SOCIAL INTERACTIONS AND PROCESSES THAT UNDERPIN POSITIVE
RELATIONSHIPS FOR ADULTS WITH SEVERE INTELLECTUAL DISABILITY
AND LIMITED SYMBOLIC COMMUNICATION SKILLS

Submitted by

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SUMMARY OF THESIS

Social interaction is central to the development of relationships and having relationships assists with participation and inclusion. Little is known about the relationships that people with severe intellectual disability have with others. The aims of this research were to investigate the processes underpinning positive relationships for people with severe intellectual disability who communicate at a symbolic but nonlinguistic level.

A constructivist grounded theory approach was adopted for data collection and analysis. Six adults with severe intellectual disability and limited communication were observed interacting with people identified as personal affinity network members. Data consisted primarily of field notes and interviews with personal affinity network members.

A nonlinear model of five core processes that underpinned positive relationships was developed from observing the interactions between a subset of personal affinity network members (paid workers and family members) and adults with intellectual disability and limited communication. Personal affinity group members experienced *sharing the moment* and having fun or hanging out while either simultaneously or sequentially getting to know the person and *recognising the individual*. A process of *connecting* strengthened the relationship based on providing security and adjusting communication. The outcome of these processes was *feeling good*, which was experienced as happiness by everyone involved in these interactions. Personal affinity network members then *shared the message* through taking responsibility for passing information and spreading the news to others. The implications are that the identified processes provide a means through
which relationships can potentially be developed and supported. These relationships form the basis of social inclusion for these individuals. Directions for future research include the translation of the processes in the model into a practice framework for disability support workers.
STATEMENT OF AUTHORSHIP

I, Hilary Johnson, certify the work contained in this thesis is my own. Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma. No other person’s work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

Associate Professor Jacinta Douglas, Professor Christine Bigby and Professor Teresa Iacono provided supervision for the candidate while completing the thesis.

The study was approved by La Trobe University Human Ethics Committee No 08-008; Scope Human Ethics Advisory Committee 33/08 and University of Monash Humans Research Ethics Committee No.2008001489.

Signature of candidate

Date. 25/5/12
PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS THESIS


Invited Conference Presentations


Peer Reviewed Abstracts and Conference Presentations


CHAPTER 1: INTRODUCTION

Over the last twenty years, inclusion has become recognised as a right for all people with an intellectual disability and is a social policy goal across the western world. Being socially included involves developing relationships in order to build a social network that enhances each individual’s well being. As people with severe intellectual disabilities are known to have difficulties engaging with others and to have relatively small social networks, they may experience social exclusion and a poor quality of life.

Little is known about the way in which people with a severe intellectual disability interact or go about their relationships. If people with a severe intellectual disability are to be socially included, it is important to explore what is involved in social interaction and perceived as contributing to positive relationships. Such exploration will provide insights into how to foster inclusive practices.

People with severe intellectual disabilities have multiple disabilities and present with complex communication challenges to the people who support them (van der Gaag, 1998). Until the 1970’s in Australia, most people with severe intellectual disabilities lived in large institutions but since that time many have been rehoused in small group homes, comprising three to five residents, situated in the community. The 1970’s not only brought changes in government policies towards institutionalisation but also philosophical changes in the care of people with an intellectual disability (Nirje, 1985; Wolfensberger, 1972). Internationally, a paradigm shift occurred with the introduction of a social model to replace that of a medical model, the remnants of which still remain today (Oliver, 1996). The social model recognises that although people may have impairments that affect their functioning, it is society that disables people by placing barriers to access. Access barriers serve to limit social connections and so maintain negative attitudes that stereotype people with disabilities. This
social paradigm shift has been slow to be embraced by allied health workers such as speech pathologists, but with the adoption of the International Classification of Functioning, Disability and Health (World Health Organisation, 2001) and the Participation model (Beukelman & Mirenda, 2005) there is now a framework for implementing socially inclusive communicative interaction processes in everyday environments.

People with severe intellectual disability present with a range of communication difficulties that constrain their independence and interactions. Many of them have limited symbolic communication and are considered to have complex communication needs. Thus, they require skilled people with whom to engage and facilitate their interactions. Unfortunately, the social networks which are the source of relationships and support for people with severe intellectual disability are often small and limited to family, paid workers, and sometimes other people with intellectual disability (Kennedy, Horner, & Newton, 1990). As people with severe intellectual disability age they are increasingly supported by staff both in group homes and in day centres. The staff with whom they regularly interact have little specialised training. They have been reported to demonstrate difficulty in recognising nonverbal behaviours (McConkey, Morris, & Purcell, 1999) and observed having problems in adjusting their communication style to meet the needs of the people they support (Purcell, Morris, & McConkey, 1999). If, according to Duck (1988) “communication is both the method and substance of relationships” (p.233), there appears a need to increase an awareness and understanding of how communication happens between social network members and people with severe intellectual disability. This ability to socially interact is relevant in the push for social inclusion – as not only are staff required to communicate with the people they support but also to facilitate others in the community to include people with severe intellectual disability in their daily lives.
Although various pieces of legislation and policies have sought to encourage the inclusion of marginalised groups, facilitating the social inclusion of people with severe intellectual disability is a complex long term goal. In Australia, the 2002 ten-year Victorian state disability plan stated that: “By 2012, Victoria will be a stronger and more inclusive community - a place where diversity is embraced and celebrated, and where everyone has the same opportunity to participate in the life of the community” (Department of Human Services, 2002, p.7). This aspiration has not been achieved, perhaps because largely untrained support workers have been expected to expedite social inclusion with little understanding of what it entails, and with limited resources or guidance.

In a search for ways to promote social inclusion, many disability services have focussed on ensuring people with intellectual disability use community facilities and are seen to have a community presence (Balandin, 2011; Clement & Bigby, 2009; Todd, Evans, & Beyer, 1990). Nevertheless, as Clement and Bigby (2009) pointed out having a presence does not constitute social or community inclusion. In fact for people with a disability, community presence has not meant inclusion, rather it has resulted in participating in a parallel activity in a community space or “breathing the same air” (P. Mirenda, personal communication, November 3, 2011).

Developing relationships are central to social inclusion. Although there is anecdotal evidence of positive and mutually rewarding relationships between people with severe intellectual disability and paid workers, the factors involved in developing these relationships are not apparent. As Professor Bigby commented at a seminar in the UK:

We don’t really know what keeps together the relationships that parents, family members, and close others have with people who have ID. It's not reciprocity in the normal sense of the word, it's not the trappings, and it’s not instrumental giving. Nevertheless the people who have close relationships gain something from it that
keeps them there. Understanding the nature of these relationships may give us insights into the humanness of people with IDs, and not only give us a better understanding of how to portray them to the outside world but also clues about engaging others in their lives (Clegg, 2010 p. 74).

With the ultimate goal of increasing social inclusion, the aims of this research were to explore the social interactions of people with severe intellectual disability and limited speech and to examine what is involved in relationships. The focus was on examining positive relationships - those that are mutually pleasurable - in order to reveal the processes and experiences involved.

As little is known about relationships and adult with severe intellectual disability a constructivist grounded theory methodology was adopted (Charmaz 2006). Grounded theory can be used to develop a theory, model or framework in order to provide insights into complex human phenomena, such as social relationships (Mills, Bonner, & Francis, 2006). This approach allows for the collection of different data types (e.g., field notes from observation, interviews, reflections) to capture what is happening and to record the perceptions of research participants. Constructivist grounded theory was considered the appropriate methodology for the research question because it helps reveal the dimensions of experiences and also allows for a symbolic interactionist stance to be incorporated. This stance is fitting for a speech pathologist intent on the process of co-construction of meaning and focussed on understanding the essence of social interaction. Thus analysis of the data drew on my professional experience and expertise.

Data was collected over two years on six adults with severe intellectual disability and limited communication, and those with whom they were observed to be interacting socially. A subset of social network members were identified as having positive relationships according to a set of criteria and termed positive affinity network members. The personal
affinity network members comprised family members, workers and peers with an intellectual disability. The trustworthiness of the data was established through discussing the findings with those involved and applying Charmaz’s criteria of credibility, originality, resonance and usefulness (Charmaz, 2006).

The research process gave rise to five publications during the course of the study. The key findings of the study have resulted in a substantive model that identified the processes in relationships and provides insights into how to foster relationships for adults with severe intellectual disability. The process of using grounded theory allowed for shifts in emphasis through the research process and although the overall aims of the research relate to understanding how social inclusion can be more clearly understood for people with severe intellectual disability, each published paper reflected slightly different aspects of social interaction and relationships. The chief outcome of the study was a model consisting of five core processes that underpinned positive relationships. The model provides a road map for developing relationships with implications for practice for speech pathologists, direct support workers and disability organisations. As social inclusion still figures high on the government/disability agenda for people with severe intellectual disability, it may be that increasing an understanding of what happens in relationships may be a critical step in increasing social interaction and social inclusion for adults with severe intellectual disability

**Organisation of the Thesis**

This thesis is by publication with five papers published or in press, each of which is integrated into the thesis. The thesis comprises nine chapters.

**Chapter 1** has introduced the problem addressed in the thesis and has given a short précis of the literature, aims, method and results. It also provides a note on terminology that may not be understood by professionals other than speech pathologists. A key concept is
explained that describes the central participants in the study – adults with severe intellectual
disability who communicate at a symbolic but nonlinguistic stage of communication.

Chapter 2 consists of the first article published in the *International Journal of Speech-Language Pathology*. The authors present a discussion of the relevant literature underpinning the provision of mainstream speech-language pathology services to adults with severe intellectual disabilities and outline the communication issues for speech pathologists working with adults with severe intellectual disability in Victoria, Australia. In particular there is a focus on practice considerations that might assist speech-language pathologists in providing effective and efficient services that support people with severe intellectual disability to be included in their communities. Five main considerations are discussed: (1) applying a holistic model to communication practice; (2) understanding terminology and the process of assessment; (3) considering the role of communication partners; (4) training communication partners; and (5) using communication supports to assist community inclusion.

Chapter 3 focuses on relationships, the central subject of the overall inquiry and summarises what is known about relationships for adults with severe intellectual disability in relation to social networks and social support. This chapter augments the previous chapter’s discussion around communication for people with a severe intellectual disability by situating communication as an integral part of building relationships.

Chapter 4 describes the foundations of the methodological approach. The objective of the chapter is to illustrate the rationale used for choosing a course of qualitative inquiry and how the decision to select a grounded theory approach was made. In addition, the constructivist grounded theory viewpoint is detailed and the congruence between the personal perspective of the researcher and the processes of grounded theory explored.
Chapter 5 outlines the design of the study, specifying the selection and recruitment of central participants and personal affinity network members. Data were collected through interviews and participant observation and details of the analysis are presented. This chapter finishes with a publication in the journal *Augmentative and Alternative Communication*. The aim of this paper was to explore the challenges faced and benefits gained in collecting participant observation data when investigating interactions between adults with severe intellectual disability and their communication partners. The methodological demands and advantages of participant observation are discussed in this paper.

Chapter 6 introduces all of the participants. An overview of the personal affinity network members is presented along with a background summary of each central participant’s impairments, educational history and family supports. In addition a poetic format was used to provide a means of evoking a striking visual image of each central participant. The poems aim to capture a sense of the impact of each person on others in their social networks through the use of strength-based imagery that provides the reader with an emotional connection.

Chapter 7 presents a case study of the first central participant involved in the research published in the *Journal of Intellectual and Developmental Disability*. This article was developed early in the course of research with the aim to describe the social interaction of an adult with a severe intellectual disability whose communication was symbolic but nonlinguistic. In doing so, her social network was identified and how members of her social network perceived her communication described. The research questions were (a) What does social interaction look like for an adult with a severe intellectual disability? (b) Who comprises her social network? and (c) How are social relationships experienced by her social network members? Implications for practice were presented that highlight the importance of a person-centred approach and provide suggestions for increasing opportunities for social
interaction.

Chapter 8 presents the findings and the theoretical model developed in two publications. The first publication in the *Journal of Applied Research in Intellectual Disability* focuses on one aspect of the model - sharing the moment. The aim of this paper was to (i) identify social interactions between the people with severe intellectual disability and those with whom they have positive relationships and (ii) detail the nature of those interactions. The interactions comprised having fun and hanging out and contributed to mutually enjoyable relationships. The second publication in the *Journal of Intellectual and Developmental Disability* describes the entire model comprising five processes that underpin relationships. The aim of this study was to investigate the processes involved in positive relationships between people with severe intellectual disability who have limited communication and workers or family members, in order to understand how such relationships can be fostered.

Chapter 9 concludes the thesis. It begins with a brief review of the contribution of each of the five publications and a discussion of issues that have arisen during the research in addition to those discussed in the preceding chapters. These issues include (a) building the capacity of workers to facilitate social inclusion, (b) embedding a workplace culture that values relationships and (c) finding better ways to conceptualise the support needs of people with a severe intellectual disability. The thesis finishes with the limitations of the study and directions for future research.

A Note on Repetition

Although the thesis constructs a complete story, the nature of a thesis by publication has resulted in some unavoidable repetition. For example, a constructivist grounded theory
approach was taken and a description of the method is repeated in all publications referring to
the study results.

A Note on Terminology

There are three key concepts in this thesis: augmentative and alternative communication,
complex communication needs and a severe intellectual disability.
The term *Augmentative and Alternative Communication* (AAC) is used but never defined.
For readers who may not be familiar with AAC, the following definition is provided.

AAC refers to an area of research, clinical and educational practice. AAC involves
attempts to study and when necessary compensate for temporary and or permanent
impairments, activity limitation and participation restrictions of individuals with
severe disorders of speech-language production and/or comprehension, including
spoken and written modes of communication (American Speech-Language-Hearing
Association 2005, p. 1)

The term *complex communication need* is used broadly in the literature. It has been
defined in the AAC literature as:

Communication problems associated with a wide range of physical, sensory and
environmental causes, which restrict/limit their ability to participate independently
in society. They and their partners may benefit from using augmentative or
alternative communication (AAC) methods either temporarily or permanently
(Balandin, 2002, p.2).

Some people with complex communication needs also have an intellectual or
cognitive disability, but cognition is not referred to in the above definition. The central
participants in this study with an intellectual disability and very limited speech are referred to
as having complex communication needs. They use both formal and informal means of AAC
to communicate, although informal means predominate, such as facial expression, body language and natural gesture. The central participants (people around whom this study is focused) are referred to as having a *severe intellectual disability*. This term is used broadly in the intellectual disability literature and may not be based on any formal assessment. Nonetheless, the formal definition of severe intellectual disability is an IQ score of 20-35, as determined through a standardised intelligence test (e.g., Wechsler Intelligence Scale for Children). However, reliance on the results of formal testing may be problematic for people with more than moderate levels of intellectual disability (Wen, 1997). The more severe the intellectual disability, the greater the likelihood of associated impairments, including speech difficulties, which can impede performance on tasks, thereby potentially masking underlying competence. The central participants were selected for their similarity in terms of cognition and expressive communication, and being at a *symbolic but nonlinguistic* level of communication. This level is one at which people demonstrate use of conventional symbols, such as spoken, signed or pictured words, but do not combine them into linguistic units: that is two- or multi-word combinations that follow a rule system (Bloom, 1993). People at this level are differentiated from those with profound intellectual disability by their use of symbolic, rather than nonsymbolic, communication.
CHAPTER 2: MAXIMIZING COMMUNITY INCLUSION THROUGH MAINSTREAM COMMUNICATION SERVICES FOR ADULTS WITH SEVERE DISABILITIES.

Overview of Chapter

This paper describes the contemporary understanding of social inclusion and communication for adults with severe intellectual disability and complex communication needs. As speech pathologists have a professional responsibility to address the communication needs of people with complex communication needs, the international research relating to speech pathology interventions and services provided for adults with severe intellectual disability is discussed. A specific focus of the paper is on the environment surrounding the provision of speech pathology services for people with intellectual disability in Victoria, Australia and frameworks for assessing and identifying adults with intellectual disabilities at different communication stages. A brief review of the literature discusses the role of communication partner training and outlines what is known about the strengths of those who have mutually rewarding relationships with adults with severe intellectual disability. These strengths include the possession of values and positive attitudes that enable relationships to develop and facilitate the implementation of practical communication skills.
Publication


Statement of Contribution

As co-authors of the following manuscript titled ‘Maximizing community inclusion through mainstream communication services for adults with severe disabilities’ we confirm that Hilary Johnson made the following contribution: Hilary Johnson was responsible for writing the complete first draft of the manuscript. Associate Professor Jacinta Douglas, Professor Christine Bigby and Professor Teresa Iacono critically appraised the manuscript and Hilary’s subsequent revisions of the manuscript.

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Maximizing community inclusion through mainstream communication services for adults with severe disabilities

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Abstract

Government policies in developed countries have emphasized the importance of community inclusion to improve the health and wellbeing of citizens. In order to achieve this, a reorientation of human services to include all people with disabilities has commenced with specialist disability services providing only limited supports. One vulnerable group of adult citizens are those with severe cognitive impairments. These citizens live either with their family or in small group homes supported by paid staff. Many of these people have little or no functional speech and are at an increased risk of social exclusion. This paper presents a discussion of the relevant literature underpinning the provision of mainstream speech-language pathology services to adults with severe cognitive disabilities. In particular we focus on practice considerations that might assist speech-language pathologists in providing effective and efficient services that support people with severe intellectual disability to live meaningful lives in the community. Five main considerations are discussed: (1) applying a holistic model to communication practice; (2) understanding terminology and the process of assessment; (3) considering the role of communication partners; (4) training communication partners; and (5) using communication supports to assist community inclusion.

Keywords: Adults, Augmentative and Alternative Communication (AAC), complex communication needs.

Introduction

Over the last 20 years, there has been a move towards the integration and inclusion of people with disabilities into the community throughout the western world (Cambridge et al., 2002; Young, Sigafoos, Suttie, Ashman, & Grevell, 1998). In particular, there has been a focus on moving adults from large residential institutions into smaller group homes, composed of three to five residents with disabilities. Government policies, both nationally and internationally, have espoused a vision where people with disabilities are valued, respected and included (Department of Health, 2001; Department of Human Services, 2002; Lecompt & Mercier, 2007; United Nations, 2006). This vision has provided a stimulus for change in the practices of people working in the disability area. Simultaneous with deinstitutionalization, the care model for these people shifted from the medical to the social model (Coles, 2001; Duchan, 2003; World Health Organization, 2006). The social model recognizes that although people may have impairments that affect their functioning, it is society that disables people by placing barriers to access. Access barriers serve to limit social connections and so maintain negative attitudes that stereotype people with disabilities. According to Duchan (2003) the social model focuses on setting goals with the person based on his/her interests and tackling community barriers as part of the intervention. O’Brien (1989) suggests that utilizing a person-centred approach recognizes the uniqueness of each individual and promotes his/her ability to make decisions. Further, consideration of processes that develop and maintain relationships with others now is seen as integral to including a person in the community.

People with intellectual disabilities form the largest group of people who have benefited from deinstitutionalization. In Australia, 3% of the population have intellectual disability (Wen, 1997) with 1.8% of the total population having a severe or profound disability (defined by IQ score below 35 on standardized intelligence tests). Communication
difficulties are a common characteristic of people with intellectual disabilities and those with severe intellectual disabilities present particularly complex communication challenges (Nigam, Schlosser, & Lloyd, 2006; van der Gaag, 1998). Indeed, people with severe intellectual disabilities may have little or no speech and may benefit from augmentative and alternative communication (AAC) systems to enhance their communication (Beukelman & Mirenda, 2005).

Difficulties in communication for people with intellectual disabilities limit community participation (Australian Institute of Health and Welfare, 2003) and greater supports are needed to ensure social inclusion. Consequently, the policy move toward community inclusion may well generate increased requests for speech-language pathology services. The service system may not have the capacity to fulfill such requests due both to the shortage of speech-language pathologists experienced in this field and the limited number of funded positions (Iacono, Johnson, Humphreys, & McAllister, 2007). In Victoria, Australia, the only significant increase in therapy funding for adults with disabilities in the last 10 years has been to develop a hub and spoke model of service to enhance the skills of generic speech-language pathologists to meet the needs of people with a disability in their local communities (Johnson, 2004). This service aims to provide peer support for speech-language pathologists, particularly in the area of AAC, develop effective and efficient services and build the capacity of the broader community to be better communication partners. Teaching communication partners to recognize the importance of modifying their communication with a person with severe intellectual disability and complex communication needs can be a demanding task. The challenges to speech-language pathologists are to modify their knowledge in assessment, intervention and modes of practice to meet the needs of different populations. In this paper, we focus on considerations that might assist speech-language pathologists in providing effective and efficient services that support people with severe intellectual disabilities to live meaningful lives in the community. These considerations include embracing a holistic model of practice that incorporates dynamic assessment, the inclusion of communication partners and individualized communication supports.

**Applying a holistic model of practice**

Clinicians are familiar with the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). The ICF establishes a common international language to further the understanding of individuals from a broad health-related perspective. It is grounded in the social model of disability and considers a person’s ability to participate in society as a dynamic interaction between the individual with a health condition and his/her total environment. Recently, O’Halloran and Larkins (2008) discussed the overlap between communication activity and communication participation. They suggested that participation can only be truly measured subjectively by the person/people involved. Thus, in order to evaluate speech-language pathology service provision, speech-language pathologists need to ensure the collaboration between the client and their environmental communication partners. The practical application of the ICF around communication impairments remains a conceptual tool still in the developmental stage. It maps and categorizes possible societal influences that affect participation, but does not guide the clinician through assessment and intervention. However, the Participation Model developed by Beukelman and Mirenda (2005) initially developed in an education framework, can be applied to working with adults in the community.

The participation model (Beukelman & Mirenda, 2005) provides a basis for planning individual communication services. There is an underlying premise that services for people with an ongoing condition may require long-term intervention. In order to make this clinically manageable and pertinent to the adult’s needs, Beukelman and Mirenda suggested the initial assessment leads to a *today* solution and further ongoing assessment leads to a *tomorrow* intervention. In this way, an adult receives a strategy he/she can use immediately while working on a strategy requiring further training for the future. Unique individual circumstances can be considered by examining two sets of barriers. These are opportunity barriers relating to the environment surrounding the person (policy, practice, attitude, knowledge and skills) and access barriers relating to the capabilities of the individual (current communication skills, environmental adaptations, operational profile, constraints profile and capability profile).

Understanding the opportunity barriers within a person’s environment can expedite a practical and achievable communication solution. Evaluating policies (e.g., the amount of funding available for support), practices (e.g., whether the person’s communication aid is readily available or locked in a cupboard to keep it safe), and the attitude, knowledge and skills of current communication partners provides a starting point for implementing intervention. Understanding access barriers further informs intervention. Evaluation of access barriers includes (a) examining current communication skills and potential for improvements (e.g., developing clearer articulation); (b) considering environmental adaptations (e.g., the ability of the person to enter the shop in order to make a purchase); and (c) assessing the possibilities for an AAC system. The possibilities of using an AAC system depend on three aspects.
The first is an operational profile, relating to the person’s ability to use it. The second is a constraints profile, relating to the preferences of the person and communication partners. The third is a capability profile, relating to the person’s physical, sensory, cognitive, linguistic and literacy skills. Overall, adoption of the participation model ensures the assessment yields information that can be used to maximize community inclusion.

**Terminology and the assessment process**

Assessment is especially challenging in the context of severe intellectual disability. Even terminology is not straightforward in that various terms have been applied to people with severe intellectual disabilities: these include severe and multiple disabilities (Bloomberg, West, & Iacono, 2003), severe developmental disabilities (Chambers & Rehfeldt, 2003; Romski, Sevcik, & Rumbaugh, 1985) and significant disabilities (Cascella, 2004). These terms are widely used in the literature without being based on formalized assessment (Anderson, Sherman, Sheldon, & McAdam, 1997; Bloomberg et al., 2003; Cascella, 2004; Zilber et al., 1994). Where formal cognitive assessments are used, the term severe intellectual disability refers to someone with an IQ score of between 20–35 on standardized intelligence tests (e.g., Wechsler Intelligence Scale for Children). More recently, adaptive behaviour scale assessments (e.g., standardized checklists of skills across life domains completed by someone who knows the person well) have been required to confirm the result. Reliance on the results of formal testing may be particularly problematic because of difficulties associated with valid assessment of people with severe intellectual disabilities (Wen, 1997). Difficulties include motor restrictions, impaired attention, and impaired comprehension of verbal instructions, all of which can result in inaccurate or inconsistent responses leading to unreliable results. Indeed, recent legislation in Victoria no longer requires standardized assessment of a person with an intellectual disability in order for that person to receive services (Victorian State Government, 2006). Other than for making a diagnosis, the aim of assessment is to provide a basis from which to form a plan of action.

A relationship between pre-linguistic cognitive skills and language has been demonstrated in the research literature (Abbeduto & Boudreau, 2004; McLean & McLean, 1993; Simeonsson, Granlund, & Bjorck-Akesson, 2006). In particular, language emerges from early symbolic skills seen in gestures and play, with associations between these skills being indicators of language delay, including in children with intellectual disabilities (Chan & Iacono, 2000; Iacono, 1999). It is generally agreed that language development is more impaired than sensori-motor skills among adults with intellectual disability (Lobato, Barrera, & Feldman, 1981). McLean and McLean (1993) emphasized the wide range of communication skills observed among adults with severe intellectual disabilities. These skills could be considered to be in one of two categories: (a) those that are linguistic as indicated by the ability to create novel utterances with words or other forms of symbols; and (b) those that are non-linguistic whereby communication includes more informal than formal modes. McLean, Brady and McLean (1996) attempted to ascertain detailed information on the communication mode of people with intellectual disability. Of 211 children and adults with intellectual disabilities who participated in their study, 94 adults met the IQ inclusion criteria of 25–40. Communication skills were categorized as symbolic, intentional informal, unintentional and other. Communication skills were rated by staff comprising speech-language pathologists (50%), qualified intellectual disability professionals (27%) and “others” (22%). Results showed significantly more adults were rated as symbolic communicators than were children. Indeed, 80% of the adults were reported to be symbolic; of the remaining, 14% were rated as informal and 6% as unintentional. These results are consistent with the suggestion that as children with intellectual disabilities grow older, their symbolic skills develop.

The McLean et al. (1996) study remains one of the largest descriptive studies of communication skills among adults with severe intellectual disabilities. The results indicate these adults express themselves through a small number of symbols (words, pictures or signs), but are not at a truly linguistic stage as indicated by the ability to combine symbols to generate novel utterances. Other smaller scale studies have provided further supplementary evidence (Chambers & Rehfeldt, 2003; Romski, White, Millen, & Rumbaugh, 1984). The particular skills evidenced may vary considerably from person to person (Bedrosian & Prutting, 1978; Chambers & Rehfeldt, 2003; McLean et al., 1996). Clearly, detailed communication assessment is required in order to ascertain an individual’s skills.

Many formal communication assessments designed for adults (usually those with acquired disabilities) commence at a level of understanding that is beyond that of a person with severe intellectual disability. Further, there are few assessments that are appropriate for adults with symbolic but non-linguistic skills (Bloomberg & West, 1999; Van der Gaag, 1988). Even if appropriate assessments are available, they should be used as part of a dynamic assessment which occurs in tandem with intervention.

Use of tools that identify early communication skills helps reveal the person’s capabilities. Such tools are typically based on developmental checklists, often underpinned by Piaget’s sensori-motor stages (Dunst, 1980; Granlund & Olsson, 1993).
Care must be exercised in drawing parallels between early communicative development in children and the level of cognition and language of an adult with intellectual disability, as the focus for intervention differs (Calculator, 1988; McLean & McLean, 1993). The focus for young children with intellectual disabilities is likely to be increasing the complexity of skills hierarchically as maturation and growth occurs. In contrast, for adults the focus is on increasing the frequency and functionality of current communication modes (Granlund, Björck-Åkesson, Brodin, & Olsson, 1995), as new skills are unlikely to emerge but could be unmasked. Moreover, an adult has had many more life experiences resulting in a communication profile that will contrast to that of an infant at a similar cognitive stage.

Currently the developmental literature provides the only model to describe early communication behaviours seen in adults and it may be useful to consider their communication stages rather than their communication age (Bloomberg & West, 1999; Coupe & Goldbart, 1988). Several researchers have suggested logically derived categories (Beukelman & Miranda, 2005; Bloomberg & West, 1999; Dowden, 2006; Romski, Sevcik, Hyatt, & Cheslock, 2002; von Tetzchner & Martens, 2000). In their study, McLean et al. (1996) were the first to apply descriptive categories to the communication skills of adults with severe intellectual disabilities. They selected three main categories of non-intentional, intentional or symbolic communication stages, with the symbolic stage being further divided into the number of symbols used and ability to produce symbol combinations. The non-intentional communication stage referred to communicators who demonstrated “like and reject” but who did not realize a communication partner could be useful to get their needs met. The intentional level included communicators who could understand some limited symbols (e.g., respond to someone calling their name), use gesture rather than words to communicate and knew to use a communication partner to get their needs met (e.g., take a person to the fridge to get a drink). Bloomberg, West and Johnson (2004) have suggested the two symbolic stages be termed basic and advanced. The basic stage refers to individuals being able to recognize that symbols stand for real objects (e.g., they can recognize a picture/photo of a cup) and can use up to five symbols (i.e., words, pictures or signs) expressively. Those who are at a symbolic advanced stage can use up to 50 symbols functionally, understand two stage commands out of context, combine some two symbol utterances functionally and may be considered at a linguistic stage.

The use of this terminology can enhance an understanding of each communication stage without referring to child development norms, thus maintaining age appropriate language. As people with intellectual disabilities are frequently reliant on paid workers for support, the presentation of assessment results in clear and simple language is essential to furthering an understanding of communication skills. In addition, such descriptive terms facilitate a dynamic approach to assessment, as they suggest a range of interventions suitable for people who sit at various points of the continuum from non-intentional to symbolic advanced communicators. Once communication strategies are put into place, the dynamic process of trialling intervention commences, such that the outcomes inform an ongoing assessment and the development of more effective communication and interaction strategies.

The role of communication partners

Communication partners are people with whom communicative interactions occur and may include a wide range of roles such as family, friends, support workers, educators and shopkeepers. Kent-Walsh and McNaughton (2005) suggested there are two main categories of communication partners—those who have an educative or paid role (e.g., support workers and health professionals) and those who have a social role (e.g., family and friends). Communication partners have a central role in the assessment of adults with severe intellectual disabilities in that observation of interactions over time and in different contexts reveals their range and breadth of communication skills, and the extent to which the adult’s skills vary with different partners (Calculator, 1988). In addition, extended observations enable the partners to share their knowledge of the person’s capabilities in different environments (Cascella, 2004).

Speech-language pathologists working with large caseloads and time constraints are particularly reliant on communication partners from a range of environments to take a key role in both the assessment and intervention processes. Van der Gaag (1989) stated that a collaborative approach, whereby communication partners are engaged from the assessment through to choosing and implementing interventions, increases the probability of successful outcomes for the adult with severe intellectual disability. Information gathered is based on the communication partner’s ability to observe and derive meaning from observations. However, it cannot be assumed that an experienced staff member can correctly interpret non-verbal behaviours. Van der Gaag (1989) demonstrated that people who knew the participants well could collect accurate data, but this data was affected by the communication opportunities observed and the amount of time spent in a particular environment. Gleason (1993) agreed with this observation stating that communication attempts among adults with severe disabilities could only be fully understood by observers where the context and activity were taken into account.
Interpretation of nonverbal signals is especially challenging for communication partners. McConkey, Purcell and Morris (1999) found that even when staff members knew the person well, they still had difficulty interpreting nonverbal signals accurately. Thus, training is needed to improve the ability of communication partners to understand nonverbal behaviour and this training may need to be tailored and focused for specific individuals. Further, staff may need to be made aware of their own role in the transactional process of communication. This process (first identified in the child development area) consists of recognizing that communication is reciprocally affected by different people, activities or environments and is dynamic, rather than static. McLean and McLean (1993) emphasized the importance of understanding this co-constructive process in order to learn how to adjust communication styles and modes to meet the changing needs of each communicative interaction.

Although the collection of information from staff members is critical to the assessment process, this needs to occur with consideration that even experienced staff can lack critical observation skills (McLeod, Houston & Seyfort, 1996). Thus, potential inaccuracies in the information need to be considered, without discounting its value. Where staff members complete checklists of observed skills, for example, accuracy can be improved if clinicians question the respondent and critically analyse the appropriateness of the responses. Where unusual communication patterns emerge from checklists, clinicians may need to spend time observing the person with disability in his/her environment. While there are limited communication assessment tools applicable for use with adults with severe intellectual disabilities, there are even fewer that yield reliable results that practically inform intervention.

Both the Communication Assessment Profile-CASP (Van der Gaag, 1988, 1998) and the Triple C: Checklist of Communicative Competencies (Bloomberg & West, 1999) were designed to be completed by people who know the individual with an intellectual disability well. The developers of both tools suggest the involvement of speech-language pathologists in the administration or interpretation of the assessment. The CASP provides an integrated planning tool while the Triple C requires an additional manual to assist with communication supports (Bloomberg et al., 2004). Clearly communication assessments do not lead to any positive change for an individual, unless the information is linked to functional communication strategies. A number of different interventions can be applied to tackle the various barriers to effective communication in a person’s life. Some strategies occur simultaneously and multi-modal AAC systems are applied. People with severe intellectual disabilities need interventions that are targeted at both themselves and their communication partners.

**Training communication partners**

Speech-language pathologists are most likely to come into contact with family and/or paid staff who are the main communication partners of their clients with severe intellectual disability. Most adults with severe intellectual disabilities have many paid staff in their social networks (Kennedy, Horner, & Newton, 1990; Robertson et al., 2001). Many attend daytime group activities or live in group homes where they are supported by paid staff who are often employed on a casual basis or, may frequently change workplaces (Department of Human Services, 2006). These paid disability support workers provide personal care, but the extent of their training and background qualifications may vary. Due to critical shortages, support workers with no training or experience may be employed. In addition, there are few opportunities for support staff to receive group or individualized training for communication with people with severe intellectual disabilities. As the aim of service provision is to support people to participate meaningfully in their communities (Department of Human Services, 2002), it is essential that staff members have knowledge about communication. Further, staff members can play a pivotal role in the quality of life of adults with severe intellectual disabilities.

A focus of providing communication support has been on teaching skills to improve paid staff’s communication (Bartlett & Bunning, 1997; Granlund et al., 1995; Granlund, Terneby, & Olsson, 1992). The need for training is evident from research showing that paid staff misunderstand the non-verbal communication of people with intellectual disability (McConkey, Morris, & Purcell, 1999; McConkey, Purcell, & Morris, 1999; Purcell, Morris, & McConkey, 1999), have difficulty adjusting their own communication to match the understanding of a familiar person with an intellectual disability (Bradshaw, 2001; McConkey, Morris et al., 1999; Purcell et al., 1999), are unaware of their own non-verbal communication styles (McConkey, Purcell et al., 1999), and place the responsibility for change and improvement on the person with intellectual disability (Purcell et al., 1999). These findings provide a focus for the content and style of communication training for staff.

In addition to examining the literature on staff training the current evidence on what makes a good communication partner needs to be considered. While the lack of skills demonstrated by support staff may be due to insufficient specialist assistance, it may also indicate that some support staff do not see communication support as part of their role. Previous knowledge and belief systems of the support
staff may also affect outcomes (Fenwick, 1995). When Dennis (2002) analysed data from focus groups, composed of support staff who saw their role as supporting communication, she identified characteristics of competent communication partners. These partners attributed their success around supporting communication to having a strong belief in the communication abilities of the person with a disability, a commitment to the person, respect for idiosyncratic ways of communicating, an awareness of their own personal attributes and limitations, and an ability to change themselves. These results support the notion that attitudes and beliefs may be important factors in integrating or validating new information.

The importance of attitudes and beliefs has been further highlighted by the work of Bogdan and Taylor (1998). They conducted a series of interviews with people (parents, staff and managers of disability services) who accepted and valued people with severe intellectual disabilities. The researchers commented on the beliefs of the interviewees who emphasized the humaneness of each person with a disability irrespective of cognitive skills. Some interviewees noted evidence of thinking and that “thinking is different from communicating thought” (p. 248). Some believed they knew what the partner was thinking or could read them intuitively. Some parents, counter to professional judgements, believed their son or daughter could think and could understand. They felt professionals frequently underestimated abilities. Family members also noted subtleties in behaviour to which they assigned meaning to those behaviours. They rejected labels, such as severely disabled, and chose nicknames that emphasized the personality of the person with a disability. They also commented on the positive, reciprocal nature of the relationship.

Speech-language pathologists need to consider all the evidence presented and work together with families and paid staff to provide the best outcome for the person with a severe intellectual disability. The use of descriptive labels that characterize a person’s communication should help all the communication partners to recognize and support communication attempts, and facilitate seeing the humaneness of each person. Anecdotally this understanding is illustrated by the words of a support worker when referring to a person with severe intellectual disability who moved from being a “client” to a “loved friend” who was visited regularly. The support worker stated “I know he is an unintentional communicator but to me he understands everything I say” (personal communication).

The results of the studies by Dennis (2002) and Bogdan and Taylor (1998) suggest that communication training should utilize a person-centred approach that promotes the positive strengths of people with an intellectual disability. Person-centred approaches focus on such positive strengths and consider what is important to the person, their dreams and aspirations and find ways to meet those desires (Holbourn & Vietze, 2002). Training that takes a strengths-based approach might enhance positive attitudes and promote respect. There is, however, very little research into the relationship between the characteristics of people with severe intellectual disabilities and staff behaviour, values and performance (Hatton, Rose, & Rose, 2004). Even less research attention has been directed to the effect of attitudes of paid staff on their communication interactions (Dobson, Upadhyaya, & Stanley, 2002; McLeod, Houston, & Seyfort, 1996; Smidt, Balandin, Reed, & Sigafos, 2007). There is some limited evidence to support the development of more positive attitudes among undergraduate and graduate speech-language pathologists towards working with people with complex communication needs (Johnson, Bloomberg, & Iacono 2008), but there has been very little emphasis on strategies that may change attitudes of support workers. Of concern, however, is the extent to which attitude shifts result in positive outcomes for people with intellectual disabilities. Hatton et al. (2004) pointed out that attitude change can occur, but sometimes without a demonstrated behaviour change. Speech-language pathology interventions aimed at support staff have not focused on changing attitudes, but rather at changing their communication interaction skills (Bloomberg et al., 2003; Bradshaw, 1998; Purcell, McConkey, & Morris, 2000). Addressing staff member values and attitudes in training may result in people with severe intellectual disabilities being supported more effectively.

Additional challenges to training staff to become effective communication partners for adults with severe intellectual disabilities has been with staff turnover and large numbers of staff. To address these challenges, several skill development communication training packages have been developed (Bloomberg et al., 2003; Jones, 1990), but there is little evidence of long-term effectiveness. Maes, Lambrechts, Hostyn, and Petry (2007), in a systematic review on quality of life for adults with profound intellectual and multiple disabilities, reported moderate success in staff training programs. They suggested that enhanced outcomes were achieved when a problem solving approach was coupled with ongoing opportunities to observe good practice examples. Adoption of such strategies requires a shift in the way speech-language pathology services are often delivered, in particular, from working with individuals in clinical contexts to working with groups in community contexts.

Group staff training has often been focused on a whole service model (e.g., residential houses and/or day service), where the capacity building of staff and families has become accepted practice (Bloom, Walker, & Grant, 1999; Dobson, Upadhyaya, & Stanley, 2002; Horne, 2005; Johnson,
Bloomberg, & Butler, 1999). Current provision of whole service models includes pre-training visits and pre- and post- workplace assessments. The pre-training visits provide the basis for developing training content, which is then supported by post-training modelling and ongoing coaching in the workplace. The aim is to provide an overarching communication framework that can be adapted to provide individualized practical strategies (Bloomberg et al., 2003). Dobson et al. (2002) suggested that collaborative problem solving followed by documented care-plans maintain positive outcomes. Clinical experience, in providing a whole service training model in homes and day services for people with little or no speech suggests that the maintenance and development of successful communication relies on a number of factors: (a) ongoing support from a speech-language pathologist or communication specialist, (b) training for all the staff in a facility, (c) a proactive manager or service coordinator who promotes a person-centred approach, (d) time release for staff members to receive specific training and/or develop aids, and (e) the provision of materials on site in order to construct communication aids.

Research findings and clinical observations reinforce the importance of working in partnership to reveal the communicative strengths of the person with a disability and providing practical training with opportunities to model good practices. Working in partnership can be time consuming, but provides the opportunity for reflection, the expression of beliefs and values, and the coaching of skills.

Communication supports
The aim of communication supports is to facilitate communication interaction in everyday activities. Communication supports include a variety of AAC systems designed to repair or minimize communication breakdowns with familiar and unfamiliar partners. To achieve these goals, four strategy types are proposed (a) those that provide information for the communication partner in order to better understand the person and interpret any idiosyncratic behaviours; (b) those that provide visual supports to compensate for any verbal comprehension or literacy difficulties; (c) those that provide an expressive means as a supplement or alternative to verbal communication; and (d) those that may augment both expressive and receptive communication. Often a person with a severe intellectual disability will have a number of AAC systems, often in the form of communication aids, that are used in different situations with different partners.

Aids that provide personal information
These aids provide a partner with information to enhance their understanding of the person’s communication. The content of these aids relies on close and accurate observation of the person by familiar communication partners from different environments. There are a variety of aids that meet these purposes, including a personal history and/or a book about me (Bloomberg et al., 2004; Life’s for Living, 2008; Rowland, Schweigart, & Dorinson, 2001), a personal communication dictionary/gesture dictionary (Beukelman & Mirenda, 2005; Bloomberg et al., 2004), a personal communication passport (Millar & Aitken, 2003) and/or multimedia profiles (http://www.acting-up.org.uk/).

Visual supports to compensate for comprehension difficulties
As speech is an abstract symbolic code, people with severe intellectual disabilities often have difficulty understanding speech alone. Once it is paired with objects, pictures/photos or gestures, the meaning becomes more transparent. The pairing of visual systems with speech may also have the effect of slowing the communication partner’s rate of speech and simplifying the language content. Information presented in both transient and static formats may be more effective (e.g., speech and pictures) than speech alone. Static information includes objects, pictures, photos and line drawings and these symbols can be used in developing environmental supports such as picture schedules, menus, shopping lists, and Who’s Here Today boards (Bloom & Treloar, 1997; Bloomberg et al., 2004; Hodgdon, 2000). For people who have difficulty understanding what is going to happen in new or infrequent situations (e.g., a visit to a dentist), simple social stories using pictures to illustrate the process may be helpful (Gray, 2003; Hodgdon, 1999).

Aids that support expression
Aids that provide a way for the person to express him/herself include those that get a need met and those that assist with social interaction. In environments that support a number of people with intellectual disabilities (e.g., residential/day services), there are often few opportunities for people to make choices as routines are established and needs anticipated. However, community inclusion offers greater opportunities to use both low tech and high tech aids. Low tech aids include picture exchange (Frost & Bondy, 1996; Liddle, 2001) and community request cards (Bloomberg, 1996; Bloomberg et al., 2004). These aids require the person to be able to pass an object or picture symbol to another person in order to get a need met. High tech aids may also be used and there is a wide range of speech generating devices (SGDs) currently available. For people with severe intellectual disabilities, SGD’s need to be simple to use, robust and easy to carry.
The devices have additional advantages of assisting communication at a distance, but may be difficult to hear in a shopping centre or similar noisy environment. As it is the responsibility of the communication partners to store, program, electrically charge and organize repair of SGDs, such devices are only effective in very supportive environments.

