>
<td></td>
<td>DB awareness week activities. [p. 23; 20-21]</td>
<td>Entrapment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dialectic - not wanting to be part of community but needing to be recognised. segregation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Different-ness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Segregation within community</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Presentation of self</td>
</tr>
</tbody>
</table>
I then clustered data segments within the tables as demonstrated in Table 7B, based on the concept code applied in the above exercise. These codes were then used to retrospectively sample through participant observation data. This enabled me to reflect on why particular data incidents could be coded as belonging to the same or a similar concept. That is, it allowed me to start working on collapsing like codes and developing properties and dimensions.

### Table 7B Example of code clustering process

<table>
<thead>
<tr>
<th>Code</th>
<th>Isolation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thoughts</td>
<td>Isolation can be physical (no one around) or social relational (people around but feel disconnected) and informational (don’t know what is happening around you). It can be intentional or unintentional, known or unknown, self or other initiated. Isolation can also vary in intensity and it can range in the length of time it is experienced. E.g., withdrawal is a form of self isolation which is relational, known, and intentional.</td>
</tr>
</tbody>
</table>
| Data    | *Period in life where there was a great deal of isolation, developed more and more over the years* [i1, p.3]. *Lived life of a recluse and didn’t realise it, because life became frightening* [i2, p.6] (Fear, withdrawal)

*Relationships with people limited to few things, handful of people, going to work, coming home* [i1, p.4]. *Scared to go out and where would I go?* [i2, p.6] (Fear, connectivity)

*No one to talk to – all they did was feed us antidepressants* [i2, p.9] (Medical management)

*Forget how little you are hearing – someone will say there is a bird singing and you have forgotten what that is. Same with vision – you don’t know how little you see, it is just normal to me* [i3, p.27]. *Get reminded in social situations when you can’t follow what is happening* [i3, p.27] (Self, exclusion)

*Worker came and didn’t understand – just was offering him services, but the problem was the combination and dealing with social isolation – he didn’t want Braille, or ADL training etc., he wanted to address the social isolation. “What’s the use of living if I am locked in a box somewhere?”* [i3, p.20-21] (Agency, others not understanding, services)
Concept clusters were then grouped across participants and subjected to constant comparison and further concept development (see Table 7C for an example).

**Table 7C Example of concept cluster tables developed across cases**

<table>
<thead>
<tr>
<th>Incidents in the data</th>
<th>Codes / comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tried to address the issues between 1995 and 1998. Went to several psychologists but they didn’t seem to grasp the social isolation issue – why don’t you go to a club? - Not understanding that interaction itself is part of the problem. ‘The whole concept of having sight and hearing loss is lost by saying go to a club’ [i3,p.24-25] (Agency, Others not understanding, Communication, Connectivity)</td>
<td>Talk, Inapp</td>
</tr>
<tr>
<td>Frightening to know what is expected of you and knowing you can’t do it, can’t function at that level [i1, p.28]. Feel judged by everyone you meet everyday to perform to a standard you can’t [i2, p.13] (fear)</td>
<td>Attitudes, Inapp expectations</td>
</tr>
<tr>
<td>Everyone has their quirks – you are confronted with world that is potentially disastrous, where people make assumptions about the way things should be done [i1, p.38] People don’t have to solve every disability (accessibility)</td>
<td>Attitudes inappropriate expectations</td>
</tr>
<tr>
<td>If you want a reasonable lifestyle, make sure CentreLink doesn’t take your pension etc – time and energy put into running around in circles – “half our world is wasted because structures out there demand of us” and do not understand our difficulties. E.g. of CentreLink – why don’t you come in? You’re DB so what? Go through standard procedural questions; don’t know anything about disability [i3, p.40]. Organisations dealing with disability should be trained [i3, p.41]. e.g. of friend and VIPTP – do things to legitimise your condition, feeling guilty for having some sight [i3, p.67] (Systems of control, Effort, Accessibility, Others not understanding, Managing others perceptions)</td>
<td>Inapp expectations</td>
</tr>
<tr>
<td></td>
<td>Expectations</td>
</tr>
<tr>
<td></td>
<td>Expectations</td>
</tr>
</tbody>
</table>
A code list was developed, as demonstrated by Table 7D, and assessed across the range of participants noting frequency of categories. This was a further tool for reviewing possibilities for collapsing similar codes or incidents. More abstract groupings were developed of incidents within and across groupings, based on constant comparison and a general looks-like/feels-like approach (see Table 7E for example of ordering of like codes). This facilitated the identification of main categories which stood for phenomena in the data (Strauss & Corbin, 1998).

Mapping, diagramming, code lists, tally sheets, and the review of concept data chunks were activities which assisted me to distinguish key concepts, building an understanding of properties, dimensions, categories and subcategories that corresponded to Strauss and Corbin’s (1998) concept of axial coding. In attempting to understand the relationships between categories and subcategories I considered a number of possibilities, including “what, where, why, who, how, and with what consequences?” as suggested by Strauss and Corbin’s (1998) paradigm approach. Additional possibilities were considered from Glaser’s (1978) 18 coding families, such as looking for stages and dimensions within the data. For example, the concept category “surviving others’ perceptions” had subcategories which roughly corresponded to the paradigm approach; that is, they formed causal context, strategies, and consequences. However, the concept category “presenting sides of self” had subcategories of strategies only that operated along an intention continuum, that is, dimensionally.

Relational statements about categories were developed, and the core category was identified through the use of diagramming, descriptive story writing, and memo reviews as suggested by Strauss and Corbin, (1998). The identification of a core category provided coherence within my analysis, assisting me to better understand the concept of a hostile world as experienced through living and acting from a position of interactional powerlessness.
<table>
<thead>
<tr>
<th>Codes</th>
<th>P8</th>
<th>P7</th>
<th>P6</th>
<th>P5</th>
<th>P4</th>
<th>P3</th>
<th>P2</th>
<th>P1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Presenting self</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Orientation</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear (control)</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changed perception</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Struggle (financial struggle &amp; functional struggle)</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control (loss of control)</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others not understanding</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Different-ness (being made to feel different, &amp; self assessment)</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>Fitting in</td>
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<td>Others perceptions</td>
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<td>X</td>
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<td>Belonging (? collapse with connectivity, fitting in?)</td>
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<td>Escape (withdrawing)</td>
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<td>X</td>
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<tr>
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<td></td>
<td>X</td>
<td>(communication)</td>
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7.4. Issues of quality

Positivist research concepts of validity and reliability have been rejected in their traditional forms in qualitative studies, yet their underlying meaning has remained important to social research. Lincoln and Guba (1985) argued that what lies at the heart of conventional terms like validity and reliability are issues of establishing trustworthiness. I used the notion of trustworthiness to guide adherence to rigour in conducting this research from a social constructionist epistemological position.

Lincoln and Guba (1985) abstracted conventional terms of internal validity, external validity, reliability and objectivity to develop an alternative set of terms more suitable for qualitative or naturalistic inquiry. Of five new criteria they proposed in the 1980s and 1990s, the first was *credibility* or truth value. Actions such as prolonged engagement in the field, triangulation, or member checks are thought to enhance credibility. The second term was *transferability*, and rich description of the setting studied assists in achieving this. To meet the third and fourth criteria, *dependability* and *confirmability*, Lincoln and Guba (1985) advised that researchers

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**Table 7E Ordering of like codes**

<table>
<thead>
<tr>
<th>Individual concept codes used</th>
<th>What do they indicate?</th>
<th>What concept category are they part of?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pace/time</td>
<td>Changing self</td>
<td>Doing things differently</td>
</tr>
<tr>
<td>Effort</td>
<td>Changing perception</td>
<td></td>
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<tr>
<td>Communication</td>
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<td></td>
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<tr>
<td>Routine</td>
<td></td>
<td></td>
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<tr>
<td>Equipment/technology</td>
<td>Functioning at a different mode</td>
<td></td>
</tr>
<tr>
<td>Touch</td>
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<tr>
<td>Space</td>
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<tr>
<td>Fear</td>
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<tr>
<td>Intensity</td>
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</table>
should provide a full account of methods and decisions in a reflective way so as to allow an audit trail be available to readers. Seale (1999) observed that the fifth term, *authenticity* was added later to acknowledge that “relativism does not sit well with attempts to establish truth” (p. 46). Authenticity was introduced to acknowledge that research accounts represent only a temporary consensus of views rather than a singular truth. It can be addressed, for example, by seeking to represent a range of different realities in research (e.g., Guba & Lincoln, 1994).

Taking a social constructionist approach in this research, my aim was to produce a clear and understandable interpretation of the reality of the everyday lives of adults who become deafblind as I understood it. I attempted to demonstrate trustworthiness in a number of different ways, such as:

1. Being explicit in revealing my position as the researcher and the assumptions I brought to the research.
2. Seeking to demonstrate theoretical rigour through displaying consistency between research goals, underlying epistemological and theoretical perspectives, and methods used (Rice & Ezzy, 1999).
3. Utilising a variety of data collection methods to ensure a depth and breadth to understanding was gained. As Denzin (1989) suggested, validity is not the prime issue within a constructionist approach but completeness and richness of understanding are important. I used data triangulation by collecting data across time, in different sites and with different individuals. I also applied method triangulation with interviews, participation and observation.
4. Attempting to be transparent in making known to the reader the processes of data collection and analysis.
5. Seeking to establish reciprocity (Harrison, MacGibbon & Morton, 2001) in my relationships with participants both during and after data collection, by doing things with them, sharing information about myself, and involving them in the development of ideas. For example, I sought their input through regularly updating correspondence and also taking the opportunity to present at the National DeafBlind Conference non-professional day in 2004, where a wider audience of people who are deafblind could comment on the research and findings.
7.5. Synopsis and orientation to Section Three

This chapter outlined the data management and analysis procedures undertaken throughout the research. Data management files included transcript files, fieldnotes, a reflective journal and memos. The process of analysis as it was experienced in this research formed an interactive cycle of inertia, incubation and doing the itty bitty.

Complementary data management procedures were used for the different data sources, and a number of tools were found useful for first breaking up and then reforming data theoretically. These tools included developing narrative summaries and grounded interview guides, clustering data chunks, developing concept tables, using code list tally sheets and ordering like codes. In addition, mapping, diagramming and memos formed important aspects of analysis and theory development.

Traditional positivist criteria for quality were not embraced in this research. Instead, the alternative stance developed by Lincoln and Guba (1985; Guba & Lincoln, 1994) for naturalistic inquiry informed actions taken to address trustworthiness throughout this research.

The many components of fieldwork and the various procedures of data management and analysis resulted in a large amount of information. This was integrated to form four conceptual categories or mini-processes in relationship with a core category.

The four results chapters which follow communicate in turn one of the four concept categories identified through the research. These concept categories are doing things differently (Chapter 8), managing support relationships (Chapter 9), surviving others’ perceptions (Chapter 10) and presenting sides of self (Chapter 11).

Each chapter follows a similar structure with the goal to present both the analytical voice of the researcher and the narrative voices of participants. An analytical description of the category, including its subcategories, properties and dimensions
is provided, along with factors identified from the data which influence how the concept plays out in individuals’ lives. The concept is also discussed in relation to the literature.

Within each chapter one participant’s story is shared in some detail. Although each concept category is seen within all participants’ stories to some degree, I chose each particular story to demonstrate most fully the characteristics of the concept under discussion. The story is, of course, only a partial representation of the individual’s life from which it has been extracted. It is the careful weaving together of conversations from different fieldwork occasions to illustrate how the concept comes alive in everyday experience. Within each chapter, to a lesser extent, I use smaller narrative pieces from other participants to demonstrate variation in the concepts.

Chapter 12, the final results chapter in section three, presents and discusses the categories in relationship, explaining how they interrelate as strategies of a larger social process, identified as the core category: negotiating a place in a hostile world.

Thereafter, Chapter 13, the “Conclusion” chapter of the thesis, offers my reflection on the research experience, discusses the strength and scope of the study, and considers some future practical and theoretical directions.
Chapter 8
DOING THINGS DIFFERENTLY

“Life becomes very different. There is routine. I was never one for routine before. I would fly by the seat of my pants at a million miles an hour... but now it is like inch by inch, little by little. Everything. You come home and the cane goes on the top of the bed and the glasses go beside and then the monocular ... Everything has got place and routine” (Debbie, interview 1, p. 26).

8.1. Introduction

“Doing things differently” is one of four concepts inherent in the life of an individual who becomes deafblind. This concept is explained in terms of its sub-categories, properties and dimensions in this chapter. Aspects of Isabel’s story are threaded together and used to illustrate this concept. Smaller narrative pieces from other participants are also used.

As seen in Figure 8.1, the causal condition for doing things differently is the individual experiencing a changing self. Doing things differently, as suggested by the quote above, is the process of engaging with the environment in new ways. Three different strategies support the process of doing things differently. These are seeking professional help, developing communication strategies and appreciating new perceptions. As a consequence of doing things differently the individual may access desired activities, require support from others, and become noticeably different to others.
Figure 8.1 Conceptual category: “Doing things differently”
8.2. Experiencing a changing self

The experience of deafblindness can cause radical changes to an individual. These include changes in their perception, sometimes in combination with changes to their body. For a number of participants who had complex or multiple conditions, such as Isabel, Debbie and Garry, changes were not limited to their vision and hearing senses.

For all participants, perceptual and bodily changes were noticed in terms of daily life because these changes affected their social and physical interaction with the external environment. They needed to do things differently, such as find new ways to perform tasks or new ways to interact with others. Doing things differently was seen, for example, when participants found they could no longer communicate effectively or mobilise independently, they needed aids or assistance, took more time to complete tasks, relied on touch and vibration, noticed a greater amount of effort to get tasks done, or had to deal with an increased sense of fear.

Isabel’s story demonstrates the concept of experiencing a changing self:

*I have been using a wheelchair probably for about nine years. For a while before that I was using one occasionally. I never walked perfectly. I often used to fall over and I fought getting a cane initially – because I didn’t walk very well I felt I would trip over it. When I got a guide dog, I had to have an older guide dog that wouldn’t pull me and things like that. When I moved to a retirement village I still had her for a year, but my walking was deteriorating rapidly and I was falling all the time. I just began to realise that I wasn’t going to manage another dog (interview 1, p. 4, 11-12).*

*I wasn’t born deafblind … My vision just deteriorated and deteriorated and I became blind. When I was nine I needed to learn Braille. I had an accident which took most of my hearing when I was 29 or 30. It all seems a long time ago now. I had a fall in the swimming pool which gave me a cerebral haemorrhage and that affected my cerebral palsy badly (interview 1, p. 2, 4).*

*I have always been incontinent: it was part of my cerebral palsy. I can’t really empty my own catheter bag now. I used to be able to play the piano, but not any more. It is quite scary really because you don’t know what’s going to happen. I don’t know in five years if I will even be able to get out of bed, or whether I will be able to feed myself. I notice my hand movements are not as smooth as they used to be, and what am I going to do if I lose my hands? If I can’t read the Braille display on the computer, the TTY, or if I can’t hold my*
hands on books to read Braille, what am I going to do? That is such a big part of my life (interview 1, p. 19-20; interview 2, p. 16).

Importantly, Isabel’s experiences demonstrate that bodily or perceptual changes are not necessarily experienced as straightforward deterioration. During the research project Isabel experienced a seizure that quite surprisingly resulted in her physical body and her hearing abilities improving. As a result Isabel again experienced altered interaction with her social and physical environment.

8.3. Seeking professional help

As individuals experience a changing self they find they can no longer interact with the environment in familiar ways. They seek professional help to explain this or to provide medical/rehabilitative treatment. At times participants initiated seeking professional help, as Isabel describes:

After the accident I went deaf for a little while and then it came back. But then my hearing kept dropping and no one could work out why. They only worked out I was profoundly deaf in 1999 when I went into hospital to have an operation. Up until then I wore hearing aids and I believed I needed my hearing aids and my Tactaid to communicate. But in the hospital I could understand the nurses without my hearing aids, with just the Tactaid. Later, when I got them to come out and test me, I had no useful hearing left and I asked them what happened and they didn’t know (interview1, p. 7-8).

I started trying a mobility aid to help me use the wheelchair. The mobility teacher finds it really challenging, trying to teach me to use the mini-guide
(interview 1, p. 46).

