CANADIAN JOURNAL OF
Disability Studies
Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

Canadian Journal of Disability Studies

Published by the Canadian Disability Studies Association
Association canadienne d'études sur le handicap

Hosted by The University of Waterloo

www.cjds.uwaterloo.ca

Ethical key learnings from participant observation with people with communication support needs

Principaux enseignements éthiques tirés de l'observation participante auprès des personnes ayant besoin d'aide à la communication

Deborah L. Lutz, Ph.D.
Professor of Inclusive Education,
Catholic University of Applied Sciences, Freiburg, Germany
Deborah.Lutz@kh-freiburg.de

Abstract

Despite ongoing advancement of inclusive research methodologies that allow people with disabilities to control, create and take ownership of the research process, the experiences of people with intellectual disabilities who use little or no verbal speech to communicate are underrepresented in research studies. A method with potential to facilitate their research participation is participant observation. Ethical concerns and questions, however, may intimidate or discourage researchers in using the method with people with communication support needs. In this article, I use ethnographic field notes and personal reflections about working as a participant observer with people with communication support needs. I describe and analyse three points of consideration in using the method to draw out ethical key learnings, which revolve around (1) the influence of third parties, (2) observing the person in the absence and presence of research participants, and (3) balancing views on research participants. I end the article with a discussion about the ethical key learnings and argue that participant observation can provide researchers with a considerable amount of time to become familiar with people's communication preferences, but that they need to be committed to reflecting on and resolving the ethical tensions and questions they experience in researching with people with communication support needs.

Résumé

Malgré les progrès continus des méthodologies de recherche inclusives qui permettent aux personnes handicapées de contrôler, de créer et de s'approprier le processus de recherche, les expériences des personnes ayant une déficience intellectuelle qui communiquent peu ou pas verbalement sont sous-représentées dans les projets de recherche. Une méthode susceptible de faciliter leur participation à la recherche est l'observation participante. Cependant, des préoccupations et des questions éthiques peuvent intimider ou décourager les scientifiques d'utiliser cette méthode avec des personnes ayant besoin d'aide à la communication. Dans cet article, j'utilise des notes de terrain ethnographiques et des réflexions personnelles sur le travail d'observation participante auprès de personnes ayant besoin d'aide à la communication. Je décris et analyse trois éléments à prendre en compte avant d'utiliser cette méthode pour en tirer des enseignements éthiques importants, qui tournent autour (1) de l'influence de personnes tierces, (2) de l'observation de la personne en l'absence et en présence des participant·es à la recherche et (3) de l'équilibre des points de vue sur les participant·es à la recherche. Je termine l'article en discutant des principaux enseignements éthiques et je soutiens que l'observation participante peut fournir aux scientifiques beaucoup de temps pour se familiariser avec les préférences de communication des gens, mais qu'elles et ils doivent s'engager à réfléchir et à résoudre les tensions et questions éthiques rencontrées lors de leurs projets avec des personnes ayant besoin d'aide à la communication.

Keywords
Participant observation, intellectual disabilities, communication support needs, reflexive ethnographic research, ethical considerations, research participation

Acknowledgements
I would like to thank Sallie-Anne Moad for reflexive research conversations and the reviewers for helpful feedback on the article. Special thanks and appreciation go to the research participants who opened up to me and let me learn from them.

Introduction

Despite ongoing advancement of inclusive research methodologies that allow people with disabilities to control, create and take ownership of the research process (e.g. García-Iriarte et al., 2021; Strnadová & Cumming, 2014), the experiences of people with intellectual disabilities who use little or no verbal speech to communicate are still underrepresented in research studies (de Haas et al., 2022; Nind & Strnadová, 2020). A method that can help in exploring and representing their perspectives in research is participant observation.

Participant observation is an ethnographic method that allows researchers to observe research participants as they participate in their lives (Gans, 1999; Hammersley & Atkinson, 2019). Qualitative researchers have discussed the application of the method in research with marginalised groups and stressed its potential in building an in-depth understanding of people's experiences and representing their views (e.g. Boccagni & Schrooten, 2018; Kolesar, 1998; Labaree, 2002; Spitzer, 2003), including those of people with disabilities (e.g. Berger & Lorenz, 2015; Davis, 2000; Goodley, 1999; McGrath & Laliberte Rudman, 2019). Little attention, however, has been paid to the method's ethical aspects in research with people with intellectual disabilities who use little or no verbal speech to express themselves. This article aims to add to this understanding by investigating ethical considerations in using the method with people with communication support needs.

