Starting to feel connected: Investigating interactions between adults with congenital deafblindness and disability support workers

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Contents

Declaration

I certify that, except where due acknowledgement has been made, the work is that of the author alone; the work has not been submitted previously, in whole or in part, to qualify for any other academic award; the content of the thesis is the result of work that has been carried out since the official commencement date of the approved research program; any editorial work, paid or unpaid, carried out by a third party is acknowledged; and that ethics procedures and guidelines have been followed.

Meredith Prain
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List of tables and figures

Summary

This thesis reports an investigation of interactions between adults with congenital deafblindness and the disability support workers who mediate their support. These interactions are examined with a view to better understanding how social togetherness, or *the good life* as posited by Reinders (2002), might be better understood, evaluated and ultimately enhanced.

A number of studies investigate interactions between children with congenital deafblindness and their parents and educators, and there is increasing evidence of the efficacy of interventions to enhance these interactions. However, there is very little information in the scientific literature which contributes to a better understanding of interactions for adults with congenital deafblindness and approaches which are effective with these adults. While some authors argue that approaches used with children are equally applicable to adults, there are a number of key differences between children and adults with congenital deafblindness. In particular, the circumstances surrounding their social and communicative interactions have not been adequately addressed in the literature. It is this paucity of knowledge which this thesis seeks to address to better inform policy and practice. The thesis draws on the literature concerning adults with profound intellectual and multiple disabilities as there are many similarities in social and emotional development, and the practical circumstances of support shared by these two groups.

In order to better understand the good life for adults with congenital deafblindness, the study employed a mixed method design. An observational coding approach was combined with interviews of interaction partners to better understand what occurs in the interactions of adults with congenital deafblindness.

This thesis highlights the importance of using mixed methods, or at least multiple perspectives, when evaluating interactions with adults with congenital deafblindness. It demonstrates that examining interactions from only one perspective, or using one method in isolation, gives a limited and partial understanding of the situation. For example, the findings from phase one of the study reported in this thesis demonstrated few instances of interaction between adults with congenital deafblindness and their support staff. Similar studies in the past have interpreted such results as suggesting that the staff required further training in how to interact with their clients. However, the findings from phase two of the study, which used a different research method, revealed higher levels of interaction. Phase two also yielded additional information that helped to explain the low levels of interaction observed in the first phase. The findings from this second phase suggest a mismatch in worldviews between disability support workers and those formulating interventions to enhance interactions for adults with congenital deafblindness. For this reason, staff training to address issues raised by the first phase of the study, without reference to the findings and insights gained from the second phase, may not deliver long-term, positive outcomes for adults with congenital deafblindness.

This is because the type of intervention does not adequately address the mismatch in worldviews between the intervener and the disability support workers.

There is a clear need for multiple methods and perspectives in both evaluating and enhancing interactions with adults with congenital deafblindness. This thesis offers some practical recommendations to progress the situation for clinicians, researchers, disability support workers, and most importantly adults with congenital deafblindness. However, much work remains to develop effective tools and methods for evaluating interactions with people with congenital deafblindness. This thesis also poses some important questions about evaluating opportunities for adults with congenital deafblindness to experience the good life within the broader quality of life construct.

Chapter One: Introduction

Little is known about the interpersonal experiences of adults with congenital deafblindness. In the course of my work as a speech pathologist visiting adults with congenital deafblindness in their own homes and day settings, I became curious about the dissonance between the evidence-based literature in the field of congenital deafblindness and the practices I observed. Upon reflection and examination of current literature I questioned the extent to which adults with congenital deafblindness experience the good life, a concept posited by Reinders (2002). According to Reinders (2002) the good life is one which includes civic friendship; a relationship that goes beyond legal and service related spheres, and which involves living together in the pursuit of shared ideals. I was also interested in how to better understand the current interactions of adults with congenital deafblindness, and how to measure the quality of their interactions and their lives.

This thesis is about interactions between adults with congenital deafblindness and the disability support workers who mediate their support. The thesis is exploratory in nature and has largely arisen out of my concern with the extremely limited success I have experienced in achieving lasting, sustainable outcomes for the adults with congenital deafblindness with whom I work. While the theory and evidence found in the scientific literature relevant to this field appear sound, they do not adequately account for the issues I have experienced in creating lasting change for adults with congenital deafblindness. Consequently, this thesis is fundamentally an exploration of relationships.

Relationships between disability support workers and adults with congenital deafblindness, between scientist practitioners and adults with congenital deafblindness, and between scientist practitioners and disability support workers. Clearly, there are multiple sets and combinations of relationships which require attention in order to better understand and create opportunities for adults with congenital deafblindness to experience the good life.

The remainder of this introductory chapter explains the reasons why particular words, styles and language are used throughout this thesis; namely, the use of full words rather than acronyms, the use of the term *deafblind*, and the use of the personal pronoun *I*. Definitions of key terms used throughout the thesis are presented, as well as an explanation of why literature on people with profound intellectual and multiple disabilities has been used. Key similarities and differences between adults with congenital deafblindness and people with profound intellectual and multiple disabilities are also discussed. The chapter concludes with an overview of the remaining chapters in this thesis.

Clarification of terms and language

The use of full words rather than acronyms

There are a number of terms used repeatedly throughout this thesis which could be abbreviated to acronyms. For example, people with congenital deafblindness could be abbreviated with an acronym to people with CDB. While it is recognised that this is a more expeditious means of expression, the full words will be used throughout the thesis for a number of reasons.

First, there is considerable disagreement and discrepancy amongst different authors about the appropriate terms to be used, including some country and regional differences. Because of these differences, if acronyms are used, some confusion can arise as to what each letter in the acronym represents. For example, people with profound intellectual and multiple disabilities (see definition below) can be referred to as people with: profound and multiple disabilities (PMD), profound and multiple learning disabilities (PMLD), profound learning disabilities (PLD), and profound intellectual and multiple disabilities (PIMD). Indeed, at the 12th World Congress of the International Association for the Scientific Study of Intellectual Disability, 11 different terms were used in 41 presentations to describe what were supposedly the same group of people (Nakken & Vlaskamp, 2007).

Second, within disciplines acronyms become a common way to expedite communication. However, for people outside or new to a discipline the acronyms have no meaning and can be alienating. The focus of this thesis is on human interaction and communication; people from a variety of disciplines are likely to find it of relevance and interest. It therefore seems important to optimise shared meaning and understanding, and minimise the opportunity for miscommunication, which acronyms have the potential to create.

Finally, Miller and Crabtree (2000) argue that most clinical research is published in a language that benefits researchers, not the people and clinicians which the research is about. Consequently, they call for this issue of language to be redressed by qualitative researchers in particular.

The use of the term deafblind

There is no one internationally recognised and accepted way of writing deafblind. Enersdvedt (1996) notes that the terms deafblind, *deaf-blind*, *dual sensory impaired*, and *multisensory impaired* are all used to describe this population. He states that while dual sensory and multisensory may be more accurate and to the point, historically deafblind and deaf-blind have been used and are still the most commonly used terms.

The term deafblind will be used in this thesis rather than the hyphenated version. This recognises that deafblindness is a condition presenting other difficulties than those caused by deafness and blindness alone, and that the whole is more than the sum of its parts (Wills, 2011, p. 2).

The use of I

The first person, *I*, will be used throughout this thesis as it is considered important to highlight and acknowledge the role of researcher as instrument and how this instrument has been calibrated (cf. Guba & Lincoln, 1981). My experiences as a speech pathologist working with people with deafblindness for over 15 years have influenced the nature of this research project and it is necessary to be aware of these experiences to better understand the project. Furthermore, Kamler and Thomson (2006) emphasise the importance of reflexivity in research. They argue that research is about the personal and the person of the researcher, and that reflexive practice involves the use of the personal I. Additionally, using the personal I helps to address the "discredited modernist pretence of impersonal objectivity in research writing" (V. Prain, 1997).

Key terms and definitions

Congenital deafblindness—see below under the clarification of populations being discussed.

Disability support worker—multiple terms are used in the literature for this role, including direct support worker, carer, attendant carer, special care worker and instructor. The term used in this thesis to denote this role is disability support worker, as this is the term used by the organisation that employs the staff who participated in this study. This term is commonly used in Australia to describe staff employed to work with people with disabilities in their homes, day centres and in the community. The term is consistent with the occupational roles covered by two definitions from the Australian Standard Classification of Occupations, Australian Bureau of Statistics:

> 3421-15 Residential Care Officer: Provides care and supervision for children or disabled persons in group housing or government institutions….
>
> 3421-17 Disabilities Services Officer: Works in a range of adult service units which provide education and community access to people with intellectual, physical, social and emotional disabilities (McLennan, 1997, p. 275).

Profound intellectual and multiple disability—see below under the clarification of populations being discussed.

Scientist practitioner—this term will be used throughout the thesis to describe clinicians, researchers and clinical researchers. The scientist practitioner model "values the contributions of both science training and practice training to the education of a psychologist" (Stricker, 2002, p. 1277). It is equally applicable to other health sciences and researcher practitioners from other disciplines such as health, allied health and education. The scientist practitioner model equally values research and practice and sees value in including both, regardless of whether it is research or practice which is being undertaken.

Given much of the research in the field of congenital deafblindness is done by practitioners who have recognised the need to evaluate the efficacy of their interventions the scientist practitioner model is of particular relevance. The literature on congenital deafblindness is equally relevant and applicable for both clinicians and researchers. Therefore, it is reasonable and expeditious to use the term scientist practitioner when referring to clinicians, researchers, and clinical researchers in this field.

It should be noted, the term scientist practitioner is not commonly used in the fields of deafblindness or profound intellectual and multiple disability, or indeed within my own profession of speech pathology. Consequently, the use of the term scientist practitioner will be examined further in chapter seven, in light of findings from the current study, to determine the relevance and application of this term to these fields.

Clarification of populations being discussed

Two distinct groups of people will be discussed throughout this study: people with congenital deafblindness and people with profound intellectual and multiple disabilities. It is important that both groups are mentioned individually throughout the study. While these two groups have much in common, there are also some important distinctions which mean they cannot be viewed as one group. However, it is useful to consider each of these groups when examining issues relating to one or the other, as much can be learnt from one group which is of relevance to the other. For example, there is extremely limited literature specifically addressing measures of quality of life for people with congenital deafblindness. However, there is more literature addressing quality of life measures for people with profound intellectual and multiple disabilities. This can provide insights into issues around measuring the quality of life of people with congenital deafblindness who have in common idiosyncratic communication and complex support needs.

Certainly there are many similarities between models of interaction and intervention strategies used with each group, and a number of authors acknowledge these similarities. For example, Hostyn and Maes (2009) note the similarity between the core characteristics of interaction with people with profound intellectual and multiple disabilities and those characteristics identified by Janssen et al. (2003b) in their study involving children with congenital deafblindness. These authors collaborated to develop the Scale for Dialogical Meaning Making (Hostyn, Janssen, Daelman, & Maes, 2009), a tool potentially useful in evaluating interactions with both people with congenital deafblindness and those with profound intellectual and multiple disabilities. Caldwell (2006) notes the similarities between the approaches of Intensive Interaction, used with people with learning difficulties who are nonverbal, and Co-creating Communication, the approach described by Nafstad and Rodbroe (1999) in guiding work with people with congenital deafblindness. In addition, the final report from a project conducted in the United States of America investigating the assessment of children with deafblindness included children with multiple disabilities. It recognised the similar issues related to assessment that these two groups, which often overlap, face (see Rowland, Chen, Stillman, & Mar, 2009).

Before looking at the similarities and differences between these two groups, it is important to define each group separately in order to establish which interventions and approaches are applicable for each group and why. Nakken and Vlaskamp (2007) argue the need to establish which treatments and interventions are most effective with people with profound intellectual and multiple disabilities as distinct from other groups which may appear to have similar characteristics.

Congenital deafblindness

The definition of deafblindness used in this study is a functional rather than a medical definition; it is the definition used by Deafblind International (see http://www.deafblindinternational.org):

> The term deafblindness describes a condition that combines in varying degrees both hearing and visual impairment. Two sensory impairments multiply and intensify the impact of each other creating a severe disability which is different and unique. All deafblind people experience problems with communication, access to information and mobility. However, their specific needs vary enormously according to age, onset and type of deafblindness.
>
> Deafblind people are unable to use one sense to fully compensate for the impairment of the other. Thus they will require services which are different from those designed exclusively for either blind people or deaf people (Deafblind International, 2012).

This study focuses on the subgroup of people with congenital deafblindness. People with congenital deafblindness were born with a combined vision and hearing impairment, or lost vision and hearing prior to the acquisition of language (Rodbroe & Janssen, 2006a).

Profound intellectual and multiple disability

The definition of profound intellectual and multiple disability used in this study is also a functional, rather than a clinical definition. It is taken from a report on the needs of, and services for, people with profound intellectual and multiple disabilities in the United Kingdom (Mansell, 2010):

> People with profound intellectual and multiple disabilities (this phrase is the term used internationally. It refers to the same people often identified in the UK as having ‘profound and multiple learning disabilities’) are among the most disabled individuals in our community. They have a profound intellectual disability, which means that their intelligence quotient is estimated to be under 20 and therefore that they have severely limited understanding (World Health Organisation, 1992). In addition, they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help. People with profound intellectual and multiple disabilities have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols. They often show limited evidence of intention. Some people have, in addition, problems of challenging behaviour such as self-injury (Mansell, 2010, p. 3).

Similarities between adults with congenital deafblindness and adults with profound intellectual and multiple disabilities

Low incidence disabilities

Congenital deafblindness and profound intellectual and multiple disability are low incidence disabilities. Their occurrence in the general population is rare and consequently they form minority groups in terms of presence in the general community, disability support services, and the research literature. Being low incidence disabilities has implications for service delivery, research, and the development of appropriate and relevant policies governing service delivery, which will be discussed at the end of this section.

While recognised as being low in incidence, considerable challenges remain in determining exact numbers of people with these disabilities. Estimates suggest, even with changes in the population of people with deafblindness, that about 200 people per million inhabitants of a developed country will have deafblindness, and about one fifth of these people will have congenital deafblindness (Rodbroe & Janssen, 2006a). In Australia, it was estimated that there were 3,984 people with deafblindness in 2005. This was based on estimates of there being 20 per 100,000 people with deafblindness in developed countries (M. Prain, 2005). However, only 682 (14.45%) of these people were identified in Prain's (2005) study due to the way in which information about disability type is recorded by governments and service providers in Australia.

It has also proven problematic to establish accurate estimates of prevalence of people with profound intellectual and multiple disabilities. Emerson (2009a, 2009b) established an estimate of the number of people with profound intellectual and multiple disabilities in England of 16,442. Given the population of England was estimated to be 51,810,000 in 2009 (Office for National Statistics, 2011) the percentage of people with profound intellectual and multiple disabilities from these estimates is 0.032%. Emerson (2009a, 2009b) also reports that this figure will accelerate further in years to come, with a greater number of people reaching adulthood. In Australia, McVilly and Forster (2010) applied a similar methodology to that adopted by Emerson (2009a, 2009b) and achieved comparable results.

In order to better understand how these low incidence groups compare with other disability groups it is necessary to also look at population estimates of other groups. For example, Wellesly, Hockey, Montgomery and Stanly (1992) found 0.76% with intellectual disability compared to 0.06% with profound intellectual and multiple disabilities. People with profound intellectual and multiple disabilities, and also often adults with congenital deafblindness, are subgroups of the larger group of people with intellectual disabilities. For this reason there is potential for their different and specific needs to go unaddressed as policies and service delivery models relevant to the majority are applied to them. The low incidence of people with congenital deafblindness and profound intellectual and multiple disabilities also means they have received less attention from researchers. Thus their needs are not as well documented and addressed as the needs of people with mild and moderate intellectual disabilities and no sensory impairments.

Shared services and the policies which shape these services

In Australia there are few accommodation services specifically for adults with congenital deafblindness and no day services specifically for this group. Consequently, these adults receive services alongside adults with profound intellectual and multiple disabilities, and other disabilities (M. Prain, 2005; Ward, 1994). For this reason, adults with congenital deafblindness receive services from staff who are guided by general, rather than disability specific, training and policies. It is therefore relevant to investigate literature on training, intervention strategies and the perceptions and attitudes of staff working with adults with profound intellectual and multiple disabilities when researching the situation for adults with congenital deafblindness, and vice versa.

Communication methods

Both adults with congenital deafblindness and those with profound intellectual and multiple disabilities use individual and idiosyncratic means of communication requiring skilled and sensitive communication partners. The reasons why each group use idiosyncratic behaviours may vary. Adults with profound intellectual and multiple disabilities use nonlinguistic means of expression due to cognitive impairments. Adults with congenital deafblindness use nonlinguistic means of expression because of dual sensory impairment. Both groups require communication partners to be highly observant and aware of facial expression, vocalisations, body language and muscle tension. It is important to note that many adults with congenital deafblindness do develop symbolic means of communication. However, the focus of this study is on those adults who communicate primarily through nonsymbolic means.

The description of people for whom Intensive Interaction (see Nind & Hewett, 1994) is an appropriate intervention describes both people with profound intellectual and multiple disabilities and many adults with congenital deafblindness.

> Intensive Interaction is relevant for people who:
> - have few or limited communication behaviors
> - lack the abilities needed for being social with other people
> - may have ritualistic, self involved, self injurious or aggressive behaviours which exclude others
> - remain untouched by traditional approaches.
> - do not yet know that being with another human being can be unthreatening and even pleasurable (Nind & Hewett, 1994, p. 11).

The importance of touch

Touch is an important aspect of communication for both adults with congenital deafblindness and adults with profound intellectual and multiple disabilities, but for different reasons. Touch is the earliest sense to develop and the last sense to fade (Nicholas, 2010). This makes it a powerful sense for augmenting or providing information to adults with profound intellectual and multiple disabilities whose other senses, particularly vision and hearing, may not always provide meaningful information. Many adults with congenital deafblindness on the other hand require information to be provided in a tactile way simply because of the absence of vision and hearing. Even those adults with congenital deafblindness who have functional vision and hearing, like adults with profound intellectual and multiple disabilities, will benefit from having visual and auditory information supplemented with tactile information.

Differences between adults with congenital deafblindness and adults with profound intellectual and multiple disabilities

From the above information it is clear that people with congenital deafblindness and those with profound intellectual and multiple disabilities have a number of attributes in common. However, it is important to recognise key differences between the groups in order to ensure their defining and specific needs are addressed from a policy and service delivery perspective.

People with profound intellectual and multiple disabilities are more likely to have vision and hearing impairments than the rest of the population (Meuwese-Jongejeugd et al., 2008). This means some adults belong to both groups. The primary difference between adults with profound intellectual and multiple disabilities and adults with congenital deafblindness is the difference in cognitive ability. Cognitive ability is often masked in adults with congenital deafblindness by their dual sensory impairment and ability to develop higher level communication skills is greater in this group. For this reason, there are intervention strategies, particularly around meaning making and development of symbolic communication, which are more applicable to adults with congenital deafblindness than those with profound intellectual and multiple disabilities (see Souriau, Rodbroe, & Janssen, 2008).

Forster, Gray, Taffe, Einfeld and Tonge (2011) point out that there are significant differences between people with severe intellectual disabilities and those with profound intellectual disabilities in scores on the Developmental Behaviour Checklist, indicating differences in behavioural and emotional problems. Because of these differences, it is important to exercise caution when treating the two separate groups as one single group.

Overview of thesis chapters

Chapter two of the thesis focuses on the relationship between adults with congenital deafblindness and scientist practitioners. It presents the ways in which scientist practitioners have understood and evaluated the situation for people with congenital deafblindness. The chapter describes the notion of the good life, which underpins the central issue to be examined in this thesis. It provides a broad overview of the construct of quality of life, within the context of intellectual disability, and discusses useful frameworks for operationalising the good life. It then examines what is currently known about interactions with people with congenital deafblindness. The chapter concludes with an examination of the differences between adults and children with congenital deafblindness, highlighting the need for specific research into the situation for adults.

One of the key differences for adults with congenital deafblindness is their interaction partners, namely disability support workers. Chapter three examines what is currently known about interactions between disability support workers and people who communicate primarily through nonsymbolic means, and how this information has been generated. As stated earlier, adults with congenital deafblindness often share services with people with profound intellectual and multiple disabilities. There is value in examining the literature on interactions between disability support workers and people who communicate nonsymbolically to gain insights into what may be occurring for adults with congenital deafblindness.

An overview of current intervention strategies aimed at enhancing and improving interactions is examined and critiqued. The key intervention strategies discussed are participative management, supervision and observational approaches, Active Support, Intensive Interaction, and video feedback strategies. As this thesis is concerned with evaluating the degree to which adults with congenital deafblindness experience the good life, typically used outcome measures are examined. The discussion highlights the inadequacy of currently used measures to satisfactorily evaluate opportunities for experiencing the good life.

The majority of the information in chapter three, and indeed in the literature, is from the perspective of scientist practitioners. There seems considerable value in gaining a greater understanding of what is occurring in interactions with disability support workers from their own perspective. Chapter three therefore also examines what is currently known and understood from the perspective of disability support workers. The chapter concludes with an examination of the broader context within which disability support workers are operating in order to provide greater insight into factors which may impact on their interactions.

Chapter four discusses how my own perspectives have been shaped and influenced. While chapters two and three raise some methodological issues about examining interactions between disability support workers and people who communicate nonsymbolically, chapter four examines some of the methodological issues inherent in research with adults with congenital deafblindness. It also looks at how the nature of congenital deafblindness influences research methodologies. In addition, the research design used for the two phases of the study in this thesis is presented.

Given the participants in phase one and phase two of the study are almost identical, chapter four concludes with descriptions of the research participants in each phase of the study and the context of the study.

Chapter five presents the aims, design and results of the first quantitative phase of the study. It concludes with an analysis of the methodological issues, challenges, and potential solutions to the problems encountered using an observational coding method. Attention is given to the potential benefits and issues related to using a consensus coding approach.

Chapter six presents the aims, design and results from the second qualitative phase of the study. Chapter six concludes with an evaluation of the quality of the research undertaken in phase two using Tracy's (2010) eight *big tent* considerations for quality in qualitative research.

Chapter seven presents a summary of key findings from the quantitative and the qualitative phases of this study in light of existing literature and theory. The need for alternative intervention and research methodologies is highlighted. These would optimise opportunities for people with congenital deafblindness and those with profound intellectual and multiple disabilities to experience the good life. Key elements addressed include the need for multiple perspectives and the need to address power imbalances in research and intervention. The concepts of reciprocity and relational agency are examined as strategies for addressing power imbalances. This section highlights the lack of reciprocity between researchers and research participants, and the dearth of processes involved in relational agency in research in congenital deafblindness to date. The application of Integral Theory and action research are presented as potential frameworks to address the current methodological and philosophical issues inherent in this field. Video Interaction Guidance is a current intervention tool used to promote opportunities to experience the good life. Video Interaction Guidance is presented, in conjunction with the principles of action research, as being consistent with many of the requirements that are necessary to foster sustainable positive outcomes. The chapter also examines organisational and governmental policies in the context of creating long-term sustainable outcomes for people with congenital deafblindness and people with profound intellectual and multiple disabilities.

Chapter eight provides a summary of the key findings and the contribution of the research documented in this thesis. It also presents the limitations of the study. Chapter eight concludes with the theoretical, philosophical, research and clinical implications of the study.

Chapter Two: Adults with congenital deafblindness and their experience of the good life

As mentioned at the start of the introduction, this thesis is fundamentally an examination of three sets of relationships involving adults with congenital deafblindness, disability support workers and scientist practitioners. This chapter focuses on the scientist practitioner’s relationship with adults with congenital deafblindness. It discusses the related issue of scientist practitioners’ relationships with adults with profound intellectual and multiple disabilities. These relationships are largely evaluative in nature. That is, for the most part scientist practitioners have endeavoured to develop models and tools with which to examine and evaluate the behaviours and development of people with congenital deafblindness. This chapter also presents the ways in which scientist practitioners have understood and interpreted the life circumstances for adults with congenital deafblindness and people with profound intellectual and multiple disabilities. The chapter includes some evaluation of the methodologies used to date and highlights some problems with these methodologies. Many of these methodological difficulties are considered in more detail in chapter four. It is important to present current theories, models and frameworks for evaluating the interactions of adults with congenital deafblindness in order to determine the best way to evaluate the efficacy of interventions with this group. It is also important to understand the limitations of current tools in order to assess options to expand on what is currently available to address these limitations.

This chapter presents Reinders’ (2002) concept of the good life, as it underpins the problems observed in the interactions of adults with congenital deafblindness which this thesis explores. The examination of the good life highlights the need for an emphasis on the social interactions of adults with congenital deafblindness in both research and practice.

However, in understanding the importance of the good life for adults with congenital deafblindness, it is necessary to appreciate how this concept fits within the quality of life construct. Therefore, an overview of what is currently understood by scientist practitioners about evaluating the quality of life of people with profound intellectual and multiple disabilities, and why this may be applied to adults with congenital deafblindness, is presented. This is followed by a more detailed look at how the good life, as posited by Reinders (2002), can be operationalised using both a quality of life framework and a framework of interaction based on human communication development theory. A number of existing models are discussed, including how they are, or could potentially be, used to gain insights into the degree to which an individual has opportunities to experience the good life.

Once these overarching concepts necessary to understanding the topic have been presented, the chapter focuses on what is currently known and understood about interactions with people with congenital deafblindness. Initially an historical perspective is taken to help frame and locate the current study in time. The chapter then focuses specifically on what is known and understood about interactions with adults with congenital deafblindness. As the literature about interactions with adults with congenital deafblindness is limited, what is known and understood about interactions with children with deafblindness is presented to gain greater insight into what may be occurring for adults. The differences between the situation for children and that of adults are also highlighted.

The good life

The good life according to (J. S. Reinders, 2002) is the central concept underpinning the problem to be addressed in this thesis. Reinders argues that:

> people with ID [intellectual disability] are People First, i.e. they are not just citizens, but human beings in the first place. They are not only bearers of institutional roles, they are also – and more importantly – identified by their proper names. To regard them in that capacity, we do not talk about students tenants, employees or clients; instead, we talk about John, Jack or Jody. To include them in that capacity we need to include them in our informal relationships as well as our institutions. If community living is a human experience, we should expect that people with disabilities want to be included in the lives of others as John, Jack or Jody, i.e. we should expect them to want us not only as bearers of institutional roles, but as friends and companions who have chosen them to be part of their lives. To be part of a social world is to be included in the bonds of civic friendship. 'Civic friendship' in this connection means a type of relationship between citizens which goes beyond the legal sphere and includes the social sphere. People who enjoy civic friendship live and work together in the pursuit of shared ideals. To be included in these kinds of relationships is what makes human life worth living for everybody, not just people with ID [intellectual disability] (J. S. Reinders, 2002, p. 3).

Reinders (2002) is reflecting primarily on the circumstances of people with an intellectual disability. As discussed in chapter one, while there are some similarities and differences, people with congenital deafblindness and those with profound intellectual and multiple disabilities invariably share services and issues related to communicating nonsymbolically. In particular, Reinders' (2002) assertions are applicable to adults with congenital deafblindness living in supported accommodation. While problematic to operationalise, as will be discussed later in this chapter, Reinders’ (2002) concept of the good life is consistent with the perspectives of a number of scientist practitioners working with adults with intellectual disabilities and those with congenital deafblindness.

Johnson, Walmsley and Wolfe, (2010, p. 131) in discussing a good life for all, including those with intellectual disabilities, state “fundamentally it is a life lived with and for others”. However, these authors go on to argue that public policy and the current workforce are ill-equipped to support this ideal for adults with intellectual disabilities. These issues will be discussed further in the following chapter.

Martens (2007), writing specifically about deafblindness, promotes ideals consistent with the good life presented by Reinders (2002). In her examination of togetherness with a woman who is deafblind she writes “a life filled with pleasure and warm relationships as a result is possible when a person meets others and gets involved with them” (Martens, 2007, pp. 24-25). Martens also uses Wikipedia's definition of togetherness, which reflects Reinders (2002) sentiments, stating it is “the feeling of being close to another person emotionally and physically. It makes one feel warm on the inside and creates an altogether positive atmosphere for the people involved”.

Similarly, and also supporting the idea of the importance of the good life for people with congenital deafblindness, Hostyn states:

> especially for persons with congenital deafblindness (CDB), harmonious relationships are indispensable for a good quality of life because of their dependency on others to explore the world and to develop their own abilities. Since the relationships between persons with CDB and their partners are at risk for problems, interventions need to address the quality of the relationship itself (Hostyn, 2008, p. i).

Human communication development theory lends support to the relevance and importance of addressing the need for the experience of social togetherness, or the good life, in order for development to occur. Zeedyk (2006) argues “intimacy is transformative. It is from emotional intimacy with another person that individualistic capacities derive, including self-awareness, representation, language, and even consciousness” (Zeedyk, 2006, p. 326). Trevarthen also argues the need to acknowledge the mutual regulation between individuals and two-way relationships, as this causes goals and processes of regulation which when positive, lead to a more effective autonomic state in both individuals (Trevarthen, 2005).

This thesis is not necessarily advocating that staff form close personal friendships with the adults with congenital deafblindness with whom they work in a way that could compromise their professional responsibilities. But it does support the view that this human need and human right is operationalised and made explicit in their work (cf. McVilly, 2007). Considerably more work is required to address ways of achieving this and these are discussed in further detail in chapter seven.

If we are to apply this concept of the good life to the lives of adults with congenital deafblindness to make judgements about the opportunities they are given for this desirable mainstream human experience, we need a way to validly and reliably measure these. However, before looking at ways of operationalising the good life, it is necessary to understand how this concept fits within the broader construct of quality of life.

Quality of life

The focus of this thesis is on interactions between adults with congenital deafblindness, disability support workers and scientist practitioners, and the impact these interactions have on the quality of life of adults with congenital deafblindness. It is therefore necessary to have a broad understanding of the construct of quality of life. However, this is a very complex construct which has received much attention from researchers. The intention in this thesis is to give a broad overview of the construct and highlight some of the key complexities and challenges inherent in its measurement. This section will not provide a detailed account of the history of the construct or the many and varied tools developed to measure it (see Petry & Maes, 2009b). This, albeit brief, reflection is important for a number of reasons. The term quality of life is used frequently in literature about people with congenital deafblindness. Most research investigating quality of life enhancing interventions, however, focus predominantly on the intervention without contextualising how the intervention fits within the quality of life construct.

Quantitative measurement of quality of life of persons with intellectual disabilities is still a new field. In fact, quality of life measures designed specifically for people with intellectual disabilities have only been developed in recent years (Schmidt et al., 2010). Thus considerably more work is required to determine both the validity and reliability of these measures. There are no quality of life measures specifically designed for people with congenital deafblindness. The literature drawn upon in this thesis about quality of life comes from work with people with intellectual disabilities and, where possible, those who communicate nonsymbolically.

Verdugo, Schalock, Keith and Stancliffe (2005) argue two key reasons for the importance of measuring quality of life. First, it gives an integral, multidimensional view of an individual’s life allowing identification of, and planning for, support needs. Or, as Petry and Maes (2009) state, “the main purpose of measuring QOL [quality of life] must be to maintain and enhance the things that already, or could, add worth to people’s lives and to take action to improve the things that currently detract from the quality of people’s lives” (Petry & Maes, pp. 25-26). Second, it helps to reorient the focus and activities of public organisations and service providers, giving the individual a central role whose views and experiences must always be considered.

Use of the term quality of life and the quality of life construct has developed and changed over time. Schalock (2004) posits that the quality of life construct within the disability context is currently used as a sensitising notion, a unifying theme and a social construct ultimately to enhance an individual's wellbeing across time and setting. Verdugo et al. (2005) assert that it is also used as a criteria for assessing the effectiveness of strategies designed to enhance an individual's quality of life. One such strategy, discussed in more detail in chapter three, is Active Support. Jones et al. (1999) argue that deinstitutionalisation alone has not satisfactorily enhanced the quality of life of people with severe intellectual disabilities. They devised a coding tool to evaluate the impact of Active Support on the engagement and interactions of adults with severe intellectual disabilities. However, there are issues with measuring quality of life enhancing strategies using tools which do not include all quality of life domains. Within the functions of the quality of life construct cited above, there is general agreement that the construct consists of a number of quality of life domains (Felce & Perry, 1995; McVilly & Rawlinson, 1998; Petry, Maes, & Vlaskamp, 2005; Verdugo et al., 2005). While the nature and number of domains varies from author to author, Verdugo et al. (2005) argue:

> the number of domains is less important than the recognition that any proposed QOL [quality of life] model must recognise the need for a multi-element framework, the realisation that people know what is important to them, and that the essential characteristics of any set of domains is that they represent in aggregate the complete QOL [quality of life] construct (Verdugo et al., 2005, p. 709).

These domains are presented more fully in the following section about operationalising the good life.

For each domain there are perceptions, behaviours or conditions that are considered to be the quality of life indicators for each quality of life domain (Schalock, 2004; Verdugo et al., 2005). Again, different authors posit varying natures and numbers of indicators for each quality of life domain. In particular, while domains of quality of life are asserted to be consistent across all people, the indicators for different domains appear to vary for people with profound intellectual and multiple disabilities relative to those with mild or moderate intellectual disabilities (Petry et al., 2005). For example, hygiene, nourishment, rest, technical aids and communication were named as important indicators of quality of life for people with profound intellectual and multiple disabilities. These indicators are not present in other models of quality of life designed with people with mild and moderate intellectual disabilities in mind, or indeed for the general population (Petry et al., 2005).

In terms of measurement, multiple authors point out the need for pluralism and a cross systems approach (Montisci & Grant, 2010; Petry & Maes, 2009b; Schalock, 2004; Schalock et al., 2002). That is, the quality of life of an individual needs to be considered at the levels of the different systems and relationships within which they operate. These can be micro/individual (e.g., partners, family and friends), meso/organisational (e.g., neighbours, service providers, and local community), or macro/societal (e.g., the overarching patterns of society, culture and sociopolitical influences) (Montisci & Grant, 2010; Petry & Maes, 2009b; Schalock, 2004). Measurement must also include both subjective and objective measures, as well as societal indicators (Felce & Perry, 1995; Schalock, 2004).

The quality of life construct within the disability context is clearly a multifaceted, complex interconnection of domains and indicators requiring subjective and objective measurement within the different systems an individual is involved in. Montisci and Grant (2010) suggest some other factors which complicate the situation further. These include the fact that to date, most research in the area of quality of life has involved people with intellectual disabilities who can speak and not those with profound intellectual and multiple disabilities. Proxies have been used in instances where individuals are unable to self-report. However, there are numerous issues around the use of proxies. In addition, most quality of life models have for the most part been developed by academics without involving those whom the measures will be used with. Montisci and Grant (2010) also note that improving services does not necessarily lead to the improvement of a service user's quality of life. These issues are discussed in more detail later in this chapter.

This highly abbreviated summary of the key features of the quality of life construct provides a theoretical context for the discussion which follows. In examining ways in which the good life might be operationalised, rather than exploring potential measures of the good life, I will refer to measures of opportunities for experiencing the good life. This shifts the focus from the highly questionable assumption that someone else's experiences can be measured, to an emphasis on creating an environment which is conducive to certain experiences.

Operationalising the good life as a domain of quality of life

As presented above, any model of quality of life must employ a multi-element framework which incorporates multiple quality of life domains. There is general agreement amongst authors as to what these domains are. Petry et al. (2005) adopt the domains described in Felce's and Perry's (1995, 1996a, 1996b) model. Their (2005) research focuses on people with profound intellectual and multiple disabilities. It has more in common with research about adults with congenital deafblindness than other research focusing on those with mild and moderate intellectual disabilities. The five domains used in Felce's and Perry's (1995, 1996a, 1996b) model are:

> physical well being (health, personal safety, fitness, mobility), material well being (finance and income, housing quality, transport, security and tenure), social well being (personal relationships, community involvement), development and activity (competence, productivity and activity), and emotional well being (positive affect, fulfilment stress, mental health, self esteem, status and respect, faith and belief, sexuality) (Felce & Perry, 1995, p. 53).

These are no different for anyone. "People with PMD [profound multiple disabilities] have the same needs as other people with regards to participation, relations, choices, competences, and physical and socio-emotional well-being" (Petry & Maes, 2007, p. 138).

While social wellbeing is just one of the multiple domains of the quality of life construct, it takes on more prominent importance for those with profound intellectual and multiple disabilities, and for those with congenital deafblindness. This is because "to gratify their needs on several domains of quality of life they need a secure relationship with a sensitive responsive parent and/or direct support staff" (Petry et al., 2005, p. 44). This will be explored further in the following section of this chapter, but for now I will continue to examine how the good life might be operationalised as a domain of the quality of life construct.

It seems reasonable to expect that any measure of quality of life which addressed the domains of interpersonal relationships and social inclusion, and the associated quality of life indicators, would give us some understanding of the extent to which an individual has opportunities to experience the good life. While some studies do demonstrate enhanced quality of interactions (Chen, Klein, & Haney, 2007; Janssen, Riksen-Walraven, & Van Dijk, 2003a), there is an implication that this enhances the individual's quality of life, without using any specific measure to evaluate this. As mentioned above, this is one of the key critiques of the quality of life construct presented by Montisci and Grant (2010).

Inversely, most quality of life measures have only been assessed to determine their psychometric properties, that is, their validity and reliability. They have not been widely used to evaluate the efficacy of interventions on the individual's quality of life. Furthermore, it is questionable whether they are adequately sensitive to detect the changes which may result from an intervention specifically focused on enhancing quality interactions, ultimately aiming to enhance personal relationships and social inclusion. This is likely due to the relatively recent shift in use of the quality of life construct. It is now used as a conceptual framework for assessing quality outcomes and a guide for quality enhancement strategies, as well as for measuring the efficacy of these strategies (Verdugo et al., 2005). As the focus with regard to quality of life has become more evaluative, it is questionable whether the tools being developed to measure it are sensitive enough to detect sometimes subtle but important changes resulting from interventions. Certainly more work is required to evaluate the current tools' sensitivity to change resulting from intervention.

Another concern with quality of life measures is their ability to actually measure what they purport to measure. "The type of quality of life being measured in a study needs to be clearly defined and congruent with the type of quality of life measurement tool used, such as generic, health related or disease specific" (Sherifali & Pinelli, 2007, p. 95). Maes, Lambrechts, Hostyn and Petry (2007) reviewed studies of quality of life enhancing interventions and highlighted this issue. Researchers tend to use a variety of tools to measure the efficacy of interventions which they suggest improve quality of life without actually using any generic or domain specific quality of life measures.

There appears to be a need for broad, holistic and domain specific quality of life measures which address issues relating to particular populations, and take into account current trends in public policy. For example, while public policy in many countries has helped to improve quality of life in some quality of life domains—such as physical and material wellbeing, and safety and security—public policy has also moved towards a focus on community or social inclusion. This has been interpreted and implemented in a way that has resulted in reduced opportunities for social togetherness. This is because of an emphasis on people accessing local community facilities where there is no one who knows them well or how to best interact with them. As Clegg et al. (1991b) argue, it is possible that educational goals have been emphasised to the point of excluding more personal goals. Such outcomes appear to be at odds with the good life of Reinders (2002) who states “community is the experience of sharing one’s life with people” (J. S. Reinders, 2002, p. 2). Community is not a location.

Research indicates that interactions with people who are congenitally deafblind are largely lacking in quantity and quality (Preisler, 2005; Vervloed, Van Dijk, Knoors, & Van Dijk, 2006). However, there is a paucity of data about how these experiences affect people’s quality of life and few tools to gather these data. As mentioned earlier, the underlying premise of intervention studies aiming to enhance the quality of interactions is that this necessarily improves the individual's quality of life; there is little evidence to support this assertion.