Sometimes people close to the participant who noticed changes in their interaction would initiate seeking professional help, as Isabel’s family did on an earlier occasion.

I got my Tactaid in 1991. My parents took me to a professor because my hearing had gone to the stage where I was missing so much. I was learning Auslan and so was Mum, but none of the rest of my family was. My sister thought if I had a cochlear implant it might make me hear again. But they couldn’t do it. The hearing loss isn’t in my ear; it’s in my brain from the fall

29 The mini-guide is a mobility assistance device which detects the presence of objects in the environment through laser beam, and communicates the presence and distance of objects via vibration intensity.
and cerebral palsy. I decided I would try a Tactaid instead. The professor said “you’re very severely disabled and I don’t think you will learn to use it, but you can try” (interview 1, p. 8).

8.4. Developing communication strategies

Without good hearing and sight, communicating and getting information about the environment becomes problematic for people who become deafblind. Participants had to develop communication strategies. One strategy was to maintain previous modes of communication by using some type of interface for support. The interface used could be technological, such as hearing aids or loops, or another person, such as the use of voice relay interpreting. Sometimes both were needed, for example, when to follow what was happening individuals required a person speaking closely and clearly to them, even when wearing hearing aids.

The second strategy was for individuals to alter their mode of communication, for example, to start using finger spelling, Tadoma, print on palm, or fingerbraille. In using these new modes of communication participants often found that, again, another person who was familiar with these methods was needed to support communication. Therefore, whether previous modes with an interface or new communication modes were used, each individual’s way of communicating became different to the way others in their environment communicated, requiring support to participate and interact.

To develop these altered or new communication strategies, participants had to explore options available, often through making contact with other people who experienced deafblindness and/or seeking professional input. Options were then trialled in a range of contexts and their utility assessed in terms of efficiency, ease of use, and receptivity.

Isabel describes trying many methods and explains some of the limitations of her communication strategies:
I could never fit into the Deaf community. I tried going to a Deaf church so I could practise sign language, but no one would talk to me. I had to put my hands on top of someone’s hands and feel the sign, and that is what they didn’t like. Also I am not a good speller because I read Braille … Now I attend another church up the road … they tell me what is going on during the service and read the words of the hymns to me. When the minister is speaking they give me prompts. It is not easy but I use the Tactaid (interview 1, p. 9-10; interview 3, p. 41).

Even between deafblind people you often have to have an interpreter because of different methods of communication. Talking with other deafblind people is very hard for me because of my hands. I can’t sign, can’t fingerspell. If they speak I pick them up on the Tactaid, but there are some people that I have no communication with. I would like to teach people fingerbraille. It’s using your knuckles, not your fingers so my splint doesn’t get in the way. Because fingerbraille is all very close together I don’t have to do hand stretches or movements so it doesn’t hurt … You can fingerspell on my hand all day long and I won’t feel it through my splints, but if you use Braille on my knuckles I will feel it and I can reply. Some deafblind people find fingerspelling very hard because they have grown up with Auslan and its different grammar (interview 2, p. 17-19, 27).

I learnt Tadoma, but there is a problem with Tadoma – a lot of people don’t like you touching them. Staff here certainly can’t do Tadoma with you, all they do is push my hand away and probably go on talking at me and wonder why I can’t understand. I have used Tadoma at the day centre though. There the staff are used to people with different communication problems. To them it is just a way they can communicate with me when I can’t hear. I don’t think I would get very far going up to someone at the shopping centre and trying to do it though. I couldn’t imagine anyone at church ever doing it with me either (interview 1, p. 30-31; interview 2, p. 19).

I have had to make adjustments, being deafblind with cerebral palsy. I can’t fingerspell through my splints, that’s why I prefer to use the Tactaid and vibration. But the Tactaid is limited. Like in a crowd with lots of people around it doesn’t make sense. Sometimes I need to organise to have an interpreter … At the day centre, they might take me to a CD shop because that’s what other people like, and then they just walk away and leave me. I feel lost and very vulnerable because I don’t know what is going on around me. If there is music playing it affects my Tactaid and I can’t understand what people are saying. I have been known to call out just because I am frightened … the Tactaid doesn’t tell me about tone or volume either, you could yell at me and I would not know … It helps me understand speech, but I can’t hear with it (interview 1, p. 24, 33, 50).
Isabel explored a range of options through contact with professionals and people who were Deaf and deafblind. As was the case with most participants, Isabel developed more than one communication strategy. When she used hearing aids to understand speech she demonstrated how she could maintain previous modes of communication with a technological interface. When she used the Tactaid or Tadoma methods, she demonstrated how she developed new modes of communication, no longer receiving speech as auditory but as vibratory-tactile input.

8.5. Appreciating new perceptions

When individuals become deafblind they perceive the world differently. This occurs in two ways. First, they may experience perceptions differently through use of technology. Second, they may choose not to strain to see or hear and instead become more aware of their other senses. Isabel, for example, came to appreciate tactile and vibratory perception through engaging at a different level by using touch in Tadoma, and also through use of technological interfaces like the Tactaid and mini-guide sensor devices.

Seeking professional help, developing communication strategies and appreciating new perceptions often occurred sequentially, as was the case for Isabel. However, all three strategies were not necessarily used by all participants, and not always in sequence. For example, without turning to professional help Joseph appreciated that his perceptual abilities were changing.

*I am very sensitive to smell. I can smell things before anyone else. In our old unit we often had trouble with the gas and I could smell that, and my partner would have to go right up and smell it and say “oh yeah, you are right” (interview 2, p. 1).*

*When I haven’t got my hearing aids on, there are things, tiny things that I feel. I feel the slightest wind on my feet or the touch of the carpet and how it changes, the vibration of something. I think I can learn to recognise some of that, and it becomes relieving in a way not to try and use hearing and sight (interview 1, p. 34; interview 2, p. 53).*
Being deafblind, you are tuned into things, the feeling or interpretation of sensations around you. Even sitting on the lounge (he stands and sits down again). Feel that? I can tell how you sit on the lounge by feel – did you flop down or sit gently? I can tell most of the time who is sitting down by how they do it, how it feels. But why would you pay attention to that when you can see and hear and just know without having to detect that? But if you can’t hear or see too well, you make meaning out of these seemingly incidental things. They are not incidental; they are pieces of communication (interview 1, p. 35-36).

8.6. Factors impacting on doing things differently

Environmental and personal factors had an impact on how each individual was able to do things differently. These are explained below, and illustrated in Figure 8.2.

The nature of impairment determines which treatment options are possible for someone who becomes deafblind. For Isabel, a cochlear implant was not an option because of the underlying physiology of her impairment. As her hearing decreased her options shifted from hearing enhancement strategies (hearing aids) to hearing substitution strategies (Tactaid), and vice versa when her hearing improved after the seizure. In addition, her cerebral palsy interacted with her sensory impairments and the combined effect influenced communication options. For example, Isabel could not receive finger spelling clearly because of her hand splints, and she had difficulty forming signs expressively because of her poor fine motor ability.

The physical and social environment also had an impact on how individuals who become deafblind come to do things differently. For Isabel, a noisy or crowded environment meant she was unable to interpret the jumble of vibrations with the Tactaid. In those contexts she had to use an interpreter who could communicate through Tadoma.

The impact of the environment on doing things differently is illustrated well in my meeting with Garry in the city. We had lunch before spending time walking around a park where Garry had extreme difficulty understanding me through his cochlear
implant. In the restaurant, sounds echoed and at one stage a cleaner started a vacuum cleaner! The glare from the window affected his small amount of vision. At one stage he called out for me “Where are you, Julie?”, unable to detect my shape while I was sitting directly beside him. Walking back to the car the road traffic was particularly heavy. As we came to a kerb I attempted to communicate to Garry to stop but had to physically grab him to prevent his stepping out onto the road. We attempted to persist with speech but had little choice but to switch to finger spelling. We were left with only basic communication and I felt frustrated, as I suspect did he. When we used e-mail to communicate, all these environmental “interruptions” were overcome, and our communication became much easier and more satisfying for both of us.

When participants sought professional help they demonstrated their beliefs about normality intertwined with the power of medical discourse which are pervasive in the broader community. All sought medical treatment as a first option, believing any changes to be abnormal. They were looking for treatment and hopefully a cure. Before participants were willing to consider a rehabilitative option, the medical avenue needed to be exhausted. Then there came a shift to a rehabilitative approach. This is evident in Sam’s story. Sam persisted with medical treatment until he reached a turning point when he could no longer work. He then made the decision to learn different ways of doing things.

*What I have is Ushers type 2 … I started off being deaf or hearing impaired. They didn’t diagnose the deafness until school. The Ushers connection wasn’t made until much later, when I was in my late teens. But the retinitis pigmentosa had kicked in quite early in terms of night blindness and field of vision being affected. My field of vision had really narrowed down, such that I could hear a truck coming, so I knew it was close, but I couldn’t see the damn thing. It could have been I was looking in the wrong place because of my hearing being so low* (interview 1, p. 7, 9-10).

*I had problems with cataracts, they were so bad that I was struggling to read anything and I had surgery. I think that bought me a couple of years. Then I had complications with macular oedema which caused it to go downhill rather rapidly … I have been left with light perception rather than vision. Like I can tell I have got the curtains open. Very occasionally strong contrast things will break through* (interview 1, p. 10).

*With the macular oedema I had distortion as well. I would see things like cartoon. Cars would look like cartoon cars, all narrow and all sorts of weird things. I would try to read things and letters would disappear, jumble. It was*
a bit like Alice in Wonderland disappearing down the hole ... They wanted to try this medication, a diuretic; the idea was it would drain the fluid behind the retina. It sort of worked for a little while, but it was zonking me out and it was looking like I would have to have bigger and bigger doses. All it was giving me was side effects ... so after I finished up working I gave it away (interview 1, p. 11-12).

I didn’t have hearing aids at that stage, I had had them before and I didn’t like them. They are a lot better now, but they only give you better hearing, not good hearing. In other words I had been relying on my vision to compensate for my hearing, and I suppose when the vision went down, I was trying to use my hearing to compensate for my vision – not a good mix when neither of them are any good (interview 1, p. 12-13).

I got hearing aids, I applied for a guide dog and I started learning Braille after I finished up working. In a way, because the vision is no longer functional I no longer struggle to use vision when really I should use another means, which can be less stressful (interview 1, p. 13, 15).

Sam’s story also illustrates the interaction of individual strategies with practices in the social environment, and how this determines the utility of communication strategies. Sam’s scanner was only as effective as each social environment allowed. The amount of information on a bill, for example, could not be effectively read by his scanner.

It takes so much longer to do things and I have to use different equipment. Even with technology it’s very involved. Like reading my mail: I have got to get it, take it out of the envelope, put it in a flatbed scanner, scan it in, do optical character recognitions on it, and then see if I can make sense of what comes out of the voice software. These days when they do bills and things, they like to make them nice and pretty, put things in little boxes all over the place. It’s jumbled if you have to try to read it with the scanner. It takes so much longer and so much concentration to listen, so it tends to be very wearing ... It takes me half an hour to work out something that somebody else looks at in five seconds ... Sure, having the equipment increases my independence, but it doesn’t put me on a level playing field (interview 1, p. 15, 21).

The development of communication strategies was also influenced by how prepared the individual perceived communication partners would be to participate in a given method. Many participants opted for communication methods which were as “normal” as possible, requiring little of their communication partners. Participants found that these more normal methods offered better opportunities across a greater number of environments. For Isabel, the Tactaid became her primary communication
strategy. Unlike Tadoma or tactile sign language it did not place unusual demands on the communication partner by way of intimate spatial relations and use of physical touch. Reactions to Tadoma had led Isabel to believe it may only be feasible around people familiar with communication impairments, such as staff at the Day Centre. She was pleased and surprised, however, when on a surfing outing the volunteer surfers assisting her (having seen us use it) were keen to try Tadoma, commenting on how “cool” it was.

The knowledge of professionals that individuals consult has an impact on how they do things differently. If Isabel’s professor had not suggested the Tactaid, however negatively, she would never have discovered it as an option. Participants commented on the lack of information provided by professionals, most of whom seemed inexperienced about the combined impairment of deafblindness. So participants generally found out about options through other deafblind people. Joseph relayed his story of dealing with professionals as his hearing decreased:

*Before I became associated with the DeafBlind Association and looking out there and feeling a bit more confident about it, I knew almost nothing about things that could help. Audiologists never told me there were assistive listening devices and vibrators and pagers and things like that. My flexibility used to be almost non-existent; I had to always be in my own environment because otherwise it was scary. I couldn’t have people knocking at the door or ringing unless I knew they were coming because I wouldn’t be able to see who it is and wouldn’t recognise their voice and wouldn’t know exactly what they are saying. I still have tinges of that when I am alone, but technical fixes do give me a bit of reassurance (interview 2, p. 31).*

*People, particularly audiologists, don’t have any concept that if you can’t see too well what it means to have hearing aids, what you have to adapt. There are so many complexities. If you have indwelling hearing aids which is what I first got, and you drop them what do you do? I would go through a panic attack – how can I find them without treading on them? I would take my shoes off and crawl around on the floor for hours sometimes looking for them … they tried to talk me into having behind the ear aids and that was a conflict because I didn’t want people to see them, but then again I did want something bigger so if I drop them I can find them. No one was there to help me with this emotional conflict. I talked to the audiologists but they didn’t understand. One doctor even told me, you can work it out, just lip read, and I said I can’t – I am talking to a doctor who knows I’ve got RP [retinitis pigmentosa] and it’s an emotional stress, hoping a doctor would understand … but you don’t get help there (interview 2, p. 8-9, 11, 33).*
Figure 8.2 Personal and environmental factors that impact on doing things differently
The individual’s **personal biography** is also a factor in how they do things differently. With Isabel for example, use of Braille (which consists of shorthand contractions) contributed to her poor spelling ability. When she attempted finger spelling as a new mode of communication her poor spelling created confusion. In a similar way, Sam found it difficult to learn Auslan, having grown up with verbal and print English. He could use finger spelling, because it is based on English and does not have grammatical differences as does Auslan.

The increase in **technological developments** for people with disabilities and others in the community can be a positive factor expanding communication options. However, this is only true if the new technological options are known to professionals, communicated to deafblind individuals, appropriate for their environment and accessible as realistic alternatives. For example, Isabel, while physically able to use Braille adapted computer technology for communication, was unable to afford it, and had difficulty getting training.

*I am having computer lessons, learning to use the internet. It has taken the blindness organisation three years to give me five lessons because it is one-on-one. I can’t take part in a class lesson unless I’ve got an interpreter, and they don’t like providing interpreters … I have found it so hard to get lessons here, so I went interstate and had lessons. I can use my computer in whole new ways now. I was talking on the msn. I was talking to other deafblind people on the computers, people I can’t usually talk with because they sign. I was putting my own stuff into Braille. I was scanning printed text and converting it to Braille and embossing it on the Brailler all by myself. But here I don’t have that equipment. Braille equipment is very expensive. I can’t afford all that equipment. Equipment schemes like PADP*30 don’t supply Braille equipment; basically they only supply medical equipment. One Braille note device costs around $20,000, so PADP can supply 2-3 people with electric wheelchairs for that price (interview 1, p. 17, 55; interview 3, p. 7).

Sam, on the other hand, commented that “Fifteen years of working is worth something, I can afford Braille equipment”, even though it is “ridiculously expensive … more than a year’s pension, so the average deafblind person probably could not afford that”.

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30 PADP is the Program of Appliances for Disabled People, a state based government funded program that provides equipment to people with long-term disability on a means tested basis (NSW Health, 2002).
**Government funding or support** was a significant factor shaping the process of doing things differently. For example, Braille equipment was not available under equipment funding schemes in Isabel’s state at the time of data collection in this study. Debbie’s option of a cochlear implant only became realistic when she was accepted as a priority on the free list. Similarly, although she had been provided a computer through a charity, Debbie was not able to benefit from computer assisted communication because, like Isabel, she had difficulty locating an organisation prepared to teach her. Had she and Isabel lived elsewhere, they could have accessed a computer training facility and used technology to convert print to more accessible formats at no individual cost. However, this option was impossible for them because of interacting environmental factors: the expense of equipment and the lack of government funding or support organisations in their geographical areas.

