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The challenges and benefits of using participant observation to understand the social interaction of adults with intellectual disability

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Keywords
Severe intellectual disability, Interaction, Adult, Participant observation

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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 disability 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 disability allows for unexpected insights and provides context and credence for other lines of inquiry. Participant observation may be useful with other groups of people.
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 disability 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, 2004; Silverman, 2001). Qualitative research utilises 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, 2004). 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). Participant observation 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).
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Gold’s (1958) classic typology outlined the differing demands of the researcher’s role on a continuum 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 as 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 utilising participant observation (McCord & Soto, 2004; 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 six-month period 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
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complexities of story telling in older adults. Over a six-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 disability 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 conduct of assessments that will yield accurate results (Abudarham & Hurd, 2002; Calculator, 1988). Nonetheless, there is evidence that adults with severe intellectual disability 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 disability and found 80% were reported to use symbols. In regard to interactions, most research has focused on communicative interactions between adults with severe intellectual disability and paid staff and has indicated that adults with severe intellectual disability have received more didactic instruction than social interaction (Markova, Jahoda, Carttermole, & Woodward, 1992; McConkey, Morris, & Purcell, 1999; Prior et al., 1979). Nevertheless, understanding of the interaction skills of adults with a severe intellectual disability has been thwarted by this group often not being considered 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 recognising 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 emphasised the importance of utilising 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 disability and challenging behaviour, then used grounded theory to analyse the data. The researchers provided vivid description of the men’s unique responses to interactions through 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 provides 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,
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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. 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 a study exploring the interaction processes between adults with severe intellectual disability and their social network members. In this source study, a constructivist grounded theory approach was utilised (Charmaz, 2006). Ethical approval for the study was granted through the Human Ethics Research Committees of two Universities and one non-government organisation.

Participants in the source study were six adults with intellectual disability (referred to as central participants, see Table 1) 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 disability, 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 disability. 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 43 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.

Data were collected on each central participant and those with whom they interacted by the first author over a period of 4 to 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 an individual’s dignity and right to privacy. Observation periods were from 0.5 to 3 hours in length. The first author utilised two participant observer roles predominantly: observer-as-
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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 from 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 poetics (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 the process of 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 experiences in the field 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 in which something was seen or heard that affected the way the research was conducted and caused critical reflection. Stalker’s (1998) paper focussed 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 disability. Similarly, the first author of the current paper 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 resultant paper was then presented at an International Society of Augmentative and Alternative Communication symposium in 2010 where feedback was received, confirming there was interest in sharing these findings more broadly. Further reflections and discussion between authors through several iterations gave rise to the final results included in the current paper.

Results

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

Challenges

Three challenging aspects, pertinent for researchers examining interaction with people with limited communication through participant observation, arose from the data. These processes were gaining consent, changing roles and researcher intrusion. Each of these processes is described and illustrated with examples taken from the researcher’s field notes.
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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 took two different approaches to informing the central participants about my role. The first mode used speech alone and took place during the initial meeting when assessing whether the participant met the research criteria. The second mode involved discussing an easy English explanatory statement to inform the central participant about the intent of my visits.

The first meeting occurred at home for two participants and for the others at their day centre. The aim of the interaction 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 as “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 the inclusion criteria were met, follow-up visits were organized with family or paid staff. Although I asked family or paid workers to inform the central participants to expect to see me, 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, nor in what I had to say to them. 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 following section.