For this investigation, I draw on ethnographic data from three people with intellectual disabilities and communication support needs who took part in a research project, which I refer to throughout the article as the support work relationship (SWR) study. The study explored how relationships between people with intellectual disabilities and their support workers in Germany and Australia were influenced by personal budgets[1] that organise support (Lutz, 2020). The three people with communication support needs were Felix[2], Thomas and Lachlan. They used little or no verbal speech to express themselves and relied on augmentative and alternative communication (AAC) and/ or assistive technology to be heard by others. Their disability support needs as participants in the research seemed greater in contrast to the research participants with intellectual disabilities who used verbal speech as they encountered communication barriers, which sometimes created ethical barriers for me as a researcher in trying to facilitate their research participation during participant observation.

By sharing field notes and personal reflections about some of these barriers, in this article, I want to examine how I managed and learned from the barriers. I intend to encourage other researchers in writing about their experiences in researching with people with communication support needs.

Ethical considerations in participant observation research

Disability activists and scholars have stressed that the perspectives of people with communication support needs are underrepresented and not adequately included in empirical research studies (e.g. de Haas et al., 2022; Vehmas & Mietola, 2021; Walmsley et al., 2018). The limited research involvement of this group of people can be due to researchers' concerns and apprehension to engage in complex ethical approval processes within universities (Boxall &

---

[1] Personal budgets are individual government funds and intended to personalise the support of a person with disabilities (Lutz, 2020).

[2] All names of research participants in this article are pseudonyms.

Ralph, 2011). Researchers, for example, might feel intimidated or discouraged by the policies of ethics review boards and the complexity of ethics applications, particularly for research studies involving people with communication support needs (e.g. Boxall & Ralph, 2009, 2011; Martino & Fudge Schormans, 2018). These experiences and perceptions can influence whether they choose or are allowed to include research participants with communication support needs and further affect their decisions in how they use methods to include this group of participants.

The so far limited research involvement of people with communication support needs is also related to gatekeeping issues (e.g. people involved in the person's support might be blocking researchers in getting access to the person), restricted access to places where the person lives and/ or socialises (e.g. group homes or day programs) and to how research methodologies are designed and applied (Boxall & Ralph, 2009, 2011; Martino & Fudge Schormans, 2018). Methodological limitations with respect to the inclusiveness of people's diverse communication support needs, for example, can be related to restrictions in time and money that compromise the design and production of appropriate tools and strategies that enable researchers to receive first-hand information from people with communication support needs in the research process (Lutz et al., 2016; Lutz & Fisher, under review). It is the researcher's responsibility to commit to ethical fieldwork procedures that create opportunities for people with communication support needs in expressing their perspectives (Lutz et al., 2016).

A research method that has potential to privilege the views of people with communication support needs in the research process is participant observation, the central method used in ethnographic research (Boccagni & Schrooten, 2018; Gans, 1999; Hammersley & Atkinson, 2019). Ethnographers observe the people they want to learn from by participating in their daily activities for an extended period of time and engaging in a process of 'getting to know' them, their relationships and culture (Goodley, 1999, p. 28). In this process, the ethnographer's own experience as observer serves as a learning tool for understanding the lived experiences of the research participants (Lutz, 2020).

The role of the learner requires the ethnographer to carefully analyse their own behaviours, including evaluative impulses, judgements and assumptions, in relation to those in the ethnographic field and to make necessary adjustments (Davis, 2000). For this self-analysis, they need to engage in critical reflexivity, a process consisting of activities, such as reflexive thinking and writing, discussions with supervisors and fellow researchers and conversations with research participants (Etherington, 2004, 2007; McGrath & Laliberte Rudman, 2019; Rogers & Ludhra, 2012). While critical reflexivity is required in any qualitative field research to balance the risks and benefits of the research in ethical ways (Etherington, 2007; Lees et al., 2022; Warin, 2011), it is an imperative tool for participant observers researching with people with communication support needs. It can support researchers in becoming aware of participants' non-verbal responses and building trusting relationships with them through a deeper understanding of their communication preferences. Developing this sensitive understanding can support researchers in identifying barriers to research participation for this group of people and removing or managing them accordingly.