**8.7. Discussion**

Medical discourse influenced how participants framed their experiences of a changing self, and they often used medical language to describe their situation. For example, Isabel described her vision as totally blind and hearing as profoundly deaf. Sam talked about his changing self in terms of visual field and visual acuity changes. All participants sought professional help and medical assessment prior to considering rehabilitative options, appearing to accept their changing self as abnormal and as something “wrong with them”. Despite hoping that medicine might cure this changing self, participants were all confronted with having to learn to do things differently.

It is not surprising that adults who become deafblind need to do things differently. Anecdotal accounts have described strategies for living differently in terms of adaptive technology (Belanich et al., 1997; Bryce & McMinn, 2002; Ferguson, 2002; Gribs et al., 1995; Jeffrey, 1995; Shapiro, 1999), and experiencing things in a new light (Coker & Sauerburger, 1995; Geason, 1999; Gilbert, 1993; Kleege, 2000; Ripley, 2002). It is clear that participants in this study came to appreciate new
perceptions through alternative use of their senses. As noted previously by Barnett (2001), the use of touch particularly becomes important for individuals experiencing deafblindness. Ronnberg et al. (2002), in research interviews with deafblind people, noted that residual vision was a dominant source of sensory information. In addition, airflow, smell and residual hearing were important perceptual tools.

A significant finding in this study is the emphasis on the constant change and need for adaptation. Both professional literature (e.g., Miner, 1995, 1997) and accounts by individuals who are deafblind (e.g., Clark, 2004; Lawson, 2002; Ripley, 2002; Sturley, 2003) have highlighted the issue of change. In this study particular emphasis was given to change at both a physiological level as well as at an environmental level. There were often additional bodily changes experienced simultaneously. These combined changes shaped each individual’s experience of doing things differently. These findings support Wendell’s (2001) view that impairment is dynamic, multi-dimensional and variable, and is given meaning by an equally dynamic and variable environmental context.

Constant change creates an ongoing need for new or altered communication strategies. Overall, participants found exploring options with others who are d/Deaf and deafblind was most beneficial, whereas professionals offered them little help. Gilden et al. (1994) suggested that low uptake of technological aids was due to difficulty getting information to deafblind people. My findings suggest poorly prepared professionals may be preventing information on technological aids getting to individuals who are deafblind.

This study confirms that the communication preferences of deafblind individuals are affected by multiple factors. In the findings here the nature of impairment(s), the individual’s biography, the environment, acceptability of methods to communication partners, and the knowledge of professionals influenced communication preferences. Other authors have noted one or more of these influences on communication strategies (e.g., Barnett, 2001; Kilsby, 2003; Jaun, 2003). These multi-dimensional influences result in varied communication and interaction strategies among people who are deafblind.
For some participants, access to equipment was hindered also by affordability, availability through government funded equipment schemes, or adequate training in its use. In terms of computer use, all but one participant in this study were able to use a computer to assist with communication and information access. This supports suggestions in the literature that computers can act as positive communication tools for individuals who are deafblind (Belanich, 1995; Jaun, 2003; Moller, 2003; Sasse, 1997; Tarrant et al., 2002; Trentini, 2000). The only participant not using a computer, Debbie, would have done so if given the opportunity to learn how. This confirms Jaun’s (2003) assertion that availability of training and affordability of technological equipment inhibits the potential benefits of technology for people with deafblindness.
9.1. Introduction

“Managing support relationships” is the second concept evident in the lives of people who become deafblind. Managing support relationships is explained in terms of its sub-categories, properties and dimensions in this chapter. Aspects of Natalie’s story are threaded together and used to illustrate this concept. Smaller narrative pieces from other participants are also used.

In doing things differently, the way individuals communicate and receive information about their environment becomes different to others and support is required to participate. Individuals who become deafblind have to manage the relationships within which this support is provided. They do so using three strategies: having expectations of others, protecting the relationship, and creating webs of support. In managing their support relationships, individuals can access desired activities, establish a sense of connectivity, or experience the presence of others as unaccommodating. Managing support relationships is represented diagrammatically in Figure 9.1.
Figure 9.1 Conceptual category: “Managing support relationships”
9.2. Doing things together

With support relationships, individuals do things together with another person. For participants, “doing things” was not limited to physically performing tasks. Rather, doing things could take the form of planning activities, or could simply involve sharing rather than being activity-focused. Natalie’s story demonstrates the concept of doing things together:

*I was talking a lot to the volunteer at work about the home stress, and she said isn’t there someone that could help you take action with these things? I said yeah maybe, and she made me promise to contact people from the deafblind group … I went out to dinner with one guy and we discussed all the options - renting, buying, units, townhouses, waiting, acting soon. He was someone a bit more objective* (interview 1, p.18-19; interview 2, p. 40).

When I was looking for places, I tried looking at real estate websites and I thought this is going to be too hard, I will just e-mail them and they can do the work for me. Two people got back to me by phone and e-mail. Mum helped me, finding numbers and contacting them … To me the hardest thing about buying a house was dealing with print, contracts. It doesn’t exactly work that I have time to get it in Braille and can read it. Mum was very good, she requested a copy and to me that was as good as my own eyes you know (interview 1, p. 19-20).

In Natalie’s story, the volunteer friend at work was someone she could share with, but not someone who could assist her to plan or move away from home. The contact person from the deafblind group was able to collaborate with her, helping her plan actions, but then it was her family who facilitated her physically buying a home and moving. Support activities can involve facilitation, collaboration or sharing, and one person can move between all three support tasks. Natalie sometimes received physical assistance from her mother, such as when her hearing aid broke down and she needed help mobilising. On other occasions Natalie’s mother assisted with planning activities such as getting information needed for church weekends.

*Mum has been a good advocate for me over the years. A few months ago one of my hearing aids went bung and the technician was behind with repairs. They said you can pick that up Tuesday. Mum said hold on a minute, she’s got a life to live, she’s got to work. I had a church conference to go to as well. I knew I would not be able to manage without my hearing aids. In the end he fixed it in his lunchtime. Mum had to push hard to explain that I wasn’t communicating well. I had to hold her hand because I just didn’t know what*
was going on around me. When I go away for church weekends, Mum helps me plan. She tells people what I need: sometimes they provide it, sometimes they don’t. She uses the computer at home and puts songs into Braille, I have taught her how to do that. It is wonderful (interview 1, p. 36; interview 2, p. 21).

Natalie’s relationship with her guide dog was another support relationship she had to manage.

_Having the guide dog is a great support. He adjusts very quickly, learns things quickly. It is just so good to have a dog like him. I had to learn about owning a dog, like if he’s sick I can’t just leave him outside, have to look after him. I have to brush him everyday. Dad washes him at the moment_ (interview 1, p. 39).

The guide dog facilitated her performing activities and Natalie felt responsible for him. This was also the case for Sam, the other guide dog user in this study who spoke about the reciprocal nature of his relationship with his dog.

_It is like having a toddler all the time because you’ve always got to look after his toys, make sure he goes to the toilet, look after his dinner, dah, dah, and dah. His routine becomes yours really. But an experienced dog can be very useful, there is no doubt about that despite the drawbacks of having to get him organised_ (interview 1, p. 24).

Support relationships can vary by type and can be temporary or enduring. Examples of both are demonstrated in Natalie’s story. In her life, enduring support relationships, where a relationship history was established through repeated experiences of doing things together, included her parents. Temporary support relationships are also evident in the following excerpt, where she solicits help from relative strangers, such as at the shopping mall or on the holiday tours.

_ \textcolor{blue}{I went down to the shopping mall ... I asked some guy “is there a hairdressers?” and he said, “oh yeah on another level”. We went around and found the lift – there was actually Braille on the lift! I was impressed. I walked into a place and I wasn’t sure if it was a hairdressers. I couldn’t smell any perming solution ... I am all for trying to do things as independently as I can. Sometimes I have relied on people because I just did not know what else to do, but now that I am out by myself I want to manage. I decided even if it is more expensive to go there, at least I can get there myself, in my own time and not wait for someone to take me (interview 1, p. 23).}

_In the following excerpt, where she solicits help from relative strangers, such as at the shopping mall or on the holiday tours._

_ \textcolor{blue}{I went interstate by myself one time. I did some tours and got people to help me around. Relying on other people can be very tricky. On some of the tours I}_
didn’t see things very well at first because I didn’t have help. Once people knew I was there and what I was capable of it was better. Once we got over that hurdle and people saw me about and realised I was not going to sit in the bus in a corner all day it worked out. It can be difficult at those sort of things because you can’t target the people that you think might be able to help you, they have got to come to you and say “do you need any help”, or even just sit next to you on the bus (interview 2, p. 15, 17-18).

The structure of support relationships can differ in three ways. Deafblind individuals may have a support relationship with another individual, as Natalie does with her mother. They may have support relationships with service systems, such as when Natalie uses the blindness organisation.

  When I moved, I contacted the blindness organisation and an OT came to help me get settled, with cooking and things. Because of how the kitchen was set up at home I had not done much before. But I actually feel better now that I don’t have someone looking over my shoulder all the time. Now I can experiment by myself in my own time and I am not pushed or rushed. It’s nice (interview 1, p. 22).

In addition, individuals may act as a representative of a group and engage in developing support relationships with other groups. Natalie did this at times, becoming involved as a committee member for the deafblind group and on different occasions also representing blindness groups.

9.3. Having expectations of others

The individual who becomes deafblind comes to have expectations of others, particularly in relation to the nature of engagement and perceived priority of needs. For example, in support relationships participants’ levels of autonomy varied. When living at home, Natalie was forced into a dependency relationship with her parents due to the inappropriate home set-up and lack of public transport options.

  A few years ago mum decided she wanted a new kitchen but when it actually came into place it was all totally inaccessible to me. The microwave was up high, nothing was Braille labelled. I guess it was her kitchen and she wanted it the way she wanted it, but it meant when she and dad were away it was a big hassle – we had to plan so that I could eat and survive (interview 1, p. 18; interview 2, p. 37).
Some things about living at home were really stressing me out ... Mum and dad are quite happy to do too much for me and they weren’t prepared to change things so that I could do things for myself. When mum was trying to teach me to do the washing at home it was not like wash your own, it was like here let’s wash three people’s stuff and that is too hard, you have got to start small. I wanted her to say what do you want to learn so you can manage if we’re away? (interview 2, p. 37-38).

My scanner was upstairs and it got to the stage where the room it was in was so messy I couldn’t even get to it. That was a most frustrating thing, not to be able to read print by myself. Not being able to get out was another thing, just because of what the family was doing. I had an awful Christmas last year, dad wasn’t able to take me many places and I felt hemmed in. Transport was a huge issue. He used to pick me up from work, but when he hurt his arm, I had to walk both ways. Thirty minutes home in the dark in the winter from the bus. It was suburban streets and things were not well lit. It wasn’t nice and it was tiring me out (interview 2, p. 38-39).

Once she moved, Natalie was able to display greater agency in the relationship with her parents, still relying on them, but in ways of her choosing rather than in ways forced upon her by their environment.

Mum and dad still support me. Sometimes if I go and get the mail and if I know I am seeing them I just leave it and ask them, because it takes me so long to work things out with the scanner ... My dad showed me how to use the vacuum cleaner the other day ... Of course I have got to be shown the first time but then it is really better to do it in my own time, I find that’s how I work best, by experimenting and doing things for myself (interview 1, p. 25-26).

Individuals’ expectations of relationships vary with relationship structure. For example, in the case of enduring individual-to-individual relationships, participants were more likely to expect closeness, warmth, understanding, time and autonomy. The needs of both parties were likely to be acknowledged. When living with her parents Natalie expected her parents to be more understanding and allow greater autonomy. At the same time, she respected that it was their house and made an effort to comply with their routines. She recognised that her parents had needs which should be valued in the interest of protecting her relationship with them.

In the case of a relationship between an individual and a formal support system, however, participants considered the emphasis should be on their needs as consumers, not on the service system. The relationship was most often with a position
rather than with a person, becoming task-oriented rather than relationship-oriented. This is exemplified when Natalie discussed the occupational therapist, and spoke of her in terms of the tasks she supported her with, and as someone looking over her shoulder.

9.4. Protecting the relationship

In managing support relationships people who become deafblind recognise the need to protect their relationship and do so via a combination of strategies. In the excerpt below, Natalie’s discusses some of these strategies:

I knew that my mum and dad were not going to be around forever to look after me. I wanted to move out and learn to stand on my own two feet while they are still here, to help me get set up. For me to be able to cope in an emergency situation I can do it much better now. If dad’s sick I can cook something here in my accessible oven and take it to him, or he could come and spend a few nights here. I am much more equipped in my own little place (interview 2, p. 40).

I have started Nutrimetics. My friend Jo has been doing it for quite a while so she’s got quite a big selection of products. We did a party yesterday … I’d like to do it myself. I mean Jo’s quite willing to help, but I feel that sometimes people are very willing to help you, but they might get sick of it after a year or something. I want to get it running myself, organise computer ordering, and do training courses. I will always have to have a driver, but if I can do it myself it won’t matter if they know nothing about the products. At the moment Jo loses out while she helps me (interview 2, p. 3-4).

One strategy to protect support relationships is relationship balancing. This means seeking to balance the demands on the supporter by involving additional support people, or by doing things in such a way as to minimise the need for any support. In Natalie’s story a case in point is when she talks about developing the Nutrimetics business onto the computer to minimise the demands on her friend Jo and to enable different people to drive her if needed.
A second strategy is to engage in relationship reciprocity by seeking to do things for the other person or beyond their individual needs with the other person. Natalie expressed her happiness at being able to be a support to her parents: if they are unwell she could cook meals for them or have them stay over.

Relationship contact is a third strategy that is important in protecting a relationship from waning, by keeping in touch and ensuring that communication is possible. Although Natalie had stopped attending the deafblind group regularly she maintained e-mail contact with some members. This enabled her to continue to view them as a support, and to involve them when planning her move out of home.

9.5. Establishing webs of support

Individuals who become deafblind seek to establish webs of support that facilitate access to doing more things. Webs are created using multiple relationships or multi-contextual relationships. In this study, if participants had very context-specific supports, additional supports were often sought from other contexts. If they had supporters who were flexible across contexts this need was minimised.

Natalie spoke of a range of contexts in which she interacted: home, work, deafblind groups, committees, holiday groups, church groups, Nutrimetics. In each of these settings she had different networks on which to depend. At times she approached a situation expecting to be independent but was confident of soliciting temporary support as needed. Her mother is an example of a supporter prepared to assist in varied contexts, at home, in dealing with business, in preparing for church commitments, etc.

Participants demonstrated that the ultimate goal for the individual who becomes deafblind is to establish access to multiple activities or situations via a web of support relationships or alliances. Links can be established deliberately, such as when individuals actively seek contacts by joining in groups, as Natalie indicates below.
I originally went along to the deafblind group because I wasn’t sure if I was going to get any deafer and I thought maybe I need to learn a bit of finger spelling just in case. I wanted to cover all my bases, to have some networks there … once you leave school a lot of your old networks are gone. I think I realised the importance of making some connections with people that were on the deafblind side … At times I have been on the committee, gone to consumer meetings at blindness organisations and things like that, represented the deafblind group. If I hadn’t made those connections, I would not have had anyone to go to for advice about wanting to move out of home (interview 1, p. 31-32; interview 2, p. 48).

Alternatively, links can be made unintentionally, where individuals meet someone who links them to others or assumes a support role coincidentally. At times a combination of deliberate and unintentional support linking was evident in participants’ lives. This is illustrated by Glen, who deliberately sought support from a job agency which led to a number of further contacts being established incidentally. Together these contacts eventually allowed him to create a web of support for himself among others with Usher Syndrome.

I wasn’t really happy at TAFE, couldn’t see the board, what was happening around me. The interpreter was too fast and I was missing so much. I decided to withdraw because I couldn’t cope. No one understood about my Ushers. I was so upset. I decided to go to a job agency and they supported me a lot. The woman said to me, “what about an appointment with the Blind Society maybe they can help you with counselling”. So I went to the Blind Society and chatted with the counsellor, talked about Ushers (interview 1, p. 13)

I got a job in the bank, doing data entry. There was one Deaf person working with me in the bank. She knew about another person with Usher. She was really helpful and told me the Deaf Society had a new Ushers workshop. So I went to the Deaf Society and I was nervous – but I was a bit happy and excited too, because I wanted to meet other people. In my life I was feeling like I really want to be involved in the Usher community. I contacted people over the internet, Usher people in America and they were a great support to me. They helped me understand my life is not limited just because I have Usher. I can get married. I can have a full life. I realised other people have Usher and have set themselves up. Yet I had heard nothing about setting up here (interview 1, p. 12, 14-15).