One of the greatest issues in assessing quality of life for people with congenital deafblindness who are nonsymbolic communicators, and thus cannot self-report, is the reliance on proxy reports of those who are deemed to know them well. The measurement of quality of life necessitates integrating the individual’s view of their quality of life. (Schmidt et al., 2010). This creates issues in relation to proxy reporting which is problematic for a variety of reasons when applied to those who cannot self-report. There is disagreement in the literature around the validity of proxy reporting (Petry & Maes, 2009b; Schmidt et al., 2010). Verdugo et al. (2005) suggest we can either ignore people who are unable to self-report or obtain data through proxies which are potentially biased and invalid. Cummins (2002) argues there is no evidence to support the use of proxy reporting as a valid measure of an individual’s quality of life. He states that a person cannot reliably report on the experiences of another when relying on indirect cues and personal knowledge because it is not possible for proxies to make a disinterested judgement (Cummins, 2002).

However, a number of studies are emerging in which proxy reports have been compared with self-reports. Some studies that use measures designed specifically for use with people with intellectual disabilities have demonstrated moderate to high agreement between individuals and their proxies (McVilly, Burton-Smith, & Davidson, 2000; Schmidt et al., 2010). This may give us an indication of the validity of some measurement tools used with proxies which might be adaptable for use with adults with profound intellectual and multiple disabilities, and those with congenital deafblindness. However, people with intellectual disabilities tend to rate their quality of life higher than their proxies do. There is also variation between the magnitude of agreement across different types of quality of life domains, with higher agreement usually identified in the physical rather than in the emotional domain (Schmidt et al., 2010).

Two other strategies are suggested in the literature to improve the validity of using proxy measures. One is to employ a mixed method approach which, as discussed above, should be employed in any quality of life measure. This means the emphasis, when using proxies, shifts from gaining an holistic perspective, to helping verify the reliability of the proxy reports. An example of this is the approach taken by Lyons (2005) in which quantitative observational data were paired with proxy reports through interviews to give a measure of life satisfaction. The main benefit of this approach is that data are triangulated using two different data collection methods, strengthening the findings.

However, there are some limitations to this multimodal approach. Creswell (2009) notes three in particular. Considerable expertise is required to study a phenomenon using two data collection methods; it is difficult to compare the analyses of data which are in different forms; and it is not always clear how to resolve discrepancies that appear when comparing the data. In addition, Cummins (2002) notes that proxy reports are more likely to be valid if the data being collected is of an objective rather than subjective nature, as was the case in Lyons' (2005) study.

The second strategy is to use proxy reports as a complementary perspective rather than to replace self-reporting. The complementary perspective reframes the issue of who can give the most accurate report. It instead focuses on what each person reporting contributes to the overall understanding of the individual's quality of life (Sherifali & Pinelli, 2007). Having a number of people who know the individual well report as proxies may enrich this understanding (Sherifali & Pinelli, 2007).

There is little information in the scientific literature about the experiences of people with congenital deafblindness and those with profound intellectual and multiple disabilities. There is even less information about the experiences of disability support workers who spend the most time with people with congenital deafblindness. It is disability support workers who complete the quality of life measures on behalf of the person with deafblindness whom they are deemed to know well. Given the key role disability support workers play in mediating the experiences of the people with whom they work, and in deciding what constitutes a good quality of life for these individuals, there seems value in better understanding the worldview of these staff. In so doing, we might better understand their perspective as proxy informants on behalf of people with congenital deafblindness or profound intellectual and multiple disabilities. This is discussed further in chapter four.

Domains of social inclusion: the good life for people with congenital deafblindness

People with profound intellectual and multiple disabilities have received significantly less attention in the literature on quality of life than their peers with moderate and mild intellectual disabilities who are able to self-report. There is also a paucity of information about people with congenital deafblindness in this literature. Measuring quality of life for people with congenital deafblindness who do not communicate symbolically poses greater challenges due to the need for proxy reporting. There are also other differences that require consideration that are not well addressed in the quality of life literature.

People with profound intellectual and multiple disabilities and those with congenital deafblindness are often isolated with few social networks, depending more heavily on service providers for social interaction. Montisci and Grant (2010) argue that disability specific services need to work in close partnership with institutions in civil society to build their capacity to include people with disabilities. This is because disability specific services meet only a part of their need for social contact with others. However, people with profound intellectual and multiple disabilities, and those with congenital deafblindness, often have little or no contact with their families and are unable to interact with the broader community without the mediation of service providers. Consequently, the quality of services provided by disability organisations largely, if not solely, influences the personal relationships and social involvement influencing the quality of life of this group of people. In addition, "the communicative and relational aspect takes on such a central place in people with PMD [profound and multiple disabilities] that it influences all other aspects of functioning" (Petry & Maes, 2007, p. 139).

It is not surprising that an increasing number of studies are emerging where the focus of quality of life measures and quality of life enhancing interventions for people with profound and multiple disabilities are on interpersonal relations, the first domain established by Petry (2006) (e.g.. Bloomberg, West, & Iacono, 2003; de Voil, 2000; Firth, .Elforde, Leeming, & Crabbe, 2008; Golden & Reese, 1996). The following section focuses on operationalising the good life in terms of social interactions and relationships.

Operationalising the good life using features of good quality interactions

The characteristics of good interaction learnt in infancy are applicable to all human interactions regardless of age or ability (Rodbroe & Janssen, 2006b). Research into human communication development has provided a framework with which to evaluate the quality of human interactions. A number of researchers in the field of congenital deafblindness and profound intellectual and multiple disability are using these features to evaluate the efficacy of interventions to enhance quality interactions. Interactions are the building blocks upon which relationships are established. We can gain important insights into what the good life might look like for adults with congenital deafblindness by examining those frameworks and studies which use measurements grounded in human communication development theory.

It is well beyond the scope of this thesis to provide an account of the extensive research that has been undertaken about the complex processes involved in the development of human interaction and communication skills. What is presented are a number of frameworks and models grounded in human communication development theory. These have been designed by scientist practitioners in the pursuit of improving the quality of life of people with congenital deafblindness and those with profound intellectual and multiple disabilities. It should be noted that it is also beyond the scope of this thesis to give a thorough account of the development and content of these frameworks. Instead, an overview of each is given and I discuss how they have been, or might be, used to operationalise the good life for people with congenital deafblindness within the broader quality of life construct.

As pointed out above, high-quality relationships between people with congenital deafblindness and the people who mediate their support are necessary in order to achieve good outcomes across a number of quality of life domains, if not all of them. For this reason a number of researchers have focused specifically on enhancing interactions between people with congenital deafblindness and significant others. While these studies aim to improve the individual's quality of life, as mentioned above, it cannot be assumed that improving the quality of interactions will necessarily result in improved quality of life. The quality of life measures which are currently available may also not be sensitive enough to detect changes in interactions and relationships resulting from intervention. The frameworks, models and tools examined below have demonstrated efficacy in evaluating intervention approaches grounded in human communication development theory. There may be value in incorporating such measures into a quality of life measure for people with congenital deafblindness or profound intellectual and multiple disabilities. To this end, I have considered five frameworks grounded in human communication development theory. This is not an exhaustive list and indeed there are numerous tools developed specifically for children with deafblindness which could potentially be used as an adjunct to a quality of life measure. The tools below have been selected based on their current use in professional practice and the evidence of their efficacy in peer reviewed literature.

The first four have been designed specifically for use with people with congenital deafblindness, and the first three were designed for use with children.

The Developmental Profile was developed by Nafstad and Rodbroe (1999). “The developmental profile is the name of a map of markers which includes cues which can support intuitive competence in interaction and communication” (Nafstad & Rodbroe, 1999, p. 49). This framework builds on the premise that intuitive competence alone is inadequate to foster quality interactions and relationships for people with congenital deafblindness.

The Developmental Profile was born out of the Co-creating Communication approach and contains “cues for categorised video analysis” in terms of social interaction, proximity, exploration and communicative expressions. The aim of the tool is to improve the quality of interaction and communication between a person with deafblindness and their communication partner.

While considerable work went into developing The Developmental Profile and it is reportedly “in frequent use” (Ehrlich, 2007), there is limited evidence of its use as a measurement tool in the literature. There is, however, one study that is particularly useful and relevant to this thesis. It involves the use of The Developmental Profile with an adult with congenital deafblindness in a residential setting. Ehrlich’s (2007) study highlights some key issues around using The Developmental Profile in this setting. Given the dearth of information about appropriate tools to evaluate communicative skills in adults with congenital deafblindness, the findings of Ehrlich’s (2007) study are valuable, particularly the benefits and limitations of using The Developmental Profile.

One benefit of The Developmental Profile was that it was possible to use the tool designed for children in an adult setting and develop an intervention plan based on the results. The participant with deafblindness in Ehrlich’s (2007) study was found to have more cognitive skills than he was able to demonstrate through communicative capabilities as some low-functioning cues were no longer observed. This led Ehrlich to suggest that “the experiences of adults seem to play a crucial role in the difference of the use of The Developmental Profile with children and with adults” (Ehrlich, 2007, p. 57). Using The Developmental Profile in a different context highlighted some differences between children and adults with congenital deafblindness. (These are elaborated on at the end of this chapter.) However, Ehrlich (2007) also raises a number of difficulties and limitations associated with this tool.

Difficulty in understanding the meaning of the cues and accomplishing the profile is reported due to the simple illustrations and lack of clear assessment questions. Recognising the cues and the way in which video sequences might be analysed is dependent on how the assessor understands the cues and how the interaction partner creates the profile result. This tool also requires a broad theoretical knowledge, as well as personal knowledge of the adult with congenital deafblindness. A further issue is the amount of time required for the whole process. This need for a thorough knowledge of the theory underpinning the measurement tool as well as personal knowledge of the individual being assessed is of key importance. Many of the tools available require the person administering them to interpret the behaviours of an individual to fit within a set of predetermined codes or types of behaviour. Typically it is scientist practitioners who administer the evaluations. This is despite the fact that disability support workers who support the individual are likely to have a greater understanding of the nature of their behaviours. However, these staff will often have an inadequate understanding of the theoretical background to the tool and, as a result, the nature of the codes. This issue is examined further in chapter seven.

Ehrlich (2007) states "during my investigations I continuously recognised the gap between dedicated attention to an individual's needs and the fulfilment of organizational and financial requirements" (Ehrlich, 2007, p. 5). These issues have not been well addressed in the pursuit of interventions which will have sustainable positive outcomes for adults with congenital deafblindness.

Given these challenges, Ehrlich (2007) suggests the following to improve The Developmental Profile for use with adults: the reiteration of the cues into assessment questions, which contain observable behaviour; inclusion of consideration of an adult's life experiences within the interpretation of the results; and that theoretical knowledge is imparted to caregivers in a concise, easy and efficient way.

While there are clearly some issues associated with using The Developmental Profile, particularly with adults, it is a way to measure and evaluate the building blocks of interaction upon which the good life is built. Ehrlich's (2007) suggested recommendations when using the tool with adults could also improve its use with this population. Ehrlich's (2007) insights might also be applied to other tools predominantly used with children as her study is one of the few that raises issues relevant to work with adults. Her recommendations will be considered further in chapter seven which examines the best options for evaluating strategies for enhancing opportunities to experience the good life.

The second framework considered is the set of categories of interactive behaviour used with the intervention approach CONTACT. This approach was developed and implemented by Janssen et al. (2003a). It was designed to evaluate the efficacy of intervention aimed at fostering harmonious interactions and relationships between children with deafblindness and their educators.

The evaluation tool is made up of eight categories of behaviour which are coded for both children and their educators. The categories of behaviour are:

1. Initiatives; starting an interaction or bringing up something new as part of an answer,
2. Confirmations; clear acknowledgement that an initiative has been noticed and recognised,
3. Answers; positive (approving) or negative (disapproving) reactions to the partners utterance,
4. Turns; turn taking or becoming the actor and turn giving, or allowing the other to become the actor,
5. Attention; focusing on the partner, the content of the interaction or the individuals and / or the objects within the interaction context,

6. Regulation of intensity of the interaction – for the educator: waiting while the child regulates the intensity of the interaction and for the child: appropriate regulation (e.g., turning his or her head away or laying a hand on the partner's hand) – and inappropriate regulation (e.g., self abusive or aggressive behaviour),
7. Affective involvement; mutual sharing of emotions and
8. Independent acting – for the educator: acting while not focusing on the child and for the child: executing actions independently (e.g., putting on a garment or part of a garment) (Janssen et al., 2003a, p. 218).

The process which incorporates the coding of these eight behaviour categories is as follows. Intervention goals are developed in collaboration with the child's care givers and educators. These intervention goals are presented as three or four aims and are translated in terms of the eight core categories of interactive behaviour presented above. For example, within a given activity intervention goals might be: turn giving more often, affective involvement more often, initiatives less often. Intervention focuses on changing educator behaviours in order to address the intervention goals. Video analysis and coaching occurs with individual educators and groups of educators in order to change their behaviours.

This tool is of potential value in operationalising and measuring possible opportunities for experiencing the good life for a number of reasons. Given its developmental orientation, it is equally applicable to adults as it is to children. This is because the targeted increase in positive behaviours and decrease in negative behaviours are selected based on the level at which the individual is currently operating. There is also flexibility in this model to focus on behaviours and activities specific to individuals and locations, making it applicable for use with adults. In addition, the tool has demonstrated interrater reliability and has been used to demonstrate the efficacy of intervention. However, to date it has only been used with children in child specific settings, so some questions remain about its application to adults with congenital deafblindness in adult specific settings.

The issue raised by Ehrlich (2007) about the requirement of the observer using the coding tool to have a good understanding of the theoretical background of the tool is also applicable here. The CONTACT intervention approach would largely preclude disability support workers from being the observers, despite the fact that they have the best personal knowledge of the individual with deafblindness, thus denying the input of this valuable knowledge in the process.

The third framework considered is the Promoting Learning through Active Interaction (PLAI) curriculum developed by Chen et al. (2007). As with the previous two frameworks, this also has been designed specifically for children rather than adults. The curriculum draws upon research on infant development, early intervention, severe disability and deafblindness.

PLAI consists of six key components: a communication interview to be conducted with the primary care giver of the child, and five modules with goals, objectives and activities for each. The five modules are: understanding child cues, identifying child preferences, establishing predictable routines, establishing turn taking, and encouraging communicative initiations (Chen et al., 2007, p. 151).

Chen et al. (2007) do not use the curriculum itself as a tool to measure its own efficacy. Nevertheless, the curriculum itself requires the observation and documentation of a variety of key observable events and behaviours. These include behaviour states, the child’s typical reaction to events and activities, and identification of activities to be carried out in the same sequence each day. All of these observable events and behaviours could potentially form measures of opportunities to experience the good life.

The measurement tools used to evaluate the efficacy of the PLAI curriculum were analysis of video recorded interactions before and at various points during the implementation of the curriculum, and pre- and post-implementation care giver questionnaires. The key criteria for analysis in both the videos and questionnaires were frequency and type of anticipatory sensory cues given by care givers. A significant increase in the frequency and type of cues given by care givers was observed using both the video analysis and care giver questionnaires following implementation of the curriculum. High interrater reliability was achieved between the two raters who coded the videos. This is a positive finding. As stated above the curriculum has the potential to track the change and development of a variety of key behaviours over time, beyond anticipatory sensory cues presented by care givers. However, as with the categories of interactive behaviour coded in the CONTACT approach, the PLAI curriculum has only been trialled with children. This leaves questions around its applicability to adults with congenital deafblindness.

The fourth framework considered is the set of guidelines developed by Rodbroe and Janssen (2006b). This is the only framework presented here which has not been used specifically to assist in documenting or evaluating an individual's current status or change in behaviours over time. The key features of Rodbroe and Janssen's (2006) guidelines for high-quality dyadic interaction are:

1a. Attunement: being aware of the child's feelings and needs and responding to them promptly and effectively,
1b Co-regulation: continual and mutual adaptation process in which adult and child dynamically alter their actions in relation to the ongoing and anticipated actions of their partner,
2. Reciprocity: social interaction involving mutual exchanges,
3. Turn taking: exchanging turns between two partners,
4. Mutual attention and proximity: when partners are oriented on and directed to each other and the theme in their dyadic interactions,
5. Rhythm and tempo: communicative musicality which organises and regulates shared rhythms and pitch in vocalisations,
6. Novelty and processing: novel stimuli from the communication partner, the environment or inside the body which requires processing and triggers an orienting response (Rodbroe & Janssen, 2006b).

The DVD accompanying the booklet in which the guidelines are described, clearly shows that each of these features is observable and potentially measurable. However, additional work is required to develop and test a tool incorporating these features of high-quality interaction and its applicability with both children and adults.

Certainly a number of authors have demonstrated ways in which some of these key features can be documented or evaluated qualitatively and quantitatively. For example, Forster (2011) demonstrates it is possible to identify and quantify the duration of affect attunement observed in disability support workers interacting with adults with profound intellectual and multiple disabilities. Both

Chen et al. (2007) and Janssen et al. (2003a), incorporate turn taking behaviour as a key feature of interaction to be evaluated. Chen et al, (2007) do this qualitatively as part of the PLAI curriculum and Janssen et al. (2003) include it as a quantifiable measure of the efficacy of intervention.

The key features of high-quality interactions set out by Rodbroe and Janssen (2006) are often subtle, complex, interrelated behaviours. These provide a sound framework grounded in human communication development theory with which to operationalise and evaluate the essential precursors to experiencing the good life.

The final tool considered as a potential means for measuring opportunities to experience the good life is the Scale for Dialogical Meaning Making (S-DMM) (Hostyn et al., 2009). It is applicable to the evaluation of any one-to-one human interaction. The S-DMM was developed by scientist practitioners with experience with people with congenital deafblindness or profound intellectual and multiple disabilities. The authors provide key considerations when using the tool with these populations. The tool has a strong theoretical background emphasising and acknowledging the asymmetrical and dynamic process of creating meaning when two people are in dialogue. One of the strengths of this tool, distinguishing it from others, is that it evaluates the process of the two people in interaction. It does not focus on the individuals within the process, but rather what occurs between them. It is the quality of this process which determines the degree to which an individual may experience the good life, that is, the sense of togetherness within the relationship. The tool has five subscales: mutual openness, joint embedding context, non-manipulative negotiating, joint confirmation, and non-evaluativeness.

To use the scale at least two observers, who have done in depth training to understand the theoretical concepts underpinning the scale, watch a video segment of two people in interaction or dialogue in a familiar situation. Once observers are achieving at least 70% agreement with other observers on practice videos, they are ready to rate actual videos. The S-DMM uses a consensus coding approach involving dialogue between the two observers to reach agreement about the ratings. However, interrater reliability can still be calculated by each observer prior to the consensus rating procedure. This is a key advantage of this tool. It creates an opportunity to test agreement between observers, but not at the expense of gaining greater insight into the processes involved in the interaction between the two in the video being rated.

One of the limitations of the S-DMM, as with all the tools discussed in this section, is the need for those using these tools to have a sound knowledge of the theory underpinning the tool. Interestingly, Hostyn et al. (2009) state there would be value in the interaction partner of the person with a disability being one of the observers. However, it would take considerable time to train them in the concepts and constructs evaluated by the tool. This issue is examined further in chapter seven.

It is important to note that each of the five frameworks considered have arisen from, and employ the use of, video analysis within their development and implementation. This highlights the value and necessity of the use of video to analyse interactions with the aim of better understanding what is occurring in these complex, nonverbal, nonsymbolic exchanges.

Each of these frameworks also has a strong emphasis on the key features of quality interaction which are documented in the literature on human communication development. These key features of quality interactions are included in measures of the efficacy of interventions. While these intervention approaches have been found to be effective (Chen et al., 2007; Janssen et al., 2003a) and to endure to some extent (Janssen, Riksen-Walraven, & van Dijk, 2004), there is no research into their efficacy in adult residential services for people with congenital deafblindness. In addition, they are limited in their scope and do not contemplate some of the issues raised by Ehrlich (2007), such as balancing the needs of individuals and those of the employing organisation, which will impact on the nature of interactions.

The intervention approaches described by Janssen et al. (2003a) and Chen et al. (2007) are developmentally oriented, strengths-based models which could potentially be used in adult services. However, there are a number of other issues in adult services which are not well addressed in the literature. To achieve enduring, long-term, positive outcomes for adults with congenital deafblindness, these issues need to be addressed prior to initiating interventions previously used successfully with children with congenital deafblindness.

In presenting ways in which the good life can be operationalised using the quality of life construct and human communication development theory it is apparent that a number of key issues are not addressed in the literature. As discussed above, a strong emphasis on the pivotal quality of life domains of social interaction and personal relationships is justified. Yet these domains are interconnected with, and will influence and be influenced by, other quality of life domains. For this reason, it is erroneous to claim a person's quality of life has been improved due to a positive change in their interactions if only tools which focus on interactions are used. However, as stated earlier, it is not clear whether quality of life measures will be sensitive enough to detect the subtle changes resulting from intervention. I therefore argue that an approach is required that uses both the broad quality of life construct together with a method specifically designed to evaluate interaction. Only by combining these two ways of operationalising the good life can we learn more about the strengths and limitations of the tools currently available to measure the impact of interventions designed to enhance opportunities for adults with congenital deafblindness to experience the good life.

The remainder of this chapter highlights a number of other issues not well addressed in the literature about the experiences of adults with congenital deafblindness. These also require consideration in determining the most useful evaluation strategies.

What is currently known about interactions with people with congenital deafblindness

Now that some potential ways to operationalise and measure opportunities for experiencing the good life have been explored, past and current tools and methods used to study the situation of people with congenital deafblindness will be examined. An historical perspective is provided to situate current research in the context that has shaped thinking in this area. The history of services and intervention in the field of congenital deafblindness is also relevant. Due to the lag between research and practice, some outdated thinking still pervades current practices.

Historical perspective

Apart from being a low incidence disability, another reason why so little is known about the experiences of people with congenital deafblindness is that there are no records of people with congenital deafblindness prior to the 1950s. Before then only children who acquired deafblindness, such as Helen Keller, were educated (Enerstvedt, 1996). Up until the 1980s the primary goal of educators of children with deafblindness was to teach them symbolic communication skills. These resembled those of sighted and hearing people, such as sign language and use of pictures and objects (Hart, 2006). This emphasis on symbolism of the dominant culture remains strong in the disability sector in Australia. It is still common to read recommendations in communication assessments which focus on the use of symbols rather than on the more interactive approaches which are emerging from the research literature.

After years of very limited success in teaching children with deafblindness to express themselves using symbols of the dominant culture, and with the development of technology to video record human interactions, scientist practitioners began to look at human communication development in a new way. Van Dijk (1966) raised the issue that inadequate attention was paid to the developmental stages before symbolism as early as 1966. But it was not until the late 1980s that publications about nonsymbolic communication were produced. These included a pamphlet on Augmented Mothering (the original name given to Intensive Interaction) (Caldwell (2006), and Siegel–Causey's and Guess' (1989) book on nonsymbolic communication. In the 1990s Nind and Hewett described and expanded on an approach they named Intensive Interaction (Nind & Hewett, 1994). Nafstad and Rodbroe proposed a Co-creating Communication framework to better understand optimal conditions for developing the communication skills of people with congenital deafblindness (Nafstad & Rodbroe, 1999) (mentioned above). Chen and Haney (1995) also published an early intervention model for children who are deafblind. It drew on the principles of contingent responding and mutual, reciprocal and pleasurable interactions described in the infant development literature.

Daelman, Nafstad, and Rodbroe (1993), and Preisler (2005) point out that what is basic developmentally seems to remain basic throughout life. This means research on early human development is very useful for scientist practitioners working with people with developmental disabilities. However, despite the call to increase the emphasis on developmentally appropriate communication and intervention informed by developmental theory, outdated thinking about age appropriateness (cf. Forster, 2010) and the principles of normalisation theory (cf. Wolfensberger, 2000) persist.

As mentioned above, there is some lag in evidence-based research being implemented in practice. The current trend in intervention with people with congenital deafblindness has shifted from an emphasis on symbolism to more developmentally oriented interactive approaches grounded in theory on human communication development. Given this, what do we know about what is currently occurring for adults with congenital deafblindness in their adult–adult interactions?

What is currently known about interactions with adults with congenital deafblindness?

Very few studies investigate interactions with adults with congenital deafblindness; most of those that do are single case designs. Despite some methodological limitations, including in being able to generalise findings, these studies help reveal the issues facing adults with congenital deafblindness and their communication partners relative to those of children. The following is a brief summary and analysis of some of these studies.

Similar to studies of child–parent and child–educator interactions, Romer and Shoenberg (1991) found staff initiated by far the majority of interactions, that these interactions were infrequent and brief in duration, and that opportunities for interaction were missed by staff. Their study is one of the very few which investigates interactions between staff and residents of a residential service specifically for people with deafblindness.

Ehrlich (2007), Hart (2001), and Nyling (2003) all look at interactions with just one adult with congenital deafblindness. Ehrlich (2007) and Hart (2001) with just one communication partner, and Nyling (2003) with a staff team. While all had a slightly different focus in their research aims, each consistently states the importance of sustained interactions with skilled partners and the staff's familiarity with the adults and their communicative behaviours. This is consistent with Reinders' (2010) assertion that a high-quality relationship between staff and client is imperative for professional knowledge. Of particular interest is Ehlich's (2007) observation about the tension between staff meeting the needs of the individual while at the same time meeting those of the organisation for which they work. This was also noted by Forster and Iacono (2008). The broader issues which influence staff and their relationships with the people they support are not well understood or documented, and require investigation to better understand staff behaviours.

Ehrlich (2007), Hart (2001) and Nyling (2003) all raise issues specific to working with adults with congenital deafblindness. These include the challenge for staff to work in a developmentally appropriate way in light of the shift in emphasis away from age appropriateness in interactions (cf. Forster, 2010). Working with adults who have become passive due to extinction of earlier communicative behaviours from lack of experience and opportunities to learn and develop these skills is also a problem. These potential issues must be taken into account if an intervention approach applied to children with congenital deafblindness is to be extrapolated to an adult setting.

What is currently known about interactions with children with congenital deafblindness?

Nafsted and Rodbroe (1999), Chen and Haney (1995), Chen et al. (2007), Janssen et al. (2003a), Senses Foundation (2000), and Hart (2006) all offer strategies and techniques for interacting with people with congenital deafblindness in a way most likely to foster and enhance opportunities for high-quality interactions, or the good life. All of these authors have drawn on the work of researchers in the field of human communication development, including the frameworks discussed above.

There is now growing agreement about the need for interventions aimed at enhancing communicative interactions with people with congenital deafblindness. The elements of these interventions include attunement, contingent responding, mutuality and reciprocity. Current researchers are discovering that these elements are lacking in the interactions with people with congenital deafblindness (see Hart, 2010; Preisler, 2005; Romer & Schoenberg, 1991; Vervloed et al., 2006).

Nevertheless, the predominant assumption that underpins intervention studies with people with deafblindness is that interactions will be improved and enhanced by training the interaction partner/s of the person with deafblindness. They do not consider the broader social framework within which the interactions are occurring. They also assume that addressing the knowledge and skills of the communication partner is the key to changing the interaction. Studies investigating interactions with people with congenital deafblindness are increasingly taking into account the social validity of the research, that is, the willingness of participants to be involved and the need to involve participants in setting goals (e.g., Janssen et al., 2003a). However, there is an underlying assumption that the participants agree there is a problem that needs solving. Willingly being involved in research and enjoying the process does not inherently imply that the participants agreed there was a problem to begin with, or that they fully agree with the solution they are being taught.

Differences for adults with congenital deafblindness

The majority of studies in this area have involved children and adolescents with deafblindness. Some authors report that the strategies and techniques used with children who are deafblind are equally applicable to adults with congenital deafblindness (e.g., Daelman et al., 2004; Nafstad & Rodbroe, 1997, 1999; Rodbroe & Janssen, 2006b; Senses Foundation, 2000). While the strategies and approaches these authors suggest may be relevant and applicable to adults with congenital deafblindness, there are a number of factors which make the situation for adults with congenital deafblindness different from that of children with congenital deafblindness. These are discussed below. It is important to consider these differences before applying the communication principles used with children to maximise the potential for sustainable positive outcomes.

There may be potential differences in the expectations of the communication partners of children and adults. Certainly more rapid development resulting from intervention with children might be expected compared to adults due to maturation effects. However, it is also likely that previously learnt skills may be uncovered when working with adults with congenital deafblindness. Ehrlich (2007) acknowledges that it may be the case with adults who are deafblind that low-functioning cues get lost and are not seen anymore, probably due to deprivation caused by nonappropriate support in the past. These potential differences in the expectations of communication partners are not well addressed or documented in the literature and require further investigation.

Nyling (2003) notes that children with congenital deafblindness are often more inspiring as many of the adults tend to be rather passive due to their lack of experiences with interaction. Nyling (2003) also acknowledges that communication partners’ intuition in interaction and communication is less reliable with adults with congenital deafblindness. It may easily become affected by the discrepancy between developmental age and chronological age. This assertion of Nyling's (2003) seems well founded and reasonable. However, there is little evidence in the research available to support it. As mentioned above, prevailing attitudes about normalisation and age appropriateness may influence service providers' behaviours. Unfortunately there is a dearth of information to inform us about what actually does influence the behaviour of interaction partners of people with congenital deafblindness. Like Nyling (2003) we can make well informed, reasonable guesses, but this is not sufficient to guide practice. Considerably more work is required to better understand what influences the behaviours of communication partners to best influence these behaviours for positive outcomes in interaction.

Janssen (2009) points out some of the additional challenges facing the interaction partners of adults with congenital deafblindness as substantial challenging behaviours and passivity. Again, there is no research in the field of deafblindness which helps us to understand how these behaviours in adults influence their interactions with others.

A final but important difference between the interactions of children with congenital deafblindness and those of adults with congenital deafblindness is the nature of their interaction partners. In investigating the good life and how it might be operationalised for adults with congenital deafblindness, it is of key importance to gain a greater understanding of what is currently occurring for them in interactions with others. It is common for adults with profound intellectual and multiple disabilities to have little or no contact with their families. For many, disability support workers are the people with whom they interact most (Forster & Iacono, 2008; Golden & Reese, 1996; McVilly & Parmenter, 2006). While there is less evidence available to support the case that adults with congenital deafblindness also have limited interaction with people other than disability support workers, they do form a subgroup of people with profound intellectual and multiple disabilities (Meuwese-Jongejeugd et al., 2008). Others who do not have a profound intellectual disability still share services and experience similarities in communication issues impacting on relationships with others.

While strategies used with children with congenital deafblindness are often applicable to adults with congenital deafblindness, the staff working in adult disability settings are rarely adequately trained in the use of these. Anecdotal evidence suggests that adults with congenital deafblindness often lose, or stop using, communication skills they learnt at school when they move to community residential units and day services. This is because few staff are familiar with sign language and even fewer with tactile signing methods. It would also be expected that parents and educators have much more interest, motivation and training in responding to children with congenital deafblindness than the disability support workers in residential and day program settings who are the primary communication partners of adults with congenital deafblindness. In Australia most states have specific services for children with deafblindness; these services are less common for adults (M. Prain, 2005; Ward, 1994).

Given that disability support workers are in many cases the primary interaction partners of adults with congenital deafblindness, they will to a large extent, if not solely, be the mediators of these adults' experience of the good life. For this reason, their reports on what occurs during their interactions with adults with congenital deafblindness is of vital importance. This perspective departs from dominant methodologies in investigating interactions with this group. The possible effects of the different dynamics inherent in these relationships are yet to be investigated (Parker, Davidson, & Banda, 2007).

This chapter has focused on the relationship between scientist practitioners and people with congenital deafblindness and those with profound intellectual and multiple disabilities. The chapter examined the theory underpinning current intervention approaches and gaps which remain in our understanding of the situation for adults with congenital deafblindness.

The following chapter looks at what is understood about staff–client interactions and the perspectives of the staff who work with people who communicate nonsymbolically. It highlights what is known to be working well in enhancing staff–client interactions to optimise opportunities to experience the good life, as well as some limitations and areas which require further investigation.

Ehrlich (2007) states "during my investigations I continuously recognised the gap between dedicated attention to an individual's needs and the fulfilment of organizational and financial requirements" (Ehrlich, 2007, p. 5). These issues are discussed further in the following chapter and in chapter seven.

Chapter Three: Disability support workers

As has already been established, one of the key differences between children and adults with congenital deafblindness is the nature of their primary communication partners: parents and educators for children, and disability support workers for adults. Given the very limited research investigating interactions between disability support workers and adults with congenital deafblindness, we can gain important and relevant information from the literature on interactions between disability support workers and adults with profound intellectual and multiple disabilities. As noted in chapter one, in Australia often the same organisations and staff provide services to both adults with congenital deafblindness and those with profound intellectual and multiple disabilities (M. Prain, 2005; Ward, 1994). Similar issues, such as missed opportunities for communication, low and infrequent levels of interaction (e.g., Finlay, Antaki, Walton, & Stribling, 2008; Romer & Schoenberg, 1991), and high staff turnover (Hall & Hall, 2002; Hewitt & Larsen, 2007) are experienced by both populations.

This chapter focuses on the relationships, or more specifically the interactions, which form the basis of relating between people who communicate nonsymbolically and the disability support workers who mediate their support. It also explores the relationship between scientist practitioners and disability support workers, in particular, how scientist practitioners have come to understand the situation for disability support workers.

Current understandings about interactions between disability support workers and adults who communicate through nonsymbolic means are discussed. In particular, how this information has been generated. Most of the literature in this field arises from the premise that there is a problem with the nature of the interactions between staff and clients, so generally the literature consists of intervention studies aimed at improving staff–client interactions. This information will help determine what strategies have proven most effective in enhancing opportunities to experience the good life and the limitations of these interventions.

The chapter also examines how the efficacy and outcomes of these interventions have been measured. The majority of research in this field has been largely directed from the perspective of scientist practitioners. The chapter concludes by exploring what is currently known about the perspectives of disability support workers on their interactions with adults with profound intellectual and multiple disabilities. These perspectives might help develop our understanding of the best way to enhance opportunities for nonsymbolic communicators to experience the good life and how best to evaluate these.

What is currently known about interactions and how has this knowledge been generated?

In order to pursue opportunities for adults with congenital deafblindness to experience the good life there is value in examining strategies which have been trialled with people who also communicate nonsymbolically. The efficacy of these interventions also needs to be examined. This will assist in determining the key features of interventions which might be applied to the situation for adults with congenital deafblindness.

In an attempt to address the apparent mismatch between staff–client communication and the associated low levels and poor quality of client engagement in meaningful and rewarding activity, the efficacy of a variety of intervention approaches, used over the past three decades, has been investigated. As noted in the previous chapter, it was not until the 1980s that more developmentally oriented approaches to intervention were introduced. What follows is a summary of the research investigating different staff training and development foci, and models aimed at enhancing improved interactions between staff and people with profound intellectual and multiple disabilities. Methodological issues and gaps in current knowledge are highlighted. These findings are then discussed in terms of what we know and what we need to know in order to provide quality support to adults with congenital deafblindness. It must be noted that the following is not an exhaustive list of intervention strategies used with adults who communicate nonsymbolically and there is an emphasis on evidence based practices currently being employed in Victoria, Australia

Overview of intervention strategies

Participative management, supervision, observational approaches and training

Studies dating back to the late 1980s and early 1990s demonstrate recognition by scientist practitioners of the need to involve disability support workers in the formulation of intervention processes. Burgio, Whitman and Reid (1983) and

Rasing and Duker (1992) used a participative management model in which staff set their own intervention goals. In the study conducted by Burgio et al. (1983) staff rated themselves on the achievement of their goals. This approach was found to be effective in increasing staff–client interactions, reducing inappropriate client behaviours, and was viewed as acceptable to staff. Like many intervention studies, this study provided no information about the endurance or sustainability of these intervention effects. While the authors report that this approach was acceptable to staff, the investigation was initiated by scientist practitioners rather than disability support workers. It is unclear what the staff's perception of the situation was prior to the intervention. This indeed is true for all the intervention studies reviewed here and is discussed later in the chapter. It should be noted that in both these studies the participants with disabilities were children. Nevertheless, the studies are of relevance in so far as the staff who participated were residential care workers.

Specific approaches to the supervision of staff have also been found to be effective in changing staff behaviour. Seys and Duker (1986) did not involve staff to the same level as Burgio et al. (1983) and Rasing and Duker (1992). Seys and Duker (1986) found increased staff–client interactions through the use of a targeted supervision approach. Dyer, Schwartz and Luce (1984) adopted a similar supervision approach to increasing age appropriateness of client activities. They found a pyramidal supervision approach to be effective in terms of cost and in changing staff behaviour. However, this study did not address the endurance or sustainability of the approach. Nevertheless, there is value in looking at the intervention process in this instance rather than the intervention goal.

Another limitation of these studies, as Seys and Duker (1986) point out, is that there was no measure or evidence of changes to client outcomes resulting from the changed staff behaviour. Van Oorsouw, Embregts, Bosman and Jahoda (2009) reviewed studies involving staff training. They found that it was more common to measure changes in staff behaviours than changes in client behaviours. This raises concerns about these evaluation tools given these interventions aim to impact positively on at least some domains of the clients' quality of life.

Some studies evaluate changes to both staff and client behaviours. They give a better indication of whether changes in staff behaviour have an impact on the clients, and if so in what way. Clegg et al. (1991a; 1991b) examine the effects on client behaviour resulting from changing staff behaviour. The intervention applied asked staff to spend 10 minutes in interaction with one client. Clegg et al. (1991a) found that people with profound intellectual and multiple disabilities responded positively to being talked to about one third of the time. Their most likely response to being talked to was neutral or a lack of response. Correlations have been found between habituation and the frequency at which mothers touched and looked at their child (Riksen-Walraven, 1978). This could help explain the low level of client response in the study done by Clegg et al. (1991a), but this requires further investigation. Clegg et al. (1991b) coded staff and client behaviours during the application of a variety of interaction strategies. They found the most frequent positive client responses occurred in response to being talked to and social games.

Most research about interactions between adults who communicate symbolically and the staff who support them evaluates the efficacy of different intervention strategies. There are some studies, though, that are more exploratory in nature. For example, Duker et al. (1989) looked at the impact of client behaviours on staff behaviours and some correlations were found. Based on their findings, Duker et al. (1989) recommended that intervention should focus on increasing ambulatory and looking behaviours, and decreasing stereotypic behaviours in clients in order to improve staff responses.

Their study highlights the marked shift in the philosophy underpinning work with people with profound intellectual and multiple disabilities which has occurred over the past 20 years. Duker et al. (1989) recommended interventions which would make the clients more appealing to staff by, for example, reducing stereotypic behaviours. In contrast, the current interactive and dialogical approaches value and respect any behaviours as potential bases for interaction and points of connection. However, as mentioned earlier, there is value in being aware of past attitudes and approaches to intervention. Due to lags between research and practice, these attitudes and practices often persist.

Many intervention studies aimed at enhancing the quality of life of adults who communicate nonsymbolically involve some degree of training for the staff who support these adults. However, there remains limited evidence that training alone improves staff performance. It is also not yet clear what the key elements of effective training are. Van Oorsouw, Embregts, Bosman and Jahoda (2009), in their meta-analysis of training for staff working with people with intellectual disabilities, provide valuable insights and considerations for running effective training. These include: a) in-service training combined with on-the-job coaching is more effective than either one in isolation; b) in-service training should vary in technique, for example, providing literature, instruction, video demonstration and modelling; and c) verbal feedback is important to achieve better outcomes both for in-service training and on-the-job coaching. They also note there is a lack of clarity around how best to evaluate the efficacy of training. Currently, mostly client outcome variables are measured rather than long-term staff behaviour change. This highlights a change from other studies discussed in this chapter which focused more heavily on staff behaviours than client behaviours in their evaluations. Based on what has been presented, clearly an optimal evaluation would include both, and address the sustainability of the outcomes.