Changing roles. One of the difficult concepts to convey in a picture consent form was the changing role of the researcher. The intended role of the researcher was one of a complete observer in order to stand back to observe interactions. However, it became evident early in the research that a more fluid approach was needed, requiring that I move between the roles of a participant-as-observer and a complete observer. These role shifts enabled me to interact with a central participant or interact with others in the environment and occurred at multiple points throughout the research. Specific challenges encountered in shifting roles 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 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 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. Partly I believe the changing role from observer-as-participant to complete observer was difficult for Sandra to comprehend and may have heightened her anxiety. In addition, the change of location (from home to the day centre) plus my urgent anxious tone of voice used because I was concerned she might burn her fingers also may have triggered her reaction. In addition, I may have broken her routine, or interfered with her position in the group (I was told she likes
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to be around males); these and other interpretations are possible. Sandra’s brother passed this 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 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. It was also difficult to explain to a central participant when I was leaving a location that I would be returning at another time, as time concepts were not easily understood. As my presence in their environments was frequently unannounced, the central participant’s affect changes 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 that role placed when I wanted to interact with the central participant. One of the aspects of the research had been to ascertain how close the central participant felt towards various members of his/her social network. This degree of closeness was to be determined through working directly with the central participant using an exploratory process with photos. As the method was individualized, and could be influenced by a communication partner who knew the central participant well, the task could not be carried out by a support worker or family member. This task was only partly achieved with three participants. The difficulties lay in 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
achieve 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. Gaining the central participants interest in spending time with me would have required a greater time commitment overall.

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. Balancing these competing roles was particularly evident where the researcher had prior knowledge that might resolve a stressful situation for the central participant or felt 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, although uncertain initially whether to intervene, felt compelled to help. The incident demonstrates the importance of practicing reflexivity and the tensions that can be experienced from previously having had a clinician role (one of needing to fix a problem) and moving to a researcher role (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 “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 a 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-UNCOMFORTABLE-PLEASE-SIT-ME-UP-STRAIGHT and Sally said “do you want to sit 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 communicative 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 important moments” (Guillemin & Gillam, 2004, p. 262). With Sandra, there was a dilemma as to whether to terminate the research process as my presence may have been seen as increasing her anxiety. However 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 Fayez. There were many other similar incidents throughout the research and each one caused me to consider whether to suggest the need for further training to supervising staff. In most situations, paid workers were doing their best and usually people in management were 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
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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 collection, 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 of these concerns, except the latter, 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 to clearly see and hear observations, usually I located myself near the edge of a room and opposite to the central participant. Typically this location 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 throughout the day centre, but in a short time I had learned his routine so he could be located quickly. Inevitably there were always some interactions that were not clearly observed. If crucial interactions (those that were unusual) were missed, I returned to the field until interactions were repeated with sufficient frequency to ensure an adequate representation.

A situation that posed a dilemma was whether my presence caused others to avoid interacting with the central participant. This concern often arose in the group homes in which a support worker might put his or her head around the door and on seeing me, not enter the
room. Such situations resulted in limited interactions between paid staff and the central participant, with consequent long periods of inactivity. Frequently the television was turned on, but was not a focus of activity. This withdrawal by the staff member may well have occurred if I had not been there as they may simply have meant to check on the person without an intention to interact, or have been busy elsewhere in the house. As a clinician, I valued interpersonal interaction, but as a researcher I needed to note the absence of interactions and factor this observation into the overall interpretation of the data.

There were times when my presence clearly was affecting the central participant’s interactions. At these times, I would either withdraw, allowing myself to be engaged with others in the area, or join in a group in the participant-as-observer role. After an observation session was completed or at a later interview time, I usually asked someone who knew the central participant well if what I had observed was typical behavior. On one occasion, a DSW commented how a central participant’s vocal interactions were less strident when I was present. I then organised a time to view the central participant’s more usual demanding, boisterous presentation by observing a large dance group where I could be several meters away. This observation confirmed the support worker’s description.

Observing interactions in family homes was more difficult in terms of concern about intruding on the family’s 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, as the researcher’s presence appeared to be forcing interaction. There were, however, alternate opportunities to observe family interactions less intrusively. These included attending family celebrations or outings. For
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example, to observe Eric interacting with his extended family, a pancake restaurant, Eric’s preferred place to eat prior to going to see a movie, was chosen. Although family interactions with central participants sometimes appeared stilted, they still provided insights into differences in interaction across communication partners and/or settings. In private homes, observation rarely exceeded an hour and was shortened if the participants showed any agitation at my presence.