After the group I met a deafblind woman and realised we had met on the e-mail list from America. We chatted and decided we would think about what would happen in the future with the Usher community. We had the same idea: that we should create one. It was really great. I was so happy and in my life I was feeling great because I was meeting with people. I have a lot of people
who can support me now and that’s better than before, before I had no support and that’s why I had such a hard life and why I was so nervous about things (interview 1, p. 16).

The individual’s relationship with a support person may be important in itself and important because of what it allows the individual to do in terms of the links it facilitates to activities or further relationships. Therefore support relationships were noted to have two functions: to provide a sense of connectedness through the relationship itself, and to support access to desired activities and situations by fulfilling an intermediary function. Unfortunately, on some occasions support relationships disintegrated and the individual experienced the presence of others as unaccommodating. All three outcomes are evident in this section from Debbie’s story.

I don’t know what the problem is with my sisters to be honest. Like after mum passed away, they were organising the funeral and they wouldn’t write or involve me. They took Mum’s body away and had the funeral guy there and I was really upset, and they wouldn’t tell me even what day she was going to be buried. All I wanted them to do was to write down when Mum was going to be buried, what was happening … You know the eulogy? Well it was everything that they remembered; I wasn’t asked a single thing to put in … They just don’t deal with the deafness and blindness at all, none of my family (interview 2, p. 4-5).

Last week it was my son’s birthday and my sister wanted to take everyone in the family out for lunch, except me! I was so angry. I decided I would go. On the way there on the bus I am teaching my son sign language alphabet. He couldn’t remember f so I said fingers crossed, and he had trouble with s so I thought well he has just turned 19, so I said think sex. He burst out laughing and we are sitting in the back seat of the bus and I said “OK, spell your name, hand on hand” and he did. He was really good and he has been doing it ever since. So the lunch went off pretty well. I was psyched up and my son was ready to help me. We were sitting there signing and it really annoyed my sisters because they had no idea what we were saying. I asked “what are you having?” and my son signs back and I go “oh chicken” and I say “what is dad having?” and he signs and I went “oh curry!” And the rest of the family, I think they were taken back. It was really good for them to see. It got as good as it could get I think (interview 2, p. 5-6).

Debbie experienced the presence of her sisters as unaccommodating. In contrast, her relationship with her son provided a sense of connectivity. His willingness to support her communication needs and act as an intermediary enabled her to participate in the family luncheon to a greater extent than she could have achieved by herself.
9.6. Factors impacting on managing support relationships

Personal and environmental factors impact on how people who become deafblind manage their support relationships. These are discussed next and are diagrammatically represented in Figure 9.2.

The level of *independence in doing things differently* determines whether individuals need to seek or manage support relationships. If they have developed strategies that allow them to access activities then they may not require the support of others. In Natalie’s story the importance of independence and developing herself as an independent person is evident. This direction is also reflected in Ralph’s life. While Ralph referred to some support relationships, for example with his mother and some agencies he had used in the past, on a day-to-day basis he tried to do things in ways which minimised the need for others. As a result, support relationships were much less a part of his daily life, as seen in the following comments:

> When I was growing up I was always encouraged to both think and do for myself. That has taught me the only one I can rely on is me. The only one that will do things that need to be done is me. When the virus took away my hearing I thought about doing away with myself. What turned me around was someone completely outside the family to talk to, who did not say do this or that, but let me explore the issues myself (August, p. 7; September, p. 16).

> I do have a hearing problem and an eye problem but I REFUSE to let either change my life any more than I have to. When I started experiencing hearing problems, I started looking for ways to cope with it and ways to manage it – not for it to manage me, if you see the distinction. So I went hunting for agencies that look after deafblind people, I got involved with some computer training and I started to learn sign language, but somehow it just was not for me (October, p. 19-20).

> I live with my mother, and we help each other out sometimes. She is getting older, so I help her with shopping and things around the house. She still drives, so sometimes she will drive me places if I need that (fieldnotes, p. 4).

> I am still working in an office and I try to take part in the normal things of office life, like meetings, which I find extremely difficult. Hearing aids are as useful as sand in the Sahara desert but some how I get by. I still hear my TV even if I have to sit on the floor at times to do it. My life is not bounded by deafblind issues. I continually look for new technology (October, p. 21).
In the workplace, the greatest challenge in this age of computers and other devices is to be able to modify them so disabled people can use them at little cost to the employer. The agencies need to get their act together they just take too long to find out if a thing can be modified and to get the work done. I have given up on agencies – of the four jobs I have had, I got three of them myself via hard work and determination (September, p. 11).

The way individuals present themselves also influences whether others perceive that support is required. Natalie, for example, commented that on the holiday tour she missed out initially on seeing things because people did not perceive that she required help or wished to participate. She had to behave in a way that disproved other’s assumptions before they realised they could support her participation.

Sometimes there can be tension between the way individuals do things and others’ perception of their need to be supported. Joseph’s story provides a case in point. He usually communicated independently with hearing aids and seldom requested communicative support from others.

At the dinner the other night, for anyone who has got partial sight and partial hearing that was a very difficult experience. It was echoing and the loop wasn’t too good which is a general trend. It was a challenging and stressful and to be honest I had no idea what was going on. I didn’t know. I could not hear what most people were saying. But I didn’t say anything, I mean what can other people do? Nothing. That’s the sort of thing if you are deafblind you can’t get used to it. You get someone who really demands their rights, like Carol. I can understand why she does it – she wants to be on par or close to what everyone else takes for granted … From my point of view, I emphasise with her. I would like to do that, I would demand that too, if I thought it would make a difference (interview 2, p. 35).

But I just sit there and can’t hear most of what is going on. If I say I can’t hear enough, people run around but what can they do? No one is a technical person who can fix the loop, because the loops are basically incorrectly put in. It is complex. Most often the orientation of support for deafblind people is towards people who don’t have any communication or who have Auslan or finger spelling … not people like me, people who need relay voice interpreters. You might occasionally have that, like at the Olympics I had someone talking to me very close and I could get most of what was happening … technology alone doesn’t always work (interview 2, p. 35-36).

It is often up to individuals who become deafblind to identify that they need support, or risk being excluded from a situation. Had Joseph said “I cannot hear and I need a
voice relay interpreter” at the dinner, he may have been able to participate better. Others failed to perceive that Joseph required the support of another person or that different environments altered his support needs, because they were accustomed to him using hearing aids.

For a support relationship to be successful, communication is required, and therefore the **communication abilities of the supporter** are important. The most important expectation participants had was that communication, no matter what form, be sustained. In fact, it was often the failure of this expectation to be met that shifted interactions with others from potentially supportive relationships to the individual simply having to tolerate the presence of others as unaccommodating.

Unless deafblind individuals are involved in an action they perceive the exchange as something happening around them or to them, rather than as an activity with another person. This can be seen in Debbie’s story recounted earlier. The failure of her sisters to communicate at her mother’s death turned the relationship into a negative experience in which Debbie felt painfully excluded. In that setting her sisters became a presence she had to tolerate rather than people present in a facilitation, collaboration or sharing role. In contrast, her son’s willingness to communicate in the manner she required and to act as an intermediary at the luncheon created a support relationship, providing a buffer between her and the excluding nature of the relationship with her sisters.

Isabel frequently said “*I often get left on my own at the deafblind group activities because I am in a wheelchair*”. During my participant observations, however, I noticed that Isabel was seldom physically separated from other group members. Rather, at times helpers needed to attend to tasks around her. On these occasions, although Isabel was not literally being left alone, there was no one directly engaging with her. In moving to a separate task the helper became for Isabel part of an ill-defined open space and she could no longer experience that person as still being with her. Consequently she perceived that communication was not sustained and that a support relationship no longer existed, where in fact the person was engaged temporarily with other tasks.
Figure 9.2 Personal and environmental factors that impact on managing support relationships.
9.7. Discussion

Findings in this study align with earlier survey research and personal accounts of people who are deafblind, which indicate that they rely on the support of other people. Both the CAUSE survey (Kilsby, 2003) in Europe and an Australian survey (Prendergast, 1996) reported high levels of support required among respondents, with the majority provided from non-formal sources such as family and friends.

Participants in this study required varying levels of support depending on the nature of their impairments and the effects, and just how differently they interacted with their environment. Support relationships were dominated by specific enduring relationships, such as those with friends and family, though temporary support relationships were also reported. Aside from individual relationships, participants also noted support relationships with agencies or organisations, though these were not often enduring and were perceived as more task-oriented than relationship-oriented.

In earlier survey research a range of support activities were listed: predominantly transport, communication, practical care tasks (DeafBlind UK, 2004a; Prendergast, 1996), and to a lesser extent, advice and information support (DeafBlind UK, 2004a). Similarly, support relationships in this study were found to involve facilitation, including physical or communicative support to participate in activities. Equally important in this study, however, were collaborative support tasks such as planning and providing assistance for informed decision-making, and sharing support tasks such as simply taking an interest in the individual’s life and conversation.

In this project, due to the variable nature of their impairments and their environments, participants required various types of support on different occasions. Sometimes they required facilitation; at other times, collaboration or sharing. An important finding is that the communication ability of the supporter is imperative to the successful negotiation and maintenance of a supportive interaction: the supporter must be flexible to the deafblind person’s changeable needs.
Previous research has not highlighted the active role taken by people who are deafblind in managing support relationships, or the negotiated nature of these relationships. In this study many participants had undertaken representative positions within groups and acted to establish supports with other groups on behalf of people who are deafblind. In addition, participants actively sought to establish webs of support through multi-level connections in their individual lives. Personal stories of deafblind persons have shown awareness of the importance of support from other groups (e.g., Ohlson 2001; Hicks, 2000) and individuals (Belanich et al., 1997; Fukushima, 2001; McNamara, 2000; Ripley, 2002), corroborating findings here that deafblind people are indeed active in the process of supporting themselves both individually and as a community.

Little research has been conducted into the nature of support relationships in the lives of adults who are deafblind. Kilsby (2003) reported that approximately 40% of the 67 CAUSE survey respondents indicated concern that receiving support from family members placed stress on the relationship. In the study reported here participants actively sought to protect their support relationships, using strategies such as balancing, reciprocity and contact. This suggests that they were aware that being in receipt of support could potentially stress the relationships.

This study reveals that people who become deafblind have expectations of their supporters, particularly in terms of how they should engage with them and prioritise their needs. From the perspective of the person who is deafblind, if these expectations are not met the support relationship dissolves. Thus it seems important to note that the presence of others in the life of someone who is deafblind does not necessarily indicate that they have access to support. A person can be in a formal support position, yet be acting toward the deafblind person in a manner which does not actually support them.

Romer and Schoenberg (1991) found that staff in group homes, while present in a support role, dominated rather than facilitated communications with residents. In a similar way, in this research study, people in participants’ lives were at times perceived as deliberately excluding or as exercising power over participants and...
limiting their participation. This problem of balancing agency and dependency in support relationships has been alluded to in earlier personal accounts (Crow, 2000; Ripley, 1995, 2002). For example, Ripley (2002) has commented that supporters are essential and can be the deafblind person’s links to the community, yet previously noted that cooperating with others without feeling one’s independence is being lost can be challenging (Ripley, 1995).
Chapter 10
SURVIVING OTHERS’ PERCEPTIONS

“Very few people actually think to identify themselves, staff here don’t. They just come in the room and I call out ‘who’s that?’ and they don’t answer, they just walk out. I have this argument all the time with people, and I say to them if you weren’t hearing and sighted you would want to know what is happening around you. They just say ‘I didn’t want you, I was just doing something’ ... they just don’t understand” (Isabel, interview 1, p. 29).

10.1. Introduction

“Surviving others’ perceptions” is the third concept in the lives of people who become deafblind. It comes about from doing things differently and managing support relationships. It is explained in this chapter in terms of its sub-categories, properties and dimensions. Aspects of Debbie’s story are threaded together and used to illustrate this concept. Smaller narrative pieces from other participants are also used.

As individuals become deafblind they find new ways to do tasks and interact with other people. Sometimes these ways of doing are noticeable and not easily disguised. Sometimes they are subtle and not easily understood. In either case, they are not typically catered for and the individuals become noticeably different in social environments. Individuals notice the presence of others as different to themselves and feel vulnerable to the judgments and actions of others. In addition, individuals’ need for support makes others’ perceptions potentially more consequential. Unfortunately, deafblind individuals often experience the presence of others in the form of inappropriate responses, unrealistic expectations or inaction. It becomes necessary for individuals to maintain a threshold of tolerance to survive others’ perceptions. The consequence of surviving others’ perceptions is that individuals who become deafblind come to view themselves as different/marginal. Surviving others’ perceptions is represented diagrammatically in Figure 10.1.
Figure 10.1 Conceptual category: “Surviving others’ perceptions”
10.2. Experiencing the presence of others

For participants, the presence of others was experienced through direct interactions or more generally through exclusionary experiences. Overall, individuals who become deafblind experience the world as an inaccessible place. Information, equipment, physical environments, social happenings and communicative practices are seldom available in ways they can use or understand. The pace of life and the frequency of change act to exclude them, and their ways of doing things are often not recognised or acceptable to others.

Individuals constantly experience barriers to participation in physical and social environments, and become very aware of able-bodied others who have little consideration for people who are deafblind. As Joseph comments:

Every human feels that no one else understands. But for people who are deafblind it is more crucial that people do because you rely on them. You just cannot get through your life without relying on somebody, because you can’t do things on your own, as much as anyone else. You can’t do things the way the world has designed itself. It is usually on paper, or it’s on television or it’s in some way presented to you in a visual form or an auditory form … It is a frightening world. I can’t hear or see what goes on around me. The environment of this world is totally hostile to deafblind people. You can’t communicate, can’t be protected and warned by the environment in the only means you can be sure of, and that’s tactually (interview 1, p. 29-30; interview 3, p. 47-48).

Individual encounters often include inappropriate responses or expectations from people. These have the effect of disallowing ways of doing, failing to recognise the unique experience of being deafblind, or devaluing that experience. The following section from Debbie’s story demonstrates:

I have had people punch me on the bus … I asked the driver to tell me when we got to my stop. I was sitting behind him and this bloke across the aisle started punching me. I had explained to the driver I am deaf and nearly blind, but he was talking to me – I didn’t know – and the guy next to me just started punching me and pulling my clothes and truly it was so terrible. I ended up with bruises. Experiences like that make me so mad (interview 1, p. 14-15)

I walk past the bus stop and I don’t have much vision but I have got some peripheral vision and I see people stare at me. Everybody’s head turns and follows me with the cane and I just feel like doing a dance or something. What
are you looking at? Haven’t you seen someone with a cane before? (interview 1, p. 15).

They put me in hospital for nine days to run tests and the staff had no experience dealing with deaf and going-blind patients … they thought I was a head case. They stuck me in a single bed ward by myself and no one would come anywhere near me. Trying to communicate was so hard … After I had a spinal puncture I wanted to go to the toilet. The volunteer tried to get me out of bed and I said I wasn’t allowed. She bought a Deaf cleaner in and they both tried to get me out of bed! And I’m going “no I am not allowed out of bed, find me a nurse please”. Finally they got a nurse, but she must have been ticked off she had to get me a pan and she just RAMMED it up under my back without my realising she was going to … I was so shocked (interview 1, p. 11, 13).

I remember going past the nurses’ desk one day and I was trying to catch the attention of about maybe five nurses. It was like I was invisible. They just didn’t want to try to communicate with me at all. I was gesturing with my hands, talking, but they all ignored me … When you are like me, the stigma of deafblindness doesn’t matter so much. What matters is nobody cares if you don’t scream loud enough. If you don’t have a voice, no one will hear you. The deaf and the blind bit is easy compared to people’s attitudes and the world. That’s the part that hurts … that really is the pits (interview 1, p. 11, 21).

Debbie described encountering interactions with others as unaccommodating. Even when she explained her deafblindness to other people, like the bus driver, they often failed to comprehend how to interact with her.