Of key relevance to this investigation are two intervention approaches that typically evaluate both staff and client behaviours in their outcome measures. These two systematic, evidence-based approaches to increasing client engagement and interactions between clients and staff are Active Support and Intensive Interaction. These approaches are examined here in some detail as they have become increasingly popular in the past decade and are being implemented in organisations which provide services to adults with congenital deafblindness in Australia. Video Interaction Guidance techniques are also discussed. These are a newer set of approaches to encouraging positive interactions, which have only very recently been applied in the disability context. They show good potential as a sustainable approach to intervention.

Active Support

Active Support is “a package of procedures which includes activity planning, support planning and training on providing effective assistance” (Jones et al., 1999, p. 164). Increasingly, studies are finding that Active Support increases the meaningful engagement of adults with intellectual disabilities, including those with severe and profound intellectual disabilities (e.g., Jones et al., 1999; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; Riches et al., 2011; Stancliffe, Harman, Toogood, & McVilly, 2007). Stancliffe et al. (2007) claim that *staff help* consistently results in and maintains the engagement of residents. This is relevant to the current study as staff help necessarily involves interactions and shared experiences upon which opportunities to experience the good life can be founded. Another outcome of Active Support reported in the research literature is that the effectiveness of Active Support is independent of a client’s level of adaptive behaviour (Stancliffe et al., 2007). This suggests its potential value for promoting opportunities to experience the good life for adults with congenital deafblindness and those with profound intellectual and multiple disabilities.

Jones et al. (1999) found that implementing Active Support did not increase levels of social engagement for the adults with intellectual disabilities in their study. This is of particular interest and relevance to this thesis. Of some concern in evaluating the efficacy of Active Support as an intervention is the construct of *meaningful engagement*. The judgement about what constitutes meaningful activity has typically been made by scientist practitioners without consultation with individuals with intellectual disabilities, their families, or the staff who support them.

Despite these potential limitations, proponents of Active Support have developed tools to evaluate the efficacy of implementing an Active Support program. These could potentially be used to examine opportunities for adults with congenital deafblindness to experience the good life. These tools have a number of advantages over some of the evaluation tools mentioned earlier in this chapter, and over those designed for use with children mentioned in the previous chapter. For example, the coding tool devised by Jones et al. (1999) to evaluate the efficacy of Active Support has established interrater reliability. It examines both client and staff behaviours, and has been used in adult residential settings with clients with severe intellectual disabilities.

Intensive Interaction

“Intensive Interaction is an approach to teaching and spending time with people with learning difficulties which is aimed specifically at developing the most fundamental social and communication abilities” (Nind, 1999, p. 96). It is an intervention approach specifically designed for people with profound intellectual and multiple disabilities. It has also been applied to people on the autism spectrum. Like Active Support, Intensive Interaction is becoming increasingly popular as a whole-of-service approach to increasing client engagement and interaction. As presented in the previous chapter, the theoretical foundations of Intensive Interaction are very similar to intervention approaches with people with congenital deafblindness and draw largely on infant communication development theories. However, unlike research into interactions with people with congenital deafblindness, there is considerably more literature available on the implementation and efficacy of Intensive Interaction programs in settings where staff support adults with profound intellectual and multiple disabilities. This research can provide valuable insights to progress work with adults with congenital deafblindness.

Studies investigating the efficacy of Intensive Interaction have found increased observable discrete behaviours related to interactive ability. These include: eye gaze, bodily orientation to partner, proximity to partner, emotional valence and joint focus (Kellett & Nind, 2003a, 2003b; Leaning & Watson, 2006; Zeedyk, Caldwell, & Davies, 2009).

One of the key issues raised by researchers investigating the outcomes of Intensive Interaction, which can help inform research with adults with congenital deafblindness, is the importance of reflective practice. “Reflection is vital to sustaining as well as improving our interaction practice” (Kellett & Nind, 2003b, p. 52). Such a professional activity could inform or suggest a useful research methodology in which participants might be asked to consider and interpret their practice. Reflective practice is an important component of supervision (Carroll, 2010), lending support to approaches that used targeted supervision as an intervention strategy. Reflective practice could and should be considered as both a potential research method for data creation, as well as an intervention strategy.

Similarly, Nind and Hewett (1994) emphasise the importance of staff sharing their experiences with each other and being mindful of pitfalls, such as being too passive, not moving on, forcing an agenda, boredom, tasklessness, and issues around age appropriateness. These topics may be important to consider during supervision or other reflective practices. Certainly, they are not well addressed in the current research literature, but warrant further investigation.

Of particular bearing to the pursuit of opportunities for the good life for adults with congenital deafblindness is Sandford's (2011) presentation of literature linking positive psychology and Intensive Interaction. She argues:

> a review of the (above) literature suggests that positive psychology can offer a number of valuable insights and questions that could usefully be explored in relation to Intensive Interaction, most especially the concept of flow and the emphasis on strengths (Sandford, 2011, p. 4).

The concept of flow was developed by Csikszentmihalyi and can be described as the moments when we *lose track of time* by being engaged and absorbed in something which poses the right degree of challenge to our level of ability (Sandford, 2011).

Similarly, Harding and Berry (2009) highlight the consistencies between Intensive Interaction and three major schools of psychological thought: humanistic psychology, attachment theory, and positive psychology. They argue that “these approaches share a core tenet that positive human relationships are crucial to our sense of self-worth, ability to realise our potential and our psychological well-being” (Harding & Berry, 2009, p. 758). Clearly, the principles of Intensive Interaction are compelling when considering ways to address the good life for adults with congenital deafblindness and those with profound intellectual and multiple disabilities.

Notwithstanding this, despite the many studies reporting positive effects of Intensive Interaction “there still appears to be a number of philosophical, practical and organisational barriers to sustained approach adoption” (Firth et al., 2008, p. 11). These issues are discussed further below.

Video Interaction Guidance and Marte Meo

Marte Meo, meaning “on one’s own strength”, is an approach which identifies and fosters skills to enable positive interactions and development (Aarts, 2008). Marte Meo employs Video Interaction Guidance, a process whereby the clinician and interaction partner review edited videos of naturally occurring interactions. They describe what is occurring on the screen, how the person with the need for development is getting their needs met, and why this is occurring. The Marte Meo intervention method is associated with an approach to coping based on empowerment (Vik & Hafting, 2009).

Reviewing videos of naturally occurring interactions is becoming increasingly popular as an approach to intervention. Marte Meo shares this strategy with a number of other approaches. These include: Video-feedback Intervention to promote Positive Parenting (see Groeneveld, Vermeer, Van Ijzendoorn, & Linting, 2011), Video Interaction Guidance (see Kennedy & Sked, 2008) used with people with congenital deafblindness, and interaction guidance with video analysis (see Martens, van de Ven, & Janssen, 2003; Snow & Telling, 2011).

There is relatively limited research investigating the efficacy of the Marte Meo approach. Studies that have employed it report improved interactions between the following groups: mothers with post-natal depression and their infants (Vik & Braten, 2009), families newly caring for internationally adopted children (Osterman & Moller, 2010), and Aboriginal mothers and their young children (Lee, Griffiths, Glossop, & Eapen, 2010). It has also been effective with children who display externalising behaviour problems in a school setting (Axberg, Hansson, Broberg, & Wertberg, 2006).

Of key interest are the assertions of Snow and Telling (2011). They note that some of the reasons for the success of video analysis are: its applicability in different environments, the way staff are supported to become active independent learners, and the limited paper work involved. These points relate specifically to staff working with adults with congenital deafblindness. However, these assertions require further research to better understand staff perspectives and possible other benefits of this approach.

Certainly these approaches are consistent with the principles of reflective practice and targeted supervision, mentioned above, as worthwhile when discussing Intensive Interaction. Indeed Video Interaction Guidance does not preclude the use of other approaches and could readily be incorporated into Active Support or Intensive Interaction processes.

Outcome measures

The above discussion touched on outcome measures that are associated with a variety of intervention strategies. This section examines typically used outcome measures in more detail. In particular, those used to determine the efficacy of interventions designed to improve interactions, or opportunities to experience the good life. There is general agreement in the literature around the need to increase and enhance the quantity and quality of interactions between disability support workers and the nonverbal adults they support (see Clegg et al., 1991a, 1991b; Finlay et al., 2008; Golden & Reese, 1996; Healy & Noonan Walsh, 2007; Jones et al., 1999; Romer & Schoenberg, 1991). These authors have reached their conclusions through observational studies using a variety of coding tools to measure behaviours. These include: initiations of interaction (Finlay et al., 2008; Romer & Schoenberg, 1991), positive behaviours (e.g., smiling, eye contact) and negative behaviours (e.g., self-stimulation) (Clegg et al., 1991a; Golden & Reese, 1996).

Clegg et al. (1991a) note that the broad coding categories used in their study limit what is revealed by it. They point out that simple systems are more likely to generate robust reproducible findings. In another study, these authors note the decrease in reliability of observations of adults with limited physical movements and those with vision impairments (Clegg et al., 1991b). This is of particular relevance to investigations of the interactions of adults with congenital deafblindness, as all will have vision impairments and associated idiosyncratic behaviours, increasing the challenge of achieving inter-observer reliability.

A variety of intervention strategies and approaches have been outlined above. Prior to trialling these interventions on adults with congenital deafblindness, there is a need to establish the validity and reliability of the outcome measures used to evaluate their effectiveness. Outcome measures for interventions in related populations have typically included levels of participant behaviours, such as eye contact, smiling, self-stimulation (Leaning & Watson, 2006); vocalisations, active engagement (Firth et al., 2008; Forster & Iacono, 2008); and staff engagement with residents (Forster & Iacono, 2008). Behaviour states, such as asleep, drowsy, awake–active, have also been used as outcome measures (e.g., Foreman, Arthur-Kelly, & Pascoe, 2007). Outcomes are commonly measured using direct observation and video recordings (e.g., Firth et al., 2008; Forster & Iacono, 2008; Leaning & Watson, 2006).

This variety of outcome measures highlights the importance of including measures that take into account both the nature of staff and client behaviours, and the frequency and duration of these behaviours. As well as establishing the reliability of outcome measures, there is also a need to involve disability support workers in determining what exactly is being measured and what would be considered a positive outcome.

There is a major issue inherent in improving and enhancing the quality and quantity of interactions between staff and adult clients through training. A number of researchers have recognised the importance of involving staff in the development of intervention goals and strategies. However, the researchers proceed with the premise that there is a problem that requires intervention without first gaining greater insight into how the staff perceive the current situation. All of the research cited above on what occurs in interactions between staff and clients, and the efficacy of intervention approaches, employed purely quantitative methods. This research fails to address or examine what is occurring from the perspective of the staff involved in the interactions.

Staff perspectives

Staff play a key role as interaction partners and mediators of the life experiences of people with profound intellectual and multiple disabilities, and those with congenital deafblindness. Yet their perspectives are largely lacking from the research in which they are involved, as is their view on the relative need for intervention. A number of studies assess staff satisfaction with the process (e.g., Burgio et al., 1983; Firth et al., 2008; Janssen et al., 2003a; Riches et al., 2011). However, they do not involve staff from the outset in the design of the research.

Much of the research into communication and interactions with people with congenital deafblindness has been about educators by educators (e.g., Amaral, 2003; Bruce, 2002; Janssen et al., 2004). Educators will inherently bring a different lens to the situation. They have worked in the role themselves and thus have a sound understanding of the context. The disability support workers who mediate the support of adults with congenital deafblindness are rarely the people who are undertaking the research. As mentioned, this is a major limitation of most of the research undertaken to date. Ehrlich’s (2007) study is one of the few where a disability support worker undertook the research. Her study indicated there were issues for staff in balancing the needs of clients and the organisation. It also discussed the difficulty for staff in administering assessment tools which require a thorough knowledge of the theory underpinning them. These issues are not well addressed in most current approaches to intervention.

A number of studies have demonstrated the efficacy of certain intervention approaches, but they have rarely involved staff in the establishment phases of the research process. There also remain issues in the long-term efficacy of approaches, particularly due to the high turnover of staff (Hall & Hall, 2002; Hewitt & Larsen, 2007), but also due to initiative decay (cf.Buchanan, Claydon, & Doyle, 1999). This occurred in the study of Firth et al. (2008) that implemented Intensive Interaction in a residential service for adults with profound intellectual and multiple disabilities.

Clegg et al. (1991a) raise the issue that staff in their study were not asked about the perception of their roles or their interactions with clients. They contend that this type of research is needed. Maes et al. (2007) similarly argue the need to involve staff as informants in research into quality of life enhancing strategies for adults with profound intellectual and multiple disabilities.

The dominant methodological approach to investigating interactions between staff and adults with profound intellectual and multiple disabilities is multiple, single case experimental design, using an observational coding tool. This is similar to research into interactions between people with congenital deafblindness and their interaction partners. In more recent years an increasing variety of research designs and methods are being employed.

Greater insights into staff perspectives are beginning to emerge with an increase in the use of qualitative research methods. As interest in, and use of, qualitative research methods has grown (Creswell, 2009), researchers investigating interactions with people with profound intellectual and multiple disabilities are increasingly using interviews as a data collection method. This enables them to gain greater insights into staff–client interactions (e.g., Forster & Iacono, 2008; Healy & Noonan Walsh, 2007; Koski, Martikainen, Burakoff, & Launonen, 2010). Koski et al. (2010) interviewed staff pre- and post-training to gain an understanding of the impact of training from the staff's perspectives. Healey and Noonan Walsh (2007) and Koski et al. (2010) interviewed staff about communicating with people with profound intellectual and multiple disabilities. They found gaps in staff's knowledge about what staff believed was important when communicating with the people they support and how they actually communicated. Overall, the researchers identified an inconsistency between the strategies used by staff to communicate and the communicative needs of the clients they supported. This is also reflected in the study by Firth et al. (2008) which indicated inconsistency between staff reports and researcher observations. These findings suggest the need for further development of intervention strategies, but they do not elucidate the best method of intervention.

Hart (2006) speculates that a mismatch in the modalities of communication between two partners might have a more significant effect on development than the sensory impairment itself. As presented in the literature above, there is increasing evidence that such mismatches in modalities of communication are common in interactions between staff and adults with congenital deafblindness, and those with profound intellectual and multiple disabilities. While much of the intervention in this area has tried to target these mismatches, little has been done to address the mismatch between what staff report and what researchers observe.

The information that is available on staff's perspectives highlights the value in seeking their views. It offers new and varied insights into the current situation for adults with profound intellectual and multiple disabilities and congenital deafblindness. For example, Forster and Iacono (2008) found that communicating in the preferred way of a person with profound intellectual and multiple disabilities was of importance to staff. However, this communication style was perceived by staff as conflicting with the policy and preferred practices of their employing organisation. This is consistent with Ehrlich's (2007) claims that staff struggle to balance the needs of clients and those of the organisation. Age appropriate communication in particular was raised as an issue. This is consistent with Nyling's (2003) assertion that working in a developmentally appropriate way is challenging for disability support workers who support adults. Forster and Iacono's (2008) study provides more valuable insight into why this may be (the perception that it is in conflict with organisational policy and practices). However, further research is required in this area to better understand the perspectives and motivations of staff with regard to interacting with adults in a developmentally appropriate way.

Interestingly, only those studies which utilised multiple methods of data creation found discrepancies between reports from staff in interviews and researcher observations, highlighting a key issue for research and practice. The methods of data collection included: participant observation using a coding tool combined with staff interviews (e.g,. Healy & Noonan Walsh, 2007), or staff interviews combined with researchers' informal observations and log trail (e.g., Firth et al., 2008). The discrepancy between the views of staff and researchers needs to be reconciled before sustainable positive outcomes can be achieved for adults with congenital deafblindness and those with profound intellectual and multiple disabilities. In contrast, McVilly's (1997) survey of staff needs took a quantitative approach to involving staff as informants. Staff rated as *high* their need for training in management of inappropriate behaviour, and in communication skills. Most rated their job readiness as *low*. McVilly's (1997) study demonstrates the potential value in using quantitative approaches to better understand staff perspectives. Nevertheless, quantitative methods necessarily limit the information gained. They also risk missing new insights not yet considered by the researcher, which qualitative methods are more likely to achieve.

Indeed, the studies that are discussed above which employed qualitative and mixed methods have yielded new information that may provide further insights into why intervention effects do not necessarily endure. The issue of long-term efficacy and sustainability of intervention is of key concern to me after years of observing strategies which were working well, but were abandoned after staff turnover. The intervention approaches employed to date do not adequately address the need for their positive outcomes to be sustained. In order to address this issue of sustainability a broader examination of the factors influencing staff–client interaction is required. The following section summarises some key issues which need to be considered when designing interventions if they are to achieve sustainable positive outcomes.

Issues to be considered when designing interventions

In examining the good life for adults with congenital deafblindness I have established the importance of gaining a greater understanding of the perspectives of disability support workers. However, to better appreciate these perspectives, there is also value in understanding the broader context in which disability support workers are operating. The literature presented so far points to the need for change, yet to facilitate long-term sustainable change there is a need to understand the history and current factors shaping the sector.

Hewitt and Larsen (2007) highlight a number of key issues for the disability sector. These are: recruitment and high turnover of staff; low wages; the need for training; staff burnout; and the need for staff supervision. All of these issues impact on service users. These are also all long-term issues which have changed little over time and essentially are the result of a lack of financial investment by government into the sector.

With regard to recruitment, Hall and Hall (2002) point out the inconsistencies from management about what characteristics are desirable in direct support staff. They conclude with a recommendation to better evaluate staff values and attitudes prior to hiring them. Given the difficulty in hiring staff in the first instance due to the low wages relative to the high demands of the role (Hewitt & Larsen, 2007), it is extremely difficult for organisations to be selective and only hire staff with a high level of alignment in their values and attitudes. There is a clear need to develop cultures of practice within organisations in which new staff can be indoctrinated.

Adults with congenital deafblindness and profound intellectual and multiple disabilities are served by the broader, much larger disability sector and are thus impacted by generalist policies and approaches. “In a way, the rhetoric of the right of participation and full citizenship might lead to limitations, instead of enlargement, of freedom of choice for these individuals and their families” (Nakken & Vlaskamp, 2007, p. 84). Of key concern is the current emphasis on community inclusion and community capacity building. *The Victorian State Disability Plan* (State Government of Victoria, 2002) posits that inclusive communities are places where people can participate in all aspects of community life. While there is nothing intrinsically wrong with this statement, problems occur in the interpretation of such statements when applied to people with profound intellectual and multiple disabilities, including those with congenital deafblindness. The primary issue is that the term *community* is understood as a place. If a person with a disability is present in a public space, such as a café, swimming pool or gymnasium, the implication is that they have then had an experience of being in the community. A number of authors argue community is an experience and not a place (Caldwell, 2007; J. S. Reinders, 2002). It is troubling that these experiences of being in the community could be exchanged for, or valued over, actual experiences of community or social connectedness or togetherness as a result of policy directives. Yet “these disconnections between policy visions and stakeholder expectations persist” (Bigby, Wilson, Balandin, & Stancliffe, 2011, p. 173). Indeed this issue with public policy is acknowledged by Johnson, Walmsley and Wolfe (2010). These authors propose that ideas of belonging and relationship-building may be more tangible than those of community and inclusion in the pursuit of a good life for people with intellectual disabilities.

This backdrop of a poorly resourced sector governed by broad governmental and organisational policies which do not necessarily address issues faced by smaller subgroups of people with disabilities should be considered in the design of quality enhancing interventions (cf. Productivity Commission, 2011). To ignore them is to most likely limit the long-term efficacy and sustainability of the approach.

The past two chapters have highlighted some of the limitations in the research conducted to date with regard to enhancing the quality of life of adults with congenital deafblindness and those with profound intellectual and multiple disabilities. I have focused specifically on research aimed at enhancing opportunities for these adults to experience the good life and how this might be evaluated. A summary of the key issues is set out below.

1. There is a lack of information as to whether the tools designed to evaluate quality of life are sensitive enough to detect changes resulting from intervention which would increase opportunities to experience the good life. In particular, there is a paucity of data that relates to the domains of quality of life which consider personal relationships and social inclusion.
2. There is a lack of tools developed specifically for adults which take into consideration differences in their needs relative to those of children.
3. There is limited information about what is currently occurring in interactions between adults with congenital deafblindness and the disability support workers who mediate their support.

4. There is a lack of information from the perspective of disability support workers on what is occurring in these interactions.
5. There is a paucity of intervention tools which adequately address the broad variety of factors influencing staff–client interactions in order to achieve more sustainable outcomes.

The following chapter explores in more detail the methodological issues associated with research with adults with congenital deafblindness. Drawing on all of this information and my own experiences and perspectives as a scientist practitioner, I present the key questions to be addressed by this study and provide an overview of the design of the study.

Chapter Four: Research design

Researchers have a responsibility to ensure the methodological integrity of their research, which includes explicitly stating the factors that shaped and influenced the research design. This chapter outlines my own orientation as a scientist practitioner and the factors that have contributed to my perspective. It reviews the methodological issues associated with the research topic from philosophical and pragmatic points of view. I then outline the rationale for the methodology I selected in light of the factors that shaped my understanding of the research topic. Ethical and practical issues relating to investigations involving participants with congenital deafblindness are also discussed. The chapter concludes with an overview of the research aims and methodology adopted.

It is important to note that the placement of research aims and questions in this chapter is intentionally unorthodox. The reader requires background information to understand how the research aims and questions were derived. Therefore, the research aims and questions are presented toward the end of the chapter under the heading: Design of the study.

My perspective as researcher

In order to evaluate the trustworthiness of research, researchers must declare their philosophical position and ensure that the methods selected produce data that satisfactorily explain the issues in question. I approached the current investigation having qualified with a bachelor’s degree in speech pathology, and having specialised in work with people with deafblindness for the past 15 years. The questions raised in this study are influenced by my clinical experience and how it has informed my understanding of the best way to provide appropriate support to disability support workers and in turn adults with congenital deafblindness.

Given my perspective has largely been shaped by my experiences as a clinician, it is important to understand the clinical research paradigm. Miller and Crabtree (2000) suggest a number of strategies for clinical research as opposed to biomedical research. These assume transformation is grounded in experience rather than being rational, and that research participants must actively engage in methods if they are to take them up. This necessitates employing research methods which diverge from the quantitative methods traditionally used in biomedical research. In order to join the evidence-based medicine space, clinical researchers need to collaborate across disciplines; use multiple methods, bridging metaphors and theories; and often emphasise participatory and advocacy-based approaches (Miller & Crabtree, 2000). “Research designs in clinical research inherently require multimethod thinking, or critical multiplism, with the particular combinations of data gathering, analysis and interpretation approaches being driven by the research question and the clinical context” (Miller & Crabtree, 2000, p. 619).

The original aim of this investigation was to identify interventions that enhance the quality of life of adults with congenital deafblindness with an emphasis on the quality of life domains of social inclusion and personal relationships. I originally intended to undertake an intervention study given the positive results being achieved using interventions designed specifically for children with congenital deafblindness. However, on reflection, I was not satisfied that the tools available were adequate or appropriate to detect or evaluate change in the quality of life of an adult with congenital deafblindness as the result of targeted intervention. These issues were highlighted in relation to possible ways of operationalising the good life in chapter two. I was also dissatisfied with the way in which disability support workers have been involved in research to date. I suspected that this issue was related to the poor endurance and sustainability of intervention outcomes that I have witnessed. For these reasons, the current study was exploratory in nature in order to gain greater and deeper insights into what is currently occurring for adults with congenital deafblindness in their interactions with staff, and the factors potentially influencing these interactions. Several other factors with regard to the nature of congenital deafblindness also influenced and shaped the research design. These issues need to be fully presented as they substantially influenced the methodology ultimately selected.

Methodological issues

Why research this group?

The number of people with deafblindness is low relative to other disability groups. However, the impact of dual sensory impairment on an individual’s wellbeing is pervasive. In addition, many of the interventions and strategies developed and applied to this group are relevant to other disability groups who experience complex communication issues. These include people with profound intellectual and multiple disabilities, autism, and dementia. It should be noted that “the number of individuals with fragile health and a combination of profound disabilities is increasing in the developed world as a result of advanced medical care, efforts of parents, and availability of facilities for education and living” (Nakken & Vlaskamp, 2007, p. 83). Better understanding the needs of, and issues facing, people with deafblindness can also benefit these other groups, which are increasing in number. The experiences of these groups are also largely mediated through paid staff, either disability support workers or nursing home staff. A sound understanding of the needs of these individuals will inform professional development for both direct support staff and other professionals involved in the lives of people with complex communication needs.

How the nature of congenital deafblindness influences the selection of research methodologies

In gaining a greater understanding of the current situation and the needs of adults with congenital deafblindness, it is important to examine where they are located in the broader disability research context. This helps to explain why little is currently known about this group. It also explains why methodologies considered to give the highest level of scientific evidence, that is, randomised control trials (cf. National Health and Medical Research Council, 1998, 2009) are not only challenging to achieve with this population but also not necessarily appropriate. “Good social science is problem driven and not methodology driven in the sense that it employs those methods that for a given problematic, best help answer the research questions at hand” (Flyvbjerg, 2006, p. 242).

The fact that deafblindness is a low incidence disability impacts on the nature of research with this group. Within the broader disability context, the field of deafblindness is relatively small. Estimates based on demographic studies in the Nordic countries during the 1970s, and more recently in Denmark in 2003, state that there will be 200 people with deafblindness per million in developed countries, and about one fifth of these people will have congenital deafblindness (Rodbroe & Janssen, 2006a). It remains extremely difficult in Australia to determine numbers of people with deafblindness. A 2005 study revealed only a very small percentage to be receiving services relative to the numbers estimated in the population. This is largely due to the lack of ability of service and government databases to adequately record dual sensory impairment (M. Prain, 2005). Only 0.2% of government funded disability service users (i.e., 322 people) were recorded as having a primary disability of deafblindness in Australia in 2008-09 (Australian Institute of Health and Wellfare, 2011). Robertson and Emerson (2010) estimate that 212 per 100,000 of the general population in the United Kingdom have severe impairments of both hearing and vision, rising to 806 per 100,000 by 2030. Robertson and Emerson (2010) used multiple population-based national surveys to estimate prevalence. While these data bases arguably provided large, well constructed samples on which to base the estimates, they were limited in that they typically relied on self-report of disability. There was therefore no guarantee of diagnostic integrity in the samples. The only possible solution to this would be to conduct large scale screening studies. In Australia, the relatively small size of the population of people with congenital deafblindness influences the resources available to conduct such studies with the desired precision. The issue of determining accurate numbers of people with deafblindness in itself highlights the low incidence of this disability, which in turn impacts on research. This is because it is difficult to locate large samples in one geographic location, necessarily limiting the nature of research options for this population.

People with congenital deafblindness within the context of deafblindness

When developing an understanding of the specific needs of people who are deafblind, there is a distinction between those who were born deafblind and those who acquire deafblindness later in life. The latter group, those with acquired deafblindness, account for about 80% of the deafblind population (Rodbroe & Janssen, 2006a). Though presenting with a dual sensory impairment, they typically display age appropriate cognitive and communicative functioning due to the delayed onset of their dual sensory impairment (Rönnberg & Borg, 2001). People with congenital deafblindness display more complex developmental issues and have greater support needs arising from their dual sensory impairment from birth (Rönnberg & Borg, 2001). Of particular concern are the major difficulties experienced by individuals with congenital deafblindness in acquiring communication skills, together with their relatively low level of interpersonal and social engagement (Pierangelo & Giuliani, 2007).

The paucity of research concerning adults with congenital deafblindness therefore emerges in the context of these persons being a minority group within an already small population of people with deafblindness. Furthermore, the developmental and associated communication difficulties experienced by this group, coupled with their idiosyncratic behavioural presentations, further confounds the selection of appropriate research methodologies. Adults with congenital deafblindness who communicate nonsymbolically cannot participate in research which requires them to work directly with the scientist practitioner providing information in either quantitative (e.g., surveys) or qualitative (e.g., interviews) forms.

Why is little known about the experiences of adults with congenital deafblindness?

Understanding why little is known about the experiences of adults with congenital deafblindness also highlights some key methodological issues in relation to research with this group. There are three likely explanations for the limited research into interactions with adults with congenital deafblindness.

1. The heterogeneity of people with deafblindness means it is difficult to find a group of individuals similar enough to apply a single and coherent intervention strategy to (Chen & Haney, 1995). This heterogeneity results from different levels of vision and hearing impairment, combined with different levels of physical and cognitive ability, depending on additional and associated disabilities. Typically, deafblind people require individualised interventions that do not lend themselves readily to large scale evaluation. Subsequently, many studies of people with congenital deafblindness utilise single case designs (Parker et al., 2007). While such studies can generate important insights to inform our understanding of the needs of such people

and meta analyses of multiple single case designs can lend weight to their findings, generalisation of findings by statistical inference is not possible.

2. There are specific education settings and services for children with congenital deafblindness, but this is rarely the case for adults. In Australia there are limited accommodation options for adults with deafblindness and no day services specifically for adults with deafblindness (M. Prain, 2005; Ward, 1994). People with deafblindness are therefore dispersed in the general population and among service settings. This fact complicates recruitment and the conduct of research. It also vitiates the implementation of comparable support and intervention programs. Mackintosh (2001) investigated an intervention strategy for adults with multiple disabilities, including a sensory impairment, living in community residences. She found that the travel between research participants limited her involvement with the intervention, thus limiting the research project.

3. While some adults with congenital deafblindness develop symbolic communication skills, many do not and rely on others to interpret their idiosyncratic behaviours. For this reason, many people with congenital deafblindness are not able to self-report about their experiences, so researchers are dependent on proxy reports from people who know the individuals with congenital deafblindness well. This, as discussed in chapter two, poses challenges around validity, as well as raising additional practical and ethical issues when working with this group.

As discussed in chapter three, disability support workers are in many instances the people who adults with congenital deafblindness interact with the most, and who know these adults best. However, due to high staff turnover in this industry in Australia (Productivity Commission, 2011, p. 703), those who know the adults with congenital deafblindness best may have only known them for a short fraction of their life span.

Issues around observing and recording idiosyncratic behaviours

At Deafblind International conferences people presenting papers on the communication of people with congenital deafblindness often show a video and interpret the behaviour of the person with deafblindness in the video. Frequently, one or more people will raise their hands to dispute the interpretation of the behaviour and suggest an alternative meaning behind the behaviour.

There are means within observation studies to minimise observer bias and maximise the objectivity of observers. For example Janssen et al. (2004) trained observers until 80% interobserver agreement was reached for all target behaviours during three sessions per participant prior to data collection. In order to control for observer drift and bias, observers were kept naïve as to the experimental hypothesis. In addition, before each observation session, the observers read the response definition. The observers were also not given feedback on the reliability of their scoring. However, one of the issues with quantitative measures is that they do not allow for alternative explanations beyond the coding schedule being used in the study. Thus they potentially limit new learning about the nature of communication and interaction of people with deafblindness.

Typically used methodologies in researching interactions with people with congenital deafblindness

As mentioned above, due to the heterogeneity and low incidence of people with congenital deafblindness there are very limited scientific investigations involving this population. The most common approach to research in this field has been single subject experimental design. Parker et al. (2007) identified 54 single subject studies with participants who are deafblind. The scope of the review covered the years from 1965 to 2006. The earliest study which met the authors' criteria was published in 1969 and most studies employed quantitative research methods.

However, qualitative methods are starting to be employed in research with people with congenital deafblindness (e.g., Hart, 2010; Martens, 2007; Preisler, 2005). Interestingly, most of these studies examine the communicative nature, meaning and purpose of body language and gestures. This adds an important contribution to knowledge about interacting with people who are deafblind. But it is very much from the perspective of scientist practitioners, supported by literature and theory around communication development. There remains almost no information from the perspective of those who spend most time interacting with adults with congenital deafblindness, namely disability support workers.

Some researchers have included social validity measures in their studies. This addresses one of the issues raised by Maes et al. (2007) that those trained in the intervention processes are not consulted about the processes. Chen, Klein and Haney (2007) reported on parent feedback following their involvement in the Promoting Learning through Active Interaction (PLAI) program. And Janssen et al. (2004) undertook several measures to ensure the educators and parents involved in their study would accept and commit to the intervention program. During their study, educators were repeatedly consulted before, during, and after the intervention. They were also involved in: the selection of target behaviours and intervention situations, adapting the interaction context, and defining the intervention aims. An adapted social validity scale was used to assess the satisfaction of the educators with: the intervention procedure, the results, the observation procedure, the manual, and the experimental design. However, the participants in these studies were not involved in selecting or creating the coding tool to be used and thus had no input into what was considered important to measure or evaluate with regard to the intervention aims.

“Because of the low incidence of deafblindness a cross section of practitioners, researchers, consumers, and families must collaborate to create a mosaic of evidence based approaches for education and rehabilitation” (Parker et al., 2007, p. 697). I would include disability support workers as having a key role to play in both informing researchers and research.

Additional methodological issues

One of the difficulties with research investigating issues for people with congenital deafblindness is the lack of tools with which to conduct reliable observations. In particular, tools with the capacity to take into account the complexities of the behaviours exhibited by adults with congenital deafblindness. Increasing numbers of studies are finding that quality of life and indices of pleasure can be observed with reasonable validity and reliability for those with complex communication needs (Green & Reid, 1996; Lyons, 2005; Petry & Maes, 2006). Despite this, significant methodological challenges remain in the measurement of quality of life for people with profound intellectual and multiple disabilities, and those with congenital deafblindness. A particular challenge is determining whether changes to quality of life have occurred as a result of quality of life enhancing interventions, as discussed in chapter two. Maes, Lambrechts, Hostyn and Petry (2007) reviewed studies investigating the efficacy of quality of life enhancing interventions for people with profound intellectual and multiple disabilities. Their review highlights a number of key methodological issues with current research in this area. Namely: sample sizes tend to be small; interobserver scores for most studies are acceptable but they are moderate and variable; there is often no control group; and some authors report wide variation in outcome between clients. In addition, some studies do not demonstrate maintenance, a key concern given the high turnover of staff in this sector, discussed in the previous chapter.

A number of additional concerns were raised in the literature and do not appear to have been satisfactorily addressed in any of the studies reviewed for this thesis. These concerns are: a lack of focus on determining the best conditions for implementing quality enhancing strategies (e.g., organisational supports, staff development strategies, location); a lack of consultation with the staff trained to implement the quality enhancing strategies as to whether the objectives of the intervention were clear; more fundamentally, the need to ask staff whether the objectives of the intervention were compatible with their values and vision; and whether the intervention attunes to staff priorities.

The selection of a methodology must of course be informed by its established validity and its practical application to the research question. The nature of the participants and the context in which the research is to be conducted can also influence the approach to the research and the selection of a methodology, or combination of methodologies. The following section addresses these issues in relation to the current research topic.

Design of the study

Research aims and questions

The impetus for this study emerged from my experiences over the past 15 years working with disability support workers to further develop the communication skills of adults with congenital deafblindness in order to improve their quality of life. The original aim of this study was to identify interventions which improve and enhance the quality of life of adults with congenital deafblindness with specific emphasis on the quality of life domains of social inclusion and personal relationships. These domains are the most relevant to an individual’s experience of the good life. (See chapter two for an explanation of the quality of life construct and why these domains are of pivotal importance in evaluating the quality of life of adults with congenital deafblindness). However, the specific aims of the study changed. This was because of a number of factors that influenced the aim, objectives and design of this study. These factors included:

- extremely limited information about the current experiences of adults with congenital deafblindness
- a paucity of tools with which to evaluate the efficacy of interventions which consider the quality of life construct
- the perspectives of the primary communication partners of adults with congenital deafblindness are lacking in the literature and it is unclear whether current interventions are consistent with their needs and values
- adults with congenital deafblindness are a very small heterogeneous group
- adults with congenital deafblindness, for the most part, are unable to self-report about their experiences.

For these reasons, considerably more information was required. It was therefore necessary to adjust the aim to reflect the need for additional information prior to commencing intervention. Thus the aim of this study was to investigate Reinders’ (2002) construct of the good life in relation to adults with congenital deafblindness and, more specifically, the issues set out below.

Research Aims

- To investigate what is currently occurring in interactions between adults with congenital deafblindness living in community residences and the staff who mediate their support. (Interactions, as stated in chapter two, provide the vehicle through which opportunities to experience the good life can occur.)
- To gain a deeper understanding of the factors influencing these interactions.
- To gain a deeper understanding of factors which would contribute to determining the most philosophically and methodologically sound and effective method for evaluating these interactions.

At the outset of this investigation I had planned to conduct an intervention study. In the initial phase, while reviewing the literature, I was searching for a measurement tool which I could use to generate baseline data. Given the dearth of tools used with adults with congenital deafblindness to evaluate their interactions, the coding tool devised by Jones et al. (1999) was selected. While it was designed to evaluate active engagement, it was also designed to determine the frequency, duration and nature of staff : client interactions, including documentation of instances of 'social engagement'. It has a number of features that address many of the issues I have discussed in earlier chapters.

- It has established validity and reliability, and has been used successfully in an Australian context (Stancliffe et al., 2007).

- It is an objective measure removing the need for proxy reports.
- It has been used in adult residential settings with adults who communicate nonverbally.
- Its theoretical underpinnings are less abstract and academic than those tools grounded in human communication development theory outlined in chapter two. This makes the tool potentially more accessible to disability support workers.
- It examines the behaviours of both staff and clients.
- It specifically identifies *social interaction* as a behavioural code, thus potentially indicating frequency of opportunities for adults with congenital deafblindness to experience the good life.

The coding tool devised by Jones et al. (1999) was selected in order to address the following research questions in line with the research aims stated above.

Research questions – phase one

1. Is the coding tool designed by Jones et al. (1999) equally useful and reliable for observing the interactions of a different but similar population, namely adults with congenital deafblindness?
2. What is the form and frequency of interactions between adults with congenital deafblindness and the staff who mediate their support?
3. Are the form and frequency of interactions between adults with congenital deafblindness and the staff who support them similar to those between adults with severe intellectual disabilities and the staff who support them? This question arises out of the fact that there is very limited information

about the form and frequency of interactions between disability support workers and the people who adults with congenital deafblindness share services with in Australia, namely adults with severe intellectual disabilities.

As stated, I had originally intended to undertake an intervention study. The results from the first phase of the study, paired with my clinical experience, fuelled the need to explore the situation further. This phase yielded more questions I felt needed to be addressed in order to better understand what was required of an intervention strategy that would be sustainable. Typically used quantitative methods were not appropriate to address the nature of the questions raised in chapter three, and that also arose from the first phase of the study.

Therefore, the second phase of the investigation, which used qualitative methods, addressed the following research questions.

Research questions – phase two

1. What are the perspectives of staff on their interactions with adults with congenital deafblindness?
2. How do accounts by staff of their interactions with adults with congenital deafblindness contribute to an understanding of the interactions observed in quantitative studies? How might this information influence intervention approaches aiming to facilitate opportunities to experience the good life?

Use of mixed methods

Given the scarcity of information about what occurs in the interactions of adults with congenital deafblindness and how best to examine them, a mixed method approach was deemed most valuable to address the research questions. Mixed method designs employ both quantitative and qualitative research methods in varying sequences or concurrently. In the current study, a qualitative methodology was used to better understand and build upon the findings of the initial quantitative phase of the study.