Social interaction can be encouraged through the use of chat books. A chat book consists of a collection of news items or mementos which arouse positive memories. These may be photos or objects accompanied by text. The aim of the book is to present information that can be shared with a communication partner who can read in order to provide opportunities to exchange information (Bloomberg et al., 2004; Hunt, Alwell, & Goetz, 1991). The aim is to extend the number of turns from one to a series of turns. The turn taking relies on the triggers that are written to accompany a photo or memento. The format chosen depends upon the communicative turn taking abilities of the person with a disability.

**AAC systems that assist with both expressive and receptive communication**

The use of key word sign, also known as Makaton, can be useful as both a receptive and expressive strategy. This unaided system can be used by the communication partner and the person with an intellectual disability. When the communication partner signs a key word in a sentence, the accompanying speech is simplified and delivery slows down, which offers the potential to enhance message comprehension for the person with an intellectual disability (Grove & Walker, 1990). The communication partner’s use of the system also signifies that he/she values the AAC system, thus promoting its everyday use to others in the environment including peers. The advantages of using key word sign are portability, guessability (includes many natural/transparent gestures) and the fact no equipment is required. There is also an extensive network of trainers and resources available in Australia (University of Newcastle, 2008) and in many other countries. The disadvantages of key word signs are that relatively good hand skills are needed, signing is transient and that some signs are opaque and not easily guessable by the general public.

**Choosing the type of AAC supports**

The communication support strategies that are chosen relate back to the presence of opportunity and access barriers in a person’s life. Policies that limit funding and service provision are key drivers in decision making with respect to choice of support strategies. For example, most Australian states have some funding available for SGDs, but currently only one state, Victoria, funds the production of non electronic communication aids for adults (NECAS). The attitude, knowledge and skills of the communication partners along with the capability profile of the individual with an intellectual disability are fundamental in the decision-making and intervention process.

**Summary and conclusions**

People with intellectual disabilities are now living in the community and needing communication strategies to ensure social inclusion. Governments are expecting mainstream services to meet the needs of a diversified community. Meeting such expectations requires community speech-language pathologists to consider different models of speech-language pathology assessment and intervention to meet the social and participation needs of adults with severe intellectual disabilities. In this paper, we have discussed several key considerations drawn from the literature to assist speech-language pathologists in providing effective and efficient services. Principal assessment and intervention recommendations from these considerations are summarized in Table I.

Although intervention focuses on developing strategies to meet the needs of an individual with communication difficulties, we recommend that a greater emphasis is placed on developing positive attitudes and communication skills of paid staff and other potential partners in the community. Providing group or whole-service training to staff members may be an effective way of building basic communication skills and awareness. Building the capacity of community members to communicate effectively with people with little or no speech will assist the

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<th>Table I. Key considerations for providing speech-language pathology services to people with severe intellectual disabilities.</th>
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<td><strong>Assessment</strong></td>
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<td>- Select a framework that links assessment to intervention</td>
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<td>- Use reliable adult communication assessments</td>
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<td>- Engage familiar communication partners from different environments</td>
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<tr>
<td>- Utilize a collaborative, dynamic, problem solving process</td>
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<td>- Incorporate naturalistic observation</td>
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<td><strong>Intervention</strong></td>
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<tr>
<td>- Utilize a person centred approach</td>
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<td>- Explore the beliefs and attitudes of communication partners</td>
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<td>- Teach interaction skills to communication partners</td>
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<td>- Provide opportunities for collaborative problem solving</td>
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<td>- Model good communication practices</td>
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<td>- Consider whole service training where organisational support exists</td>
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References


CHAPTER 3: SOCIAL NETWORKS AND RELATIONSHIPS

Overview of the Chapter

Some of the limiting factors in relation to communication for people with severe intellectual disability were described in the previous chapter/publication. The aims of this chapter are to summarise what is known about social networks and relationships for adults with severe intellectual disability, and in doing so discuss concepts that are central to the thesis. The literature is discussed in relation to family members, paid workers and unpaid network members concerning the size and structure of social networks and the nature of social support.

Social Networks and Social Support

The development of relationships enables a sense of personal connectedness and social value through being part of a community (Duck, 1988). A strategy used by researchers to determine how people connect to each other has been to analyse their social network (Albrecht & Adelman, 1987; Cohen, Underwood, & Gottleib, 2000; Lippold & Burns, 2009). The term social network was first used by the anthropologist Barnes (1954). While studying people who lived in a Norwegian fishing village, Barnes mapped the bonds between people, exploring and documenting the way these ties influenced, not only relationships between dyads (two people), but also the overall functioning of the community. According to Gleeson (2004), the need for social connections exists in all communities and is underpinned by a “complex and diverse spectrum of motivations that drive the search for social ties ranging from enlightened self-interest to unrestrained altruism” (p.315).

Researchers have argued that examining the ways in which social networks can influence a person’s wellbeing assists to determine their functions (Goode, 1990; Schalock, Keith, & Hoffman, 1990). Family members of people with a disability and self-advocates
have expressed the need for a greater emphasis on the facilitation of personal relationships and social networks, which are seen as means of enhancing quality of life (Kennedy, 2004; McIntyre, Kraemer, Blacher, & Simmerman, 2004; Newton, Horner, Ard, LeBaron, & Sappington, 1994). The aspects of network theory that apply specifically to developing relationships for people with a disability are in the domain of personal social networks (Antonucci, 1985; D'Abbs, 1991). According to McCallister and Fischer (1983), personal social networks are “the set of people who are most likely to be sources of a variety of rewarding interactions, such as discussing a personal problem, borrowing money, or social recreation” (p. 78). Personal networks have also been referred to as core, egocentric or partial, or as personal communities of meaning (Scott, 1991; Vaux, 1988). These personal networks are dynamic structures comprising individuals who interact and develop a range of interconnections over time.

**Social Network Structure**

Social networks have been described in terms of their inherent structure. The structural aspects of networks include their total size, how closely people are related to each other (density), the interpersonal connectedness or strength of the bond (tie) between any two people, the duration of the relationships (stability), and the number of roles people take in the relationship (multiplexity). Using a structural framework, network members, sometimes referred to as social actors or nodes, are connected by ties that together form the network (Cohen, Underwood, & Gottleib, 2000; Mitchell & Trickett, 1980). Network size is calculated by counting the nodes in a person’s network; the result is dependent both on how the network members are defined and on the data collection method used. Thus, there can be considerable variation across reports of individual network sizes (Burt & Ronchi, 1994; Hill & Dunbar, 2002).
Generally, a limited network is one that is considered to consist of fewer than 50 people and a large network consists of hundreds or thousands of people (Burt & Ronchi, 1994). One example of estimating typical network size was by counting the names on Christmas card lists of British families and estimating the mean size of the social network as 124 people (Hill & Dunbar, 2002). This study by Hill and Dunbar, included people who were geographically distant and perhaps connected only once a year. Although larger networks allow for support from a wide range of people with varied characteristics, it has been argued that the size of the network does not necessarily indicate overall quality of life, such that smaller networks maybe more supportive than larger networks (Tracy & Abell, 1994). The recent growth in the number of people using the internet through social networking media has caused an increase in the reported size of networks and in the type and frequency of connections (Hampton, Sessions, & Her, 2011). The growth in network size as a consequence of the use of the internet has not been paralleled in the area of intellectual disability, as few people have regular access to technology (Carey, Friedman, & Bryen, 2005; Renblad, 1999, 2000). Thus, in discussing the networks that include people with disabilities, the focus will be traditional face-to-face contact (Dagnan & Ruddick 1997; Forrester-Jones, Jones, Heason, & Di’Terlizzi 2004; Pescosolido, 2001).

There are various aspects of social network structure that impact on how relationships are developed. Researchers have described the density of a social network in relation to the extent to which network members know and interact with each other (Albrecht & Adelman, 1987; Cohen et al., 2000). Immediate family members are often considered to have high density relationships, while low density members may be professional service providers such as the hairdresser or physiotherapist. Cohen et al. (2000) discussed how moderate to high density relationships have been argued to be important for providing sustained support while low density relationships have provided increased opportunities for a variety of activities or
casual interactions to occur. The latter relationships have also been described as being connected by *weak ties* (Granovetter, 1973, p.1361) and these low density relationships have been considered important for providing new work or leisure opportunities outside a fixed circle of friends (Granovetter, 1973, 1982; Scott, 1991).

Although the number and types of relationships in a network fluctuate over time, most networks include one or more people with long term relationships that provide stability. According to Crow (2004), the stability of relationships may vary, but having long term friendships has been highly valued and may be important for overall wellbeing. Family members frequently supply the stability in relationships and in small networks some people may take on multiple roles: that is, have multiplexity of roles. (Grant, 1993; Krauss, Seltzer, & Goodman, 1992). Multiplexity refers to the extent of the links or roles of an individual in a person’s network, such as family member, service provider or friend (Albrecht & Adelman, 1987; Rosen & Burchard, 1990). For example, a family member may be a loved one who takes on a carer role in times of illness and adopts multiple roles, such as partner, friend, unpaid carer and housekeeper. Multiplexity may be detrimental to a relationship if it results in a person experiencing a sense of being overburdened; this situation can be seen in relationships in which partners become carers (Grant, 1993; Fischer, 1982). Whatever roles a person takes on in a relationship, the essence of a relationship is provided through social support.

**Social Support**

Although structural aspects of a network are important, it has been generally agreed that the quality of a relationship is measured by social support (D’Abbs, 1982; Heller & Rook, 1997; Phillipson, 2004). Social networks can be considered to be “vehicles through which social support is distributed or exchanged” (Antonucci, 1985, p. 96). Social support has been variously defined, but there is general agreement that it exists only within the
context of a social relationship (Newton et al., 1994; Williams, Barclay, & Schmied, 2004). Kahn and Antonucci (1980) referred to social support as “interpersonal transactions” (p.266) that include aspects of aid, affect and affirmation. Aid refers to the physical or instrumental support given or received, such as time, financial assistance and information. Affective and affirming transactions refer to emotional interactions, including the ways in which respect and value are attributed to a person. According to Wellman (1981), social support was viewed as being a two-way transaction underpinned by a notion of giving and receiving, a concept of reciprocity.

Wellman (1981) discussed the different reciprocal exchanges through which individuals related to each other. These exchanges were through positive or negative behaviours exhibited in an interaction. Positive behaviours include providing approval, money or gifts; negative behaviours include demonstrating excessive criticism, physical violence or emotional abuse. Types of reciprocity differ, with tangible reciprocity referring to an exchange of material items and interpreted reciprocity to times when the meaning attached to an act or item is perceived rather than being obvious. According to Newton, Olson and Horner (1995) interpreted reciprocity was perceived in relationships where one of the partners was unable to express him/herself verbally: for example, as is the case for an infant, or an adult with little or no speech. Reciprocal interactions are not always balanced in terms of type or immediacy of exchange: for example, they may be derived from a sense of obligation or altruism. Nonetheless, reciprocal interactions as part of social support have been identified as integral to an individual’s health and quality of life (Lippold & Burns, 2009; Sanderson, Rahm, & Beigbeder, 2005; Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006; Yang, 2006). As a result, understanding the reciprocal nature of social support would appear integral to understanding how relationships are developed and
maintained. In relationships that involve people with severe intellectual disability, the reciprocal nature of social support has received little research attention.

**Social Networks and People with Intellectual Disability**

It was not until the 1980s that the social networks of people with a disability began to be investigated, and possibly was sparked by the deinstitutionalisation movement (De Kock, Saxby, Thomas, & Felce, 1988; Garvey & Stenfert Kroese, 1991; Krauss & Erickson, 1988; Landesman-Dwyer, Berkson, & Romer, 1979; McConkey, Naughton, & Nugent, 1983). There were expectations that once people left segregated residential institutions, they would automatically make new friends and become accepted into community life, but this did not happen (Bigby, 2008). Although there is evidence that the move into the community increased contacts with family members, it did not ensure residents met new people (Donnelly et al., 1996). In fact, the move into the community may have reduced the size of some people’s networks, depending on the place of relocation (De Kock et al., 1988).

The definitions of social network members in the disability research literature have varied from (a) people who are important or really liked (Forrester-Jones et al., 2004; Kennedy et al., 1990) or considered important right now (Antonucci, 1986); (b) those who have had recent contact, such as being seen in the last week (Renblad, 2002) or two weeks (J.S. Newton, personal communication, August 7, 2007) or who have been in contact in the last month (Robertson et al., 2001); or (c) people who have a special bond or provide social support (Krauss & Erickson, 1988; Krauss et al, 1992). Some social networks have been defined by utilising exclusion criteria, such as excluding paid workers (Dagnan & Ruddick, 1997).

As well as the complexity arising from the use of various definitions of networks, comparison across studies of social networks of people who have intellectual disability has been complicated by the variety in the data collection methods employed. In addition,
Although people with intellectual disability are a heterogeneous group, definitions regarding the severity of the intellectual disability of the participants involved often have been imprecise or absent. As this study focused on relationships between adults with severe intellectual disability and people in their networks, only the findings from studies that addressed or included people with severe intellectual disability have been discussed.

**Relationships for People with Severe Intellectual Disability**

According to research, the social networks of people with severe intellectual disability have similar features to those of people with mild disabilities, but are smaller in size and contain fewer friends (Kennedy, Horner, & Newton 1989; Robertson et al., 2001). However, many social network studies have included people with a range of intellectual abilities, making the extraction of data specific to severe intellectual disability difficult (Kennedy et al., 1989; Krauss & Erickson, 1988; Krauss et al., 1992; Robertson et al., 2001).

There is a common methodological difference between social network studies addressing mild versus severe intellectual disability. Data collection for people with severe intellectual disability has largely occurred using proxy reports (someone reporting on the target individual’s behalf) in light of their difficulties in expressing themselves through speech, while for people with mild intellectual disability, self reports have been used. Although the issues relating to using proxy report have been discussed in the quality of life (QoL) literature, there has been less discussion in the social network literature. Researchers have described concerns regarding the reliability of asking paid workers to complete QoL questionnaires on behalf of the people they support (proxy report), particularly when these individuals have communication difficulties (Rapley, Ridgway, & Beyer, 1998; Stancliffè, 2000). Rapley et al. (1998) reported acceptable correlations across scores derived from QoL questionnaires completed by two paid workers about the same person with intellectual disability, but poor correlations across paid worker completed questionnaires and those
completed by the person with intellectual disability him/herself. Stancliffe (2000) suggested that care needed to be taken when comparing proxy reports of people who were verbal and those of people who had little or no verbal communication, as these client groups had different characteristics. The problems involved using proxy report for QoL measures may also apply to the use of proxy reports on some aspects of a social network. Relying on social network member perceptions to portray the experiences or feelings of people with intellectual disability may be of particular concern when the people involved have limited verbal communication and, possibly, few people who know them well, allowing fewer opportunities to compare agreement across reports.

**Relationships with paid workers and family members**

Robertson et al. (2001) conducted a large social network study of 500 residents with a range of intellectual disabilities, 281 of whom lived in community-based residences. Residents with mild disabilities lived in village communities and those with the most severe disabilities lived in residential institutions. Of relevance to this thesis were the 281 residents living in the community-based residences, who were most likely to have severe but not profound intellectual disability. The community-based residences ranged in size from single occupancy to group homes of up to eight people. These residents had networks with a median of six members and a range of 0 to 20. Of these network members, 45% were paid workers. If workers were taken out of the network composition, 10% of people with intellectual disability had no-one in their networks. It was unusual for the residents to provide social support to others or to demonstrate reciprocity. Proxy report for each person with intellectual disability who was unable to speak for him/herself was provided by only one paid worker from one service setting.

Not all studies have demonstrated such limited networks. Two studies of adults with moderate to profound intellectual disabilities who lived in small group homes described
larger and more supportive social networks (Kennedy et al., 1990; Krauss & Erickson, 1988).

Kennedy et al. (1990) described the structure of the social networks of 20 adults with moderate to profound intellectual disabilities aged 22 to 56 years. Interviews were held with the resident and two people who had had daily contact with the resident over the last six months. These people were asked to name people who were socially important (i.e., people the resident really liked) in the domains of family, paid workers, co-residents, friends and neighbours. The mean network consisted of 15 people: 4.4 (29%) were family, 6 (40%) were paid workers, 3 (20%) were co-residents, 1.4 (9%) were friends and 0.4 (3%) were neighbours.

Krauss and Erickson (1988) described the social networks of 49 adults, aged over 40 years, from three different residential settings. Eleven adults lived in family homes, 29 in group homes and 9 in a residential institution. Criteria for selection included the ability to communicate and having monthly contact with family members. The researchers stated that participants from across the three residential settings were of a similar ability type, with people ranging from mild to profound levels of intellectual disability. Twenty people were identified as being in the severe to profound category, of whom four were in family homes, 13 in group homes and three in institutional care. All residents participated in a structured interview with a family member, and a service provider provided supplemental information. The inclusion criterion for network members was having frequent contact (not defined) with the person with intellectual disability, with members of paid workers excluded unless they contributed beyond basic professional duties. People who lived with their families had a mean of 5.7 contacts (composed of 4.3 family, 1.3 friends and 0.2 workers). People living in a group home or an institution had a mean of 9.3 and 9.2 people in their networks, respectively, comprised almost equally of family and friends (3-4 people), with some paid workers. Social support was recorded, if it was provided, in any of six areas of affective support: serving as a
confidante, providing reassurance, providing respect, providing care when ill, listening when upset, and discussing health matters. Support, advice and guidance predominantly came from workers in the group home and from family in the family home, while personal and emotional support was provided by family, friends and workers. Unfortunately, specific network results could not be extracted for people with severe intellectual disability. Krauss and Erickson also noted that much of their data was reliant on proxy report and parents may not always have been aware of peer supports the individual with intellectual disability had in environments outside the home.

The results of the studies by Kennedy et al. (1990), Robertson et al. (2001) and Krauss and Erickson (1988) cannot be easily compared given differences in their data collection methods. For example, Robertson et al. reported median rather than mean network sizes. In addition, the social networks studied by Kennedy et al. included residents from well staffed group homes with a high staff to resident ratio of 4.25:5. Each of these group homes had been involved in previous community research programs. As a consequence, paid workers may have received more training in supporting relationships than the workers in the two other studies, which may have positively influenced the social network size. Also, interviews with more than one informant who knew the resident well in the studies of Kennedy et al. and Krauss and Erickson possibly tapped into pooled knowledge about residents and may have been more accurate than the single paid worker reports in the Robertson et al. study.

The social network reports may also have been influenced by the type of respondents, whether family members, people with disability or paid workers. Krauss et al. (1992) relied on proxy report from a single source: that is, in in-depth structured interviews with mothers of 418 adults with intellectual disability living at home. Detailed information was collected for the first ten network members named by each adult’s mother. The researchers examined
not only network size, but also social support. They found that the mean size of the social networks was 7.1, but a standard deviation of 3.7 indicated considerable variability. There was a high level of stability in the networks, with the duration of relationships being long (26.6 years) and the frequency of interaction high (weekly to several times a week). In terms of social support, mothers were asked to state whether the members of their son or daughter’s network provided affective support in the areas as outlined in Krauss and Erikson (1988). Network members provided almost twice as much support as they received. People with severe or profound disability had smaller networks and received the most limited types of support.

Overall, the social networks for adults with severe intellectual disability living at home were dense, reciprocal and with a high level of multiplexity. This finding was supported by Seltzer and Krauss’s (2001) review of the QoL literature in relation to adults with intellectual disability who lived with family members, as family members offered support across the lifespan and were considered central in the network of people with severe disabilities. However, little is known about the relationships that exist between adults with severe intellectual disability who live in group homes and their paid workers. There has been little exploration of the existing relationships between paid workers and people with intellectual disability (Hastings, 2010), which is surprising as there has been extensive research into paid worker job satisfaction and stress (Dyer & Quine, 1998; Hatton & Emerson, 1998; Hatton et al., 1999; Hatton, Rose, & Rose, 2004). A recent Australian workplace survey of 2089 paid workers across 92 nongovernment organisation showed that 63% felt that the opportunity to “contribute to the well-being of others” (Rimfire Resources, 2011. p.79) was one of three major motivations for working in the disability area. Although the reported altruism of the paid workers may be commended, there remains a need to further understand the development of their relationships with the people they support.
Understanding the processes involved may assist developing more and varied relationships for people with severe intellectual disability,

**Relationships with unpaid social network members**

Social network research has predominantly focused on relationships with paid workers and family members and relied on them as social network informants. There have been reports of the presence of social network members, for instance, friends, co-residents, and neighbours, who are not paid to be in their network but they are few in number. The research has shown that people with the most severe disabilities tend to have the fewest friends (Krauss et al., 1992; Krauss & Eriksson, 1988; Robertson et al., 2001), with those living at home having the least (Krauss & Erikson, 1988). Friends with an intellectual disability who have been identified in a social network have been noted to play an important role in providing emotional support (Krauss & Erikson, 1988).

Apart from studying the structure and social support of networks, there have been a few studies into interaction in unpaid relationships that involved people with severe disabilities (Bogdan & Taylor, 1998; Landesman-Dwyer et al., 1979; Newton et al., 1995). Of these three studies, Landesman-Dwyer et al. focussed on the difficulties identifying peer friendships; Newton et al., focussed on how friends without a disability perceived their relationship with their friend with an intellectual disability and Bogdan and Taylor studied what underpinned relationships between stable partners and adults with severe and profound intellectual disability. The unpaid relationships studied included friends with and without intellectual disability. Identifying peer relationships was through direct observation (Landesman-Dwyer et al., 1979) and proxy report (Bogdan & Taylor, 1998; Newton et al., 1995). A greater understanding of the reasons underpinning the relationships between people with and without disabilities was sought through unstructured in-depth interviews (Bogdan & Taylor, 1998; Newton et al., 1995).
Landesman-Dwyer et al. (1979), studied peer friendships by observing the social behaviours of 208 adults with an intellectual disability across 18 group homes and coded these at 15 minutes intervals over a 2-day period. A peer friendship was defined as one in which residents were observed to spend more than 10% of their time together. Sixteen pairs of friends were identified through coded observation. When paid workers were asked to state who they thought were friends, only 12 pairs were identified. The discrepancy across the numbers of friends identified may, in part, have been due to workers difficulty in interpreting communication behaviours that have signalled a friendship. This possible inability of paid workers to identify a peer friendship suggests one disadvantage of relying on proxy report and the importance of naturalistic observation as a research method for revealing peer friendships.

Newton et al.’s (1995) study of friendships of people with severe and profound intellectual disability provided evidence of the ability of people with severe intellectual disability to reciprocate in relationships. The researchers interviewed 14 friends without a disability (termed community members) of 11 adults with intellectual disabilities, 10 of whom had a moderate to profound level of impairment. The community members’ perceptions of reciprocity were sought through a social network questionnaire developed by Newton et al. and a qualitative semi-structured interview. In response to a request to describe their relationship to the person with an intellectual disability, four of the community members described themselves as best friends, nine as friends and one as an acquaintance. In terms of developing the friendship, one of the themes that emerged from the interview data was “We clicked from the beginning” (p.386). The compatibility of personalities was one of the reasons offered to explain the community members’ attraction to an individual with an intellectual disability. Community members also reported that being needed and seeing themselves as providing the support that a family member might have given entrenched them
in the relationship. Community members stated that in terms of emotional support, they gave and received about the same amount. Interpreted reciprocity was highly valued. Some community members discussed how they felt appreciated by the person with an intellectual disability and one member commented that she could unburden herself because her friend had “no compulsion to fix things” (p. 389). Tangible reciprocity was reported as a missing aspect of the friendship. In particular, friends commented on the lack of birthday cards or presents received from the friend with an intellectual disability. They further noted that paid workers did not practically support residents’ relationships that occurred outside the group home. Overall, the community members valued their interactions and reported receiving benefits from the relationships with people with intellectual disability.

Bogdan and Taylor (1998) explored further the aspects that underpinned relationships in a study that involved interviewing stable partners (friends, family, paid workers) of people associated with over 100 people with severe and profound disabilities. The researchers’ interpretive research was based on a symbolic interaction stance and a thematic coding approach to in-depth unstructured interviews. In their analysis of results, Bogdan and Taylor stated that relationships were based on friends perceiving the humaneness in people with intellectual disability. This concept of humaneness provided a basis for the attributes of positive relationships to be demonstrated through (a) attributing thinking to the other, (b) seeing individuality in others, (c) viewing the other as reciprocating, and (d) defining a social place for the other. Interpreted reciprocity was perceived by partners in the relationships. They talked about the pleasure of having a person with a severe disability in their lives, particularly in terms of companionship. The results of this study suggest that positive and reciprocal relationships that include friendships for people with severe intellectual disability do exist.
Summary

Research has demonstrated that people with severe intellectual disability have small, dense social networks with few friends. Paid workers and family members gave more practical support than they received and interpreted the presence of reciprocity in the relationships. Some people had stable and rewarding relationships with adults with severe intellectual disability. Given that people with severe intellectual disability have shown they can attract people with whom to spend time, it would help to identify the components of this attraction in order to understand and support these and other relationships.

There is strong evidence that relationships are sustained by reciprocal exchange. The constituents of any exchange involving people with a severe intellectual disability mostly have been described from a family member’s perspective or to a lesser extent from the perspective of unpaid network members. Paid workers have contributed to extending the structural knowledge of social networks relating to people with severe intellectual disability, but there has been little exploration of relationships between paid workers and people with intellectual disability. In addition, the scarcity of reports examining the relationships between people with a severe intellectual disability and friends without a disability suggests this area also needs further exploration. There remains a need to systematically unpack the processes involved in relationships, in order to shed some light on what occurs in positive relationships and work towards social inclusion.
CHAPTER 4: METHODOLOGICAL FOUNDATIONS

Overview of the Chapter

The objective of the chapter is to illustrate the rationale used for choosing a course of qualitative inquiry and how the decision to select a grounded theory approach was made. In addition, the constructivist grounded theory viewpoint is detailed and the congruence between the personal perspective of the researcher and the processes of grounded theory explored.

Qualitative Research

The aim of the research was to develop an understanding of the processes involved in relationships between adults with severe intellectual disability who have limited communication skills and their preferred others. As little is known about this area, qualitative methodology was selected as its use can help to “discover understanding or to achieve explanation from the data instead of from (or in addition to) prior knowledge or theory” (Morse & Richards, 2002, p.2). Qualitative research is both naturalistic and interpretive: that is, the study is based in natural settings and the phenomena explored by making meaning of what is seen and heard (Crotty, 1998; Silverman, 2005). Interpretive research relies on inductive logic, “a type of reasoning that begins with a study of a range of individual cases and extrapolates from them to form a conceptual category” (Charmaz, 2006, p.188). Inductive logic requires the researcher to put aside prior assumptions and preconceived ideas and embark on a rigorous search for patterns and new meanings (Crotty, 1998; Morse & Richards, 2002; Patton, 2002). It has been argued that whatever the methodology and methods utilised, producing high-quality research requires the researcher to practise “good thinking” (Stake, 1995, p.19).
Selecting a Methodology

Qualitative research encompasses several rigorous approaches that reflect various philosophical stances involving a range of methodologies and methods used in the collection and analysis of data. Although different methodologies may involve the use of the same methods, the analysis of the data and the interpretations of the meaning of the data are specific to a particular methodology and require methodological congruence. Using the same technique in a different methodology could lead to a different interpretation, depending on the methodological stance adopted. Creswell (2007) identified five main qualitative research approaches: (1) narrative, (2) phenomenology, (3) ethnography, (4) case studies, and (5) grounded theory. Creswell selected these approaches because each is structured and thorough, derived from a range of disciplines, and informed by a body of literature.

Phenomenology, ethnography, and grounded theory have been adopted in prior research with adults who have severe and/or profound intellectual disability (Angrosino, 1997; Clement & Bigby, 2009; Coles, 2001; Forster & Iacono, 2008; Hubert & Hollins, 2006; Murphy, Clegg, & Almack, 2011).

Selecting an appropriate methodology is dependent on the type of research question being asked. Questions such as "what is the experience of …?" may best be addressed by a phenomenological approach that involves the search for meaning of a phenomenon or life experience from the participant’s point of view, and provides a reflective description (Morse & Richards, 2002). The application of a phenomenological approach has provided insight into the lived experience of supporting adults with a profound intellectual disability (Forster & Iacono, 2008). Ethnography is often selected when the behaviours of a culture or group of people are to be investigated and the question asked is “what are the behaviours ….?(Morse & Richards, 2002). Ethnographic research involves long term fieldwork, whereby the
immersion of the researcher into an environment facilitates the development of illuminating
descriptions of cultures and practices (Angrosino, 1997; Clement & Bigby, 2009). Grounded
theory focuses on revealing the dimensions of experiences and involves developing a theory
or model from data grounded in the studied phenomenon, in situations where the question
asked is “what are the processes involved...?” (Bogdan & Taylor, 1998; Morse & Richards,
2002). A grounded theory approach was selected for this study in order to develop a theory
that could describe new knowledge, but also impact on the practice of social action and drive
future research in under researched areas.

**Grounded Theory**

Grounded theory represents a rigorous approach to extracting meaning from participants’
experiences (Schwandt, 2007). Glaser and Strauss (1967) developed grounded theory by
explicating specific and demanding approaches to data analysis. Over the years, grounded
theory approaches have evolved under different tutelages, yet some constants remain. One of
these is that data collection and analysis occur simultaneously. Data are compared and
contrasted using a method termed *constant comparison*. Another constant is that grounded
theorists emphasise the centrality of *theoretical sensitivity*: that is, there is an ongoing and
detailed search to develop new theories or ways of presenting the data conceptually. Over
time, prominent grounded theorists have adopted different theoretical stances and approaches
to coding (Glaser & Strauss, 1967; Strauss & Corbin, 1990; Bryant & Charmaz, 2007). The
approach taken in this study was one that operates from a social constructivist theoretical
perspective and follows the work of Charmaz (2006).

**Constructivist Grounded Theory**

Kathy Charmaz, formerly a student of both Glaser and Strauss, has maintained the basic
tenets of grounded theory but differs from Glaser by emphasising the importance of adopting
a social constructivist approach (Glaser, 2002; Charmaz, 2000). In this approach, the
importance of recognising that people see the world differently and construct their own realities is stressed. The belief that people perceive multiple realities is inherent in a constructionist epistemology, in which “meaning is not discovered but constructed” (Crotty, 1998, p.9). Social constructivists who adopt a symbolic interactionist perspective perceive that meaning is imparted through symbols, with words being one type of symbol. They believe the social world is constructed through interaction and are “most concerned with the meanings that people give to actions and events and with understanding how these meanings are constructed and negotiated” (Sandstrom, Martin, & Fine, 2010, p.3). The understandings derived from utilising symbolic interaction also “rely on language and communication” (Charmaz, 2006, p.7).

In addition, a constructivist grounded theory approach recognises the researcher as an integral part of the process, a co–producer and verifier of meaning (Charmaz, 2000). Charmaz asserted that theories are not discovered, rather they are created through the researcher’s practices, interactions with the participants, and his or her own interpretations of meanings. Guba and Lincoln (2005) agreed, stating that “the way in which we know is most assuredly tied up with both what we know and our relationships with our research participants” (p.209).

The end point of most grounded theory research is to develop a mid-range or substantive theory that describes a model or conceptualises a particular phenomenon (Bex Lempert, 2007; Charmaz, 2006). Charmaz emphasised that theory should be accessible, recognisable and grounded in the data pertinent to social action or social policy, particularly where contradictions between practice and policy may exist. A constructivist approach acknowledges that theories need to resonate with and be recognised by the stakeholders in order to be considered trustworthy and ethically valid (Guba & Lincoln, 2005; Charmaz,
Trustworthy data implies that the findings will provide a sound and believable basis from which social policy can be developed.

Charmaz’s epistemological approach to data collection and analysis, the acknowledged relationship between researcher and participants, and the potential for developing practical theory as a basis for social action were aspects that resonated with my personal perspective and the purpose of the study. Consequently, grounded theory was selected as the approach to this study.

**Personal Perspective**

As a speech pathologist supporting people with limited communication, the accurate interpretation of a communicative message has always been of paramount concern. My perspective is that communication is a transactional process between two people that is always co-constructed and incorporates a symbolic interactionist perspective. This perspective is particularly relevant when interactions include one or more people with limited symbolic communication. In this situation, the role of the communication partner is to extract the requisite meaning in order to interact appropriately. In doing so, the partner has to shift his or her attention between idiosyncratic symbolic and nonsymbolic forms of communication in order to interpret meaning. The feedback and learning from one interaction affect the next set of interactions, and a cyclical process of interpretation and feedback continues.

Subscribing to a social constructivist approach presupposes that individuals who experience the same action, interaction or activity may report their experience differently. When interpreting ambiguous communicative exchanges communication partners may react or respond differently to a communicative interaction. The role of the speech pathologist when working with communication partners of people with limited communication is challenging, as each message interpretation needs to be discussed jointly, until an agreed
meaning can be constructed and shared. This process of interpretation could be considered to parallel the processes involved in qualitative research. Developing a mutual understanding requires detailed listening and observing (data collection), interpreting and checking back (coding and member checking), and taking time to reflect (reflexivity) before constructing a plan and moving forward (theorising). Thus I brought to the study a practical approach to interpretative research.

In addition, I was attracted by the way grounded theory researchers emphasise the rigorous and careful coding process, constant reflection and memo writing. This repeated engagement with the data increases the possibilities of developing a profound understanding and illuminating new theoretical concepts. The careful selection of terms is a key issue close to my personal and professional heart. First, the women’s movement in the 1970s sparked in me a strong sense of social justice and awareness of how language can be misused to deny equal representation. Additionally, I have a long term interest in the more creative and evocative aspects of establishing multiple meanings through writing poetry. Finally, I have many friends with disabilities and have worked on campaigns in both a professional and personal capacity to avoid stereotyping, enhance the status of people with a disability and make a difference.

I chose grounded theory as it encourages an understanding of the processes involved in relationships, acknowledges the professional or personal perspectives, incorporates reflection to the assumptions brought to an interaction and applies flexibility in data analysis methods (Charmaz, 2006). The application of grounded theory to the research questions in the current study is appropriate because (a) observing and interpreting the interactions of participants will assist in developing an understanding of the processes that underpin and form their relationships; (b) the multiple realities of all stakeholders can be included; (c) building knowledge about interactions and relationships of people with severe intellectual
disability will assist in a detailed understanding of the issues involved in social inclusion; (d) the research question addresses a marginalised group whose needs should be considered within a framework of social justice; (e) grounded theory approaches are appropriate for examining contradictions between the policies espoused and everyday practices; and (f) it is theory that will provide guidance to policy and practices in order to improve relationships and hence social inclusion for adults with intellectual disabilities and limited communication.

Summary

Qualitative research comes in many forms. Deciding on a methodological approach requires methodological congruence with the research questions and the researcher’s perspective. My role as a speech pathologist has influenced my approach to research, taking a symbolic interactionist approach. Charmaz’s (2006) grounded theory approach was selected to assist in explaining relationship processes in the form of a model or theory and to guide future practice.
CHAPTER 5: METHODS AND PROCEDURES

Overview of Chapter
This chapter presents the design of the study and details the selection and recruitment process of both the central participants and the personal affinity network members. The ways in which data were collected are described and details of the analysis are presented. The comprehensive account of data collection and analysis provides a reference point for the abbreviated method sections in the publications in chapters six and seven. The chapter finishes with a publication that details the challenges of one form of data collection, participant observation, when used with adults who have severe intellectual disability.

Design
A constructivist grounded theory approach was used to collect and interpret the data in order to identify implications for social change. In this research, Charmaz’s (2006) suggestions for using grounded theory guidelines were adopted. Ethical approval for the study was granted through the Human Ethics Research Committees of two universities and one nongovernment organisation that assisted with recruitment.

The participants included central participants and social network members. The central participants were recruited and selected prior to the social network members. The social network members were selected through proxy report and observation of interactions with the central participant.

Selection and Recruitment of Central Participants

Recruitment and Consent
The two main inclusion criteria for the selection of central participants were (a) a diagnosis of severe intellectual disability, and (b) demonstration of symbolic but nonlinguistic communication skills. Central participants have a complex presentation and their lack of
clear speech may mask social abilities, resulting in incorrect estimation of skills. People with a severe intellectual disability and symbolic but nonlinguistic communication skills have been given little attention in the research literature. They previously may have been subsumed into other groups of people with an intellectual disability, most frequently people with severe and profound disabilities. For this research, a careful and detailed process was undertaken, involving a number of different assessment tools, described below, in order to assess the skills and abilities of the central participants as accurately as possible. These criteria were determined through a combination of direct observation, review of any existing documentation and formal assessment. The initial encounter with each central participant involved observing the person interacting with others in one or more of his/her natural surroundings (e.g., at home with family; at the day centre in a group program) and spending some time in face-to-face interaction.

In order to locate central participants, I contacted speech pathologists who I knew were working with adults with intellectual disability, and briefed them about my study. I also contacted several day service coordinators and sent them a brief outline of the project and criteria for the desired participants (see Appendix A staff information). Four potential central participants from one centre were identified through a discussion of the research at a day-staff meeting. Another six potential central participants were suggested by the speech pathologists who were contacted. Paid workers of potential participants sent the study information to family members who were asked to return the forms to me by post if they were interested in their son or daughter taking part in the study (see Appendix B central participant information and Appendix C consent forms). Family members were also given my phone and email details and encouraged to contact me with any questions. All but one person with an intellectual disability required family members to provide written consent. Once the completed consent forms were returned to me, appointments were scheduled to meet the
central participants and assess their suitability for the project. Over the two years of data collection, consent was received for 10 central participants to take part in the study and six were assessed as meeting the selection criteria.

**Anonymity of central participants.** The area of severe intellectual disability is relatively small within the intellectual disability sector more broadly. Confidentiality was addressed by assigning pseudonyms to all named participants in reports or discussions. In addition, certain identifying data have been withheld or changed.

**Assessment Tools and Procedure**

Three forms of assessment were used to establish whether the central participant met the selection criteria. The Vineland Adaptive Behaviour Scales (VABS) (Sparrow, Balla, & Cicchetti, 1984) provided an overview of each central participant’s living skills; the Checklist of Communication Competencies (Triple C) (Bloomberg, West, Johnson, & Iacono, 2009) provided data to enable establishment of symbolic communication and the Peabody Picture Vocabulary Test-III (PPVT) (Dunn & Dunn, 1997) was used to assess receptive language ability.

**Vineland Adaptive Behaviour Scales (VABS) (Sparrow et al., 1984).** Legislation in Victoria no longer includes the requirement of an Intelligence test resulting in a formal Intelligence quotient (IQ) for a person with an intellectual disability in order for that person to receive services (Victorian State Government, 2006). Instead, adaptive behaviour scale assessments (e.g., standardised checklists of skills across life domains completed by someone who knows the person well) have been used to determine a person’s skill levels and support needs. Many types of adaptive behaviour scales have been developed, each with different strengths (Thompson et al., 2004; Bruininks, Woodcock, Weatherman, & Hill, 1986; Bruininks et al., 1996; Nihira, Leland, & Lambert, 1993). From the various options, the VABS Interview edition was selected for this study because the first central participant had
been assessed on the school-aged version, thereby providing the basis for ensuring a uniform measure across all the central participants (Sparrow et al., 1984). The VABS is completed by interviewing someone who knows the person well. Skills are measured across three domains: communication, daily living skills and socialisation. The scale has been found to have acceptable construct, content and criterion related validity (Sparrow et al., 1984).

Nevertheless, the VABS has limitations when applied to an adult population as it was normed on people from birth to 19 years of age. The VABS was not selected to provide a measure of cognitive skills: this is not its purpose, as evidenced by low correlations between the VABS and the Kaufman Assessment Battery for Children (Kaufman & Kaufmann, 1983). The authors of the VABS extended the reach of the scale by developing supplementary normed percentile ranks on 1,050 mobile and non-mobile adults with intellectual disability who lived in either residential or non-residential facilities. Consequently, the VABS results for the central participants in this study can be presented in two ways: (a) as percentile ranks based on the supplementary norms for adults over 18 years of age with an intellectual disability; and (b) as age equivalence scores based on norms from people without a disability.

**Checklist of Communication Competencies (Triple C) (Bloomberg et al., 2009).**

The Triple C checklist is appropriate for determining the broad symbolic or nonsymbolic level of skills of adults who have severe to profound intellectual disabilities. It was developed and evaluated in Victoria, Australia and is widely used in Victorian day services (Iacono, Bloomberg, & West, 2005). The assessment comprises a checklist of behaviours organised within five communication stages: unintentional passive, unintentional active, intentional informal, intentional formal basic symbolic, and established symbolic. A high level of internal consistency and construct validity has been demonstrated (Iacono et al., 2005). For accurate completion of the checklist, two people who have been familiar with the person with an intellectual disability for over 6 months and are knowledgeable about the
person across or in different environments conduct the assessment. The completed checklist is then discussed with a speech pathologist to verify the scoring and ascertain the relevant stage, according to instructions provided in a manual (Bloomberg et al., 2009). A stage of basic or established symbolic communicator was required for participation in the research.

**Peabody Picture Vocabulary Test-III (PPVT) (Dunn & Dunn, 1997).** The PPVT provides a measure of receptive vocabulary. It has been found to correlate highly with mental age and in particular with the vocabulary subtests of the Wechsler Intelligence Scale for Children – Third Edition (WISC-III) (Wechsler, 1974; Dunn & Dunn, 1997). The PPVT has been standardised for adults (as well as children) and has been found to have acceptable content validity, construct validity, and internal validity. In addition, it is considered by the test developers to be a “screening test of intellectual functioning” (Dunn & Dunn, 1997, p.48). To complete the test, the participant is shown a page of four black and white line drawings and asked to point to one: for example, “show me the …”. The participant continues until eight errors within a set are recorded. The scoring procedure was followed as outlined in the manual. Receptive vocabulary age levels from 1 year 9 months to 22 years can be obtained on the basis of standard scores. Language skills that are symbolic but nonlinguistic are likely to have receptive language scores of 1 to 2 years (Dore, 1974; Dore, 1978; Owens, 2005).

**Observation and Formal Assessment**

The central participants were observed in functional activities (e.g., making a sandwich, eating a meal) and in social activities (e.g., watching TV with others, morning routine interaction). During this time, a Triple C checklist was completed if required. For three participants, Triple C checklists had been completed prior to the study. I completed the checklists for the other three and discussed the results with people who were familiar with the central participants. During the observation of interactions, sufficient information to satisfy
the communication selection criteria was obtained with three central participants in a single environment (two in a group home and one at a day centre). For the other three participants, observations were carried out in two main environments: either the family home and day centre, or group home and day centre.

Observations indicated that all the central participants’ communication was at a symbolic but nonlinguistic level. Details are provided in Table 1. All used multimodal communication, combining informal means, such as natural gesture, with formal means, such as speech. All central participants were observed to use pictures to communicate, with three showing a preference for this modality. Five central participants used some key word signs that often accompanied speech or attempts to vocalise. One participant demonstrated use of a few stereotyped two-word phrases (see Table 1).