10.3. Maintaining a threshold of tolerance

Individuals seek to maintain a threshold of tolerance, to endure what typically are hurtful misperceptions, lack of understanding, or lack of accommodation by others. Participants used a number of strategies which were categorised as strategies of resistance or surrender. These strategies were psycho-emotional responses rather than necessarily being observable behavioural responses.

Participants at times used resistive strategies, such as fuelling or dismissing. In fuelling, the perceptions of others become a source of motivation, energy or
justification for the individual to engage in confronting behaviours. For example, the person who is deafblind might challenge the perceptions of another person during interaction. If the other person’s perceptions are somewhat inconsequential, they may catalogue the experience as motivation for tackling bigger battles at a later time. Debbie spoke about confronting others. In the following story, fuelled by the nurse’s reaction and the audiologist’s comments, Debbie challenged their perceptions. Incidents like these merged together in her memory and motivated Debbie to become involved in public speaking about her experiences and what is important to people who are deafblind.

_I’m just invisible, but I am still very determined, I don’t take no for an answer very often. Basically if I go to shops or Centrelink, well I am in your face and I am not getting out of it until I get what I want, so you may as well communicate with me. I have to do that or I am ignored_ (interview 2, p. 37).

When I was in hospital for the cochlear implant operation, my nose was bleeding into the mask and I was wiping it, wiping blood all up my face. I made the sister look at a snotty tissue and she was disgusted. She came back afterwards and I had had time to think about it and I said “well you have to tell blind people they are bleeding or they don’t know, it could be sweat or anything”. She just looked at me and I thought “oh oh oh”. She still didn’t understand. It was so frustrating (interview 3, p. 4).

_The audiologist said to me “oh well you’ll be able to throw away the whiteboard and stop signing now”. I don’t think I will ever not sign and I will never be without a whiteboard, because that is how people communicate with me. A lot of my friends are Deaf and deafblind now. I said to her, “they are just like you and I, just their bodies won’t behave”. I couldn’t believe she had said that – as if having the cochlear implant was going to change the experience of the last few years_ (interview 2, p. 20-21).

An individual may dismiss the perceptions of others by choosing not to acknowledge them and continuing doing whatever they desire. An illustration follows of how Debbie dismissed a security guard’s behaviour. Her tendency to assume everyone is being cooperative, unless they “wallop” her, demonstrates another form of dismissing.

_When I am out, I do the deaf and blind thing – “oh excuse me, are you crossing the road? Oh good can I come with you”. I don’t care, I can’t tell if people are swearing at me or telling me to F- off. I just go “Oh thanks” … I am becoming this person that just thinks everyone is being nice to me, unless they wallop me or something … I prefer to assume people are being really_
nice, then [if they are not] it is their problem not mine, and I don’t have to wear the stress (interview 2, p. 24).

The other day, in the shops the security man hovered around me … they think I am trying to steal something because it takes me so long and I have to hold things up close to my geeks (thick glasses). But I wanted to go there for ages and normally if I go shopping with someone else I only get to look at what everyone else wants to … So I thought stuff it, I was determined to take whatever time I needed (interview 3, p. 12).

In a similar way, Isabel used the strategy of dismissing when staff responded negatively to her use of the computer.

Staff here hate the computer. They come in and say turn that awful thing off. I have the voice set so I can understand it with the Tactaid as well as using the Braille display. I know I am allowed to use it up to 9 o’clock at night, so I don’t worry what they think (interview 2, p. 36).

At times participants used psycho-emotional strategies of surrender, such as empathising or opting out. In empathising, individuals who become deafblind reassure themselves that it is difficult for someone who is not deafblind to have a good level of understanding. This strategy is not evident in Debbie’s story but can be seen in the following comments made by Joseph:

In an environment like that I lose all my confidence because there is nothing I can do. If I say to people “don’t do this”, “be quiet”, then you can’t relate to people anyway, so either way you have lost that. You can’t trust that people will accommodate you. You find an example every day, every minute, where they don’t, because no-one remembers all the time, and there are always things in the normal environment that prevent you communicating. It frustrates a lot of people trying to communicate with me and I can sort of understand their frustration … because you can’t sort of say, see that over there, that’s what I mean … People don’t know what to do and I can comprehend that is very difficult for them. But the emotion for me is painful, because I can communicate; you just have got to be patient. It is not their fault, but emotionally it makes me feel like where do I belong? Nowhere (interview 1, p. 10-11; interview 3, p. 23-24).

Joseph empathises with people trying to assist him, believing they are in a difficult position and not really at fault. He also demonstrates the strategy of opting out by emotionally desensitising himself to situations where others fail to cater for him.
You’ve got heightened levels of fear about things because the world has been designed for people who have some level of sight and hearing and you don’t have that. I’ve become very insensitive about things for survival reasons – certain touch, being pushed, bumped, grabbed, manhandled. You become a bit insensitive to that because it’s common … with me, if I am in a crowd I can’t hear anything and I can’t see much, so the best people can do is just think they’re talking to me and shove me around. That’s all they can do and they don’t think about it … You have to desensitise or you totally have a fear of going anywhere (interview 1, p. 30-31).

Another way to opt out is to emotionally withdraw from others, by seeking to avoid public situations. Debbie opts out when she “takes five” from the party below so she can return and endure further exclusion.

It doesn’t matter if there are thousands of people around you, you can still be really really alone if nobody’s communicating with you. That’s more hurtful than sitting at home alone, maybe that is why people do that. I know a lot of the time, I stay home, don’t go to things. I did go to my neighbour’s party the other night. There were heaps of people sitting there watching me and I am thinking “oh no” … I just felt like a freak. A lot of the time I am sitting there with no idea. It’s not like my friends from church who will sign and write to me … but I have learnt to just sit there sometimes. Every now and then I would take five to get myself together so I could go back and handle being left out of conversations and I just kept thinking you rude people. Normally, after an experience like that I would freak out and come home and be really depressed. But this time, knowing it won’t always be like this, once I have the cochlear implant, I could handle it a bit better. I tried to use it as an experience so that when I do get switched on I will not forget what to tell people: how important it is to let deafblind people know what is happening around them, to include them, describe things to them (interview 2, p. 25-26).

10.4. Experiencing self as different/marginal

Experiencing the presence of others and the need to survive others’ perceptions causes individuals who become deafblind to view themselves as different/marginal. In doing things differently they come to experience a different/changing self. Through surviving others’ perceptions this shifts to a sense of self as different/marginal: their difference becomes reinforced through the perceptions of others and the consequences of a changing self become realised. As Joseph explained, how other people interact with him, although he feels it is not their fault, makes him
feel emotionally as though he does not belong anywhere. In a similar way, different participants spoke about their interactions with others causing them to feel subhuman and alienated. Debbie, for example, said:

I remember going to the Deaf Society, I wanted to go on their outings, but because I didn’t sign they basically told me not to come. The Blind Society ... I am in the too hard basket. I am really struggling with getting help ... Deaf Society, I didn’t belong there. Blind Society, I didn’t belong there. The deafblind group, I sort of don’t feel like I belong there, but I feel more at home there than anywhere else. Even there, I don’t feel like I belong because I still feel like a hearing-seeing person: inside my brain I am still seeing and hearing, but my body isn’t. I still expect to be treated like a seeing-hearing person. That really hurts, when people don’t treat you that way (interview 1, p. 18, 20).

The day I was going home from hospital, I was in the shower, and I came out and they had taken all my stuff out of the wardrobe and they had moved my bed, and all my belongings. I didn’t know. I came out and everything was gone! ... No one was telling me what they were doing. They would just come in and take me and not tell me where they were taking me. Or they would be trying to do something and I wouldn’t know what they were doing and it was just so rude. I wasn’t treated like a human being. One of the hardest things is that people don’t treat you with dignity, and it wasn’t just in the hospital: I have found the whole experience of becoming deafblind is people think that your brain has evaporated with your hearing and sight (interview 1, p. 13-14).

10.5. Factors impacting on surviving the perceptions of others

A number of factors impact on surviving the perceptions of others, as illustrated in Figure 10.2. First, the need to survive others’ perceptions is affected by the extent to which individuals engage with their environment. The more they engage, the more likely they are to encounter the presence of others, directly in interactions, or indirectly through navigating built and informational environments which are non-accommodating.

Second, individuals’ ability to perceive the presence of others varies, and as Debbie revealed in her story, this can affect the need for tolerance strategies.

I used to be really embarrassed to wear the geeks. I used to be embarrassed to use the cane. Now my vision is so low that I can’t see people’s reactions so I
Debbie’s decreasing ability to see meant that she was less aware of others, concentrating instead on her own ability to get around. When I visited Garry, he was also relatively unaware of others in his environment. After I had returned home we exchanged e-mails discussing the visit. He apologised for the difficulty of communicating. I relayed my feelings of frustration with the normal environment which had affected his use of the cochlear implant. I told him how angry I was when staff started the vacuum cleaner in the room. To me it was so obvious we were having difficulty communicating, hunched so closely together, me talking into his implant loudly and often repeating things. I had previously requested no background music and explained to staff about Garry’s deafblindness. I felt frustrated at constantly having to negotiate others’ understanding, after only a few hours! I wondered how Garry lived with this constantly, every day. Garry found this amusing, replying he had not known all that was happening: he had only known he was having difficulty communicating. Therefore, while I was acutely aware of the environment with all its unrealistic demands and lack of accommodations, he was not.

Thirdly, individuals’ expectations of others can also affect their tolerance. It is more difficult for individuals to maintain a threshold of tolerance if they believe the person in question should know better. For example, deafblind individuals expect “involved others”, such as partners, disability services or professional workers in the field, to be more understanding, and when they are not, tolerance is strained to a greater extent. Isabel often expressed her frustration at staff not accommodating her communication needs. She was also annoyed by the blindness organisation sending her tapes when she required Braille. Joseph spoke about how hurtful it was when his partner forgot to accommodate him by mumbling or talking away from him.

Fourthly, and related, individuals’ expectations are impacted by their previous experiences of accommodation. The more accustomed or aware individuals are of
how much better they can be accommodated the greater the strain on their tolerance. This can be seen in Natalie’s comments when discussing a church camp experience:

*I had none of the worship songs available to me and the lady leading the worship decided to use the book of Psalms quite a lot. I could have bought that book if I had known, I have it in Braille. So that makes it a bit rough. All read this psalm aloud or let us read out different psalms together. Well I can’t. I can just sit here. And I think because there is so much more available and so many people are aware of it, you find it harder than you would have 10 years ago because I do have this sometimes and if people don’t provide for me nowadays I feel it more. Mum told people what I needed and they just didn’t provide it. That is very difficult to deal with* (interview 2, p. 18-19).
Figure 10.2 Personal factors that impact on surviving the perceptions of others

- Engagement with environment
- Ability to perceive others
- History of accommodation
- Expectations of others

Surviving others’ perceptions

- Experiencing the presence of others
- Maintaining a threshold of tolerance
- Viewing self as different/marginal

Key: yellow = personal factors
10.6. Discussion

The problem posed by the attitudes of others is a strong theme in the personal accounts of people who are deafblind (e.g., Clark, 2004; Crow, 2000; Doran, 2003; Fukushima, 2001; Gilbert, 1993; Hicks, 2000; Kadokawa, 2002; Kleege, 2000; Marcous, 1998; Reed & Dwek, 2003). However, the topic is either not reported or not well addressed in research studies.

Individuals who are deafblind find public perception of their impairment to be simplistic at best (e.g., Fukushima, 2001), and dominated by a medicalised understanding of them as abnormal or tragic at worst (e.g., Reed & Dwek, 2003). Many have noted that it is not adapting to the impairment and its effects which is the greatest challenge but rather adjusting to the attitudes and ignorance of the broader community (e.g., Doran, 2003; Gilbert, 1993; Hicks, 2000).

Several disability writers have argued that there is a relationship between disablism and psycho-emotional issues (e.g., Finkelstein & French, 1993; Thomas, 1999a). French (1993a, 1993b, 1993c, 1999) pointed out that the attitudes of others in relation to normality and independence are problematic and can be a form of oppression. Studies by Miner (1995, 1997) of the psychosocial implications of Usher Syndrome type 1 and 2 have been similarly helpful in highlighting a link between psycho-emotional issues, social context and experiences of disablism. Like Miner’s research, the findings of the study reported here advocate that the emotional challenges faced by adults who become deafblind are directly linked to how they experience the presence of others and their environment.

Some important factors which impact on the deafblind person’s tolerance threshold were identified, including the expectations they held of others and their history of accommodation. The more accustomed or aware participants were about how they could be accommodated, the less able they were to tolerate exclusionary behaviours in others. This may be why the personal accounts literature has emphasised the benefit of people who are deafblind gaining support from coming together (e.g.,
Anderson, 1994; Hartmen, 1993; Kadokawa, 2003; Lawson, 2002; Roult & Miner, 1993; Tunison, 1998; Wright et al., 1993). Coming together with others who are deafblind enables individuals to learn of options available in doing things differently, and exposes them to a less personalised or individualised understanding of the difficulties they face in daily life.

Importantly, this study showed that individuals who become deafblind, depending on the nature of their impairments, may become unaware of people in the environment and of how the behaviours of others directly impact the difficulties they encounter. This may place them at risk of internalising difficulties encountered as personal limitations.
Chapter 11
PRESENTING SIDES OF SELF

“People don’t want to know about all the pain and the agony … You see, in normal day-to-day activities you don’t want to say too much because if you do that people just turn off and go away and don’t want to know you because it scares them … So what you do is you keep things on the light-hearted” (Joseph, interview 1, p. 41-42).

11.1. Introduction

People who become deafblind strategically present different sides of themselves in different situations with the goal of controlling to some extent how others perceive them. This is done in an attempt to balance efficiency and need for assistance, with a desire to protect against alienation or negative judgment. Thus, presenting sides of self is a strategy which individuals use in conjunction with surviving the perceptions of others and managing support relationships.

The way in which people who become deafblind present themselves oscillates as they balance revealing and concealing aspects of their deafblindness. In addition, they can present themselves as an individual or as a representative of a group of people who are deafblind. Different presentation tools are used during interactions to situate themselves. For example, individuals may present through physical location/placement, social alignment with others, equipment they use, and behaviours or explanations about themselves and their deafblindness. Presenting sides of self is represented diagrammatically in Figure 11.1.
Figure 11.1 Conceptual category: “Presenting sides of self”
11.2. Balancing revealing and concealing

11.2.1. Putting on a front

Putting on a front is the most active presentation used by people who become deafblind to conceal their difference. They actively engage in behaviour(s) they believe to be typical of hearing and sighted people. They seek to maintain as much normality as possible in interactions, concealing some or all of their impairment(s). Joseph, fearful others would perceive him to be a lesser human being if they became aware of the extent of his impairments, put on a front when he pretended to hear others, or changed the subject instead of admitting he could not follow communications. He also put on a front when taking care to portray eye contact and use correct pronunciation of words.

When you are having communications with someone it’s so easily looked upon as natural without others realising the amount of work done to maintain it … one thing I used to do when I didn’t understand something was change the subject altogether, and lead the communication. That would mean that I’m controlling it … if you do let on you can’t understand, consequently the psyche of that is that you’re a lesser human being because you can’t do what most people can (interview 1, p. 13-14; interview 3, p. 28-29).

It depends how agile your mind is, sometimes you can keep up conversations and guess what people are saying. You pretend that you hear and it’s amazing how conversations can have a context and you can understand that … Sometimes you get it wrong and you feel like an idiot (interview 3, p. 28).

I used to act very well about seeing things. Even though I can’t see people I am pretty good at acting eye contact … I have made a lot of effort in that and also … I am very careful in my enunciation, because with my hearing problem I always misunderstand things and I don’t want people to realise that so I make the effort to over-emphasise my diction (interview 2, p. 28-29).

11.2.2. Disengaging

Disengaging is a passive concealing strategy used by people who become deafblind to remain uncontroversial and avoid criticism by others. Disengaging can be achieved in two ways. The first way is withdrawing from interaction and spending time alone. For many years Joseph did this because he was not comfortable to disclose to others that he was deafblind or could not understand them.
Before I got associated with knowing anything about other people who are deafblind there was quite a great deal of isolation in my life. That developed more and more over the years because deteriorating sight and hearing is a very emotional thing and very difficult in a social environment. Relationships with people were very limited. I struggled with the idea of anyone knowing I was hearing impaired. So that in itself became more and more isolating (interview 1, p. 3-4).