The strategy of inquiry employed in this investigation is best described as the concurrent triangulation strategy outlined by Creswell (2009). The data were generated in two distinct phases, that is, sequentially rather than concurrently. The two data sets were compared to determine convergence, difference, or a combination of both, which is typical of the concurrent triangulation strategy. The mixing of the qualitative and quantitative methods occurs at the level of interpretation, at which point the two data sets need to be transformed in order to be in a state in which they can be compared.

The concurrent triangulation strategy was chosen to offset the limitations of one method with the strengths of the other. However, this strategy has its own limitations. It requires considerable effort and expertise to adequately investigate a phenomenon with two separate methods. It can also be difficult comparing analyses of data of two different forms. In addition, there is potential difficulty in dealing with discrepancies that may arise when comparing the data (Creswell, 2009).

The method used in the quantitative phase of the study was observation using the quantitative coding tool devised by Jones et al. (1999). The qualitative method used in phase two was interview combined with researcher's log trail. These methods are described in more detail in subsequent chapters. The remainder of this chapter outlines the ethics procedure that governed the two phases of the study. The sampling method used to recruit participants in the investigation and the setting where the study took place is discussed. More detailed descriptions of the participants are provided in chapters five and six.

Ethics

Ethics approval was granted to undertake the study proposed in BSETAPP 66 – 07 PRAIN by the Royal Melbourne Institute of Technology University Human Research Ethics Committee (HREC) (see Appendix A.). The application was supported by the organisation where the participants with congenital deafblindness were provided with accommodation support and where the disability support workers were employed. A discussion about the ethical issues arising during the study and how these were addressed is included at the end of chapter six.

Participants

Participants in this study were selected using a typical case sampling approach; one of the purposive sampling strategies usually used for qualitative research outlined by Patton (2002). As is common in research with people with congenital deafblindness, the sample was taken from the researcher's place of work. While this is a relatively common practice, its merits and limitations are rarely discussed. Issues associated with immersion of researcher in the context of the phenomenon being researched, and researcher bias, are examined in the discussion of consensus coding in the following chapter.

Two houses (residential services owned and operated for people with multiple disabilities) were selected to increase the potential number of participants. It was limited to two due to time constraints around data collection and analysis. The two houses were specifically for adults with congenital deafblindness; the adults living in these two houses communicated predominantly through nonverbal means. In Australia, there are extremely few accommodation services specifically for adults with congenital deafblindness, with services operating in only four of the eight states and territories. These services do not adequately meet the needs of the relevant populations (M. Prain, 2005).

The methodologies and results of the quantitative and qualitative phases of the study are presented in chapter five (quantitative) and chapter six (qualitative). These chapters conclude with key findings and recommendations arising from these discrete phases of the study. An integrated discussion of these findings, as well as implications, is provided in chapter seven.

Chapter Five: Phase one

The previous chapters presented information about what is currently understood about interactions between adults with congenital deafblindness and the staff who support them. I have discussed how this understanding has been determined by scientist practitioners to date, my own clinical experiences, and how these have shaped my understanding of the situation. It is the interaction between these bodies of knowledge and ways of knowing which gave rise to the first phase of this study.

This chapter presents the research aims, design, procedure, and results from the first phase of the study. The chapter discusses the results in light of the relevant literature and my own experiences and observations. It concludes with recommendations for future research, which includes a rationale for the second phase of the study. It should be noted that much of the content from this chapter is published in the articles “Observing the behaviour and interactions of adults with congenital deafblindness living in community residences” (M. Prain, McVilly, Ramcharan, Currie, & Reece, 2010) and “Being reliable: issues in determining the reliability and making sense of observations of adults with congenital deafblindness”. (M. Prain, McVilly, & Ramcharan, 2012a). However, the rationale for the second phase of the study is not presented in either of these articles.

Aims of phase one

The aims of the first phase of the study were to examine the topography of current interactions between adults with congenital deafblindness and their support staff, and to compare these with the interactions of adults with severe intellectual disabilities. A concurrent aim was to investigate the reliability of a coding system originally designed by Jones et al. (1999) for use in the observation of adults with severe intellectual disabilities when applied to adults with congenital deafblindness.

The coding system was selected for a number of reasons. First, the Jones et al. (1999) coding system had been specifically designed for use in observations involving adults with severe disabilities interacting with staff. This is in contrast to many other tools that have been designed with parent(mother)–infant interaction as their theoretical basis. Second, the items in the observation schedule reflected typical everyday activities for adults with severe and multiple disabilities in community residential settings. This was consistent with the context in which the observations were to be conducted. Third, the original tool had established validity and reliability, and these psychometric properties had been replicated in an Australian community residential service setting for adults with intellectual disabilities (Stancliffe, Harman, Toogood & McVilly, 2007). Finally, the use of the tool would enable meaningful comparisons to be made between the interactions of adults with congenital deafblindness and those with severe intellectual disabilities.

The research questions addressed by this first phase of the study are set out below.

1. Is the coding tool designed by Jones et al. (1999) useful and reliable for observing the interactions of adults with congenital deafblindness?
2. What is the form and frequency of interactions between adults with congenital deafblindness and the staff who mediate their support? In other words what are the current opportunities for adults with congenital deafblindness to experience the good life?
3. Are the form and frequency of interactions between adults with congenital deafblindness and the staff who support them similar to those between adults with severe intellectual disabilities and the staff who support them?

Design of phase one

This phase of the study was conducted as observational research in a naturalistic setting and involved a purposive sample. It was essentially exploratory, consistent with the research objective to ascertain the form and frequency of the interactions between adults with congenital deafblindness and the staff who mediate their support. A multiple, single case design was used, which is typical in deafblind research, due to the relatively small size of the potential participant population (Parker et al., 2007).

Ethics

As outlined in chapter four, this investigation was approved by the Royal Melbourne Institute of Technology University Human Research Ethics

Committee. Staff and legal guardians of the adults with congenital deafblindness were given statements in plain English that explained the research to be undertaken (see Appendix B). They were also given consent forms to be completed if they agreed to participate in the research. Issues related to consent are discussed in more detail later in this chapter.

Participants in phase one

Adults with congenital deafblindness

Nine adults with congenital deafblindness from two community residences in an Australian metropolitan setting participated in the first phase of the study: five from house one and four from house two. Three residents were male and six were female, aged between 22 and 44 years (*M* = 34.33 years, *SD* = 6.78 years). All participants had lived in the residences for at least 10 years and all satisfied the criteria for congenital deafblindness as described by Rodbroe & Janssen (2006a). Three also had diagnoses of cerebral palsy, one had an additional diagnosis of epilepsy, and one had both diagnoses of cerebral palsy and epilepsy. Deafblindness was defined in chapter one and it is generally agreed that a functional definition is of more use than a medical definition. For research purposes, however, there is value in having a greater understanding of the nature of the vision and hearing impairments of the research participants. The following provides some additional information about the participants in the current study.

The precise nature of the vision and hearing impairments varied among residents; all were reported in agency records to satisfy the criteria for having a hearing disability. The Australian Institute of Health and Welfare (2007) describes a hearing disability as encompassing deafness, hearing impairment and hearing loss. The World Health Organisation defines these terms in the following way:

> Deafness refers to the complete loss of hearing ability in one or two ears. Hearing impairment refers to both complete and partial loss of the ability to hear.
>
> There are two types of hearing impairment, according to which part of the ear is affected. Conductive hearing impairment is a problem in the outer or middle ear. It is often medically or surgically treatable. A common example is chronic middle ear infection. Sensorineural hearing impairment is a problem with the inner ear, or, occasionally with the hearing nerve. It is usually permanent and requires rehabilitation such as the use of a hearing aid. Sensorineural hearing impairment is commonly due to excessive noise, ageing and infectious diseases such as meningitis, measles rubella and mumps (World Health Organisation, 2012a).

Agency records also indicated that all participants satisfied the criteria for being legally blind. A person who is legally blind in Australia has a visual acuity of 6/60 or less, or a visual field of less than 10 degrees, or both (Retina Australia, 2009). The definition of legal blindness in Australia is consistent with the World Health Organisation's definition of *low vision* and *blindness*, which are as follows:

> There are four levels of visual function, according to the International Classification of Diseases – 10 (Update and Revision 2006):
>
> - normal vision
> - moderate visual impairment
> - severe visual impairment
> - blindness.
>
> Moderate visual impairment combined with severe visual impairment are grouped under the term “low vision”: low vision taken together with blindness represents all visual impairment (World Health Organisation, 2012b).

It should be noted that some people with moderate visual impairment may not satisfy the criteria for legal blindness in Australia.

Each of the participants with deafblindness was assessed using the Vineland Adaptive Behaviour Scales (Sparrow, Cicchetti, & Balla, 2005). Adaptive behaviour is defined by the authors of the Vineland Adaptive Behaviour Scales as the performance of daily activities required for personal and social sufficiency (Sparrow et al., 2005). All the participants with deafblindness scored low on adaptive level. A score of low on adaptive level is equivalent to a percentile rank range of 2 and below (Sparrow et al., 2005).

Speech pathology reports indicated that all residents were intentional communicators and used primarily nonsymbolic means for expressive communication (e.g., vocalisations, facial expression and body language). See Tables 1 and 2 for more detailed participant information.

Table 1: Participants with congenital deafblindness

House	Code	Gender	Age (years)	Hearing	Vision	Time in house	Ambulant	Additional disabilities	Adaptive level on the Vineland Adaptive Behaviour Scales
1	Belinda	female	34	impaired	blind	15+ years	Y	N/A	low
1	Belle	female	36	deaf	blind	15+ years	Y	cerebral palsy	low
1	Bonnie	female	38	deaf	blind	15+ years	N	N/A	low
1	Brett	male	28	severe neural deafness	blind	12+ years	N	cerebral palsy, epilepsy	low
1	Ben	male	22	deaf	impaired	10+ years	Y	cerebral palsy	low
2	Ada	female	42	profound hearing loss	no vision in L eye, functional vision in R eye	10+ years	Y	epilepsy	low
2	Annie	female	33	impaired	legally blind	10+ years	Y	N/A	low
2	Alison	female	32	impaired	impaired	10+ years	Y	cerebral palsy	low
2	Aaron	male	44	impaired	blind	10+ years	Y	N/A	low

Note. Information from agency records

Disability Support Workers:

Nine disability support workers participated in the first phase of the investigation: five in house one and four in house two. There were seven females and two males aged between 24 and 59 years (*M* = 34.33 years, *SD* = 14.36 years). Both males worked in house one. Eight staff had completed a national vocational qualification (a pretertiary, certificate level course); the other staff member was enrolled to complete the same course during the first phase of the study. The staff had worked with people with congenital deafblindness for an average of five years, 10 months (range = 22-154 months). See Table 2 for further information.

Table 2: Participants—disability support workers

House	Pseudonym	Gender	Age (years)	Qualifications	Experience with people with congenital deafblindness
1	Joe	male	30	Certificate IV in Disability Studies	8yrs
1	Jess	female	58	Studying Certificate IV in Disability Studies	1yr 10mths
1	Jane	female	29	Certificate IV in Disability Studies	1yr 10mths
1	James	male	24	Certificate IV in Disability Studies	4yrs 2mths
1	Jenny	female	37	Certificate IV in Disability Studies	12yrs 10mths
2	Christine	female	24	Certificate IV in Disability Studies	5yrs 3mths
2	Kate	female	24	Certificate IV in Disability Studies	5yrs 10mths
2	Carla	female	24	Certificate IV in Disability Studies	6yrs 2mths
2	Kim	female	59	Certificate IV in Disability Studies	6yrs 6mths

Note 1. Certificate IV in Disability Studies is an Australian National Vocational qualification
Note 2. Experience with congenital deafblindness—time staff had worked with individuals with deafblindness, not necessarily in current house.

Rationale for time and place of observations in phase one

Interactions with staff in the clients' homes rather than their day services or with their families were selected for analysis as the adults with deafblindness spend more time with the staff in their houses than any other person. Consequently, it was asserted that the residential staff would be best positioned to interact with the participants and report on their behaviours and support needs.

All the residents attend day services from approximately 9:00 a.m. to 3:00 p.m. Monday to Friday. Five of the nine adults with deafblindness have regular contact with their families, two have infrequent contact, and two have no contact, thus they have most interactions with staff who work in their homes.

Observers

Two observers coded the residents' behaviour, including any interactions they had with staff. Observer 1 was a qualified speech pathologist with over 10 years' experience working with people with deafblindness and observer 2 was a psychology honours student. Observer-rater training included two meetings with the whole research team. The research team in phase one of the study consisted of myself, my two PhD supervisors, and a graduate student. The observation codes were discussed in light of examples drawn from the initial time spent in the houses videoing. In addition, the two coders independently coded seven video segments and compared their results in discussion.

Materials

A JVC Everio hard disk camcorder was used to film the residents' behaviour and coding was conducted post hoc using the observation schedule devised by Jones et al. (1999). The resident behaviours in this tool were: social engagement, nonsocial engagement—domestic, nonsocial engagement—personal, nonsocial engagement—other, challenging behaviour, and disengagement (see Table 3a. for descriptions). Staff behaviours in the tool were: assistance, praise, restraint, other conversation, and processing (see Table 3b for descriptions). Disengagement was mutually exclusive of the social and nonsocial engagement codes. Each observer independently recorded behaviours defined in the coding system at every second of the 10-minute observation periods. Data were entered into a coding spreadsheet that broke the 10-minute sessions into one second intervals (or 600 seconds per observation). These data were subsequently analysed using the statistical software SPSS (IBM, 2008).

Table 3a: Observation codes for clients, adapted from Jones et al. (1999)

Social engagement	Comprised recognisable speech or attempts to speak, signs, gestures or other attempts to gain or retain the attention of another person (except by challenging behaviour), or the giving of attention, as evidenced by eye contact or orientation of the head, to another person who is reciprocally interacting.
Nonsocial engagement —domestic	Comprised getting ready for, doing, or clearing away, a household or gardening activity (e.g., washing clothes or setting the table).
Nonsocial engagement —personal	Comprised getting ready for, doing, or clearing away a self-help or personal activity (e.g., brushing teeth).
Nonsocial engagement —other	Comprised getting ready for, doing or clearing away a recreational activity (e.g., looking at a magazine) or educational activity, the content of which could not be coded under the two codes above (e.g., matching colours).
Challenging behaviour	Comprised self-injury, aggression to others, damage to property, stereotypy or other inappropriate behaviours (e.g., public masturbation, stripping, spitting, pica, tugging at someone or pestering/pushing/pulling a person).
Disengagement	Comprised all other behaviour (i.e., when not engaged socially, nonsocially or in challenging behaviour), including no activity, passively holding materials, walking/wandering outside of the context of an engagement activity, smoking and unpurposeful activity (e.g., manipulating materials to no apparent purpose, minor self-stimulation, talking quietly to self, fiddling with buttons or picking at clothing).

Table 3b: Observation codes for staff, adapted from Jones et al. (1999)

Assistance	Comprised explicit instruction to perform an activity (e.g., “pick up the spoon”), implicit instruction (e.g., questions about what step of the activity comes next) or presentation of materials in the context of an activity (e.g., handing a resident a towel to dry their hands), gestural prompting of an activity (e.g., pointing to the tin to be put in the cupboard), demonstration (e.g., showing the person what to do and then prompting him or her to do it), physical prompting or guidance (e.g., giving hand over hand guidance as a resident pours a cup of tea), guiding or arranging the materials being used by the resident in an activity (e.g., holding an item steady on a chopping board as a resident cuts it), or giving corrective feedback containing guidance or instruction.
Praise	Comprised verbal, gestural or physical praise (e.g., saying “Good!” or “That's right” or patting a resident on the back).
Restraint	Comprised physical or verbal disapproval without correction or physically preventing activity (e.g., saying “No”, holding a resident’s hands down or saying the resident's name in a controlling manner).
Conversation	Comprised all other interactions neither encouraging nor discouraging of activity (e.g., pleasantries).
Processing	Comprised doing something to a resident without assisting their participation (e.g., dressing a resident or holding a resident by the hand while walking).

Procedure

Consent

Given the complexity of the disability of participants and the extent of their support needs, consent was provided by guardians or family members who ordinarily acted in that capacity. Consent was also obtained for one resident who was not part of the study, but who could have inadvertently been filmed during data collection.

Participant observation

The decision to film staff–client interactions was made for two primary reasons.

1. Interactions between staff and adults with deafblindness are often tactile in nature involving positioning of body parts, movement and varying degrees of strength or force. Interactions can be fleeting and subtle and filming them allows the opportunity to replay the footage repeatedly to analyse in finer detail what is happening in the interaction.
2. Filming the interactions enables staff to observe them afterwards to stimulate their memory of the interaction and give the researcher further insight into what is happening in the interaction.

Each participant with congenital deafblindness was filmed in half-hour blocks on varied days and in random order, over three-hour filming periods, starting in the afternoon from approximately 3:00 p.m. This time period was selected as staff suggested it was the most active time in the house. This was also consistent with the observation times used by Jones et al. (1999). At the start of the study, each house was visited on two occasions in order for the researchers to meet the residents and staff, and allow them to become desensitised to having someone filming; the data collected during this time was not included in the analysis. During the filming, staff were instructed to interact with residents as they would ordinarily.

Filming took place in the shared areas within the homes (kitchen, dining room, lounge room, and outdoor area). Personal areas (bedroom, bathroom, and toilet) were not filmed, nor were any personal care routines (washing, toileting). Filming was not done in public or away from the home, and only occurred when two consenting staff members were working. This was in line with what had been approved by the Royal Melbourne Institute of Technology Human Research Ethics Committee.

Data analysis

Thirty-four 30-minute observations were recorded over eight days of filming. See Table 4 for distribution of the data across participants. Only one video for Ben was coded as he spent most of the time in his bedroom which was an unfilmed area. Some additional footage was discarded (*n* = 12) where the segments were less than 15 minutes long (i.e., a resident left a shared area), the lighting was too low, or if the camera positioning was inadequate. The 10-minute segments were taken from the 5- to 15-minute mark of the 30-minute observations. These time frames were selected to allow staff and residents a period of adjustment to the filming.

The initial observation periods to allow the participants time to become accustomed to being filmed also allowed the two observers who would code the videos an opportunity to observe the types of behaviours which were occurring and discuss how these would be coded. The coding schedule was discussed by the research team at length over two meetings to ensure the researchers were in agreement about how certain behaviours would be coded.

It must be noted it is recognised there are various ways of constructing reality. This is why the current program of research has employed a mixed method design, incorporating both quantitative and qualitative approaches. The first phase of the study employed a quantitative observational coding strategy. The limitations of this approach are discussed and ameliorated through the use of qualitative strategies employed in the second phase of the study.

Table 4: Number of times participants with deafblindness were filmed

Pseudonym	Number of times filmed
Belinda	4
Belle	6
Bonnie	6
Brett	7
Ben	1
Alison	2
Aaron	3
Annie	3
Ada	2
Total	**34**

Phase one results

Interrater reliability using percentage agreement

Percentage agreement does not address reliability in the strict psychometric sense of true score variance and error variance. It does, however, address the inconsistency of measurements that can be attributed to differences between observers (Cordes, 1994). Percentage agreement was initially calculated by taking the number of agreements between observers and dividing these by the sum of agreements and disagreements between observers, multiplied by 100. This is a method frequently used in behavioural research (Cordes, 1994; Watkins & Pacheco, 2000).

For the initial calculations, a random sample of seven videos from the 34, (approximately 20%) was used to calculate interrater reliability (or the percentage agreement between the two observers). Three different time intervals were used for observation to ascertain which gave the best result (highest percentage agreement). The time intervals used were: 1-second intervals across all codes observed concurrently; 2-second intervals across all codes observed concurrently; and 3-second intervals across all codes observed concurrently.

The highest level of agreement was attained for 1-second intervals (88%), compared to 2-second (87%) and 3-second (86%) intervals. All subsequent calculations were made using 1-second time intervals, that is, agreement was calculated for every second of the 600-second videos.

Examination of the individual resident and staff codes at 1-second intervals including every second observed, that is, occurrence and nonoccurrence of the behaviour, resulted in high percentage agreement scores. Two codes achieved perfect interrater reliability and all were above 90% (see Table 5).

However, the high level of agreement could have been accounted for by agreement on absence of occurrence of most staff and client behaviours. Sturmey's (2009) investigation of the interrater reliability of the Functional Analysis Checklist similarly resulted in inflated percentage agreement due to large levels of agreement about the nonoccurrence of particular items on the coding tool. For this reason, percentage agreement was then calculated for occurrence only. That is, only 1-second intervals, where at least one rater noted the occurrence of a behaviour, were included in the calculations. Again, agreement was divided by agreement plus disagreement and multiplied by 100. This method of analysis resulted in a notably different profile of percentage agreement for the observations. Using this method, only three behavioural codes had *acceptable levels* of agreement, that is, over 60%, with two behavioural codes having 0% agreement (see Table 5).

Finally, the potential impact on the results of disagreement resulting from slight variation in recording onset and end of behaviours between the two raters was investigated. The percentage agreement was calculated by comparing the total number of occurrences of each behaviour within the 600-second sample. This increased the percentage agreement for each code. But it did not change the interpretation of the results based on the criteria proposed by Watkins and Pacheco (2000) (i.e., achieving a result of 0.6 or 60% or greater) for any of the codes (see Table 5).

Of key interest is the substantial variation in results depending on how percentage agreement is calculated. Probable reasons for this variation and key considerations for future research are presented later in this chapter.

Table 5: Interrater reliability calculated using percentage agreement and Cohen's kappa

Behaviour code	Percentage Agreement			Cohen's kappa
	Occurrence and non occurrence second by second	Occurrence only second by second	Occurrence only number of occurrences across 600 seconds	
Client behaviours				
Disengagement	94.7	91.8	91.9	.89 (*p* .01)
Challenging behaviour	94.7	26.2	33.82	.41 (*p* .13)
Nonsocial domestic	100	100	100	1 (*p* < .001)
Nonsocial personal	99.4	83	84.25	.96 (*p* < .001)
Nonsocial other	95.6	12.3	12.33	.48 (*p* < .001)
Social	99.8	0	0	NA
Staff behaviours				
Assistance	99.1	22.7	45.3	.43 (*p* .001)
Processing	99.6	26.6	35	.46 (*p* .26)
Conversation	99.8	13.8	49	.28 (*p* .93)
Praise	100	100	100	NA
Restraint	99.9	0	10	<.01 (*p* .42)

The second observer, as part of her Psychology Honours thesis, calculated percentage agreement for just the original sample of seven videos (i.e., 20% of the videos available) used initially to determine which time interval resulted in the highest percentage agreement score. A comparison of the results from the total data set with the results of the sample of seven is shown in Table 6. While there is some evidence of concurrence between the findings based on the sample and those of the total data set (e.g., nonsocial—domestic and social), in most instances there are substantial discrepancies (e.g., nonsocial—other, processing, conversation, and praise).

Table 6: Comparison of percentage agreement results from total data set with sample from data set

Behaviour code	Percentage Agreement (occurrence only)	
	Total data set	Sample
Client behaviours		
Disengagement	91.8	70.7
Challenging behaviour	26.2	51.22
Non-social domestic	100	100
Non-social personal	83	94.96
Non-social other	12.3	N
Social	N	N
Staff behaviours		
Assistance	22.7	21.3
Processing	26.6	0
Conversation	13.8	N
Praise	100	N
Restraint	N	N

N = no behaviours coded

Interrater reliability using Cohen's kappa

Interrater reliability was also calculated using Cohen's kappa (Cohen, 1960). Cohen's kappa provides an estimate of agreement between two independent observers, taking into account levels of chance agreement (Portney & Watkins, 2000). It is important to note that out of the 34 video segments only kappa scores for behaviours coded within each video segment were calculated. If neither rater observed any instances of challenging behaviour during a particular video segment, the kappa for challenging behaviour for that video was not calculated.

While a total of 90 behaviours were recorded, kappa could only be calculated for 67 of these, as in 23 instances one of the variables was a constant. In such cases kappa can sometimes be calculated by adding weighted variables so that there are no constants. However, due to the extreme distribution of data, when this approach was tried even adding the weighted variables did not give sufficient variance in the data to calculate kappa. This was also the case for perfect agreement, instances of which were given a default kappa value of 1. See Table 5 for kappa values for the resident and staff behaviours.

It is suggested that a kappa value of 0.6 or higher is acceptable for observational research (Suen & Ary, 1989; Watkins & Pacheco, 2000). Therefore, the occurrence of disengagement, non-social-personal and non-social-domestic activities could be reliably distinguished. Kappa for resident behaviours coded as non-social-other and challenging behaviour fell below the criteria recommended. For staff behaviours, kappa values were all lower than 0.6, and so should be interpreted with caution. See Table 5 for a summary of kappa scores.

Resident and staff behaviour

While data from the two observers was used to calculate interrater reliability, only the data recorded by the first observer will be reported in this section of the results. Typically only a sample of the full data set is used to calculate interrater reliability, thus only data from one observer are used when reporting the topography of behaviours. In this instance, while two full data sets were available, given the high overall percentage agreement between the two observers, it was deemed reasonable to use only the primary researcher’s data set when looking at participant behaviours.

The most frequently observed resident behaviour was disengagement at 85%, followed by non-social-personal engagement at 13%, and challenging behaviour at nine percent. Challenging behaviour was often coded at the same time as other behaviours. This is why adding all the average percentages together did not achieve a sum of 100% of time observed. Total resident engagement (social engagement, non-social-personal/other/domestic engagement) was 15%.

Total staff engagement (assistance, restraint, praise, other, conversation, processing) accounted for less than two percent of the observations. Interactions between residents and staff were observed in only 10 out of the 34, 10-minute sessions (i.e., 30%). The most frequently observed staff behaviour during interactions was assistance (0.8% of total observed time), followed by processing (0.2% of total observed time). Praise was not observed in any session. See Tables 5, 7a and 7b and 9 for results summaries. See Appendix C for a sample of the data sheets.

Table 7a: Percentage of observation time (34 x 10-minute sessions) for each client observation code

Behaviour code	percentage of 20,400 seconds of observation time
Social engagement	0.27%
Nonsocial engagement—domestic	0.25%
Nonsocial engagement—personal	13.25%
Nonsocial engagement—other	0.82%
Challenging behaviour	9.45%
Disengagement	84.84%

Table 7b: Percentage of observation time (34 x 10-minute sessions) for each staff observation code

Behaviour code	percentage of 20,400 seconds of observation time
Assistance	0.79%
Praise	0%
Restraint	0.005%
Conversation	0.18%
Processing	0.21%
Total engagement with clients	1.19%

One of the aims of this study was to compare the engagement and interaction of adults with congenital deafblindness with their peers with severe intellectual disabilities with whom they often share services. Table 8 shows results from the current study compared with the results from the study conducted by Jones et al. (1999) using the same coding schedule. The different profiles of engagement between the participants in the current study and the research conducted by Jones et al. (1999) are discussed below.

Table 8: Comparison between current study and Jones et al. (1999) findings of percentage of observation time engaged in defined behaviours

Type of engagement	Current study	Jones et al. (1999)
Nonsocial engagement	14.29%	25.2%
Social interactions	1.19%	17.5%
Total engagement	15.19%	33.1%

Discussion

Aims of phase one

The following are the principal aims of phase one of the study.

1. To evaluate the utility of an existing observation coding system, previously used in relation to the experiences of adults with intellectual disabilities in community residences.
2. To document the topography of the behaviours and interactions of adults with congenital deafblindness.

Discussion relating to the first aim of phase one of the study

Interrater reliability

The utility of the Jones et al. (1999) tool was investigated in terms of interrater reliability. Interrater reliability was assessed using the coded data from two raters from different disciplines (speech pathology and psychology). Given the discrete nature of the observations, and the potential for difficulty observing these behaviours in the participant population, observations were video recorded.

Comparison between interrater reliability using percentage agreement and Cohen’s kappa

The results from phase one of this investigation, similar to Sturmey’s (2009) analysis of the reliability of the Functional Analysis Checklist, revealed inflated overall interrater reliability using percentage agreement. This was due to high levels of agreement about nonoccurrence of behaviours. Again, like Sturmey’s (2009) study, when interrater reliability was recalculated using occurrence only or Cohen’s kappa, the agreement between raters diminished markedly. There was a large variation in results between percentage agreement calculated using both occurrence and nonoccurrence of behaviours, and Cohen’s kappa, and marked high levels of agreement around nonoccurrence of behaviours. This signalled the need to calculate percentage agreement in other ways.

Reporting an interobserver percentage agreement figure is not sufficient in itself to establish the reliability of observational data (Cordes, 1994). Regardless of an overall percentage agreement figure, further analysis will always be required to best evaluate the reliability of a study. This is highlighted in this investigation by the broad variability in the results depending on the method used to calculate interobserver reliability.

While calculating percentage agreement using occurrences only, it was noted that one rater often perceived the onset of behaviour one second before or one second after the other observer. Notwithstanding this, there was general agreement between the two raters about an episode of a particular behaviour. For this reason, to take into account variation in perception of onset and ending of behaviour, percentage agreement was calculated using overall number of occurrences, rather than occurrences second by second. (See the section on analysis using percentage agreement.) While this approach did not increase the level of acceptability of the results of any of the behaviour codes (i.e., achieving a result above 0.6 or 60%), it did increase them all and potentially could alter the interpretation of results.

It should also be noted that several different ways of calculating kappa have been developed (Randolph, 2005). These variations have been proposed to address the paradox of apparent high levels of agreement in data, but comparatively poor kappa scores. These paradoxical results have been attributed to observer bias and the disproportionate use of particular observation codes, the latter phenomena being evident in the current data set.

Interrater reliability using Cohen's kappa was found to be variable from code to code. Three resident behaviours had very high levels of interrater reliability: disengagement, non-social-personal, and non-social-domestic. These three behavioural codes all achieved interrater reliability of > 0.89. The other two resident codes, and all staff codes, were < 0.48. Interrater reliability could be increased to an acceptable level by trimming off the first and last seconds of the staff-client interactions when using percentage agreement. Originally, the coding system was designed for use with adults with severe intellectual disabilities. These data suggest that the coding system also has some merit for observing and documenting the behaviours and interactions of adults with congenital deafblindness. However, inferences based on analysis of the interactions directly between staff and residents should be made with caution due to the comparatively low level of interrater reliability. It is anticipated that higher interrater reliability would be achieved with slight variations in the parameters of some codes, particularly challenging behaviour and non-social-other engagement. This is discussed later in this chapter.

Issues with sampling data

Most quantitative studies take a sample of results when calculating interrater reliability. The current study found that a sample of seven coded videos, approximately 20% of the data set, revealed different results to those achieved when all the data were taken into account. One behaviour observed in three videos was coded differently by each observer, substantially reducing the overall agreement. In the sample of seven videos, this particular behaviour was not observed at all by either observer, thus not providing an accurate reflection of the entire data set.

This first phase of the study raises questions around the construct validity, that is, the ability of a tool to measure an abstract concept or construct (Portney & Watkins, 2000). The coding tool originally devised by Jones et al. (1999) was found to have satisfactory reliability with both English and Australian populations of adults with severe intellectual disabilities (Jones et al., 1999; Stancliffe et al., 2007). The reasons this tool was used in the current study with adults with congenital deafblindness are set out earlier in this chapter. However, a number of issues were revealed when using the tool with a different population, which impacted on its reliability in the study.

Of particular concern was the client code disengagement and the staff codes assistance and processing. In three videos one client was seen briefly exploring and then casting toys from a box. These behaviours were consistent with the description in the coding tool of disengagement. However, one rater recognised the behaviour as being developmentally appropriate engagement and coded the behaviour as non-social-other. This significantly reduced the agreement between observers in these three videos. It is important to be mindful that data obtained from direct observation may depend as much on the behaviour of the observers as on the behaviour of the subjects (Cordes, 1994), as evidenced in the above example.

In addition, interactions between staff and clients are often tactile. Determining whether a staff member is fully acting upon (as in the code processing) or assisting the client can be more difficult with adults with congenital deafblindness than it is with adults with severe intellectual disabilities who can see and hear. There are three potential ways to address this issue. First, the criteria for each behaviour code could undergo modifications if the tool is to be used with a population who are deafblind. Second, more attention could be paid to these issues when training the observers. Third, a consensus coding approach could be taken. Consensus coding is discussed later in this chapter.

The issue with the construct validity of the codes in the tool also highlights the need to always calculate reliability code by code, rather than simply calculating global reliability. This is because problems can only be revealed by the code during code calculations (Cissna, Garvin, & Kennedy, 1990). Cordes (1994) also highlights the importance of evaluating both the reliability and validity of observational data to determine how meaningful and interpretable the results are. Cordes (1994) points out that two raters could score inaccurately and still show high agreement as they may both be inaccurate in the same way. There is no point to being reliable if the validity or underlying premise of what is being measured is flawed.

Potential benefits of consensus coding

In observational studies the better the description of target behaviour the better the observational data, but very specific behaviours require extensive observer training (Suen & Ary, 1989). For adults with profound intellectual and multiple disabilities, and those with congenital deafblindness, it can be difficult to train observers in the full range of an individual’s behaviours and what they might mean in different contexts. This poses challenges to adequately calibrating the observers in order to achieve acceptable levels of interobserver agreement.

As stated earlier, percentage agreement is commonly used to estimate inter-rater reliability in observational studies. However, when interpreting reports of percentage agreement of calculations it is often unclear what defined an opportunity for an agreement or how different judgements were compared. Consensus coding on the other hand may lead to an increased awareness of the extent and location of disagreements between observers, and even provide explanations and possible solutions to these disagreements (Cordes, 1994).

Consensus coding shows promise as a means of improving interobserver agreement. It also potentially provides an opportunity to gain greater insights and learning about the interactions of adults with idiosyncratic behaviours, such as those with congenital deafblindness. Roch (2006) investigated rating accuracy in the context of group rating and found the anticipation of group discussion and the process of reaching consensus positively influenced rating accuracy. Roch (2006) also posits that consensus may produce more valid results. In the current study, had the two observers had the opportunity to discuss the toy casting behaviour of one of the participants, the construct validity of the coding tool could have been challenged. As a result, substantially higher agreement may have been achieved on the code non-social-other engagement. Consensus coding ostensibly seems the least scientific approach in light of benchmarks set out by government organisations, such as the National Health and Medical Research Council. The Council argues for randomised control trials as providing the highest quality of evidence (National Health and Medical Research Council, 1998, 2009). However, if undertaken with clear parameters, consensus coding can be done in a rigorous and scientific manner. It may yield greater insights and learning, and increase reliability without losing trustworthiness.

The Scale for Dialogical Meaning Making (S-DMM) was discussed in chapter two as a potential means of operationalising and evaluating opportunities for experiencing the good life. It highlights the potential value of using a consensus coding approach. In their study evaluating the efficacy of the S-DMM Hostyn, Daelman, Janssen & Maes (2010) outline a rigorous initial observer training process similar to other observational studies not employing consensus coding (e.g., Janssen et al., 2004; Vervloed et al., 2006). The training included a review of the theoretical background of the S-DMM and practice coding videos not included in the study. The observers were then given specific information about the people in the videos they would be coding, such as their typical ways of expressing satisfaction, dissatisfaction, engagement and disengagement. The two observers then independently coded the videos in the study, but unlike other observational studies, the observers noted down qualitative reasoning for their coding. This made the coding process replicable to a degree. Following the observers' independent coding, they compared and discussed both similar and differing scores, as well as their justification for each, and finally a shared score was agreed upon. This process was audio taped. Through this approach, interrater reliability can be ascertained using the scores given by each observer prior to the negotiation phase and then compared with the postnegotiation scores. The advantage is that more is learnt about the coding process from reviewing the discussion between the two observers.

A further distinct advantage of consensus coding over more straight quantitative coding approaches is its mixed method orientation. Mixed method approaches can potentially elicit new knowledge and test and verify this knowledge in the challenging context of research and evaluation in the field of intellectual disability (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2008). While there are some clear benefits to using consensus coding to achieve interobserver agreement, Cordes (1994) argues that it shares the same limitations as other measures. Consequently, its use in combination with other analyses appears advisable.

Additional methodological and theoretical issues associated with phase one

In terms of the coding system, the resident code nonsocial engagement-personal almost exclusively involved mealtimes. (This code encompasses preparing for, doing, or cleaning up after a personal self-help activity.) This can be attributed to the filming occurring within the shared living areas of the homes and excluding personal areas and personal care activities. Had filming not been restricted to specific areas within the residences, the level of nonsocial engagement-personal, and the frequency and length of interactions between the staff and residents, might have been higher. Anecdotal evidence from the researcher who conducted the filming indicated that Ben spent most time in the nonfilmed areas of the house, only coming into the shared areas for mealtimes. This might account for the lack of disengagement and preponderance of nonsocial engagement—personal (i.e., mealtimes) of Ben relative to the other residents.

One rater coded Brett as engaging in non-social-other behaviour in three separate videos; the other rater did not use this code at all for this participant. The behaviour which the rater coded as non-social-other, was removing children’s toys from a box, exploring them briefly and then casting them away. The coding category disengagement includes nonpurposeful manipulation of objects (Jones et al., (1999). Brief exploration and casting away of toys would therefore fit within this definition. However, given the developmental level of the participant and the nature of the objects being manipulated, his actions could also be viewed as developmentally appropriate engagement. Similarly, Belle spent some time in some of the videos tapping different objects against her body. Both raters coded this as disengagement. However, taking into consideration her level of development and profound vision and hearing deficits, this behaviour could be interpreted as engagement. Additional work is required to fine tune the coding categories with regard to engagement. The aim should be to more clearly acknowledge abilities consistent with the psycho-social developmental levels of adults with congenital deafblindness and also the idiosyncratic nature of their behaviours.

The two raters also showed marked variation in their coding of social behaviour, highlighting the problematic nature of this particular coding category when observing adults with congenital deafblindness. The lack of agreement on this particular code resulted in no kappa value being calculated for it. Only six instances of social behaviour were coded, all of which were recorded by one rater alone. Given the idiosyncratic nature of the behaviours of adults with congenital deafblindness, it is recommended that future studies adjust the description of the code social to recognise individual differences. These should be discussed thoroughly prior to commencing the coding process.

Phase one of the study employed video recordings to capture the behaviour of adults with congenital deafblindness and support staff. The recordings were subsequently watched and coded by two observers. In contrast, Jones et al. (1999) coded the observations in real time using Psion palmtop computers programmed to capture the 11 behaviour codes. An advantage of the approach used in the current study was the ability to replay the footage to accurately code the behaviours. Live coding, despite its less intrusive nature, may reduce precision. It requires a high level of focused attention from the observers, compared with video recordings. Furthermore, considering the idiosyncratic and discrete nature of some of the observations, capturing these on video allows for additional analyses using consensus coding techniques. The application of consensus coding to these data, possibly involving direct support staff as observers, could be the subject of a further study.

In relation to the sample, the small number of participants, though typical of deafblind studies (Parker et al., 2007), prevented data analysis using inferential statistics. Therefore the present study is limited to being descriptive in nature.

Discussion relating to the second aim of phase one of the study

Staff/client behaviours

A second aim of the first phase of the study was to identify the topography of the interactions between adults with congenital deafblindness and the staff who support them. The adults with congenital deafblindness were predominantly observed to be disengaged according to the parameters of the coding schedule. The lack of involvement in activity, social or nonsocial, was notably high, particularly relative to the level of engagement of the participants in the Jones et al. (1999) study at their baseline (preintervention) measure. For comparisons, see Table 8.

Nonsocial engagement-personal and challenging behaviour were the second and third highest occurring resident behaviour categories, respectively. However, even these categories of behaviour were considerably lower than disengagement.