Adults with an intellectual disability within the service system from which they were recruited were unlikely to have had a recent formal determination of their level of intellectual disability, given this is not a requirement for service access. For one participant, results from a previous cognitive assessment were available and for three participants, previous communication assessment results were available. After observing the central participants in their natural environments, an attempt was made to administer the formal assessments with each participant. The PPVT was attempted with all but one central participant who had insufficient vision for the task. Three central participants complied with the assessment procedures, and two completed the first few items but indicated unwillingness to continue. A summary of the results is presented in Table 1. The PPVT scores for two participants were too low to be converted into a standard score, so their receptive vocabulary levels were judged to be lower than an age equivalence of 1 year 9 months. However, one participant’s (Eric) raw score corresponded to an age equivalence of 5 years, and indicated an increase of 6
### Table 1

**Summary of Communication & Cognition Assessments for each Central Participant**

<table>
<thead>
<tr>
<th>Name</th>
<th>Sandra</th>
<th>Brian</th>
<th>Colin</th>
<th>Diane</th>
<th>Eric</th>
<th>Fayez</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Expressive communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Speech &lt;100 single words. A limited number of repeated two-word phrases (e.g., <em>mum happy, dad happy</em>). Uses 10 Key word signs</td>
<td>Has 30 spontaneous words. Uses approximately 20 Key word signs</td>
<td>Uses &lt;30 Key word signs. Can initiate interactions by pointing to photos</td>
<td>Has a static display SGD with 60 pictographs. Relies on vocalisation &amp; natural gesture and &lt;10 Key word signs.</td>
<td>Uses &lt;100 spoken words. Uses &gt;100 Key word signs. Can use photos/pictures to share requests or comments</td>
<td>Has a communication book &gt;100 pictographs which she points to for requests or comments.</td>
</tr>
<tr>
<td>PPVT</td>
<td>Raw Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not completed</td>
<td>N/A</td>
<td>Not completed</td>
<td>17</td>
<td>72</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Standard Score</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Age Equivalence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&gt;1 yr. 9 mths</td>
<td>5 yrs. 1 mths (4-4.5 yrs)</td>
<td>&gt;1 yr. 9 mths</td>
</tr>
<tr>
<td></td>
<td>Triple C Stage</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Symbolic Advanced</td>
<td></td>
<td>Symbolic basic</td>
<td>Symbolic advanced</td>
<td>Symbolic advanced</td>
<td>Symbolic advanced</td>
</tr>
<tr>
<td>VABS</td>
<td>AB Composite</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Communication Total AE</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Expressive</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Daily living skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total AE</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>Total SP</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Personal</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Domestic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Socialisation Total AE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>SP</td>
<td></td>
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</tr>
</tbody>
</table>

*PPVT Standard Scores not available for scores > 22. PPVT age score from prior assessment at age 8 yrs. All scores too low for a SS of 20+. Prior score at age 12 on VABS (Classroom). Age Equivalence. Supplementary Norm Group Percentile rank.
months from the results of a PPVT conducted when he was 8 years old. This result appeared to demonstrate strength in receptive vocabulary.

In addition, I completed a VABS over a number of sessions with people who knew the central participants well. The composite raw scores from the VABS were too low to be converted into the minimum standard score of 20; so all central participants scored 19. The raw scores from each domain were compared to the appropriate supplementary normed group and all results fell in the below average range. Overall, all central participants scored at a low adaptive level that was also referred to in the VABS interview edition survey form manual as a profound deficit. Comparison of the Supplementary Norm Group Percentile (SP) across the three domains shows variation from SP1 to SP10, with the narrowest range in scores found in the communication domain, from SP5 to SP10. Thus the central participants were most similar in regard to communication skills and most dissimilar in daily living skills (SP1-SP10) (see Table 1). The overall low scores may have been associated with the participants’ multiple disabilities, which included poor motor skills. This situation was exemplified by Fayez, whose low scores on daily living (SP1) and social skills (SP2) reflected her restricted motor abilities. When the central participants’ raw scores were compared to equivalent age levels of a non-disabled cohort under 18 years of age, their communication scores ranged from 1 year to 1 year 9 months.

McCauley and Swisher (1984) noted problems with the use of age equivalence scores as a means of summarising performance on a standardised measure. In particular, they argued that interpolation of scores from normative samples that do not include individuals at the chronological age of persons being assessed involves inaccurate assumptions about continuity of language development as a person ages. Such continuity is unlikely for adults with limited communication ability, given the unknown impact of years of life experience on both underlying skills and performance in adaptive function as assessed on the VABS, which
may explain results obtained over time for some participants. The results from Sandra’s VABS (Classroom), for example, conducted when she was 12 years old, indicated a greater range of skills than demonstrated on the current VABS. These results do not denote skill deterioration but rather demonstrate that she has not followed a normal developmental trajectory and, consequently, as she ages, her performance appears to worsen. Sandra’s receptive language skills at the time of the assessment for this study could not be verified on the PPVT as she was not interested in participating in formal testing.

Overall, the VABS assessment data indicates a low level of functioning for all central participants. The PPVT results were available for three central participants only, the scores for Diane and Fayez equating to performance at a level under 1 year 9 months. Nonetheless, two aspects of the observation and assessment data indicated that the central participants’ skills were more comparable to adults with severe than profound intellectual disability. First, each participant’s communication skills exceeded that expected for profound intellectual disability. People with profound intellectual disability rely on informal communication and have little or no symbolic skills (Hostyn, Petry, Lambrechts, & Maes, 2011; Forster & Iacono, 2008). Although central participants predominantly used informal communication, they did demonstrate symbolic skills. All of the central participants used or were reported to use 30-100 symbols to communicate (see Table 1). Second, the supports reportedly required for daily living (on the VABS) were commensurate with extensive rather than pervasive support needs. In fact, McLean et al. (1996) described people with severe intellectual disability as needing “extensive levels of support in multiple adaptive domains” (p.580).

In summary, although the central participants showed a diversity of skills, they all demonstrated (a) symbolic but nonlinguistic communication, and (b) daily living skills commensurate with severe rather than profound intellectual disability. Hence, the central
participants as a group have been described as adults with severe intellectual disability with symbolic but nonlinguistic communication skills.

**Selection and Recruitment of Social Network Members**

The following four criteria were used to identify the social network members: (a) people whom the central participant could name (by speech, sign or pointing to photos) when not in their presence; (b) people with whom interactions were observed to be positive and in which the central participant showed pleasure (Forrester-Jones et al., 2004, Kennedy et al., 1990); (c) people with whom an interaction/activity had lasted more than 15 minutes (Newton, 2007 personal communication); and (d) people who had a special bond with the central participant or who had known him/her for several years (Krauss and Erickson, 1988, Krauss et al., 1992). Each person needed to meet a minimum of two criteria to be deemed a social network member.

Members from each central participant’s social network were identified in two ways. The first was through my observation of the central participants’ responses to people as they interacted and the second through other people’s recommendations (proxy report). When possible, central participants’ reactions were also sought through observing their responses to photographs of social network members. This technique was not attempted with two central participants: one was disinterested in photos and my presence increased the anxiety levels of the other. A Talking Mats strategy™ (Murphy & Cameron 2002), in which photos are sorted on a continuum from “like” to “don’t like” categories, was trialled with one central participant, but after showing initial interest, he became unwilling to continue.

Some central participants were able to verify the selection of social network members by photo indication techniques. Three central participants demonstrated pleasure and recognition of the photos in different ways. Sandra repeatedly named the people in the photos she most preferred, Colin pointed to the photos and showed them to other staff.
members and Fayez smiled and pointed repeatedly to certain people on a photographic display.

Once identified, the social network members were invited to be interviewed, and given an information sheet and consent form (see Appendix D and Appendix E). The consent form was either returned by post or collected by a senior staff member. Only one paid worker refused consent to be interviewed, due to lack of time, but gave permission for the use of the data collected during observations. When peers with intellectual disability were identified as social network members, information sheets and consent forms were sent out to family members. Family members were asked to talk about the study with the peer using an additional picture form for clarification (see Appendix F for picture consent forms).

Overall, 57 social network members were recruited. Twenty-three members met all four criteria, 25 met three and 9 met two: 84% of network members met three or more criteria. All network members met the second criteria, of participating in positive and pleasurable interactions with central participants. To delineate the difference between the people involved with the central participant in the research and others in the central participants’ environment, the term personal affinity network member has been used to refer to network members with whom the central participant had a positive relationship. This term has been adopted in recognition of the unique relationship and the special connection that the personal affinity network members have with the central participants.

**Data Collection**

Although grounded theory does not require specific data collection techniques, Charmaz (2000) emphasised that whatever the data source/s utilised (e.g., interviews, observation, historical documents), there needs to be “rich data with thick description” (p.514). The researcher engages reflexively with the data and produces a “story about people, social processes and situations” (p.522). This iterative process is particularly pertinent in research.
that involves people with limited communication skills because the meaning of their messages requires observation and discussion with others who know the person well. Data for this study consisted of field notes from observations, transcripts of interviews and documents, including previous assessment and emails with personal affinity network members, as well as the researcher’s personal reflexive journal. Data collection and analysis occurred concurrently. The questions that occurred during that process affected the selection of participants and how they were sampled.

**Sampling**

*Convenience sampling* was utilised to identify the first central participant. Convenience sampling refers to selecting participants who possess the basic characteristic required for the study (Morse, 2007). Successive participants were chosen through *purposeful sampling* (Morse, 2007; Creswell, 1998; Patton 2002). Purposeful sampling is utilised when seeking a specific typology or feature to explore fully. As Morse (2007) stated, “we are solving problems detective-style, looking for clues, sifting and sorting, and creating a plausible case” (p.238).

In addition, *theoretical sampling* was also involved when selecting central participants. Charmaz (2006) emphasised that theoretical sampling in grounded theory involves analysing the data and discovering emergent categories that are not preconceived or predetermined. Theoretical sampling was utilised in order to identify the relevance and significance of codes as they emerged, and these codes were modified and further developed as data were collected from successive participants (Bryant & Charmaz, 2007; Morse & Richards, 2002). During the sampling, a negative case emerged, Diane, whose actions, reactions and social network member responses challenged the emerging concepts. In grounded theory, negative cases cause the researcher to develop alternate or additional explanations, and are considered part of theoretical sampling (Charmaz, 2006; Morse, 2007).
A process of maximum variation was utilised to include a diversity of central participants (Creswell, 2007; Maykut & Morehouse 1994; Morse, 2007; Patton, 2002). The diversity amongst central participants was evident in their key characteristics, (see Table 2 for a summary of sampling characteristics of central participants). Central participants comprised three males and three females, whose ages ranged from 20 to 44 years. They had various multiple diagnoses, including cerebral palsy and autism spectrum disorder, two people were reliant on a wheelchair for mobility, and two had significant visual impairments. Residential differences were evident with three central participants living in the family home and three in group homes, and ethnic diversity was reflected in two being from non-Anglo/Australian homes.

Successive central participant selection occurred through a process that developed during the study. Sandra was the first participant and her selection was based on convenience sampling. Sandra had physically hurt people in her social environment and while collecting and analysing data, a question arose as to how relationships might be different if the central participant did not hurt others. Adopting purposive sampling, the second participant, Brian, was selected for his easy-going nature but shared some characteristics with Sandra in that he was young and also lived at home. Analysis of Brian’s data prompted questions about whether the protection the family members provided might be different if the participant was not living at home and how this might affect the development of other relationships. These questions led to locating the third participant, Colin, who as with Brian, was physically active and initiated much of the social interaction that was observed.

In addition, a sense of having fun in the relationships was emerging from the data, which drove theoretical sampling in regard to the remaining participants. One of the questions that arose from reflecting on the first three participants was how much of the interaction was contingent on their physical skills. This reliance was further explored...
Table 2

Sampling Characteristics of Central Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Sandra</th>
<th>Brian</th>
<th>Colin</th>
<th>Diane</th>
<th>Eric</th>
<th>Fayez</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>20</td>
<td>23</td>
<td>27</td>
<td>44</td>
<td>24</td>
<td>38</td>
</tr>
<tr>
<td>Diagnoses</td>
<td>Intellectual Disability</td>
<td>Intellectual Disability</td>
<td>Intellectual Disability</td>
<td>Intellectual Disability</td>
<td>Intellectual Disability</td>
<td>Intellectual Disability</td>
</tr>
<tr>
<td>Spectrum Disorder</td>
<td>Scoliosis</td>
<td>Scoliosis</td>
<td>Scoliosis</td>
<td>Scoliosis</td>
<td>Scoliosis</td>
<td>Scoliosis</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>Epilepsy</td>
<td>Epilepsy</td>
<td>Epilepsy</td>
<td>Epilepsy</td>
<td>Epilepsy</td>
<td>Epilepsy</td>
</tr>
<tr>
<td>Main residence &amp; location</td>
<td>Family home</td>
<td>Family home</td>
<td>Group home</td>
<td>Family home</td>
<td>Group home</td>
<td>Group home</td>
</tr>
<tr>
<td></td>
<td>Metro</td>
<td>Metro</td>
<td>Rural</td>
<td>Metro</td>
<td>Metro</td>
<td>Metro</td>
</tr>
<tr>
<td>Physical mobility</td>
<td>Mobile</td>
<td>Mobile</td>
<td>Mobile</td>
<td>Manual wheelchair</td>
<td>Manual wheelchair for distance</td>
<td>Electric wheelchair</td>
</tr>
<tr>
<td>Visual skills</td>
<td>Within normal limits</td>
<td>Limited vision</td>
<td>Legally blind</td>
<td>Within normal limits</td>
<td>Within normal limits</td>
<td>Within normal limits</td>
</tr>
<tr>
<td></td>
<td>Wears glasses</td>
<td>Wears glasses</td>
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<td>Wears glasses</td>
<td>Wears glasses</td>
<td>Wears glasses</td>
</tr>
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<td>Family ethnicity</td>
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<td>Non-Anglo-Australian</td>
<td>Anglo-Australian</td>
<td>Anglo-Australian</td>
<td>Anglo-Australian</td>
<td>Non-Anglo-Australian</td>
</tr>
</tbody>
</table>

through the next three participants, who had limited mobility. The fourth participant, Diane, lived at home with her parents, used a manual wheelchair for mobility and actively sought out other family members or staff members, but unlike the others, did not seek interaction with peers with intellectual disability. The fifth participant, Eric, used a manual wheelchair, but for long distances only. He was recruited primarily because he actively sought out relationships with people with an intellectual disability. The last central participant, Fayez, used an electric wheelchair and was selected to further explore the understandings that might arise from studying someone with restricted motor skills and little family contact.
Data Sources

The two major data sources were participant observation and interviews. Interviews are a particular type of conversation and a common source of data used by qualitative researchers (Green & Thorogood, 2009; Morse & Richards, 2002; Patton, 2002). Rather than rely solely on interviews from carers and families, however, some researchers have emphasised the importance of including participant observation in order to understand the world from the viewpoint of the person with complex communication needs (Taylor & Bogdan, 1989; Angrosino, 2004). Interestingly, there has been little participant observation research with a focus on relationships that involve people with intellectual disability who have limited communication skills. In the current study, participant observation proved to be a powerful tool both to establish researcher credibility and provide core information from which to base a textured analysis of interviewee responses.

Participant observation. Observations occurred over 239 hours in a variety of settings, including family homes, group homes, day centres and community settings. Each observation period varied in duration from 0.5 to 3 hours (see Table 3 for details of durations and locations). The total number of observation hours varied across central participants, ranging from 19 to 47 hours. The variation in hours was related to each central participant’s comfort with being observed; environmental restrictions, such as the size of the location, the number of people present and the nature of the activity; and range of interactions. For some central participants, data took longer to collect because there were long periods of inactivity, while other participants were engaged frequently. The observation data were drawn from field notes taken during observations of the central participants. Conversations or emails with network members were included in field notes. Information about the central
participants was also drawn from personal files and documentation at the day centre or group home.
### Table 3

**Duration of Engagement with Central Participants, Number of Occasions and Locations**

<table>
<thead>
<tr>
<th>Period &amp; place of engagement&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Sandra</th>
<th>Brian</th>
<th>Colin</th>
<th>Diane</th>
<th>Eric</th>
<th>Fayez</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total length of engagement</strong></td>
<td>5 months</td>
<td>6 months</td>
<td>4 months</td>
<td>5 months</td>
<td>6 months</td>
<td>6 months</td>
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<tr>
<td><strong>Homes</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Hours of observation (Number of occasions)</td>
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<td>17</td>
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<td>17</td>
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<td></td>
<td>(13)</td>
<td>(6)</td>
<td>(7)</td>
<td>(3)</td>
<td>(11)</td>
<td>(9)</td>
</tr>
<tr>
<td><strong>Day service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hours of observation (Number of occasions)</td>
<td>10</td>
<td>23</td>
<td>21</td>
<td>15</td>
<td>30</td>
<td>16</td>
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<td></td>
<td>(13)</td>
<td>(10)</td>
<td>(6)</td>
<td>(4)</td>
<td>(10)</td>
<td>(7)</td>
</tr>
<tr>
<td><strong>Other locations</strong>&lt;sup&gt;c&lt;/sup&gt;</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hours of observation (Number of occasions)</td>
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<td>4</td>
<td></td>
<td></td>
<td></td>
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<td>(2)</td>
<td>(1)</td>
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<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>31</td>
<td>40</td>
<td>42</td>
<td>19</td>
<td>47</td>
<td>34</td>
</tr>
<tr>
<td>Hours of observation (Number of occasions)</td>
<td>(26)</td>
<td>(19)</td>
<td>(14)</td>
<td>(7)</td>
<td>(21)</td>
<td>(15)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Duration over which observations occurred. <sup>b</sup> Family and/or group home. <sup>c</sup> Other locations included leisure activities (not associated with day service).

Conversations between the participants and me sometimes occurred during observations, following a request for clarifications of their understanding of interactions; these were recorded in field notes. Extracts from field notes were coded using a unique three-part alphanumeric code to assist in providing an audit trail (e.g., FN/D5). The first two letters identified the extract as coming from the field notes, the next letter was the initial of the central participant’s pseudonym, and the number (5) was that of the observation session. In this example, FN/D5 denotes field notes for Diane’s fifth observation session.
Two participant observer roles were used predominantly: these were observer-as-participant and complete observer. Specific challenges encountered in this study and the benefits of using participant observation have been explored in the publication found at the end of this chapter.

**Interviews.** The aim of the interviews was to supplement the information gained through the participant observations in order to understand personal affinity network members’ perspectives on their relationships with central participants. According to Patton (2002), the quality of the information gained through interviews is reliant on the interviewer and their skills. The interviews were a rich source of data. All personal affiliated network members were invited to participate in interviews. Wherever possible, interviews occurred after I had observed the interviewee interacting with the central participant for at least one or two sessions. This order allowed me to compare the interviewee’s reflections on central participant interactions with my perception of the same interactions, and further my understanding of their responses through probing questioning.

Interviews ranged in duration from 30 to 75 minutes; each took place in a quiet space chosen by the interviewee. Some interviews were situated in the workplace, while others were in private homes. Each interview involved a combination of interview styles, in that each commenced with a structured open-ended in-depth interview that included some unstructured informal conversational elements (Patton, 2002). An interview guide was developed and used as a prompt (Creswell, 1998; Patton, 2002) (see Appendix G for the initial interview guide). The types of questions used were those that elicited the interviewee’s experiences, knowledge of the person and opinions (Patton, 2002). All interviews opened with the question “Could you tell me about your relationship with [name of central participant] and how communication in this relationship occurs?” The guide also included questions such as “How would you describe your relationship with [name of central
participant]?” and “What do you give in this relationship?” Probes on the guide changed over time as some questions became less relevant (e.g., “What do you think s/he understands?”), while other concepts that emerged from the data required a follow-up interview. The credence I gained from participant observation of the central participants probably assisted with rapport, resulting in my perception that both the interviewees and I were relaxed, which facilitated conversation. As Patton stated, “a good interview feels like a connection has been established in which communication is flowing both ways” (p.374). In order to ensure that the interviewee could express his or her opinions and experiences, more factual information relating to demographic information and work history was sought at the end of each interview.

Of the 57 personal affinity network members, two were interviewed twice in order to follow-up on aspects not covered in the initial interview. Five members were contacted by phone for additional information. Fifty-one members were formally interviewed. Of the remaining six, one spoke insufficient English and five had insufficient understanding of language to enable their participation in an interview. One interview participant had difficulty with the unstructured format of the interview. Consequently, pictures were used to clarify responses and assist him to maintain focus. The interviews were digitally recorded and later transcribed verbatim.

**Data Analysis**

The data were entered into NVivo 8 (QSR International, 1999-2008). Each transcript was read independently by my principal supervisor. A journal was kept to record insights from the data and literature in a form of memo-writing (Charmaz, 2006).

**Memo Writing**

Memo writing is considered an essential step in the stages between data collection and theory development. Ideas relating to codes are expanded and revisited or discarded as new data are
collected, old concepts are revised and new categories emerge (Bryant & Charmaz, 2007). Striking aspects of the observational data, whether they were unusual or frequent occurrences, were noted in the field notes and expanded in reflections in the journal. In addition, in order to understand, encapsulate and illustrate the emotional impact of the central participants’ interactions, poetry was used as a form of memo writing. The economy of expression required for poetic expression assisted in the coding process. In qualitative research, poems have taken many forms and have been constructed from the content of interviews, journal reflections, and participant observations (Carr, 2003; Faulkner, 2007; Glesne, 1997). Qualitative researchers have discussed a range of different ways in which poetry has been used to synthesise human experiences and provide the reader with a stronger emotional connection to the data than that of prose writing (Langer & Furman, 2004; Öhlen, 2003; Richardson, 1992). Richardson (1998), an ethnographer, described how writing poetry enabled moments of insight and clarification: “Poetry, as a special language, is particularly suited for those special, strange, even mysterious moments when bits and pieces suddenly coalesce” (p.451). My first realisation of the usefulness of reflection through poetry occurred with my first participant as I grappled with trying to understand her complex presentation during the first stage of line-by-line coding. I was puzzled and intrigued by the effect of her presence on others and needed to re-engage with her in an abstract holistic way. This need led me to writing interpretive poetry, which has been described as a means of vividly encapsulating a person’s core being (Langer & Furman, 2004).

Coding

Data were coded line by line, examined for in vivo codes (descriptive terms used by interviewees) and focussed codes were developed. For example, in vivo codes such “party girl” and “social butterfly” became part of being sociable – a focussed code. Along with other data related to being sociable, being sociable became a part of an open code being.
likeable. These codes became part of a major category of recognising the individual. Figure 1 provides a simplified visual description of one process of the model, but does not illustrate the reality of the complex nature of coding—with false starts, abandonment of codes, reflections, memos, recoding and member checking. One of the key strategies applied during analysis was continued data comparison from within and across sources. Throughout the nonlinear analysis process, my supervisors met with me fortnightly to discuss coding categories, relevant literature and probing questions to ask the data. Questions were applied to the data, such as “how is this the same or different for other participants and why?” or “how does the negative case affect the category development?”, until clear categories and sub-categories emerged. Saturation of data occurred during data collection for the sixth central participant when repeated codes were seen to occur, categories were being confirmed and no new categories were being discovered (Morse, 2007; Noerager Stern, 2007; Holton, 2007).
Figure 1 Example of Coding Categories

Quote

“sense people who are likeable characters and they like to interact with”

Engaging with whom ever, the social butterfly

“She would be a party girl for sure”

“She’ll do anything to get your attention”

“he’s very concerned with other people’s well being”

“He doesn’t require a lot of hard support”

“She’s demanding, she’s a perfectionist”

“She does what we would all like to do”

She’s a little princess”

“The lioness attacking me”

When he gets upset his family refer to this behaviour as coming from the “evil twin”

In vivo code

Open code

Focussed code

Theoretical category

Being social

Social butterfly

Party girl

Empathic

Easy going

Controlling

Recognising individuality

Being likeable

Princess

Lioness

Evil twin

Free spirit

Being self determined

Being likeable
Trustworthiness

Trustworthiness of the study is achieved by ensuring the data comes from prolonged engagement, has a rich, thick description and includes member checks. Prolonged engagement occurred with each central participant being observed over a period of 4-6 months during which rich data were collected, predominantly in the form of field notes and interviews. Charmaz (2006) suggested four criteria are considered in regard to trustworthiness: credibility, originality, resonance and usefulness.

The multi-source data from field notes, documents, interviews and member checking allowed for triangulation (Boeije, 2002; Creswell 1998; Tracy, 2010). Triangulation involves applying the same questions to different data sources or methods focussed on the same topic and incorporating multiple perspectives (Richards & Morse, 2007). Given the data for this study emerged from different sources and were compared and contrasted, a substantive and robust theory could be developed. These data also provided an audit trail that established their order and rigor (Finlay, 2006; Koch, 1994; Llewellyn, 1995). Unique three part alphanumeric codes have been used to identify quotes by personal affinity network members (e.g., SF8 which represents central participant’s initial +personal affinity network member’s role + number). The use of these codes helped to establish an audit trail.

Questions regarding credibility, originality, resonance and usefulness were applied to the interpretations as part of the iterative process (Charmaz, 2006). Credibility was established through discussions with my supervisors during regular meetings and the sharing of these insights with people within the networks through member checking. Originality, resonance and usefulness were also confirmed through member checking.

All family members of the central participants were offered a feedback session related to the findings, but only the families of three central participants accepted this offer. Forty-one people who had regular interaction with central participants attended the sessions that
included 14 personal affinity network members. All feedback sessions were conducted in work place settings. No family members attended Sandra’s session (other family priorities arose on that day), and one family member attended Brian’s session. Eric’s session included many family members and representatives from both the day centre and group home. The central participants did not attend any of the sessions, as their family members did not think they would be interested. Sessions varied in duration from 45 minutes to 2 hours. PowerPoint™ presentations from these sessions are in Appendices H, I, and J. The procedure for each session was similar. Each session began by introducing the participants and providing a brief summary of the aims of the research. A recitation of the central participant’s poem followed, accompanied by a visual projection of images that illustrated the central participant’s characteristics and attributes. I shared what I had learned through the data collection process with the people at the session. I allowed time for, and encouraged, questions or general discussion. The sessions concluded with a discussion focused on positive relationships. The sessions appeared fruitful and constructive with positive feedback provided by those who attended about my findings and the power of the poetic transcriptions.

The insights provided by the rich descriptive data demonstrated originality and resonance, and were honed and verified through member checking. The emerging model in various stages of development has been presented at seven conferences or seminars. The final versions of the model have met with interest by professional colleagues who work in related but different areas of disability.

**Summary**

This chapter has explained the methods and procedures involved in the study. A grounded theory design was selected that included sampling of central participants and selection of personal affinity network members. The main forms of data collection were interviews and
participant observation. The grounded theory analysis involved memo writing, coding and strategies to ensure the trustworthiness of the data.

The last part of this chapter is a published paper which discusses the process of participant observation with adults with severe intellectual disability and the contribution of this methodological process.
Publication


Statement of Contribution

As co-authors of the following manuscript titled ‘The challenges and benefits of using participant observation to understand the social interaction of adults with intellectual disabilities’ we confirm that Hilary Johnson made the following contribution: Hilary Johnson was responsible for writing the complete first draft of the manuscript. Associate Professor Jacinta Douglas, Professor Christine Bigby and Professor Teresa Iacono critically appraised the manuscript and Hilary’s subsequent revisions of the manuscript.

Signed: [Signature]
Date: 25/5/12

Associate Professor Jacinta Douglas

Signed: [Signature]
Date: 25/5/12

Professor Christine Bigby

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Date: 25/5/12

Professor Teresa Iacono
RESEARCH ARTICLE

The Challenges and Benefits of Using Participant Observation to Understand the Social Interaction of Adults with Intellectual Disabilities

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Abstract
Observation methods have been used in both communication and interaction research. Qualitative interpretive approaches are rare where participants have complex communication needs. Issues for qualitative researchers utilizing participant observation research methods have been well documented, but a similar discussion is lacking where the participants are people with severe intellectual disability. Observational data collected from a study of adults with severe intellectual disabilities in interaction with their social network members were scrutinized to identify challenges and benefits of participant observation. Challenges identified include the consent process, changing roles, and researcher intrusion. The use of participant observation with adults with severe intellectual disabilities allows for unexpected insights and provides context and credence for other lines of inquiry. Participant observation may be useful with other groups of people.

Keywords: Severe intellectual disability; Interaction; Adult; Participant observation

Introduction
Observation has been used as a means of collecting data within both quantitative and qualitative research in the area of communication and interaction (Antaki & Widdicombe, 1998; Bloom & Lahey, 1978; Halliday, 1975; Zilber et al., 1994). Observational techniques have been used in natural everyday settings to count and describe the type and frequency of discrete behaviours (Bakeman & Gottman, 1997; Dolloghan & Miller, 1986) or to interpret the social processes of interaction through qualitative approaches (Antaki, 1988; Duck, West, & Acitelli, 1997; Simmons-Mackie & Damico, 1996). The broad objective of this paper is to raise awareness of this latter approach to observation in the context of research involving people with intellectual disabilities and complex communication needs.

Using observational methods within qualitative methodologies is useful in contexts in which little is known about a topic and/or complex phenomena need to be understood (Creswell, 1998; Denzin & Lincoln, 2005; Morse & Richards, 2002; Silverman, 2001). Qualitative research utilizes an interpretive framework that requires the researcher to use inductive thinking when exploring a topic or question, and incorporates constant reflection in a non-linear, flexible, iterative process (Liamputtong, 2009; Morse & Richards, 2002). In situations where researchers aim to interact with participants in order to understand their perspective, observational research has been referred to as participant observation (Adler & Adler, 1994; Angrosino, 2004; Jorgensen, 1989), which has been described as a means by which the researcher engages in a “process of learning through exposure to or involvement within the day-to-day routine activities of participants in the research setting” (Schensul, Schensul, & LeCompte, 1999, p. 91). The researcher’s degree of involvement with participants may vary during the course of the research, sometimes being situated on the periphery as an observer, other times being actively engaged with participants in daily activities (Hammersley & Atkinson, 1995).

Gold’s (1958) classic typology outlined the differing demands of the researcher’s role on a continuum ranging from complete participant to complete observer. The two middle roles, participant-as-observer and observer-as-participant, are the more usual roles adopted in participant observation research because they allow opportunities for detachment and/or engagement with participants (Adler & Adler, 1994; Green & Thorogood, 2009). According to Adler and Adler (1994), the researcher’s roles should allow for observation that “...consists of gathering impressions of the surrounding world through all relevant faculties” (p. 378). These perceptions are then recorded as field notes. The field notes commence with broad descriptions that become...
progressively more focused and interpretive as the researcher hones in to specific aspects driven by the researcher’s emergent questions (Werner & Schoepfle, 1987). The recording of detailed field notes and adoption of observer roles are key components of participant observation. Participant observation is core to ethnography, where long-term engagement is required to investigate the behaviours of a culture or group of people (Creswell, 1998; Hammersley & Atkinson, 1995, 2007). To a lesser extent, grounded theory methodology has also incorporated participant observation methods to explore under-researched areas and develop innovative theories (Hubert & Hollins, 2006; Taylor & Bogdan, 1989).

It appears that there is a dearth of studies using participant observation involving people with complex communication needs. A CINAHL database search of the AAC journal over the last 25 years revealed only two studies utilizing participant observation: McCord and Soto (2004) and Stuart (2000). McCord and Soto (2004) employed descriptive ethnography to understand how American-Mexican families perceived the impact of AAC on their lives. Observation occurred over a 6-month period in order to gain an understanding of the families’ situations and develop rapport, thus adding to the credibility of in-depth interview data. In contrast, Stuart (2000) employed the qualitative method of grounded theory to examine the complexities of story telling in older adults. Over a 6-month period, Stuart spent 400 hours with 28 participants and compared and contrasted the observation data with interview data. Observation data verified and strengthened the credibility of the emergent communicative patterns. Both studies contributed to a greater understanding of the issues involved for AAC users and clinicians.

Similarly, in the broader disability literature, there is little interpretive observational research on interaction with adults with complex communication needs. Adults with severe intellectual disabilities are a group who may use AAC but are heterogeneous in their communication skills (McLean & McLean, 1993). They lack literacy skills and the ability to use complex symbolic systems, but little detail is known about their communication skills and modes of interaction because of inherent challenges in the conducting of assessments that will yield accurate results (Abudarham & Hurd, 2002; Calculator, 1988). Nonetheless, there is evidence that adults with severe intellectual disabilities can formally communicate through the use of symbols. McLean et al. (1996) surveyed professionals about the mode of communication used by 94 adults with severe intellectual disabilities and found that 80% were reported to use symbols. In regard to interactions, most research has focused on communicative interactions between adults with severe intellectual disabilities and paid staff, and has indicated that adults with severe intellectual disabilities have received more didactic instruction than social interaction (Markova, Jahoda, Cartermole, & Woodward, 1992; McConkey, Morris, & Purcell, 1999; Prior et al., 1979). Nevertheless, understanding of the interaction skills of adults with severe intellectual disabilities has been thwarted because they are often not considered to be a discrete group. Instead, their interaction skills have been reported in studies along with adults with more profound and multiple disabilities (Bloomberg, West, & Iacono, 2003; Golden & Reese, 1996; McLean & McLean, 1993).

Some researchers have focussed on understanding the aspects of interaction that engage or attract a communication partner (Bogdan & Taylor, 1998; Dennis, 2002; Newton, Olson, & Horner, 1995). Bogdan and Taylor (1998) conducted a grounded theory study consisting of participant observation and interviews with familiar people of over 100 adults with severe and multiple disabilities. The researchers found that recognizing the individuality of the person with a disability and viewing that person as reciprocating were binding elements of interaction. In research in which participants have not been able to speak for themselves, interviews with communication partners have been instructive in understanding some aspects of interaction (Bogdan & Taylor, 1998; Newton, et al., 1995; Taylor & Bogdan, 1989). Nevertheless, observation may be a more powerful tool than interviews in illuminating mismatches between what participants say and what they do. Moreover, researchers have emphasized the importance of utilizing participant observation in order to understand the world from the viewpoint of the person with an intellectual disability, rather than relying solely on interviews from carers and families (Angrosino, 2004; Taylor & Bogdan, 1989). Hubert and Hollins (2006) spent 250 hours as participant observers within a locked ward of a residential institution for men with severe intellectual disabilities and challenging behaviour, then used grounded theory to analyze the data. The researchers provided vivid descriptions of the men’s unique responses to interactions, using field-note examples that highlight the insights afforded through observation with a vulnerable and under-researched group. Having an understanding of modes of communication used, the functions of interactions, and with whom interaction occurs, would seem to provide a starting point for supporting interaction skills.

Clearly, participant observation is a useful observation method, with much discussion about the techniques involved, particularly in ethnographic research, evident in the literature (Denzin, 1997; Fetterman, 1989; Hammersley & Atkinson, 2007; Liamputtong, 2007, 2009). Yet, there have been few papers on the methodological issues that researchers face when studying adults with severe intellectual disability (Stalker, 1998), and there are no published papers that have focussed on issues arising for researchers using participant observation with this group. To bridge this gap, the complexities of participant observation need to be shared with other researchers as a means of encouraging the use of participant observation to further research involving adults with severe intellectual disability and complex communication needs.
The aim of this paper was to explore the challenges faced and benefits gained in collecting participant observation data when investigating interactions between adults with severe intellectual disability and their communication partners. The methodological demands and advantages of participant observation discussed in this paper were identified in the context of a larger study, which we have termed the source study. The following method section begins with a brief description of this source study as background to the current paper.

Method

Background and Participants

Challenges and benefits of participant observation became apparent during the data collection phase of the study, which explored interaction processes between adults with severe intellectual disabilities and their social network members. In this source study, a constructivist grounded theory approach was utilized (Charmaz, 2006). Ethical approval for the study was granted through the Human Ethics Research Committees of two Universities and one non-government organization.

Participants in the source study were six adults with intellectual disabilities (referred to as central participants, see Table I) and the people with whom they interacted. Informed consent was obtained on behalf of the central participants from their next-of-kin, and directly from the participating paid workers and central participants’ family members. All six central participants had an intellectual disability and communicated at a symbolic, but non-linguistic, level of communication. The term non-linguistic was used in this study to describe communication in which conventional symbols (e.g., single spoken, signed, or pictured words) were used, but symbols were not flexibly combined into novel utterances and lacked “rule governed linguistic constructions” (Fischer & Corrigan, 1981, p. 263). This level of communication skill is synonymous with people with severe intellectual disabilities, who need “extensive levels of support in multiple adaptive domains” (McLean, et al., 1996, p. 580). Thus, the central participants are referred to as adults with severe intellectual disabilities. All central participants had multiple impairments that included, in addition to intellectual disability, a combination of epilepsy, autism spectrum disorder, cerebral palsy, scoliosis, and/or visual impairment. They were aged from 20 to 44 years; three lived at home and three in group homes; and all attended day services in Victoria, Australia. Other participants were those observed interacting with the central participants, and consisted of paid workers, family members, and peers. Convenience sampling was used to select the first central participant. Theoretical sampling for maximum variation was used with successive central participants. Variation was sought by considering specific aspects, such as age, gender, vision, residential situation, family involvement, physical ability, and peers as friends. Confidentiality was addressed by allotting pseudonyms to all named participants in reports or discussions. In addition, some details have been withheld or changed to assist with anonymity.

The first author collected data on each central participant and those with whom they interacted, over a period of 4–6 months. Observations occurred over 239 hours in a variety of settings, including family homes, group homes, day centres, and community settings. Some frequent activities, such as personal care interactions around routines (e.g., bathing and dressing) were avoided because of their intimate nature and to ensure respect for participants’ dignity and right to privacy.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Diagnoses</th>
<th>Mobility</th>
<th>Expressive communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sandra</td>
<td>20</td>
<td>Intellectual disability, Autism spectrum disorder, Epilepsy</td>
<td>Mobile</td>
<td>Her speech consists of up to 100 single words, a large proportion consisting of people’s names. She uses a limited number of two-word phrases repeatedly (e.g., mum happy, dad happy). She occasionally points to a photo from her photo book and uses 10 Key Word Signs that accompany her speech.</td>
</tr>
<tr>
<td>Brian</td>
<td>23</td>
<td>Intellectual disability, Scoliosis, Epilepsy</td>
<td>Mobile (mostly independent)</td>
<td>He has more than 30 words he can initiate and more than 100 he can imitate. His one-word utterances are recognizable only to those who know him well. He uses objects and more than 20 Key Word Signs for requests. He can make a selection from 5 large photos when requested.</td>
</tr>
<tr>
<td>Colin</td>
<td>27</td>
<td>Intellectual disability, Visual impairment disorder, Epilepsy</td>
<td>Mobile</td>
<td>He imitates gestures, uses vocalizations and can spontaneously use less than 30 Key Word Signs. He can initiate interactions by pointing to photos.</td>
</tr>
<tr>
<td>Diane</td>
<td>44</td>
<td>Intellectual disability, Spastic quadriplegia disorder, Epilepsy</td>
<td>Manual wheelchair (can push herself short distances)</td>
<td>She has a static display SGD with 60 pictographs that she rarely uses. She relies on vocalization and intonation to get her message across; natural gesture and fewer than 10 Key Word Signs for general interaction.</td>
</tr>
<tr>
<td>Eric</td>
<td>24</td>
<td>Intellectual disability, Spastic quadriplegia disorder, Epilepsy</td>
<td>Mobile but poor balance (uses wheelchair for long distances)</td>
<td>He has fewer than 10 spoken words familiar only to those who know him well. He uses more than 100 Key Word Signs some of which are idiosyncratic. He uses some limited first letter finger spelling, usually to represent people’s names. He recognizes many pictures and may use photos/pictures to share requests or comments.</td>
</tr>
<tr>
<td>Faye</td>
<td>38</td>
<td>Intellectual disability, Spastic quadriplegia disorder, Epilepsy</td>
<td>Electric wheelchair</td>
<td>She has a communication book of about 100 pictographs which she points to for requests or comments. She also uses eye gaze for attention and some natural gesture.</td>
</tr>
</tbody>
</table>

Note. Age is in years.
Observation periods were from 0.5–3 hours in length. The first author utilized two participant observer roles predominantly: observer-as-participant and complete observer, with the participant-as-observer role used infrequently (Hammersley & Atkinson, 1995).

Documentation included field notes, a journal, and minutes of meetings. During observation, field notes were recorded that contained both observations and reflections and followed guidelines suggested by Emerson, Fretz, and Shaw (1995). Brief notes were taken during observations, after which more comprehensive notes and reflections were spoken into a digital recorder. On typing the notes later, further reflections were added as additional insights were gained through the process of engaging repeatedly with the data. An ongoing journal was kept to record insights from the data and literature, in a form of memo writing (Charmaz, 2006) and poetic (Ely, Vinz, Anzul, & Downing, 1997). Minutes were recorded after meetings with co-authors, and notes were taken after feedback forums with people who interacted with the central participants.

Identifying the Challenges and Benefits of Participant Observation

During data collection, many questions arose for the first author about how to effectively and ethically conduct observational research. As issues occurred they were documented in field notes, the reflexive journal, and minutes of discussions at fortnightly meetings with co-authors (supervisors). The practice of reflexivity was “to explore the ways in which a researcher’s involvement with a particular study influences, acts upon and informs such research” (Nightingale & Cromby, 1999, p. 228).

After data analysis for the source study was completed, the first author examined the documentation for evidence related to the challenges and benefits of using the participant observation process. Identifying specific challenges came from studying the first author’s journal and field notes, and reflecting on which field experiences were examples of dilemmas that permeated the research or provided specific insights that directed aspects of the study. Although the issues identified came from practicing reflexivity, ideas from two methodology papers provided an additional guide to the critique (Guillemin & Gillam, 2004; Stalker, 1998). Guillemin and Gillam (2004) discussed ethical issues in the practice of qualitative research, with specific considerations given to “ethically important moments” (p. 262). These incidents were identified as something that was seen or heard that affected the way the research was conducted and caused critical reflection. Stalker’s (1998) paper focused on ethical and methodological issues in intellectual disability research and included the author’s reflections on the challenges she identified from participating in fieldwork with people with severe and profound intellectual disabilities. For the current paper, the first author collated written recordings of significant issues that arose during participant observation in the source study. The meaning of these issues was discussed by the authors and documented. The resulting paper was then presented at an International Society of Augmentative and Alternative Communication research symposium in 2010, where the feedback received confirmed that there was interest in sharing these findings more broadly. Further reflections and discussion between authors through several iterations gave rise to the final results that are included in the current paper.

Results

Descriptions of observations in the results that follow are relayed in the first person (the first author), in order to capture the authenticity of participant observation experiences in the field.

Challenges

Three challenging aspects, pertinent for researchers examining interactions with people with limited communication through participant observation, arose from the data. These processes were gaining consent, changing roles, and researcher intrusion, each of which is described and illustrated with examples taken from the researcher’s field notes.

Gaining Consent. Although in all cases procedural consent was gained from a family member, there was an ongoing tension in the research concerning whether the central participant understood and consented to the researcher’s presence. I used two different approaches to inform the central participants about my role. The first mode used speech alone and took place during the initial meeting to assess whether the participant met the research criteria. The second mode involved discussing an explanatory statement, in plain English, to inform the central participant about the intent of the visits.

The first meeting for two of the participants occurred at their homes; first meetings for the rest were held at their day centres. The aim of these interactions was to establish that the central participant met the criteria to be included in the research. No picture-based explanatory statement had been prepared to explain this aspect of the research. Instead, I introduced myself thusly: I just want to talk with you and watch what you are doing. Three participants willingly looked at some pictures with me for a few minutes. Three others paused momentarily to look at me and indicated hello, then showed no interest in the task or relating to me, and turned away. Later I was able to observe them with staff or family members identifying or selecting pictures from a choice of multiple pictures.