For many, many years I wouldn’t go out. I even got frightened to answer the door because not seeing or not understanding what people tell you is pretty frightening. I would have anxiety that I can’t hear every word someone is saying – I never will be able to – and I feared that. I feared having to say “look, sorry I didn’t hear you” … You know, the image was FREAK, weird, alien. That kept coming to my mind and was plaguing me (interview 1, p. 4-5; interview 2, p. 7-8).

When you are deafblind, the world is your own little world, and the time when you are alone, you spend a lot of time thinking because that’s all you can do. You can’t participate in a lot of things … you can give up and say this visually is too hard, this is too hard to listen to. So you sit there alone and think. Getting immersed in something and shutting the rest of the world out is one of my other strategies. If you’re actively doing something, and the rest of the world is there doing something else, you don’t have to face … that you have to walk out there and be left out all the time (interview 1, p. 16-17; interview 2, p. 24).

Joseph isolated himself at home, and spent a lot of time thinking or immersing himself in his own activity rather than interacting with the world. Garry similarly commented about disengaging in this way:

I do not mix with the general society these days. I think, because of the severity of the disability (deafblindness), barriers to relating are on both sides of the fence. As communication is limited, there are problems for both communities. Quite often I feel hearing-sighted people won’t bother if they have to express themselves in an overly concentrated way. On the other hand, deafblind people tend to shy away from mixing with hearing and sighted people because they don’t want to show their weaknesses (November, p. 48-49).

The second way in which a person can disengage is by continuing to interact with others, but passively. In other words, individuals who become deafblind may neither confront others with their impairments nor deliberately seek to conceal them. For example, Joseph disengages when he goes “sight-hearing-impaired shy”.

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One minute you can be in an environment that’s nice and quiet and you’re familiar with. The next minute a few people enter the room, things get moved and people are talking and you’ve just lost control. You can’t communicate any more. People tell me I am a very confident person, capable person. I am. You just have to put me in a room with 3 people and I go sight-hearing-impaired shy. I have turned shy because I can’t hear what is going on and I can’t see what’s going on, so I can’t say anything. I can’t participate. People who have OK hearing and sight, their mode of functioning each day is at that level. It is very hard to relate to that when you have partial hearing and partial sight (interview 1, p. 10-12; interview 2, p. 5; interview 3, p. 26).

11.2.3. Conforming

Conforming requires people who become deafblind to present in such a way as to meet the expectations they believe others hold of someone who is deaf or blind. Joseph spoke of concealing the true nature of his impairments and acting the stereotype instead. For example, rather than explain the complexities of partial vision he would let people assume, through use of his white cane, that he was totally blind. He behaved in ways expected of him as a deafblind person, taking care to complete the forms required by Centrelink and getting documentation that validated his disability. The strategy of conforming is strongly linked to the individual wanting to get by without causing controversy. Joseph did not want to have his legitimacy as a disabled person questioned, as happened to his friend at the train station, seen in the following excerpt:

One deafblind friend, he never bothered getting a vision-impaired travel pass, but he uses a guide dog. Someone stopped him at the trains and said “where’s your pass?” ... He was getting a hard time – how can you be blind and use sign? How can you be deaf and sort of hear? Sometimes you feel you have to justify your deafblindness. You feel guilty about the bit of hearing or sight you do have. You have to make sure you get your pass or do all these things to be legitimate. Like I used to try to look with my bit of vision, but then people think I can see. Usually people assume because I use a cane I must be totally blind. If I use my vision it is like “hey you saw that didn’t you?” And you have to try and explain, “Yes, I have some sight” ... Other people can’t understand that and ... it gets awfully complex. But there are people in the world that make you feel guilty, make you feel that you’re putting it on. People involved in the deafblind group understand, but in the everyday world people don’t (interview 2, p. 13, 51; interview 3, p. 67).
11.2.4. Guarding

Guarding occurs when individuals reveal their deafblindness to some degree but remain mindful of not overwhelming or expecting too much from others. Guarding is strongly linked with the sense of wanting alliances in the world: not wanting to put others off, people who become deafblind protect others from particular aspects of their reality. Here, Joseph talks about the importance of not overwhelming people with a lot of detail.

*How do you explain the situation to others? It’s something you never get to talk about much – who listens? Who understands or wants to know? ... People don’t want to know about all the pain and the agony ... You see, in normal day-to-day activities you don’t say too much because if you do people just turn off and go away and don’t want to know you because it scares them ... So what you do is you keep things on the light-hearted and ... You can’t admit how difficult things are really because if you tell someone they don’t know what to say, and they say something patronising. It’s confronting for them ... that’s the real difficulty (interview 1, p. 32, 40-42).*

Joseph also spoke about trying to balance his need to do things differently against how others might judge that. So he tried using touch when nobody was around. In other words, he used guarding in seeking to do things away from the surveillance of others rather than reveal the full extent of his difference.

*I am scared to touch people because of how society is going these days and all the concerns they have now, touch has become a bit of a scary thing. But because of the need to do it, you don’t think sometimes. You can’t quite see the world very well, you can’t quite hear it, you like to go and you can investigate it and feel things. Sometimes I go like this (reaches out and feels the coffee table and items on it), but people say “what are you looking for?” “Nothing”, I’m not looking for anything, I just want to know what’s there. People don’t understand that I am discovering. People say I will give you this or that and not let me discover ... I try to touch things when no one is going to see me (interview 2, p. 17-18).*

Even when Joseph became involved with fund-raising for deafblindness, he explains how he was careful to establish a relationship before revealing his own deafblindness to potential sponsors.

*I have been involved in getting funding for the Association. I did not tell the sponsor I was deafblind myself for quite a while. I just kept ringing and sending faxes, and once they knew me I let them know. But it is too confronting for other people. At one of the meetings, the manager was calling it the deaf-dumb-blind society you know. The arbiters of correct-speak would have laid into him, but I thought “don’t lose the context: this guy has not had
any understanding before” … by the last meeting I didn’t have to say anything because he changed it himself. Deafblind people are a bit more familiar to him now. Of course there is a hell of a lot he doesn’t know, but he feels more comfortable and I think that is great (interview 3, p. 43, 61).

People who become deafblind can also present themselves as a representative of a group of deafblind people. This requires them to reveal their deafblindness. However, participants in this study who were involved in deafblind advocacy work also wanted to promote a positive image of deafblindness. In some instances this required revealing through guarding, as the excerpt from Sam indicates.

I had to do a presentation for the sponsors. I only had a couple of minutes so there is no way to go into all the different conditions, communications or the fact people can’t get interpreters or support that they need, you just keep it general (interview 3, p. 4).

It is important that there is a positive image for deafblindness out there, people out and about and doing things, rather than people going give to the poor … It’s much easier to sell that you are doing things than sell that you want a handout. People are much more likely to want to get involved in a project … So I guess it is being able to help people make a difference as opposed to just maintaining the status quo that is important. In the deafblind community there are people like Stuart and Joseph actually doing a job despite their disability. That’s the sort of thing people like to hear, rather than poor Joe Blow can’t do anything because he can’t see and can’t hear. If they get that message they just tend to think “oh well nothing I can do about it” and off they go. People need to see that if they put something into deafblindness there is going to be a positive result. It is important that we are able to show what we can do (interview 3, p. 32).

11.2.5. Confronting

People who become deafblind also confront others with their deafblindness and this is the most revealing presentation strategy. Confronting involves individuals letting others know their needs and/or abilities as a deafblind person, and not showing concern if the way they are acting is different from others’ expectations. This strategy is informed by a disability rights discourse and based on an expectation others must take some responsibility for facilitating the involvement of deafblind individuals in a situation. It is linked with a sense of wanting to create a better world or wanting to change the world for themselves and others who are deafblind.
After many years, as demonstrated in the excerpt below, Joseph finally revealed to his employer he was deafblind, not just vision-impaired. In doing so he was able to confront the employer about his needs in the workplace. When the employer was uncooperative, he was able to involve HREOC (Human Rights and Equal Opportunity Commission) to support his rights as a deafblind employee. If he had continued to hide his deafblindness he would not have had the power to challenge others’ perceptions and treatment of him to this extent.

_In my job, I was hired for all the wrong reasons, to fulfil the equal opportunity requirements. They had no expectations of me, had me doing almost nothing when I got there … I never told them that I had a hearing impairment. They knew I was vision-impaired. When I had an emotional illness and was away for a few months, I came back and told them about that and my hearing impairment. It was very cathartic to do that, because I always had hidden it. It felt very relieving … I always feared they would find out and get rid of me for ill health. My boss, he didn’t know. I thought sometimes my hearing aids might show a little bit or sometimes he might detect that I did not understand him. But he hadn’t_ (interview 1, p. 20, 23; interview 2, p. 28).

_I am going through a real problem at the moment with work. They changed a lot of software and it is not accessible for me. They were supposed to consult me … I have bought HREOC in about 2 months ago. I asked my partner “Are you sure I should do this? I am not sure I can cope with all this”. She said “you know it’s about time you try”. My tendency with all the problems I have is to say I want to crawl in my little hole and go away. The confidence my partner gives me, I couldn’t do it without her support. It isn’t easy but the thing is you DO have to fight to change things (interview 3, p. 8-9, 59)._}

11.3. Factors impacting on presenting sides of self

A number of personal and environmental factors have an impact on presenting sides of self and these are illustrated in Figure 11.2.

The _nature of impairment_ and the degree of difference in doing things have an impact on how an individual who is deafblind can present. If using hearing or vision substitution strategies, such as alternative modes of communication, there is little option but to reveal deafblindness to some extent. Those who use enhancement strategies are more likely to be in a position to “put on a front”. Depending on the
nature of each of their impairments, participants at times would reveal one aspect of their deafblindness and not the other. As indicated in the story below, for Joseph, his use of a CCTV at work made it impossible for him to hide his vision impairment. However, Joseph grew his hair long and was able to conceal his hearing aids successfully for many years.

_Sometimes I feel under scrutiny when people are helping me. People question my habits, the way I do things. Reading the CCTV, others can see it ages away. At work it feels like things I do are public property. There was a training session at work and I needed the CCTV, so I tried to sit in a certain spot so I could have privacy. People don’t understand, they think they are being helpful. I might be looking for something and they will say “no Joseph, go to the next page”. Because I am disabled I feel I have got people scrutinising every single thing … sometimes it is a trade-off between privacy and isolation (interview 3, p. 66-67)._*

Natalie also described her tendency to reveal one impairment but conceal the other. Her hearing aids enabled her to pick up what was happening around her much of the time and allowed her to function “normally”, so she tended not to disclose her deafness unless it came up as an issue.

_When I saw your message wanting deafblind people for the research I didn’t know if I was actually deafblind enough to be part of the project. I know a lot of people who are a lot deafer than I am …I don’t always identify myself straight off as deafblind, and maybe I should … I might tell them I am blind … Sometimes I will say I am vision-impaired so they know I can see a little bit … [but] If I say vision-impaired they think I can see heaps more than I can, so I might say I am blind (interview 2, p. 47)._*

_If I am on the phone to someone I can’t say well I am deafblind because I think the first thing they will say is how come you are talking to me now, and they wouldn’t understand all the deafness issues straight off. I just find the blind one easier to deal with I think. I have probably in myself had a bit of a problem there in acknowledging the deaf side of myself because it has not been a part of me all my life. To live as a deafblind person as opposed to a blind person I find a bit more of a challenge. I might say “yes I am a blind person, I might need help with x,y,z”, but I don’t say about the deafness. Sometimes I forget I am deaf, because if the hearing aids are working properly I’m pretty normal. I try not to think of the deafness, until it needs to come up. Then I just say I have a hearing impairment but I don’t say I am deaf. Yeah it is sad but I think [that] it is how best to manage the whole stereotypical thing. Sometimes I will even say I am hearing- and vision-impaired or something to that effect so that people know there are two impairments but there is something of both (interview 2, p. 47-48)._
The impairment which requires the most adaptation is the one more likely to be revealed, regardless of how comfortable the individual is in doing so. With Sam, for example, although his hearing impairment was the one he had experienced from birth, it was his blindness that was more obvious. He used hearing enhancement strategies, maintaining verbal communication with hearing aids, but his guide dog or white cane and use of Braille “gave away” his vision impairment.

The presence of additional impairments also impacts on presentation strategies. For example, Isabel’s presentation of self was complicated by the presence of physical impairments in addition to her deafblindness. She complained that people would see her only as a person in a wheelchair and not realise she was deafblind because she did not use symbols of vision impairment or hearing impairment. Thus she had little choice but to confront others with her deafblindness if she was going to overcome their inaccurate assumptions about her and get the support she required.

The type of support available to an individual can influence how they conceal or reveal their deafblindness. Ralph’s situation illustrates this. His thick “coke bottle” glasses enlarged his eyes and gave away his vision impairment. We met together in a pub on one occasion where a staff member approached us and requested we move. Ralph allowed the man to walk off and then asked me to clarify what had happened, saying he could not hear. As he did not wear hearing aids it was not possible to identify his hearing impairment and my presence enabled him to conceal his hearing impairment from other people in that environment.

In this way, the presence of support can enable the individual to “put on a front”. This was also evident in Debbie’s story when she described waiting until her daughter could assist before going to visit her son’s workplace. Not wanting to use her white cane and embarrass her son, she used her daughter as a guide to conceal the fact that she had low vision.

The presence of support can also give individuals the confidence to confront the perceptions of others, like Joseph challenging his employer to cater for his needs when he had the support of his partner. Sometimes the presence of a supporter
enabled participants to reveal their deafblindness in a positive way, and protected against others making negative assumptions about their capabilities. When Debbie’s son accompanied her at the birthday luncheon he led by example, allowing her to present to others how capable she was given appropriate support.

**Contact with others who are deafblind** and access to support organisations influence the way an individual presents. Links with others who are deafblind helped empower some participants to reveal deafblindness. For Joseph, meeting others who were deafblind helped him see the possibilities of doing things differently, given adequate support or accommodation, as he explains here:

> I suppose the image in my mind about deafblindness, quite rightly or wrongly, used to be the image of the abyss is where I am falling into. No sight and no hearing. It’s a horrible, scary thing to think about. The idea of not being able to communicate scared me the most … Now, after all the experiences I have had with people who are deafblind, it’s better. I’m still fearful, but the fears have changed. Now knowing of all the possibilities I could have to communicate, but all the limitations that society has – it’s more the limitations of communities and society to allow or facilitate it that scares me now (interview 1, p. 8-9).

For some participants, becoming a part of a group of people who are deafblind added a sense of responsibility, as how they behaved could affect others’ perceptions of people who are deafblind generally.

Not surprisingly, the extent to which individuals are exposed to a *disability rights discourse* has an impact on how comfortable they are presenting as deafblind. It impacts on the expectations individuals holds of others and the likelihood that they will use revealing strategies such as confronting. Without understanding about disability rights, individuals may believe their deafblindness is a personal abnormality, as dominant medical discourse suggests. This was how Joseph saw his deafblindness initially, when he was plagued by the image of himself as “freak, weird, alien” and “sub-human being”. As a result he felt unable to reveal his deafblind self to others. Through his contact with others who were deafblind and his involvement in advocacy work, Joseph came to recognise the problem was not within himself, but within his relationship with the often un-accommodating environment in which he lived.
Presenting self is an interactional strategy that occurs in a social context. Thus the way individuals present is influenced by their expectations of their audience. For example, if participants were interacting with someone they knew well they were unlikely to put on a front. Natalie spoke about her tendency to conceal her hearing impairment in social situations, based on a belief that generally others would have poor understanding of the combination deafblindness. In contrast, with her family she was more likely to say when she could not hear.

_You tell people you are deafblind and they really don’t get it. The understanding of deafblindness I find is a lot harder for people than either just deafness or just blindness. They understand one and not the other usually. I find it hard to express deafblindness sometimes ... I have real trouble in facing up to the fact that I have to say pardon lots, that I miss a lot of information. It is not naturally me because I used to have perfect hearing. I like to almost play-act that I still do sometimes. I am a very good actress. I know I shouldn’t do it but sometimes it is easier, you know. I find I don’t do it so much with family because they actually want me to hear what they are saying. But if you are just in a social situation and there is a few people talking and you don’t hear what they say, they don’t really care, they are just passing time [so] I will not say much and pretend I am listening (interview 2, p. 45-46)._
Figure 11.2 Personal and environmental factors that impact on presenting sides of self.