There were some restrictions in being able to carry out observations when I was engaged in conversations by another person, resulting in difficulties in immediately and accurately recording the central participants’ interactions in the field notes. 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 in my hearing. In day centers, other people with an intellectual disability often attempted to engage me, but these were usually brief interactions, such as a greeting. Sometime I sought clarifications of an interaction from a staff member and these were recorded in field notes.

Researcher intrusion did have some effects on interactions, 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
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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 with 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 signii and Auslaniii. 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 utilise aided communication supports that were available in his environment. However, these observations led me to wonder how Eric’s familiar people learned the signs? How much did it matter to Eric that people could understand his communication? To widen my search for a fuller understanding I visited Eric’s group home. There 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 familiarise themselves with them. Was this negligence, ignorance or disrespect from the staff? These questions focused my future observations and opened up a line of
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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 focused observations were essential to enhance 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 analysing data and different methods for pursuing further data collection.

One of the overarching challenges is the time taken to collect the data. The time commitment involves not only observing but organising suitable times and/or locations and finding key people with whom to liaise. Adult day 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: for instance, residential staff and day center staff.
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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 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 and specific aims may need to be reviewed.

Informing participants about the research process is driven by an ethical responsibility and also a belief in self-determination. When adults with severe intellectual disability 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 disability (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 disability often have multiple impairments, short attentions spans, and a disinterest in formal table-top 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
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not be achievable because of time constraints, leading to an inevitable switching between various participant observer roles. Courtesy and ethical behaviour demand the researcher to ask a participant for permission to accompany him or her to new locations or for different activities. Nonetheless, participants who do not understand the researcher’s request may find repeated requests for permission overtly intrusive. There may be value in examining alternate ways to inform people with severe cognitive difficulties about the research process in order to ensure maximising their feelings of security.

The switching of 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 severe intellectual disability, a participant-as-observer role may allow for more opportunities to develop trust and interaction than the role of observer. On the other hand, the participant-as-observer role would result in having 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 disability have included video recording as part of field studies (Antaki, Finlay, & Walton, 2007; Finlay, Antaki, & Walton, 2007; Patton, 2002). Video recordings allow for analysing 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 thought to be 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). As participant observation with adults with severe
intellectual disability 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 grounding 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 in-depth interviews. In fact, developing an understanding of people with complex communication needs through observation before interviewing their communication partners may help establish the researcher’s credibility as an interviewer, as well as facilitate the generation of more finely focused questions.

Overall, the benefits of observational data include both expected and unexpected outcomes. Participant observation works well with an iterative process of exploration and can reveal new lines of inquiry. These insights can then be further analysed through qualitative methodologies, such as grounded theory, in order to develop novel theories of interaction or ethnography to develop a fuller understanding of a culture. Research directions
and further questions that emerge from the inquiry may then be tackled through qualitative or quantitative methods, finding the best fit for each question.

The authors of this paper aimed to share the challenges and benefits of participant observation with other researchers in order to initiate a reflective exchange of the value of using fieldwork when studying interaction. Participant observation, although time consuming, can facilitate a deeper understanding of a phenomenon and provide fresh discoveries in under-researched areas. In this paper a specific set of methodological and ethical issues have been identified in regard to participant 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. As 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.

Author Note

This research was supported by a University Postgraduate Research Scholarship awarded to the first author. The authors gratefully thank the organisations and the participants for their time. A preliminary version of this paper was presented on July 31st 2010 as part of the ISAAC research symposium in Barcelona, Spain.
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doi:10.1080/07434610012331278864

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FOOTNOTES

i FN represents the field notes, S the first letter of the central participant’s name and 10 for the 10th observation session

ii Sign and gesture used with people with an intellectual disability (Grove & Walker, 1990)

iii Australian sign language (Johnston, 2010)