After establishing that the inclusion criteria had been met, follow-up visits were organized with family or paid staff members who were asked to inform the central participants that I would be coming; however, this may or may not have occurred. At the next visit,
I verbally introduced myself to the central participant as soon as was appropriate. I explained my presence by showing them a brief, picture-enhanced text version of the written explanatory form while simultaneously reading aloud the contents. The aim in using the form was to provide the central participants with a permanent record that signified the reason for the researcher’s presence. I also asked family or staff members to read these forms with the central participants over the course of the research, to remind them of my role. None of the central participants showed much interest in the picture explanation or what I had to say. One central participant did not have sufficient visual perceptual skills for the display I had prepared, and he did not stay still long enough to listen to the explanation. Another listened and looked at the form, but then motioned to put the paper in the rubbish bin. Explaining the research process was a difficult task, with many of the concepts being abstract and perhaps of little interest or relevance to the central participants. Throughout the research there were times when I was unsure if I was welcome in the central participants’ lives, but there was often no way to ascertain this with certainty. Although all of the central participants were aware of my presence, only Sandra and Diane demonstrated any change in their interactions when in my presence. These changes in behaviour are reported in the section that follows.

Changing Roles. One concept that was difficult to convey in a picture consent form was the changing role of the researcher. My intended role as researcher was to be a complete observer so that I could stand back and observe interactions; however, it became evident early in the research that a more fluid approach was needed, that is, that I should move between the roles of participant-as-observer and complete observer. These role shifts enabled me to interact with a central participant or others in the environment and occurred at multiple points throughout the research. Specific challenges included changing the extent of participation within the observer role and balancing the researcher and expert clinician role, while at the same time considering any ethical issues that arose.

Overall, the peripheral role of observer was preferred, in order to observe interactions with others. The role shifts between observer and observer-as-participant may have been difficult for some of the central participants to understand or accept. This difficulty was illustrated in the case of Sandra, who initially had shown positive physical interaction towards me, stroking my hand and pulling me close to her. Sandra was known to physically hurt people, and her support workers warned me about getting too close. The day service had been on holiday for a week, and I had been observing Sandra nearly every day at home with her family or home support workers. Mostly I had tried to remain on the periphery so that I could observe interactions. The following week I had an appointment to observe Sandra at the day centre. The interaction that occurred during this encounter has been described in an earlier article (Johnson, Douglas, Bigby, & Iacono, 2010). It is documented in the following field notes recorded after observation at her day centre with day support workers (DSWs):

9.45am. Sandra was in a cooking group when I arrived. The group was all male. A DSW was giving her food to stir in the frypan. Sandra pulled me close and said look! [naming the DSW]. A few minutes later she reached out to hug me. She then continued stirring for 5 minutes or so. Both DSWs on different occasions came to tell her she was doing a good job and mum pleased. She was using her fingers to pick the bacon off the wooded spoon. One of the DSWs had turned the fry pan up. I was concerned she might burn her fingers − I said be careful it’s hot. She lashed out with her free hand reaching for my throat. Then she went back to stirring looking at me and saying − mum … pleased, James … pleased. Neither of the staff made any comment. I started to back away but she got hold of my hand saying hand then lashed out for my neck again − followed by go away. I retreated to the back of the cooking room and then went into the room outside. I felt a bit shaken, but I knew lashing out was not infrequent behavior for her. As I was writing up my notes, I looked up and I noticed her standing silently outside the cooking room in the shadows looking at me. The coordinator of the centre came past and told her how mum would be so pleased at what she had been doing. She put both her thumbs up and smiled. She then walked past me and sat in her usual place in the lunch room. When she heard singing and clapping in her group room she went in, but then spent most of her time looking out of the window. I stayed where I was as I could see through the door to her room some of the things that were happening. It was 10.10am and a DSW said goodbye as she went on her morning break. Another DSW took Sandra’s other group members outside. Sandra stayed where she was − she could see me in the dining room. After a few minutes there was no one about and she walked towards me − I was a bit uneasy but her facial expression looked sorrowful as if she might want to apologise. As she came up to me I thought she said friend but she lunged with both hands for my neck and as I was sitting down, she was on top of me. I tried to reach for her hands to pull them down. I was successful momentarily and started to stand up but she lunged again − eventually I got her on the floor and someone turned up to help. All I said to her was quietly calm down. Her face was bright pink and grimacing at me when she lunged. Sandra then said sorry when someone came up to help me. (FN/S/10) (Johnson, et al., 2010, pp. 178–179).

The reason for Sandra’s aggression towards me was difficult to interpret. I believe that, in part, it was
difficult for Sandra to comprehend the changing roles (observer-as-participant to complete observer) and may have heightened her anxiety. The reaction may also have been triggered by the change of location (from home to the day centre) plus the urgent anxious tone of voice I used because I was concerned that she might burn her fingers. In addition, I may have broken her routine or interfered with her position in the group (I was told she likes to be around males). There may have been other reasons as well. Sandra’s brother passed the incident off with “It happens to everyone if they hang around long enough.” Nonetheless, when I was next in a supervised observation session with Sandra, I talked her through the pictured explanatory statement, in order to feel that I had explained my complex role in the most concrete way possible.

One of the other central participants, Diane, exhibited anxiety when new people were around. On one occasion when I entered her dayroom, she burst into tears upon seeing me. Her support workers calmed her down and explained that her reaction was due to an unfamiliar person being present. As observations progressed, her anxiety lessened and, although she would sometimes look across at me, her facial expression was reasonably neutral. In addition, Diane and other central participants did not easily understand time concepts, which made it difficult for me to explain when leaving a location that I would be returning at another time. Because my presence in their environments was frequently unannounced, the central participants’ changes in affect may have been due to unexpected changes in routine rather than disquiet arising from my presence.

Another ongoing tension that arose from taking a peripheral observer role was the limitations it presented when I wanted to interact with a central participant. One of the aspects of the research had been to ascertain the degree of closeness that central participants felt towards individuals in their social networks. This was to be determined by working directly with each participant, using an exploratory process with photos. A support worker or family member could not carry out this task because the method was individualized and could be influenced by a communication partner who knew the central participant well. This activity was only partly completed with three participants. The difficulties were due partly to the task being a table-top activity similar to school work (which seemed least preferred), and partly because of the central participant’s disinterest in relating to me. To complete this type of task, I would have needed to have completed my observations, changed my role to participant-as-observer, and spent time interacting with the central participant in order to gain some trust — a process that would have required a much greater time commitment.

Taking on a researcher role (in light of my background as an expert clinician) required achieving a balance between the aims of the research, the tendency to fall into the clinician role, and being able to respond to ethical issues that might arise. The need to balance these competing roles was particularly evident where the researcher had prior knowledge that might resolve a stressful situation for the central participant, or felt that the central participant may have been supported inadequately by paid workers.

The following extract from the field notes describes a situation that illustrates this dilemma. The situation took place at a bowling alley, where I could see some potential difficulties and felt compelled to help, even though I was uncertain initially about whether to intervene. The incident demonstrates the importance of practicing reflexivity, and the tensions that can be experienced from moving from the role of clinician (i.e., to fix a problem) and to the role of researcher (where observing an incident is required).

Fayez and Jane took it in turns to bowl. Sally needed to help them by positioning the ball on the top of the ramp. With Fayez, she usually had to give her a little hand support to get the ball going. I was at the far side of Fayez, but helped out by retrieving the ball and cheering loudly as the pins went down. Towards the sixth or seventh turn, Fayez started to show considerable difficulty in getting her arm up to push the ball down and was physically struggling. I wanted to help her, but felt uncertain about intervening. Sally tried supporting Fayez’s arm to move. I could see Fayez’s increasing distress. After a few minutes, Fayez burst into tears and started to point to her communication book. As I knew Sally was not very familiar with Fayez, I opened up Fayez’s book where she pointed to a symbol of I’M-UNCOMFORTABLE. I knew from previous observations that meant she had to be repositioned in her chair and so with Sally, we took off her tray and pulled her up and repositioned her and put the tray back on. We had used a different positioning technique the other day with another support worker, but I didn’t comment. However, Fayez continued to cry. She went back to pointing to her book and again pointed to the same symbol. Sally then started to ask her lots of questions and when Fayez responded, the response was unclear. One example was Sally saying do you want us to do it again? I think Fayez shook her head for ‘no.’ Sally mentioned to me that it might be menstrual pain. Sally tried to get her to indicate what part of her body was in pain. By now, Fayez was getting more distressed and started to cry more loudly. I thought we should try her book again and I asked Fayez to show us what was wrong. This time she pointed to symbol JEWELLERY which was on the same position on the page, as I’M-UNCOMFORTABLE but on a different page. I knew her communication book was new and wondered if she had made a mistake. Fayez then turned the page, pointed to a page which only has the I’M-UNCOMFORTABLE picture and pointed to that one. I said you’re still uncomfortable? Again her response was unclear. Sally closed her book and Fayez was still quite distressed. Fayez went
back to the book and pointed to a different picture
accompanied by the phrase of I'M-UNCOMFORT-
ABLE- PLEASE-SIT-ME-UP-STRAIGHT and she nodded
'yes.' We took off her tray and repositioned her again
and then she smiled happily. (FN/F/6)

This incident provided insights into a communica-
tive interaction in which a relatively naive staff member
was involved. Fayez had had her new communication
book for only a few weeks and the symbol choice was
limited to about 80 pictures. Before having her book,
staff members had relied on asking yes/no questions.
The staff member had had no training in supporting a
person to use a communication aid and was not aware
of the available vocabulary. There was no doubt that
Sally was keen to help Fayez and attempted to use her
knowledge of Fayez and the situation to come up with
a resolution. As I reflected on this interaction later, I
wondered what would have happened if I had not been
there. Even as an expert clinician I had been unable to
accurately interpret Fayez's response. I felt inadequate
in that situation. Should I have kept to my observer
role? Would the other DSW who was with another
group of people come across to help? Could I have
learned more by observing rather than participating?
Nevertheless, in order to observe Fayez pointing to the
item in her book, I needed to be in close proximity, and
even in my role as an observer I could not let Fayez be
in unnecessary distress.

In different ways, the field notes of interactions
for both Sandra and Fayez illustrated “ethically impor-
tant moments” (Guillemin & Gillam, 2004, p. 262).
With Sandra, there was a dilemma as to whether to
terminate the research process because my presence
may have been seen as increasing her anxiety. How-
ever, her family, although concerned that Sandra had
hurt me, were happy for me to continue. The dilemma
of being supported by staff members who had not
received sufficient training was not restricted to my
interactions with Fayez. There were many other similar
incidents throughout the research and each one caused
me to consider whether to suggest the need for fur-
ther training to supervising staff. In most situations,
paid workers were doing their best, and people in
management were generally aware of ongoing training
needs, particularly if many casual staff were employed.
The role as researcher required a different response to
that of clinician, and I did not volunteer information
unless I was asked specifically; even then, I avoided
singling out incidents or specific staff members.
Observing in the field required on-the-spot decisions,
many of which altered the course of future data col-
lection and focussed observations and questions in a
different direction.

**Researcher Intrusion.** At the commencement of the study,
I had concerns about how the intrusion of a researcher
into an environment might change or alter interactions.

These concerns included how observations could be
recorded in a timely and accurate manner without
interfering with interactions; how my presence might
alter the nature of the interactions; how to deal with
other people wanting to engage with me rather than the
central participant; and whether the central participant
might come to view me as a friend. All except the latter
concern surfaced during the research and are illustrated
by examples from the data.

Recording interactions in day centres or places
where there were large groups of people was relatively
simple. In terms of finding a position where I could
clearly see and hear what was occurring, I usually
located myself near the edge of a room and opposite
to the central participant. Typically, this provided a
comprehensive view of the people in the room. There
were, however, many instances in which the central
participant turned his or her back to me or walked
away around a corner. Brian, for example, was very
active and sought out preferred people or activities
together, I observed him and Brian doing this activity
and then she smiled happily. (FN/F/6)

This incident provided insights into a communica-
tive interaction in which a relatively naive staff member
was involved. Fayez had had her new communication
book for only a few weeks and the symbol choice was
limited to about 80 pictures. Before having her book,
staff members had relied on asking yes/no questions.
The staff member had had no training in supporting a
person to use a communication aid and was not aware
of the available vocabulary. There was no doubt that
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that of clinician, and I did not volunteer information
unless I was asked specifically; even then, I avoided
singling out incidents or specific staff members.
Observing in the field required on-the-spot decisions,
many of which altered the course of future data col-
lection and focussed observations and questions in a
different direction.

**Researcher Intrusion.** At the commencement of the study,
I had concerns about how the intrusion of a researcher
into an environment might change or alter interactions.
Observing interactions in family homes was more difficult because of concerns about intruding on their personal space and time. Family members did not accord me the same indifference as was displayed by paid workers. They often included me in the conversation or asked about the research, perhaps in an effort to fill the conversational silences. Note taking during family observations was reduced to brief jottings or avoided entirely because they reinforced the researcher/observer role and made interactions awkward. In one family home, observation was abandoned because they seemed to be making a special effort to interact due to the presence of a researcher. There were, however, other opportunities to observe family interactions less intrusively, such as attending family celebrations or outings. For example, to observe Eric interacting with his extended family, we chose to meet at a pancake restaurant, Eric’s preferred place to eat prior to going to see a movie. Although family interactions with central participants sometimes appeared stilted, they nevertheless provided insights into differences in interaction across communication partners and/or settings. In private homes, observation rarely exceeded 1 hour and was shortened if any of the participants showed any agitation at my presence.

My ability to carry out observations was restricted when I was engaged in conversation by another person, and this made it difficult to immediately and accurately record field notes of the participants’ interactions. Support workers often included me in brief conversations, but mostly they were busy providing personal support. My presence seemed to have little effect on workers, as evidenced by frank conversations that occurred around me or within hearing range. In day centers, other people with intellectual disabilities often attempted to engage me, but these were usually brief interactions, such as a greeting. Sometimes, I sought clarifications about an interaction from a staff member, and these were recorded in field notes.

Researcher intrusion did have some effects on interactions, and this was particularly noticeable in small spaces or where I was the only other speaking adult present. Having time to revisit locations or activities was essential components of the research. It was also important to accept that the involvement of a researcher in some preferred activities was not possible, especially where family or personal circumstances were stressful. Thus, the challenges involved steered the data collection in certain directions that resulted in more hours spent in observing interactions with paid workers than family members.

Benefits

The benefits of participant observation were apparent primarily in the nature and richness of the data collected. As an experienced clinician, I saw interactions that I had not observed before, with content that triggered the development of new learning through reflexivity. Although some of the data collected concurred with information from interviews, much could only have been collected through participant observation. The following example, an extract from field notes, demonstrates one such situation.

A discussion was observed between three staff members talking about the difference between Makaton Key Word Sign and Auslan. It was evident from the discussion that the staff members understood the main theoretical differences. Nonetheless, later, it became obvious that Key Word Sign knowledge was limited among staff members. Eric was one of the central participants and the following interaction occurred. Eric went up to a staff member and finger spelled B to the staff as he was waiting for Betty to come back from a program. The staff member did not recognize the sign so Eric went and took a picture, a photo of Betty from the wall, and showed it to the staff. She promptly replied I don’t know, but she’ll be back. (FN/E/4)

This observation demonstrated that Eric could initiate a request and repair a communication breakdown with a partner who was unfamiliar with his signs. He could also utilize aided communication supports that were available in his environment. However, these observations led me to wonder how Eric’s familiar people learned the signs, and how much it mattered to him that people could understand his communication. To widen my search for a fuller understanding, I visited Eric’s group home, where I saw a passive and less engaged young man who spent most of his time watching TV. The paid staff knew little or no signs and, although Eric had a large book of his own idiosyncratic signs, no one had taken the time to learn or familiarize themselves with them. Was this negligence, ignorance, or disrespect from the staff? These questions focused my future observations and opened up a line of enquiry into the modes of communication used by Eric with different partners in different environments.

Direct observation of peer interaction was also valuable. Some peers could converse; however, one of the central participants had a significant relationship that did not rely on words. Other network members had described Eric as having a girlfriend, but it was not until I observed Eric and Betty together that the importance of this relationship could be appreciated. A field-note excerpt describing one of their typical interactions and my reflection on the observation follows:

Both Eric and Betty used this pressure on the jaw, with their fingers on either side of their jaw. They took it in turns to hold really hard and press or shake each other’s head. Eric didn’t really seem to kiss, but put his head forward to be kissed while Betty did a lot of kissing. At one point she pulled his hair really hard and it looked like it hurt and he just looked at her. It was a sort of ‘how could you do this to me’ look but there was no reprimand. And then she kissed him, and rubbed his nose and face repeatedly. (FN/E/4)
In observing this intimate moment, I was struck by the reciprocal turn taking, certainly not seen in more everyday communication exchanges, not hampered by the slowness of using pictures, nor constrained by a communication partner’s knowledge of AAC strategies. Although this type of interaction was not observed across all participants, wordless games, in which imitation and central participant initiation were pivotal to interactions, were embedded into four of the six central participant’s lives. For the other two, intimate interactions were conveyed through simple physical closeness, body language, and smiles. I reflected on my past clinical, clumsy, and inadequate efforts to provide communication aids for people who had limited symbolic skills, when I had not observed or valued the skill of wordless intimacy, nor understood the importance of peer relationships.

Overall, the extensive and focused observations were essential to enhancing the richness of the data, providing an immediate and lasting impact that influenced the direction of data collection. The first-hand experience of interactions provoked questions on which to reflect and further investigate.

Discussion

Collecting observational data of interactions through an iterative process provides a means of exploring communication, particularly with participants unable to express their needs or desires and recount their own stories using formal or conventional means. Participant observation has the benefit of unearthing new lines of inquiry and revealing new knowledge, particularly where people with limited formal communication skills and cognitive impairments are involved. However, it is clearly not without its challenges. The challenges and benefits identified in this study have several implications for future studies involving participant observation with adults with complex communication needs. These implications include ensuring sufficient time for the study, managing the consent process, assiduously considering the researcher’s role, reviewing the value of collecting data in different locations, and opening up different methodological options for analyzing data and using different methods for pursuing further data collection.

One of the overarching challenges is the time required to collect the data, a process that involves not only observing but organizing suitable times and/or locations and finding key people with whom to liaise. In Victoria, Australia, adult day services and residential services are staffed by many part time or casual staff; the result is that relaying requests or obtaining correct information requires perseverance. In addition, there are multiple contact people across different locations who may not interact with each other (e.g., residential and day center staff).

Stalker (1998) pointed out the challenge of dealing with gatekeepers who may facilitate or block access because of their values, opinions, or knowledge base. Interactions with gatekeepers require delicate negotiations in order to keep communication channels open. Even when access is freely given, there are times when the researcher is not notified of a program change, medical appointment, or a central participant’s absence. Furthermore, in situations in which field observations occur over several months, staff changes, participant illnesses, and central-participant family stressors add to the time required to collect data. The amount of time allotted to a project needs regular review, as may specific aims.

Informing participants about the research process is driven by an ethical responsibility and also a belief in self-determination. When adults with severe intellectual disabilities and limited symbolic skills are involved in research, the issues become particularly complex. Several researchers have discussed the use of different strategies to enhance comprehension for enabling consent and participation in research that involves individuals with intellectual disabilities (Cameron & Murphy, 2007; Griffin & Balandin, 2004; Iacono & Murray, 2003; Stalker, 1998). The use of easy English forms was not successful in the research described in this paper. This lack of success may have resulted from a problem with the form, the researcher’s approach, or the abstract nature of concepts that required explanation. In order to engage adults with severe intellectual disability, a relationship needs to be developed and some form of trust established. Adults with severe intellectual disabilities often have multiple impairments, short attentions spans, and a disinterest in formal tabletop activities. Thus, engaging them in an activity that is merely to impart information is of minimal interest. In addition, determining what a person understands, where formal assessment is not an option, requires repeated observation. Discovering the best way to convey information involves the trial of different formats. The conduct of such trials adds to the time requirements, and may not be achievable because of time constraints, leading to an inevitable switching between various participant observer roles. Courtesy and ethical behaviour demand that the researcher ask a participant for permission to accompany him or her to new locations for different activities. Nonetheless, participants who do not understand the researcher’s request may find repeated requests for permission overly intrusive. There may be value in examining alternate ways to inform people with severe cognitive difficulties about the research process, in order to maximize their feelings of security.

The switching between observer roles and the misunderstanding of the role of the researcher have been referred to in relation to the issues around informing participants about the research process. Perhaps in situations in which the researcher requires engagement with the person with a severe intellectual disability, a participant-as-observer rather than observer role may allow for more opportunities to develop trust and interaction. On the other hand, the participant-as-observer role would result in fewer opportunities for written recordings of interaction data and would require excellent memory.
skills. Other researchers adopting a complete observer role with participants with severe intellectual disabilities have included video recording as part of their field studies (Antaki, Finlay, & Walton, 2007; Finlay, Antaki, & Walton, 2007; Patton, 2002). Video recordings allow for analyzing precise details of interaction, but provide a narrower focus of interaction than other participant observation roles. Although the presence of a researcher has an effect on the data, being able to change roles has been considered beneficial because it allows for multiple perspectives in the research process that, in turn, may reduce researcher effect on the data (Hammersley & Atkinson 1995). The nature of iterative research is that researcher effect is taken into account and considered carefully through reflective thinking and journaling (Hammersley & Atkinson, 1995; Morse & Richards, 2002). Because participant observation with adults with severe intellectual disabilities is still a relatively under-utilized method, careful documentation by researchers of the roles they adopt is warranted.

Researchers have also discussed the difficulties of researcher intrusion when collecting data in specific personal locations, such as family homes (Cartwright & Limandri, 1997; Stalker, 1998). Certainly some locations may be stressful, sometimes for the researcher and sometimes for the participants who may be awkward or constrained in their interactions. However, the opportunity to observe in these environments provides a valuable insight into familial interactions. Discomfort for all involved can be reduced by the researcher embracing the role of participant-as-observer to allow for family members to include the researcher more fully in the interactions, along with discussing beforehand the purpose of the visits and how the research goals might best be achieved. The challenges of ensuring participants are comfortable with the researcher in a range of environments and roles present several issues that need further inquiry.

The benefits of participant observation lie in the complex and unique data collected. The observational data provide grounds for contrasting and comparing information and also allow for a more in-depth interpretation. The data revealed can be as powerful and rich and as open for interpretation as the data collected from in-depth interviews. In fact, developing an understanding of people with complex communication needs through observation research with adults with severe intellectual disability. However, these issues are also likely to resonate with the experiences of researchers who study different groups with complex communication needs. Because there remains much to be discovered about interaction, participant observation may be a useful tool to investigate interactions that include different groups with complex communication needs.

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Notes

1. AAC conventions were added for the purposes of the article, although they may not have been applied in the author's original field notes.
2. FN represents the field notes, S represents the first letter of the central participant's name, 10 represents the 10th observation session.
3. Sign and gesture used with people with an intellectual disability (Grove & Walker, 1990).

References

individuals with intellectual disabilities and other community members. Mental Retardation, 33, 383–393.
CHAPTER 6: PARTICIPANTS

Overview of Chapter

This chapter provides information on all participants, both the central participants and the personal affinity network members (those who had positive relationships with the central participants). Basic demographic data are presented for personal affinity network members with detailed background information on central participants. Each central participant profile is accompanied by an individual poetic representation.

Personal Affinity Network Members

There were a total of 57 personal affinity network members (see Table 4 for details of personal affinity network members). Each network ranged in size from six to 14 members. Personal affinity network members varied in their roles in relation to central participants: 22 were family members, 29 were paid workers and six were peers. Family members included those people directly related to the central participants and partners of those relations (e.g., brother’s partner). Paid workers were employed by government or non-government organisations and classified in one of four ways: as disability support workers (DSWs), home support workers (HSWs), group home coordinators (HOs), and day service coordinators (DOs). Paid workers provided direct support in the areas of personal care, the activities of daily living, and leisure. DSWs provided support to people with disabilities in adult day services, HSWs workers provided support in family homes or small group homes, and most HOs or DOs had previous experience as support workers and were employed in staff and program coordination roles.
<table>
<thead>
<tr>
<th>Central Participants</th>
<th>Personal Affinity Network Members (Total)</th>
<th>Family members</th>
<th>Paid workers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sandra</strong></td>
<td>4 Family members</td>
<td>Mother</td>
<td>3 Home Support Workers</td>
</tr>
<tr>
<td></td>
<td>8 Paid workers</td>
<td>Father</td>
<td>5 Day Support Workers</td>
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<td></td>
<td>2 Peers</td>
<td>Sibling</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total 14</td>
<td>Sibling’s partner</td>
<td></td>
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<tr>
<td><strong>Brian</strong></td>
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<td>3 Home Support Workers</td>
</tr>
<tr>
<td></td>
<td>8 Paid workers</td>
<td>Father</td>
<td>4 Day Support Workers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sibling</td>
<td>1 Day Coordinator</td>
</tr>
<tr>
<td></td>
<td>Total 12</td>
<td>Grandmother</td>
<td></td>
</tr>
<tr>
<td><strong>Colin</strong></td>
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<td>Grandmother</td>
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<tr>
<td></td>
<td>3 Paid workers</td>
<td>Grandfather</td>
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<td></td>
<td>Total 7</td>
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<td>Father</td>
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<td></td>
<td>Total 6</td>
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<td><strong>Eric</strong></td>
<td>5 Family members</td>
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<td>Father</td>
<td>1 Day Coordinator</td>
</tr>
<tr>
<td></td>
<td>2 Peers</td>
<td>Stepfather</td>
<td>1 Home Support Worker</td>
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<tr>
<td></td>
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<td>Sibling</td>
<td></td>
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<tr>
<td><strong>Fayez</strong></td>
<td>1 Family member</td>
<td>Sibling</td>
<td>1 Day Coordinator</td>
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<tr>
<td></td>
<td>2 Peers</td>
<td></td>
<td>3 Home Support Workers</td>
</tr>
</tbody>
</table>
There were 32 females and 25 males. Their ages ranged from 20 to over 60 years with the largest age group \((n=15)\) being aged from 30 to 39 years. Each central participant’s network had family members (1-5) and paid workers (2-8). Three of the networks included peers with an intellectual disability, two in each network. Family members’ ages ranged from 18 years to 78 years, and except for two family members (step-father and brother’s partner), they had known the central participants all their lives.

The workers had known the central participant from 5 months to over 10 years (see Table 5 for details). The majority of workers \((n=18)\) were aged from 30 to 49 years and held disability related qualifications at Certificate III or IV levels \((n=19)\) (Community Health Services Industry Council, 2008). These data bore close similarity to other Australian workforce data, with the exception of a greater gender balance (55% female) in comparison to previous reports of a female dominated workforce (Martin & Healy, 2010).
Table 5

*Paid Worker Characteristics*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Disability Support Workers (n=15)</th>
<th>Home Support Workers (n=9)</th>
<th>Coordinators (n=5)</th>
<th>Total Workers (n=29) no.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
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<tr>
<td>&lt;29</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>5</td>
<td>17</td>
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<tr>
<td>30-39</td>
<td>3</td>
<td>4</td>
<td>2</td>
<td>9</td>
<td>31</td>
</tr>
<tr>
<td>40-49</td>
<td>3</td>
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<td>1</td>
<td>6</td>
<td>21</td>
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<tr>
<td>50-59</td>
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<td>0</td>
<td>2</td>
<td>7</td>
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<td>2</td>
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<td>Gender</td>
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<td>6</td>
<td>7</td>
<td>3</td>
<td>16</td>
<td>55</td>
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<tr>
<td>Male</td>
<td>9</td>
<td>2</td>
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<td>13</td>
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<td>Qualifications in disability</td>
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<td>Degree/diploma</td>
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<td>2</td>
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<tr>
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<td>6</td>
<td>3</td>
<td>19</td>
<td>66</td>
</tr>
<tr>
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<td>2</td>
<td>0</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Time worked in disability sector</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&gt;11mths</td>
<td>4</td>
<td>5</td>
<td>0</td>
<td>9</td>
<td>31</td>
</tr>
<tr>
<td>1yr-2.11mths</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>3yrs-9.11mths</td>
<td>6</td>
<td>2</td>
<td>1</td>
<td>9</td>
<td>31</td>
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<tr>
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<td>1</td>
<td>4</td>
<td>7</td>
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<tr>
<td>Time known central participant</td>
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<tr>
<td>&gt;11mths</td>
<td>5</td>
<td>5</td>
<td>0</td>
<td>10</td>
<td>34</td>
</tr>
<tr>
<td>1yr-2.11mths</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>8</td>
<td>28</td>
</tr>
<tr>
<td>3yrs-9.11mths</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>8</td>
<td>28</td>
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<tr>
<td>10+years</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>10</td>
</tr>
</tbody>
</table>

*aNationally recognised qualifications in disability support*
Central Participants

A synopsis of each central participant is presented in the order that recruitment occurred. A short poem, written at the end of each participant observation period, follows the description.

Sandra

Sandra was 20 years old and lived at home with her family. She had been educated at an early intervention program and progressed to a mainstream primary school with one-to-one support from an aide. From there she had attended a special school and at 18 years of age went to a local adult day centre for five days a week. Medical reports indicated Sandra had a severe intellectual disability, moderate Autism Spectrum Disorder (ASD) and epilepsy. Her epilepsy was not controlled and her medication levels were monitored regularly. She had long periods of diminished alertness.

Sandra used speech and non-speech modes of communication when she interacted with people in her environment (see table on page 52 for more clinical assessment details). Her speech consisted of up to 100 single words, a large proportion being people’s names. She had a limited number of two-word phrases that she used repeatedly (e.g., “mum happy, dad happy”). She could recognise photos, line drawings and pictures and occasionally used them to communicate. She had a book of photos that was developed and updated by day centre staff members. She also used some key word signs that accompanied her speech for additional emphasis. For example, Sandra said “car, car” and pointed to herself, then with both hands signed CAR (F/N8). She also used touch, which could be gentle when she was expressing affection, but would also strike other people when they were in her way, too close or for unknown reasons. Her disposition was changeable from highly anxious to exuberant high spirits.

I observed Sandra over a period of five months with, during which she frequented two main locations: the day service and home. I did not observe her in other infrequent locations,
such as at her family birthday dinner in a restaurant or an occasional weekend in a family
country house. Mostly she refused to leave her home, where she predominantly sat in a front
room and watched TV. She would also sit in the family room near the kitchen bench and
watch TV. At the day centre she spent most of the day sitting in the main dining area where
she could observe people coming and going. Occasionally she would join her group for a
program in the kitchen or go into her group room.

Sandra

I am Sandra

I am anxious

I take comfort from speaking words

they convey my stress

Mum, mum, Michael, Michael, home, soon.

I am Sands

unsteady when I stand, I shift on my feet

the rocking grounds me

I wait, staring out the door

I circle my head,

I call out, mum mum, soon.

I am Sandra

something happens when I sleep

I wake afraid

I do not understand seizures
only feel uncertainty and displacement

Mum mum, home, soon.

I am Sands
I like to sit and watch
I laugh at silly antics
I clown around
I can engage you, mimic your hand movements
Facial expression and tone of voice
I laugh with you, linking for a moment.

I am Sandra
I need to control
I order the TV, the table top
I order you, “look” - be with me
pay attention share my focus
not too long, not too close
on my terms.

I am Sandra
I have moods
dark clouds gather in my head
I reach for you “hand, hand, -wait”
I may stroke you
or pinch or hit or strangle
I am in charge, I have purpose.

I am Sandy
Mum mum, dad, Michael
I echo your words
I want mum happy
Dad happy
Michael happy
I need to be safe, understood, loved.

I am Sandra
I have labels
Autism Spectrum Disorder
Severe Intellectual Disability
Behaviours of Concern
Epileptic, Obsessive/Compulsive
I am more than that.

I am Sandra
I feel deep inside
I cry with your sorrow
I laugh with real joy
I am a princess, a lioness
A sweetheart, a pain
I am your friend.
Brian

Brian was 23 years old and lived at home with his family. Brian had an elder brother with a disability. Brian had attended an early intervention program, prior to a Special Developmental School. At 18 years of age, he commenced full time at a local adult Day service that he still attends five days a week. Brian had a scoliosis (a lateral curvature of the spine) and a history of epilepsy. He was independently mobile. He had a significant visual impairment and wore glasses.

Brian communicated through facial expression, body language, use of about 10 key word signs, and some gestures and touch (see table on page 52 for more clinical assessment details). He also used about 50 spoken words, many of which were clear only to familiar people. Brian’s mother had compiled a list of his spoken words with his pronunciation to help inform new home support workers. In conjunction with Brian’s mother, I updated this list and developed a personal communication dictionary for him. Brian could recognise his own photo from a choice of four; however, he showed little interest in photos or pictures. Brian would often hit people he liked, or accidentally crush them with an overzealous hug.

I observed Brian over six months, predominantly in two locations: these were at home or at the day service (see Table 3). Brian’s favourite activities were shredding paper, turning on lights, flushing the toilet and physically interacting with people. At the day centre, he frequented the laundry and kitchen (where he sat with his back to any vibratory machine (e.g., clothes dryer, fridge), the toilets (where he flushed or just looked at the toilet), his home group room and the places where his preferred people would be found. He also went into the community with a small group from his day centre, mainly to have lunch in the park or for walks. At home he spent time in the laundry, toilet, and lounge room, often seeking drinks from the kitchen. Once a fortnight, two HSWs took him and his brother out for the day, usually for a train trip, bowling and to a cafe. Several times a year, he and his brother
attended an evening disco for people with a disability, initiated and organised through a recreation service.

Brian

Bam, you’ve arrived
flicking light switch on
It’s into the room, the door hits the wall
you head straight for the sink
must have a drink
your bag comes later, with the driver.

You dart into the hall
light on your feet, you skirt
the tables and chairs
check out the loo
look out for who
might be fair game.

After a squeal and a giggle
You plop beside the fridge
To retreat for a while
quiet on the floor
not wanting more
than a whole body sensation.
Then it’s time for some latex
but your grab is foiled
it’s gloves in the bin.
Still you keep an eye on the door
as people to explore
beckon.

Which way to go now
another door open
time for an office chair trip
return a high five
So good to be alive
might stare at the light to conjure a sneeze.

Then back to your room
But wait, haven’t yet been
to the washing machine
which thumps in spin
and tingles your skin
And relaxes.

Oh, what a day
another social round
and it’s back on the bus
home for a kiss and a hug
a flop on the couch
dinner with your brother.

Mum does the dishes
and you get your wishes
rough and tumble with dad
to kick and get tickled
until with bed in your sights
it’s an I love you, and Goodnight.
Colin

Colin was 27 years old and lived in a group home in rural Victoria. He had been educated at a special school and at 18 years commenced attending two part-time day centre programs. He had uncontrolled epilepsy. He was legally blind and wore glasses with thick lenses, but it was difficult to ascertain if the glasses assisted his vision. His hearing seemed to be adequate for interaction on a one-to-one basis. He was very physically active, but not always stable on his feet. He was reported to have poor fine motor control, but could pick up specks of dirt from the ground.

Colin appeared to understand everyday simple speech and had about 10 spoken words (see table on page 52 for more clinical assessment details). He initiated communication, used a lot of gesture, a few key word signs, and sometimes pointed to or picked up photos to communicate his needs and wants. Often his communication was unclear and he appeared to talk to himself using gestures. He was very goal directed and could damage property, his own or other people’s.

I observed Colin over four months, during which he spent most of his time at two day centres and his group home. Usually he went to visit family members for a weekend every fortnight, but recently, due to family reasons, he had been unable to stay overnight. Once a month, he attended a leisure program, which he had been doing for several years. Although he had a reasonably large extended family, contact with anyone other than his grandparents was sporadic. Eighteen months prior to his participation in the study, he had moved to a group home with five other people with intellectual disability. There had been a number of staff changes at the group home and Colin had not established strong relationships.
Colin

You sit by the table, legs crossed
your head on one side
The thinker
Listener
waiting for the next move
waiting for routine.

You stand in front of the TV
pacing, stroking the shelf
back and forth
Imitate the waving image
focus briefly
Move on.

You become absorbed
moving pieces on a peg board
in and out
lick, pause
place and replace
Complete and destroy.

You pour over the newspaper
peer closely at the photos
glasses on, glasses off
point and show him
point and show her
Point and share.

You stand by the window
gesticulate and vocalise
imaginary partners
Mister Bean persona
The apprenticed electrician
fascinated by cables.

A familiar face appears at the door
you extend your cheeky grin
A high and low five
more than words
Two thumbs up at everyone
you are delighted/delightful.

Nothing lasts, you flit the room
A wheelchair to examine
buttons, and ankles to inspect
fluff to pill
doors to shut
rituals to cement.
**Diane**

Diane was 44 years old and lived at home with her parents. She had received no formal education, having attended a preschool group at a hospital before receiving therapy at a nongovernment organisation. She started in the school section and then moved to one and then another day centre. She had a diagnosis of cerebral palsy and epilepsy. The cerebral palsy affected all four limbs (quadriplegia). She was unable to walk and used a manual wheelchair. Medication was prescribed for her epilepsy, but she still had occasional seizures. She had limited fine motor ability: she could feed herself sandwiches and point to pictures, but not fasten buttons.

She communicated through vocalizations, gestures, a few key word signs (e.g., toilet, go, video) and some pictures. She had a number of different communication aids, including a book containing information about the way in which she communicated and her likes and dislikes (prepared for unfamiliar people to read and quickly learn about Diane), and a speech generating device with a static display of about 50 pictures (see table on page 52 for more clinical assessment details). She had speech pathology intervention that resulted in developing and updating these aids, although she rarely used them. Instead, she relied on vocalization and gesture, and on others who knew her well to interpret her messages. Although Diane was considered an easy-going person by the paid workers, they all agreed she could be demanding of their attention.

I observed Diane over five months, during which she spent most of her time at home, at family members’ homes and at the day service. Observation time with Diane was limited as she seemed uncomfortable with my presence, particularly at home. She went to the same respite accommodation service a few times a year, but was reluctant to stay overnight. She had a large extended family and participated in all family celebrations.
Diane

You sit all ears and eyes
alert but still
listening for a cue
a josh to laugh at
a reason to reach out
to be included, engaged.

Positioned between doors
you are the reception
eyes that see all
the first hiya
after the frog croak
the welcoming door bell.

The room is buzzing
people passing on their way
to lunch
to the toilet
opportunities on offer
for the social butterfly.

You call out
demanding attention
raising your volume and pitch
awaiting the “what’s up Diane”
a friendly face up close
a comforting word.

You can sit quiet, head down
amidst others activity
fixate on yourself
your belt’s not tight
your strap’s not straight
you fiddle, neaten, order.

At home you monopolise mum
with gesture explain
your needs
You clutch the phone and
midst deep conversation, cry
tears overtaking reason.

You hang on anxiously to what you know
Johnny Farnham
Shopping
Morning routine
Familiars to pass the time with
Days sequenced safely.
**Eric**

Eric was 24 years old and moved to a group home a year prior to data collection. As a child, he attended early intervention programs and completed formal education at mainstream schools supported by an aide. At 18 years of age he commenced fulltime attendance at an adult day service.

He had a diagnosis of cerebral palsy and epilepsy. Although he was mobile, he walked with a lurching gait and fell frequently. He used a manual wheelchair for travelling long distances. He took medication for his uncontrolled epilepsy. His fine motor skills were limited; however, he could use the arrow keys on a computer keyboard to play simple computer games.

Eric had about 10 single words (usually names of people or yes/no) and used approximately 50 key word signs (see table on page 52 for more clinical assessment details). He used finger spelling for the initial letters of a person’s name, and also pointed to objects, pictures and photos to communicate. He had a long history of speech pathology intervention. He used mainly single formal symbols, but sometimes in combination with gestures and vocalisations. The family developed photo sheets with text describing activities in which Eric had been involved in order to provide topics for conversation.

I observed Eric over six months. He had an active social life that comprised going to movies and art galleries and participating in family celebrations. He regularly spent time in five locations: three of these were homes of various family members, one a government group home and one a day service and had social network members from each location. Eric always had difficulty transitioning between activities and could get quite distressed if asked to move or go somewhere before he was ready to do so. He spent most weekends with his family.
Eric

Eric the lover
adoringly he hovers
staring deep into her eyes
never sure of her response
face ready for a surprise
A peck; a blurt; a stroke; a laugh.

Eric the boyfriend
he sits; he waits; she socialises
she returns; they embrace
heads touching
profoundly engaged
she kisses his silence.

Eric the evil twin
as transition takes hold, control is gone
distress shoots from every limb
his awkward body thrashing and flailing
beyond reason, beyond explanation
a reflexive, unmediated response.

Eric the culture vulture
Michael Jackson; action movies
the Simpsons; a Disney experience
a slave to song and slapstick
pressing the rewind, mouthing the words
Involved in other realities, other worlds.

Eric the friend
a corner of the eye contact
a passing flick, bumping bodies
holding hands, waggling knees
crashing and connecting
boys espousing cool indifference.

Eric the communicator
engaging you expectantly
muttering a sound, waving a finger
he wills you to translate his thoughts
into coherent order
harnessing your knowledge of his world.

Eric the independent
He toggles the arrow keys
Techno-savvy, electronically entranced.
checking the mailbox, he lurches outside
seeking the next prop, defying gravity
He crashes, bruised but not daunted.
Eric the observer
finding a strategic chair, he sits
scanning all areas- all passers by
studying his hand as time ticks by
taking a turn as door man
keeping an eye on the street.

Eric the loved
secure in social routines
sharing a joke; death by chocolate
teasing Daisy, scaring nanna
playing out the familiar score
each bit player understanding, reciprocating.
Fayez

Fayez was 38 years old and lived in a group home. She was born in Australia and was the eldest of three siblings. As a small child, she went and lived with her grandmother in a European country for 10 years, where she did not attend school. On returning to Australia, she stayed with her family for a few years, but then went to a nongovernment school and lived in a hostel nearby. A few years later, she moved into a small group house with two people from the original hostel.

She had diagnoses of cerebral palsy, epilepsy and scoliosis. The cerebral palsy affected all four limbs and she required an electric wheelchair for mobility. She had limited fine motor skills, but could operate her wheelchair by pressing her hand against a flat switch. When outdoors, the house staff operated her wheelchair manually, particularly in the community where pavements were narrow.

Fayez communicated predominantly through the use of facial expression, vocalisations, nodding/shaking head for yes/no, pointing and gestures (see table on page 52 for more clinical assessment details). She also pointed to pictures and just prior to participating in the study had been given a new communication book with approximately 80 pictures. Prior to that, Fayez had no formal way to communicate. She used only a few of the pictures, but was persistent in getting her message across. She also had magazine pictures on her wheelchair tray and would point to them as a way of engaging network members.

I observed Fayez over six months. Fayez spent time in two main locations: her group home and day centre. She visited her family once or twice a year, and they visited her every month or two. Her sister was the point of family contact as her parents had little spoken English.
Fayez

You sit silently, still
your fragile beauty
marred by anxious eyes
Patiently you wait
for preferred company.

Handbag on your arm
you cast your eyes around
staring fixedly, awaiting contact
Ignored, you close your eyes
retreat and sleep.

You call out, screaming
turning pages slowly, fervently searching
point out “uncomfortable”
you are lifted, re-seated
you smile, brightening up the room.

You share your secrets
tucked into your bag
photos, babies, a former life
you display them briefly
keeping your past safe.
You watch TV
cracking up at slapstick
laughing with company
    a burp or a fart
lifting your spirits.