Key:
Yellow = personal factors
Green = environmental factors
11.4. Discussion

As the professional literature suggests, the term deafblindness includes a diversity of conditions (Alsop, 2002; Bidenko & James, 1999) and different types of impairment and onset (Alsop, 2002; Godfrey & Costello, 1995; Lewis, 1998) that creates heterogeneity within the deafblind community. Not surprisingly, therefore, people who become deafblind may present themselves in different ways.

Kilsby (2003), Prendergast (1996) and Barnett (2001) have suggested that people who are deafblind often identify with one part of their deafblind identity more than the other. The results of this project support this assertion and add to it. Participants in this study not only identified more easily with one side of their deafblindness, they actively presented different sides of themselves in different social situations.

Barnett (2001) noted that people who acquire deafblindness understand it to be a disability label rather than as a cultural label. In this study, participants presented themselves based on how they thought others might understand deafblindness. Overall, they were reluctant to fully disclose their deafblindness because they believed it was too overwhelming or complicated for others. Whether this derived from their own view of deafblindness as a negative disability label or from concern for the reactions of others remains questionable.

In this study there was variation in how people who become deafblind chose to present themselves, some revealing their deafblindness and others seeking to conceal it. This mirrors the diversity of perspectives found within the personal literature of people who are deafblind. For example, the importance of educating the public was noted by Doran (2003) and Marcous (1998), who asserted that understanding among others would not improve by concealing deafblindness. In other personal accounts however, people who are deafblind appeared reluctant to draw attention to themselves and were therefore more likely to conceal (e.g., Pessin, 1995; Reed & Dwek, 2003).
In addition, people can choose to present themselves in different ways depending on the situation, at times revealing and on other occasions concealing aspects of their deafblindness. Factors influencing these behaviours include, for example, the support available to individuals, their expectations of their audience, their level of contact with others who are deafblind, and exposure to a disability rights discourse.

Regardless of which impairment is more longstanding, the more severe of the impairments is most likely to be revealed in social situations. Vision and hearing substitution strategies make it difficult to conceal impairments because their effects are typically noticeable in public.

In this study, when participants presented themselves as representing a collective of people who are deafblind, they typically used guarding strategies, and sometimes confronting behaviour. This may be why the personal accounts literature emphasises the benefits of deafblind people coming together (e.g., Anderson, 1994; Hartmen, 1993; Kadokawa, 2003; Lawson, 2002; Roult & Miner, 1993; Tunison, 1998; Wright et al., 1993). By doing so they are more likely to be empowered to reveal their deafblindness and presumably are then better positioned to influence the community’s understanding of people who are deafblind.
The preceding four chapters have outlined in some detail four major concept categories identified through this research project. These major categories come together in my theoretical interpretation of the experience of becoming deafblind. I argue that doing things differently, managing support relationships, surviving the perceptions of others, and presenting sides of self interrelate as strategies of similar intent within a core social process of “negotiating a place in a hostile world”.

Negotiating a place is a continuum of experience. At one extreme individuals who become deafblind experience feeling out of place in a hostile world, face multiple exclusions and are placed in positions of powerlessness in interacting with others and their environment. At the other extreme, persons who become deafblind work interactively to achieve recognised belonging in an otherwise hostile world.

In developing the core category, the term “hostile” is used as a descriptor of the everyday world deafblind people encounter, and is a term derived from the words of participants themselves. Joseph stated outright “the environment of this world is totally hostile to deafblind people” (interview 1, p. 29). This notion of hostility reverberates through the data, in the sense that people who become deafblind feel “opposed” when trying to go about their everyday lives (in accordance with the Macquarie Dictionary (2005) definition of hostile). Hostility may seem a strong word in these circumstances, given that there is no one enemy as such intentionally opposing people who become deafblind, or deliberately wishing them evil as is often implied by use of the word hostile. However, people who become deafblind constantly encounter inaccessibility, exclusion and isolation in navigating physical and social environments, and therefore perceive hostility in the world around them. The constancy of difficulties faced establishes for people who become deafblind this sense of a hostile world; that is, one in which the unhelpful, invasive, sometimes threatening and disruptive behaviours on the part of others while not generally
purposefully antagonistic, do indeed force ongoing ‘work’ by the individual who is deafblind, as they go about their daily life.

12.1. **Negotiating in the context of interactional powerlessness**

Negotiating a place is the fundamental experience for adults who become deafblind, because having an impairment of hearing and vision leaves people unable to know or act in the world in the same way as people who can see and hear.

Our world is a hearing-sighted world: having use of both these senses is considered normal or typical. Given that these senses are viewed as typical they are privileged; using other ways of knowing and engaging is regarded as atypical or dysfunctional, or is simply not considered. The result of being in the world differently and having the world not recognise your way of being, or judging you as dysfunctional, is feeling and experiencing interactional powerlessness.

Interactional powerlessness is an experience of helplessness, a reduced ability to act within or impact on the behaviour of others within one’s environment. It is the inverse of experiencing a sense of place. People who become deafblind cannot recognise themselves as belonging because interactional powerlessness represents a lack of fit between how they can act and the expectations of their environment.

Interactional powerlessness is experienced differently by different people. Four variables contribute to this differential experience. The first is the agency of the person who becomes deafblind, that is, how or if such individuals regard themselves as agents able to resist interactional powerlessness. The second is whether the experience of both the emotion and actuality of interactional powerlessness is increased or decreased by the actions of other individuals. The third is whether the physical and organisational environments in which people act have the effect of increasing or decreasing interactional powerlessness, and the fourth is the way interactional powerlessness is affected by individuals’ unique experience of their impairment.
Experiencing interactional powerlessness leads to a need to negotiate a place in a hostile world. To do so, adults who become deafblind employ a range of strategies. As described in Chapters 8-11, these are doing things differently, managing support relationships, presenting sides of self, and surviving the perceptions of others. These four strategies together interrelate in the process of negotiating, as illustrated in Figure 12.1.

In doing things differently, people who become deafblind try to approximate how others operate in the world, developing communication strategies to allow them to know the environment and overcome the actuality of interactional powerlessness.

In managing support relationships, adults who become deafblind try to get other people on their side. In doing so they are working to overcome both the actuality and emotion of interactional powerlessness. Support allows them to know and act in their environment more easily and also allows them to feel less marginal.

In presenting sides of self, people who become deafblind make choices between reducing the actuality or reducing the emotion of interactional powerlessness.

In surviving others’ perceptions, people who become deafblind seek to cope with the emotion of interactional powerlessness by retaining a sense of their own worth.
Figure 12.1 Negotiating: interrelationships between categories and subcategories.

- **Doing things differently**
  - Experiencing a changing self
  - Seeking professional help
  - Developing communication strategies
  - Appreciating new perceptions

- **Managing support relationships**
  - Doing things together
  - Having expectations
  - Protecting the relationship
  - Establishing webs

- **Surviving others’ perceptions**
  - Experiencing the presence of others
  - Maintaining a threshold of tolerance
  - Experiencing self as different/marginal

- **Presenting sides of self**
  - Balancing revealing and concealing
12.2. Negotiating a place in a hostile world: an illustrative case

Toward the end of my research the following story written by Liz Ball (2005) was circulated through the e-mail list group. I include it here, as I believe it illustrates the interaction of the four concept categories in the lived experience of negotiating a place in a hostile world.

**The deafblind traveller**

I’ve been blind since childhood, so having to do things ‘differently’ is the norm for me. When I acquired a profound hearing loss recently though, I was plunged into a brand new world of deafblindness. It means I now have to exclusively rely on what I know in my head and what I can feel with my hands, body or cane.

Interacting with the outside world can be very difficult and bizarre, so when I step outside my front door for a bit of lone travelling, it is a real adventure. When I first became deaf, getting around was a big challenge. It was made worse by people telling me that since I’d always been blind, it should be easy. Not so. I was used to relying on sounds to orientate me - the rumble of escalators, voices, footsteps, traffic, public announcements and all the other everyday noises out there which can be extremely useful. Suddenly, I had to find ways to manage without audio clues. It took some time, but I did it. Every post, fence, kerb and crack in the pavement took on a new significance. Most people were glad when the local council repaired a pavement full of bumps and pits, but I was mildly annoyed because I got lost: the tactile cues that I depend on had all gone.

When waiting for a train, I feel the wind as it approaches and the vibration of the platform as the carriages draw alongside before attempting to get on. Once on board, I count the number of station stops so that I know when to get off. The doors open at each station, which give a breath of slightly fresher air, and this is how I tell the difference between a station and a signal stop. Sadly this method doesn’t always work, particularly on crowded tubes with sweaty bodies obstructing the air flow.

Crossing roads is interesting too. As I can’t see traffic, when I cross I have to either go for it – taking the risk of getting squashed – or wait for assistance. But who’s to say that getting assistance is any safer? I learnt quickly that getting around without vision and hearing is fairly easy. The biggest challenge is other people.
Most people cannot understand that someone can be both deaf and blind. They see that I’m blind so they assume I have supersonic hearing. They don’t know that my red and white cane indicates that I’m deafblind. When I tell them, they can’t get their heads around it.

Sometimes people tap me to get my attention. I try to work out what they might be saying based on where I am. If I’m standing on the tube, I take a guess they’re offering me a seat and tell them verbally that I would prefer to stand. Then I try to explain how they can communicate with me: by putting my finger on letters on a Braille/print alphabet card. Most people just keep on voicing. Others put their own finger on the Braille dots. Some eventually get that I’m deaf, but then forget I’m blind and think that I cannot speak. I really confuse people, it seems. One such person told me to show him on the map which station I was travelling to. But at least the people who tap me to get my attention are starting in the right way; many others frequently get it very wrong from the beginning.

Sometimes on my travels, I get off a train, only to be grabbed and pulled back on by a person who assumes I want to catch it. Other times I am bundled onto completely the wrong train. My protests, verbal and physical, are ignored. When this kind of thing happens, I am regularly dragged a short distance before I break free. This normally disorients me. When I try to communicate with someone to help me re-orientate, of course they don’t get it. I often wonder what fellow travellers think or voice when either I fail to respond to them speaking, answer inappropriately, or when I repeatedly attempt to explain that I’m deaf and they must communicate with me using a Braille alphabet card. Sometimes I get a little insight into this from my friends.

I regularly travel by tube to King’s Cross station, where I meet a pal. When she arrives, she frequently finds a small huddle of people debating what they should do with me because I’ve ignored them when they offered me help — well, if they speak to me from a distance, how am I supposed to know? Sometimes, as my friend approaches, they tell her that I cannot speak. Perhaps it’s best that mostly I don’t know how people react.

When I first became deaf, I felt ill-prepared to get around without sounds. Two years on, I know that’s the easy bit. What I was, and still am, ill-prepared for is the challenge of dealing with other people. The things that are done to me as a deafblind traveller are frustrating, sometimes even dangerous or frightening, but at the same time often amusing. One other thing is certain, travelling as a blind person is totally different to travelling as a deafblind person.
12.3. Contribution

In the discussion of the individual concept categories (Chapters 8-11) it is evident that some aspects of the theoretical interpretation developed in this research have previously been identified in the literature, if only in limited ways. That said, this study moves beyond description or anecdotal account to offer a unique contribution by presenting a theoretical understanding of how and why people who become deafblind carry out their everyday lives in particular ways. In essence, their everyday lives are necessarily an ongoing process of negotiating participation in a world so hostile that they feel and experience interactional powerlessness.

This concept of interactional powerlessness has not been previously recognised in the literature on deafblindness, although components of it, such as disadvantage in terms of accessing information (e.g., Aiken, 2000; Belanich, 1995; Huebner et al., 1995) and feelings of marginalisation from others (e.g., Vernon, 1976; Miner, 1997, 1999) have been acknowledged.

Decreasing their powerlessness relative to others and their environment drives the lives of people who become deafblind. It is most evident in the strategies by which individuals negotiate their place in this hostile world. The idea of negotiating recognition of a “same but different” status is supported by anecdotal literature, where adults have stressed both being just like everyone else (e.g., Brioso, 2003; Doran, 2003; Lawson, 2002; Wright et al., 1993) as well how they live differently (e.g., Belanich et al., 1997; Bryce & McMinn, 2002; Jones, 1997; Malcolm, 1998; Mitchell 2001; Shapiro, 1999; Sturley, 2003).

The process of negotiating is also evident in personal accounts detailing a struggle for support through self-advocacy and self-organisation (e.g., Belanich et al., 1997; Harland, 1992, 1993; Lawson, 2002; McNamara, 1999; Talbot-Williams, 1996), and through discussion of the importance of alliances for supporting participation (e.g., Ripley, 2002) and making their demands carry more weight (e.g., Ohlson, 2001; Reyes, 2001). As has been pointed out in anecdotal accounts, sharing the world is not
easy, and the process of negotiation often involves working interactively with people who have little understanding of deafblindness (e.g., Cielens, 1995; Clark, 2004; Doran, 2003; Fukushima, 2001; Gilbert, 1993; Kadakowa, 2002; Roult & Miner, 1993; Talbot-Williams, 1996). This process of negotiating evident within individual lives also operates at different community levels for people who are deafblind: internationally, nationally and locally.

Internationally, people who are deafblind have been negotiating for a place in the world over a long period of time, first coming together in 1928 (Reyes, 2001) and continuing to form their own organisations, such as the World Federation of the DeafBlind established in 2001 (Ohlson, 2001). They work interactively through support relationships with larger, longer established, and possibly more influential organisations including single sensory impairment groups and disability groups like DeafBlind International, World Blind Union, and World Federation of the Deaf (Ohlson, 2001).

These efforts are an attempt to assert their voice in international disability forums and negotiate recognition of their “same but different” status as citizens with equal rights, yet in need of support to achieve those rights. This year, 2005, saw the 8th Helen Keller World Conference held in Finland. The title of the conference was telling: “Our right to be deafblind with full participation in society” (World Federation of the DeafBlind and the Finnish DeafBlind Association, 2005). Shortly after, the DeafBlind International Sixth European Conference on DeafBlindness was held in Slovakia. Titled “Making the invisible visible” it similarly communicated a desire for recognition (DeafBlind International, 2005).

At a national level in Australia, the ADBC has negotiated with government bodies to gain funding for research (e.g., Ward, 1994, 1996), and undertaken collaborative efforts to have deafblindness recognised as a distinct impairment (e.g., Steer, 2002, 2003). Locally, within New South Wales, the voluntary DeafBlind Association has worked with the Royal Blind Society, government funding bodies and independent sponsors to achieve the establishment of rehabilitation services specifically for adults who are deafblind in 2003 (e.g., Lalich, 2004).
This study, by exploring the situation of adults who become deafblind, also contributes to the ongoing academic discourse regarding the nature of disability and disablism.

My theoretical understanding of interactional powerlessness and its relationship to the experience of a hostile world is consistent with the Nordic theoretical understanding of disability as social relational. For people who become deafblind, disability is experienced through the interaction of the impairment, its effects, the built and informational environment, and how people “typically” relate within society. Disability is not their impairment, as suggested by the bio-medical model. Nor is it external social barriers or something created only by the environment, as hypothesised by the strong UK social model. I have found that for those who become deafblind, disability is relative and situational. Disability emerges in their interactions, as a mismatch between the social and physical environment which caters only for the typical or “normal”. The effects of impairment for people who become deafblind require actions and adaptations that fall outside these “normal” experiences (Gustavsson, Tossebro & Traustadottir, 2005; Tossebro, 2004).

The findings from this study therefore support the view that disability is more than external structures or barriers, as suggested when the strong UK social model is applied. Within a symbolic interactionist theoretical orientation it is understood that structures exist only as joint actions. Structures are comprised of people who must consider and act toward each other in collective forms of action (Blumer, 1969). For people who become deafblind the process of disablement (Tossebro & Kittelsaa, 2004) plays out in social interaction when others fail to consider and act toward them in supportive ways.

A second contribution to the discourse on disability focuses on the notion that social relational disability has a psycho-emotional component. Negotiating a place encompasses negotiating access to information about and participation within physical environments, as emphasised traditionally in the material focus of the strong UK social model. More than this, however, it entails negotiating access to the social
environment comprised of relationships with one another in society, in other words, the psycho-emotional sense of belonging.