It is reasonable to suggest that there might only be a moderate level of nonsocial engagement-personal observed due to filming occurring late in the afternoon. Therefore, this finding is not surprising. However, the relatively high levels of challenging behaviour during this time-predominantly head hitting and rocking back and forth, constituting almost 10% of the observation time-warrants further investigation. Such analyses could inform the focus of interventions designed specifically to increase and enhance social engagement, or opportunities to experience the good life. Techniques could be used like those in approaches such as: Co-creating Communication (see Nafstad &

Rodbroe, 1999), Intensive Interaction (see Nind and Hewitt, 1994) and the guidelines outlined by Rodbroe and Janssen (2006a, 2006b).

Total resident engagement (comprising the social and three nonsocial engagement codes) accounted for 15.13% of the overall observations. This is in contrast to the findings of Jones et al. (1999) who reported an average 33.1% total resident engagement (range = 23-38%) at the baseline level of their intervention study. It is important to note that the sample used in the Jones et al. (1999) study consisted of 19 adults with severe intellectual disabilities, only five of whom were described as having sensory impairments. The degree to which sensory impairment alone affects levels of engagement and the effects of a staff training intervention on levels of engagement for adults with congenital deafblindness is yet to be investigated.

Total staff engagement with the residents was negligible across all observation categories, with assistance, restraint, other conversation and processing each accounting for less than one per cent of the observations. Praise was not observed on any occasion. It was noted that the code for conversation was only used in relation to three clients known to have hearing assessed as adequate to perceive speech. Verbal acts on the part of staff were coded this way. None of the clients who were reported to be deaf had interactions with staff that met criteria to be coded as conversation, though the code was sufficiently broad as to include nonverbal conversation. Interestingly, in the second phase of the study, staff offer accounts of more social tactile interactions with the adults with deafblindness. This significant discrepancy between the two data sets is examined in chapter seven.

The frequency and length of the interactions between the staff and residents was relatively low. On average, each 10-minute session contained one interaction that lasted approximately eight seconds. It is feasible that this might be attributed to staff feeling discomfort being filmed and therefore avoiding interaction with the resident under observation. However, by visiting each house on two occasions prior to collecting usable data, it was anticipated that staff would become desensitised to having someone filming in the house. Furthermore, by analysing the 5- to 15-minute segment from the 30-minute observations, it was predicted that the initial 5-minute buffer would allow the staff and residents to adjust to being filmed. All staff who took part in this investigation reported that what had been filmed was typical and that their behaviour had changed very little, if at all, due to being filmed. This was reported during interviews conducted after filming that involved explicit reflection about the filmed segments.

Implications and recommendations from phase one

The coding system devised by Jones et al. (1999) for the observation of adults with severe intellectual disabilities living in community residences was found to have variable reliability. The low reliability score for interactions between staff and residents highlighted the discrete nature of the participants’ behaviour and subsequent difficulties associated with coding such complex human behaviours.

The findings from phase one highlighted the lack of resident involvement in activities and a paucity of (social) interaction with staff. Practice solutions to increase the frequency, duration and quality of staff–client interactions, and the subsequent effect of these on the residents' quality of life, or potential experience of the good life warrant investigation. The current findings highlight the need for further work on observation tools to establish baseline measures for an intervention study. The study should be designed to increase levels of social activity and interaction among adults with congenital deafblindness.

Recommendations

Seven recommendations for future studies are made based on the findings from phase one of the study.

1. That interrater reliability be calculated using both percentage agreement and kappa, then, if there is large variation between the two, calculate percentage agreement using only occurrences.
2. That for sequential observational studies, percentage agreement be calculated using number of occurrences of each behaviour overall, regardless of the time interval they occur at, as a reasonable means to allow for slight human variation which potentially lowers the significance of the findings.
3. That if a sample of the entire data set is to be used, the entire data set should be scanned to see if there are any major variations between observers on any given code. Caution should be exercised when evaluating the merits of observational studies that use a sample of the results rather than the entire data set.
4. If the coding system is to be used again with adults with congenital deafblindness, it is recommended that the parameters describing each coding category be adjusted slightly to take into consideration the participants' level of psycho-social development and the idiosyncratic ways in which adults with congenital deafblindness engage with themselves, others and the environment.
5. Consensus coding should be considered for use in observational studies of populations which use idiosyncratic, context dependent behaviours.

6. Longer observation periods and/or observation periods at different times of the day should be considered. This recommendation is also made by Correa-Torres (2008) with regard to observations of the interactions of students with deafblindness in classrooms.
7. An intervention such as the Hanging Out Program (Forster, 2008) should be considered. It suggests staff spend 10 minutes with a client giving them their full attention, then reflecting on what worked well in the interaction, what did not work so well, and what might be tried in future. Such a process would ensure adults with congenital deafblindness receive more consistent and sustained attention from staff than they were observed to in this phase of the study.

Rationale for phase two

The above recommendations could be applied to future studies employing quantitative observational research methods. Nevertheless, this phase of the study does not satisfactorily address some of the overarching aims of the study, thus presenting the need to consider alternative research methods. While this phase of the study reveals low levels of staff–client interaction, it gives no insight as to why these levels are so low. Notes taken during the filming periods indicate that initially staff requested direction from the researcher and appeared somewhat uncomfortable with the low levels of interaction and client engagement. The staff commented that not much usually happens at that time of the day and asked whether the researcher wanted them to do something in particular. These observations raise a number of questions: how do staff perceive what is occurring during the observation periods, what are staff perceptions of their interactions with the adults they support, and can a better understanding of staff perspectives help explain the low levels of interaction observed? Further work is required for these questions to be answered.

Given the lack of literature investigating the interactions of adults with congenital deafblindness, valuable insights can be gained from the research on interactions between people with profound intellectual and multiple disabilities and their support staff. This literature is considered both relevant and important for three reasons. First, many adults with congenital deafblindness, like adults with profound intellectual and multiple disabilities, express themselves primarily through idiosyncratic nonsymbolic means. Second, their communication partners are often primarily disability support workers (Forster & Iacono, 2008; Golden & Reese, 1996). Third, in the research literature on interactions with people with congenital deafblindness and people with profound intellectual and multiple disabilities there is evidence of missed opportunities for communication, communication breakdowns, and limited engagement in social interaction (Clegg et al., 1991b; Finlay et al., 2008; Golden & Reese, 1996; Healy & Noonan Walsh, 2007; Romer & Schoenberg, 1991). These findings have important implications for people with congenital deafblindness and their experience of personal relationships and social engagement. These experiences are imperative to a person's quality of life (Felce & Perry, 1996b; Petry et al., 2005) and indeed their experience of the good life (cf. J. S. Reinders, 2002).

As well as drawing upon literature from a different but related area, there is a need to take a different methodological approach to investigating staff–client interactions in order to adequately address the nature of the questions being posed. There are increasing numbers of observation based studies investigating staff-client interactions, as interpreted by researchers (e.g., Clegg et al., 1991a, 1991b; Janssen et al., 2003a; Romer & Schoenberg, 1991; Vervloed et al., 2006). Very few of these have involved the staff as direct informants, giving them an opportunity to express what is happening in the interaction from their perspective. In an evaluation of quality enhancing interventions for people with profound intellectual and multiple disabilities Maes, Lambrechts, Hostyn and Petry (2007) found that none addressed whether the interventions were compatible with the values and priorities of staff. That is, if they had ecological validity, and if so how staff were motivated to utilise the interventions. The limited evidence available indicates that how staff perceive and make sense of their role can influence their interactions with their clients. Consequently, these staff perceptions require further investigation.

Chapter Six: Phase two

This chapter presents the research design, procedure and findings from the second phase of the study. The findings are discussed in light of the first phase of the study, the literature, and my experiences and observations. Much of the content of this chapter has been published in the article "Interacting with adults with congenital deafblindness: the experience of disability support workers" (M. Prain, McVilly, & Ramcharan, 2012b). However, due to constraints around word limits, the article focused on the following research questions which arose from a review of the literature and the results from the first phase of the study.

1. What are the perspectives of staff on their interactions with adults with congenital deafblindness?
2. How do accounts by staff of their interactions with adults with congenital deafblindness contribute to an understanding of the limited interactions observed in quantitative studies?

This chapter adds to what was presented in the article by examining the concept of tacit knowledge in relationship to the good life for adults with congenital deafblindness. It also raises some additional key points about communication from analysis of the data. The chapter concludes with an examination of the quality of the qualitative work undertaken in this second phase of the study.

Design of phase two

The first phase of the study used quantitative methods to investigate the form, frequency and duration of interactions between adults with congenital deafblindness and their support staff (see M. Prain et al., 2010). The second phase addressed different questions. These required qualitative research methods to generate adequate data. A number of authors have argued for the need to improve our understanding of the perspectives of interaction partners of people with profound intellectual and multiple disabilities and those with congenital deafblindness (see Maes et al., 2007; Parker et al., 2007). For this reason, semistructured interviews were selected as the most appropriate research method to address the research aims. A concurrent advantage of using interviews as the research method is their inherent facility for offering opportunities for reflection upon work practices. The benefits of this were highlighted in chapter three during the discussion about the insights that can be gained from Intensive Interaction practices.

Ethics

As documented previously in chapters four and five, this study was approved by the Royal Melbourne Institute of Technology University Human Research Ethics Committee.

Participants

The criteria for inclusion in the second phase of the study were that the participants were staff members supporting adults with congenital deaf blindness. For the purpose of the ethics application, those persons supported by the staff, namely adults with congenital deaf blindness, were also considered participants.

Disability support workers

The same nine disability support workers who participated in the first phase of the study were invited to participate in the second phase. All but one agreed to participate in the second phase, leaving eight participants: four from house one and four from house two. The number of staff interviewed represented 80% of the entire potential of permanent staff working across the two houses.

Six participants were female and two were male. Age range was between 24 and 59 years (*M* = 31 years, 5 months *SD* = 12 years, 9 months). Both males worked in house one. All eight staff had completed a Certificate IV in Disability Studies (a pretertiary, national vocational certificate level course). Their experience working with people with congenital deafblindness varied from 22 to 154 months. See Table 9 for details of the staff who participated in this phase of the study.

Table 9: Participants—disability support workers (Phase two)

House	Pseudonym	Gender	Age (yrs)	Experience working with people with congenital deafblindness
1	Joe	male	30	8yrs
1	Jane	female	29	1yr 10mths
1	James	male	24	4yrs 2mths
1	Jenny	female	37	12yrs 10mths
2	Christine	female	24	5yrs 3mths
2	Kate	female	24	5yrs 10mths
2	Carla	female	24	6yrs 2mths
2	Kim	female	59	6yrs 6mths

Age. (*M* = 31 years, 5 months, *SD* = 12 years, 9 months)
Note 1. All staff had the same qualification, Certificate IV in Disability Studies, which is an Australian National Vocational qualification.
Note 2. Experience working with people with congenital deafblindness—time staff had worked with individuals with congenital deafblindness, not necessarily in current house.
Note 3. Eight of the nine staff that participated in the first phase of this study were interviewed. Jess from the first study was not interviewed.

Adults with congenital deafblindness

The same nine adults with congenital deafblindness who participated in the first phase of the study participated indirectly in phase two in that staff interactions with these individuals were the topic of discussion during the interviews. See Table 1 for details of the adults with congenital deafblindness.

Interview procedure

The eight staff participants were interviewed to gain their perspectives on their interactions with the adults they supported. A semi structured interview was deemed the best method to address the research questions. This method involves researchers developing an interview guide to address a specific topic of enquiry. It is more flexible than a survey style interview which can reduce comparability of interviews within the study, but results in a better understanding of the informants' perceptions (Minichiello, Aroni, Timewell, & Alexander, 1995). The issue of comparability of interviews is addressed at the end of this chapter when discussing credibility and resonance of the results.

An interview schedule, which consisted of eight open-ended questions (see Appendix D), was designed to guide the interview but also allow the participants to give rich descriptions of their work with adults with congenital deafblindness. Assistance was sought from an experienced qualitative researcher not involved in the research project to devise the interview schedule. This ensured the schedule was free of leading terminology. Examples of the questions asked are: tell me about your last shift, tell me about time you spent with Belle during your last shift, tell me about other times you've spent with Belle.

Towards the end of the interview, all but three of the staff member participants were shown video footage in which they were interacting with the adults with congenital deafblindness with whom they work. "The immediate nature of the videotape captures emotional nuances, embodied perceptions, spatial influences, relational understandings, situational factors and temporal manifestations" (Raingruber, 2003, p. 1155). Given the nonverbal nature of many interactions with adults with congenital deafblindness, video cued reflection is a useful tool to elicit information which most likely would not be yielded through interview alone.

The video footage had been obtained during the earlier phase of the study and was used to prompt the staff to recall their interactions and give a description from their perspective of their interactions. General prompts were used, for example, “Can you talk me through what is happening here?” Three of the eight participants did not view video footage of themselves due to inadequate audio visual facilities in the house. These staff were given a brief, broad description of an interaction which the researcher had observed and were asked to talk the researcher through the interaction in more detail.

Six of the interviews took place in the house where the staff member worked either immediately prior to or following a shift. Two of the interviews took place at the head office of the organisation where the staff were employed, as at the time of interviewing two of the staff had been promoted to team leader roles and were not working in the houses. (See Appendix E for a sample interview.)

Each interview was audio recorded and lasted approximately half an hour. The audio recorded interviews were then transcribed and imported to NVivo Version 8 (QSR International, 2008) by me.

Interview analysis procedure

Analysis was conducted using NVivo software and the approach outlined by Charmaz (2006). However, theoretical sampling was not employed, making the process more consistent with thematic analysis (Liamputtong & Ezzy, 2005). The sampling was designed to address the questions raised by the first phase of the study. Given the relatively small number of staff who provide dedicated support to adults with congenital deafblindness, the potential participant population for the current study was limited. Consequently, there was insufficient data available to generate a single generalisable theory which Charmaz (2003) might identify as substantive or formal grounded theory. However, adopting Charmaz's approach provided a robust framework to elicit important conceptual and practical issues that addressed the topic of inquiry. In the results section of this chapter I present details of the themes arising from the data and provide direction for professional development for direct support staff. My two PhD supervisors independently reviewed my analysis and the final results were derived from a consensus approach involving myself and my supervisors. The key steps in the process were:

- several readings of the data to obtain an holistic perspective
- initial themes were identified, clustered and checked against data, research literature, and my observations
- a working hypothesis was induced from the themes
- constant comparison between data, observations and literature was undertaken to test and refine the hypothesis.

Using this process, themes were recorded in the NVivo software as *free nodes*. Coded material was then grouped into broader themes. Free nodes were grouped into organised catalogues (tree nodes) after multiple rounds of fine tuning the coding of themes. Text search queries were run on key words in the themes, such as *happy*, to ensure all the data segments on this theme were explored. Memos were created and sorted during the coding process as described by Charmaz (2006) to assist the analytical process. (See Appendix F for coded categories induced using NVivo.)

Rigour of the methodology

Lincoln and Guba (1985) recommend a number of strategies to strengthen rigour and credibility of findings in naturalistic inquiry. These include prolonged engagement (in the current instance I had worked with people with congenital deafblindness in their homes for 15 years), persistent observation (inherent in the analysis process as described above), and triangulation through use of different sources and methods.

As discussed in the previous chapter, the perspectives of disability support workers are largely lacking from the scientific literature. Frankham (2009) raises three problems relating to disability service users as informants in research which are equally applicable to disability support workers. These are:

- 1. that one person may be viewed as representing the group and this need not be the case;

- 2. that because they have had the experience they are assumed to understand the experience beyond just describing it; and

- 3. if the stories and accounts of informants in research are not questioned, information about how experiences and realities are constructed will be missed.

In the current study, the first two points have been addressed through elements of the methodology which were developed to increase the credibility and resonance of the study. These will be discussed at length at the end of this chapter.

The third point, however, is a critical issue for research and practice involving both scientist practitioners and disability support workers working with adults with profound intellectual and multiple disabilities, and those with congenital deafblindness. It is important to reflect upon the epistemological frameworks and broader social and cultural context which influence the perspectives of disability support workers. This will be discussed in more detail in the following chapter when exploring the concept of relational agency (Edwards, 2009) as a process to facilitate collaboration between different professionals.

This second qualitative phase elucidates findings from the first quantitative phase of the study, as well as the current scientific literature and the researcher's observations.

Phase two results

While a grounded theory methodology was employed in this study, it was not possible to generate a single generalisable theory. This was largely due to the small sample size which was restricted because of the nature of the population being investigated. Through analysis of the data three themes were formulated: (1) the construction of client happiness; (2) accounting for client disengagement; and (3) imperatives of the staff role.

Theme 1-The construction of client happiness

Underpinned by staff's tacit knowledge of the adults they support, the theme the construction of client happiness was induced as a factor important to staff. It influences how they interact with the adults with congenital deafblindness. All staff described how the adults they supported expressed happiness. For example, "You tell by all her noises now that she's happy" (Christine about Annie), and "Well with Ben, when he's happy he'll giggle and laugh and smile" (James about Ben). All staff also described activities and events which they asserted made the clients happy. For example, " … you kind of just have to you know stick to her routine to keep her happy" (Kate about Ada), and "Oh happy face. He likes the shower so he can stay in the water as long as he wants" (Jenny about Ben, when asked to elaborate on how she knows he likes the shower).

However, staff were not always able to determine the moods and preferences of the adults with whom they worked. Six staff expressed uncertainty in reading the clients' body language. This is significant as it is the tacit knowledge of the clients' idiosyncratic behaviours which appears to guide staff responses. Uncertainty in knowing how best to respond could impact on the staff–client relationship. Examples of this uncertainty included: “it’s a lot of guess work” (Joe, in response to the question, “Do you feel pretty confident you can always judge their (responses)?”), and “Ada’s a really hard one to interact with because she doesn’t really show emotions” (Christine about Ada).

In response to different questions throughout their interviews, three staff stated that the adults with congenital deafblindness were generally happy. In response to the question, “Is there anything else you think is important to add, or anything you’d like to add about working with this group?” Christine answered, “Um, no not really. I just really think they’re happy, our clients”.

Similarly, Joe was asked, “And how do you think that shift (his most recent shift at work) was for the clients?” Joe responded by saying, “Routine. I think they like the routine. I think it goes quite routinely for them and it makes them happy and comfortable, they know what’s coming and they know what they’re doing. Everything’s provided and they’re happy”.

Three staff also stated that they felt clients were happy based on a lack of behaviours perceived as negative, exemplified by the descriptions: “… not huffing, not upset” (Carla about Ada), and “… not fidgety or anxious, not acting abnormal” (Jane generally about the clients).

Both the interview and video data revealed a lack of staff engagement and interaction if the clients are not displaying overt signs of unhappiness. The statement “… if he’s happy we just leave him” (Jane about Ben), exemplifies the staff’s reasoning for their lack of engagement with the clients. However, staff did respond to clients when they were perceived as being unhappy.

Four staff spoke of how they respond to perceived client unhappiness, for example “Annie gets up and down so whenever she gets up and down we sort of talk to her on the way” (Kim about Annie), and “it’s her way of saying she’s not happy with something so I’m just rubbing her arm making her feel more comfortable” (Carla about Ada while watching a video of their interaction).

Theme 2-Accounting for client disengagement

Like the construction of client happiness, it is the tacit knowledge developed by staff which underpins their rationalisation of their clients’ disengagement. One of the recurrent characteristics of this theme was staff’s description of client disengagement in terms of *relaxing*. This is of importance as seven staff spoke of disengagement in these terms. Viewing disengagement in this way potentially limited clients’ opportunities for engagement. This component is exemplified by the statements: “They’ve got all week, they’re doing this, that and the other and the weekends they they’re just, they don’t want to do much” (Kim generally about the clients), and “… it’s like, a person that works in an office job or whatever um, they work nine to five and when they come home they don’t want to do anything” (James generally about the clients).

Five staff posited that the clients did not want to engage, again potentially limiting their opportunities for engagement. This was exemplified by the statements, “Well they’ve got their own routines that they just like to do themselves and you feel like you could step in and help but you don’t. You don’t because you know they’re happy doing their thing you know” (Joe generally about the clients), and “… unless you invite him down to an activity or go out he doesn’t really interact with anyone, like he’s got his room” (Kate about Aaron).

Four staff expressed perceived failure at past attempts to engage clients which potentially limited staff’s willingness to attempt to engage the clients now. For example, “It’s like, years ago our house manager wanted us to um work, work one on one with the clients in the afternoon. But we found that the clients didn’t want to do anything. They just played up and had tantrums” (James), and “A lot of times he’s just very disinterested, uninterested. Um, when you get him involved in stuff he just sort of, just has this snotty look on his face and he puts his nose up at you. Um, and gives you this I don’t know, like a no, I’m not interested” (Jane about Brett).

And five staff stated that the clients were difficult to interact with for a variety of reasons. For example, “… oh Ada’s a really hard one to interact with because she doesn’t really show emotions”, (Kate about Ada), and “Um with Brett. ‘Cause he’s one of the least functional in the house I find it quite difficult to interact with him” (Jane about Brett).

To a lesser extent, (four) staff rationalised client disengagement using logistical issues. For example, “But we’ve got three wheelchairs that need to be pushed so it doesn’t work out if we want to go out on the weekends with them” (Jane).

Loss of client abilities was also cited as an issue by (three) staff. For example, "… um she likes you know just sitting outside, sitting on the swing. She used to like trampoline but she doesn't like that so much the older she gets she's not as like sensory wise like not I don't know, you can't really get proper hearing tests done on her 'cause she can't go to the doctors 'cause she just lashes out" (Christine about Annie).

Theme 3 – Imperatives of the staff role

The way in which staff constructed their work role appeared to impact on the nature of their interactions with their clients. The interview data, to a large extent, was consistent with the quantitative data from the first phase of the study, which coded video observations and revealed extremely few interactions between staff and residents (M. Prain et al., 2010).

When recounting their most recent shift, all the staff spoke of domestic and personal care tasks. Most staff were consistent in their description, talking through the routine of tasks. The tasks consisted of varying sequences of getting clients out of bed, bathing, dressing, feeding and medicating clients, preparing meals, putting clients to bed, house cleaning, book work and shopping, depending on the time of day and day of the week of the shift. The overwhelming majority of responses from staff to the question "Talk me through your most recent shift" (i.e., describe in sequence your shift) fell under the categories of personal care and domestic chores.

All but one staff member spoke of domestic chores and personal care tasks in relation to their most recent shift. Typical descriptions within the data were:

> I came in at 7 o'clock, got Brett up, took him to the toilet, showered him, got him back to his room and um changed him get him ready for school, day service. Um once I got him to breakfast I got Ben, get him up, get him in the shower, changed him and he had his breakfast as well then I started cleaning up the house vacuuming and um mopping the floors um yeah the other staff usually does the girls. Belle, Belinda and um Bonnie [James about his most recent shift].
>
> [And] Serve dinner, sort them out, um we have to spoon feed some of the clients at [the house] if they can't feed themselves. Then we shower, yeah we shower one of them, change nappies around that time, change nappies on about three of them [Joe about his most recent shift].
>
> [And] … it's up at 6 and you've got to get up and everyone up and bathed and medicated and fed ready to go out the door at you know certain times [Kim about her most recent shift].

From the interview data it is clear that these tasks are considered by staff to be the imperative of the role and that social interaction with the clients independent of functional tasks is not. The staff's responses to this question focused on what they did and not how they did it, which may suggest a limitation of the question asked. Certainly, any human interaction can be viewed as social by its very nature and therefore the interactions occurring during personal care and domestic chores could be viewed by staff as social. However, the only staff member who made comment on the nature of her interactions with clients being social or otherwise was Jane. She said, "I would have interacted with all the clients but not in a social way". This is also consistent with the findings of the first phase of the study. Further work is required to better understand how staff perceive their interactions with clients in light of most of these being around functional domestic and personal care tasks.

Other minor themes which emerged under imperatives of the staff role were: activities out of the house (four staff) and adherence to the routine (four staff). For example: “But on weekends we take them out like a drive through the park” (James generally about the clients), and “… they mainly get their needs met through the routine anyway which we all know” (Kate generally about the clients).

Discussion

The second phase of this investigation was designed to build upon and triangulate the data from the first phase of the study, as is common in mixed method investigations (Creswell, 2009). The first phase of the study identified low levels of engagement in a range of interpersonal and practical activities by adults with congenital deafblindness living in community residences (M. Prain et al., 2010). This was a matter of concern, as personal relationships and social engagement are asserted as important to a person’s quality of life (Felce & Perry, 1995; Petry et al., 2005). For people with complex disabilities, support staff are often their principal source of interpersonal interaction and mediators of engagement. The study saw value in investigating how staff view and interpret engagement experienced by the adults they support.

The second phase of the study was designed to gain an understanding of staff perspectives. This was seen as an important step towards developing an intervention to promote the engagement of adults with congenital deafblindness in meaningful interaction that would enhance their health, wellbeing and quality of life. This second phase investigated the perspectives of staff on their interactions with adults with congenital deafblindness. It sought to elucidate how these perspectives might influence staff behaviours, based on reports from staff themselves. It also sought to use staff accounts of their own interactions with adults with congenital deafblindness to develop an explanation of the limited interactions observed in the previous quantitative phase of the study (see M. Prain et al., 2010).

Three central and recurrent themes were generated from the analysis of the data from the second phase of the study: construction of client happiness, accounting for disengagement, and imperatives of the staff role. Key issues relating to these themes are now examined.

Construction of client happiness

The current data suggest happiness, a private personal state, is ascribed by staff to a variety of behaviours exhibited by the adults with congenital deafblindness, including smiling, giggling, laughing, and a happy face. Every staff member interviewed gave accounts of client behaviours which they had interpreted as signalling the clients' happiness or pleasure. Research by Lyons (2005) and Green and Reid (1996) found indices of happiness could be reliably evaluated by people familiar with a person with profound intellectual and multiple disabilities. Therefore, the associations staff are making between these overt expressions within a social context seem reasonable. The frequency and context (e.g., time and place) of these occurrences however, requires further investigation. This is because the types of interactions described by the staff during the interviews were not seen on the videos and, consequently, not coded in the previous study. As mentioned above, only three adults with congenital deafblindness were observed in the first phase of the study to have staff members interacting with them in a way which was consistent with the code conversation. However, during the interviews a number of accounts were given by staff of interactions they had with the adults they support which, if observed, would have been coded as conversation. For example: “tickling her legs”, “making her laugh”, “playing peek-a-boo”. Further investigation is required to ascertain potential reasons for this discrepancy between what was observed in phase one and what was reported in phase two. Potential reasons for this discrepancy are discussed below.

It seems that a two-pronged approach would be useful in further examining happiness from the perspective of adults with congenital deafblindness. First, to examine what is currently happening during situations in which the adults with congenital deafblindness are overtly happy (e.g., smiling, laughing), and looking at how these situations can be extended, increased and expanded. Second, to engage in discussion with the staff around key aspects of quality of life and how they can be translated on an individual basis to the lives of the adults with congenital deafblindness with whom they work. This would involve looking at activities where the adults with congenital deafblindness express happiness overtly. It would also challenge the notion that a lack of distress, unhappiness or behaviours of concern indicate that the individual is happy.

This fundamental disparity in the way the behaviours of adults with deafblindness are interpreted by different observers highlights a key issue for scientist practitioners in this field. Where I, and indeed Jones et al. (1999) and Stancliffe et al. (2007), see disengagement and an issue with quality of life, the staff see almost the inverse: happiness. The observations of both groups are relative and bound by context. For example, scientist practitioners see the clients in the context of what is valuable and possible, as reported by the research literature. Staff view the clients in the context of the range of behaviours they have observed them to exhibit. These contexts bring each group to very different conclusions and interpretations of what they are seeing. This major difference in interpretation poses a number of challenges and questions for future work in this area.

1. In order to progress the situation for adults with congenital disabilities and those with profound intellectual and multiple disabilities, the perspectives of both scientist practitioners and disability support workers need to be considered in both research and practice settings, and especially when coding or attributing meaning to client behaviours.
2. Similarly, both the perspectives of scientist practitioners and disability support workers should be considered when assessing the quality of life of adults with congenital deafblindness and those with profound intellectual and multiple disabilities.

3. When discrepancies between the perspectives of scientist practitioners and disability support workers are evident, negotiation is required with a view to achieving consensus agreement, ultimately to better the situation for the client. This process could be further enhanced by involving family members or others who know the client well, if available.

Accounting for client disengagement

Staff in the current study gave repeated and multiple accounts for why the adults with congenital deafblindness appeared to be largely disengaged. Not wanting to engage and relaxing were two of the key explanations given by staff for the clients' disengagement. Potentially it is the passivity of the adults with congenital deafblindness which leads the staff to assume they are tired. Janssen (2009) and Nyling (2003) state that adults with congenital deafblindness tend to be more passive than children with congenital deafblindness. This is due to lack of experience in interaction, posing additional challenges for their communication partners.

It is possible that adults with congenital deafblindness have not previously received consistent positive responses to their attempts to engage with others and so have simply given up on social interaction, and developed *learned helplessness* (cf. Seligman, 1975). If this is so, it has important implications for developing and prioritising clinical and other support programs. These would need to focus on intentional social interaction in an effort to address the (re)acquisition of skills and rejuvenate motivation to engage with others. Ehrlich

(2007) used the Co-creating Communication developmental framework in her study of a man with congenital deafblindness. She found that low functioning cues were lost from the man's communicative repertoire and were not seen anymore, probably due to deprivation caused by nonappropriate support in the past.

Again, at the heart of this issue is the difference in tacit knowledge and hence interpretations of behaviour by the staff, compared to those of scientist practitioners. What I and other scientist practitioners view as disengagement, the staff view as relaxing or tired. Only one staff member suggested the clients might be bored.

Imperatives of the staff role

Using an analytical framework based on the commonly accepted life domains asserted to constitute quality of life (see Felce & Perry, 1995; Petry et al., 2005), there is a strong emphasis on physical, material and emotional wellbeing in the staff accounts of their role in supporting adults with congenital deafblindness. There is however, little or no mention of social wellbeing or personal growth and development. Staff play a significant role in mediating the experiences of the adults they support. Staff development practices and organisational policy and procedures could better emphasise the importance of supporting these adults in all life domains. In addition, ongoing evaluation of the impact of changes to staff development and policy and procedures should occur.

The emphasis staff place on meeting the physical and material needs of the adults they support may help to account for the discrepancy between interactions observed in phase one of the study and reported in phase two. As the staff were being filmed, it is likely they wanted to be seen as doing a good job. If social interaction is not considered by the staff to be an imperative of their role, they may not feel comfortable demonstrating this type of interactive behaviour on film. During the course of my work, disability support workers have expressed some discomfort about being observed by the public interacting with adults with congenital deafblindness in ways which more effectively engage the adult. This is because of the perception of staff that these appear unusual. Clearly, further work is needed to better appreciate these issues. They are not currently well understood or documented, but they potentially limit opportunities for adults with congenital deafblindness to experience the good life.

Additional issues that warrant further investigation

The contribution of tacit knowledge

In the initial analysis of the data, the staff's tacit knowledge about the adults with congenital deafblindness emerged strongly as a central and recurrent theme. However, it was not included in the key themes. While it largely underpins the first two themes-construction of client happiness and accounting for disengagement-on its own it added little to help explain the low levels of interaction observed in the first phase of the study. Upon reflection about the methodological issues and challenges in examining the good life for adults with congenital deafblindness, the tacit knowledge of staff about the adults they support is potentially a valuable asset in a cooperative research paradigm.

During the analysis of the interviews, as coded categories were grouped together and compared with other categories, the theme which emerged most strongly was tacit knowledge about the adults with congenital deafblindness. This was supported by the most coded statements from all staff. Elements of this theme emerged from the answers to every question asked of the staff about their work and interactions with the clients.

A key component of this theme was knowledge about the likes and dislikes of the adults with congenital deafblindness. This is considered important as all staff gave unsolicited accounts of client likes and dislikes and how this knowledge impacts on how they engage with the adults they support. Examples of this component from the data are: "… she kind of likes to be with you and be in the kitchen" (Kate about Alison), and "She just likes us tickling and playing with her" (Jane about Belle).

Similarly, staff knowledge of the abilities and disabilities of the adults with congenital deafblindness was raised by all staff. This knowledge also impacts on how staff engage with clients. This component is exemplified by statements such as: "… they help you with the routine as well. They … lift their body up or whatever" (James about Brett and Ben), and "I took her for a ride and she peddles. She's getting better at peddling. She realised if she wanted to go a bit faster she'd need to try more" (Joe about Belinda).

All staff also gave examples of recognition of clients' physical and emotional states. Given that all the adults with congenital deafblindness in this study are primarily nonsymbolic communicators, this component is of key importance for staff in knowing how to best respond to their clients. This component is exemplified by statements such as: "He's quite comfortable when he's outside" (Jenny about Brett), and "I hadn't seen them in ages so Aaron was pretty excited" (Christine about Aaron).

Six staff made reference to the personality traits of the adults they support. This component highlights the knowledge staff have developed over time about their clients' natures and personalities, and this contributes to how they engage with them. It is exemplified in statements such as: "Alison and Annie are really lazy". (Christine about Alison and Annie), and "He's quite an impatient bloke" (Jane about Ben).

This tacit knowledge, developed over time, largely underpins how the staff initiate interactions and respond to their clients. A number of authors have recognised the important role that tacit knowledge of staff plays in the development of high-quality relationships with service users (e.g., H. Reinders, 2010; Schuengel, Kef, Damen, & Worm, 2010).

Data from the current study highlights the role which tacit knowledge plays in how staff respond to and engage with the adults they support. Researchers and service organisations need to work to harness the benefits of the potentially large reservoir of tacit knowledge held by support staff. At the same time, it is important to develop an understanding of how this knowledge is formed, modified and used by staff in day-to-day decision making. Given the large extent to which staff mediate the experiences of adults with congenital deafblindness, understanding how the tacit knowledge of staff is shaped is necessary when looking to enhance the likelihood of improved quality outcomes for the clients. The following chapter suggests ways staff can be involved more equally in intervention and research processes. It also discusses how the knowledge of disability support workers and scientist practitioners can be declared and negotiated to benefit each other, as well as the adults with congenital deafblindness and profound intellectual and multiple disabilities with whom they work.

Mismatch in communication modes

There was insufficient data to include mismatch in communication modes as a key theme in the study. Nevertheless, there did appear to be some consistent issues across the interviews and observations which contribute to an increased understanding of the situation, and warrant further investigation. Given the study's focus was on interaction, there is intrinsic value in examining staff perspectives on communication.

There appears to be a distinct mismatch between staff reports about how the adults with congenital deafblindness express themselves and how the staff express themselves to the adults with congenital deafblindness. In particular, the clients are reported to express themselves using informal vocalisations and the staff report using speech. For example, when talking about Annie, Kim said, “And you can talk to Annie and go right up to her and say you or you’re beautiful Annie and she’ll go ooohhh”, and “I’d talk to her and as she’d get going she’d start vocalising sort of, sometimes she sort of sings” (Joe about Belinda).

Similarly, the clients are reported to use body language and facial expression and the staff use signs. This is illustrated by statements such as: “With Belle I usually sign food or toilet and she’s pretty good she usually goes” (Jenny about Belle), and “… if you sign toilet she goes straight to the toilet so if you sign to her she understands signs like dinner and toilet and bus” (James about Belle), and “Yeah if you sign man, she’ll go Yeah” (Kim about Alison). There is no mention of any of the adults with congenital deafblindness using signs to express themselves throughout the interviews.

There is nothing inherently wrong with communication partners using different modes of communication. Given what is now understood from the literature on infant communication development and the importance of reciprocity and intersubjectivity, as discussed in chapter two, it is likely that the mismatch in communication modes in these instances is reducing opportunities for high-quality interactions.

The staff also raise issues about the challenges of communicating with the adults with congenital deafblindness. For example, statements such as, “… there’s no communication in that house at all, well there is but there’s no direct communication with the clients” (Joe), and “… because they can’t talk and you've got to kind of watch their body actions and their noises” (Christine), and “they’re really difficult clients because they don’t communicate properly” (Kate). Throughout the interviews staff repeatedly reported understanding and responding to a wide range of communicative behaviours of the adults they support. But they appeared to struggle to articulate the ways the clients do communicate and express themselves. From my experience this appears to be a double-edged sword: the staff find it difficult to label and acknowledge as valid, the communicative behaviours of the adults they support.

For these reasons interventions such as Video Interaction Guidance and Marte Meo, discussed in chapter three, have potential to bring into focus, and generate language for, what is occurring, and address mismatches in communication modes. Both these interventions have an emphasis on labelling and reflecting upon behaviours underpinned by tacit knowledge. However, these interventions are relatively new and much more research is required to investigate their efficacy in a range of settings, including residential settings for adults with congenital deafblindness.

Issues around methodology

The second phase of the study used a qualitative approach. This generated data which have provided a greater understanding of how staff perceive their role. It also enabled insights about the interaction (or lack of interaction) between adults with congenital deafblindness and their support staff than was available from the quantitative analysis alone. However, there were discrepancies between the two phases of the study. The first phase indicated limited social interactions (M. Prain et al., 2010). In the second phase, staff described social interaction occurring during personal care and other activities not captured during the observation sessions in phase one. This suggests a major limitation to the first phase of the study. In the first phase, observations of personal care activities were not conducted for ethical reasons. However, it could be that had such observations been conducted, quite different conclusions might have been made with respect to the form and frequency of social interaction between adults with congenital deafblindness and the staff who support them. Furthermore, these same findings raise questions as to why social interaction might only take place in the context of the privacy of personal care, and not at other times in people's lives. Given the staff in the current study indicated that they did not consider social interaction with their clients as an imperative of their role, it is possible they interacted with their clients less than usual while being filmed. This is because they wanted to be seen as carrying out what they perceived to be the functional imperatives of their role. This also requires further investigation.

While the first phase alone clearly did not adequately capture the full nature of what occurs between staff and adults with congenital deafblindness, neither did the second phase alone. This highlights the value and contribution that a mixed method approach can make. Staff spoke of social interactions which if observed would have been coded as conversation. But it is difficult from the interviews to know how frequently these type of interactions occur and for how long, which a quantitative approach can offer.

Limitations

No single, generalisable theory was generated from this phase of the study. While the method outlined by Charmaz (2006) was used to guide the analytic process, theoretical sampling was not undertaken, making the process more consistent with thematic analysis (Liamputtong & Ezzy, 2005). Although no single substantive theory was generated, the analytic process elucidated some conceptual, philosophical and practical issues, which impact on interactions between adults with congenital deafblindness and the staff who support them.

In addition, member checking only occurred at the end of the data collection phase of the research. That is, participants were given an opportunity to comment on the transcripts of their interviews. A future study could extend the current investigation to include an opportunity for participants to comment on the themes induced from their data. Indeed, the following chapter examines more closely the philosophical and methodological issues associated with researching adults with congenital deafblindness. It is argued that rather than simply member checking the final outcome of the data analysis, staff need to be much more actively involved in the research process. Issues relating to staff involvement and engagement, and the potential benefits of employing an action research methodology in the current context, are also explored.

Evaluating the quality of phase two of the study

This chapter concludes with an examination of the quality of the work presented in light of the preceding chapters. This study employed qualitative research methods in a field which predominantly employs quantitative research methods. As a result there is a need to highlight and elaborate on the quality of the qualitative work undertaken in this study. In addition, Tracy (2010) argues the need to demonstrate quality of qualitative research given the methodological conservatism evident in government and funding agencies. For example, the National Health and Medical Research Council has a preference for quantitative research (see National Health and Medical Research Council, 1998, 2009).

Tracy (2010) presents a model for ascertaining quality in qualitative research and proposes eight big tent criteria for excellent qualitative research. The following addresses each of these criteria and documents how these criteria have been addressed.