You are dressed with care
A colourful scarf, glittery shoes
    brightly painted nails
You beam with warmth
meting out your rays of pleasure.
Summary

The personal affinity network members were either family members, paid workers or peers with intellectual disability. Although all central participants had symbolic but nonlinguistic communication skills and functioned as adults with a severe intellectual disability, they differed in many ways along physical, social and emotional parameters. They ranged in age from 20 to 44 years. They had multiple diagnoses, but all had epilepsy and an intellectual disability. Although only one central participant had a diagnosis of Autism Spectrum Disorder, others demonstrated features that have been associated with autism: five required regular routines in order to feel secure and five demonstrated extreme anxiety on occasions. Two central participants had significant visual impairments; for one, it could not be corrected by wearing glasses. Although all central participants had poor balance, only two relied on wheelchairs for mobility. They communicated by diverse means: five used some speech, all used some key word signs, and five used pictures either to share information or to get needs met. Regardless of their difficulties with formal communication, they were social beings and sought opportunities to interact with other people.
CHAPTER 7: A CASE STUDY

Overview of Chapter

The publication “The pearl in the middle: A case study of social interactions in an individual with a severe intellectual disability” presents the first central participant to be recruited, Sandra, in the form of a case study. This article was developed early in the course of research with the aim to describe the social interaction of an adult with a severe intellectual disability whose communication was symbolic but nonlinguistic. In doing so, her social network was identified and how members of her social network perceived her communication described. Implications for practice were presented that highlight the importance of a person-centred approach and provide suggestions for increasing opportunities for social interaction.
Publication


Statement of Contribution

As co-authors of the following manuscript titled ‘The pearl in the middle: A case study of social interactions in an individual with a severe intellectual disability’ we confirm that Hilary Johnson made the following contribution: Hilary Johnson was responsible for writing the complete first draft of the manuscript. Associate Professor Jacinta Douglas, Professor Christine Bigby and Professor Teresa Iacono critically appraised the manuscript and Hilary’s subsequent revisions of the manuscript.

Signed: Date: 25/5/12

Associate Professor Jacinta Douglas

Signed: Date: 25/5/12

Professor Christine Bigby

Signed: Date: 25/5/12

Professor Teresa Iacono
The pearl in the middle: A case study of social interactions in an individual with a severe intellectual disability

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Abstract

Background People with severe intellectual disability have limited communication skills, small social networks, and may experience isolation. Little is known about how interactions occur with social network members and the role of social support.

Method An adult with a severe intellectual disability was observed in her daily environments. Her social network members were identified and interviewed. Data were analysed using a grounded theory approach.

Results Fourteen social network members were identified. People with severe intellectual disability interact in different ways, which may not be understood by network members or conform to normative expectations. Still, network members experienced enjoyment, personal satisfaction, and love in their interactions.

Conclusions Social interactions with people with severe intellectual disability are challenging. The results point to the benefits of a focus on learning that makes interactions meaningful for each individual, sharing that information with network members, and considering ways to increase interactions and extend the social network.

Keywords: severe intellectual disability, communication, social networks, adult, interaction

Introduction

Social inclusion is an important aspect of Australian government policy (Australian Government, 2009). Various pieces of legislation and policies have been enacted to encourage the inclusion of marginalised groups, particularly those with intellectual disability, but with limited success (Department of Health, 2001; Department of Human Services, 2002; Lecompt & Mercier, 2007). For example, in a recent national report, over half of 750 submissions received from people with disability and disability organisations stated that social inclusion and community participation were still unrealised goals (National People with Disabilities and Carer Council, 2009). Facilitating the social inclusion of people with severe intellectual disability presents complex issues. As Finlay, Antaki, Walton, and Stribling (2008) suggested, inclusion is not only about presence but also about “respectful, mutual exchanges between individuals, which are rewarding for both parties” (p. 532). Such exchanges or interactions are often underpinned by successful communication. Successful interactions may be difficult to achieve when one or more of the communication partners have limited communication abilities associated with physical and/or intellectual disabilities (Johnson, Douglas, Bigby, & Iacono, 2009).

People with intellectual disability have been estimated to comprise 3% of the population (Wen, 1997) and many experience difficulties with communication (Australian Institute of Health and Welfare, 2003). The more severe the intellectual disability, the greater the likelihood of other associated disabilities, such as limited speech, epilepsy, and autism spectrum disorders (ASD) (Arvio & Sillanpää, 2003). It has been suggested that a combination of diagnoses results in specific and distinct subgroups, such as people with ID and ASD (Matson & Shoemaker, 2009). The greater the severity of intellectual disability, the more complex the process of ascribing communication or behaviours to a specific diagnosis. People with severe or profound intellectual disability fall along a spectrum of communication ability, from
being nonsymbolic (i.e., unable to use words, pictures, or signs), to having limited linguistic skills (i.e., some ability to combine symbols flexibly) (McLean, Brady, & McLean, 1996). Individuals with limited linguistic skills predominantly use informal means of communication, such as body language, gesture, and facial expression.

In Australia, until the 1970s, most adults with severe intellectual disability lived in large congregate care institutions; now they live in the community, often in group homes of 4–6 residents (Clement & Bigby, 2010). The move from large institutions to living in the community has not resulted in making new friends or social inclusion (Clement & Bigby, 2010). Many of the residents attend segregated day centres from which they participate in group community outings (e.g., shopping, bowling, or visiting parks). Concomitant with the move from large congregate care facilities has been a major paradigm shift from a medical model towards a social model of service provision. An essential element of this paradigm shift has been the development of person-centred approaches that celebrate each individual’s strengths, promote acceptance of difference, and encourage the development of valued social roles for people with intellectual disability (C. L. O’Brien, O’Brien, & Mount, 1997; J. O’Brien & Lyle, 1987). Many services have embraced the new frameworks for programs, but are inexperienced in supporting individuals with complex needs in the process of social inclusion.

Social networks

Building relationships has been considered an important element in the journey towards community inclusion (J. O’Brien, 1989). However, social networks of people with severe disability are often small and limited to family, paid workers, and sometimes other people with intellectual disability (Kennedy, Horner, & Newton, 1990). For some people, their social networks are entirely comprised of paid staff, who have sometimes been discounted because their presence, although frequent, has not been voluntary. Nevertheless, positive outcomes from staff and client interactions that show changes in relationships over time have been reported in the research literature. For example, Newton, Olson, and Horner (1995) found that paid staff members sought to maintain relationships with residents after leaving the workplace, regularly visiting or taking them out. Similarly, some paid staff have been reported as working in the same house for years, partly because they enjoyed spending time with specific residents (Forster & Iacono, 2008).

Unfortunately, social networks that rely solely on paid workers can be unstable due to a high turnover in staff (Hatton, Rose, & Rose, 2004) and may not fulfill functions that can be played by network members, such as advocacy or monitoring the quality of services (Bigby, 2008). In addition, staff members may not always be skilled in interactions in that they have been reported to demonstrate difficulty in recognising nonverbal behaviours (McConkey, Morris, & Purcell, 1999) and observed having problems in adjusting their communication style to meet the needs of the people they support (Purcell, Morris, & McConkey, 1999). These difficulties with basic communication interactions are relevant in light of communication having multiple purposes. Light (1988) reflected on this and noted the purpose of communication extends beyond having needs met (typically a focus of intervention) to sharing information, fulfilling social etiquette, and social closeness. As requests and directions often dominate support worker interactions, the social interaction functions of communication in the workplace may be limited. On the other hand, if supporting relationships and building social networks are important for social inclusion, understanding how to support staff to be skilled communication partners is desirable. Dennis (2002) addressed this issue by examining skilled communication partners of people with limited communication. She found the communication partners attributed their success in developing and maintaining relationships to having a strong belief in the communication abilities of the person with a disability, respect for idiosyncratic ways of communicating, an awareness of their own personal attributes and limitations, an ability to change themselves, and a commitment to the person.

Social support

Social support has been described as the emotional and/or physical support given by families or friends to each other (Antonucci, 1985). Support that is reciprocated can contribute to improving the quality of relationships. The concept of reciprocity comes from exchange theory, whereby both giving and taking can coexist, and not always on equal terms (Wellman, 1981). The role of reciprocity in relationships has not been explored extensively in the social networks of people with severe intellectual disability. An exception is a large group study (n = 500) by Robertson et al. (2001), who found that it was unusual for these adults to provide support to others or to demonstrate reciprocity. However, studies that have adopted qualitative approaches to investigating relationships between people with very limited
communication and their social network members have demonstrated the existence of reciprocity (Bogdan & Taylor, 1998; Newton et al., 1995). Still, the components that encourage reciprocity in a relationship have not yet been determined; nor is it clear whether a particular style or mode of communication facilitates reciprocity. Bogdan and Taylor (1998), after analysing over a 100 interviews from staff members, family, and friends of people with severe and profound disability, suggested that if partners viewed the person with a disability as reciprocating in relationships, their inherent humanity was reinforced and a positive rapport provided. These researchers, in an earlier study, discovered accepting, reciprocal relationships were formed where the network's members were either family, had religious conviction, believed in the principles of social justice, or became friends through having fun together (Taylor & Bogdan, 1989).

Evidence for the ability of people with disability to participate in reciprocal relationships was provided by Newton et al. (1995), who interviewed 14 social network members of people with severe intellectual disability and limited communication. Some social network members discussed how they felt appreciated by the person with disability. One member commented that she could unburden herself because her friend had “no compulsion to fix things” (p. 389). According to the researchers, some network members commented on the differences between their own communication mode and that of the person with a disability, but this did not seem to impinge on the closeness of their relationship.

The research literature addressing social networks has neglected or provided limited description of the communication skills of people who use symbolic but nonlinguistic communication, those who use conventional symbols, such as spoken, signed, or pictured words, but do not combine them in linguistic units. These people are unable to use rule-governed language and their use of two-word phrases operates as single unit utterances (Bloom, 1993). People with limited formal communication are unable to express complex ideas; hence, knowledge of their social networks largely comes from proxy reports. There is little reason to assume that the aspirations of people who are nonlinguistic communicators are the same as for people with milder intellectual disability who have more advanced communication skills. Such advanced communication skills allow a person to engage in conversational interactions around a diverse range of topics, which may provide the basis for shared interest for relationships to develop. Little is known about the composition of the social networks of individuals who are nonlinguistic, the role of communication, and the functions of social support in those social networks.

In this study, the aim was to describe the social interaction of an adult with a severe intellectual disability who was a symbolic but nonlinguistic communicator. In doing so, her social network was identified and how members of her social network perceived her communication described. The research questions were (a) What does social interaction look like for an adult with a severe intellectual disability? (b) Who comprises her social network? and (c) How are social relationships experienced by her social network members?

Method

Design

As little is known about the interactions and social networks of adults who are nonlinguistic, a qualitative approach to data collection and analysis was taken (Morse & Richards, 2004; Strauss & Corbin, 1990). In this project, the authors have adopted Charmaz’s (2006) suggestions of using grounded theory guidelines as a rigorous but flexible way of utilising and interpreting data from different sources. Charmaz (2005) applies a constructivist approach as a theoretical underpinning to grounded theory, where the subjective role of the researcher in developing meanings is acknowledged. In the present study, a constructivist grounded theory approach was used to examine how people establish meanings and why they establish those meanings in order to identify implications for social change. The data were drawn from field notes taken during observations of the person with intellectual disability and transcripts of interviews with members of her social network.

Ethical approval

Ethical approval for the study was granted through the Human Research Ethics Committees of the two universities with which the authors were affiliated. Informed consent was obtained on behalf of the participants with intellectual disability from their next of kin, and directly for the participating support workers and central participant’s family.

Participants

The participants included a central participant and that person’s social network. Sandra (pseudonym) was 20 years old and lived at home with her
parents. As a young child she had attended a mainstream school with an integration aide and later attended a special school. At 18 years of age, she commenced full-time at a day service for adults with intellectual disability. Educational and medical reports indicated Sandra had a severe intellectual disability, a moderate ASD, and epilepsy. Her hearing and vision was reported to be within normal limits.

Sandra used speech and nonspeech modes of communication when she interacted with people in her environment. Her speech consisted of up to 100 single words, a large proportion being people’s names. She had a limited number of two-word phrases that she used repeatedly (e.g., “mum happy,” “dad happy”). She could recognise photos, line drawings and pictures, and occasionally used them to communicate. She also used some key word signs that accompanied her speech. Thus her communication was symbolic but nonlinguistic. A Triple C: Checklist of Communication Competencies (Bloomberg & West, 1999) had been completed at the time of her transition from school to the day service, which indicated she was an advanced symbolic communicator.

Other participants were members of her social network. They were observed both during social interaction with Sandra and interviewed about their experiences with her. There are many different definitions of what constitutes a social network member. For this research, four criteria were considered for identifying social network members: (a) people whom Sandra could name when not in her presence, (b) people with whom interactions were positive and in which Sandra showed pleasure (Forrester-Jones, Jones, Heason, & DiTerlizzi, 2004; Kennedy et al., 1990), (c) people with whom an interaction/activity had lasted more than 15 minutes (J. S. Newton, personal communication, 7 August 2007), and (d) people who had a special bond with her or who had known her for several years (Krauss & Erickson, 1988; Krauss, Seltzer, & Goodman, 1992). Each person needed to meet a minimum of two criteria to be deemed a social network member.

Family and day centre staff members were asked to identify people important to Sandra. Seventeen people were identified. These were four family members, three home support workers (HSWs), five day support workers (DSWs), one friend (ex-support worker), and four peers with intellectual disability. All family members and the eight support workers were observed in interactions with Sandra and also participated in interviews. The friend who was an ex-support worker was not available to participate in the research. Only two of the four peers met the social network inclusion criteria, and those two were observed and interviewed.

Procedure

Sandra was observed at a day centre and at home, and all data were collected over a 5-month period. The first author predominantly utilised two participant observer roles: those of observer-as-participant to complete observer. However, some occasions demanded her to move to the complete participant, or participant-as-observer roles (Hammersley & Atkinson, 1995). During observations, the researcher attempted wherever possible to hear clearly and see interactions while trying to blend into the environment. Observations varied in length from half an hour to two and a half hours. At the day centre a total of 10 hours was spent observing Sandra on 13 separate occasions. Observation occurred in three day centre contexts: the lunch room, when she was cooking in the kitchen, and during program time in her group room. Over the previous year, Sandra had been reluctant to leave her house, other than to go to the day centre, and all social activities were house-based. A total of 21 hours were spent observing Sandra at home on 13 separate occasions. Observations took place in the front room or in the kitchen with family, family friends, and her home support workers.

Field notes were recorded as interactions occurred or immediately after, whichever was more appropriate. As Hammersley and Atkinson (1995) stated, “field notes consist of relatively concrete descriptions of social processes and their contexts” (p. 175). No structured observation tool or preconceived coding was used; rather, Sandra’s interactions with people in her surroundings during her regular daily activities were observed. An example of a field note follows:

It was 12.30 and a DSW was helping Sandra make a sandwich in the kitchen for her lunch. He gave her the knife to spread the margarine, which she used independently for the first few knife strokes. She then put the knife down and he then helped her complete the task. She said “mum, . . . look.” The DSW did not respond to this but said “put it on the plate” (the plate was sitting on the kitchen bench in front of her) instead she followed the DSW as he walked to the drawer across the room. However when he said “give it to Jenny” she gave the plate to Jenny for washing up. The DSW gave her a bag of food (looked like lettuce) and she walked with him into the staff room to return unused food to the fridge—that she did and attempted to neaten down the edges of the bag so it fitted in the vegetable container—
this was not successful and she did not persevere. (FN1/1)

People with whom Sandra initiated interactions or appeared interested in were invited to be interviewed. The interviews aimed to supplement the information gained through the observations in order to more completely understand the social network members’ perceptions of Sandra and their relationship with her. Interviews ranged from 30 to 75 minutes and utilised an unstructured format. All interviews were conducted by the first author and opened with the question “Could you tell me about your relationship with Sandra and how communication in this relationship occurs?” Additional probes included asking about the role they played in Sandra’s life, and what they gave and received in their relationship with Sandra. The interviews were digitally recorded and later transcribed.

One of the interviewees who had an intellectual disability had difficulty with the unstructured format. As a result, pictures were used to clarify responses and assist him to maintain focus. Individual photos of social network members who were interviewed were presented to Sandra and her reactions transcribed.

Analysis

The data collection and analysis occurred simultaneously over a 5-month period. As indicated above, the data were textual, comprising verbatim transcripts of interviews and field notes taken during observation. All of the transcripts were read independently by the second author prior to analysis. One of the key strategies applied during analysis was continued comparison of the data from the two data sources. The authors acknowledge themselves as an integral part of the analytical process through conversations and reflexivity. The data were entered into NVivo 8 (QSR International, 1999–2008), coded line by line, and examined for in vivo codes (descriptive terms used by interviewees). Questions were applied to the data such as “what is happening here?” Early in the analysis, two separate aspects of the social interaction process emerged. The first was how Sandra interacted with those around her and the second was how social network members perceived interactions with Sandra. The codes for both aspects were then reexamined in a process of focused coding, as the data from each successive interview were compared and contrasted with information from the field notes, until clear categories emerged.

Throughout the analysis process, the authors met fortnightly to discuss coding and extrapolate the categories. In line with Charmaz’s (2006) grounded theory guidelines, the process was nonlinear. As concepts relevant to practice emerged, these were constantly compared with the rich data and rechecked against codes. A strengths-based perspective informed the coding (J. O’Brien & Lyle, 1987), and metaphors were developed that incorporated Sandra’s roles into a recognisable and meaningful framework for her social network. Saturation was reached when no new categories emerged from the data. A journal was kept to record insights from the data and literature in a form of memo writing (Charmaz, 2006). Questions regarding credibility, originality, resonance, and usefulness were applied to the interpretations as part of the iterative process (Charmaz, 2006). Credibility was evidenced through discussions with the research group over regular meetings and through sharing these insights with the social network for verification. New insights in supporting people like Sandra demonstrated originality and resonance and were verified in feedback received from conference presentations. The usefulness of the interpretations lies in their implications for practice. These implications are considered in the context of interpretive theory; that is, how interpretations contribute to a greater understanding of the studied phenomena—in this case, how these interpretations contribute to understanding interactions with people like Sandra.

Results and discussion

The results of data analysis are presented and discussed in terms of the themes that emerged in relation to the three research questions. The first question involved understanding what social interactions looked like for Sandra. The major theme that emerged in relation to this question was that meaning in social interaction with Sandra was underpinned by various dispositional roles she was seen to play in her environments. Her communicative interactions fulfilled three main purposes: to get her needs met, to share information (mostly about other people), and for social interaction and social closeness. Sandra’s communication included the use of facial expression, body language, touch, objects, gesture, key word signs, and spoken words; these modes varied in frequency across her roles. Three distinct roles emerged from the data that highlighted her different interaction patterns and how she communicated with those around her. These roles were Sandra as the “lioness,” “anxious child,” and “entertainer.” The term lioness was an in vivo code suggested by a DSW, but it was also underpinned in transcripts of several interviews, with the use of terms
such as “track” and “lunge.” The authors considered the possible negative connotation of using animal imagery when referring to a person with disability, but balanced this consideration against the strength of the image. The characteristics of protection, fierceness, and independence emerged repeatedly from the data and these were captured in the positive and powerful notions of a lioness. The researcher observed Sandra in the role of anxious child at the day centre, and the term “anxious” appeared repeatedly in the interviews. The child aspect of the role reflected her vulnerability and need for protection, which contrasted with her lioness image. Sandra in the role of entertainer emerged from the data in descriptions and observations of the enjoyable interactions experienced by all in her network, but especially family and support workers employed in Sandra’s home.

Roles and social interaction

Sandra as a lioness exerted control on her personal belongings, her personal space, and her relationships. She communicated this control predominantly through informal means, such as the use of objects, her body movements, facial expressions, and touch. One of the objects that was central to many of her interactions at home was the TV. She changed the channel at will. As a family member related, “It can also be pretty frustrating because she occasionally swaps channels, turns the volume down, turns the volume up. I mean she likes to, I think that’s sort of a bit of a power thing with her.”

Interactions with Sandra in her lioness role could be difficult because her use of words was sometimes ambiguous. Sometimes she used words such as “wait” (which could mean stop, don’t do anything, or signify impending anger) and “go away” to terminate an interaction. Sometimes she would also say “hand, hand” as if she wanted you to hold her hand, but as you came close she would sometimes reach out to strike you. This unpredictable response happened while Sandra was assisting with cooking lunch at the day service. The following is an excerpt from the field notes:

Sandra was in the kitchen, in a cooking group when I arrived. The group was all male. One DSW was giving her food to stir in the frypan. Sandra pulled me close and said “look—[naming the DSW].” A few minutes later she reached out to hug me. She continued stirring for 5 minutes or so. Both male DSWs on different occasions came to tell her she was doing a “good job” and “mum pleased.” She was using her fingers to pick the bacon off the wooden spoon. One of the DSW turned the fry pan up. I was concerned she might burn her fingers—I said “be careful it’s hot.” She lashed out with her free hand, reaching for my throat. Then she went back to stirring, saying “mum . . . pleased, James . . . pleased.” Neither of the stuff made any comment. I started to back away but she got hold of my hand saying “hand” then lashed out for my neck again—followed by “go away.” (FN/10)

Her powerful lioness presence was evident across both environments. During these interactions, her social network member observed her facial expression and body language carefully, while noting her speech and tone of voice. At the day centre, those who did not know her well avoided interactions. One of the DSWs noted

She’s a private person and she has her reasons if she doesn’t want you in her space, if she wants to bring you into her space. Yeah we have a fairly good sort of relationship but I am always a bit wary.

Where Sandra was seen as an anxious child, her interactions appeared to be driven by a high level of anxiety. The word anxious was used by one DSW when asked to describe Sandra in one word. Sometimes Sandra’s anxiety appeared to be overwhelming, and she would seek others for consolation. Here she showed the vulnerability of the child, reaching out for comfort and protection, and was visibly distressed. The following example demonstrated how her anxiety was usually communicated through her body language, facial expression, speech, and tone of voice:

There was a lot of noise at a birthday party in the main room where Sandra usually sits. Almost in tears, she began to get agitated and said “stop, stop” repeatedly. Her whole body started to shake. A DSW took her into a side room with a familiar peer and she just kept reaching out for their hands and shaking. Eventually she relaxed a little, remaining seated and holding hands with both of them. (FN/4)

Her anxiety was usually communicated through her body language, facial expression, speech, and tone of voice. Her anxiety levels varied from demonstrating her vulnerability and desiring comfort, to lashing out when others came close; as a result, a family member commented on how her behaviour was not always easy to interpret or understand.

So there are things where she sort of does this, and I mean a lot of people will look at that and get confused because she sort of tenses up and shakes her hands and I know immediately that that means she’s anxious or a bit
worried, that kind of stuff and a lot of other people that haven't met her very often sort of get a bit . . .

A home support worker (HSW) suggested her repetition of words also signified anxiety.

She does get very anxious and, for reasons that probably you're very aware of too. You want to minimise that anxiety. And sometimes because her dad was away, I think that that might have added to the anxiety. But she was constantly repeating, "Mum, Dad, home, home," you know like, and she does that quite often.

The words she used when she was anxious were sometimes difficult to understand and sounded like she was using a language other than English. These were sometimes used in fun situations, but also when Sandra was anxious and could indicate an escalation of her anxiety. One of the DSWs noted her mood could be complex to interpret and suggested a need to intervene. She stated, "I don't know whether it's anxiety or something I don't know what's going on with her, but I just try to redirect her into thinking something else she goes 'farfar' bizarre gibberish words she says."

Sandra's interactions were also seen as reflecting the role of the entertainer. Although Sandra's behaviour could be both puzzling and frightening, network members commented on the fun they could have with Sandra. In this entertainer role, she played a mimic, copying accurately people's facial expressions and body language. She would repeat words in order to engage in interaction; she could be outrageous and outgoing, dancing energetically. Although she used some speech, her range of facial expressions and body language conveyed powerful messages. She reached out to people by mimicking them and playing games. One of the HSWs noted, "Well I touch my lips a lot and I haven't noticed that I do that and now every time, every Tuesday, Sandra is going 'mmm' and that's exactly what I do." This ability to mimic and share was seen as a positive skill and valued by network members. Mimicking was often an important component of relationship building as the network members felt Sandra was individualising her responses to them. Mimicking also provided some safe ground for interaction, as described by a family member:

And also more on a sort of one-to-one level of communication, because you're communicating through laughing and watching something together as opposed to try and have direct dialogue which is impossible. So it probably makes her feel a little bit better because you don't need to have a thousand words, you can just laugh and make faces.

Mimicking also included repeating words and these could result in enjoyable interactions. Her father explained:

So if I'm here and she wants attention it'll be "Dad, Dad, Dad" and it really won't stop until you go up there, and she'll say "sit, sit, sit" and you sit there for a while. Then she'll say "talk, talk, talk." So you sit down and say "what do you want to talk about?" and she'll go "talk," and you go "what do you want to talk about and she'll go "talk." I say "do you want to talk about school?" and then I'll say something like "Katie's a good friend" and she'll go "friend."

Sandra's behaviour was also seen as outrageous and defying convention. A HSW commented on the enjoyment she experienced witnessing Sandra's behaviour:

She does what we would all love to be able to do and that is punch the person in the face who just stole your car park, or take your pants off when you're hot and just sit there and not give a toss, stick your finger up your nose or scratch your backside in public or your front bits or whatever . . . she does and then things like when she does dancing and then she comes home she just cracks me up.

As Sandra had limited speech, her social network members needed to be alert to her non-speech communication. Reading her mood and understanding her communication within her dispositional roles was vital to the safety of the network member, and influenced when and how interactions occurred. A family member stated she was the "barometer of the household," and on entering the house, visitors would be warned when she was considered to be "on the prowl." Social network members learned to read the nuances in her behaviour and react accordingly. One DSW commented, "it's easy to be a little bit wary of Sandra I suppose, and I started out that way. So I started making sure I got a smile out of her and a sort of friendly response before I would approach her."

Sandra's communication means varied across roles and domains. She used both formal and informal communication to get her message across. In her role as entertainer, she used exuberant pitch and tone to express emotion, engaging others by her use of mimicry and word play. In contrast, in her role as lioness, she used her body language and facial expression to demonstrate control and create distance between herself and those around her. As an
anxious child, she appeared to be overcome by her emotions, appealing to others for comfort while trembling and sometimes shrieking with distress. At home, particularly when surrounded by family, she was most relaxed and the entertainer role predominated. When uneasy or in a changing environment, such as the day centre, the lioness role prevailed.

Social network and relationships

The second research question involved identification of people in Sandra's social network. Members of Sandra's social network were identified by asking key family and staff members for names and confirmed (or not) using the previously described criteria. A total of 14 people met the criteria defined for social network membership.

Her home social network was relatively stable. Three of the family members lived with Sandra and had known her all her life, while the fourth (Sandra’s brother's partner) had known her for less than 10 years. The HSWs had known her from less than 1 year to over 10 years. One HSW had met Sandra when she was in preschool care and then worked with her most of her life. Another had worked with Sandra when she was younger, left to have a baby, and then returned. The DSWs had known her from 1 to 3 years and her peers from less than 6 months to 3 years.

Although some support workers stated Sandra preferred males, only eight of her 14 network members were male. Eight of her network members saw her daily, so interacted frequently. The social network was dense, with most people knowing of each other, but only Sandra knew everyone. The DSWs at the centre did not know the HSWs, and not all of the DSWs knew the parents. One of the DSWs was a bus driver and had briefly met some of the HSWs.

Of the two peers, one had known her for only a few months and attended the day centre for only 2 days a week. He stated he was merely helping the staff with lunches and showed some concern about Sandra’s aggressive behaviour to others. Although Sandra was interested in this person (indicated by the way she said his name when she saw him or his photo), this young man repeatedly said in his interview “she is not my girlfriend” and “I just help her.” The data suggest this relationship was not reciprocal. The other peer who had known Sandra for a few years seemed to enjoy being with her. Sitting with Sandra entailed sitting in an open lunchroom in the day centre where there was a lot of interaction, and this may have increased his enjoyment. His communication was difficult to understand, but he seemed to enjoy talking and Sandra did not interrupt. When asked what he liked about Sandra, he responded “just talking.” The staff supported peer interaction with Sandra by giving each of the peers a role, such as helping out with her lunch. This support meant that the peers received additional positive attention from the staff. Sandra could sometimes be encouraged to join in a group activity if one of the two peers also attended.

The third research question concerned how the network members experienced social relationships with Sandra. Although Sandra had limited communication and could physically attack, people were still attracted to her and social support was evident in her relationships. Data analysis revealed four aspects of social support were experienced by Sandra’s network members: enjoying her company, love, personal satisfaction, and feeling fortunate. Taylor and Bogdan (1989) suggested that the first three of these four aspects are characteristics of accepting relationships. In Sandra’s case, the first two aspects—enjoying her company and receiving love—were seen most often in the home environment where Sandra appeared the most comfortable. The feeling of love was expressed only by family members.

Enjoying her company. The feeling of having fun and enjoying keeping company emerged from Sandra’s ability to entertain and play games, whether it was mimicking another’s movements, repetitive word games, dancing wildly, or copying the wrestling on the TV. Her sense of humour and fun was infectious, as described by a family member:

> When she’s not being a pain in the arse she can really brighten up a room. Like sometimes when she comes home from school and she’s been doing dancing or disco or whatever, probably bopping around and I’ll come out and she’d be lying on the floor trying to do a dance move or stretching or you’ll come out and she’ll be sort of listening. She’ll be sort of thundering backwards and forwards and it’s just, she has a real freedom.

Love. Sandra’s ability to invoke love was identified most clearly by family members: “I just love everything about her. I love her sense of humour. I love her affection towards me. I just love the way she looks, you know, how she looks at me sometimes.” Her mother recounted an incident to emphasise the delight she had in her daughter. It concerned an integration aide (Ben), who had assisted Sandra at school for several years. Ben and his partner, Sue, would visit Sandra. Sandra used to walk with them but always between them: Ben, then Sandra, and then Sue. As Sandra’s mother described,
“She’s really telling him (what your place is), this is how I am, the pearl in the middle.”

**Personal satisfaction.** Support workers from the home and day centre reported feeling personally satisfied working with Sandra. Partly it was the challenge of supporting Sandra and a feeling of achievement when mutual respect was accorded. One HSW commented

So yeah, I really find sitting back and watching her how she does look at certain people or how she responds to the way people talk to her and all that and I do get something out of her. I do actually enjoy the shift.

Another HSW said, “Like when we’re dancing and stuff it makes me feel that I’ve made a difference to her day.” A third HSW commented on the positive response she received from Sandra on showing her new baby: “... she prefers males. So to be able to be like that with her is actually I guess quite a privilege to think I’ve actually broken down that stereotype.”

**Feeling fortunate.** Although several support staff stated they achieved personal satisfaction from working with Sandra, this was sometimes related to the challenge involved in supporting her without an adverse incident. Indeed, two members of the support network reflected on their own lives and commented on how grateful they were not to have a child with a disability in their own family life. One DSW stated

There with the grace of God goes I, I have two sons, I have five grandchildren and I look at her and the others and I think well it was only one gene that perhaps caused her to be this way, it could have been my kids. So I consider that I am very blessed in that respect.

A HSW also echoed the sentiment of feeling fortunate.

It also gives me a reality check that how blessed I actually am to have a child of my own and how very lucky I am to do that. But it’s also you know because I work with lots of other people’s children and it just gives me a really good reality check that, you know, some people do it really tough and have to strive really hard.

**Summary**

Sandra communicated in many different ways. Her interactions were encapsulated in three main dispositional roles that were identifiable to Sandra’s network. Her network, excluding family, consisted predominantly of paid and domain-specific relationships. She was seen by those who knew her as an attractive person and one with whom interaction could be challenging, but valued. Her relationships at home were the most stable. Two of her home support workers have supported her for several years, both returning after work breaks. One HSW reported she could not see a time in her life without Sandra being present. This same HSW also attended some family functions primarily driven by her interest and connection with the family. This commitment to support the family was also echoed by some DSWs, however, none of them volunteered to spend time outside the workplace with Sandra. Members of her social network experienced reciprocity in their relationships with her.

**Conclusions and implications**

As Finlay et al. (2008) suggested, developing an individual’s supportive social network can assist with the processes of inclusion. Currently Sandra has chosen, in order to feel secure, to limit the public spaces in which she participates, but she has clearly initiated, maintained, and developed reciprocal relationships with family, support workers, and peers.

In the course of this inquiry, lessons were learned from Sandra that could be explored further for similar individuals who are symbolic but nonlinguistic communicators. These are (a) understanding what makes interaction meaningful for those involved, (b) sharing that information with current and environment-specific network members, (c) providing a focus on developing social interaction, and (d) extending the social network.

There were two critical elements of meaningful interactions evident for Sandra. These were environmental influence and network members’ understanding of Sandra’s interactions. The two environments were the home and day centre, and each environment influenced her interactions. At home, she was most relaxed with her family around and interacted most flexibly. The stability of home support made a consistent approach easier, facilitated familiar routines, lessened anxiety, and promoted opportunities for enjoyable interactions. Attending a day service allowed a large number of possible interaction opportunities, often brief, but repeated. The unpredictability of the environment, however, was associated with more anxious behaviour, so not all interactions were positive.

Using strengths-based positive imagery was a helpful way for staff members to gain a framework for understanding Sandra’s communication; this
may be a useful technique in other similar situations. Learning how to interact with Sandra took time and both her spoken and non-speech communication required skilled interpretation that benefited from understanding the roles Sandra brought to the interaction. Her conversations were not conventional in form, but once the exchange between partners was established, it could support satisfying reciprocal interactions. The types of exchanges that proved satisfying for Sandra were those that enhanced social closeness. As Dennis (2002) noted, with good communication partners, understanding and learning to interact also requires relinquishment of control, a commitment to the interaction and focus on the interests of the partner—important elements to develop social closeness. Support workers who demonstrated some of these abilities developed enjoyable relationships and experienced reciprocity.

There was very little evidence of network members sharing information about Sandra’s interactions. As described previously, this was a dense but fragmented network and as Sandra’s communication was limited, it was important that that information was shared especially across environments. For example, experienced staff rarely facilitated interactions with new or less experienced staff members. In fact, staff members did not routinely share the way they co-constructed meaningful interactions with individuals with whom they worked, often seeming unaware of their own skills, or that their modes of interaction differed from those of other staff members. As meaningful interactions underpin possibilities for relationships, it seems critical to provide time for information sharing across environments and to reflect on interactional practices in order that network members can support an individual’s communication process.

Sharing information could be accomplished through discussion, training and/or modelling. Specialist staff, such as speech pathologists, when available, may facilitate making sense of the shared information. The benefits of sharing may develop staff skills and confidence, thus providing more and varied opportunities for social engagement with people with severe intellectual disability. In services where there is frequent staff turnover, or limited time for regular staff meetings, there is a danger that knowledge about individuals’ interaction preferences may be lost when network members leave. Although documenting the skills needed to interact meaningfully may be helpful, the value of sharing of information may lie in serving to increase understanding and, in Sandra’s case, led to a problem-solving discussion. It may be helpful to consider various ways information sharing can be tailored to be the most effective for the intended audience.

As the majority of Sandra’s preferred interactions were with staff members, interaction training would seem most appropriately focused on improving the day-to-day support she receives from relatively untrained support workers. Further, an emphasis on relationships and interactions may be best embedded in the everyday role of support workers. The results of this study indicated that rather than providing a focus for social interaction, the day service focused on providing activities or group programs and, wherever possible, these occurred in the community. The implication of this difficulty is that community activities may result in providing fewer opportunities for preferred social interaction, although an activity can provide a joint focus within which to share time. If the elements that contribute to having a good day are embedded in the interactions between select network members, then the interactions may be more important, per se, than the programmed activities. Meaningful interactions rely on an ability to read communicative signals accurately and respond appropriately. These abilities are unlikely to be demonstrated by people in the community; hence, spending time in these settings may not be the best option for all people with an intellectual disability. People like Sandra clearly benefit from frequent and brief interactions with a variety of familiar people in secure and predictable environments.

Given that paid and family network members find satisfaction in relationships with people like Sandra, there is reason to suggest that others may also enjoy their company. This suggestion opens up possibilities for extending the networks of people with severe intellectual disability by introducing unpaid community members, which could occur in familiar rather than unknown community environments.

Current networks are often environment specific, such as is the case for home or day service support workers. Attempts could be made to strengthen the support for an individual outside the family by setting up circles of support across environments (Falvey, Forest, Pearpoint, & Rosenberg, 1994). Circles of support include people who know the person with a disability well, but also offer opportunities for introducing new people into the network who may not have a paid relationship. Existing network members, if given the chance to reflect on their interactional knowledge, could contribute valuable information that can be shared with new potential network members. Critical to building new relationships is providing new network members with an understanding of who the person is and ways
to support interaction from which they can develop and derive their own unique positive relationships.

This study provides some important insights into how the process of social inclusion for people with severe intellectual disability might be supported. Service organisations could take a more direct role in practising person-centred approaches to promote relationship building. Inclusion is more than promoting activities that engage people in public spaces and community settings. Rather, it is the development of a rich personal network that, in the end, will facilitate social inclusion of people with severe intellectual disability.

Author note

This research was not funded and there are no conflicting interests.

Note

FN represents the field notes and the first observation session at the day centre.

References


Chapter 8: RESULTS AND FINDINGS

Overview of Chapter

This chapter presents the findings and the theoretical model developed in two publications. The first publication in the *Journal of Applied Research in Intellectual Disability* focuses on one aspect of the model - sharing the moment. The aim of this paper was to (i) identify social interactions between the people with severe intellectual disability and those with whom they have positive relationships and (ii) detail the nature of those interactions. The interactions comprised having fun and hanging out and contributed to mutually enjoyable relationships. The second publication in the *Journal of Intellectual and Developmental Disability* describes the entire model comprising five processes that underpin relationships. The aim of this study was to investigate the processes involved in positive relationships between people with severe intellectual disability who have limited communication and workers or family members, in order to understand how such relationships can be fostered. The first part is a publication in the *Journal of Applied Research in Intellectual Disability*, the focus of which is one aspect of the final model of processes underpinning positive relationships: sharing the moment. Different types of interactions between central participants and all personal affinity network members that contributed to mutually enjoyable relationships have been identified and described. The second part presents a model that demonstrates the five processes that underpin social relationships between adults with severe intellectual disabilities and a subset of the personal affinity network members: family members and paid workers. This paper is in press with the *Journal of Intellectual and Developmental Disability.*
Publication


Statement of Contribution

As co-authors of the following manuscript titled ‘Social interaction with adults with severe intellectual disability: Having fun and hanging out’ we confirm that Hilary Johnson made the following contribution: Hilary Johnson was responsible for writing the complete first draft of the manuscript. Associate Professor Jacinta Douglas, Professor Christine Bigby and Professor Teresa Iacono critically appraised the manuscript and Hilary’s subsequent revisions of the manuscript.

Signed: 

Date: 25/5/12

Associate Professor Jacinta Douglas

Signed: 

Date: 25/5/12

Professor Christine Bigby

Signed: 

Date: 25/5/12

Professor Teresa Iacono
Social Interaction with Adults with Severe Intellectual Disability: Having Fun and Hanging Out

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Background Social interaction is integral to social inclusion. Little is known about the nature of social interaction between adults with severe intellectual disability and those with whom they engage.

Method Participants were six adults with intellectual disability and people identified as those with whom they shared demonstrable pleasurable interactions. Data were collected through observation and interviews, and data were analysed using a constructivist grounded theory approach.

Results An overarching category of sharing time together with two main sub-categories of Having fun and Hanging out emerged. Having fun was composed of routines and comedic interaction; hanging out was comprised of contact and presence.

Conclusions Legitimizing mirth and sharing time in social interactions may supplement paid worker job satisfaction and increase opportunities for social inclusion by people with severe intellectual disability.

Keywords: adults, communication, severe intellectual disability, social interaction

Introduction

Social interaction is integral to the development of relationships, which in turn are important to people’s well-being (Duck 1995, 1998; Argyle 2001). Many adults with intellectual disability experience difficulty developing relationships, a problem exacerbated for those at the severe end of the spectrum who generally have limited communication (McLean et al. 1996). As a consequence, adults with severe intellectual disability may be at a greater disadvantage socially than people with mild intellectual disability. Furthermore, people with severe intellectual disability have fewer relationships, overall, than adults at the mild end of the spectrum; existing relationships have been found to be predominantly with paid workers and family (Krauss & Erickson 1988; Kennedy et al. 1990; Krauss et al. 1992; Kennedy 2001; Robertson et al. 2001). Unfortunately, paid workers have been observed to provide limited opportunities for social interaction (Hile & Walbran 1991; Markova et al. 1992; Scheps & Reid 1994). Interactions in congregate care have been described as brief and infrequent, comprising mostly instructions (Hile & Walbran 1991; Markova et al. 1992; Scheps & Reid 1994). Similarly, more recent studies conducted in day centres and group homes have revealed limited opportunities for social interactions between staff and service users. Paid workers have been observed to (i) control interactions (Antaki et al. 2007); (ii) use more instructions than questions (McConkey et al. 1999a); (iii) show difficulty interpreting the non-verbal signals of their clients (McConkey et al. 1999b; Finlay et al. 2007); and (iv) lack understanding of the extra time needed to interact successfully (Purcell et al. 1999).

Although information is available on the preponderance of instrumental interaction, little is known about social interactions between people with severe intellectual disability and their families and friends. The focus of this article is on social interactions; those that have ‘no obvious instrumental purpose’ (Finlay et al. 2008, p. 532) and are perceived as pleasurable. Enjoyable interactions have been reported by family members who
have positive relationships with adults with severe and profound disabilities (Taylor & Bogdan 1989; Bogdan & Taylor 1998). Similar reports have been made by friends, but little detail has been provided about the nature of their social interactions (Landesman-Dwyer et al. 1979; Newton et al. 1995; Jameson 1998). Landesman-Dwyer et al., in a study examining friendships, observed 208 adults with varying levels of intellectual disability from 18 group homes and found peers spent more time socializing with each other than with staff or visitors. They also found greater socializing between peers in dyads than with paid staff, and that social interactions were with chosen peers. Although this study provided evidence that adults with severe intellectual disability desired social interaction with each other, it did not shed light on how social interaction might be supported or facilitated for this group.

Social interaction involves sharing time together that is not always purposeful but is mutually rewarding (Duck 2007). For people without a disability, the most frequent types of social interactions include gossiping, small talk and sharing humorous exchanges (Goldsmith & Baxter 1996). It has been well documented that humorous interactions assist in developing relationships and that social closeness is enhanced when people share jokes and laugh together (Duck 2007; Martin 2007). For people with little or no formal communication skills, social interactions that are reliant on words, such as gossip, are problematic and it may be that other pleasurable non-verbal interactions predominate. Finlay et al. (2008) demonstrated how the use of playful games between paid workers and residents with profound intellectual disabilities promoted pleasure and social interaction for the residents. However, whether similar social interactions occur between adults who have severe intellectual disability and the diversity of people with whom they interact, remains largely unexplored in the literature.

Hence, overall very little is known about the nature of social interactions that facilitate relationships with people with intellectual disability. Hastings (2010) emphasized that, although support workers play a significant role in assisting people with intellectual disability to lead fulfilled lives, there has been little research focussed on theory development in relation to the formation of positive relationships between workers and people with intellectual disability. In-depth exploration of social interactions between people with severe intellectual disability and those with whom they have positive relationships offers the potential to provide insights into how such relationships develop and their importance. It may also shed some light on how paid workers can be encouraged to facilitate differing types of social interactions.

The data reported here are drawn from a larger study examining the role of communication within the social networks of adults with severe intellectual disability.

The aim of this article was to (i) identify social interactions between the people with severe intellectual disability and those with whom they have positive relationships and (ii) detail the nature of those interactions.

Method

Design and ethical approval

The larger study was exploratory with the aim of gaining insights into interaction, utilizing a constructivist grounded theory approach (Bryant & Charmaz 2007). Ethical approval for the study was granted through the Human Research Ethics Committees of the two Universities and one non-government organization with which the authors were affiliated.