The emotional aspect of living with a feeling of interactional powerlessness as uncovered in this study relates to what Thomas (1999a) has previously identified as the psycho-emotional dimensions of disablism. For the participants, feelings of displacement and powerlessness were magnified through interacting with the social environment and experiencing the presence of others as non-accommodating. This suggests that the gap between person and environment referred to in the Nordic social relational perspective is not exclusively functional or physical. Importantly, there is also a psycho-emotional chasm, where people who become deafblind experience aloneness from the everyday social world.

A third contribution of this study is that disability implies unequal relationships, specifically power held by others over those with impairment. Corker (1999; Corker & French, 1999) has argued that for people who are d/Deaf, disablism occurs in relation to knowledge, information and communication. This is also the case for people who become deafblind. Even more striking, however, is the extent of their disablism in every social environment. The lack of access to “what is going on” significantly strengthens the power position of those who are not deafblind and in turn markedly diminishes the place and influence of those who are.

French (1999) has noted the difficulty of having her needs met as a vision-impaired person without curtailing the needs of other people, thus creating an unequal relationship. Similarly, for those who become deafblind, their relations with others are most often, if not always, unequal. Others have the power to support, ignore or interfere with how they, as deafblind people, act to know, experience, or participate in the world around them.

Through their behaviour, others “gate-keep” what people who become deafblind are privy to in social situations. Disablism in this form may be obvious, such as an interpreter refusing to allow an individual to ask questions. It can also be quite subtle. McNamara (1999) for example, has written about being in meetings where no
communication rules were established and where she was not provided with materials beforehand. This prevented her participation on equal terms: she could not attend simultaneously to knowing what was in the material as well as what was being discussed, as those with hearing and sight could. Access for one group and exclusion for the other, is evident throughout the lives of people who become deafblind, and suggests that unequal power relations may be the prominent aspect of the social relational nature of disability, as noted by Thomas (1999a, 2004).

For adults who become deafblind, disablism is interactional powerlessness constructed in the physical-functional-informational and the psycho-emotional gap between individual and environment. Unequal power relations in this gap contribute to and significantly enlarge the experience of interactional powerlessness. What is the role of impairment effects vis à vis social oppression in the construction of interactional powerlessness? I suggest there is an interaction of both. As Thomas (1999a, p. 43) herself noted, within lived experience there is blurring between impairment effects and disablism.

The findings of this study demonstrate incidents of oppression in participants’ lives, particularly if the view is taken that oppression involves denial of rights or refusal to assist an individual overcoming functional limitations by allowing unconventional ways of doing (Thomas, 1999a). The impairment effects of deafblindness are such that it impacts not only on an individual’s ways of doing but also on an individual’s ability to know. It is an altered perceptual state. If we do not support deafblind people to know, as we do, what is around them, are we being oppressive? I recall with some discomfort an occasion when outside the research context I saw Sam in a café. I decided not to approach him and tell him I was there because I had limited time. In my denying Sam knowledge of my presence, was I oppressing him?

The degree of interactional powerlessness and conversely, the likelihood of successful negotiation, are to a large extent under the control of individual and organisational others. The feeling and actuality of interactional powerlessness increases when others, intentionally or otherwise, prevent people who are deafblind from negotiating their place in a hostile world.
13.1. Personal reflections

Throughout fieldwork, it became apparent that I started this project from a professional position. I was influenced heavily by medical and rehabilitative discourses that privilege the condition and its consequences for function. Throughout the process of conducting the research I was confronted by disability rights discourse and came to appreciate the social relational nature of disability. On reflection, my reaction to the development of deafblind services within the local blindness agency was possibly my first realisation of my changing awareness. While colleagues encouraged me to apply for a professional position within the service I remained unconvinced, perplexing them by saying, “I don’t know that I am the person for it, I don’t really think occupational therapy is what these people need”. Rather, I was coming to realise that rehabilitation discourse that focused only on individual skill building represented an insufficient tool for framing the situation of people who become deafblind.

Through engaging with adults who have become deafblind and through analysing data, I reached the understanding that people who become deafblind have to negotiate their place in a hostile world. People who are deafblind have understood their lives as an issue of citizenship and belonging for a long time: desire for a place and the complexity of being deafblind in a social world that fails to recognise or value one’s different ways of doing, being and knowing have been issues eloquently raised within the anecdotal literature. Now understanding this for myself, I have moved from a position of professionally marginalising people who are deafblind to a position of respect and desire to facilitate their participation. Through communicating my research findings to professional and disability studies audiences I aim to promote understanding of the position and concerns of people who become deafblind.
Importantly, the theoretical framework developed here is grounded in the experiences of adults who become deafblind, with their voices bringing the concepts to life throughout this thesis. For a long time, people who are deafblind have been active in constructing spaces for themselves to act and share experiences, as evidenced by the history and regularity of their conference gatherings. In the process of doing this they have been able to achieve a form of “situated belonging” where they have successfully mediated exclusion and minimised interactional powerlessness with the support of others. However, there is little evidence that people who are deafblind have achieved this on a wider scale in Australia. While people who are deafblind have some “spaces” of their own, I believe that without recognition from society they will continue to lack, and will seek, a place for themselves. Hopefully, a project such as this can assist them in their endeavour.

13.2. Strengths and scope of the research

In conducting this project I have taken note of evaluative criteria proposed by both Corbin and Strauss (1990) and Glaser (1978). In doing so, I sought to avoid “common pitfalls” of grounded theory research as highlighted by Becker (1993) as detailed below.

In this grounded theory project I sought to understand the central concerns in the lives of adults who become deafblind through the research process itself. I sought description and discovery of concepts relevant to participants through fieldwork, rather than assuming particular concepts to be of importance prior to fieldwork (Becker, 1993; Glaser, 1978). I identified concept categories by exploring participants’ experiences, and sought to describe these through narrative with sufficient detail to allow for their development or modification in further research (Glaser, 1978).

I related concept categories to subcategories and a core category (Becker, 1993; Corbin & Strauss, 1990). The core category, negotiating a place in a hostile world, describes theoretically the need for adults who become deafblind to work
interactively within a context of interactional powerlessness to achieve a sense of belonging. The theory “works” for different participants and demonstrates variation in experience (Glaser, 1978). The experience of interactional powerlessness itself is differential. Also, within the process of negotiating a place, a range of strategies are employed differently by different individuals. However, all the strategies are aimed at achieving a sense of belonging within a social and physical environment which excludes them in extreme ways.

I applied theoretical sampling throughout the research, using analysis to direct what data should be collected and to inform the re-sampling of existing data. This ensured that the grounded theory process was both inductive and deductive (Corbin & Strauss, 1990). Constant comparison ensured that data collection and analysis remained interrelated, and that concepts developed adequately indicated or fitted the data (Glaser, 1978). Additionally, I used memos during analysis, as recommended by both Strauss and Corbin (1990) and Glaser (1978), and attempted to link broader conditions with action in participants’ lives.

The scope of this project was restricted to in-depth knowledge in a substantive area developed from a select group of people who have become deafblind. As such it may not be representative of, or generalisable to, the experiences of all adults who are deafblind, or even those acquiring deafblindness. The concepts developed from the findings have not at this time been verified beyond the sample in this study. Theoretical sampling itself was limited to persons who were willing to participate. For example, although I attempted to theoretically sample participants who grew up in Deaf Culture prior to becoming deafblind so as to explore the implications of that for presenting sides of self, the final interview sample contained only one such person. Therefore, variation developed in my theoretical framework is relevant only to the sample and settings available to me over the course of the study.

The project was conducted by a novice researcher within the time constraints of a PhD candidature. This necessarily impacted on the sample size and scope. Further, the purpose of this study was to focus on interactions and peoples’ perspectives rather than on social structures or systems, which therefore are not dealt with in any detail.
This study was conducted at a particular point in time. Set against this is the fact that people’s lives and their social contexts are dynamic not static. Already there have been a number of developments in participants’ lives and in the systems with which they interact. For example, the development of the specific deafblind service has taken place in New South Wales, and more broadly, advocacy has resulted in approval for government-funded supply of various equipment items, such as vibrating pagers.

In spite of these potential limitations, the theoretical framework developed in this research holds promise as a platform for shared understanding between professionals and people who are deafblind that they serve. It contributes both to our understanding of the experience becoming deafblind, and our ongoing discussions about the nature of disability.

13.3 Challenges for the future

13.3.1. Some practical implications

Although it was not the goal of this research to seek practical recommendations, I believe the findings of this study have application for professionals working in the field of sensory impairment.

When experiencing a changing self, people who become deafblind tend first to seek medical help to explain or treat perceived abnormalities in their perceptual or bodily function. It is critical, therefore, that medical professionals are well informed, and recognise and accept their role as broader than providing a diagnosis. Medical professionals need to give information, or know where to direct the individual to receive information, regarding the implications of deafblindness (e.g., aids and equipment, entitlements, support organisations). Given the fragmented and variable services available throughout Australia, information provision becomes vital to prevent individuals who become deafblind feeling powerless to access information to help themselves.
As this study demonstrates, equipment is a vital part of the support required by individuals who become deafblind to do things differently. If aids specifically designed for combined hearing and vision loss are not available, it may be beneficial to have a system where individual needs can be addressed to develop unique solutions. In other countries, various models of equipment/technology development and training exist (e.g., Hinton, 1989). Perhaps similar services could be achieved in Australia through collaboration between existing organisations such as Technical Aids for the Disabled (TAD) and the DeafBlind Associations or Council.

The results of this study suggest that people who are deafblind require ongoing in-person support to assist them to negotiate public understanding, and to provide information about the environment in a collaborative, facilitative and sharing manner. Loss of hearing and vision cannot be adequately replaced by aids or equipment alone, although they may decrease the actuality of interactional powerless. However, overcoming interactional powerlessness is not as simple as removing external barriers, providing access to printed materials in appropriate formats, or minimising the impairment with assistive devices. Barriers emerge in interaction and thus must be mediated in interaction. Having a place entails social spaces and individuals as accepted agents within them; aids or provision of information in alternative formats are unlikely to eradicate the feeling of interactional powerlessness in terms of displacement from others.

It is important to recognise that support for people who become deafblind does not involve provision of sign language interpreters only. In doing things differently, people who become deafblind adopt a range of communication strategies and require different types of support. Supporters act as person interfaces not only for the interpretation of language but for relaying information in many forms. This requires awareness and skill in communicating details about the environment, not merely conversation, in order to give deafblind individuals an understanding of their context.

Through this study I encourage those working with adults who are deafblind to value them as agents and experts on their own life. If professionals or practitioners fail to
do so they risk playing an even larger part in the negative hostile world. In consideration of the link between psycho-emotional issues and disablism, intervention could include critical assessment of non-accommodating environments and education of people in the deafblind individual’s social network to encourage ways of engaging that alleviate interactional powerlessness.

13.3.2. Research directions

This research, conducted with the intent of gaining a holistic appreciation for the everyday life experiences of adults who become deafblind from their own perspectives, has raised questions in need of further inquiry.

According to data gathered in this research, support relationships are a strategy with potential to decrease both the emotion and actuality of interactional powerlessness. This study has demonstrated that it is not only individual others but organisational environments that contribute to the differential experience of interactional powerlessness. In this study, support relationships that participants identified in their lives were predominately informal individual relationships, whereas contact with organisational others was predominantly reported as negative, often provoking the need to survive others’ perceptions.

A question remains about the interrelationship of organisational others and informal support relationships and their combined impact on interactional powerlessness. A triadic approach, combining the perspectives of adults with deafblindness, professionals as representatives of organisational others, and informal supporters, would allow further understanding to be gained about how support contexts are negotiated and what makes them successful. In addition, a triadic approach would facilitate exploration of why organisational others are not perceived as supportive; how organisational others fit or fail to fit with informal supports already active in individuals’ lives, and what broader conditions impede or assist organisations to take a positive role in decreasing interactional powerlessness for adults who are deafblind.
Is it a realistic goal that Australians who become deafblind will achieve some recognition of their need for support? Success in other countries suggests it could be. DeafBlind UK recently joined with Sense, a second charity in the UK, and successfully campaigned for better recognition of the need for one-to-one support for people who are deafblind in order for them to take an “informed, full, and responsible part in everyday life” (Hicks, 2000\(^\ast\)). In April 2001, the UK Government issued guidelines stating that people who are deafblind should have access to specialised assessment and services, including one-to-one support in their everyday lives (see Appendix 2 in DeafBlind UK, 2004a). More recently in April 2004, as a result of collaborative advocacy efforts, the European Government made a Declaration of Rights of DeafBlind People (Deafblind UK, 2004b). There is no good reason for Australia to lag behind in developing policies that recognise persons with deafblindness as citizens who belong equally in our shared community.

\(^\ast\) An asterisk indicates that the quote is taken from an electronic source where no page numbers are available.
REFERENCES


ACROD. (1993). *Services in Australia for people who are both deaf and blind. A discussion paper.* Curtin, ACT: ACROD Ltd.


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APPENDICES
Appendix 1: Notification of Ethical Approval

(copy of original available if requested)
Appendix 2: Ethical Approval Renewal Notification for 2004

(copy of original available if requested)
Appendix 3: Ethical Approval Renewal Notification for 2005

(copy of original available if requested)
Sharing Connections: Everyday lives of adults who are deafblind.

Information Sheet for Participants

You are invited to take part in a research project.

1. What is the research about?
This research is about what life is like for adults who experience deafblindness.

2. Who is carrying out this study?
Julie Schneider, a research student at the University of Sydney is running the project, to meet the requirements for the degree of PhD. Julie is being supervised by researchers at the University of Sydney, and the Centre for Developmental Disability Studies. Their names are Gwynnyth Llewellyn and Trevor Parmenter.

3. What will I be asked to do?
If you are willing to take part, you will be asked to:  
Meet and talk with Julie for one or two hours, every few months, during 2003-2004.  
These discussions with Julie may be face to face, or via e-mail.

If meetings are face to face you need to:-
- Decide where and when you will meet Julie.
- If you would prefer not to be alone, you can have another person present at the meetings with Julie.
- Tell Julie if you require an interpreter for the meetings and she will arrange one.
- Allow Julie to tape record or video the meetings.

4. What will I be expected to talk about?
Discussions will involve:-
- What has happened in your life so far and your thoughts about the future.
- What relationships and people are important or have an affect on your life.
What activities or interests are important in your life.
Your personal views of what it is like to become deafblind.

5. Can I withdraw from the study?
- Participation is voluntary. This means you do not have to participate if you do not want to. Whether you participate or not will have no affect on any existing services or support you receive.
- If you do participate, you can choose to stop or withdraw at any time.

6. Will anyone else know what I said?
- What you say is confidential as is required by law. Only the researchers will know what you have said.
- Only the researchers will have access to information about you and other people who participate.
- When the project is finished, a report about the study will be written and will be available for other people to read. No person involved in the study will actually be named in the report.

7. Will the study help me?
- The study will give you an opportunity to share your stories of what has happened and what is important in your life.
- The findings of the study will be used to increase awareness and understanding of what it is like to be an adult who is deafblind, from your perspective.

8. Before I make up my mind, is there someone I can talk to?
- If you have any questions or decide you would like to take part, you can contact Julie at the University of Sydney by phone on (02) 9351 9833 or e-mail her at jschneider@fhs.usyd.edu.au.
- If you use a TTY you can contact Julie using the National Relay Service (Australian Communication Exchange) by dialing 133 677.

This form is for you to keep.

Any person with concerns or complaints about the conduct of a research study can contact the Manager of Ethics and BioSafety Administration, University of Sydney, on (02) 9351 4811.
Appendix 5: Participant Consent Form

Sharing Connections: Everyday lives of adults who are deafblind.

Participant Consent Form

I have read, or had explained to me, the participant information sheet. I am aware of the procedures involved in the study and agree to participate in a series of meetings or e-mail conversations. I understand that conversations will be recorded or taped unless I request otherwise.

I understand my participation is voluntary. I understand my decision to participate or not participate will in no way affect any existing service or support arrangements I have. I am aware I am free to withdraw from the project at any time.

I also understand the information I share will be kept confidential as is required by law, and no identifying personal information will be kept with the research or published.

I hereby agree to participate in this research study.

Signature:.................................................................

Name:.................................................................

Date:.................................................................

Signature of Witness:......................................................

Name of witness:......................................................