1. Worthy topic

This criterion, addressed more fully in the first three chapters, is clearly addressed by this study. There is inherent interest in the topic. It has received little direct attention from researchers, although a number have identified the need for further studies (e.g., Maes et al., 2007; Parker et al., 2007). As stated earlier, though the population of adults with congenital deafblindness is small, findings in this area are applicable more broadly to others with complex communication needs, such as those with profound intellectual and multiple disabilities, autism, acquired brain injury and dementia.

2. Rich rigour

The rigour of this study is addressed in the methods section of this chapter which specifically discusses criteria for rigour in qualitative research or naturalistic inquiry as presented by Lincoln and Guba (1985).

3. Sincerity

While any researcher will bring subjective values and biases to their subject of investigation, there is a need to document these explicitly when undertaking qualitative research given the researcher is the research instrument. Key points in this thesis demonstrate reflexivity, acknowledgement of biases, and transparency about methods and challenges. These are found in chapter four, where my perspectives as a researcher are declared, and in the current chapter when acknowledging the limitations of this study.

4. Credibility

The term credibility is commonly used to refer to the reliability and replicability of quantitative studies. It is achieved through different processes when applied to qualitative research, such as thick description, triangulation and/or crystallisation, multivocality and partiality (Tracy, 2010). The following demonstrates how each of these has been achieved in the current study.

The researcher's tacit knowledge of the culture in which they are researching is of high importance. Good qualitative research examines what is occurring below the surface and explores that which is assumed, implicit and has become common sense to the research participants (Tracy, 2010). This is one of the greatest strengths of the current study. My prolonged exposure to the research setting and culture enabled a deeper understanding of the meanings behind the language used during the interviews. It also gave me knowledge of what was not mentioned or elaborated on by the staff. My tacit knowledge of the setting also enabled me to provide the thick descriptions, using the language of the staff, necessary for credibility.

The second phase of the study triangulates the quantitative data from the first observational phase, as it highlights a lack of emphasis on social interaction between staff and adults with congenital deafblindness. It perhaps therefore offers an even greater contribution to current knowledge by crystallising the topic. Crystallisation involves utilising multiple methods, researchers, and theoretical frameworks to open up a more complex and in depth understanding of the topic while remaining partial.

Multivocality is achieved in the current study by presenting the viewpoints of the staff, which both support and diverge from the viewpoints of myself and other scientist practitioners. Indeed, it is this multivocality within the current study which highlights the need for alternative intervention and research methods in this field. These are discussed in further detail in the following chapter.

5. Resonance

Tracy (2010) presents two key practices which achieve resonance: aesthetic merit and transferability. She argues a good quality qualitative report will employ at least one of these practices, but that they often go hand in hand. My report of the data analysis is somewhat lacking in aesthetic merit largely due to the discrepancy between my own perspective and that of the staff. This is discussed at length in the next chapter. However, resonance is achieved through the applicability of the findings from this phase of the research to other populations and settings. These include dementia patients in nursing homes and adults who communicate nonsymbolically in any residential setting. While qualitative research cannot claim generalisability in a statistical sense, its findings can still be useful with other populations and in other circumstances and settings.

6. Significant contribution

The current study makes a theoretical contribution to the field. Its findings highlight that to achieve sustainable, improved, quality interactions between staff and adults with congenital deafbindness, closer attention must be paid to the relationships and interactions between scientist practitioners and the staff working with the adults with congenital deafblindness. These relationships and interactions have received little attention from researchers but are paramount to achieving positive results for adults with congenital deafblindness. This issue is discussed further in the next chapter.

This in turn gives the current study heuristic significance as it demands further investigation into the efficacy of more collaborative research and intervention processes. It also overlaps into the realm of policy by highlighting the need to make explicit the role of staff in providing sustained opportunities for social engagement with adults with congenital deafblindness. In addition, the current study is practically and methodologically significant. It presents alternative approaches to both intervention and research as a result of its findings.

7. Ethical

This study was approved by the Royal Melbourne Institute of Technology University Human Research Ethics Committee, which largely addresses procedural ethics. Nevertheless, Tracy (2010) notes the importance of addressing a number of additional ethical considerations, namely: situational, cultural, relational and exiting ethics.

“A situational ethic assumes that each circumstance is different and that researchers must repeatedly reflect on, critique and question their ethical decisions” (Tracy, 2010, p. 847). These situational ethical considerations arise repeatedly throughout a research project and need to be reflected upon and evaluated on an ongoing basis. Some of the types of situational ethical considerations which arose during phase two of the study were: whether to interview staff during or outside their paid work hours (this was negotiated with each participant), whether to go ahead with filming when staff had not received the message that filming would be occurring (this was also negotiated each time), and what to do when a resident of the house not participating in the research walked into the line of the video camera (consent was sought for this resident to be filmed).

It is impractical to list every situational ethical consideration which arises during a research project, but it is important to recognise the researcher has been mindful of these issues. In this instance, for the most part these issues were addressed through supervision and negotiation with the research participants as the need arose.

In considering relational ethics, I would assert there was no fundamental breach of trust or ethical misconduct. However, on reflection, a significant limitation of the research process was the asymmetry in the relationship between myself as researcher/interviewer and the research participants/interviewees. I discuss and elaborate on the importance of reciprocity and collaboration for both intervention and research purposes in the following chapter. It is important to note here though, that while the processes I followed are well documented research protocols, I experienced a level of discomfort because of the inherent asymmetry in an interview format.

Exiting ethics, or those beyond the data collection phase, have been largely addressed through the publication of the article “Interacting with adults with congenital deafblindness – the experiences of disability support workers” (M. Prain et al., 2012b). The article enabled the perspectives of staff, which are largely absent from the literature, to be presented. The following chapter also addresses future directions for research which have been informed and shaped by this study.

8. Meaningful coherence

Elements relevant to this final criterion are: the use of methods and procedures which fit the stated research objective and achieve these objectives, and meaningfully interconnect literature, research questions, findings and interpretations. The second and third chapters highlight the need for qualitative investigations into the perspectives of disability support workers on their interactions with the adults they support. The findings not only achieve the goal of gaining greater insight into staff perspectives, but demonstrate the value of using qualitative methods to generate such insights. Literature is drawn upon throughout the discussion section of this chapter to support assertions made in light of the findings of the study.

The following chapter summarises the findings from the two phases of the study and examines these in relation to the existing literature and overarching aims of the study. Key issues and questions raised by the study are discussed and the chapter concludes with recommendations for future work from philosophical, theoretical and practical perspectives.

Chapter Seven: Discussion

This thesis builds on the existing body of research literature about people with congenital deafblindness and offers new insights and recommendations for further work in the field. It explores the application of a mixed method design and is informed by work concerning adults with profound intellectual and multiple disabilities. This chapter examines key findings from the study as a whole in light of existing literature and theory. Based on these findings the chapter discusses the need for alternative methodologies for research and interventions aimed at examining and promoting further opportunities for adults with congenital deafblindness to experience the good life.

The organising concept which links and elucidates the findings of each phase of the study is the perspectival dissonance between disability support workers and what is proposed by existing research conducted by scientist practitioners. Dissonance—meaning a lack of agreement, consistency or harmony—is documented repeatedly in the research literature on interactions with people with congenital deafblindness (e.g., Hart, 2010; Janssen, Riksen-Walraven, & van Dijk, 2002; M. Prain et al., 2010; Romer & Schoenberg, 1991; Vervloed et al., 2006). However, it is rarely discussed with regard to the relationships and interactions between scientist practitioners and disability support workers. The study of Wareing and Newell (2005) is one of the few which considers the relationships between scientist practitioners, disability support workers and clients. Their analysis of a discussion between a scientist practitioner and a team of disability support workers about a client reveals the connectedness of staff and clients as opposed to being separate and discrete entities. “Understanding the device ‘Worker/Client’ as tied has significant implications not just for how we support people constituted as having an intellectual disability, but also for understanding the largely unexplored relationship between all of us who provide support and our silent partner – the client” (Wareing & Newell, 2005, p. 113). This chapter discusses some potential ways to further examine these relationships with a view to sustainable approaches to staff and client development.

Revisiting the good life

This thesis has examined the good life, as posited by Reinders (2002), and elucidated some key issues and factors which require consideration with regard to its measurement and evaluation. Reinders (2002) refers to the good life as civic friendship, or positive interactive experiences beyond being a client of a service for people with disabilities. This is not possible for most adults with congenital deafblindness without the mediation of staff. The current study identified limited opportunities for the adults with congenital deafblindness to experience the good life within the disability specific services they receive. Considerably more work is required within these services before staff can better facilitate and mediate interactions between their clients and the communities in which they live. This again highlights the need for intervention at the disability service level. Disability support workers need to be able to create opportunities for adults with congenital deafblindness to experience social togetherness, or the good life, initially with disability support workers themselves. Once these workers better understand how this is achieved, they may be able to facilitate the good life with others less familiar with their clients.

As stated at the outset, this thesis is essentially an examination of three relationships which contribute to an understanding of the good life, and to creating opportunities for experiencing the good life. These three relationships are: those between scientist practitioners and people with congenital deafblindness, those between disability support workers and people with congenital deafblindness, and those between scientist practitioners and disability support workers. The same principles scientist practitioners apply to improve relationships and interactions between people with congenital deafblindness and their communication partners can be applied to the relationships and interactions between these communication partners and scientist practitioners.

Hart (2010) argues that “if language is to be an outcome for partnerships involving congenitally deafblind people, equal contributions must be made by both partners, deafblind and nondeafblind” (Hart, 2010, p. 23). I would apply this same principle a little more broadly. It is relevant to opportunities to experience the good life as an outcome without necessarily aiming for language. It is also relevant to the partnerships between scientist practitioners and the primary interaction partners of people with congenital deafblindness. That is, the interaction partners of people with congenital deafblindness need to make equal contributions to the formulation of intervention and research goals and processes if they are to fully engage with, and participate in, these processes. Scientist practitioners need to ensure these are negotiated. Issues raised by the communication partners of people with congenital deafblindness need to be acknowledged and accounted for within the process of negotiating clinical and research goals.

The acknowledgement of the perspectival dissonance between scientist practitioners and disability support workers is a key contribution of this investigation into what is currently understood about interactions with people with congenital deafblindness. This study also provides insights into issues which must be addressed for intervention approaches to be effective and sustainable. The next section provides a summary of the study's key findings and issues which require further investigation and consideration.

Summary of key findings

Phase one of the study aimed to examine the current topography, frequency and duration of interactions between adults with congenital deafblindness and the staff who support them. It also investigated the utility and reliability of a coding tool previously used with adults with severe intellectual disabilities with whom adults with congenital deafblindness share services. The first phase of the study revealed extremely low levels of interaction between the staff and adults with congenital deafblindness (less than two percent of the observed time). It also revealed high levels of disengagement of the adults with congenital deafblindness and a preponderance of assisting and supporting behaviours by the staff; extremely limited social or conversational behaviour was observed. The interrater reliability of the coding tool with this different population was found to be variable. A number of issues with regard to observational studies and the interrater reliability of observational studies were raised. Seven recommendations were made based on the findings of phase one of the study.

1. That interrater reliability be calculated using both percentage agreement and kappa, then, if there is large variation between the two, calculate percentage agreement using only occurrences.
2. That for sequential observational studies, percentage agreement be calculated using number of occurrences of each behaviour overall, regardless of the time interval they occur at, as a reasonable means to allow for slight human variation which potentially lowers the significance of the findings.
3. That caution is exercised when using samples from data sets.
4. That changes be made to the coding tool used if employed with people with congenital deafblindness.
5. Consider using a consensus coding approach.
6. Consider filming for longer periods at different times of the day.
7. The implementation of an intervention such as the Hanging Out Program (Forster, 2008) should be considered to increase time staff spend interacting with clients.

See chapter five for a more detailed presentation of these recommendations.

These recommendations centre around ways to improve phase one of the study if it were to be conducted again. Phase one also raised some questions which are not well addressed in the literature. The rationale for phase two of the study emerged from reflection upon both the literature and the findings from phase one of the study.

Phase two, like phase one, was exploratory in nature and also aimed to gain insight into what is currently occurring for adults with congenital deafblindness in their interactions with staff. However, phase two was conducted from the perspective of the staff, ultimately to better understand how best to operationalise and evaluate the good life for adults with congenital deafblindness. Interviews were conducted with disability support workers to generate qualitative data in order to gain an understanding of the perspectives of those who spend the most time with adults with congenital deafblindness. The interview data were analysed in light of the very low levels of interaction observed in the first phase of the study. The analysis both triangulated the data from the first phase and provided insights into potential explanations for the low levels of interaction observed. The analysis of the interviews also highlighted the differences between the perspectives of staff relative to those of scientist practitioners, as evidenced in the literature. A number of issues and questions arose from the analysis of the interview data in phase two.

1. It is scientist practitioners who code behaviours in intervention studies, but should the opinions of those who know the clients better, namely the

disability support workers who mediate the support of adults with congenital deafblindness, be given more creed?

2. It is people who know the clients well who complete proxy quality of life questionnaires, but should the observations of researchers be given more creed?
3. How are these discrepancies between the worldviews of scientist practitioners and disability support workers reconciled with the best outcome for adults with congenital deafblindness?

The two phases of this study present data in different forms and collected through different methods. However, when integrated, these data indicate that the adults with congenital deafblindness who participated in the study experienced extremely low levels of interaction outside of personal care and domestic tasks. Given the perspectives of the staff who mediate their support, there were very limited opportunities for these adults to experience the good life.

The remainder of this chapter examines this issue from various philosophical and theoretical perspectives to determine the most beneficial paradigm with which to progress the current situation for scientist practitioners, disability support workers and most importantly adults with congenital deafblindness. Information presented in the earlier chapters of this thesis will be drawn upon to substantiate the claims made.

Directions for future research and practice

The need for multiple perspectives

This study has highlighted the need for pluralism when determining methods to investigate interactions with people who are unable to self-report, in this instance, adults with congenital deafblindness. The mixed method approach that was used both triangulated and crystallised (see Tracy, 2010) data, but also revealed inconsistencies in the findings, depending on the method used. For example, the observational coding tool devised by Jones et al. (1999) and used in the first phase of the study revealed that the adults with congenital deafblindness were for the most part disengaged. The interviews used in the second phase of the study revealed clients to be happy and relaxed, but also confirmed that they experience very limited opportunities for social interaction.

If multiple methods are not employed, it is recommended that the nature of participants vary to optimise the opportunity for multiple perspectives on the situation being researched. For example, Neander and Skott (2008) interviewed both parents and therapists about their experiences of early intervention processes. This yielded considerably different perspectives from the two participant groups, opening up the possibility for a broader, deeper understanding of the situation. While the present study employed different methods, it is likely that the difference in perspectives identified would have been revealed had interviews also been carried out with multiple categories of staff (e.g., interviewing both direct support staff and allied health clinicians), had they been available.

There is considerable value in seeking multiple perspectives on a situation. In analysing the interview data, I was frequently challenged by reading how staff interpreted the behaviours of the adults they support relative to the way I, as a scientist practitioner, would have interpreted them. Interpretations of observers are necessarily underpinned by the observers' tacit knowledge, which shapes their ontological beliefs and epistemological framework. That is, researchers will only see something which they believe exists and will select methods for documenting and measuring its existence accordingly. For example, a disability support worker may see an adult with deafblindness who urinates while clothed as carrying out an act of spite as it means the support worker will have to change them. A scientist practitioner on the other hand may view this same act as one of sensory stimulation to alleviate boredom or create a pleasurable experience. These two people's ontological beliefs, their beliefs about what exists in this instance, are quite different. One is grounded in day-to-day, case-by-case, experiential practice; the other is grounded in a theoretical framework for explaining motivations of behaviours of concern. (Note: the term *behaviours of concern* is used in Victoria, Australia, rather than challenging behaviour, to shift the focus of how these behaviours are perceived and understood.)

Nevertheless, in other instances staff clearly recognise idiosyncratic indications of pleasure or displeasure in context, which a scientist practitioner unfamiliar with the person with deafblindness may misinterpret. Both disability support workers and scientist practitioners, while having different epistemological frameworks, have valuable information to bring to an open discussion on interpretation of behaviours of individuals with congenital deafblindness or profound intellectual and multiple disabilities. For this reason, any intervention or research methodology which aims to address quality of interactions or quality of life for people with congenital deafblindness, should necessarily involve the perspectives of their primary communication partners. Given that these will often differ substantially, it is necessary to continue negotiations about meanings and goals until each perspective has been adequately considered and accounted for.

The need to address power imbalances in research and intervention

This study has highlighted the difference in perspectives between scientist practitioners, as represented in both the literature and my own perspective, and disability support workers. In examining the best way forward for research and intervention with people with congenital deafblindness it is apparent that there is not only a difference in perspectives, but a difference in power. There is a need to address the current power imbalances in research and intervention in this field. This is discussed further below. A number of research and practice methodologies are also suggested. These can be utilised to ensure issues around power are taken into consideration and ameliorated as much as possible.

The need to address the power imbalance between scientist practitioners and disability support workers can be argued as a moral imperative. It is also a means to ensure more sustainable outcomes in research aiming to achieve better outcomes for people with disabilities. Researchers investigating interactions with people with congenital deafblindness and profound intellectual and multiple disabilities have an implicit motivation to enhance and improve the circumstances for these groups. This means there is a need to reflect upon the nature of power within the research process.

Kamler and Thomson (2006) note the importance of reflexivity as a researcher. They argue that reflexivity involves examining how we may perpetuate power relationships and advancing particular ways of labelling and discussing people, experiences and events. As discussed in chapter three, the perspectives of disability support workers are largely lacking from the research in which they are involved. Rather, it is researchers who report on interventions involving staff and make recommendations to train staff so that the staff see the situation more from the researchers' perspective. The researchers do not appear to value, examine or incorporate the perspectives of staff in the research or intervention processes. However, "the moral principle of respect for persons is most fully honoured when power is shared not only in the application of knowledge about persons, but also in the generation of such knowledge" (Heron, 1981, p. 35).

Miller and Crabtree (2000) state "clinical researchers share ownership of the research with clinical participants, thus undermining the patriarchal bias of the dominant paradigm and opening its assumptions to investigation" (Miller & Crabtree, 2000, p. 616). This is certainly an ideal of clinical research. However, most research examining the efficacy of different intervention models with adults with congenital deafblindness and for people with profound intellectual and multiple disabilities fails to involve disability support workers as equals in the research process. This potentially limits the long-term efficacy of the intervention due to lack of ownership and intentionality on the part of the staff. It also runs counter to Heron’s (1981) argument that researching people requires a commitment to providing conditions under which research participants can develop skills in independent inquiry into the human condition.

Increasingly, people with disabilities and their families are becoming more equitably involved in informing and shaping the services they receive and the research in which they are involved (e.g., Gilbert, 2004; McLaughlin, 2010; Ramcharan, Grant, & Flynn, 2004; Walmsley & Johnson, 2003). Verdugo et al. (2005) note the increasing involvement of people with intellectual disabilities and their families in the design and implementation of research around quality of life measurement and evaluation. However, for those who cannot self-report and have little contact with family, it is the staff who mediate their support who will need to be involved in these research and practice activities. In any event, regardless of whether the adult with a disability is able to self-report or not, the perspective of their primary communication partners, usually staff, is of importance in understanding and shaping the situation.

When exploring power imbalances there is value in examining Lukes’ (2005) three-dimensional model of power in which he stresses the importance of the concept of latent conflict (Lorenzi, 2006). Lukes argues that the conflict is latent because those subject to power (i.e., adults with congenital deafblindness in their relationships with disability support workers and disability support workers in their relationships with scientist practitioners) do not express, or are unaware of, their own interests. Lukes asserts that those in power can exercise power over those subject to their power by influencing and shaping their wants and preferences. He also states that power can be exercised by preventing grievances in order to ensure the status quo. Lukes argues it is important to investigate this third dimension of power-the power to prevent the formation of grievances. “In order to gather evidence to support the claim that an apparent case of consensus is not genuine, but imposed, one must investigate inaction, consider structural and institutional power, and consider ways in which demands are prevented from being raised” (Lorenzi, 2006, p. 93). These ideas are consistent with Wareing and Newell’s (2002) notion of *a choice between no choice* inherent in the power imbalances evident in the disability sector. In addition, these ideas are useful to consider when looking at how the staff construct client happiness and account for their disengagement. They are also useful when contemplating the relationship between disability support workers and scientist practitioners. I will return to these ideas when looking at theory and practice in enhancing opportunities for adults with congenital deafblindness to experience the good life.

This study has highlighted the need for different research processes in order to achieve different research outcomes. We need to change the way we undertake research processes in order to do justice to the complexities inherent in the individuals and interactions involved in the research process (Reason & Rowan, 1981). This is also necessary to achieve more long-term sustainable outcomes.

Most research into interaction with people with congenital deafblindness, and those with profound intellectual and multiple disabilities, is of a clinical nature and many of the researchers involved in these fields are current or former practising clinicians. It is therefore reasonable to assume that the power imbalances evident in the research are equally present in clinical settings. For example, Neander and Skott's (2008) study of therapeutic processes in early intervention revealed marked perceived power imbalances from those receiving services. This however, requires further investigation in relation to services for adults with congenital deafblindness and profound intellectual and multiple disabilities.

There is also value in considering the language used in both clinical and research settings to maximise collaboration. In particular, how roles and titles are named. At the outset of this thesis I argued a case for using the term scientist practitioner to encapsulate the valuing of both science training and practice training of clinicians and clinical researchers. However, this term seems particularly alienating in the context of examining the quality of life of adults with congenital deafblindness or profound intellectual and multiple disabilities. Given the above argument for the need for more mutual, reciprocal, collaborative practice, I suggest scientist practitioners carefully consider the title they give themselves when working in the disability sector. The aim should be to minimise alienation and foster collaboration with families, staff and people with disabilities. Disability support workers are best placed to collaborate with scientist practitioners in improving the quality of life of adults with congenital deafblindness. I suggest scientist practitioners-working as researchers, clinicians or clinical researchers-name themselves *disability resource workers*. It denotes both the similarities, namely that both are working within the disability sector, as well as the differences, namely that support workers provide direct support while resource workers provide structures and strategies to enable this support. Regardless of the terminology used, it is imperative that at the outset of collaboration, roles and responsibilities within the relationship are made explicit and negotiated if necessary. It is reasonable to expect that disability support workers will engage with, and reflect upon, the processes if these are negotiated at the outset. Disability resource workers will bring information from the scientific literature and both groups will bring information from their workplace observations.

There are a number of philosophies, methodologies and constructs which appear more compatible with the needs articulated above. They show promise for progressing the situation for adults with congenital deafblindness and profound intellectual and multiple disabilities. Key concepts and principles inherent in good quality interactions, as presented by Rodbroe and Janssen (2006b), provide a useful framework for ensuring multiple perspectives are considered and that power is distributed more equitably. In particular, the concept of reciprocity appears to be a necessary element in fostering harmonious relationships between scientist practitioners and disability support workers. Edwards’ (2007, 2009) construct of relational agency also provides a useful backdrop to using an action research methodology and an integral theory approach to research and intervention that is more likely to effect positive long-term sustainable outcomes. These ideas are discussed further below.

An additional challenge in researching interactions with people with congenital deafblindness and those with profound intellectual and multiple disabilities is that there are necessarily two *others* with different roles, experiences and perspectives: the person with deafblindness and their interaction partner. Most research to date has focused on the interactions and relationships between the person with a disability and their communication partner. It has not addressed the interactions and relationships between the communication partner and the scientist practitioner.

Reciprocity

I assert that scientist practitioners need to practice what we preach in the field of congenital deafblindness: symmetrical, reciprocal, attuned co-created interactions with participants in our research and those involved in therapy with us. It is practice based on these principles of interaction that will create the conditions for new insights, learning and empowerment.

Reciprocity is a key concept to emerge from research into human communication development and a key principle in models of intervention with people with congenital deafblindness and profound intellectual and multiple disabilities (Chen et al., 2007; Rodbroe & Janssen, 2006b). Indeed, Daelman, Nafstad and Rodbroe (1993) assert that one of the greatest risks for a person with congenital deafblindness is a lack of reciprocity between themself and their environment. However, we need to apply this concept beyond interactions between clients and their communication partners, to our own interaction with the communication partners of our clients and the participants in our research.

Increasingly, scientist practitioners are recognising the importance of reciprocity in relationships in both clinical and research practices. A major theme generated by Neander and Skott (2008) in their study about parents' and therapists' experiences of early intervention was striving towards reciprocal responsiveness. Both parents and therapists remarked upon the fact that "those qualities that are important in normal relationships are just as important in the therapeutic relationship" (Neander & Skott, 2008, p. 300). Along these lines, Pound (2011) argues the need for more reciprocal, two-way relationships between healthcare professionals, including support workers, and people with communication disabilities. She states, "dominant cultural narratives of disability and rehabilitation tend to emphasise a unilateral perspective on need, dependency, and giving" (Pound, 2011, p. 197). Just as these narratives and cultures appear to persist in interactions and relationships between adults with congenital deafblindness and support staff, so too the dominant positivist research paradigm perpetuates this "unilateral perspective on need" of research participants. However, employing the social model of disability helps redress this imbalance and increases opportunities for more reciprocal interactions and relationships. “Social capital retains a focus on social connectedness and revisits the economic metaphor of the capital to be gained from investing in social ties and social networks” (Pound, 2011, p. 205).

Pound (2011) argues that paying attention to the social model of disability allows us to :

- create opportunities and conditions for people to develop as active citizens
- value explicitly human resources such as experience, knowhow, passion and compassion
- reconstrue service recipients as colleagues, providers and role models
- harness the resources they bring to therapeutic endeavours and civic wellbeing.

This in no way devalues the expertise of clinicians and researchers. Although Pound (2011) is talking about relationships between service providers and people with disabilities, the same holds true for relationships between scientist practitioners and agents of intervention, namely the communication partners of adults with congenital deafblindness. Indeed, her first point-“create opportunities and conditions for people to develop as active citizens”-can only be achieved if we apply the remaining principles to our relationships with the interaction partners of adults with nonsymbolic communication.

While Pound (2011) argues the need for reciprocity within therapeutic relationships, the need exists equally within the context of research. Petersen (2011) also argues for the need for reciprocity within the process of research with human participants. She claims that if we cannot say we have risked ourselves throughout the research process, potentially by declaring our intentions, beliefs and biases to the research participants, we cannot say it is reciprocal.

Tregaskis (2004) suggests a number of key principles that are useful to consider when examining how to progress the current situation for scientist practitioners, disability support workers and adults with congenital deafblindness. Using the social model of disability, she offers from her personal experience, “strategies to engage in dialogue through difference” which, while not explicitly stated, are clearly underpinned by valuing mutual and reciprocal interactions and relationships. The strategies she proposes are: developing a shared agenda for change; acknowledging and understanding the pressures faced by the other party; and sharing skills and knowledge to speed up achieving change. These strategies are consistent with Edwards’ (2007, 2009) notion of relational agency .

Relational agency

Edwards’ concept of relational agency “is intended to capture a capacity to align one’s thoughts and actions with those of others to interpret aspects of one’s world and to act on and respond to those interpretations” (Edwards, 2007, p. 4). It also aims to “strengthen purposeful responses to complex problems”

(Edwards, 2009, p. 39). One of the key findings of this study is the perspectival dissonance between scientist practitioners and disability support workers. The concept of relational agency is therefore useful to address this mismatch of worldviews and ultimately progress the situation for adults with congenital deafblindness and profound intellectual and multiple disabilities.

Edwards (2011) poses an argument which highlights one of the limitations in research with people with congenital deafblindness to date. She states “relational engagement with the knowledge and motives of others can produce a form of common knowledge which comprises a partially shared understanding of what matters for other contributing experts. This knowledge can then mediate responsive professional action”. Edwards (2011) also states that aiming for responsive professional action without engaging with the knowledge and motives of all those involved in the situation is erroneous. In terms of current research, there is evidence to suggest the efficacy of intervention strategies with people with congenital deafblindness and profound intellectual and multiple disabilities. However, the studies investigating these strategies have not examined the knowledge and motivations of the communication partners of the person with a disability. The current study highlights the marked difference in the knowledge and motives of scientist practitioners and disability support workers, and the need to acknowledge and consider these differences in worldviews before initiating, or as part of, the intervention process.

According to Edwards (2007):

- Strong forms of agency are necessary for professional practice in complex settings and can be learnt.
- Such agency needs to be evident outside the institutional shelters of established systems.
- Individual agency can be strengthened through a capacity for joint attention (Edwards, 2007, pp. 8-9).
- It is possible to contest interpretations of the object of activity, while working within sets of professional values.
- The nature of the object of activity mobilises and changes.
- Relationships are fluid, collaborations may be with different people, and relationships may shift within the action.
- Expanding objects of activity occur within co-evolving systems.

As mentioned previously, a limitation of intervention studies to date is that it is unclear whether the interventions are aligned with the values and priorities of staff, and the extent to which any mismatch in values and priorities might influence or affect intervention outcomes. However, in light of the findings from phase two of this study, the accounts and perceptions of support staff could lead us to believe there is no need for intervention. There is a need to problematise this situation in a meaningful way for disability support workers who work with adults who communicate nonsymbolically. A dialogue between scientist practitioners and disability support workers which necessarily challenges epistemological commitments is required in order to determine a shared goal or object of activity. As Edwards (2009) states “if object of activity and object motives are not aligned in the same way for each collaborator, attention needs to be paid to aligning their motives."

Further investigation is required to determine different professional groups' understanding of the good life, belonging and happiness, as their alignment is important to bring coherence across their specialist practices. This is the first stage of a three-stage process of preparation prior to relational engagement (Edwards, 2009). As a first step in this process, quality of life measures, such as the Quality of Life – Profound Multiple Disability (Petry & Maes, 2009a), could be used to start discussion around the experiences of clients in relation to belonging and relationship building. This could provide an opportunity to determine and negotiate shared objects of activity between different professionals working with adults who communicate nonsymbolically. Conversations are required about how we determine what constitutes a good life, belonging and happiness, and draw into question current epistemological commitments and social and cultural expectations.

With regard to the second and third stages stated above, how the good life is valued and evaluated is one of the multiple points upon which the perspectives of scientist practitioners and disability support workers are dissonant. It appears that the staff who are responsible for mediating the experiences of adults with congenital deafblindness have a perspective on this lack of opportunity that differs from what is typically valued in the research literature. This could feasibly present as a barrier to the enhancement of practice. In identifying these differences in worldview, the current study has started to elucidate the values, categories and motives which require discussion in order to negotiate action with regard to the good life for adults with congenital deafblindness.

Edwards' description of the two-stage process of relational agency within a constant dynamic is clearly applicable and valuable in addressing the nature of interactions with adults with congenital deafblindness and profound intellectual and multiple disabilities. These stages are:

> 1. Working with others to expand the 'object of activity' or task being worked on, by recognising the motives and the resources that others bring to bear as they interpret it
> 2. Aligning one's own responses to the newly enhanced interpretations with the responses being made by the other professionals to act on the expanded object (Edwards, 2009, p. 39).

The current study has commenced the process involved in this first stage articulated by Edwards. It has recognised some of the motives and resources of both scientist practitioners and disability support workers to expand an understanding of the good life for adults with congenital deafblindness. Clearly there is much more work to be done, however again, this affirms the need for seeking and working with multiple perspectives, and the value of qualitative methodologies.

There is little evidence of the second stage of relational agency in the scientific literature on work between scientist practitioners and disability support workers. Current intervention and research methodologies utilised in the field of congenital deafblindness require adaptation or expansion in order to support and facilitate these processes of relational agency to benefit all involved.

As discussed above, the current methodologies used in intervention studies with adults with congenital deafblindness are largely lacking in genuine reciprocity between researchers and participants. In addition, the role and value of relational agency is not addressed. In the next section I discuss methodologies that may help to tackle this situation. In particular, two mutually compatible approaches to research: Integral Theory and Action Research. Both are capable of addressing the complexities of researching interactions with adults with congenital deafblindness.

Recommended philosophical and theoretical frameworks

Integral Theory

Integral Theory is a relatively new approach to addressing and understanding multifaceted complex phenomenon. It offers a useful framework for considering both research and intervention with regard to the good life for people with congenital deafblindness and profound intellectual and multiple disabilities. There are multiple perspectives, social, political, economic and cultural factors influencing and impacting on the situation for adults with congenital deafblindness. An Integral Theory framework can help to ensure each of these elements is considered and addressed in progressing what is a complex situation. “An integral approach ensures that you are utilizing the full range of resources for any situation with the greatest likelihood of success” (Wilbur, 2006, p. 2).

Integral Theory, as a result of its applicability within, across and between disciplinary boundaries, has a wide range of applications. It has been used in fields such as healthcare, organisational management, ecology, economics, psychotherapy and community development (Esbjorn-Hargens, 2010; Hochachka, 2010). In looking at the residential settings of adults with congenital deafblindness as communities, Integral Theory's applicability across disciplines is valuable. It ensures the perspectives of all members of the community, regardless of role or discipline (e.g., resident, clinician, disability support worker, or family member), are valued and accounted for. This is also consistent with applying the notion of relational agency as discussed earlier.

According to Integral Theory, there are at least four irreducible perspectives which must be considered in the process of coming to understand any given topic or issue. Ken Wilber first introduced the integral approach and these perspectives in a quadrant model in 1995 (Esbjorn-Hargens, 2010). The four perspectives are: in the upper left quadrant, subjective (I, intentional); in the lower left quadrant, intersubjective (we, cultural); in the upper right quadrant, objective (it, behavioural); and in the lower right quadrant, interobjective (it is, social) (see Figure 1).

Figure 1: The four quadrants of Integral Theory

[Copyrighted material omitted]

This model demonstrates that any phenomenon can be viewed from an inside and an outside perspective, and from singular and plural perspectives (Esbjorn-Hargens, 2010). The right-sided quadrants are associated with practical systems and involve quantifiable, measurable exterior components of development. Practices associated with the right-sided quadrants include quantitative research, assessments, skill building and policy making (Hochachka, 2010). The left-sided quadrants are associated with the personal and interpersonal, and practices tend to be qualitative in nature. Practices associated with the lower right quadrant include dialogue, participatory methods, focus groups, participant-observer techniques, and appreciative inquiry. Practices associated with the upper left quadrant include self-reflection, self-inquiry, counselling, journaling, and meditation. It is worthy of note that participant-observer techniques potentially fall within the realm of Video Interaction Guidance techniques. These were discussed in chapter three and are becoming increasingly popular as an intervention technique to enhance interactions with people with congenital deafblindness and profound intellectual and multiple disabilities. However, when used in these contexts, the qualitative aspect of their transformative nature is not well documented or understood. The majority of research in this field has been of a quantitative nature. Few researchers who are working with the communication partners of people with disabilities have documented any reflections on the interpersonal or cultural aspect of their interventions. This is discussed further below in the context of a literature review of papers focusing on interactions with people with profound intellectual and multiple disabilities.

Applying these perspectives to the examination of the good life for adults with congenital deafblindness we can see there are at least three subjective, personal perspectives: that of the scientist practitioner, that of the disability support worker, and that of the adult with congenital deafblindness. It should be noted there is much work to be done to develop technologies which better contribute to an understanding of the perspective of adults who cannot self-report. Nevertheless, there are a variety of observable behaviours associated with the upper right quadrant within interactions as exemplified by most of the research in this field to date. For example, appropriate and inappropriate educator responses (see Janssen et al., 2003a), child and teacher actions and reactions (see Vervloed et al., 2006), and initiatives, confirmations, answers, turn taking, turn giving (see Janssen, Riksen-Walraven, Van Dijk, Huisman, & Ruijssenaars, 2011). The social, political and economic factors influencing policies governing the expectations of behaviour of the staff is associated with the lower right quadrant. The cultural context, determining the meanings given to interactions between staff and clients, and staff and scientist practitioners, is associated with the lower left quadrant. These are particularly important in the process of relational agency.

These four perspectives or dimensions are always present at any given moment. “Integral theory insists that you cannot understand one of these realities through the lens of any of the others” (Esbjorn-Hargens, 2010, p. 36). An individual has direct access to experiential, behavioural, cultural and social or systemic aspects of any given situation at any given time. So too, the quadrants can be applied to a given phenomenon, for example, the good life for adults with congenital deafblindness. Thus it offers a more integrated framework for both understanding situations and enabling sustainable transformation.

Each quadrant in Wilbur’s model contains levels of development; levels of depth within the quadrants on the left hand side, and levels of complexity within the quadrants on the right hand side. “The inclusion of levels is important because they allow us to appreciate and better interface with the realities associated with each quadrant" (Esbjorn-Hargens, 2010, p. 41).

Integral Theory applies a framework of quadrants, levels, lines, states and types. To exclude an element in any inquiry or explanation is to settle for a less comprehensive understanding of, or a reduced engagement with, reality (Esbjorn-Hargens, 2010). However, constraints of time and funding on research in the current climate are prohibitive to employing the full range of elements involved in Integral Theory. Notwithstanding this, addressing the first two elements of quadrants and developmental levels can still provide a considerably more integrated model than most other available research approaches.

Another advantage of an Integral Theory approach over other theoretical frameworks is its demonstrated capacity to address sustainable development. "Increasingly development practitioners recognise that people's interiority (feelings, beliefs, worldviews) influence and inform development interventions" (Hochachka, 2010). Sustainable approaches require individual needs to be met and "as an individual's sphere of consideration and care expands to include others beyond oneself, and as that person acts in concert with others who also share this expanded worldview, the closer the community or society comes to sustainability" (Hochachka, 2010).

The current study has highlighted that most research to date has focused primarily on the needs of the adults with congenital deafblindness without paying much attention to the needs of their interaction partners. As is stated above, when an individual’s needs are met they are able to expand their own focus of consideration to include others. Consequently, scientist practitioners must spend more time addressing the needs of interaction partners in order to achieve sustainable outcomes for people with congenital deafblindness.

The model in the literature review presented by Hostyn and Maes (2009) to demonstrate the key areas examined by researchers when investigating interactions with people with profound intellectual and multiple disabilities can be viewed in terms of the Integral Theory framework of quadrants. In doing this we can see aspects lacking from the research approach in work done in this area to date. The right and left sides of the quadrants are associated with qualitative and quantitative research methods, respectively. Thus to more fully understand a phenomenon of inquiry, mixed methods are required. However, none of the studies reviewed addressed all four of the quadrants or perspectives from which the phenomenon of interacting with someone with profound intellectual and multiple disabilities can be viewed. Only one of the 15 studies reviewed employed a mixed method design. It is noteworthy that most studies in this field centre on the upper two quadrants which address the perspectives and behaviours of individuals. Hostyn and Maes (2009) identified four studies out of 15 which provide some information about the influence of the setting, mostly from the perspective of staff. But much more work is needed to better understand if and how factors relating to the lower two quadrants, that is, cultural and social factors, influence interactions with people who communicate nonsymbolically.

A limitation of resources necessitates pragmatism in the current research environment. Studies such as that conducted by Hostyn and Maes (2009) which review current literature in terms of aims, design and findings, are of great value. They enable us to gain a more integrated understanding of the phenomenon in question, as they can pool the perspectives from different Integral Theory quadrants.

Applying an Integral Theory approach to the current study indicates that it has not considered the lower left quadrant, that is, the household co-created culture, or the lower right quadrant (its), that is, how organisation and government policies influence the situation and staff behaviours. There is clearly a need to examine what is occurring from the perspective of these lower quadrants. Given the current emphasis in governmental and organisational policies on community inclusion and community capacity building, it is of concern that the fundamentals of social interaction and relationship building are not evident as priorities in the discourse of those mediating support. As Reinders (2002) argues, community is an experience, not a place. It is beyond the scope of this thesis to address this issue more fully. But it is recommended that for a more comprehensive understanding of the situation for adults with congenital deafblindness that the perspectives from these lower quadrants are included in future research.