Aspects of observation have been included in qualitative fieldwork in research with people with intellectual disabilities by using, for example, non-traditional interview approaches with communication aids, such as photovoice methods (e.g. Cluley, 2016; Robinson et al., 2021; Macdonald et al., 2021), body-mapping (e.g. Curryer et al., 2019; Dew et al., 2018), focus groups with stimulus materials and visual methods (Nind & Vinha, 2016) or ethnographic interviews (Lutz et al., 2016). These methods, however, are usually shorter in length than participant observation, which can be scheduled for days, weeks or months. Having enough time during fieldwork to learn from people's experiences directly is important when researchers aim to facilitate people's research participation (de Haas et al., 2022). Sufficient time can help them in building trusting relationships and becoming familiar with the person's communication preferences (Forster 2020; Lutz & Fisher, under review), which may increase the chances of receiving first-hand information from them (Lutz et al., 2016). In this article, I aim to contribute to an understanding about using participant observation with people with communication support needs and explore ethical considerations in terms of their research participation. I will next describe the ethnographic fieldwork that I conducted in the SWR study before I draw attention to the ethical considerations of the method arising from reflections on personal experiences.

Participant observation in the SWR study

The ethnographic fieldwork of the SWR study occurred in Germany and Australia. It was part of my PhD study, which I conducted from August 2014 to March 2019 (Lutz, 2020). I did not apply an inclusive research methodology that promotes ownership and authorship of the research for people with disabilities due to time and budget constraints, but also due to the fact that I was limited in my capacity as a PhD researcher to do so. The research was part of a degree and a university requirement was that I owned and authored the thesis. During fieldwork, however, I always intended to create opportunities to maximise participation for people with communication support needs. This approach was based on my belief that by learning about their communication preferences and familiarising myself with these, I could gather first-hand information from them which could represent their perspectives more adequately.

I used Institutional Ethnography (e.g. Smith, 2006) as a research methodology to explore how policy processes affect the lived experience of people with disabilities and their support workers in their relationships and vice versa (Lutz, 2020), and applied the traditional research methods used in Institutional Ethnography, which are interviews, participant observation and document analysis. The fieldwork involved participant observation with ten people with disabilities and their support worker/s, five in each country. The interviews were single interviews with each person (if the people with disabilities had some verbal speech or used a communication tool to express themselves) in the relationship as well as joint interviews with the ten pairs. In addition to the fieldwork with the pairs, I conducted interviews with twenty service professionals coordinating support for people with intellectual disabilities, ten in each country and analysed disability policy documents about people's support and their personal budgets. Interviews were audio-recorded and transcribed verbatim.

I used an unstructured form of participant observation (Balcom et al., 2021), which helped me to react to the communication support needs of research participants in adequate and spontaneous ways, to focus on their experience and to learn about their interests and preferred communication options. Remaining flexible during fieldwork and adopting the AAC and/ or assistive technology methods (e.g. communication App on the iPad, using a computer keyboard to write responses in a word-document, engaging with pictorial aids included in an interview schedule and consent form) that people with communication support needs already used, further helped in developing trusting relationships with them and accommodating their communication preferences. I usually observed each pair for a period of three to four weeks. The days and hours within one week varied. This depended on the support hours and participant's preferences regarding the length of time they wanted to spend on taking part in the research. Fifty-two hours across a period of three and a half weeks was the longest and sixteen hours across a period of four weeks was the shortest amount of time I spent with research participants. The observation time included the interviews.

The Human Research Ethics Advisory Panel and the Human Research Ethics Committee at the University of New South Wales in Sydney, Australia (HREAP 9_14_047 and HC15738) granted ethics approval. The conduct of social science research in Germany did not require additional ethics approval from a German institution, confirmed by the German Association of Medical Ethics Committees and the German Ethics Council.