Participants

Participants were six adults with intellectual disability (referred to as central participants) and others identified as people with whom they have a pleasurable relationship (see Table 1). Informed consent was obtained on behalf of all central participants with intellectual disability from their next-of-kin. All paid workers and family members provided their own consent. Peers with intellectual disability either consented themselves or consent was obtained on their behalf. All six central participants had intellectual disability and communicated at a symbolic, non-linguistic level. Only one of the central participants had a specified level of intellectual disability, identified as severe. Results from the Vineland Adaptive Behaviour Scales (Sparrow et al. 1984) indicated daily living skills were commensurate with extensive rather than pervasive support for all central participants. The term non-linguistic was used to describe communication in which conventional symbols were used (e.g. single spoken, signed or pictured words), but were not flexibly combined into novel utterances, thereby lacking ‘rule governed linguistic constructions’ (Fischer & Corrigan 1981, p. 263). This level of communication skill is synonymous with people with severe intellectual disability, who need ‘extensive levels of support in multiple adaptive domains’ (McLean et al. 1996). Hence, as a group, the central participants are described as adults with
severe intellectual disability with symbolic but non-linguistic communication skills.

All central participants had multiple impairments that included, in addition to intellectual disability, one or more of epilepsy, autism spectrum disorder, cerebral palsy, scoliosis and visual impairments. They were aged from 20 to 44 years; three lived at home and three in group homes; all attended day services in Victoria, Australia. Convenience sampling was used to select the first central participant, followed by theoretical sampling for maximum variation to select successive central participants (Morse 2007). Variation was sought by considering specific aspects, such as age, gender, vision, residential situation, family involvement, physical ability and peers as friends.

Other participants were those who had a positive relationship with a central participant. Positive relationships were defined as the central participant, showing pleasure in interactions and/or seeking out that person. The positive relationships comprised 22 family members, six peers and 29 paid workers. The paid workers included day support workers (DSWs), home support workers who went into family or group homes (HSWs), day programme coordinators (DOs) and group home coordinators (HOs).

### Table 1 Characteristics of central participants and positive participant roles

<table>
<thead>
<tr>
<th>Central participants</th>
<th>Age</th>
<th>Participants</th>
<th>Family members</th>
<th>Roles of paid workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sandra</td>
<td>20</td>
<td>Family members 4</td>
<td>Mother</td>
<td>Home support workers 3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paid workers 8</td>
<td>Father</td>
<td>Day support workers 5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Peers 2</td>
<td>Sibling</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total 14</td>
<td>Sibling’s partner</td>
<td></td>
</tr>
<tr>
<td>Brian</td>
<td>23</td>
<td>Family members 4</td>
<td>Mother</td>
<td>Home support workers 3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paid workers 8</td>
<td>Father</td>
<td>Day support workers 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total 12</td>
<td>Sibling</td>
<td>Day programme coordinator 1</td>
</tr>
<tr>
<td>Colin</td>
<td>27</td>
<td>Family members 4</td>
<td>Grandmother</td>
<td>House coordinator 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paid workers 3</td>
<td>Grandfather</td>
<td>Day support workers 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total 7</td>
<td>Aunts 2</td>
<td></td>
</tr>
<tr>
<td>Diane</td>
<td>44</td>
<td>Family members 4</td>
<td>Mother</td>
<td>Day support worker 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paid workers 2</td>
<td>Father</td>
<td>Day programme</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total 6</td>
<td>Aunts 2</td>
<td>Coordinator 1</td>
</tr>
<tr>
<td>Eric</td>
<td>24</td>
<td>Family members 5</td>
<td>Mother</td>
<td>Home support worker 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paid workers 3</td>
<td>Father</td>
<td>Day support worker 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Peers 2</td>
<td>Stepfather</td>
<td>Day programme</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total 10</td>
<td>Grandmother</td>
<td>Coordinator 1</td>
</tr>
<tr>
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<td></td>
<td></td>
<td>Sibling</td>
<td></td>
</tr>
<tr>
<td>Fayez</td>
<td>38</td>
<td>Family member 1</td>
<td>Sibling</td>
<td>Home coordinator 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Paid workers 5</td>
<td></td>
<td>Home support workers 3</td>
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<tr>
<td></td>
<td></td>
<td>Peers 2</td>
<td></td>
<td>Day programme coordinator 1</td>
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<td></td>
<td></td>
<td>Total 8</td>
<td></td>
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</tbody>
</table>

### Procedures

Data were collected for each central participant and those with whom they interacted by the first author over periods of 4–6 months through observation and interviews. Observations occurred over 239 h in a variety of settings, including family homes, group homes, day centres and community settings; each observation period varied in length from 0.5 to 3 h. The data were drawn from field notes taken during observations of the central participants, transcripts of interviews with those with whom they had positive relationships and, in one case, an email account. The first author predominantly utilized two participant observer roles: observer-as-participant and complete observer (Johnson et al. in press). Conversations between the first author and participants sometimes occurred during observations to clarify the first author’s understanding of interactions; these were recorded in field notes.

People who had positive relationships with a central participant were invited to be interviewed. The aim of the interviews was to supplement the information gained through the participant observations to understand more completely the social interactions with the central participant. Interview durations ranged from 30
to 75 min and followed an unstructured format. All interviews opened with the question ‘Could you tell me about your relationship with (name of central participant) and how communication in this relationship occurs?’ Two people had follow-up interviews, while the remainder participated in a single interview. The interviews were digitally recorded and later transcribed verbatim.

All 57 people, identified as having positive relationships with the central participant, were invited to be interviewed, and 51 were formally interviewed. Of the remaining six, one spoke insufficient English and five had insufficient symbolic language to enable their participation in an interview. One interview participant, with an intellectual disability, had difficulty with the unstructured format of the interview. Consequently, pictures were used to clarify responses and assist him to maintain focus.

Confidentiality was addressed by assigning pseudonyms to all named participants in reports or discussions. In addition, certain identifying data have been withheld or changed.

Analysis

All of the transcripts were read independently by the second author prior to analysis. A journal was kept to record insights from the data and literature in a form of memo-writing (Charmaz 2006). The data were entered into NVivo 8 (QSR International, 1999–2008), coded line-by-line, examined for in vivo codes (descriptive terms used by interviewees) and focussed codes developed. One of the key strategies applied during analysis was continued data comparison from the sources and across participants. Throughout the non-linear analysis process, the first, second and third authors met fortnightly to discuss coding categories, relevant literature and further questions to ask the data. Questions were applied to the data, such as ‘how is this the same or different for other participants and why?’ This process was followed until clear categories and sub-categories emerged, and data saturation was reached.

Questions regarding credibility, originality, resonance and usefulness were applied to the interpretations as part of the iterative process (Charmaz 2006). Credibility was established through discussions with the research group (all authors) during regular meetings and sharing these insights with people who had positive relationships with central participants. The insights provided by the rich descriptive data demonstrated originality and resonance and were honed and verified after three feedback sessions with people who interacted with the central participant. In addition, resonance with other colleagues was confirmed at four conference presentations.

Results

Social interaction with the central participants was situated in a shared moment (Sharing the moment) characterized by two processes: having fun together and hanging out (see Figure 1). Each category encapsulated subsets of interactions that supported the shared social experience. All central participants experienced aspects of having fun with paid workers, family and peers, while hanging out occurred mostly with family and peers. Mostly social interactions occurred within a dyad, but occasionally in a larger group.

Having fun

Having fun was short-term convivial encounters resulting in mutual fun. Interactions with central participants were characterized by laughing, experiencing enjoyment and/or sharing a sense of humour that clearly were important in their relationships. Family members and paid workers created opportunities for merriment and could identify an individual’s humour preference (e.g. general banter or slapstick). Diane would come home with ‘had a happy day’ written in her diary; a family member explained it meant her daughter had enjoyed listening to the staffs’ banter and gossip. Family members recognized the value of mirth and the impact on people when it was missing. For example, one family member repeatedly advocated for more fun in her son’s group home environment, stating in an email ‘He needs

Figure 1 Sharing the moment.
more fun, more laughter, more jokes, more shared experiences, more sense of belonging to an active, fun, energetic, engaged community. He needs to talk and joke and laugh and share with others". (EF3)

Family and paid workers commented that they drew happiness from observing the central participant having fun: for example, ‘we get joy to see her happy’ (DF12); ‘I have a lot of fun’ (CHO1); and ‘when we have fun together it’s great’ (SHSW1). Fun interactions were often short and not demanding. One family member noted the central participant alerted her to the fun that can be experienced in everyday activities: ‘he’s got a tremendous ability to enjoy the moment and to laugh at the moment and to find intense .. well, fun and engagement in the moment’ (EF3). Having fun consisted of different kinds of social interactions coded as routines and comedy. Routines were personalized and idiosyncratic interactions within dyads, while comedic interactions contained elements that could be identified as belonging to a broader comedic culture and were not restricted to dyads.

**Routines**

Routines consisted of repeated physical and/or vocal interactions, usually in the form of rhythmic play, games or songs or mimicry, resulting in mirth for one or both participants. Differing forms of routines were demonstrated across all central participants’ interactions with family and paid workers. Each participant had a unique set of routines that were not necessarily shared with everybody. The origins of routines initiated by central participants had often been forgotten. Frequently, routines were people-specific, with the central participant requiring a particular response. Some participants added a twist that increased the variety of routines (e.g. changing words or altering expected motoric responses).

Rhythmic play consisted of vocal repetition, either real or nonsense words, characterized by varied intonation and loudness. Rhythmic play occurred between central participants and family members and/or support workers. Enjoyment ensued when the partner provided the expected response. Three central participants incorporated rhythmic play into their interactions. An example of using repeated words with exaggerated pitch and tone changes occurred in a regular interaction between a bus driver and a central participant, which was usually but not always initiated by the central participant:

She’d say Paul, Paul, I’d say yes, yes all different tones, all different pitches … every now and then she’d say Paul, Paul and it would go on and I’d say Sandra, yes Sandra, what do you want Sandra and then she’d keep on Paul, Paul. And I’d say no and she’d burst into laughter. (SDSW4)

Some interactions needed to be initiated by the central participant, as indicated in the following quote from a HSW:

He tells us and says ‘pest’ and he’s smiling. Then I’ll say ‘big pest’, and oh you’ve made his day there, you call him a ‘big pest’. … He knows doing that, ripping the paper, he knows that he’s probably annoying … and he wants to be ‘hey I’m a pest’, ‘no you’re a big pest’ and he likes that. (BHSW5)

Two central participants initiated enjoyable nonsense word play with family members. One of Eric’s family members commented on the way rhythmic word play provided a way of connecting:

The other day he was sitting in the chair and he looked at me and laughed ‘bam way mama’ and I went ‘yam bad yamma’ and we did that for 4 min both laughing … he knew it was nonsense. (EF4)

Games and songs, also routines, were complete interactions in themselves, with a set format of turn-taking and ordered event sequence. These interactions, initiated by central participants, often consisted of well-rehearsed songs, rhymes or greetings, which were individualized by altering a word or action for further amusement. Sometimes, greetings were exaggerated and turned into simple games, such as when Colin commenced attending the day centre and the following occurred:

The programme coordinator enters the room and calls out to Colin ‘How are you’, waving across the room. Colin looks up and enthusiastically waves back and goes across to her. Then she does a high and low five with Colin. He joins in animatedly, with a beam spreading across his face (FN-C2).1

Colin had a similar greeting with another DSW who had added a novel twist: ‘With the bus driver he does high fives, low fives and the bus driver sort of fakes

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1FN represents the field notes; C the first letter of the central participant’s name and 2 for the 2nd observation session.
every so often and pulls his hand away so then Colin starts laughing’. (CDSW12)

Action songs featured in two central participants’ repertoires. Brian was popular with paid workers and he had been recognized at his day service’s annual general meeting for ‘his ability to put a smile on your face’ (BDSW8). He enjoyed songs involving physical interaction. He would initiate a favourite song of ‘row, row, row your boat’, by pulling a person’s arms towards him in a rowing action. A staff member changed the last line of the song to ‘put him in the washing machine’ because of Brian’s fascination with washing machines. Brian was delighted and waited with anticipation for the last line, sometimes inserting the word ‘machine’ if the DSW left an expectant pause. He would then laugh and repeat the request for the song with a rowing gesture.

Mimicry, another routine, differed to rhythmic play, and games and songs in that facial expressions and body language were copied and/or vocalizations echoed. Although all central participants demonstrated mimicry, only four used it in humorous interaction. Sandra’s mimicry elicited amusement in others as demonstrated in the following quote:

She does find it amusing mimicking people, which I love. I find it really good and she doesn’t just mimic, she mimics certain things like a laugh or a stance. The other day, like last Tuesday, her dad put his hands on his hips and I stretched and I went ‘Oooh’ like that, so that was more exaggerated, and she went ‘Oooh’ [laughs] yeah, I think its certain things she takes the quirkiness out of people’s personalities. (SHSW3)

Echoing vocalizations also provided the central participant with an entree into social interaction. Diane often vocalized loudly or mimicked a word she had heard. She appeared attracted to loud, high pitched or animated voices, and she would echo one of the words, amusing the paid workers: for example, ‘One of the DSW’s was talking and Diane started vocalising. When another DSW raised her voice and said ‘no, no.’ Diane also raised her voice too and said ‘no, no.’ One of the DSWs smiled across at her’. (FN/5D)

Laughter was another vocalization that was mimicked, but did not always indicate recognition of a humorous event. A family member commented ‘She used to laugh and they’d laugh but whether she understood what they were laughing at or whether she was just laughing because they laughed, I don’t know’. (DF13). Nevertheless, such laughter was bonding for the participants. A support worker commented on the positive effect of laughter on others, stating ‘He’s got laughter and a personality that’s very contagious’ (BDSW7). Another summed up the effects of laughter on others in the immediate environment by saying ‘It’s all about everyone is laughing and having a good time’. (DDSW14)

Comedy

Comedic interactions comprised several humorous forms in which all central participants engaged. Forms included vulgarity, pranks, jests and banter. Vulgarity arose from references to certain body parts or toilet humour. Pranks were more visual, such as practical jokes. Jests, a term coined by Freud (as cited in Bergen 2003), have been described as an early form of joking, indicating some linguistic understanding. Banter has been defined as ‘playful teasing language’ (Macquarie, 1981) and occurred usually between paid workers, but included central participants. Three central participants could initiate comedic interactions; the others were active respondents and joined in when other participants initiated a humorous interaction.

Five central participants found bodily functions, such as burping or farting, amusing, hence laughter ensued from saying the word related to a bodily noise (termed dirty words) or hearing the actual sound. Vulgarity was always initiated by central participants or brought to their attention by another. Fayez had a long-term relationship with a peer (Dean) in a group home. A house coordinator described Fayez’s response to an interaction that involved bodily noises:

Dean loves to burp and fart and that burping and farting, you know, Fayez finds incredibly … and there’s a running joke that’s been going on for years anytime Fayez burps, anyone within earshot will blame Dean and she finds that uproariously amusing. (FHO2)

Although paid workers and family did not always encourage this type of humour, the central participants laughed after hearing bodily noises and paid workers reacted positively to the laughter. The coordinator continued in the above extract by saying ‘… maybe Dean will burp and then Fayez will start laughing and that makes Dean laugh and … I enjoy sharing those experiences with them’ (FHO2)

Sandra liked to sit in the dining room of the day centre as there was a constant stream of people passing
through. The following field notes describe the central participant’s reactions to bodily noises of other clients in the same room:

Sandra laughed out loud at the banter, particularly when one of the clients accidentally hit his knee on the table and farted. She also seemed more animated perhaps enjoying the cadence of their voices. (FN/S2)

Brian enjoyed using dirty words in a game with his family, such as in the following example that occurred when he was cuddling his father. Some of the time, he vocalized saying ‘shit’ and ‘poo’ and trying to get Dad to say them back to him; when his father responded, Brian giggled. (FN/B14)

Not all comedic interactions were equally humorous for both participants in a dyad. In particular, the amusement generated by the use of dirty words was greater for the central participant than for the others. However, the laughter generated was enjoyed by everyone.

Pranks also resulted in humour. They relied more on visual than verbal humour, comprising practical jokes or slapstick. Practical jokes usually result in the recipient feeling foolish or embarrassed. Two central participants shared practical jokes with family members. Participation including initiating these jokes or laughing at the appropriate moment. These jokes focussed on common family activities and nurtured a sense of belonging. A family member recounted a practical joke that evolved from food stealing.

But we do it, all of us; we’d do it to each other. Even Mum, when we were having a meal, we’d be sitting there and we’d be going ‘there’s a spare potato over there, oh look’. Colin would sit there and go ‘he, he, he’. He’d giggle. It was just a family thing. (CF9)

Slapstick humour was enjoyed by four central participants. Television programmes that included home videos of people getting hurt were favourites. A HSW talked about the slapstick sense of humour shared between Fayez and another HSW, stating ‘Like they have quite a similar humour, like they both like to laugh at other people’s pain’. (FHSW8)

Another HSW suggested that Fayez’s preference for slapstick may have been related to the content being visual humour and not relying on verbal skills. Referring to Fayez, the HSW stated ‘She likes the slapstick humour, she seems to react to the slapstick kind of humour, like the really visual humour that doesn’t require much verbal communication’ (FHSW9).

Jests were a form of comedic interaction that were joke – like in that the content comprised verbal or visual humour in a story format. These jests were not in the traditional joke format – comprising an opening line that set up a humorous expectation, the main content of the joke and then finishing with a punch line (Martin 2007). Jests were one-off occurrences, unlike teasing, which was often a repeated activity. Jests involved the central participants sharing what they perceived to be amusing and relying on others to recognize incongruity in the story and perceive humour. Only Eric and Colin demonstrated that they could attempt to construct or respond to a jest that incorporated incongruity, as exampled by one of Colin’s paid workers, in the context of he and Eric squeezing each other’s biceps: ‘and said like, you know, look at that sort of, look at those guns … and he looked at me … and then looked at my gut and then patted my gut [laughs] …and with a wry smile walked away in front of everyone’. (CDSW13)

One of Eric’s family recounted an example of Eric’s awareness of verbal incongruity evoked during a meal at a restaurant with his family:

Eric ordered, thought he’d have death by chocolate, it was one of the desserts, and so we started joking about what a great way it would be to die, eating chocolate and he thought that was absolutely hilarious. (EF7)

The last type of comedic interaction was banter or jocular talk (Croser 1959). Although banter could be directed at one person, it often included others. Banter was initiated by paid staff and family members with five central participants. It was characterized by different vocal tones and inflections, and often exaggerated facial expressions, including winks or nods. Banter also included light-hearted teasing. Nevertheless, teasing, when initiated by central participants with peers, was not always enjoyed by both partners. Family members and paid workers never used teasing with Sandra. On the one occasion, Sandra was observed being teased by a peer and she became visibly upset.

An example of teasing/banter was described by a central participant’s family member. The interviewee reflected how her husband was a more preferred communication partner because of the way he ‘mucks around’:
They (her husband and Diane) do walk; go for walks of a night time, so it’s always about that. Look probably silly things like I might say to her, you know, ‘do you want a cup of tea?’ and she might not answer me, and I’ll say ‘if you’re not listening to me I’m not going to make you the cup of tea’, and my husband might say ‘don’t give her a cup of tea, give her a beer’. See she finds that really funny... Also ‘oh tell her (me) to shut up’, she’d finds that funny. (DF11)

Looking happy was valued by staff members, and attempts were made to increase mirth through banter. One paid staff member described her banter with a central participant, stating ‘I can be in there at times and she’s got this little sour look on her face and I’ll say ‘why have you got your cheeky bum face on for?’ And then she’ll start to laugh’. (DD03)

Teasing was most common among family members and also seen between people with intellectual disability. Teasing often included acts of trickery and sometimes resulted in the receiver feeling irritated. Teasing, unlike slapstick, rarely resulted in pain or physical discomfort for the recipient. At home, Diane liked objects to be in a particular place, noticing if anything had been moved. Her father teased her by re-arranging her medicines into an untidy line on the bench; she would react by vocalizing in annoyance at her father and pointing at the medicines. He would laugh, but she did not always find his actions amusing. One family member perceived the central participant spent all night planning a tease and gave an example of his teasing behaviour: ‘Well he might put out his hand and I’ll take it thinking he might want to get up and he’ll pull me over and that’s a joke’. (EF4)

Colin enjoyed teasing other people at his day centre. An example was the use of slapstick, whereby he would take away a chair just before a peer sat down. A DSW talked about how Colin liked to take a magazine away from a client, merely to get a reaction: ‘He knows how far he can go. He knows the reactions he can get and he, because she screams and squeals and squeals and you know, and he just absolutely loves that’. (CDSW12).

In summary, having fun was an integral part of social interaction. Routine and comedic interactions were enjoyable ways to spend brief periods of time together.

Hanging out

Although having fun was one way of spending time together, another valued activity was sharing quieter time, termed hanging out. This major category included activities that required spending non-demanding, pleasurable time together, involving varying degrees of physical closeness; these were subdivided into contact and presence. Sharing time was not about words (interactions were mostly nonverbal), complex interactions or elaborate activities, but had a spatial dimension involving different ways of communicating social closeness. The hanging out relationship was usually expressed in social interactions between central participants, family and friends. Only with Diane were paid workers included. All central participants initiated some physical contact when hanging out with family members, and Brian and Eric demonstrated the importance of close contact in peer relationships. For other central participants, physical closeness did not seem any more desirable than sharing the same space and/or a simple activity, such as watching television. The central participants actively chose to spend time with certain people, with some paid workers commenting that they chose activities according to the staff member that would be involved. Sandra, Eric and Fayez also had peers with whom they spent time in social interaction. Only Eric had peer relationships with whom socialization occurred across contexts: for example, at the day centre, going out for dinner and in his home.

Contact

Contact consisted of different physical forms and was demonstrated between each of the central participants and their families. Physical contact consisted of hugs and kisses, although this type was initiated only by Sandra. For Sandra, Brian and Eric, contact was extended to peers, varying from a whole body experience to simply holding hands. Sandra initiated holding hands with two male peers, but seemed equally satisfied to sit beside them without touching. Brian liked to hit people as a way of saying ‘hello’ and also spent time being physically close to others. A staff member commented ‘he’s a very tiny person but would just squish right in there and he’d be just in his element squished against people’. (BDO1)

Sometimes close physical contact was achieved through activity. Eric had a close relationship with a peer, John, characterized by playfully hitting each other as they passed by, holding hands and swinging them vigorously, and chasing each other but rarely exchanging gazes. Their physical interaction indicated their liking for each other and the recognition of the importance
of each other. It seemed they had no need for words as evidenced in the following field note:

Eric moved to sit on a chair between the two main rooms and John went and sat beside him. Eric did not turn to look at John. John looked at him from time to time smiling but Eric did not return the gaze. After a few minutes John got up and left. Eric continued to sit there. A few minutes later, John returned and sat down. He put his hands on Eric’s knee and vigorously shook his knee from side to side. Eric had a half smile on his face as if he was enjoying this interaction, but did not acknowledge John. (FN/E5)

At other times, Eric was actively playful with John, swinging arms together or hitting him on the head with an empty plastic bottle. It seemed to be a way of saying ‘hello’: Eric picked up an empty drink bottle and banged it playfully on John’s head. John laughed and Eric repeated this several times. (FN/E17)

Presence

All central participants sought out preferred company at certain times. Exuberant physical contact was not always necessary, but many interactions contained some forms of touch. Merely having a reassuring presence increased pleasure in hanging out. Sandra sat for most of the daytime in the dining room of a day centre. This vantage point enabled her to see people moving around the centre and opportunities to hang out with them. Brian would occasionally visit another room in the day centre just to sit near (but not beside) a young woman. Eric spent hours in close proximity with Betty, staring adoringly at her, while she pulled his nose, stroked his face and kissed him. In contrast, at other times, they both just needed to quietly spend time together and found comfort in each other’s company as illustrated in the following situation, in which Eric was agitated waiting for Betty to arrive.

Eric sees a bus arrive and stands by the door. Betty comes in, but somehow he’s looking up too high and she just passes by his knees and neither of them see each other. He comes back into the room and looks at me as if to say ‘where is she’? and I point to where she is and he turns around and doesn’t see her immediately. She’s standing there and she’s looking really sad. As he walked over to her she put her arms around his waist. They stand there for some time just holding each other. (FN/E5)

Eric also enjoyed hanging out with John and often moved to be near him. John needed personal space and usually sat by himself at the movies. However, once their relationship had developed, they sat side by side in the movies.

Fayez’s peer relationships did not involve physical contact. Hanging out together was just sitting quietly. For Fayez, time spent with Susan at the day centre was often in companionable silence, although Susan had good communication skills. At home, Fayez often sat separately from Dean but her acknowledgement of him was reported by one of the paid workers, who stated ‘if she’s coming down to the bathroom and goes past Dean, she’ll stop and Dean will come and give her a little sniff or something and I can tell that she, yeah, I think they have a special relationship’. (FHSW8)

Similarly, formal communication was not a feature of Sandra’s relationship with two peers. In fact, for one peer, Sandra’s lack of speech might have been considered a bonus. When the peer was asked what he liked about the relationship, he replied ‘just talking’ (SPI) as he seemed to enjoy talking when not being interrupted. Colin also seemed to like to be with others but did not necessarily seek out the opportunity to spend companionable time with people with whom he had positive interactions, as illustrated in the following anecdote from a DSW about attending a football match in which Colin moved from where he was sitting and sat next to a couple who was unknown to him: ‘and the bloke’s like, you know, and we went over and spoke to this bloke ….He said it wasn’t a problem, it’s Ok, and Colin sat there and watched the football with them for the day’. (CDSW13)

Diane had no peer relationships, but liked to be around people. She appeared to be happy to sit with her sister looking out of the windows for hours or watching TV with her. She also followed staff members on their tea breaks and sat quietly beside them.

Sharing time together by hanging out was a way of social interaction that did not rely on any formal communication skills but was an important aspect of family and peer relationships.

Discussion

Spending time together was illustrated through the process of sharing the moment. This process consisted of examples that illustrate the diversity of social interac-
tions between adults with limited symbolic communication and those with whom they have positive relationships. Although the data presented relate to a few adults with limited communication, the implications may be considered in relation to a broader group of adults who have limited formal and/or ambiguous communication, many of whom currently attend adult day services.

The social interactions comprising having fun produced mirth. Laughter, an outcome of having fun, has been recognized for encouraging people to bond (Martin 2007), thus encouraging social interaction. The types of mirthful encounters, comprised of routines and comedic interactions, appear to resemble the humorous interactions that emerge in early childhood (Tamashiro 1979; Bergen 2003). These interactions in the first year of life include games and mimicry; with wrestling, jostling and slapstick appearing around 2–3 years-of-age; and scatology, nonsense words and simple jests being produced by 4 years-of-age (McGhee 1979; Bergen 2003). Although all humour seems to originate within playful interactions, the growth of language skills allows endless permutations of humour including witticisms, irony and sarcasm (Bergen 2006; Martin 2007). As language skills are limited in adults with severe intellectual disability, the range of humorous forms are restricted. Nonetheless, the central participants in the study demonstrated creativity and variety in their attempts at humorous social interaction.

There is some evidence that children and adults with mild/moderate intellectual disability may prefer physical or visual humour rather than verbal humour, possibly because of the degree of language comprehension skills required for the latter (Brown 1994; Degabriele & Walsh 2010). However, there appears to be no research on humour experienced by adults with severe intellectual disability. Wyer & Collins (1992) suggested that humour might be the ‘fundamental ingredient of social communication’ (p. 663). If this is so, and sharing laughter and a sense of humour results in increasing a person’s likeability and possibilities for social interactions with others, then this aspect of social interaction merits further research.

The use of humour was not as prevalent in interactions between peers and central participants as it was in their interactions with family or staff members. Three of the six central participants had positive relationships with other peers. A characteristic of these relationships was hanging out together. Although most peers in the current study could engage in spoken conversations, their communicative exchanges with central participants were predominantly informal, involving facial expressions, body language and touch. Interactions were brief but repeated, and, overall, central participants spent longer periods with peers than with paid workers—a finding reflecting that of Landesman-Dwyer et al. (1979). However, most peer relationships were limited by location, with paid staff and families not encouraging or supporting them across locations. All but one of the central participants demonstrated an interest in connecting with other people with intellectual disability through physical contact or companionship. Given that peer relationships can cross locations without a confusion of role boundaries (unlike for paid workers), there is scope for future research to explore reasons for peer interactions not being actively encouraged. Such research could reveal strategies to support and extend opportunities for these relationships.

In recent years, there has been a focus on providing increased participation for adults with disabilities. One of the ways of achieving such participation has been the use of active support to influence staff practices to enable engagement and to ensure staff provide enough help to enable successful participation in meaningful activities and relationships by people with intellectual disabilities (Stancliffe et al. 2007; Mansell et al. 2008). Active support has been demonstrated as particularly effective for people with severe intellectual disability (Stancliffe et al. 2008). As adults with severe intellectual disability currently spend most of their time supported by paid staff, introducing a greater focus on social interaction into active support may increase social inclusion. Staff members need to understand how to support people to not only be more active and independent, but also to participate in social interactions to maintain and develop relationships.

In the current study, all paid workers who had positive relationships with the central participants were involved in repeated social interactions that were brief and mutually enjoyable. Rarely were these interactions the explicit focus of an activity; rather the focus was on a specific programmed activity (e.g. bowling, shopping). Social interaction may need to be seen as not only integral to many activities, but also as a meaningful activity or goal in itself. The consequence could be the legitimization of social interaction as an activity in which paid workers might engage with their clients with disabilities, and implementation of strategies to extend such interactions. Finlay et al. (2008) discussed how ‘playing a game’ provided opportunities for paid workers to socially interact in a manner that met the institutionally mandated imperative of staff being seen as involved.
partners. The authors discussed how the staff’s perceived need to be visibly active may result in routine games being repeated even when the person with intellectual disability appeared disinterested. Thus, hanging out, an activity in which people spend companionable time together in a mode directed by the person with an intellectual disability and on their own terms, may need to be similarly validated.

Because the research literature lacks examples of how social interaction with people who have limited formal communication skills occurs, the categories revealed in this article are suggested as a basis for further investigation.

For paid workers, one of the outcomes of positive social interaction was increased enjoyment at work. Although having fun is rarely an explicit requirement in the workplace, having fun and developing relationships have been identified as important life areas in the Victorian Quality Framework for Disability Services (Department of Human Services, n.d.). This framework requires services to demonstrate outcomes for service users in the areas including life enjoyment and well-being. Thus, within Victoria, there are not only ethical imperatives to ensure people have fun and develop relationships, but also practice ones. Nonetheless, standards and quality requirement outcomes do not ensure that all service providers develop strategies that provide individuals with intellectual disability opportunities for positive engagement. In fact, the absence of fun in one of the group home environments was poignantly expressed by a family member who repeatedly struggled to develop opportunities for positive engagement for the family member. The family focussed on supporting the staff to increase the range of activities, spend time interacting with residents, facilitate interactions between peers and utilize appropriate communication modes. However, this facilitator role remains ongoing for the family.

Overall, support workers have an increasing set of responsibilities for which many receive little training (Iacono 2010), and social interaction is not always seen as a priority. Nevertheless, as social inclusion is a broad goal for the disability sectors in the developed world, the employment of workers who can generate an enjoyable and companionable atmosphere for adults with severe intellectual disability is warranted. Maintaining and increasing positive interactions may be achieved by ensuring attention is paid to the types of social interactions a person with severe intellectual disability prefers, ensuring that the workers involved are comfortable providing a specific type of interaction, and that there are opportunities for interaction within a chosen activity.

Some paid workers experienced enjoyment from interacting through playful humour that matched the needs of the person with a severe intellectual disability. One observed trait among those with positive relationships was an ability to engage in a light-hearted manner, sometimes displayed as banter or joking. Similar to Newton et al.’s (1995) findings from studying relationships between community members and people with severe intellectual disability, some paid workers stated that they related to the central participants just as they would to other friends. Although family and paid workers in the current study were not always sure whether the content of words used was understood by the people with severe intellectual disability, the laughter that ensued promoted similar, repeated interactions. The laughter also signalled a relaxed environment, which may have been an enabling factor in encouraging interaction. Bergen (2006) discussed how playfulness between children and adults may provide a safe environment in which to explore interaction and suggested that ‘it is also likely that there are some personality variables that make both “playfulness” and “sense of humor” more prevalent in some children and adults (p. 153).

As the current study focussed only on positive relationships, it is not known whether staff who were less preferred would have been willing to adapt their style of interaction given instruction or mentoring. Observing interactions with less preferred others and studying the difference between the two groups could lead to a deeper understanding of positive social interactions and the discovery of additional ways to increase social interactions for people with limited communication skills.

Given the ageing workforce in Australia and a projected shortage of available disability support workers, emphasizing and supporting the opportunities for workplace satisfaction may assist in recruitment (National Disability Service, 2007; Infohrm Consulting Services, 2008). When recruiting new employees to provide individual support, specific social interaction skills may be sought that match the needs of the person with intellectual disability. However, as most support workers will support individuals with varying degrees of intellectual disability, training or mentoring in social interaction may need to be considered. Mentoring could be provided by those workers who already demonstrate positive social interaction skills, thus recognizing and acknowledging their skills. The promotion of having fun in social interactions as being as important as the broader activity may give permission to paid staff to spend companionable time with the people they
support. For some support workers, the ability to have fun while at work was appreciated. The expectation that participating in social interactions is a rewarding part of a support worker’s role may make the role a more attractive career choice. That possibility is suggested by a comment made by a paid worker after she was observed dancing as she interacted with clients: ‘they pay me to be a dag.’

**References**


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**Dag** is Australian slang for an ‘odd, eccentric or amusing person’ [The Macquarie (1981) Dictionary].


Publication


Statement of Contribution

As co-authors of the following manuscript titled ‘A model of processes that underpin positive relationships for adults with severe intellectual disability’ we confirm that Hilary Johnson made the following contribution: Hilary Johnson was responsible for writing the complete first draft of the manuscript. Associate Professor Jacinta Douglas, Professor Christine Bigby and Professor Teresa Iacono critically appraised the manuscript and Hilary’s subsequent revisions of the manuscript.

Signed: Date: 25/5/12

Associate Professor Jacinta Douglas

Signed: Date: 25/5/12

Professor Christine Bigby

Signed: Date: 25/5/12

Professor Teresa Iacono
A Model of Processes that Underpin Positive Relationships for Adults with Severe Intellectual Disability

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Keywords
Severe intellectual disability, relationships, adult, grounded theory, interaction

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Abstract

Background

Relationships develop through social interaction and assist with participation and inclusion. Little is known about how relationships develop between people with severe intellectual disability who have limited communication and others.

Method

Interactions were observed between 6 adults with severe intellectual disability and paid workers or family members with whom those adults had positive relationships. Workers and family members were interviewed. The data were analysed through a grounded theory approach.

Results

Analysis of the data led to the identification of 5 processes that underpin positive relationships: recognising individuality, sharing the moment, connecting, feeling good and sharing the message.

Conclusions

A relationship model with clearly identified processes and sub-elements provides a framework for teaching others how to have positive relationships with people with severe intellectual disability. The model could be applied in training to support relationships between workers and people with a disability and more widely with other community members.
People with an intellectual disability have an established right to social inclusion (United Nations, 2006). Central to increasing a sense of social inclusion is personal relationships. For people without intellectual disability, there is strong evidence that social support strengthens the development of personal relationships (Andersen, 1993; Duck, 1998, 2007; Kahn & Antonucci, 1980). Kahn and Antonucci (1980) defined social support as “interpersonal transactions” (p.266) that include aspects of aid, affect and affirmation. Aid refers to physical or instrumental support given or received, such as time, financial assistance and information. Affective and affirming transactions are emotional interactions that attribute respect and value to an individual. The concept of giving and receiving social support is known as reciprocity (Wellman, 1981). According to Heller, Price and Hogg (1990), the real or perceived exchange of tangible or interpreted reciprocity is integral to supportive relationships and provides feelings of “competence, esteem and a sense of belonging” (p.484). Although social support is reciprocal and integral to developing relationships, the reciprocal elements operating in relationships that involve people with an intellectual disability are much less clear. Considerable investigation of the relationships of people with a mild intellectual disability (Amado, 1993; Garvey & Stenfert Kroese, 1991; Knox & Hickson, 2001; Moore & Carey, 2005) attests to their difficulties with forming and maintaining robust social relationships. For people with severe intellectual disability, these difficulties are magnified; they have few social relationships, and these are predominantly with paid workers and family members (Kennedy, Horner, & Newton, 1990; Krauss & Erickson, 1988; Krauss, Seltzer, & Goodman, 1992; Robertson et al., 2001). A contributing factor for these people is communication difficulty (McLean, Brady, & McLean, 1996). As a result of limited
symbolic communication, they rely on the experience and ability of others to build relationships. Consequently, workers require skills in interacting with people and supporting them to develop relationships in the community.

There is little known about the processes that might assist the development of relationships for people with severe intellectual disability. Studies with a focus on relationships have included people with varied levels of intellectual disability and communication skills. Researchers have identified characteristics associated with positive relationships between family and/or workers, and people with severe intellectual disability (Bogdan & Taylor, 1998; Dennis, 2002; Jameson, 1998; Krauss et al., 1992; Newton, Olson, & Horner, 1995; Taylor & Bogdan, 1989). In four studies, interpretative methods were used, including focus groups (Dennis, 2002), interviews (Newton et al., 1995), and both participant observation and interviews (Bogdan & Taylor, 1998; Taylor & Bogdan, 1989); in two studies quantitative survey instruments were used (Jameson, 1998; Krauss et al, 1992). Characteristics of positive relationships identified in these studies were an acceptance of difference, and sometimes, the celebration of difference (Bogdan & Taylor, 1998; Taylor & Bogdan, 1989); trust (Dennis, 2002; Jameson, 1998); adjustment of communication style (Dennis, 2002); mutual respect (Bogdan & Taylor, 1998; Dennis, 2002; Krauss et al., 1992); perceived reciprocity (Bogdan & Taylor, 1998); and recognition of individuality (Bogdan & Taylor 1998). These characteristics, singly or together, have not been utilised to further an understanding of how to build and support relationships. The aim of this study was to investigate the processes involved in positive relationships between people with severe intellectual disability who have limited
communication and workers or family members, in order to understand how such relationships can be fostered.

**Method**

**Design and Ethical Approval**

A constructivist grounded theory approach was adopted to identify the processes involved in positive relationships (Charmaz, 2006). Ethical approval was granted through relevant Human Ethics Research Committees.

**Participants**

The participants were six adults with severe intellectual disability with symbolic but nonlinguistic communication skills (referred to as central participants), and the family members and paid workers with whom they had a positive relationship (see Table 1). In light of the difficulties in conducting direct formal assessments with people with severe intellectual disability, each central participant was assessed by the first author (speech pathologist) using observation, interaction and administration of the following informant measures: the survey edition of the Vineland Adaptive Behaviour Scales (VABS; Sparrow, Balla, & Cicchetti, 1984) and Triple C: Checklist of Communication Competencies (Bloomberg, West, Johnson, & Iacono, 2009). The VABS data indicated that all participants had a low level of functioning, with communication skills from the combined assessment data indicating skills commensurate with severe intellectual disability. Further, this combined information indicated that all central participants needed “extensive levels of support in multiple adaptive domains” (McLean et al., 1996, p.580). The term nonlinguistic is used to describe communication in which conventional symbols are present (e.g., single spoken, signed or pictured words), but not flexibly
combined into novel utterances, thereby lacking “rule governed linguistic constructions” (Fischer & Corrigan, 1981, p. 263).

Informed consent on behalf of each central participant with intellectual disability was obtained from his or her next-of-kin. Workers and family members provided their own consent.

All central participants had physical and sensory impairments in addition to intellectual disability. They were aged from 20 to 44 years. Three lived in their family home and three in small group homes; all attended day services in Victoria, Australia. Convenience sampling was used to select the first central participant. A purposeful sampling strategy in relation to specific typologies was then used to ensure maximum variation on dimensions of age, gender, vision, residence, family involvement and physical ability (Morse, 2007).

The other participants are referred to as personal affinity network members (affinity members). They were people who were observed to have a positive relationship with one of the central participants and met at least two of four criteria: (a) being named by the central participant when not the affinity members’ presence; (b) interactions with the affinity member were positive, and during which central participants showed pleasure (Forrester-Jones, Jones, Heason, & Di’Terlizzi, 2004; Kennedy et al., 1990); (c) an interaction and/or an activity with the affinity member lasted more than 15 minutes (Newton, personal communication, August 7th 2007); and (d) the affinity member had a special bond with the central participant or who had known him or her for several years (Krauss & Erickson, 1988; Krauss et al., 1992).
In total, 22 family members and 29 paid workers met criteria for network members following screening. Family members were aged from 18 years to 78 years, and
except for two (step-father and brother’s partner) they had known the central participants all their lives. The workers comprised day support workers (DSWs), home support workers who went into family or group homes (HSWs), day program coordinators (DOs) and group home coordinators (HOs); they had known the central participant from five months to over 10 years. In comparison with Australian disability workforce data (Martin & Healy, 2010), workers were similar in terms of age range and disability related qualification, but with a higher proportion being male (20% vs. 45%).

**Procedures**

The first author collected data for each central participant over four to six months through open ended interviews and observations in family homes, group homes, day centres and community settings. A total of 239 hours of observations lasting between 0.5 to 3 hours were conducted. The central participants’ interactions in daily activities were observed. Field notes were recorded when interactions occurred or immediately after. The first author predominantly utilised observer-as-participant and complete observer roles (Johnson, Douglas, Bigby, & Iacono, 2011). Interviews with 48 affinity members provided supplemental information. Three family members had insufficient English ($n = 1$) or limited speech associated with intellectual disability ($n = 2$), precluding their participation in interviews. Two people participated in follow-up interviews. Interviews were unstructured and were from 30- to-75 minutes’ duration. All interviews opened with the question “Could you tell me about your relationship with [name of central participant] and how communication in this relationship occurs?” The interviews were digitally recorded and transcribed verbatim.
Table 2.

Paid Worker Characteristics

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<th>Characteristics</th>
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<th>Coordinators (n = 5)</th>
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Confidentiality was addressed by assigning pseudonyms to all named participants.

In addition, certain identifying data have been withheld or changed. Unique three-part
alnumeraric codes have been used to identify affinity members (e.g. CDSW12, which represents the central participant’s initial + affinity member’s role + number).

**Analysis**

All transcripts were read independently by the second author prior to analysis. Insights from the data and literature were recorded in a journal as a form of memo-writing (Charmaz, 2006). The data were entered into NVivo 8 (QSR International, 1999-2008), coded line-by-line and examined for *in vivo* codes (descriptive terms used by interviewees), thereby allowing open and focused codes, and theoretical categories to be developed, as illustrated in Figure 1. A key strategy was ongoing data comparison from all sources and across participants. The authors came from the disciplines of psychology, speech pathology and social work and each had extensive experience of working with people with intellectual disability. Throughout the nonlinear analysis process, the authors met fortnightly to discuss coding categories, relevant literature and further questions, such as “How is this the same or different for other participants and why?” This process continued until clear categories and sub-categories emerged and data saturation was reached (see figure 1 for details).

Charmaz’s concepts of credibility, originality, resonance and usefulness were part of the methodological process (Charmaz, 2006). Credibility was enhanced through regular discussions between the authors. Further credibility was gained through three feedback sessions, attended by 41 people who had regular interaction with central participants, including 14 affinity members, during which the usefulness of insights gained from the descriptive data were discussed. Originality and resonance with other colleagues was confirmed during discussions following each of seven conference presentations.
Figure 1 Example of a Coding Category. Recognising Individuality

Quote

"Sense people who are likeable characters and they like to interact with"

"Engaging with whom ever, the social butterfly"

"She would be a party girl for sure"

"He'll do anything to get your attention"

"He's very concerned with other people's well being"

"He doesn't require a lot of hard support"

"She's demanding, she’s a perfectionist"

"She does what we would all like to do"

"She’s a little princess"

"The lioness attacking me"

When he gets upset his family refer to this behaviour as coming from the “evil twin”

In vivo code

Social butterfly

Being social

Being likeable

Empathic

Easy going

Controlling

Princess

Lioness

Evil Twin

Open code

Focussed code

Theoretical category

Recognising individuality

Being self determined

Free spirit
Results

Five processes supporting positive relationships were identified from the data: *recognising individuality, sharing the moment, connecting, feeling good* and *sharing the message*. A model was developed to reflect a combination of and interactional nature of processes underpinning positive relationships, and is presented in Figure 2. It is not clear whether the processes occur sequentially or simultaneously.