Participatory Action Research

This section does not go into a detailed account of Participatory Action Research. Rather, it gives a broad overview of the philosophical underpinnings of the approach and presents the key features that address the issues raised in this thesis. In this section I also present some key issues to be mindful of if the approach is to be used in the context of residential services for adults with congenital deafblindness.

The current study has revealed a number of concerns with typically used methodologies employed when investigating interactions of adults with congenital deafblindness and those with profound intellectual and multiple disabilities, as well as intervention studies aiming to enhance and improve these interactions. Participatory Action Research offers an alternative methodology for research in this field which addresses many of the concerns raised by the current study. The term Participatory Action Research encompasses a variety of approaches and has broad origins in human rights activism. Three attributes distinguish Participatory Action Research: shared ownership of research projects, community-based analysis of social problems, and an orientation toward community action (Kemmis & McTaggart, 2000). There is inherent value in taking a community action orientation, given that research with adults with congenital deafblindness necessarily takes place within the communities to which they belong. In addition, as identified in the above section on Integral

Theory, few researchers have addressed the perspective of the lower left quadrant which relates to the perspective of the cultural, we.

The application of Participatory Action Research to the residential communities of adults with congenital deafblindness is somewhat different to its traditional applications to communities who are oppressed and marginalised, often living in developing countries. However, the current study, combined with the available literature, consistently points to the need for development within the residential communities of adults with congenital deafblindness and those with profound intellectual and multiple disabilities. Indeed, one of the central issues to emerge from this study is that disability support workers do not view the extreme disengagement and limited opportunities for experiencing the good life of clients as a problem, and thus see no need for research. This again indicates that the needs of the staff should be examined more closely; as mentioned above it is only when individuals' needs are met that their sphere of care can expand.

Despite the setting being different to those in which Participatory Action Research has been traditionally undertaken, its central processes are well suited to addressing the issues inherent in typical research methods used in intervention studies with people with congenital deafblindness discussed above. The features of this methodology which address these issues are as follows.

- It recognises that there are differences between the frameworks and models used to understand and interpret reality by health professionals and by the people they are working with.

- It allows respect and empathy for the insights and knowledge people from different backgrounds have and the issues they face.
- It helps to avoid mistakes and develop programs that take into account the cultural, socioeconomic and political influences on the outcome of programs (De Koning & Martin, 1996).

Various names are used for very similar processes of research. Here, I am using the term Participatory Action Research. However, any action research method necessarily emphasises participation. This is noted by Greenwood and Levin (2007) who state that action research is composed of a balance of three elements: action, research, and participation. It is important to understand that Participatory Action Research means different things to different researchers and that it is not a method per se, but rather a methodology influenced by phenomenology, hermeneutics and feminist theory (Liamputtong & Ezzy, 2005). Both quantitative and qualitative research methods may be employed within a Participatory Action Research project. However, qualitative methods, such as in depth interviews, focus groups, life histories and participant-observation are most commonly used (Liamputtong & Ezzy, 2005). “Participatory Action Research aims to create new forms of knowledge through a creative synthesis of the different understandings and experiences of those who take part” (Liamputtong & Ezzy, 2005).

During Participatory Action Research, a key criterion for evaluating the quality of the research is to evaluate the quality of the participation. De Koning and Martin (1996) suggest the quality of participation is evaluated by questioning: does community participation happen at all stages of the research? Which groups in the community represent which parts of the process? However, as articulated by Hochachka (2010), participation is not a panacea and participatory methodologies require further work to achieve two key outcomes. First, the capacity of practitioners to employ participatory methodologies, and second, that the methodologies necessarily facilitate an understanding of the participants and the process of empowerment (Hochachka, 2010). “To work with participatory approaches effectively, requires a new understanding of development that is internalized in our institutions, interactions, attitudes and mind sets” (Hochachka, 2010, p. 24).

One of the central issues to emerge from this study is that disability support workers do not view the extreme disengagement and limited opportunities for experiencing the good life as a problem, and thus see no need for research. A research space is therefore required in which all participants’ perspectives can be contributed, acknowledged and valued equally.

> One of the unique qualities of PAR [Participatory Action Research] is that the research project should serve the shared interests of both the researchers and the researched community. In achieving this, a complex negotiation process is needed and most often it involves a shift of power between the researcher and the community (Liamputtong & Ezzy, 2005, pp. 195-196).

Integral Theory and Participatory Action Research processes offer philosophical and theoretical frameworks which address many of the issues inherent in the research carried out to date with people with congenital deafblindness and their interaction partners. The following section examines how a research and practice method might be operationalised within these philosophical and theoretical frameworks. Some Participatory Action Research projects begin with an intervention and, through this intervention, participation and dialogue lead to further development (Liamputtong & Ezzy, 2005). This approach fits well with the action research cycle, which involves repeated cycles of planning, acting, observing or collecting data or information, reflecting and reviewing, then starting the cycle again. Video Interaction Guidance (see Kennedy, Landor, & Todd, 2011) offers a potential means for achieving this and it is discussed in the next section.

Potential methods for operationalising the good life in research and practice

Intervention studies in the fields of congenital deafblindness and profound intellectual and multiple disabilities are starting to recognise the advantages of adopting a more participatory approach. As mentioned in chapter three, approaches such as Video Interaction Guidance and Marte Meo, which utilise the analysis of naturally occurring interactions which have been video recorded, are becoming increasingly popular. These approaches share some common philosophical underpinnings with Participatory Action Research. They both involve knowledge creation and learning through action and reflection. The Hanging Out Program (Forster, 2008), recommended as an intervention in chapter five to increase interactions between staff and clients, sits perfectly with Video Interaction Guidance. The filmed interaction is essentially a *hanging out* or HOP session. Video Interaction Guidance adds to the Hanging Out Program because it enables staff to observe their interactions and reflect on them with a trained guide.

This type of approach also addresses a key issue raised in chapter two. That is, evaluation of an interaction with a person with congenital deafblindness requires both a sound knowledge of the theory underpinning the evaluation tool as well as personal knowledge of the person with congenital deafblindness. Video Interaction Guidance is a collaborative process whereby the guide, a person with a sound knowledge of theories of human communication development and human interaction, works with the communication partner of a person with congenital deafblindness. As a result, both gain greater insights into the needs of both interaction partners. Consequently, this approach largely addresses the need for these two specific knowledge sets, which is required for a more thorough evaluation of an interaction.

However, most research to date that has involved Video Interaction Guidance with people with deafblindness has used quantitative research methods to evaluate its efficacy. As mentioned in chapter four, this limits the research participants' involvement in determining what is important to measure or evaluate. Using a more participatory research approach and more qualitative methods initially during a Video Interaction Guidance based intervention, would produce a more shared and collaborative approach to determining what needs to be evaluated and how. This approach is consistent with the process of relational agency discussed earlier in this chapter. In addition, as Video Interaction Guidance necessitates the filming of interactions, the videos can be observed and coded post hoc once the scientist practitioner and disability support worker have negotiated what there would be value in coding. If a quantitative approach is agreed upon, the recommendations with regard to coding and determining interrater reliability, which arose from the first phase of the study in this thesis, should be considered. However, all aspects of the research process would necessarily be discussed and negotiated between all research participants.

The outcome of this process would essentially be a means for operationalising the good life. This could take into consideration the need for a knowledge of the theories around quality of life and human communication development (responsibility of the scientist practitioner), the need for knowledge specific to the individual with deafblindness (responsibility of the disability support worker), the need for a co-created understanding of what the good life looks like for specific individuals, and the need for the research participants to have equal control in all aspects of the research process.

A potential tool that could be used for both intervention and evaluation in relation to increasing and enhancing opportunities for adults with congenital deafblindness to experience the good life is the Scale for Dialogical Meaning Making (see Hostyn et al., 2009). This tool was mentioned in chapter two when looking at potential ways of operationalising the good life and in chapter five when examining the merits of consensus coding. The more collaborative approach to coding and sound theoretical underpinnings in this tool means it has strong potential to address some of the issues with current methods for evaluating interactions. Nevertheless, its concept dense language would most likely be alienating to disability support workers. Therefore, further work would be required to explore how disability support workers perceive and express the concepts of the Scale for Dialogical Meaning Making. This could enable the language of the coded features of interaction to be changed to make it more accessible to them. These features could be negotiated by the scientist practitioner during Video Interaction Guidance sessions, and then videos of interactions with the same person with congenital deafblindness could be analysed using the negotiated codes and the consensus coding approach.

Depending on evaluation methods determined by the scientist practitioner and disability support workers within the context of a Participatory Action Research project, it is feasible and likely that the upper two and lower right quadrants of the Integral Theory framework of quadrants would be considered. However, I suggest there is great value in explicitly stating at the start of the research that current policy with relation to quality of life will be examined and interpreted by the community. An explicit statement should also be made at the outset that findings and learnings from the research process will be disseminated to policy makers in order to help inform and shape policy around quality of life for people with congenital deafblindness and profound intellectual and multiple disabilities. This ensures that the lower right quadrant is also addressed and incorporated into the process. The following section elaborates on the need for this information within the research process.

The need for specific policies

There is very limited information available about the impact of organisational and government policies on staff behaviours. As seen above when presenting the ways in which phenomena are examined using Integral Theory, it is imperative that the external social world, the sphere of the lower right quadrant, is considered, to have a full understanding of the situation. The need to address the influence of the external social world is highlighted by the current emphasis on community inclusion and community capacity building in government policy. It is of concern that the fundamentals of social interaction and relationship building are not evident as priorities in the discourse of those mediating support, particularly given that, as Reinders (2002) argues, community is an experience, not a place. For people with congenital deafblindness and profound intellectual and multiple disabilities it seems that there are some precursors to community inclusion which need to be addressed in organisational policy and staff development. These include the importance of supporting frequent, sustained and pleasurable social interactions, including with peers, family members and paid staff. However, based on the current findings, it cannot be taken for granted that these social interactions, fundamental to achieving what Reinders (2002) refers to as the good life, will occur. The expectation and the means by which they are to occur need to be made explicit in policy, service standards, procedures, and in staff development. As mentioned in chapter two, this thesis is not advocating that disability support workers become friends with the clients they support. Instead, I am arguing that disability support workers provide, as part of their work role, opportunities for intimacy, social togetherness and an experience of the good life. The aim of this is to optimise the quality of life of the adult they are working with. To achieve this, such an objective must be made explicit in policy and procedural documents.

Additional issues for consideration

While I have recommended an Integral Theory approach be taken to ensure sustainable outcomes of intervention with adults with congenital deafblindness, considerable work is required in addressing the perspectives of all participants from all four quadrants. As demonstrated by the literature review of Maes et al. (2007), multiple studies can lead to a more integrated understanding of what is occurring in a given situation. There would be great value in scientist practitioners working together collaboratively, but examining intervention approaches from different Integral Theory perspectives or quadrants.

Chapter Eight: Conclusion

This final chapter returns to the problem identified at the outset of this thesis when I questioned the extent to which adults with congenital deafblindness experience the good life. The chapter revisits the issues which became apparent when looking at how best to answer this question. Key learnings from the thesis are presented. The thesis concludes with a presentation of the limitations of the study and the theoretical, philosophical, research and clinical implications of the work undertaken in this study.

As described in chapter two, the good life can be operationalised as part of, as well as sitting within, the quality of life construct. Quality of life is a term used frequently in conjunction with interventions aimed at enhancing interactions with people who are congenitally deafblind. But little has been done to evaluate the impact of these interventions on the individual's quality of life, or their experience of the good life.

A major aim of this thesis was to investigate Reinders' (2002) construct of the good life in relation to adults with congenital deafblindness. Subsequently, when investigating the life experience of adults with congenital deafblindness, three key questions emerged.

1. How do we measure the quality of life of adults with congenital deafblindness who cannot self-report?

2. What are the perspectives of the primary interaction partners of adults with congenital deafblindness, namely disability support workers, and how might these perspectives contribute to an explanation of the low levels of interaction observed in quantitative studies?
3. What is needed to increase the likelihood that adults with congenital deafblindness will experience the good life?

There is much work required to develop valid and reliable measures of good quality interactions and relationships, especially for those with complex communication support needs, such as those with congenital deafblindness. This thesis provides some insights into features that need to be addressed when developing such measures, and approaches that could be adopted. These are set out below.

1. **A mixed method or multiple perspective approach.** This thesis highlights the value of using a mixed method, or mixed perspective, approach to ameliorate the shortcomings of individual methods or perspectives when used in isolation. A major issue with only using one method or perspective is that it provides only a partial understanding of the phenomenon being investigated. However, if only one research method is to be used, then the limitations of this method could be at least partially addressed by considering the perspectives of multiple stakeholders. For example, scientist practitioners, disability support workers, family members, and policy makers.

2. **The value of drawing upon literature on adults with profound intellectual and multiple disabilities to provide potential insights into the situation for adults with congenital deafblindness.** Given that both are low incidence disabilities, and thus will most likely attract less attention from researchers than other larger disability groups, there is potential value in collaboration between researchers from each field of interest. A good example of this type of collaboration is seen in how the Scale for Dialogical Meaning Making was developed. Input to the development of this tool came from both researchers with backgrounds in working with people with profound intellectual and multiple disability and those with backgrounds in working with people with congenital deafblindness.

3. **The need to more equally involve disability support workers in the research processes in which they are involved.** The disability support workers involved in the current study demonstrated a wealth of knowledge about the adults with whom they work: their abilities, disabilities, preferences, personalities and typical behaviours. As Schuengel, Kef, Damen and Worm (2010) state, the hearts and minds of disability support workers are our most valuable resource in working with people with profound intellectual and multiple disabilities. When seeking to ensure that the commitment, knowledge and skills of disability support workers are directed towards the best interests of their clients, it is vital that those providing direction and support to disability support workers first understand their perspectives. It is possible that past attempts to influence staff

behaviour in relation to their clients have not been successful because of a lack of alignment between policy, educational strategies and the a priori perspective of disability support workers. It is the power of these a priori perspectives to influence staff behaviour, and subsequently the experience and outcomes for people with congenital deafblindness, that was most evident in the findings presented in chapter six.

4. **Clear policies and procedures regarding the value and nature of social interaction with clients who are nonsymbolic communicators are required.** Evident in some of the findings of this thesis was that the disability support workers are often not applying all that they know about their clients to the clients' best advantage. For these reasons, clear policy, education, and effective frontline leadership are critical.

5. **The need to foster harmonious relationships between scientist practitioners and disability support workers.** Insufficient attention has been paid to these relationships in the research to date. Yet the philosophical perspectives of the social model of disability, relational agency, Integral Theory, and Participatory Action Research all concur with the importance of fostering and examining these relationships in order to effect positive sustainable change for adults with congenital deafblindness.

Based on the findings of the current investigation, a three-pronged approach to increasing the likelihood of adults with congenital deafblindness experiencing the good life is suggested.

1. **Create opportunities for intentionally building relationships between scientist practitioners and disability support workers, and between disability support workers and adults with congenital deafblindness.** The development of these relationships has the potential to increase the capacity of the support environment, including the direct support workforce, in a culturally sensitive, developmentally appropriate way. Video Interaction Guidance (see Kennedy et al., 2011; Kennedy & Sked, 2008), as discussed in the previous chapter, shows promise as a means of achieving this. It includes all three parties and employs processes consistent with those required for sustainable outcomes. The principles and practices of Active Support also provide a useful framework with an increasing evidence base within which Video Interaction Guidance could be utilised. These and other valuable programs have already been developed, but a lot more attention should be paid to the rationales and experiences of the direct support staff before implementing these programs. Given the critical role direct support staff have in the consistent implementation of support and intervention, programs that do not take into account the vision, experience and concerns of direct support staff run the risk of being ineffective and limiting positive change. This would address the lower left quadrant (cultural, we) when applying the Integral Theory framework for understanding phenomena, and

potentially the upper right quadrant (behavioural, it) depending on the nature of evaluating interactions and relationships.

2. **Factor time into every day to ensure opportunities to build and expand on social interactions and relationships.** Such processes need to be supported by mechanisms to formally monitor the allocation of this time and evaluate its impact on the lives of people with congenital deafblindness, and the staff providing their support. The Hanging Out Program (Forster, 2008), as discussed in chapters five and seven, suggests a protocol for ensuring such time is spent with clients. The principles and practices of reflective practice would also support this (see Carroll, 2010). This addresses the upper left quadrant of the Integral Theory framework (personal, I) and potentially the upper right quadrant (behavioural, it) depending again on how this is evaluated.

3. **Policies need to support staff in this challenging process by explicitly stating that they have a primary role of providing regular opportunities for sustained interactions with adults with congenital deafblindness.** Furthermore, staff rostering and budgeting need to acknowledge and reflect these activities as valued priorities. This would address the lower right quadrant of the Integral Theory framework (sociopolitical, its).

Limitations of this study

Small sample size

As discussed in chapter four, the low incidence and heterogeneity of deafblindness necessitates certain types of research design. The current study used, what is in deafblind research, a typically small sample. It is worth noting that nine is actually a much larger than usual sample in research in deafblindness. While small sample size means the statistical generalisability of the findings is problematic, the results from both phases of the study have been found to achieve resonance as discussed at the end of chapter six. Tracy (2010) argues that resonance is achieved through a study's potential value across contexts or situations, that is, its transferability. Certainly, both the theoretical and practical implications of this thesis have broader application than simply being limited to the context of the study. They are broadly applicable to any professional context in which team members working with a target group have different worldviews. They would apply in most residential facilities, such as nursing homes, hostels, generic disability residential services, and day services. It is also worth noting that the methods and findings of each phase of the study have been published in peer reviewed journals, thus undergoing additional scrutiny from those outside the research team involved in the project.

Impact of video recording

Video recording is becoming increasingly popular and common in research and practice with people with congenital deafblindness, yet it is not well understood how being video recorded impacts on people's behaviour. Erickson (1992) suggests that when people agree to be video recorded and trust the researcher, a video camera is no more obtrusive than a notepad or audio recorder. However, it remains difficult to ascertain the effect on behaviour of being video recorded. During the interviews all staff were asked if they thought what had been recorded was typical. All staff affirmed that it was, with some saying they were a little uncomfortable about being filmed at first but that this discomfort passed. It remains wise to exercise caution in presuming that human behaviour would have been the same, had it not been observed (see Angrosino & Mays de Perez, 2000).

Member checking

While all staff were asked to read transcripts of their interviews and those who responded reported them to be accurate accounts, no feedback was sought from staff on the final formulation of the results from the analysis of the interviews. Again, as mentioned above, while resonance was achieved, the method would have been improved by using a member checking process to further strengthen the trustworthiness of the results. This process was not possible in the current study due to time and other resource constraints (including the availability of the staff), but should be considered in future research of this nature.

Variable reliability

As presented in chapter five, the interrater reliability calculated in the first phase of the study demonstrated marked variability. Results for coded categories which achieved less than 60% interrater agreement should be considered with caution given that Watkins and Pacheco (2000) specify a criteria of interrater reliability of >60% to be acceptable.

Theoretical implications

The current study highlights the need for adjustments when applying human communication development theory (applied successfully with children), to intervention with adults with congenital deafblindness. As Forster (2011) argues, developmental theories of human communication are relevant to a degree when applied to adults with developmental disabilities, such as those with congenital deafblindness and profound intellectual and multiple disabilities. Indeed, as presented in chapter two, these theoretical frameworks for understanding human communication development offer a potential means of operationalising the good life. Models and frameworks, such as The Developmental Profile (Nafstad & Rodbroe, 1999), the PLAI (Promoting Learning through Active Interaction) curriculum (Chen et al., 2007), and the Scale for Dialogical Meaning Making (Hostyn et al., 2009) all draw upon human communication development theory. They also all highlight important processes, such as attunement, reciprocity, turn taking and giving, and coregulation of proximity and tempo necessary for mutually pleasurable sustainable interactions within which interaction and communication skills can be developed. However, Forster (2011) notes a number of reasons why interacting with an adult with profound intellectual and multiple disabilities might be different to interacting with an infant. These include: restricted movement, limited reaching behaviour and use of gesture, and reduced alertness. All of these contribute to fewer behaviours that might elicit attunement from interaction partners. These are consistent with the arguments of Ehrlich (2007), Nyling (2003) and Janssen (2009) They write about the differences between interacting with adults with congenital deafblindness as opposed to children with congenital deafblindness, as discussed in chapter two. Theories of human communication development have proved useful in shaping guidelines and strategies for further developing communication skills with people with congenital deafblindness. However, the current study together with Forster's (2011) work, highlight some unique differences for adults. These need to be considered and accounted for when applying a developmental framework grounded in human communication development theory to their interactions.

Taking an Integral Theory approach (as presented in chapter seven) can address these issues without diminishing the value of applying the theory of human communication development. Integral Theory provides a more holistic perspective and takes into account the sociopolitical and cultural influences on the interactions in question. The current study demonstrated the need to expand on existing theory in order to account for the differences observed in the situation for adults. Integral Theory provides a potential theoretical framework to achieve this, and its potential application could be the focus of future research.

Philosophical implications

As presented at the outset of this thesis, Reinders (2002) argues the need to consider the good life for people with intellectual disabilities. One of the key contributions of this thesis is the notion that if the relationships between scientist practitioners and disability support workers more resembled the relationships which Reinders (2002) describes when he is talking about experiencing the good life for people with disabilities, the greater the likelihood adults with congenital deafblindness may also experience the good life. The philosophical underpinnings of the social model of disability, relational agency, and Integral Theory, as discussed in the previous chapter, are all consistent with and support this assertion.

This philosophical stance means valuing and ensuring that multiple methods and perspectives are considered within collaborative, participatory processes involving all key stakeholders (most likely scientist practitioners, disability support workers, management within disability and government organisations and policy makers). This is potentially problematic in the current context. The disability sector has extremely limited resources and the research context more highly values quantitative methods than qualitative methods. This means considerable work is required to promote the value in working with more qualitative, participatory, philosophical underpinnings. Nevertheless, I maintain that to achieve sustainable systemic outcomes which increase the likelihood of all parties experiencing the good life, these more qualitative, emergent processes are required.

Hart (2010) articulates the paradox in the need for interaction partners of people with congenital deafblindness to be equals within the interaction while at the same time taking responsibility for the outcomes of interaction. This exact paradox mirrors what is required of scientist practitioners in working with disability support workers. To date these interactions have largely been unilateral with little evidence of reciprocity. While it is important to acknowledge the inherent power imbalances in these relationships, there is considerable scope for a more open discourse within the relationship. This will enable each others' understanding of the situation for adults with congenital deafblindness to be expanded, and ultimately progress this situation.

Research implications

The current study has highlighted a number of issues with methodologies typically used to examine interactions with adults with congenital deafblindness. It makes a number of key recommendations for future research in this area.

1. That mixed methods, or if not mixed methods at least multiple perspectives, are considered in the research process.
2. That scientist practitioners practice the type of attuned, reciprocal, balanced interactions with the participants in their research with disability support workers, which they expect disability support workers to practice with adults with congenital deafblindness.

3. Given the limited numbers of people with congenital deafblindness and limited resources to conduct research, it is recommended that scientist practitioners with similar research interests work together across state and national boundaries to increase the breadth and depth of studies undertaken.

Clinical implications

The worldviews of scientist practitioners and disability support workers differ markedly, as evidenced in this study. There is considerable value in using Edwards' (2007, 2009) construct of relational agency to foster harmonious relationships between scientist practitioners working in clinical practice and disability support workers working with adults with congenital deafblindness. The relationships between scientist practitioners and disability support workers were explored in chapter three. It was evident that the worldviews of scientist practitioners have largely dominated the discourse around interacting with people with congenital deafblindness and those with profound intellectual and multiple disabilities. In addition, for the most part the sustainability of intervention strategies used to date has been questionable. Using the construct of relational agency as a backdrop to interactions between scientist practitioners and disability support workers will better assist each to understand the needs and perspectives of the other. This will ultimately progress the situation for their shared clients and help to redress the lack of voice of disability support workers in the discourse around interacting with adults they support.

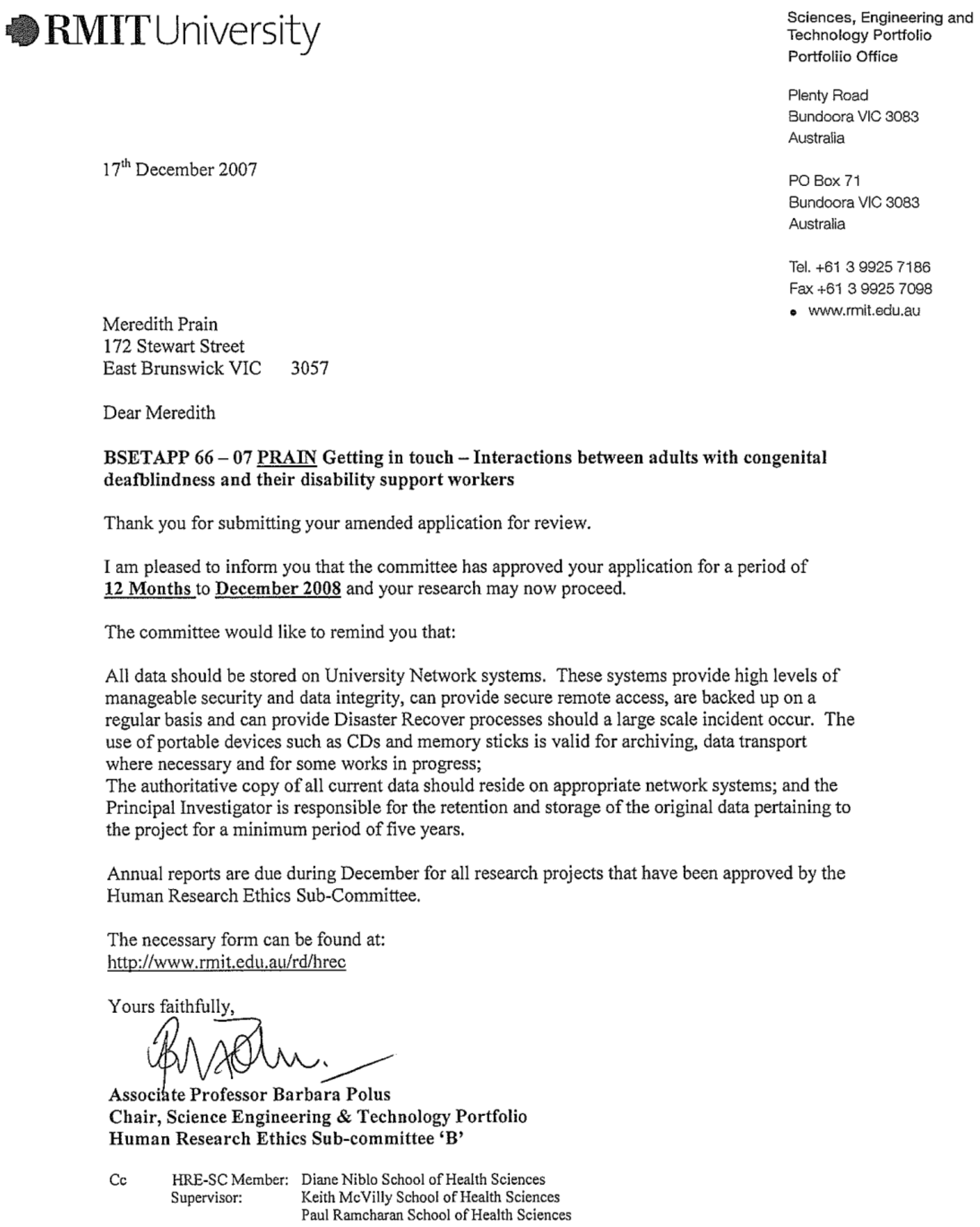
Closing remarks

This study has highlighted that both scientist practitioners and disability support workers share the object of activity of contributing towards positive emotional feelings in the adults with congenital deafblindness with whom they work. I have articulated these feelings in this thesis as being an experience of the good life, while in their interviews staff articulated this feeling as happiness. The study has also highlighted that considerable work remains in both determining how these positive feelings are evaluated and how conditions conducive to evoking these feelings are created on a regular basis in a sustainable way.

There are power imbalances inherent in both relationships between disability support workers and adults with congenital deafblindness, and those between scientist practitioners and disability support workers. Yet I maintain that with power comes responsibility. It is time for scientist practitioners to take responsibility and acknowledge and relinquish some of the power they have in order to engage in more reciprocal interactions with disability support workers. This will enable us to achieve the shared aim of positive feelings or the good life for adults with congenital deafblindness. In turn, this process may make the disability support workers’ sphere of care expand, enabling them to relinquish some of the power that affects the relationships they have with the adults with congenital deafblindness whom they support, and so achieve the all important experience of social togetherness that Reinders (2002) asserts as the basis of the good life.

Appendixes

Appendix A: Ethics approval



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17th December 2007

Meredith Prain
172 Stewart Street
East Brunswick VIC 3057

Dear Meredith

BSETAPP 66 – 07 PRAIN Getting in touch – Interactions between adults with congenital deafblindness and their disability support workers

Thank you for submitting your amended application for review.

I am pleased to inform you that the committee has approved your application for a period of **12 Months** to **December 2008** and your research may now proceed.

The committee would like to remind you that:

All data should be stored on University Network systems. These systems provide high levels of manageable security and data integrity, can provide secure remote access, are backed up on a regular basis and can provide Disaster Recover processes should a large scale incident occur. The use of portable devices such as CDs and memory sticks is valid for archiving, data transport where necessary and for some works in progress;
The authoritative copy of all current data should reside on appropriate network systems; and the Principal Investigator is responsible for the retention and storage of the original data pertaining to the project for a minimum period of five years.

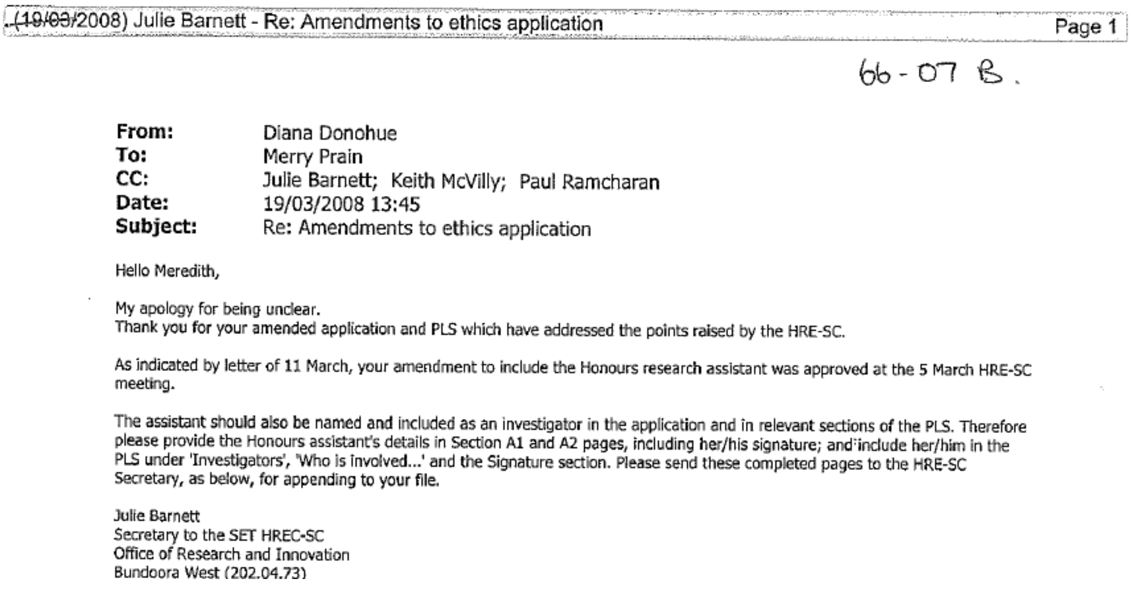
Annual reports are due during December for all research projects that have been approved by the Human Research Ethics Sub-Committee.

The necessary form can be found at:
http://www.rmit.edu.au/rd/hrec

Yours faithfully,

Associate Professor Barbara Polus
Chair, Science Engineering & Technology Portfolio
Human Research Ethics Sub-committee 'B'

Cc HRE-SC Member: Diane Niblo School of Health Sciences
Supervisor: Keith McVilly School of Health Sciences
Paul Ramcharan School of Health Sciences



66-07 B.

From: Diana Donohue
To: Merry Prain
CC: Julie Barnett; Keith McVilly; Paul Ramcharan
Date: 19/03/2008 13:45
Subject: Re: Amendments to ethics application

Hello Meredith,

My apology for being unclear.
Thank you for your amended application and PLS which have addressed the points raised by the HRE-SC.

As indicated by letter of 11 March, your amendment to include the Honours research assistant was approved at the 5 March HRE-SC meeting.

The assistant should also be named and included as an investigator in the application and in relevant sections of the PLS. Therefore please provide the Honours assistant's details in Section A1 and A2 pages, including her/his signature; and include her/him in the PLS under 'Investigators', 'Who is involved...' and the Signature section. Please send these completed pages to the HRE-SC Secretary, as below, for appending to your file.

Julie Barnett
Secretary to the SET HREC-SC
Office of Research and Innovation
Bundoora West (202.04.73)

RMIT University

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School of Health Science
Division of Disability Studies

PO Box 71
Bundoora VIC 3083
Australia

Appendix B: Invitation to participate in a research project

INVITATION TO PARTICIPATE IN A RESEARCH PROJECT
PROJECT INFORMATION STATEMENT

[This information sheet is to be provided to clients & / or their Guardians or family advocates, with assistance provided to read as appropriate, and to staff members who might volunteer to participate]

Project Title:
Getting in touch: interactions between adults with congenital deafblindness and disability support workers

Investigators:

Ms Meredith Prain (PhD Candidate, RMIT University)

Dr Keith McVilly (Project Supervisor: Lecturer, RMIT University,
E-mail: keith.mcvilly@rmit.edu.au, Telephone: 03 9925 7362

Dr Paul Ramcharan (Project Supervisor: Lecturer, RMIT University,
E-mail: paul.ramcharan@rmit.edu.au, Telephone: 03 9985 7521

Dear …

You are invited to participate in a research project being conducted by RMIT University. This information sheet describes the project in straightforward language, or ‘plain English’. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please ask one of the investigators.

Who is involved in this research project? Why is it being conducted?

This research project is being undertaken by Meredith Prain, as part of a PhD program at RMIT University. Meredith is investigating communication between adults with congenital deafblindness and those who provide support services. The project is being supervised by Dr Keith McVilly and Dr Paul Ramcharan who both lecture in the School of Health Sciences, Division of Disability Studies at RMIT University.

The project has been approved by the RMIT Human Research Ethics Committee. Able Australia, an organisation providing services to people with deafblindness is in support of the research project.

Why have you been approached?

You are either a family member or Guardian of an adult with congenital deafblindness and intellectual disability, or a person providing direct support services to adults with congenital deafblindness and intellectual disability living in supported accommodation.

What is the project about? What are the questions being addressed?

We know very little about how adults with congenital deafblindness interact and communicate with those who provide their support services. The purpose of this project, the first in a series of such studies, is to identify how and why adults with congenital deafblindness and the staff who work with them currently interact. The project will also explore the attitudes and perspectives of the staff towards interactions with their deafblind clients.

The key questions to be addressed by this research project are:

- What are the main functions of the interactions between adults with congenital deafblindness and their support workers currently?
- How do disability support workers currently view their interactions with adults with congenital deafblindness?

It is expected that 8 adults with congenital deafblindness and approximately 12 – 16 disability support workers will be involved in this initial study.

If I agree to participate, what will I be required to do?

Adults with congenital deafblindness - Your family member with congenital deafblindness will be videoed while at home during interactions with the staff in their house. There will be a person with a video camera at the house for approximately 15 x 3 hour sessions. These videos will be watched by two different people and the interactions will be analysed.

Disability Support Workers – You will be interviewed about your interactions with the adults with deafblindness with whom you work. The interviews will be 1:1 with the researcher and will take approximately one hour. Questions asked will focus on what happens during the interaction and how you feel about the interactions. You could also be invited to participate in a small focus group.

You will also be videoed during interactions you have with your clients. There will be a person with a video camera at the house you work in for approximately 15 x 3 hour sessions. These videos will be watched by two different people and the interactions will be analysed.

What are the risks or disadvantages associated with participation?

There are no perceived risks outside the participants' normal day to day activities. No one will see the videos except the researchers and research assistants. What you say and do is confidential between yourself and the researchers, except where the researchers are aware of any activity that places, or potentially places the person with disability at risk of harm or exploitation. In which case, the researchers are obliged to bring this to the attention of the appropriate authorities.

If you are concerned about your responses to any of the questions during the interview or if you find participation in the project distressing, you should contact Meredith Prain or Dr Keith McVilly as soon as convenient. Meredith or Keith will discuss your concerns with you confidentially and suggest appropriate follow-up, if necessary. Alternatively you can speak with an advocate or other appropriate person.

What are the benefits associated with participation?

While there are no direct personal benefits to any of the participants in this study, there are potentially longer term benefits for both adults with congenital deafblindness and their disability support workers. These potential benefits include developing a better understanding of both adults with congenital deafblindness and those who support them and thus having an evidence base to inform staff training and on which to develop and deliver better services.

What will happen to the information I provide?

Information you provide will be kept in a locked, secure place or in password protected computer files. The research data will be kept securely at RMIT for a period of 5 years before being destroyed.

Only the researchers and research assistants will view video footage of you or your family member.

Any information that you provide can be disclosed only if (1) it is to protect you or others from harm, (2) a court order is produced, or (3) you provide the researchers with written permission.

It is anticipated that the results will be disseminated in papers for publication and conference presentations. However, in any publications or conference presentations, no real names will be used when disseminating information and every effort will be made to hide the identity of participants.

What are my rights as a participant?

- ✓ The right to withdraw your participation at any time, without effecting the services provided to your family member or, if you are a staff member, your employment.
- ✓ The right to have any unprocessed data withdrawn and destroyed, provided it can be reliably identified, and provided that so doing does not increase the risk for the participant.
- ✓ The right to have any questions answered at any time.

What other issues should I be aware of before deciding whether to participate?

This is most likely the first study in a series of studies and you may be requested to take part in future research projects. You can of course decline to participate in future studies.

Whom should I contact if I have any questions?

Dr Keith McVilly; E-mail: keith.mcvilly@rmit.edu.au; Telephone: 03 9925 7362

Yours sincerely

Ms Meredith Prain	**Dr Keith McVilly**	**Dr Paul Ramcharan**
PhD Candidate	Project Supervisor	Project Supervisor

This information sheet is for you to keep.

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation,
RMIT, GPO Box 2476V, Melbourne, 3001.
Details of the complaints procedure are available at:
http://www.rmit.edu.au/rd/hrec_complaints

Appendix C: Sample of interrater reliability calculations

Date: 30 April 2008

Movie: 031

Name: WM

	Resident Behaviour						**Staff Behaviour**						**Resident Behaviour**						**Staff Behaviour**					IRR
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Appendix D: Interview schedule

Tell me about your background - what led you to this job?

Tell me about your last shift?

How was that shift for the clients? a, b, c, d, e

Tell me about a time you spent with the clients during your last shift a, b, c, d e

Can you tell me about other times you've spent with them? a, b, c, d, e

Prior to watching the video – how has it been for you being filmed?

Show video

Tell me about what's happening here

Is this typical?

Is there anything else you'd like to tell me about interacting with the clients or in general?