**Recognising individuality**

Recognising individuality was founded on the affinity members’ perceptions of central participants’ attributes or qualities that symbolised their individual personalities. “Character” was frequently used by affinity members to describe the central participant holistically, as a unique individual. Having character was seen as a positive and attractive attribute that encouraged spending time with a central participant. A worker commented “I tend to be spending more time with him than the other three. I think it’s just because of his personality” (BDSW9). The attributes that signalled individuality were not always conventionally attractive, often comprising the opposing qualities of *being likeable* and *being self-determined*.

**Being likeable.** Likeability was associated with recognition of the central participants’ inherent sociable and empathic natures: for instance, someone who is “willing, he doesn’t require a lot of hard support to initiate things” (EDO2). Sociability was perceived when central participants were observed to have frequent social interactions with a range of people and epithets such as a “social butterfly” or “party girl” were applied. Central participant interactions that appeared to demonstrate genuine
caring and consideration for others also signalled likeability and individuality. Family members remembered and valued empathic moments, often when someone had been in distress or unwell. One family member recalled the actions of her grandson, Colin, when she told him she was unwell, saying:
“‘Nanna’s not feeling well’”, … I heard him in the kitchen. I’d said “‘where’s Poppa, tell him Poppa, I’d like a cup of tea’”. Anyway I heard cups going and I said, “‘Oh Colin doesn’t touch the electric jug or anything, or the hot water.’” Anyway he came in and his little hand was shaking with a cup of cold water with a tea bag. (CF18)

**Being self-determined.** Affinity members also acknowledged more challenging characteristics of central participants, typically including being self-determined, tenacious and goal-directed, sometimes with little regard to other people’s needs: Affinity members acknowledged and remained positive about the individuality expressed through awkward or difficult interactions. One worker affectionately described a central participant as a “Casanova” when he greeted unfamiliar women by putting his arm around their necks and gripping them tightly, sometimes scaring them. Another worker attributed her enjoyment of a central participant to him being “a sweet person” and “charismatic,” despite recalling an upsetting incident that exemplified his strong determination. She reported

> We had an instance with some duck poo, and he really wanted that and we didn’t want him to have it because we knew it was going to go in his mouth, so another DSW just put her foot on it. He was there for ages and ages and he was absolutely determined and in the end, the DSW had to remove her foot and let him do what he wanted to do. (CDSW12)

Overall, affinity members demonstrated appreciation of central participants’ individuality through recognition of attributes that served to characterise them as complex and multi-faceted, with attractive, admirable and/or curious qualities.
Recognition came from observing the individual with others, listening to each other’s stories, participating in social interaction and spending time together.

Sharing the moment\textsuperscript{1}

The process of sharing the moment consisted of having fun and hanging out, which captured the experience of immediate and mutually enjoyable social interactions. Each element consisted of subsets of interactions. All affinity members experienced aspects of having fun, but mostly family members experienced hanging out.

**Having fun.** Laughter and a shared sense of humour were important to the relationship. Fun interactions were often short and undemanding, resulting in delight or joy. One worker attributed her enjoyment of work to a central participant’s ability to “put a smile on your face” (BDSW8). Having fun included routine social interactions and comedy. Routines were personalised and idiosyncratic interactions, including rhythmic play, games and songs, and mimicry, while comedic interactions contained four comedic typologies; vulgarity, pranks, jest and banter.

**Routines.** Routines were repeated physical and/or vocal interactions, occurring in a variety of forms of pleasurable rhythmic play. Each participant had a unique set of routines that were not necessarily shared with everybody. One worker discussed how she had developed her own rhythmic play interaction based on a central participant’s playful interaction with others: “[I] see other clients teasing him and pulling him, and you hear

\textsuperscript{1} F1 A broader discussion of this process that includes peers, family members and workers can be found in Johnson et al. (2012).
him yelling and making that ““ah”” sound, that’s what I found really funny and I thought
“‘I’m going to imitate that’”(BDSW10).

Comedy. Different forms of comedic interaction appealed to different affinity
members. Although vulgarity (references to body parts or toilet humour) appealed more
to central participants than affinity members, the laughter that ensued was contagious, as
exemplified by one worker: “maybe Dean will burp and then Fayez will start laughing
and that makes Dean laugh and I enjoy sharing those experiences with them” (FHO2;

Pranks were amusing tricks that resulted in the recipient feeling silly or
embarrassed, and sometimes incorporated slapstick humour. These pranks were more
common between family members and central participants, and often consisted of
amusing context-specific family routines; for example

Dad used to do the teaspoon with all of us and then he started doing it with Colin.
He’d stir the cup of tea then he’d “‘tch’” on your hand [gesture of tapping the
tea spoon on the back of the other person’s hand]. Colin would start getting it and
then Colin learnt to do it back. He’d stir his tea and then watch and he’d a couple
of times got [Gran] dad back before [Gran] dad got him. It was like “‘Ha ha, I got
you first’”. (CF8)

As with jokes, jests had a story line, but usually incorporated visual humour,
requiring less abstract understanding than formal jokes. One worker described a jest that
developed from comparing arm muscles:
So I’m like oh yeah. So I then squeezed his arms and then flexed mine …and said like, you know, look at that sort of, look at those guns, and he looked at me, and then looked at my gut and then patted my gut [laughs] and with a wry smile walked away in front of everyone. (CDSW13; Johnson et al., 2012)

Banter relied on speech, so was always initiated by affinity members. It was characterised by exaggerated vocal tones and inflections, physical gestures and facial expressions. Content included light hearted chat or throw away lines designed to produce a smile or a laugh from the respondent. An example from a family member was “She loves when I go [gesticulates wildly] … Like they’re here and watching the footy and I’m saying ‘stop yelling out’ and ‘ohhh’ she’s going, so I do it a couple of times to get her, she likes that” (DF12).

_Hanging out._ Hanging out involved mutually satisfying interactions that were less intense than having fun. These social interactions were mostly expressed between central participants and family members, and involved spending non-demanding, pleasurable time together with varying degrees of physical closeness. They fell into two distinct types: **contact** and **presence**.

**Contact.** The central participant usually initiated physical contact. One family member commented that as they had been separated for a 10 year period while growing up, she let her sister initiate a need for physical closeness, stating “She’ll lift her arm up …she’ll say ‘come here’ and hug you and she’ll start rocking you” (FF16).

**Presence.** Relationships with central participants involved affinity members being in close proximity and providing a comforting presence. The central participants
who lived in group homes regularly visited family members, usually staying overnight. Family members discussed how they spent unstructured time either together or separately. One family member remarked that since she had been unwell, she had missed seeing her grandson regularly and how he was no trouble to her as they happily co-existed. She said, sadly, “There’s no way they’re going to let me have him back home again full time” (CF8).

Sharing the moment interactions appeared to support relationships and encouraged opportunities for discovering more about the central participant. In this way it was evident that recognising the individual and sharing the moment were closely intertwined.

**Connecting**

The process of connecting appeared to strengthen and sustain the bond between an affinity member and a central participant. For example, a worker stated, “If you relate to him as well and relate sincerely, that builds a relationship and he connects with you. If you don’t relate sincerely, he doesn’t connect” (EDO2). The connecting process fell into two main categories: **providing security** and **adjusting the message**.

**Providing security.** To connect with central participants, affinity members provided security through trust and respect, a sense of belonging and practical care. Family members also provided love. Workers highlighted a link between communication and trust. One worker stated that the development of mutual trust had helped the central participant to demonstrate speech skills, previously displayed only at home: “it took a little while and I think it was more just getting to know each other and him getting to know me and to trust me because he speaks to mum a lot”(BDSW8). Respect arose from
recognising a central participant’s specific needs. In relation to a central participant’s challenging behaviour, a worker said “I think we have a mutual respect, like I truly respect her need for space because I am not someone who likes being crowded” (SHSW2).

Affinity members also perceived that nurturing a sense of belonging enhanced feelings of security. One family member ensured that the male central participant had a specific niche in a predominantly female family by introducing quintessential male topics, such as guns, into conversations in order to provide a sense of camaraderie. He said, “Eric likes guns and no-one in his family likes guns” (EF7).

Family members talked about ways in which they loved the central participant. One encapsulated the relationship by saying “The word that comes immediately to me with Eric is love. And I think he’s secure in knowing that I love him” (EF4).

Affinity members helped the central participant to feel secure and connected with him/her by providing quality practical care, including support for everyday activities. A central participant’s brother said, “She’ll always sort of come to me or whatever. She knows that she can rely on me for stuff like that” (SF3). The elderly parents of one central participant stated they were the only ones who could adequately provide the routine care required to support their daughter; they perceived respite care services as failing because “they don’t do things the same” (DF13). Workers also understood the importance of quality practical care, with one worker commenting

I think it’s really important that she feels safe, whether that be using equipment or just feeling that she’s not going to be hurt by someone; all of those things. Not
feeling threatened, not feeling um pressured to do things, yeah, I think that’s what safety might be about. (FHSW9)

Affinity members recognised that their interactions with central participants were improved by providing both physical and emotional security. By adjusting the message, they also demonstrated an understanding that specific support of communication assisted their connection with central participants.

Adjusting the message. Affinity members were observed to adjust the way they communicated in order to connect more effectively with central participants. A paid worker stated “So it’s kind of me adjusting to him rather [than] him adjusting to me. That’s how I felt it would work better for him and me” (BDSW6). Central participants also adapted their messages, although they had fewer strategies. For example, when Eric used a sign that was not understood, he located and pointed to a photo.

Although many affinity members reported that the central participants understood everything that was said to them, they nevertheless adjusted their communication to compensate for comprehension difficulties. This adjustment involved simplifying their language, repeating the message, allowing extra time for an interaction, predicting routine requests, and asking questions that required a simple yes or no response. One worker talked about keeping her utterances short in order to keep the person’s attention: “It’s clear language, I think, with her, as in short and precise, you know you go on and on about, because she loses concentration, so it’s got to be simple and short, short language” (DDSW14). A family member talked about having multiple strategies and knowing how and at what point to adjust his communication, stating “With Sandra you always speak a bit slower because there’s no point racing through something. Even if she understands, it
takes a little while to process it” (SF3). The repetition of information was also widely used. One parent said, “I guess we’d be more repetitive. Maybe a little bit slower” (BF1).

Affinity members were more likely to use informal than formal augmentative communication strategies to clarify communication and strengthen their connection. Family members rarely used augmentative strategies but most paid staff used a few basic strategies, such as objects, key word signs and gesture, and pictures or photos to help the central participants convey their message. An example from field notes shows how a worker used objects to clarify the central participant’s choice of milkshake flavours: “Diane said something that was interpreted as chocolate. She was then shown a choice of objects, the chocolate sauce or the strawberry sauce and she reached out for the strawberry” (FN/2D).

Connecting was a two-way process that involved both parties providing reciprocal trust and respect, and also adjusting their message. Some affinity members felt there was more they could be doing to build connections. A worker emphasised the importance of using a range of communication techniques, but was aware that this did not happen routinely:

If we communicate properly with Eric we would all know his signs, and we would all use pictures much more frequently with him and we would all wait for him, and …probably supply him with many more choices in his life. (ED02)

**Feeling good**

Connecting, recognising the individual and sharing the moment resulted in a relationship in which all personal affinity members felt good. This positive emotional
response promoted an interest in re-engagement. Feeling good was perceived in different ways, including *happiness*, *satisfaction* and *feeling special*.

**Happiness.** The only reciprocal emotion shared by all participants was happiness. It ensued from sharing time together and having connected relationships. One family member said, “we get joy to see her happy” (DF12). Similarly, workers commented on how the central participants’ enjoyment triggered their own positive feelings. One worker said “The sheer delight that she has sometimes, on something on television or something like that, it just makes me laugh” (SHSW2).

**Satisfaction.** The satisfaction workers derived from the relationship stemmed from successful one-to-one interactions, having variety and challenges in their work, and learning new things about themselves, which also provided motivation. A worker said “Money’s not my motivation of staying here ’cause I can get more money somewhere, but it’s just I relate to them[2] and they know me and we’ve been having all this” (EDSW11). Another worker stated “You don’t know what he’s going to do. Every minute is totally different. So you just sort of go ‘wow’” (CSW12).

**Feeling special.** Relationships with central participants could lead affinity members to feel special. Several workers reported feeling privileged to have a relationship with a central participant and talked about how feeling special resulted from being singled out at times because of their ability to understand this person’s

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2 F2 Referring to a central participant and his two friends with severe intellectual disability
communication. One worker said “So he will come to me to open the kitchen door because he knows that I know he wants to get in there. Somebody else might not know what Brian’s doing there” (BDSW8). Another worker reported an increase in ability to interpret the central participant’s complex behaviour. She said, “It is the privilege of just working with someone for many years and I think that’s probably why other new workers have problems” (SHSW1). The term “privilege” also suggests a sense of being rewarded, sometimes only in the form of a facial expression, with one worker noting “It’s a special thing to see” (FH02). Feeling special meant more than being satisfied at the end of the day; it signified being selected over other people and rewarded for putting in extra effort.

In summary, positive interactions made both affinity members and central participants feel good. When ties between workers and central participants developed, the workers felt privileged and special, and this encouraged them to share the central participants’ message with others. Sharing the message provided a pathway through which other social network members could learn about the central participants’ interactions and further their appreciation of his or her uniqueness.

**Sharing the message**

Sharing the message consisted of *taking responsibility* and *spreading the news*, and contributed to encouraging others to engage with the central participant. As many affinity members were restricted to one context (e.g. day support workers at the day centre), conveying information that might assist network members in different contexts presented a challenge.
**Taking responsibility.** Affinity members took on the responsibility of maximising the success of the central participant’s interactions. Family members emphasised the importance of having information strategies that transcended individual workers and contexts as they struggled to interpret the communication of a son or daughter. One parent stated she took on a “heavy burden of responsibility” in trying to communicate effectively with her son, describing the process as “like playing high stakes charades” (EF7). She further stated

> If I’m not in the moment of understanding what’s been going on in his life, it’s very difficult. That’s why communication between members of Eric’s community is very important, in fact it’s critical, ‘cause without that sometimes we’re all up against it, trying to understand him” (EF7).

It was uncommon for workers to check their interpretation of a central participant’s communication or clarify communication difficulties with others. One worker, for example, reported being worried about misunderstandings, stated

> “Sometimes he’d say ‘yes, yes’ sometimes say ‘no’ you know, because the whole day you, I don’t know if anybody else does, but the whole day I sort of think, I wonder what he’s talking about”(EDSW11). Workers, particularly HSWs, who frequently worked alone, often lacked opportunities to share information. Workers who took responsibility for conveying information usually had designated coordinating positions. Generally, family members would persist for longer than workers in clarifying communication attempts or in trying a broad range of strategies.

**Spreading the news.** Sharing an individual’s rich history and experiences, and documenting communication skills, involved passing information: that is, sharing the
news with others. Both spoken and written modes were used, with paid staff showing a preference for word-of-mouth. One coordinator described how a parent would phone her in the evening if a central participant was struggling to tell her about something that had happened during the day. She commented, “As the staff would walk out the door they’d say to me ‘if Diane’s mum rings it’s because Diane saw this or she saw that’” (DDO3). Other affinity members preferred written documentation of idiosyncratic communication skills, with one worker developing a booklet of gestures and meanings. She talked about how she shared this knowledge with other workers: “I would be saying that he’s got some basic signs that are important to him, which we’ve got that little book up, you know and to have a look through ‘my book’” (CHO1). Other workers in the group home who were not affinity members usually asked for help, rather than referring to documentation. News books containing daily (or weekly) information about the central participant’s activities were used to convey information (in the form of text or photos) between homes or services. One family member reported she had used the news book to solve a communication difficulty with her son, commenting “That’s why his diary is so important from [the day centre], and often we can get somewhere from that” (EF3). Workers also commented on the importance of talking to family members, with one stating “They filled in the gaps for us” (CDSW13).

When affinity members from one context or activity took responsibility for sharing information with others, it resulted in more successful interactions and potentially more relationships for the central participant. Strategies that took time (such as writing news) were used less often by paid staff, who preferred to leave a message with another
staff member or communicate by phone. Direct conversation provided the richest way to share information, encouraging others to share the moment and recognise the individual.

Discussion

The model described here illustrates the processes that underpinned positive relationships in which family members and workers developed their relationships with adults with severe intellectual disability. The processes of supportive relationships were drawn from different data sources, interviews and extended observations, providing complementary methods to verify the data (Johnson, et al., 2011). The result was a nonlinear model of discrete, but overlapping processes that were individually robust, as presented in Figure 2. As the relationships were studied after they had commenced, the order in which the process occurred could not be established. In fact, in each relationship, the processes varied in order, intensity and frequency. The greatest impact of this work comes not from these individual components or the order in which they occur, but from viewing the model as a complete entity, which provides a roadmap for strengthening relationships. Some individual elements have been identified by previous researchers, providing additional credence to the grounded nature of the data. New elements also have been revealed.

*Individual elements that enhance relationships*

Elements, such as recognising the individual and applying a positive spin to less attractive behaviours, have been identified in this and previous research as integral to accepting relationships and recognising an essential humanness (Bogdan & Taylor, 1998; Taylor & Bogdan, 1989). For example, in recognising the individual, there is a pair of
key, yet seemingly oppositional characteristics. This duality, being likeable and being self-determined, allows for people to be seen as rounded individuals with both endearing and challenging qualities. These key constructs clarify different ways in which a person may be appreciated and provide workers with a practical strategy by which to recognise individuality. The constructs add support to Klotz’s (2004) argument that people with severe disability can be accepted for who they are and their “particular actions and behaviours must be acknowledged and engaged with as legitimate, meaningful and purposeful” (p101).

The process of sharing the moment shows how engagement occurred through diverse types of social interactions that did not rely on advanced speech skills. Elements, such as vocal play and routine games, have been identified in the child development literature (Bergen, 2006) and applied through intensive interaction with people with profound disabilities (Nind & Hewitt, 1994), but previously have not been utilised with people with severe intellectual disability. The examples of routine and comedic interactions provide practical suggestions of ways to engage with people with severe disability (Johnson, et al., 2012). Having fun has been recognised as an integral part of all relationships, rather than confined to relationships involving people with disability (Duck, 2007; Martin, 2007). The value that affinity members placed on having fun together suggests fun needs to be clearly articulated as a potential avenue to positive interaction and developing relationships. Legitimising mirth may result in greater worker satisfaction, a clearer understanding of their role, increased social interaction and a more attractive workplace for new employees. A more complete discussion of the role of mirth in the workplace is reported elsewhere (Johnson, et al., 2012).
The process of connecting fostered a sense of security and adjusted communication. Trust and respect underpinned providing security. Trust has previously been shown to enable people with limited understanding and/or expressive skills to reveal their communication abilities (Dennis, 2002; Jameson, 1998). Further, Andersen (1993), in outlining the dimensions of a relationship noted that “To trust another is to make a relationship possible” (p.12). Respect has similarly been identified as a mutual connector in social support research (Antonucci & Akiyama, 1987), and has been promoted as key to successful inclusion for people with a disability (Finlay, Antaki, Walton, & Stribling, 2008; Wolfensberger, 1972).

Training workers to adjust their message has been a focus of improving interactions, but often without success (Bartlett & Bunning, 1997; Purcell, Morris, & McConkey, 1999). Affinity members recognised the need to adjust their communication style in the absence of prior individualised formal training, perhaps because developing respect for and enjoying social interactions with a person with severe intellectual disability sensitised them to the interaction skills required. All workers and some family members had some intermittent involvement with speech pathology services. Still, the extent to which access to such services facilitated the affinity members’ skills or whether developing a relationship encouraged adjustment to communication style requires further investigation.

The processes of sharing the moment, connecting and feeling good provided interpreted emotional reciprocity. These results are in line with reports of reciprocity in the disability literature on social support (Bogdan & Taylor, 1998; Newton et al., 1995). Tangible reciprocity was not reported by affinity members, but they were clearly
rewarded through job satisfaction or feeling happy and special, which were possible drivers to sharing the message. Many family members took on greater responsibility than workers for facilitating the central participants’ communication. Perhaps workers interacted in the here-and-now, in a similar way to the central participants, while family members’ deeper emotional involvement and sense of responsibility resulted in a greater investment in the central participants’ enduring happiness. Nonetheless, other workers, such as coordinators and program managers, took a more active role in sharing the message with families and across locations (e.g. day service to group home) which may have been due to the responsibilities inherent in their roles. Further research is needed into the skills, roles, expectations and responsibilities of paid staff in relationship building, thereby shedding light on how to extend relationships for people with severe intellectual disability beyond workers to other community members.

**Implications of a model for building and strengthening relationships**

Overall, this relationship processes model provides a framework from which to analyse current relationships and assist workers to develop skills in building and supporting relationships with people with severe intellectual disability. An investment in training workers in how to strengthen relationships could result in multiple rewards. One such reward might be workers continuing their relationships with people with disabilities after they have left the workplace in which those relationships were formed (Newton et al., 1995). The findings of this study also have application for building relationships involving people with speech difficulties associated with other forms of disability. Indeed, some aspects of the model bear close similarity to the development of relationships described in the social psychology literature (Andersen, 1993; Duck, 1998).
It would seem plausible, then, that the relationships of people with limited speech and intellectual disability might be found to have similarities to relationships between people with speech, thereby demonstrating a wider application of the model.

There are several limitations to this study that also suggest further areas of research. First, given that only positive relationships were studied, no conclusions can be drawn about the differences between people with positive relationships and those who have less positive relationships. Future research may also investigate the different worker characteristics by studying relationship motivations and dynamics of staff interpersonal behaviour. This model of relationship processes involved familymembers and workers only. It did not include friends without intellectual disability as none could be located. Further study is required into processes that take place between different types of relationships. Furthermore, translating this relationship process model into a practical training tool and trialling it in the workplace would assist in revealing its usefulness in promoting relationships in everyday situations and identifying any systemic barriers to be overcome.

Relationships consist of dynamic, continuous and complex processes that rely on communication and are products of personal experience (Duck, 1998, 2007). There remain challenges to fully understanding how to develop and strengthen a range of relationships for people with severe intellectual disability

Finally, it is contingent on policy makers and disability service organisations to ensure that the development of relationships is valued. Such valuing needs to be articulated to workers who can then provide practical support to build relationships for people with severe intellectual disability.
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References


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CHAPTER 9: DISCUSSION, IMPLICATIONS AND CONCLUSIONS

Overview of Chapter
The aim of this study was to investigate the processes underpinning positive relationships for people with severe intellectual disability who have limited communication in order to understand how such relationships can be fostered. The purpose of this chapter is to summarise the way in which the publications that comprise this study have contributed to the research aims, to discuss the social network roles relevant to people with a severe intellectual disability and the service implications arising from the research. These implications include (a) building the capacity of workers to facilitate social inclusion, (b) embedding a workplace culture that values relationships and (c) finding better ways to conceptualise the support needs of people with a severe intellectual disability. The chapter concludes with a discussion of the limitations of the study and directions for future research.

Contribution of Publications
During the research process, five papers were accepted for publication, with one still in press at the time of thesis submission. Each publication was developed for a specific purpose, had slightly different aims but all were directed at the overall aim of the study to better understanding social inclusion for adults with severe intellectual disability. The different aims and research questions in each paper reflect the process of a grounded theory approach and the questions that arose during that journey.
Maximizing Community Inclusion through Mainstream Communication

Services for Adults with Severe Disabilities

The first publication (Johnson et al., 2009) presented an overview of communication issues for speech pathologists working with adults with severe intellectual disability in Victoria, Australia. The paper had a primary aim of educating Australian speech pathologists about existing models of speech pathology service provision and communication interventions for people with severe intellectual disability to enhance community inclusion. As a result, it was submitted to the Australian speech pathology journal, International Journal of Speech-Language Pathology (IJSLP). In the wake of deinstitutionalization, people with severe disabilities are accessing services in their local community and relying on generic local services for interventions. Speech pathology service providers for adults with disabilities have often prioritised problems with eating and drinking over problems with communication. In addition, given that speech pathology undergraduates have ranked working with people with developmental disability as of low interest (Johnson, Bloomberg, & Iacono, 2007), there is a need to increase speech pathologists’ understanding of the challenges and rewards that can be gained from supporting the communication of people with intellectual disability.

The lack of focus on providing communication support to people with lifelong disabilities in undergraduate speech pathology curricula is slowly changing (Balandin & Hines, 2011). This change has been driven, in part, by the revision of entry-level graduate speech pathologist competencies to include multimodal communication as an additional area of practice (Speech Pathology Australia, 2011). Multimodal communication encompasses augmentative communication, which is used commonly by people with severe intellectual disability. Hence, there is a need for speech
pathologists to become more aware of good clinical practice in the area of intellectual
disability and the role they can play in promoting social inclusion.

A search of the website of IJSLP using the term intellectual disability
indicated that this paper was the first publication on service delivery and approaches
to supporting adults with intellectual disability published in that journal. The lack of
professional publications on this topic may reflect the difficulties of obtaining
research funding to address issues of concern to this relatively low incidence group,
the complexities involved in researching them in light of their heterogeneity, the
demands of the process required to gain consent for research given they are
considered vulnerable, and/or the small number of professionals who work in this area
and have work capacity to establish an evidence base for their practice. These issues
suggest a need to promote research in the area of communication and severe
intellectual disability and reinforce the importance of my results in providing a basis
for future research.

The Pearl in the Middle: A Case Study of Social Interactions in an Individual
with a Severe Intellectual Disability

The second publication (Johnson et al., 2010) was a case study about the first central
participant in the study, Sandra, who had a severe intellectual disability, challenging
behaviour and an additional diagnosis of Autism Spectrum Disorder. The aims of this
publication were to present early results from my research in the form of a detailed
case study describing social interactions between Sandra and her social network
members. At the time of publishing, the criteria for selecting positive relationships
had been established, but the term personal affinity network members had not been
established, so the term social network member was used in this paper. The data were
drawn from observations and interviews with Sandra’s network members with whom
she had a positive relationship (then termed social network members), including two peers with an intellectual disability, as both peers could participate in interviews. The impact of the paper was in detailing the interactions of a complex individual with a severe intellectual disability, documenting the importance of using strength-based metaphors, and the emergence of concepts for describing relationship processes that were further developed after data collection with later participants.

The case study incorporated the use of a strength-based approach to data analysis, illustrated through the use of metaphors that gave rise to the process of recognising the individual. The practice of developing figurative metaphors (e.g., entertainer) and sharing with all Sandra’s network members the metaphors that arose from the interview data (e.g., lioness) suggested a useful technique for engaging the broader network members in thinking differently and recognising that person’s unique personality and strengths.

Other aspects of the relationships experienced by social network members included enjoying her company, love, personal satisfaction and feeling fortunate, with all but the last being further expanded on in the final relationship model. As there has been a dearth of case studies detailing aspects of relationships for people with severe intellectual disability, this case study makes an important contribution to the literature. The coding categories outlined in this publication were further developed in the later publications in this thesis, demonstrating the strength of using a grounded theory approach until saturation of data occurs, in order to develop a robust functional model.
The Challenges and Benefits of Using Participant Observation to Understand the Social Interaction of Adults with Intellectual Disabilities

The third publication (Johnson et al., 2011) was a methodology paper focusing on participant observation. This paper grew out of a presentation at an AAC conference, after which I was encouraged to further develop the paper for publication. The use of participant observation as a method has been under utilised in the health sciences area, perhaps because of the predominance of the quantitative research paradigm. Participant observation has been well established in ethnographic studies, with seminal studies in the published literature in which participant observation has been used to determine the meaning of interactions between children with severe and profound intellectual disability (Gleason, 1989; Goode 1994), but little concerning adults with severe intellectual disability and those who support them (Clement & Bigby, 2010; Hubert & Hollins, 2006; Reinders, 2010). It seems surprising that participant observation has not been used more frequently in research involving people with limited verbal skills who cannot be interviewed. For the current study, participant observation was helpful in establishing my credibility as a researcher with the people I interviewed and provided core information from which to base a textured analysis of interviewees’ responses. However, participant observation took considerable time and there were limitations as to where I could observe. For instance, participant observation is intrusive in small spaces or when participants are sharing intimate moments.

This article was identified as a high demand paper in the Informa healthcare newsletter produced by the journal publishers. In January 2012 it was ranked one of the two most read articles from their range of communication related journals. I hope that sharing the insights into the challenges and benefits of participant observation
will encourage researchers to consider this approach to data collection with a fuller awareness of the strengths and limitations involved.

**Social Interaction with Adults with Severe Intellectual Disability: Having Fun and Hanging Out**

The fourth publication (Johnson et al., 2012) illustrated one of the relationship processes - sharing the moment - from the perspective of all personal affinity network members (i.e., social network members with positive relationships). The key feature and strength of this paper was in defining different types of having fun and hanging out involvements in order to examine the way people spent time together, including peer-to-peer interactions. Having fun was experienced by all personal affinity network members and was a powerful motivator to repeat social interactions. Having fun has been recognised as an integral part of all relationships, rather than being confined to relationships involving people with disability (Duck, 2007; Goldsmith & Baxter 1996; Martin, 2007). Thus, fun needs to be clearly articulated as a valid positive social interaction and as a potential avenue to initiating and strengthening relationships.

The largest category of personal affinity network members was workers, who are thus an important group in terms of assisting people with severe intellectual disability to develop relationships. In addition, as people with severe intellectual disability age, they will spend more time being supported by paid workers.

Legitimising mirth in the workplace and providing organisational direction that acknowledges the importance of strengthening relationships between workers and the people they support has the potential to allow workers to feel justified in spending time in enjoyable social interaction. Social interaction may include simply hanging out together, something rarely seen in service environments. The paucity of time
spent hanging out by workers may have come about because they are too busy completing daily personal care tasks. Another reason may be a belief that simply sitting beside someone could be perceived by co-workers or supervisors as not being meaningfully engaged. Workers are affected by the cultural expectations prevalent within their organisation and rely on feedback from supervisors about valued social interaction practices. Thus, managers and supervisors need to acknowledge the equal importance of the two aspects of sharing the moment (having fun and hanging out) if social interactions for people with intellectual disability are to be openly encouraged.

If organisations provide training for their workers in understanding how to assist people with severe intellectual disability to develop relationships, the road to social inclusion can be said to have commenced. A first step in encouraging freely chosen relationships is for workers to recognise any current or budding friendships among peers and provide opportunities for those relationships to develop. It appeared from the results of this study that it is difficult for workers to arrange for people with severe intellectual disability to spend time together, if the people with intellectual disability did not live in the same group home. Part of the problem seemed to stem from workers being unsure of the importance of a specific relationship and, therefore, being unwilling to spend time and money on supporting the relationship. This situation is an ongoing dilemma for workers, as not all relationships progress to friendship, but unless there are opportunities to spend time together, relationships cannot develop.

The sharing the moment publication is an important paper because it presents various types of mutually enjoyable activities that can constitute social interaction for people with severe intellectual disability, which have not been documented previously. In addition, evidence that there is more than one way of spending time
together (having fun or hanging out) allows people to choose how to share time together. Establishing the validity of spending mutually enjoyable time in the workplace has the potential, not only to improve the quality of life of people with severe intellectual disability and their sense of social inclusion but also to make the workplace more satisfying for current employees and more attractive to new employees.

**A Model of Processes that Underpin Positive Relationships for Adults with Severe Intellectual Disability**

The final paper accepted for publication April 2\textsuperscript{nd}, 2012, presents a model of processes underpinning positive relationships in its entirety, consisting of five interconnected processes: *recognising the individual*, *sharing the moment*, *connecting*, *feeling good* and *sharing the message*. These processes form a substantive theory that developed from the research. The model illustrates how a subset of the personal affinity network members - family members and workers - engaged with people with severe intellectual disability, and defines the elements that strengthened their relationships. These relationships were shaped by the unique personalities of the central participants, the family members and the workers, the experiences they shared and the environments in which they spent time. In light of the fact that none of the relationships were observed from their onset, the order of the processes was difficult to determine. Still, the processes did not appear to occur in a particular order. Processes sometimes took place simultaneously and, although each process appeared in every relationship, individuals ascribed varying degrees of importance to different processes.

*Recognising the individuality* of the person with severe intellectual disability and *sharing the moment* were identified as important processes in attracting the
personal affinity network members to the person with severe intellectual disability.

Recognising individuality did not always involve interaction and occurred when a person perceived attributes or qualities that highlighted aspects of the character of the person with severe intellectual disability, sometimes revealing dualities that continued to manifest throughout their relationship. *Sharing the moment* involved mutual participation in activities and provided instant gratification to both parties involved. The enjoyable nature of these interactions often led personal affinity network members to recognise and discover more about the central participant and the two experiences fed back and forth, reconfirming the relationship. The process of *connecting* strengthened the relationship bond by providing a sense of security through which the relationship could grow and personal affinity network members deepened their connection with the central participant by adjusting the way they communicated.

*Feeling good* resulted from one or more of the previous three processes, sustaining the relationship and encouraging personal affinity network members to take responsibility for exchanging information or talking positively with others about the central participant. This process of *sharing the message* opened up the possibility of new relationships for the people with severe intellectual disability by engaging others in each person’s life.

**Contribution of the theory to practice.** The model reflects the experiences of family members and workers who supported people with severe intellectual disability. Given there is little research evidence on key social processes in strengthening relationships for people with severe intellectual disability, the model is a significant contribution to knowledge in this area. The social interactions between people with severe intellectual disability and personal affinity network members were
often challenging because of the limited verbal skills of the people with severe intellectual disability. Nonetheless, sharing enjoyable time together was pivotal to these relationships. If relationships are rooted in having fun together, they may be attractive to others outside the personal affinity network, thereby opening up the potential to increase the number of relationships for people with severe intellectual disability. The process of sharing the moment provides evidence of the types of social interactions that are integral to positive relationships. The frequent presence of enjoyable interactions evident in the results of this study suggests that relationships for people with limited speech and intellectual disability have significant similarities to relationships that occur more typically between people with speech, a finding which may have broad application. Thus, the outcomes of this study have potential to provide an evidence-based direction for relationship building between people with severe intellectual disability and others.

**Social Networks and Relationships**

I commenced this research by examining the relevant literature on social networks, hoping to learn about the ways in which people with severe intellectual disability experienced social inclusion through their social networks. According to Newton et al. (1994) social networks are “the most essential elements of, and indicators of, societal inclusion” (p.399). Once I began collecting data, I realised that for people with severe intellectual disability, like all people, the quality of the individual relationships was more important than the size of the network. For example, a person might have frequent interactions with a person with intellectual disability but if these interactions are not valued a positive relationship does not develop. Thus, I focused on examining mutual positive relationships and social interactions within the relationship dyad in order to understand what made such relationships work.
personal affinity network members included family members, peers with intellectual
disability and workers. All three groups played different roles in their relationships
with the person with severe intellectual disability, with the largest group of personal
affinity network members being workers. Workers play a major part in supporting
the daily experiences of adults with severe intellectual disability and therefore have
multiple opportunities to assist with social inclusion.

Relationships between Family Members and People with Severe Intellectual
Disability

Researchers have shown how the quality of life for people with severe intellectual
disability has been improved by the involvement of family members (Brodin &
Lindstrand, 2004; Grant, 1993). Although the discussion in this chapter on social
network members focuses on the role of workers’ relationships with people with an
intellectual disability, the importance of family was also evident in the results of the
current study. The family members provided love and long term enduring support
that enriched the lives of the people with severe intellectual disability. Family
members are less involved in day to day interactions once the person with an
intellectual disability moves out of the family home, but are likely to continue to play
an important role in providing a stable network as the person with intellectual
disability ages. Family members varied in their advocacy role around supporting
relationships with many parents mourning the lack of peer friendships for their son or
daughter.

Relationships between Peers and People with a Severe Intellectual Disability

In the literature the social networks of people with a severe intellectual disability have
been found to be generally lacking in friends, with or without disabilities (Kennedy et
al., 1989). I had hoped to explore relationships between people with severe
intellectual disability and friends without disability, but no examples could be identified during the six months I spent with people with severe intellectual disability. Sandra was reported to have had a friend, who used to be her teacher’s aide when she was at school, but he was no longer in regular contact. However, three central participants had friends with intellectual disability, each relationship having different levels of emotional intensity, with one central participant referencing two close relationships. The process of understanding how the relationships were perceived, both from the perspective of the person with severe intellectual disability and the friend’s perspective, was a complex matter. Four of the central participants’ friends had restricted communication skills, so interpretation of their relationship was largely reliant on participant observation and discussions with others who knew them well. The intensity or the repeated nature of their interactions demonstrated that these friendships were important but the relative importance of these relationships could only be surmised. Friendships are dynamic and some friendships may have been missed or misinterpreted in this study. For instance, workers identified some peers with intellectual disability who had seemed of interest to the central participants but when these peers were observed together, they did not meet any of the four criteria established as prerequisites for having positive relationships.

The established friendships brought immense pleasure to the central participants. These relationships were not always encouraged by other personal affinity network members. One central participant, Eric, had a special girlfriend, Betty, whom his parents included in family events or outings whenever possible. However, Betty’s group home coordinator did not believe that the relationship was important for Betty and actively discouraged it. Similarly, another group home coordinator talked about difficulties in organising transport and felt unsure about
spending the person’s money on fostering relationships about which little was known. With the exception of Eric, the peer friendships in this study were context-bound, taking place only at the day centre or in the group home. Some of the rich data on the central participants’ relationships with friends with intellectual disability was described in Johnson et al. (2012), expressed in the simple activity of hanging out together. As people with severe intellectual disability are often unable to articulate their need for friendship, it is necessary for others to be vigilant in noticing their preferences for certain individuals and to actively support opportunities to develop those relationships.

The data from interactions between the central participants and friends with intellectual disability were excluded from the relationship model because there were so few peers with intellectual disability who socially interacted with people with severe intellectual disability and the limited number of observed interactions. There were only six peers with an intellectual disability in the study and, although rich interactions between the peers and central participants were observed, neither party was able to reflect on their perceptions of their relationships (because of their disabilities). In addition, with the exception of one central participant, peer interactions were infrequently observed. By removing the peer data from the model, I avoided the danger of misrepresenting their relationships through researcher over-interpretation, but rather focussed on describing their interactions in one of the processes of the relationship (Johnson et al., 2012). The exclusion of the peer interaction data from the model and the absence of peers without intellectual disability in the research does not exclude the possibility of peers being personal affinity network members and benefitting from possible applications of the relationship model.
Relationships between Workers and People with a Severe Intellectual Disability

Paid support is crucial for people who have limited communication skills as they have few opportunities to independently socially interact or form relationships. Positive relationships between staff and people with severe and/or profound disabilities have been reported (Forster & Iacono, 2008) and in some cases relationships have endured after the worker’s employment ceased (Newton et al., 1995). However a tension exists in the disability sector as to what constitutes an appropriate relationship between workers and people they support. Many employers express concerns about paid workers developing relationships with the people they support and they may send their workers ambiguous messages about how to interact. A worker from one organisation involved in my study explained that the practice of rotating workers across services (i.e., across the different day services in an organisation or different groups within a day service) was designed to prevent people with a disability from developing expectations about accessing certain workers at certain times or places, thus discouraging them from developing a dependence on particular workers. In another organisation, workers were seen as transitory presences in the lives of people with disabilities. Discouragement of relationships between workers and the people they support was seen as protecting people with intellectual disability from experiencing frequent relationship disruption and resultant distress. As one worker said, “I’ve seen staff come and go and mess with clients’ emotions by pretending they are their best friend and they leave, and I’m always wary of that.” (FHO2). However, restricting the possibility of rich social interaction between workers and people they support may limit the satisfaction that both the worker and the person with disability could derive from a reciprocal relationship. Reciprocal relationships can be friendly
and respectful but many workers may need some direction from their organisations to
determine how best to develop and construct relationships with people they support.

**Implications**

In addition to discussing the impact of the publications that comprise the thesis, there
are three main service implications that can assist in furthering social inclusion for
people with intellectual disability. These are (a) building the capacity of workers to
facilitate social inclusion (b) embedding a culture that values relationships in the
workplace, and (c) finding better ways to conceptualise the complex presentation of
people with a severe intellectual disability.

**Building the Capacity of Workers to Facilitate Social Inclusion**

Specific professional development may need to be targeted towards increasing skills
to facilitate social inclusion. Although there have been no formalised approaches to
developing social interactions with people with severe intellectual disability, an
approach has been developed with people who have profound and multiple
intellectual disabilities (PMID), which is gaining an increasing research base. This
approach is Intensive Interaction (Nind & Hewitt, 2001) and is based on the fun
routines (games, songs, mimicry) that have been documented in research in both child
development and humour literature (Bergen, 2006; Mc Ghee, 1971; Martin, 2007).
Within the Intensive Interaction approach, these kinds of playful interactions are used
to promote social engagement for people with PMID. An adaptation of the Intensive
Interaction approach is the Hanging out Program (HOP), specifically designed to
enhance DSWs abilities to spend enjoyable time with people with little symbolic
communication (Forster, 2008). Using this approach, DSWs are given strategies to
initiate interactions and respond to subtle communication signals. Some of the
principles of intensive interaction that underpin the HOP program overlap with
elements found in sharing the moment: for example, having enjoyable interactions, copying sounds or actions, and playing repetitive games (Nind & Hewett, 2001). People with severe intellectual disability appear to share the same need to have fun as people with PMID, but are more able to initiate social interactions, either by a physical action or a formal means of intentional communication. Whether the HOP would be more useful for people with less severe disabilities than for those with PMID is not yet known. It may be that the HOP could be extended, or integrated into more generalised relationships training, utilising some of the more formal word games from the current research.

A more holistic approach than the HOP would be to translate the model from this research into a useful workplace tool, and develop a practice framework. Training workers in a practice framework in how to implement the processes that underpin positive relationships could result in people with severe intellectual disability developing new relationships, some of which may be with people outside the service sector. Unfortunately within Australia, due to funding restrictions, people with severe intellectual disability access the community in small groups which limits the possibility of forming new relationships. Researchers have commented that, rather than promoting social inclusion, the group approach places an invisible barrier around the people with a disability and their paid workers and provides a “distinct social space” (Todd, 1990, p.215). Thus skilled workers need to identify ways in which an individualised approach might be managed when supporting each person within a group. Training in the processes that underpin relationships could strengthen the intermediary role of workers and hone their skills in assisting others to share the moment and have brief positive interactions. Regular brief interactions between people with severe intellectual disability and community members, such as shop
keepers, receptionists, or other regular customers are ways that could open these social spaces. Having fun comprises many short interactions, such as a high five, some of which are already acceptable in community settings. If paid workers are familiar with and understand a person’s ways of interacting, they may be able to support brief encounters that will increase the person’s social interactions and provide a step towards social inclusion.

**Embedding a Workplace Culture that Values Relationships**

Although the disability sector has embraced the concept of social inclusion, the actions that need to be undertaken in order to facilitate relationship building for people with intellectual disabilities remain unclear. Clement and Bigby (2010) have discussed how the distinct lack of focus on developing relationships and social inclusion has resulted in poor work practices. My research findings provide evidence for developing practices to enhance and strengthen relationships. An overarching aim for the disability sector would be to ensure that members of senior management within each organisation recognise and mandate for the critical components of relationship building to be embedded in a social inclusion role for their workers.

The cultural change would need to be incorporated not only into the organisational mission and vision, but into job descriptions and performance management at every level of the organisation, according recognition to the role played by workers in facilitating social interaction and inclusion. Many workers remarked on how feeling good was one of the reasons they remained in the job, with comments such as “they pay me to be a dag” (Johnson et al., 2012, p.12) and “I love these guys” (DDSW14) and if this part of their job is valued in the workplace, greater stability in the workforce may be promoted.
Finding Better Ways to Conceptualise the Complex Presentation of People with Severe Intellectual Disability

People with differing degrees of intellectual disability have diverse and distinct needs. Detailed descriptions of these differences, as reported in research, are needed to ensure that broad policies can be translated into practices to support potential relationships involving people with varying degrees of intellectual disability: that is, so they can be dedifferentiated to take account of those differences. In addition, paid workers need to be able to recognise the different levels of support required across individuals with intellectual disability and be able to adapt the ways in which they provide support.

One issue apparent from my research was the absence of any frame of reference through which to understand how a person with severe intellectual disability might present. Although there has been a move away from using labels to describe people, there is a compelling argument for developing and applying terms that do not only describe research participants but also signal to workers the necessary level of support required. Luckasson and Reeve (2001) discussed the importance of naming—“applying a specific term to something or someone” (p.47) - but at the same time being aware that the label does not have precedence over recognising the individuality of the person or seeing the person first. Descriptive labels can help us conceptualise the functional abilities and needs of those with whom we work. Some of the terms used in the existing research to describe the level of impairment of a person, such as severe intellectual disability, do not appear useful to the people who support them. In this study, the search for central participants with a severe intellectual disability elicited a baffled response from both workers in day programs and speech pathologists. This response is not surprising, considering the variety of conditions
associated with having a severe intellectual disability (Arvio & Sillanpää, 2003) and the broad range of skill levels encompassed by the term severe intellectual disability (McLean et al., 1996).

The form and complexity of expressive communication may be one type of descriptor necessary to help delineate how a severe intellectual disability impacts functionally in interactions. McLean and McLean (1996) identified people with severe intellectual disability as predominantly having symbolic skills but in some cases having difficulty in flexibly combining symbols to form novel utterances. Thus, for this study, I selected people who had a severe intellectual disability and limited symbolic expression (single words, pictures and/or signs) describing the communication skills as symbolic and nonlinguistic, not a familiar term for people in the disability sector but one that encapsulated expressive communication skills as maximally consisting of one or two word utterances. Using this selection criterion resulted in the communication domain on the adaptive behaviour assessment showing the least variation of the three domains and confirming the similarity between central participants.

It is challenging to find words that are respectful but accurately reflect a person’s support needs. Advocates of person-centred practices state individualised approaches are needed and grouping people together who are already marginalized and excluded only devalues them further. However, having no simple descriptive ways to discuss the capacity of people also denies them the types of support they need. To some extent, the severity of the impairment can be mitigated by providing appropriate supports but in order to do this, the level and type of impairment needs to be clearly identified. There is a need for new labels or new ways of recognising specific needs which if met will provide the person with a better quality of life. Until
we have better labels to describe capacity there is a need to train workers to understand what the label of severe intellectual disability entails, as it can act as a sensitiser to the type of supports needed and give an entrée to group needs. For workers and for research purposes other labels may also be useful and one which describes the form and complexity of expressive communication may be one type of descriptor required to delineate the functional impact of severe intellectual disability.

**Limitations, Strengths and Future Research**

The limitations, strengths and directions for future research are discussed together as many of the limitations of the research have concomitant strengths, with implications for future research. Two limitations were identified in the recruitment process: the length of the process and issues relating to consent. Locating the central participants was more time-consuming than expected, due to the difficulty that service providers had in understanding the descriptive terms “severe intellectual disability” and “symbolic but nonlinguistic communication”. These concepts were not only difficult to interpret for managers in disability services but also for speech pathologists and families, causing them to put forward possible research participants who did not meet the study criteria. The process was lengthened by ethics constraints that required written consent for the involvement of the people with severe intellectual disability in the study, prior to my assessment of their suitability. Consent needed to be sought from parents or guardians as central participants were unable to give their own consent. Since gaining consent from guardians could be a lengthy process, I selected central participants who had a family member who could provide consent. This decision resulted in all networks containing at least one family member, which was both a limitation but also a strength, as family members were a rich source of information. Future research is needed to explore the networks of adults with severe
intellectual disability who have little or no contact with family members. One possible cohort includes those who lived much of their lives in institutions and lost contact or were abandoned by family members. Another group involves people with disabilities who outlive their family members.

As little was known about relationships for people with severe intellectual disability, a qualitative and exploratory research methodology was adopted. A grounded theory approach was chosen, constituting a strength of the research process, but with limitations in regard to the generalisation of results. Grounded theory allowed for different modes of data collection, for example, observation and interviews that enabled triangulation and ongoing comparisons of data across participants that resulted in a robust model. The development of a model lays the groundwork for future research following either quantitative or qualitative methods. Participant observation was a strength of the study in that it allowed (a) the observation of interactions that included people who could not be interviewed as a result of lacking speech, and (b) the establishment of researcher credibility for those who could talk before the interview process began. However, observations were time intensive, with the total process requiring over two years. The time required for ongoing observations restricted the location of central participants to my home state, which further restricted participants in terms of receiving services from the same service system, albeit delivered by both government and nongovernment sectors. In addition, participant observation was emotionally demanding as it involved balancing the need to collect data with the need to ensure the safety and comfort of the participants and researcher. A study of this type requires an extensive time commitment, with the potential for adequate funding a limitation.
Despite the time requirement, prolonged engagement was a strength of the study. The researcher spent 239 hours observing the 57 personal affinity network members interacting in a variety of settings, including family homes, group homes, day centres and community settings. In addition, 52 interviews with the personal affinity network members, added richness and veracity to the observational data. Another strength was the variety of the central participants, who were selected to represent a range of differences among people with severe intellectual disability. An obvious limitation was the inability of central participants to contribute their opinions through interviews, but extensive observation provided an alternative form of data collection. Only three of the six peers could be interviewed and only three of the six central participants had peers with intellectual disability as friends. Further research is needed to identify friendships between peers and to investigate service practices that can facilitate the development of relationships between peers with intellectual disability.

There were no friends without an intellectual disability, which was a limitation of my research. The unique perspective of people without a disability who choose to have relationships with people with severe intellectual disability may have added a different dimension to the data. As there has been so little published research on friends of people with severe intellectual disability, further research would be beneficial in understanding the relationships between adults with severe intellectual disability and friends both with and without an intellectual disability.

Another limitation inherent to the study was the involvement of only those people who were identified as having positive relationships. Because only positive relationships were studied, no conclusions can be drawn about how relationships might differ between people with positive relationships and those who have less
positive and even negative relationships. The reasons why some social network members are preferred over others are not well-understood. Studying the differences between preferred and non-preferred relationships may shed light on the reasons for preference and strengthen the current model. Examining all the relationships in a social network, rather than limiting the focus to personal affinity network members, would broaden the scope of the research and has the potential to add processes or elements to the relationship model and/or reinforce or refine other processes.

A research direction not pursued in the current study relates to the characteristics of the workers. All workers evidenced enjoyment of having uncomplicated fun with people with severe intellectual disability. It may be that certain workers have characteristics that predispose them to enjoy relationships with people with severe intellectual disability. An investigation of these characteristics may be useful in staff recruitment processes and to enhance staff retention. Studying worker characteristics may involve studying relationship motivations and dynamics of staff interpersonal behavior or investigating how people develop attachments and their own attachment styles.

Further research is needed in understanding the impact that the stability or otherwise of social network members has on the people with severe intellectual disability. As each networks was only studied for up to six months data could not be collected on the effect of stability of network members. Family members found dealing with different staff a constant challenge in terms of information sharing. There was no indication that staff changes were of concern to the people with severe intellectual disability, who readily engaged with new workers in interactions (although worker resignations were only relevant to two people with severe intellectual disability). Only a longitudinal study of relationships could show how
stability or instability affects the strength of relationships for people with a severe intellectual disability.

A major strength of the study was the substantive model of processes underpinning relationships that opens future avenues for research. Although the model may have application to other people with communication impairments, further research with specific groups is needed to confirm the transferability of the model. Individual aspects of the model, such as adjusting the message, could be further investigated. This component was an important aspect of the connecting process, but much of the literature points to the difficulty workers have in adjusting their communication, even after training. Clearly it would be useful to better understand how people in positive relationships learn how to adjust their messages. Further research to reveal how people adjust their message may help speech pathologists to target communication training in a timely and specific manner.

Further research is also needed to identify successful modes of sharing the message in order to increase successful interactions. As written information seemed the least preferred mode of transferring information, understanding time efficient techniques that help to share the message might assist in helping to build and broaden the range of relationships in an individual’s life.

Although the model provides a road map of processes in positive relationships, it is not yet a practical tool. Future research that incorporates mixed research methods would be useful in order to translate the model into a practical workplace tool. Quantitative measures could include investigating changes in the quality and quantity of interactions, while in-depth interviews with workers would increase an understanding of the perceived usefulness of the model. In addition, the identification of service barriers and facilitators would assist in understanding how a
quality relationship framework can be utilised in daily practice. If the results from this research endorsed the fit of the relationship framework, a trial of the framework with paid workers dealing with people with different disabilities (e.g., acquired brain injury) who have limited communication skills could be conducted. The results of these proposed studies would provide evidence-based data for developing training materials, in order to facilitate training in the development of relationships. It would then be possible to investigate whether increased positive relationships lead to social inclusion.

**Concluding Statement**

Over the past 15 years in Victoria, most of the institutions that used to house people with severe intellectual disability have been closed and people have been moved to small group homes in the community; this change has been reflected in similar changes throughout the western world. The initial expectation that this move would of itself give people with severe intellectual disability the benefits of community participation and social inclusion have been dismissed as romantic folly and the serious quest for social inclusion has begun.

Governments, in the western world, have developed policies to enhance social inclusion. However, the principles of social inclusion are still aspirational, with relatively meagre guidelines on how to support people with intellectual disability to be socially included. In order for policies to have an effect, they need to be translated into practices that support people with severe intellectual disability in the community. There is an abundance of rhetoric but an absence of models that show how to include people with a severe intellectual disability.

As relationships are integral to social inclusion and develop through interaction, I commenced by studying the social interaction involved in relationships,
taking into consideration Clegg’s words (2010): “We need to have a different way of respecting the inherent humanity of people with ID: not just different versions of ourselves because they are themselves” (p.15). In order to start afresh, I chose an exploratory framework and adopted a grounded theory approach to reveal the processes underpinning supportive relationships for adults with severe intellectual disability. The first inklings of a theory began to emerge after the initial coding of the data from the first participant with severe intellectual disability. As further data were collected and analysed, it became apparent that unique discoveries about the ways in which communication occurred between the personal affinity members and central participants were being made, but that there was also a bigger picture waiting to be revealed. The emergence of a five part model of relationships, encompassing aspects of communication embedded in relationship processes, represents a new way of looking at what occurs in social relationships and provides an important step in promoting relationship building for people with severe intellectual disability. Although some of the aspects of the theory are not new, this research has revealed processes that interconnect to form a complete model. In order to establish this model into a framework for everyday practice, further research questions need to be addressed. Nonetheless, there is an immediate priority to inform disability services and government about the existence of the model and its potential for application.

A practical application of the relationship model will provide a basis from which to build social inclusion for people with severe intellectual disability, requiring service organisations to incorporate practices that encourage the development of relationships for people with severe intellectual disability. Strategies to encourage relationships can be commenced by factoring opportunities for social interaction into everyday practices and providing a different focus on relationship building in
induction and professional development training. This change in focus is likely to result in the increased job satisfaction of paid workers and an increased quality of life for people with severe intellectual disability.
REFERENCES


Clement, T., & Bigby, C. (2009). Breaking out of a distinct social space: Reflections on supporting community participation for people with severe and profound intellectual


Dennis, R. (2002). Nonverbal narratives: Listening to people with severe intellectual disability. Research and Practice for Persons with Severe Disabilities, 27, 239-249. doi: 10.2511/rpsd.27.4.239


development. *Urban Policy and Research, 22*, 315-322. doi:
10.1080/0811114042000269326

*Qualitative Inquiry, 3*, 202-221. doi: 10.1177/107780049700300204


staff and residents who have severe or profound mental retardation. *Research in

speech events in social and personal relationships. *Human Communication Research,

*Quality of life: Perspectives and issues* (pp. 41-57). Washington, DC: American
Association on Mental Retardation.


intervention for persons with profound disabilities: A Swedish perspective.

retarded persons: A comparison of two methods of obtaining information about
communicative behaviour. *Mental Handicap Research, 6*, 112-130.


Hostyn, I., Petry, K., Lambrechts, G., & Maes, B. (2011). Evaluating the quality of the interaction between persons with profound intellectual and multiple disabilities and


Life's for Living. (2008). What I’d like you to know about me. Adelaide, Australia: Author


Smidt, A., Balandin, S., Reed, V., & Sigafous, J. (2007). A communication training programme for residential staff working with adults with challenging behaviour: Pilot


APPENDIX A: STAFF INFORMATION

DETERMINING THE ROLE OF COMMUNICATION IN THE SOCIAL NETWORKS OF ADULTS WITH SEVERE INTELLECTUAL DISABILITIES AND COMPLEX COMMUNICATION NEEDS”.

This project aims to provide information on the role of communication in the development of social networks for people with an intellectual disability. This project has been approved by La Trobe Human Ethics Committee and Scope Ethics committee.

I am looking for participants (clients) who
• Are aged between 20-50 years
• Have a severe intellectual disability
• Live at home or in a group home
• Have contact with one or more family members

The participants will have the following skills:
• Vision within normal limits
• Can hear normal conversation
• Can recognize up to 50 photos/pictures and may use these to communicate
• Can speak and/or sign less than 50 single words (stage 5 or 6 on Triple C)
• May walk independently but may use a frame or a wheelchair

I am happy to visit you and your staff to provide a short information session to explain the study. I will also give you information sheets and consent forms for participants and next-of-kin. I would like you or staff members to identify possible participants and send the written information about the project home with each potential participant. I would appreciate if you can make a follow-up phone call to clarify any questions that may arise. The next-of-kin will need to send consent forms directly to me.

Once I have received the consent forms I will organise with the participant to look at some pictures together to ensure the participant meets the communication criteria for the study. I would like to do this in a quiet room with a staff member who knows the participant well. I may require some background information on the participant such as age, diagnosis, any communication assessments or reports.

I will also need to know information about the participant’s daily timetable, observe the participant in her/his daily activities and accompany her/him on any
community visits. During the study, social network members who are staff members or other clients may be identified as part of the participant’s social network. Where this involves staff members I will need written consent from each staff member in order to collect data. I may also ask to interview staff, video them during interactions and take their photos.

Where social network members are other clients, I will give information and consent forms and stamped addressed envelopes to a key staff member to be sent home with a client. Written consent will need to be posted back to me.

I do hope you will consider my request and look forward to spending time with your staff and clients. If you have any questions please phone me on 0417126 471,

Regards
Hilary Johnson – principal researcher
APPENDIX B: INFORMATION SHEET FOR CENTRAL PARTICIPANT’S NEXT-OF-KIN

Project Title
DETERMINING THE ROLE OF COMMUNICATION IN THE SOCIAL NETWORKS OF PEOPLE WITH SEVERE INTELLECTUAL DISABILITIES AND LITTLE OR NO SPEECH.

Introduction
My name is Hilary Johnson and I am a PhD student at La Trobe University. My supervisors are Dr Jacinta Douglas, primary supervisor, in the School of Human Communication Sciences and Dr Chris Bigby, secondary supervisor, in the School of Social Work and Social Policy. I also have an external supervisor Dr Teresa Iacono, from the Department of Developmental Disability Health Victoria, Monash University. The following information is provided for you to decide if the person with a disability wants to participate in my project. I am collecting information on communication in several social networks. For the purpose of this project a social network is one made up of people who are liked by a person with a severe intellectual disability who has little or no speech.

Reason for doing this project
Many people with severe intellectual disabilities have difficulty communicating. I want to learn more about their social networks and how people within a person with a disability’s social network deal with the communication difficulties.

Participants needed for this project
I have spoken to staff at the day centre who have sent this information on to you. For this project, I am looking for an adult with a severe intellectual disability who will be one of the central participants in this project. Specifically I am looking for adults with severe intellectual disabilities who
• are aged between 20-55 years
• live at home or in a non-government group home
• have contact with one or more family members
• have a severe intellectual disability

They will have the following skills:
• Vision is within normal limits
• Can hear normal conversation
• Can recognize up to 50 photos or pictures and may use these to communicate
• Can speak and/or sign less than 50 words
• Can walk independently but may use a frame or a wheelchair

What does being involved in this project mean for the central participant
I need to spend time with all the people the central participant meets or knows. This means I will spend time in the central participant’s home, go out with her/him on all activities and watch the central participant interact. I will make written notes and may take videos or photographs if she/he agrees.

What I will do at the first visit (about 2 hours)
This visit is to make sure she/he meets the criteria for the central participant. I will meet her/him for no more than two hours in a quiet room at her/his day service where she/he is
comfortable. You are welcome to be present or someone else who knows the central participant well. First I will explain the research and will talk with her/him about what is going to happen using an information form with pictures. Once the central participant appears to be comfortable with me being there and is enjoying the activities we will look at some objects and pictures together. We will do the following tasks:

- We will look at 10 common objects for example, cup, spoon, comb, along with photographs and matched with a line drawing. She/he will be asked to respond to the questions “give me or show me the …?” If s/he can recognise pictures we will do the second task.
- I will find out her/his vocabulary level on the Peabody Picture Vocabulary Test – 3rd Edition. I will show her/him a page of four black and white line drawings and ask her/him to point to one: for example “show me the ….” I will keep turning pages and asking the same questions until he or she is unable to correctly identify 8 pictures.

I will ask you or someone who knows the central participant well if she/he has had a Checklist of Communication Competencies (Triple C) completed. This is a checklist of communication behaviours, which may already be in her/his file. If it has not been completed I will ask two people who has known her/him for over 6 months across different environments (for example at home and at the day service) to complete the assessment. I can help if any of the questions seem difficult. In this way, I can make sure the central participant has some basic communication skills that will enable her/him to participate in the research.

I will also need to get some background information from you or someone who know her/him well. The background information I need will include the person’s age, her/his type of disability and the main language spoken at home. I would also like a list of the activities she/he is involved in and places she/he goes regularly. I will then make a convenient time with the central participant to commence observing interactions. If she/he does not fit the criteria for the research I will explain the assessment results to you and thank you for your and the central participant’s time.

I would also like to know will if there is anyone the central participant likes but does not see regularly (for instance, at Christmas). If so, I will ask you to contact those people and ask them if they would be available to be interviewed and/or be observed by me interacting with the central participant. If they agree I will give you information and consent forms and a stamped addressed envelope in a blank stamped envelope (for you to address) to be forwarded to these people.

Visits at home
Where the central participant lives in a group home, I will observe her/him three times for the duration of each entire staff shift over a two month period. A staff shift may vary from 3-8 hours. I will not be present during the night, after she/he has gone to bed and I will not conduct any observations in bathrooms or other private places: in fact, I will take care to respect the participant’s privacy and wishes regarding my presence at all times.

Where she/he lives with family, appropriate times will be negotiated with you/family members who support the central participant. I will also accompany the central participant on regular visits and activities out of the home.

What I will do outside the home with the central participant
From the list of activities, and places you have given me, I will observe the central participant at each place for the duration of each activity. It is anticipated my visits will be for a minimum of three occurrences over a two month period for each activity. For instance, I may accompany
the central participant on a shopping session from the day service with the same staff members and clients on three occasions.

I will be looking for her/his social network members. These are people that the central participant indicates in some way that she/he likes. Each social network member will be given an information sheet and a consent form that they need to sign and return to me if they are happy be involved in the research.

**What I will do once I have established all the network members**

I will try out some strategies with the central participant to see if I can work out how close she/he feels to each social network member who has also agreed to participate in the project. All the strategies involve looking at photos of central network members. I will sit down with the central participant somewhere quiet and private and use one or more of the following strategies:

- **The Friendship Judgement Interview.** Here a photo of the central participant is placed with a photo of one of the social network members on a rod to indicate the closeness of the friends. The participant will be asked to place the photographs in relation to “how much do you like to spend time together?” The spacing between the photographs will be measured on a scale with “very much” response (where the photographs touch) being zero.

- **Talking Mats™.** The central participant will be asked to place each photo of a social network member on one part of a three point scale (like a lot, don’t care, don’t like at all) as to whom she/he feels close. The scale helps categorises the relationships of the social network. Once the mat is completed a photograph or photocopy of that mat will be kept by me and given to the central participant if desired.

- **A circle of friends.** The central participant will be presented with a picture of set of three concentric circles around a central circle marked with his/her photo. Each of the circles represents a level of closeness to the person in the centre, decreasing as the circles move outwards. The central participant will then be asked to place in the inner circle photos of people with whom she/he feels so close that it is hard to imagine life without them, or those whom she/he kisses (often parent child/partner, best friend). Secondly the central participant will be asked to place in the middle circle people to who are not quite that close but who are still important.

**Data collection**

I will be writing notes of what I see happening with regard to social networks and communication. My notes will include observations of the setting, activities occurring in the setting and the interaction of the central participant in relation to others in the environment. I may also ask to video the central participant. The video will be used by myself and my supervisors to look at what is happening in the interaction between social network members and the central participant.

I will be entering the information into a computer. I will use the social network photos to see how close the central participant feels she/he is to other social network members. These results will be entered into a computer.

**How will the collected information be used?**

The information which has been collected will be presented in a thesis and may be presented in conference or journal papers. The information may also be presented at conferences or seminars. If I wish to use any of the video for teaching purposes I will go back and ask you for your written permission.
You and/or the central participant can receive a summary of the results of the project, by contacting me or my supervisor, using the contact details below.

If you wish to have a copy of any personal data collected about the central participant you may do so by contacting me or my supervisors, using the contact details below.

**What are the risks for participating in this project?**
There are no obvious risks, however the central participant may not wish me to accompany her/him all of the time. Where any discomfort is noticed I will ask the central participant if she/he wants some privacy and if so withdraw.

As the research requires a process of long term engagement the central participant may come to see me as part of her/his social network. To mark the end of the project I will organize a leaving party. This party will celebrate the time spent together. I will invite her/his social network members and let them know I am finishing this part of the project.

Should the person with a disability demonstrate continued distress after the project finishes, counseling services can be provided through Scope Counseling Service (Community Client Scheme; Glenroy office, contact number: 8311 4000).

**What are the possible benefits for participating in this project?**
The person with a disability may not directly gain from participating in this project; however people who live and work with him/her may become more aware of her/his social network and encourage more interaction. It is hoped that as evidence builds from several other social networks in the larger study the research will positively affect services for adults with severe intellectual disability.

**Confidentiality of the person with a disability will be ensured**
During the time of information collection, the information collected from you, the person with a disability and/or the staff member will be stored initially in a notebook and transferred on to a computer that will be locked with a password. Photos and videos will also be stored on the computer.

Only the central participant myself and my supervisors will see the photos and the videos.. The photos of the social network members will only be used with the central participant to look at the closeness of her/his social network. The video will be used by myself and my supervisors to look at what is happening in the interaction between the central participant and her/his social network.

All participants will be referred to by false names. At all times, only people with authority (myself and my supervisors) will have access to the information. At the end of the project, this data will be stored for five years and after that time, it will be destroyed.

**Signing the Consent Form**
You will need to sign the attached consent form and return it to me using the enclosed envelope if, and only if, you would like the person with a disability to participate in my project. Signing the consent form also means that you give permission for me to ask the staff members of the day and/or residential service for:

- background information/communication reports about the person with a disability
- a list of activities in the central participant’s life and places she/he goes.
The consent form allows you to select options as to whether you wish to have photos or video taken of the central participant.

_Canceling this Consent_
You may withdraw your consent to allow the person with a disability to participate in this project at any time. You also have the right to cancel your permission to use the information collected about the person with a disability at any time, by contacting me, Hilary Johnson at 039479 1802 or my supervisors as below. It will not affect your relationship with any organization from which the person with a disability is receiving services.

If you cancel permission to use the information, I will stop collecting additional information about the person with a disability. Information that has been collected will also be destroyed.

_Questions Regarding this Project_
Any questions about this project may be directed to me, Hilary Johnson on 03 9479 1802/0417 126 471 or by email:H.Johnson@latrobe.edu.au. Otherwise, you may contact my supervisors, see below for details.

If you have any complaints or queries that I and/or my supervisors have not been able to answer to your satisfaction, you may contact the Secretary, Human Ethics, Research and Graduate Studies Office, La Trobe University, Victoria, 3086, (ph: 03 9479 1443), email: humanethics@latrobe.edu.au.
APPENDIX C: CONSENT FORM FOR NEXT OF KIN

Project Title

DETERMINING THE ROLE OF COMMUNICATION IN THE SOCIAL NETWORKS OF PEOPLE WITH SEVERE INTELLECTUAL DISABILITIES AND LITTLE OR NO SPEECH

Statement of Agreement

I, ____________________________, next-of-kin/person responsible for ____________________________ have read and understood the participant’s next-of-kin/person responsible information sheet and consent form, and any questions I have asked have been answered to my satisfaction. I agree to allow (insert central participant’s name) to participate in the project, knowing that she/he may withdraw at any time.

I agree that research information given by her/him or with my permission during the project may be included in a thesis, presented at conferences and published in journals on the condition that neither the name of the person with a disability nor any other identifying information is used unless agreed to as below. I understand I may have a copy of any personal data collected about (insert the central participant’s name) by contacting Hilary or her supervisor, using the contact details below.

I give permission for Hilary to ask the staff members of the day or residential service for background information about insert the central participant’s name). She may also ask the staff members to look into the files of (insert the central participant’s name) for background information if necessary.

I understand photos will be taken during the study.

I agree to the following (please tick the appropriate box)

Yes ☐ No ☐ Digital photos of (insert central participant’s name) will be taken in the project and will not be published.
Yes □ No □ Video of (insert central participant’s name) will be taken during interactions with others to be viewed only by the researcher and her supervisors.

Name of Participant (block letters):
__________________________________________________________________

Name of participant’s next-of-kin/person responsible (block letters):
__________________________________________________________________

Signature: ______________________________________

Date: _________________________

Contact Number: ________________________________________
APPENDIX D: INFORMATION SHEET FOR A PAID WORKER/FAMILY MEMBER

Project Title
DETERMINING THE ROLE OF COMMUNICATION IN THE SOCIAL NETWORKS OF PEOPLE WITH SEVERE INTELLECTUAL DISABILITIES AND LITTLE OR NO SPEECH.

Introduction
My name is Hilary Johnson and I am a PhD student at La Trobe University. My supervisors are Dr Jacinta Douglas, primary supervisor, in the School of Human Communication Sciences and Dr Chris Bigby, secondary supervisor, in the School of Social Work and Social Policy. I also have an external supervisor, Dr Teresa Iacono, from the Department of Developmental Disability Health Victoria, Monash University. The following information is provided for you to decide if you want to participate in my project. I am collecting information on communication in several social networks. For the purpose of this project a social network is one made up of people who are liked by a person with a severe intellectual disability who has little or no speech.

Reason for doing this project
Many people with severe intellectual disabilities have difficulty communicating. I want to learn more about their social networks and how people within a person with a disability’s social network deal with the communication difficulties.

What does being a social network member mean for you in this project?
It has become apparent you are a social network member of xxxxx by observing you interacting with him. I need to spend time with all the people xxxxx meets or knows. This means I will spend time in xxxxx’s home, go out with him on all activities and watch him interact with social network members.

I will make written notes and may take videos or photographs if xxxxx and social network members agree. I want to interview all social network members and audio record the interviews.

Interviews
I will ask you for a suitable time and I will provide a private comfortable location where we can meet and you can talk to me about social interaction and communication with xxxxx. The interview will last for up to an hour and will be private and confidential. I may also come back to you at a later date and ask you some more questions. I will audio record the interview and transcribe the interview on to the computer.

I will use a false name to ensure your confidentiality. In addition to the main interview question I will ask you for some information on your age, post code and educational and work background.
Data collection
I will be writing notes of what I see happening with regard to social networks and communication. My notes will include observations of the setting, activities occurring in the setting and the interaction of xxxxx in relation to you. Where consent has been given I will take photos and may also take video.

I will be entering all the information into a computer. I will be looking at videos of interactions to see if I can work out how xxxxxxx interacts with you and how you interact with her/him.

If you give permission I will take a photo of you. Once I have identified all xxxxx’s social network members, I will use the photos with xxxxx to see how he sees his relationship with all social network members. Photos of social network members will not be used in any conference presentations, publications or with anyone other than my research supervisors.

I may also ask to video you and xxxxx. The video will be used by myself and my supervisors to look at what is happening in the interaction between yourself and xxx

How will the collected information be used?

The information which has been collected will be presented in a thesis and may be presented in conference or journal papers. The information may also be presented at conferences or seminars.

If I wish to use any of the video for teaching purposes I will go back to you and ask for your written permission.

You may request to see a transcript of your interview. You can also receive a summary of the results of the project, by contacting me or my supervisors, using the contact details below.

If you wish to have a copy of any personal data collected about you, you may do so by contacting me or my supervisors, using the contact details below.

What are the risks for participating in this project?
There are no obvious risks however if you were to feel upset or disturbed by my continued presence you can ask me to leave. If during the interview you feel distressed or upset we can stop the interview and have a break. Although it is unlikely, should the distress continue counseling services can be provided through your employer. Whether you participate or not will not affect your employment.

What are the possible benefits for participating in this project?
You may not directly gain from participating in this project; however you may become more aware of his social network and communication strategies. It is hoped that as evidence builds from including other social networks in my study the results will positively affect services and supports for adults with severe intellectual disabilities.

Confidentiality will be ensured
During the time of information collection, the information collected from you and xxx will be stored initially in a notebook and transferred on to a computer that will be locked with a password. All participants will be referred to by false names.
At all times, only people with authority (myself or my supervisors) will have access to the information. At the end of the project, this data will be stored for five years and after that time, it will be destroyed.

**Signing the Consent Form**
You will need to sign the attached consent form and return it to me using the enclosed envelope. When you sign the consent form it means you are giving permission for me to write down information about the interactions between you and xxxx.. It also means you are giving permission to be interviewed. The consent form allows you to select options as to whether you wish to have photos or video taken of you.

**Refusal to Sign Consent Form**
You may refuse to sign this form. It will not affect your relationship with the organisation where you work. However, if you refuse to sign, you cannot participate in this project.

**Cancelling this Consent**
You may withdraw your consent to participate in this project at any time. You also have the right to cancel your permission to use the information collected about you or your interactions with xxxx at any time, by contacting me, Hilary Johnson at 03 9482 1851 or my supervisors (see contact details below). It will not affect your relationship with the organisation where you work.

If you cancel permission to use the information, I will stop collecting additional information about your interactions with xxxx Information that has been collected will also be removed.

**Questions Regarding this Project**
Any questions about this project may be directed to me, Hilary Johnson on 0417 126 471 or by email:H.Johnson@latrobe.edu.au. Otherwise, you may contact my supervisors as below

If you have any complaints or queries that I and/or my supervisors have not been able to answer to your satisfaction, you may contact the Secretary, Human Ethics, Research and Graduate Studies Office, La Trobe University, Victoria, 3086, (ph: 03 9479 1443), email: humanethics@latrobe.edu.au.
APPENDIX E: CONSENT FORM FOR SOCIAL NETWORK MEMBER

Project Title

DETERMINING THE ROLE OF COMMUNICATION IN THE SOCIAL NETWORKS OF PEOPLE WITH SEVERE INTELLECTUAL DISABILITIES AND LITTLE OR NO SPEECH

Statement of Agreement

I, ________________________________________________, staff member

(name)

have read and understood the staff member information sheet and consent form, and any questions I have asked have been answered to my satisfaction. I agree to being involved in the project, knowing that I may withdraw at any time. I understand that participation in this project will not effect my employment in any way.

I agree that information given by me during the project may be included in a thesis, presented at conferences and published in journals I understand that this is on the condition that no personal identifying information is used unless agreed to as below
I understand I may have a copy of any personal data collected about myself by contacting Hilary or her supervisors, using the contact details below.

I understand photos will be taken during the study.

I agree to the following (pleasetick the box)

Yes☐ No ☐ Digital photos of myself that will not be published

Yes☐ No ☐ Video of myself during interactions with the central participant to be viewed only by the researcher and her supervisors

Yes☐ No ☐ Audio recording of my interview with Hilary

Yes☐ No ☐ Audio recording of my communication with (insert the central participant’s name)
Name of Staff member (block letters):

__________________________________________________________________

__________________________________________________________________

Signature: ______________________________________

Date: _________________________

Name of service : ________________________________
APPENDIX F: INFORMATION FOR FRIENDS

Friends and Communication
Information sheet - friends

My name is Hilary and I want you be part of my project with xxx

The project is to find out more about making friends and communication.

I want to spend time with you and xxx I want to write down what you do.

I want to take your photo.

I want to take a video of you and xxx
I want to talk with you about your friendship with xxx

I want to video tape you talking to me.

I will be writing it all down in a computer.

I will share the information you give me with other people, in books – or at conferences. I will not use your real name.

I will only use your picture with other people if you say yes.
I will tell you what I found out.

You can ask me or my supervisor for a copy of the information about you.

You can stop anytime and say NO

If you don’t like what I am doing you can complain. Ask a friend to phone me 9479 1802 or by email: H.johnson@latrobe.edu.au.

Otherwise contact my supervisor, Jacinta Douglas at 03 9479 1797.

If you still have any complaints ask someone to contact the Secretary, Human Ethics, Research and Graduate Studies Office, La Trobe University, Victoria, 3086, (ph: 03 9479 1443), email: humanethics@latrobe.edu.au.
APPENDIX G: INTERVIEW GUIDE

“Could you tell me about your relationship with central participant and how communication in this relationship occurs?”

If at the end of the interview specific information has not been provided all or some of the following additional questions may be asked.

a) Can you remember what happened the first time you met?( if not family)
b) Tell me about your first interactions and if this has changed over time?
c) How does central participant communicate with you? regards needs and wants/exchanging information/social interactions.
d) How do you interact with central participant?
e) How would you describe your relationship with central participant?
f) What do you give in this relationship? (emotional support, companionship, material, information, help in decision making, support when ill or around medical issues).
g) What do you get in this relationship?
i) How long have you known the central participant? (if not immediate family)
j) How frequently do you see the central participant?
k) Do you live nearby?
l) Who knows whom in the central participant’s network?

In addition information on age, gender and educational and work background will be sought.
### APPENDIX H: SANDRA’S FEEDBACK PRESENTATION FOR MEMBER CHECKING

#### My broad focus
- “talk, conversation, and the communication which moves the wheels of social interaction (p.4)
- “whatever else is true of personal relationships, it is undeniable that they are ‘situated’ and given context through communication” (p.5)

#### My aim
To observe Sandra
- to get to know her as a person
- how she communicates
- how others communicate with her
- how she indicates “friends”
- how her friends see her
- I would like your feedback – have I got it right?

#### Information Collected
- 21 hours - observing at home
- 10 hours - observing at Day centre
- Her “friends” were identified from observations, family recommendations and from talking to people at the Day service. People selected were in one or more of the following categories
  - Sandra would say the person’s name when they were not there and/or
  - Interactions with Sandra were very positive and in which Sandra showed pleasure
  - Had provided support over a number of years
  - Had interacted with her over the last 3 months
- 14 interviews
  - Immediate family (4),
  - DSW at home (3),
  - DSW at Day centre (5),
  - Friends with an intellectual disability (2)

#### The many faces of Sandra
- Lioness
- The entertainer

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APPENDIX H: SANDRA’S FEEDBACK PRESENTATION FOR MEMBER CHECKING

**Communicative functions**
- to express needs & wants,
- social closeness,
- exchange information,
- social etiquette (Light 1989)
- She uses all these functions
- She uses facial expression, body language, proxemics, gesture, sign, pictures, words & prosody,
- She uses the easiest form of communication for her to get her message across

**How Sandra communicates**
- Facial exp./body language
- Mostly readable
- Covering her left eye
- Head down
- Blank expression
- The “look”
- Intimate & personal space
- “the pearl in the middle”
- Gestures-Reach out for you- hand, hand; away
- “it seems to be a lot about touching, it’s all about affection …”

**How Sandra communicates- Symbolic**
- Words (50-100)
  - Names
  - Single syllables
  - Vowel distortion
  - Prosody
  - pitch/intonation
- Name; request; comment; self-talk; look
- Nonsense words
- Silence
- Sign-has < 10 (co-occur with speech)
- Pictures/photos
  - Uses TV to converse
  - Uses people in the here and now
  - Rarely initiates photo/picture sharing
  - Has initiated absence of people in routine

**Knowing what Sandra understands**
- Difficult to assess
- May vary from situation to situation
- Mostly routine/here and now
- Picks up a key word
- Time concepts difficult
- Tone of voice important
- I would think almost key words because I think that’s why she likes the signing as well because they, the key words make things clearer. It’s the mumble jumble in between I don’t think she necessarily takes on.”
- With Sandra you always speak a bit slower because there’s no point racing through something. Even if she understands she’s not going, it takes a little while to process it.
- She has always given you the impression that she is very, she understands a lot of verbal, but I think she picks up more on peoples’ energy and body language. If people are in a circle laughing, I don’t think Sandra necessarily would understand what the joke was about. She wants to join in with the laughter
Strategies for successful interactions

- BOC - many possible reasons
- Limit her interactions
- She limits her life
  - Anxiety
  - Routine
- People oriented preferences

Social Networks

- People with whom Sandra has had contact (last 3 months)
- Contact - at least 15 minutes of being engaged together in an activity
- Reciprocity - what do you give / what do you get

Density of relationships

Characteristics of friends (14)

- Age
  - 5 - 20-29; 5 -30-39; 2 - 50-59; 2 - 60+
- 9/14 tertiary educated
- 8/14 see her daily
- 8/14 are male
- All live locally

- Stability
  - 6 <1 year
  - 4 1-10 years
  - 4 >10 years
APPENDIX I: BRIAN’S FEEDBACK PRESENTATION FOR MEMBER CHECKING

Brian - Observation Time

<table>
<thead>
<tr>
<th>Activity</th>
<th>Total Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>At home</td>
<td>7 hours</td>
</tr>
<tr>
<td>In the community with in-home support</td>
<td>6 hours</td>
</tr>
<tr>
<td>In an evening leisure program</td>
<td>4.5 hours</td>
</tr>
<tr>
<td>In Day service activities</td>
<td>23.5 hours</td>
</tr>
<tr>
<td>Total</td>
<td>41 hours</td>
</tr>
</tbody>
</table>

13 social network members were identified, 11 were interviewed
5 Day Support Workers (DSW)
1 Program Support manager (PS)
3 Home Support workers (HDSW)
2 family members (FM)

Being Brian's social network member

What is the role?
- Being a friend
- Making him happy
- Developing skills
- Giving the parents a break
- Providing a protective role

What people give
- New experiences
- Attention
- Good quality interactions
- Practical assistance
- Nurturance and support

What people get
- Job satisfaction
- Affection
- Pleasure

Special things about Brian

Eyesight
- Loves exaggerated intonation

Sensory Responses
- Likes fluffy towel around his neck
- Hits too hard

Toilets
- Likes crunchy foods

Light switches
- Likes tearing paper

Brian's Communication

How Brian Communicates
- Facial expression
- Touch
- Proximity
- Vocalisations
- Sign & gesture
- Words

Communicating with Brian
- Proximity
- Getting his attention
- Exaggerated intonation
- Vocal imitation
- Demanding words

To help him understand
- Short simple phrases
- Get his attention
- Routine
- Repetition
- Physical prompt
- Use objects

Interacting with Brian

Hanging out together
- Action/song games
  - e.g. Row row row, happy and you know it
- Word games
  - Little piggy went to market
  - Alphabet

Features of interaction
- Touch
- Taking turns/pausing
- Vocalisations/words
- Intonation
- Repetition

Does it have to be staff?????
Engagement-Interaction

- “whatever else is true of personal relationships, it is undeniable that they are ‘situated’ and given context through communication” (p.5)
- “talk, conversation, and the communication which moves the wheels of social interaction” (p.4)


Social network- social support

Developing relationships
- Meeting new people
- Having support to meet new people
- Share experiences
- Develop shared interests/activities
- Have ways/means to share information
- Giving and getting something back (reciprocity)

What happens when a person doesn’t have speech/literacy (limited symbolic communicator)?
- Small transient networks (mostly paid workers)
- Have no friends
- Family are very important
- Participate in a small number of activities-often with other people with disabilities;
- Little reciprocity

My aim-

To observe Eric
- to get to know him as a person
- how he communicates
- how others interact with him
- who is in his social network
- how his social network see him
- and look at what supports interaction

Information Collected

- 43 hours of observations occurred in the following places
  - Eric’s family homes/activities out 6.5 hours
  - Day centre/activities out 29.5 hours
  - Eric’s group home/activities out 6 hours
- His social network were identified from observations and from talking to people who were interviewed.
  People selected were in two or more of the following categories
  - Eric would say/sign the person’s name when they were not there and/or
  - The person had spent time individually with Eric at least once a month.
  - Eric initiated or had repeated contact (by choice) with that person
- 8 interviews
  - family (5),
  - DSW at group home (1),
  - staff at Daycentre (2)
The evil twin

The home bod

What we use communication for

- to express needs & wants,
- social closeness,
- exchange information,
- social etiquette (Light 1989)

Eric uses the easiest or most available form of communication for him to get his message across -

- The more complex the message, the greater the need for it to be supported

How Eric communicates- Formally

- Words -10?
  - Names
  - Yes/no (informal too)
- Alphabet-initial letter-names
- Signs (gesture)
  - 40+
- Pictures/photos

I very much want to understand what he’s trying to tell me but I sense his frustration and because he might sense my frustration I can’t understand what he means. So usually when that happens I try to sort of flash around and try and figure out what it might be; try a range of different things and if I get it right, he’ll let me know straight away; or sometimes I could suggest a range of things and, yes, I think it is significant that when you’re communicating with Eric, I find it important when I’m offering him a choice of things...one of Eric’s I guess more difficult parts of his communication is his response to yes and no. It’s not really verbal, its more of a subtle movement of his face. Sometimes he’ll say yes if he’s in bed with the light out but I can’t tell what’s going on, so it’s much easier if he points to what he wants (family member)
Linking words/symbols/signs

- He signs ‘Bettty’ to a DSW as he’s looking for her. She doesn’t know the sign so he went and got a photo of Betty from the wall and showed it to the DSW who had last seen her (not shown, but after this the DSW signs ‘Bettty’). Fieldnotes 10/12/2009
- He pointed to his hair, it was like he was pointing to the hair and then someone said ‘Betty had wanted him to have a haircut’. Eric got up and signed ‘Betty had wanted him to have a haircut’. Fieldnotes 30/01/2010

What do people get from Eric

- Happiness: Fun–simple fun, Joy, Love/emotional support
- Personal strengths: Patience/self control, compassion

How engagement works for Eric

- Interacts differently with different people
- Shares different routines/types of activities
- Will initiate more where there is support/means to communicate

How do we support engagement – grow/maintain his social network

- Expand and develop new routines – feeling safe
- Repeating fun activities
- Something to talk about with someone
- Consistent people knowing details of his life
- Memories

Wheel of social interaction

Establish mutually enjoyable routines
Share mutually satisfying experiences