Appendix E: Sample interview

WAL interview 20/10/08 34 mins

First of all I was wondering if you could just tell me a bit about your background. I know you just did that but can you say it again for the tape recorder? So what brought you into this field?

Yeah, so I used to be an IT consultant, um and I took a year off as part of a community service program for Extensia where I used to work. And it was minimal pay leave for a year and I decided to try disability and I loved it so much I decided not to go back to my old job.

That's pretty impressive. So did they, like did Able Australia pay you or your…

No, um it was equal to unemployment pay for people to go out and do what they wanted to do.

Right.

And during that time I decided to do the TAFE course and work part time for Able as well during that year.

Right, okay, so the position was advertised at Able?

Yep.

Oh cool. I've never heard of anyone coming to Disability that way. Um and can you tell me about your last shift? Just talk me through what happened on your last shift. Were you here over night?

No I do morning shifts usually.

Yep okay that's fine.

So just what I do? Um like what?

Um, I guess just tell me what happened from the time you got here.

Um, well I come in at 7 and whoever does the sleepover the routine is pretty set 'cause we all know pretty much who does what. Um so the sleepover person will have three people of their choice showered um by the time I come in. Then I come in and um shower whoever is still in bed.

So who was it today?

Today was the two guys.

Mmhmm.

So yeah I did, I showered XX and XX. Just usual, nothing out of the ordinary, they were very cooperative, they you know they knew their stuff. You know they knew what to do, um and then yeah I gave them breakfast um, got them dressed, gave them breakfast, um did the laundry, made the beds while they were eating.

Mmhmm.

So when they finished eating what did they do? They um, yeah XX was ready to be picked up about quarter past eight and XX was just walking around the house um or crawling around the house, whatever he does. Um and then I got the bus ready. Um.

So, how, what do you do to get the bus ready?

Oh I just reverse it out of the car port and it’s easier for them to walk straight to the door.

Oh great. Yeah that’s a good idea.

So at the end of the rail, I sort of stop the door at the end of the rail so they just jump in and they don’t have to wander off somewhere else. They can feel the bus at the end of the railing.

That’s really good.

I just, yeah, I don’t know what the other guys do but that’s what I do. So I park it right next to the railing.

You don’t know if any of the others do that as well?

No, I think we all do it differently. I think some of them let the clients walk around the railing and then into the bus which you could do as well um or you can do what I do which is just park it straight just…

Keep it straight.

Yeah, then you can open the door as wide as you want for them to get in and not damage the car. Um and then they pretty much walk themselves to the car, into the car. Um I seatbelt them and then I get XX into the car last because he doesn’t like waiting. He’s quite an impatient bloke. What else? And then I drive them to their day service.

Oh okay so whoever comes in in the morning does the bus run.

Yeah I do the bus run ‘cause the night, they might have had a bad night, didn’t have enough sleep or whatever so it’s best not to let them drive the car.

Mmhmm.

So that’s our thing here.

Okay.

And then um pick up, yeah drop off the medication. Monday mornings we drop off the medication at the chemist after I do the bus run. Um do you want me to get into detail or just…

Um…

Like when I drop them off what they do?

Yeah that would be good.

So when I drop XX off at Gateway, it’s just around the corner ‘cause he doesn’t like being in the bus. He gets agitated when it’s too warm in the bus, gets agitated when it takes too long ‘cause we’re stuck in traffic and agitated at the red lights um yeah.

So what does he do when he’s agitated?

He just starts to kick things.

Mmm.

The seat, he starts to bang back, he’s thrashing around the back and he starts biting his knuckles. He never hurts us. He doesn’t, he knows, he might reach out and sort of touch us but very gently.

Mmhmm.

He’ll self-harm and harm property but never other clients or staff. So, he’s good that way. But yeah, take him out and pretty much they’re ready to take him into the, take him into Gateway. Yeah straight away.

Okay that’s good.

Um, cause they know he doesn’t like to wait too.

[Laughs] He’s got everyone sussed out.

Um and then I drop XX and XX at um Knox. It's Scope's day service. Um yeah and it's all ladies there and it's quite nice and they do activities. They really enjoy going.

What makes you think that?

Um because they come home, they're just really happy.

Okay.

You can feel their um, not all the time 'cause I think sometimes they might have new staff or try new things, they might get a bit anxious but when it's set into a routine I think they like it. Yep.

And so when you said they come happy, what is it about them?

Um, they just come home really relaxed um you know not fidgety or anxious or not um acting abnormal. Well not normal for them. You know. Um 'cause we know what is abnormal for them and we know when they're not relaxed.

Mmhmm.

Just yeah.

So they might be vocalising more?

Yeah, jumpy, or they might be noisy in their vocal sounds or they might be, might do things that are not normal behaviour, you know like um XX might go and sit somewhere that's not her usual position.

Gee I've never seen her do that.

She doesn't do that but you know for example you know something's a bit not right.

And so what would you do if they are behaving differently?

Um I try to investigate what, you know, why she's like that medically and what happened during day service. Sometimes it happens too with XX when she comes home. She's not quite herself and we sort of we would ask at day service how she was.

Mmhmm, okay that's great. So, you dropped XX and the two women and the bus gets the other two.

Yeah the other bus comes before we leave. We leave at 9 and the other bus comes pretty early about 8:15, 8:30.

Mmhmm, okay and then you just come back and do…

And then I finish the cleaning yeah when I come back.

And how do you think the last shift was for the clients.

Um the shift, no, yeah, just routine. Nothing out of the ordinary, just, they just, they knew, like I tap XX on the shoulder and she knows that it's time to get on the bus. And I sort of shuffle XX. She knows that yeah yeah it's time to get into the wheelchair and it's time to, 'cause she knows she's not going to the toilet at that time, like she just knows, she knows.

'Cause they've got dressed…

Yeah like XX, if I tap her on the shoulder at you know any other time she would go to the toilet or she would think that she's eating but that time she just knows. They all know, their, their, what they need to do.

Mmhmm, so the morning is one of the most routine times.

Yeah it's very structured 'cause there are just so many things to do.

Mmhmm.

And we've got a very limited time frame to do it.

Mmhmm and I guess that's a sign that they enjoy it, that they do get up and…

Yeah, yep, yep, XX was um, he couldn't wait to go this morning, he was just standing by the security door looking out like you know just trying to get out.

Is that unusual?

Yeah, no, sometimes he does that. Sometimes yeah.

It's a good sign isn't it?

Yeah.

That they enjoy their placement. It's interesting, so clearly he likes it but that time on the bus.

He doesn't like it yeah. He just doesn't like the bus.

Um, and can you tell me about a time that you interacted with each of the clients during the last shift. So, yeah, I mean you've done that a little bit. Would you have interacted with all five clients?

No, yeah, in some way I would have to, because yeah, I would have to get everybody ready or I'd have to tell them it's time to eat or it's, but not in a social sense, in a sense that oh you know, you have to go to the toilet now or you need to you know eat now. It's time for your medication. It's more it's very um what do you call it, sort of more…

Functional.

Yeah yeah in the mornings yeah.

So are there times in the day when there is more social?

Yeah that would be in the afternoon or on the weekend. Probably more on the weekend than in the afternoon. The afternoon we sort of just let them relax and chill out a bit so, yeah other than when we take them to the doctors or whatever.

So can you even think of a weekend or afternoon shift that you've worked recently and talk about times that you interacted with each of the clients.

Yep. Um, I worked yesterday but yesterday I was pretty much busy doing paper work.

Right.

Getting all the um profiles, typing up…

For the audit?

Yeah, I was pretty busy yesterday. XX and I are XX's key worker so yesterday sort of we were doing that um but we took 'em outside um Saturday and Sunday just to sit outside, enjoy the sunshine, get a bit of sun on their skin 'cause they're a bit pale. Um, get on the trampoline with XX. That's what we did this weekend. Yeah, pretty much. Did the paper work.

Okay um and how have you felt about being videoed?

Yeah I'm fine with that.

Okay that's good.

Yeah yeah.

Do you think it changed the way you would normally be?

Not really, I mean, I'm more conscious obviously of how I'm looking and you know but other than that we just do what we need to do.

Mmhmm and do you feel that what was videoed was pretty typical?

Yeah, yeah, probably, yeah.

Mmhmm okay.

There was one video really early on when you were sitting with XX.

Yeah yeah, yeah.

So could you talk me through that?

Um so in the afternoons we like to usually chill out a bit um except when we have to take them out for appointments or whatever. Um when we don't I like to spend a little bit of time, I mean I can't spend time with all of them. But because XX XX and probably XX are more functional. XX just likes being on his own. Occasionally he might sort of want a cuddle or you know just follow you round a little but he's not, he just likes being alone.

So what happens if you would approach him?

Um he would just do that (pushes with her forearm) that get away, I don't want you near me um when we introduce new things especially. Um yeah, if he's happy he's right, if he's happy we just leave him unless we need to go out for some reason.

Mmhmm.

Um with XX. 'Cause he's one of the least functional in the house I find it quite difficult to interact with him and know what his response is. A lot of times he's just very disinterested, uninterested. Um, when you get him involved in stuff he just sort of, just has this snotty look on his face and he puts his nose up at you. Um, and gives you this I don't know, like a no, I'm not interested, and just sort of covers himself with a T-shirt or puts himself in a ball and he's just not, that's just how he is.

He actually pulls away from the…

He, when you try to get him to do whatever, like maybe play strings with him or you know or give him a towel to pull or whatever he'll just yeah, he'll just do that. So he's the least sort of you know functional in terms of I don't know cooperative or interested. He's the least interested is probably the right word.

Mmhmm.

Um, but XX, XX and XX love interaction from us.

Mmhmm.

Yep. So it encourages us obviously more to spend some time with them.

Sure, yep okay. So perhaps talk me through that time with XX.

So yeah, before dinner we've got a bit of time like about 3:30 to 4:30 before cooking and after coming home and afternoon tea that sort of one hour I try to spend that hour with someone and that day was XX, giving her, you know she gets bored. She can hear us and you know she can hear the TV but um I think she gets bored in the afternoon. So I tend to I don't know, like we don't take her for walks every day but we do something and I was just trying to give her an activity to do. She hadn't strung beads and pasta for a while so yeah I thought I'd let her do that.

Mmhmm and so that's something she enjoys?

She likes stringing stuff. Yeah. But not all the time. You wouldn't give her like beads and pasta to string every day. She wouldn't do it.

Mmhmm.

But if you bring, it's like with my son, if with his toys you know I'll let him play with them for a few weeks and then I'll hide them for a few months and then when they come out it's always, it's brand new, oh wow. New activities, new toys. It save money.

That's a good strategy.

Yep

What about with XX and XX?

Yep. XX is more like physical so we give her massages. She loves sort of physical interaction with us. Um, head massages, shoulder massages, back rubs, she loves that or just holding hands and stroking. Yep. She loves touch and she's very gentle. Um we do that with XX.

And so how do you know she loves that.

Because she'll cuddle up to you when you do it. She'll watch and she'll, when you go away she'll grab you and put your hand to wherever she wants you to touch her like her head or wherever and ask for more.

Mmhmm good, that's rewarding.

Yeah she'll be like, you just know when, she leans into you when you do those things.

Mmhmm.

Yep.

Okay and XX?

With XX lately it’s been a bit harder ‘cause she’s been quite ill.

Mmhmm.

And we’ve had to be a bit more careful with her arm.

Mmhmm.

‘Cause she had a fracture and it’s still healing.

When was that?

Oh, during day service.

Oh no.

Yeah, so it’s taken her a long time to heal over it. Yeah internally as well. So with XX we tend to be more gentle, we, we don’t do as much as we used to with XX.

Mmhmm.

‘Cause XX used to really like doing stuff, like play dough, but she’s lost some feeling or some movement in one of her arms with the fracture um yeah so it’s a bit sad that way.

Mmhmm.

Or she just likes us tickling her and playing with her like she just has the biggest smile on her face like she’s enjoying it. We’ll play peek-a-boo with her, hide her face with a blanket. Yeah she loves that.

Someone was telling me that’s a ritual is it before bed?

XX, yeah, XX does that with her.

Oh good okay.

Yeah, she just has the biggest smile on her face.

Good okay, so is there, so there’s things with each of them, even with XX that he likes. Is there anything you can think of that XX likes?

XX has his box of toys, he’s got his box of toys and he pretty much plays with them on his own with like his one good arm. So he’ll um I’m not sure if you video taped but what he does is, I put it on the side, I think the others do too, I put it on the side of his good arm. That’s what I do. You know he’s got one good arm um so we put the box on that side all these little toys for him and he knows or if he knows that when he sits on his chair like he knows to reach around for his box of toys and when it’s not there ‘cause it’s cleaned up it’s not there, oh there’s one there, I didn’t see that. He’ll um, yeah we’ll know he’s looking for it.

Because you’ll see…

Yeah sweeping the floor for it and then we’ll bring it over and he spends quite a lot of time entertaining himself with all the toys.

Mmhmm

Um putting them in his mouth and then touching it, feeling it and he finds it quite hilarious throwing it around the room. It hasn’t hit anyone so it’s not a destructive behaviour.

It’s not too far that they go is it?

No. So that’s what he does.

And you can’t join him in it?

Well there’s not really much that we could, other than pick up his toys and put them, and he could continue flinging it. ‘Cause when he runs out he just gets bored and then he just falls asleep when he’s bored.

Uhuh okay. So you said XX sometimes comes up and will cuddle you?

Yeah he comes up and cuddles us.

So then does that mean he wants…

He wants some time with us yeah.

So what would you do?

So then we’ll just give him a cuddle. Walk around. ‘Cause he holds onto us. When we walk around. He cuddles up from the back um so we’ll walk around with him hanging onto us from the back um yeah and just let him do that for a while until he pushes us away and he’s had enough.

So you just go about your routine

Yeah we just, yeah yeah yeah. He does, he'll hold on and if for example I go to oh make the lunches or something he'll just hold on while I make the lunches um and he's not um, he's not, he doesn't physically. He doesn't distract you, like he won't grab my hand and say no don't butter the bread. He'll just hold on.

He's just there.

Yeah. He'll just hold on.

Does he watch what you're doing?

He sees through, sort of through one eye. He can see us.

So he's a bit interested in whatever you're up to.

Yeah.

Okay okay that's great. That's pretty much all I had so is there anything else you think's important to mention or say about working with these clients.

Um I really enjoy working here. With them.

That shows.

I really like working here.

What is it that you think you like?

I don't know. I'm really happy when I finish my shifts and go home. I feel good.

Terrific.

I feel like I've been out and about doing stuff.

Mmhmm.

Um, obviously this job pays a lot less than what I used to get paid for but it's more um in the community interacting with different people that I like about it.

Okay.

Yeah and it's not just a nine to five stuck in the office sort of a job.

Sure.

That I like.

Okay that's great. We're lucky to have you.

Yeah.

Okay terrific thank you so much for your time I really appreciate it.

[Stopped interview and then started again when more information came up in post interview conversation.]

Oh also, I was just going to say that when they're at home sometimes they have an appointment like with a specialist in the middle of the day 'cause it's hard to get these appointments we keep them at home. If they're unwell or, for some reason we have to keep them at home

Mmhmm.

Usually we have one or two people at home um it's often a really good opportunity with us, and I know the others do this too, um because the ratio is in favour of the staff, it's either 1:1 or 1:2 depending on the combination of the residents

If they have to stay home does the roster change so that someone is there?

Yeah yeah.

You have extra staff right through the middle of the day?

If there are more than four then we have two staff on but if there are only one resident or two then there's just one staff. Like I'll just stay through my morning shift until 2 o'clock. Um and it's a really good opportunity for us to um take them out one on one or one on two and what we usually do is we take them out to the grocery shopping, we take them out doing chores with us.

Mmhmm.

And they really really like it. They, it's like a special time um you know they get that one on one time with us. Um and we yeah we often do that when they're at home.

And so how do you know they like it?

Um because they're really good when we go out. Um if they didn't like it they would vocalise, like they would let us know and they would not cooperate with us when we go out but all the time they will just go along.

And that's true of all five of them?

No, no, XX doesn't like going out, period.

Okay.

XX doesn’t like going out. We’ve taken him out and he just doesn’t, he really doesn’t like it. So we, yeah, he really just doesn’t like, he wants to stay here.

Okay.

XX doesn’t mind either way. Um XX LOVES going out during the day time ‘cause I might take her out to buy some bread, some milk, or we’ll have a coffee, she loves her… she’ll carry the groceries um push the trolley. She loves it. XX’s really really great. Um XX you’ve got to push her in but she likes it as well ‘cause she’ll feel the air and um XX’s really good as well.

Mmhmm.

So XX XX and XX.

You said XX in particular really loves it. What is it she does that makes you know that she really…

I don’t know, but she really likes going out. As long as it’s not a noisy place like during Christmas time is not a good time to take XX out.

Sure.

But um usually yeah, like she really really really likes it.

Okay, that’s great. So it’s only if they have an appointment.

Yeah, usually if they’re at home and for some reason that they’re at home and we stay home with them.

Mmm.

That is a great opportunity to take them out. Yeah ‘cause on the weekends ‘cause we don’t, we can’t use the bus for the wheelchairs, cause that bus won’t allow us to use a wheelchair and the old bus we could only fit in one or two wheelchairs and three of them sit in wheelchairs so we’ve got a sort of like a transport issue. Logistics with these guys and number of staff um number of wheelchairs.

It’s usually two staff to five.

But we’ve got three wheelchairs that need to be pushed so it doesn’t work out if we want to go out on the weekends with them it would more likely be…

Could one go out with two?

Yeah if, one could go out as long as um there is only one wheelchair to push and the other so that when we go out because XX needs a wheelchair, XX needs a wheelchair um XX needs a wheelchair and XX doesn’t like going out you know the chances are you would take XX in the wheelchair and let XX hold onto the handle of the wheelchair.

Mmhmm.

Or take XX out and have XX hold the handles of the wheelchair.

So really, one of the three and XX.

Yeah that’s right.

Uhuh.

Yeah with one staff.

So does that happen sometimes?

Yeah it happens sometimes, yeah when we need to run out and do stuff we’ll take them.

Mmhmm.

Yeah but it’s just organising um the…

It’s a bit hit and miss.

Yeah it’s got to be the right place.

Mmhmm.

For, ‘cause you don’t wanna be stuck in a place that’s unfamiliar with two unhappy residents.

[Both laugh.]

You just wouldn’t want to be in that situation.

Sure.

Okay that’s terrific to hear that. How often would that happen?

It depends. Like the other day XX took um who did he take. He took XX ‘cause XX always gets to go out ‘cause she’s the most physically able and he chose to take XX to a BBQ in Croydon ‘cause they have a trampoline and XX loves trampolines. Um when they went there they both chucked a tantrum ‘cause it was noisy and there were a lot of people.

Was it at the Croydon house?

Yeah.

Okay.

Yeah they didn’t have a very good time.

Oh that’s a shame.

Yeah.

It was a good idea. Did XX go on the trampoline?

Yeah. He doesn’t like people XX. He likes to be on his own. Yeah. We’ll try and do something else.

So if those situations come up you’ll always give it a go?

Yeah like if there’s an opportunity like we’ll do it, but there’s always that possibility, it’s often a really good possibility that they won’t enjoy it and if they don’t enjoy it we won’t enjoy it. So yeah.

Mmhmm.

It’s got to be the right combination of place time and resident.

Uhuh and not too noisy, fingers crossed. Would you say most of the time they do enjoy it and it only backfires sometimes?

Well I play it safe ‘cause I don’t want to put myself in that situation. I play it safe and I know what works. And what works is taking XX out with me one on one gong for a walk, going to the shops, doing the groceries and I know that works. And I also know that it works with XX and XX and I know that it works with um XX and like XX in combination with XX, doing these things with me um but I wouldn’t attempt it in a shopping centre or take them for a walk with XX and XX or XX and XX ‘cause you know the chances of it turning bad are pretty high.

Yeah sure. And what do you do at the supermarket and shopping centre?

Well um XX just holds onto the side of the wheelchair so I don’t need to guide her.

She can just…

She follows, she holds onto the handle of the wheelchair yeah and I push the wheelchair and when I need to buy something XX holds the groceries for me and then XX or XX will have the other groceries or whatever on her lap.

Okay great so they're involved and they know there's stuff going on.

That's, it works for me.

Yeah that's really good for them too. Yeah okay, I'm really glad you said that. Okay. Is there anything else?

No, I don't, not really, unless you've got any other questions to ask.

They're the main questions. That's really, yeah.

And yeah, that's just dong that is from learning over time you know.

How long do you think it took you?

Oh it took me a while to um feel comfortable enough to take them to the doctors or take them to do things like that because when I started with Able I was a respite worker so that helped a lot and coming into the house you know you've got another staff to help you but when you're doing respite you're on your own so coming from a more challenging area.

And do you think you learnt a lot from the other staff members?

Yeah we always exchange tips which helps.

Yeah it seems to be a pretty stable group of staff here which is good. I think it makes a big difference for the clients.

Yeah and when we do, like we had a new casual um XX come home on the bus because she just knows your voice. Her sense of hearing is very acute and she just knew this person was new and she she was, she just cracked it you know, she started to bang her head, she started to scream, bang her head on the ground banged her head against the wall and she hasn't done that for a long long time.

And it was because of the new…

She knew we had a new person um yeah.

So what do you do when that happens?

We medicated her because that staff was sleeping over and she calmed down. Yeah she got used to the staff after a few hours. She was fine.

Okay

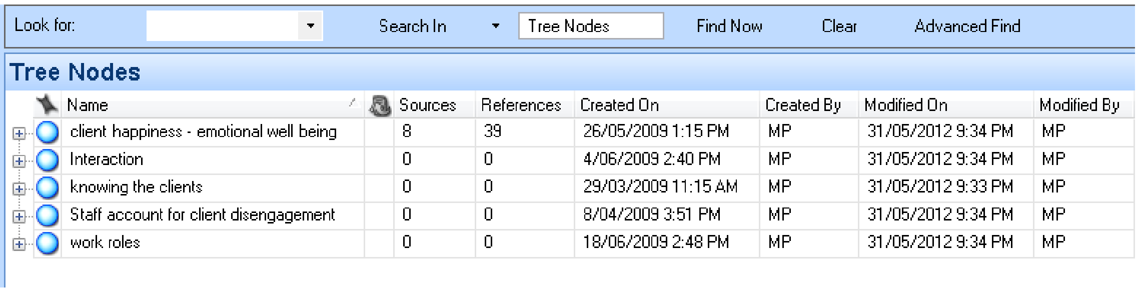
Like she was really good after dinner but it was just the first three hours that she sort of didn’t.

It’s hard isn’t it? Okay. Great.

[Interview ends.]

Appendix F: Coded categories induced using NVivo

1: NVivo project showing coded categories induced



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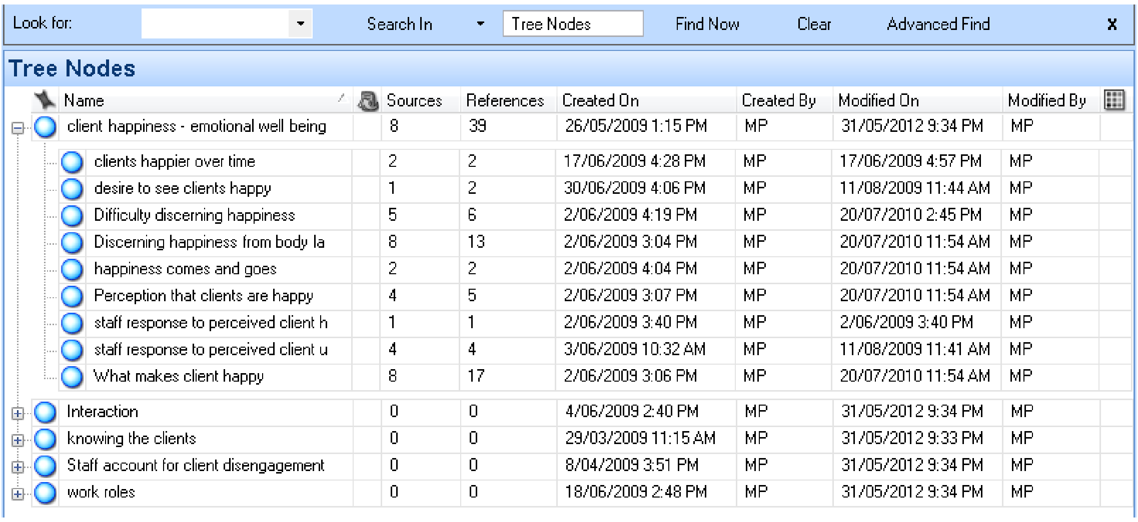
Interaction	0	0	4/06/2009 2:40 PM	MP	31/05/2012 9:34 PM	MP
knowing the clients	0	0	29/03/2009 11:15 AM	MP	31/05/2012 9:33 PM	MP
Staff account for client disengagement	0	0	8/04/2009 3:51 PM	MP	31/05/2012 9:34 PM	MP
work roles	0	0	18/06/2009 2:48 PM	MP	31/05/2012 9:34 PM	MP

2: NVivo project showing coded categories induced related to client happiness



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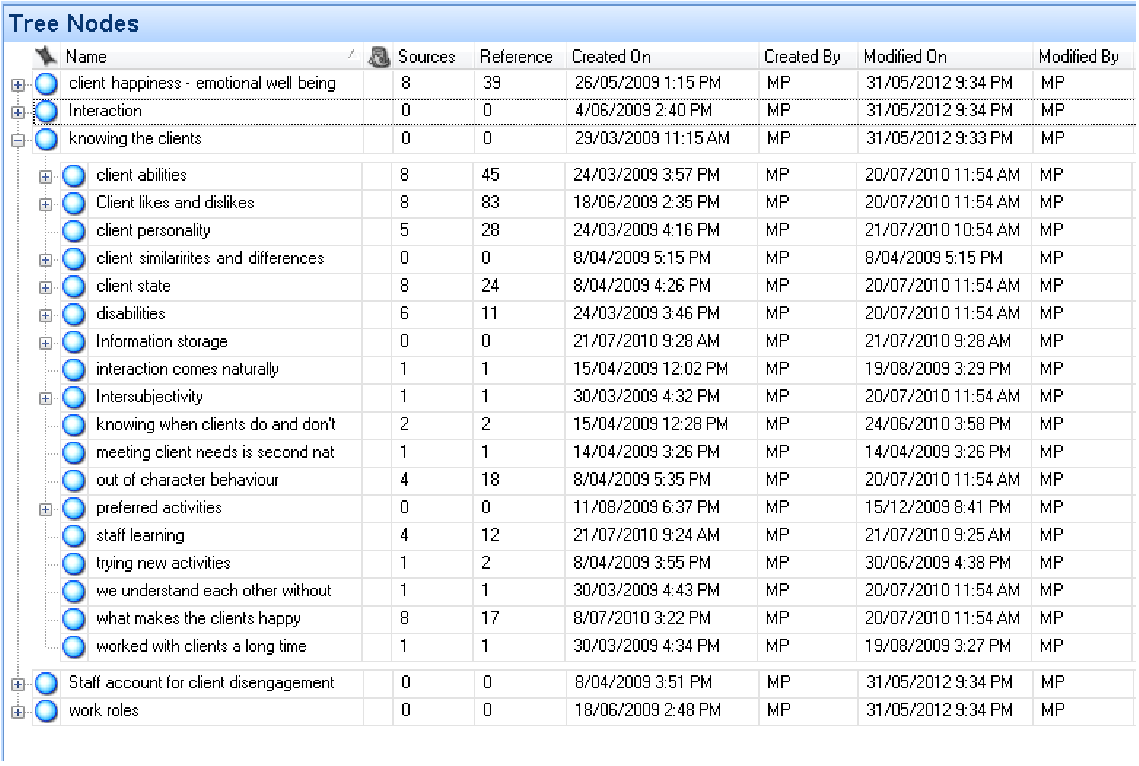
clients happier over time	2	2	17/06/2009 4:28 PM	MP	17/06/2009 4:57 PM	MP
desire to see clients happy	1	2	30/06/2009 4:06 PM	MP	11/08/2009 11:44 AM	MP
Difficulty discerning happiness	5	6	2/06/2009 4:19 PM	MP	20/07/2010 2:45 PM	MP
Discerning happiness from body la	8	13	2/06/2009 3:04 PM	MP	20/07/2010 11:54 AM	MP
happiness comes and goes	2	2	2/06/2009 4:04 PM	MP	20/07/2010 11:54 AM	MP
Perception that clients are happy	4	5	2/06/2009 3:07 PM	MP	20/07/2010 11:54 AM	MP
staff response to perceived client h	1	1	2/06/2009 3:40 PM	MP	2/06/2009 3:40 PM	MP
staff response to perceived client u	4	4	3/06/2009 10:32 AM	MP	11/08/2009 11:41 AM	MP
What makes client happy	8	17	2/06/2009 3:06 PM	MP	20/07/2010 11:54 AM	MP
Interaction	0	0	4/06/2009 2:40 PM	MP	31/05/2012 9:34 PM	MP
knowing the clients	0	0	29/03/2009 11:15 AM	MP	31/05/2012 9:33 PM	MP
Staff account for client disengagement	0	0	8/04/2009 3:51 PM	MP	31/05/2012 9:34 PM	MP
work roles	0	0	18/06/2009 2:48 PM	MP	31/05/2012 9:34 PM	MP

3: NVivo project showing coded categories induced related to knowing the client



Tree Nodes

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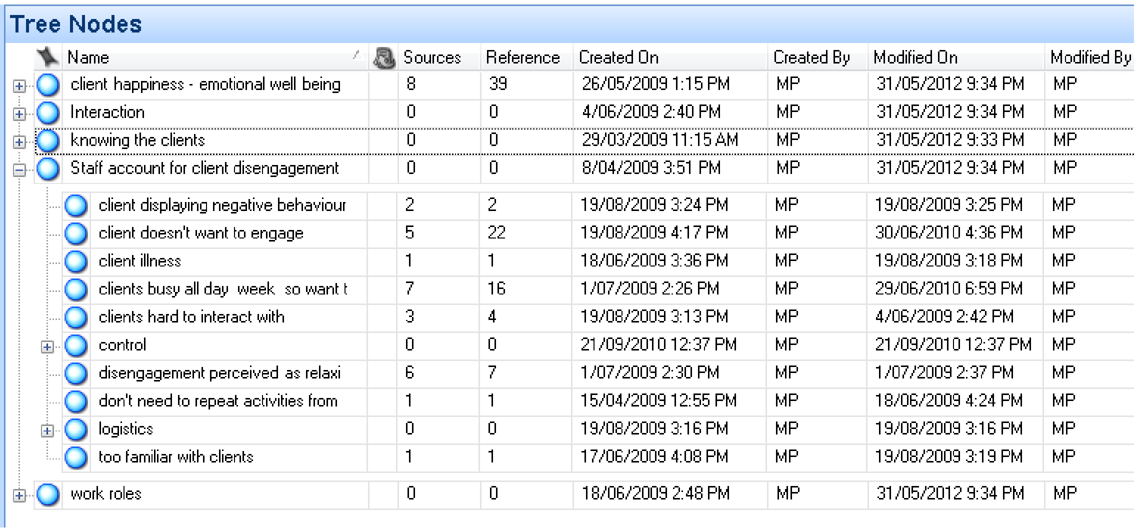
Interaction	0	0	4/06/2009 2:40 PM	MP	31/05/2012 9:34 PM	MP
knowing the clients	0	0	29/03/2009 11:15 AM	MP	31/05/2012 9:33 PM	MP
client abilities	8	45	24/03/2009 3:57 PM	MP	20/07/2010 11:54 AM	MP
Client likes and dislikes	8	83	18/06/2009 2:35 PM	MP	20/07/2010 11:54 AM	MP
client personality	5	28	24/03/2009 4:16 PM	MP	21/07/2010 10:54 AM	MP
client similarirites and differences	0	0	8/04/2009 5:15 PM	MP	8/04/2009 5:15 PM	MP
client state	8	24	8/04/2009 4:26 PM	MP	20/07/2010 11:54 AM	MP
disabilities	6	11	24/03/2009 3:46 PM	MP	20/07/2010 11:54 AM	MP
Information storage	0	0	21/07/2010 9:28 AM	MP	21/07/2010 9:28 AM	MP
interaction comes naturally	1	1	15/04/2009 12:02 PM	MP	19/08/2009 3:29 PM	MP
Intersubjectivity	1	1	30/03/2009 4:32 PM	MP	20/07/2010 11:54 AM	MP
knowing when clients do and don't	2	2	15/04/2009 12:28 PM	MP	24/06/2010 3:58 PM	MP
meeting client needs is second nat	1	1	14/04/2009 3:26 PM	MP	14/04/2009 3:26 PM	MP
out of character behaviour	4	18	8/04/2009 5:35 PM	MP	20/07/2010 11:54 AM	MP
preferred activities	0	0	11/08/2009 6:37 PM	MP	15/12/2009 8:41 PM	MP
staff learning	4	12	21/07/2010 9:24 AM	MP	21/07/2010 9:25 AM	MP
trying new activities	1	2	8/04/2009 3:55 PM	MP	30/06/2009 4:38 PM	MP
we understand each other without	1	1	30/03/2009 4:43 PM	MP	20/07/2010 11:54 AM	MP
what makes the clients happy	8	17	8/07/2010 3:22 PM	MP	20/07/2010 11:54 AM	MP
worked with clients a long time	1	1	30/03/2009 4:34 PM	MP	19/08/2009 3:27 PM	MP
Staff account for client disengagement	0	0	8/04/2009 3:51 PM	MP	31/05/2012 9:34 PM	MP
work roles	0	0	18/06/2009 2:48 PM	MP	31/05/2012 9:34 PM	MP

4: NVivo project showing coded categories induced related to staff account for disengagement



Tree Nodes

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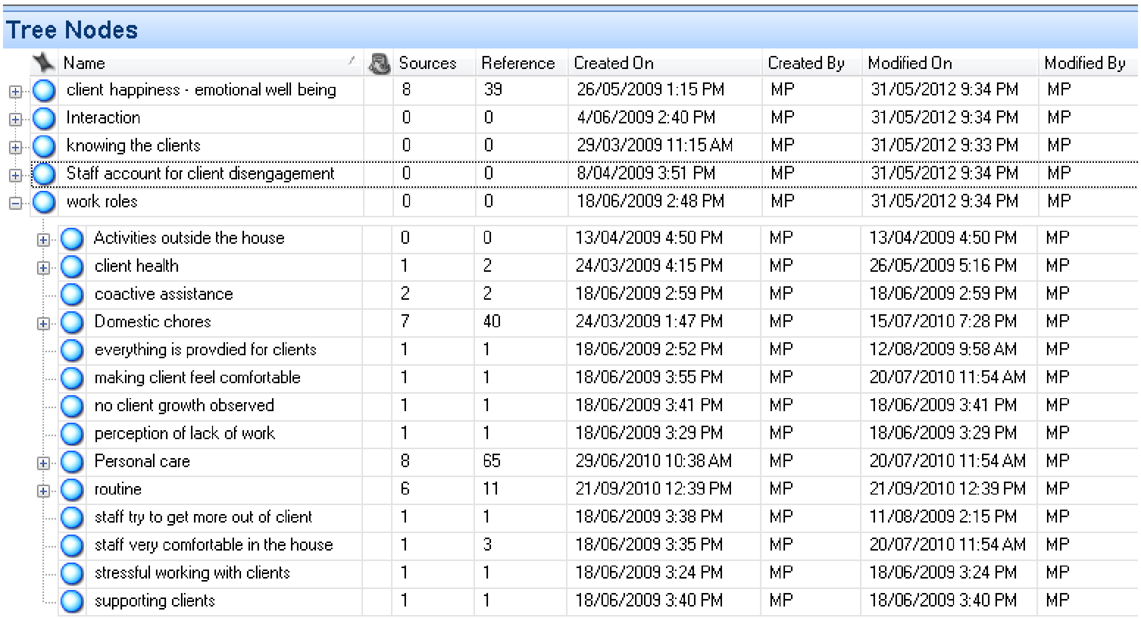
Interaction	0	0	4/06/2009 2:40 PM	MP	31/05/2012 9:34 PM	MP
knowing the clients	0	0	29/03/2009 11:15 AM	MP	31/05/2012 9:33 PM	MP
Staff account for client disengagement	0	0	8/04/2009 3:51 PM	MP	31/05/2012 9:34 PM	MP
client displaying negative behaviour	2	2	19/08/2009 3:24 PM	MP	19/08/2009 3:25 PM	MP
client doesn't want to engage	5	22	19/08/2009 4:17 PM	MP	30/06/2010 4:36 PM	MP
client illness	1	1	18/06/2009 3:36 PM	MP	19/08/2009 3:18 PM	MP
clients busy all day week so want t	7	16	1/07/2009 2:26 PM	MP	29/06/2010 6:59 PM	MP
clients hard to interact with	3	4	19/08/2009 3:13 PM	MP	4/06/2009 2:42 PM	MP
control	0	0	21/09/2010 12:37 PM	MP	21/09/2010 12:37 PM	MP
disengagement perceived as relaxi	6	7	1/07/2009 2:30 PM	MP	1/07/2009 2:37 PM	MP
don't need to repeat activities from	1	1	15/04/2009 12:55 PM	MP	18/06/2009 4:24 PM	MP
logistics	0	0	19/08/2009 3:16 PM	MP	19/08/2009 3:16 PM	MP
too familiar with clients	1	1	17/06/2009 4:08 PM	MP	19/08/2009 3:19 PM	MP
work roles	0	0	18/06/2009 2:48 PM	MP	31/05/2012 9:34 PM	MP

5: NVivo project showing coded categories induced related to work roles



Tree Nodes

Name		Sources	Reference	Created On	Created By	Modified On	Modified By
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Interaction		0	0	4/06/2009 2:40 PM	MP	31/05/2012 9:34 PM	MP
knowing the clients		0	0	29/03/2009 11:15 AM	MP	31/05/2012 9:33 PM	MP
Staff account for client disengagement		0	0	8/04/2009 3:51 PM	MP	31/05/2012 9:34 PM	MP
work roles		0	0	18/06/2009 2:48 PM	MP	31/05/2012 9:34 PM	MP
Activities outside the house		0	0	13/04/2009 4:50 PM	MP	13/04/2009 4:50 PM	MP
client health		1	2	24/03/2009 4:15 PM	MP	26/05/2009 5:16 PM	MP
coactive assistance		2	2	18/06/2009 2:59 PM	MP	18/06/2009 2:59 PM	MP
Domestic chores		7	40	24/03/2009 1:47 PM	MP	15/07/2010 7:28 PM	MP
everything is provdied for clients		1	1	18/06/2009 2:52 PM	MP	12/08/2009 9:58 AM	MP
making client feel comfortable		1	1	18/06/2009 3:55 PM	MP	20/07/2010 11:54 AM	MP
no client growth observed		1	1	18/06/2009 3:41 PM	MP	18/06/2009 3:41 PM	MP
perception of lack of work		1	1	18/06/2009 3:29 PM	MP	18/06/2009 3:29 PM	MP
Personal care		8	65	29/06/2010 10:38 AM	MP	20/07/2010 11:54 AM	MP
routine		6	11	21/09/2010 12:39 PM	MP	21/09/2010 12:39 PM	MP
staff try to get more out of client		1	1	18/06/2009 3:38 PM	MP	11/08/2009 2:15 PM	MP
staff very comfortable in the house		1	3	18/06/2009 3:35 PM	MP	20/07/2010 11:54 AM	MP
stressful working with clients		1	1	18/06/2009 3:24 PM	MP	18/06/2009 3:24 PM	MP
supporting clients		1	1	18/06/2009 3:40 PM	MP	18/06/2009 3:40 PM	MP

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