After I received the formal ethics approval, I made contact with research participants and sought consent from them. Consent did not apply to one single situation, but rather happened throughout the entire ethnographic study (Cutcliffe & Ramcharan, 2002; Rogers & Ludhra, 2012). This meant, for example, that I obtained consent before I conducted the interviews and asked if it was okay if I joined them prior to an activity. I used two types of consent forms for people with communication support needs; one in an easy-read format with pictures from Photosymbols Ltd 2016 and the other in plain language only. The latter type of consent form was an appropriate tool for the research with people with intellectual disabilities who could read. The former type served as a communication aid to explain and support participants to understand the study and obtain verbal (e.g. by saying ‘yes’, making a sound that implies an agreement), non-verbal (e.g. by nodding, other signs of approval) and/or written consent (e.g. in some instances participants wrote their first name or a letter of their first name on the form). I used this consent form in the fieldwork with those participants with intellectual disabilities who had communication support needs, as it was their preferred form. These participants could not read, but the pictures on the sheet and my explanations seemed to facilitate their understanding of the study and its research activities. I observed that they carefully listened to me as I read the information on the form and seemed happy and comfortable as I was doing this. One participant also asked me questions about myself after I had read the form. These were some of the signs that helped me to determine if they understood some of what they were consenting to. In addition, I received written and verbal consent from all legal guardians of research participants with communication support needs. These were usually the parents of the participants.

Compared to the ethnographic interviews I had done in previous research projects (e.g. Lutz et al., 2016), I noticed that I had more time as a participant observer to develop trusting relationships with research participants with communication support needs. I was, however, sometimes challenged by ethical tensions and questions that arose as I carried out the fieldwork. I will next reflect on some of these tensions by drawing on personal reflections researching with people with communication support needs.

Reflections on ethical tensions and questions

For the analytical reflections presented in this article, I re-read data from field notes I had taken as a participant observer, including notes from my personal fieldwork diary, and parts of interview transcripts. This data stems from three ethnographic settings. An ethnographic setting was the living and support environment of the person with disabilities. This data was specific to Felix, Thomas and Lachlan.

I had coded the data used in this article as ‘ethically important moments’ (Guillemin & Gillam, 2004, p. 261) to refer to ethical tensions and questions which arose on the micro-level of working as a participant observer and which needed to be managed in-situ. I transformed these moments into learning experiences for myself through further reflexive research. I engaged in reflexive writing at the same time I wrote field notes. At the end of each observation day, I jotted field notes into my paper journal, which I wrote into an online journal immediately the day after. For each observation day, I had created a word document, which formed part of my online journal. Field notes and personal reflections about field notes were included in one document. The personal reflections, however, were separated from the field notes and captured in foot notes as they included my personal feelings in relation to what I observed.

In the SWR study, my reflexive writing and thinking was supported by regular meetings with my two supervisors. For the analysis in this article, however, I discussed my reflections in monthly meetings over a period of six months with a friend who had also worked as an ethnographer with people with intellectual disabilities. We spoke about the similarities and differences in our experiences of being confronted with ethical tensions and questions, and how they were connected to people's communication support needs. We also spoke about our pleasant and unpleasant feelings associated with these tensions. Unpleasant feelings often involved feelings of guilt or regret about not having accommodated the communication preferences of people sufficiently, which then, to our minds, compromised their level of research participation. During these reflexive discussions, we always maintained confidentiality to protect the privacy of research participants and our own experiences.

Further analysis of my reflections revolved around three points of ethical consideration. These were (1) the influence of third parties, (2) observing the person in the absence and presence of research participants, and (3) balancing views on research participants. Each point relates to what I understand to be an ethical key learning within an ethnographic setting.

I am addressing a particular ethical tension in each setting, which has specific implications for the research participation of the person with communication support needs present in the setting. While some of the tensions were also palpable in other research settings, they became particularly meaningful in a specific setting affecting the research participation of a single participant. I selected the three settings as the key learnings were inextricably linked to the person's communication support needs.

The three settings were specific to the individual support context and to a particular time of data collection and are therefore limited in generalising findings to a larger population. It is, however, not the article's aim to generalise these findings, but rather to sensitise researchers to ethical tensions and questions they may encounter in participant observation with people with communication support needs.

The influence of third parties

In each ethnographic environment, third parties in observation surrounded people with communication support needs. These were people who inevitably become part of the fieldwork, but who were not the person with disabilities, nor their support worker or the researcher. They included house mates, friends or family members of people with communication support needs and other support workers/ support staff.

A key learning revolved around their influence and usefulness in facilitating research participation for people with communication support needs. Their views and expectations of the person's capacity to be involved in the research influenced the person's level of research participation, which happened in Felix' setting, for example. In this research environment, his parents (Margaret and Victor) influenced his research participation as the research took place at their house. Felix was living with them.

I had a phone conversation with Margaret prior to meeting Felix to talk to her about the study and obtain consent to meet with Felix. I learned that Margaret and her husband were in agreement with Felix taking part in the research. She had prepared him and his support workers by giving them notice of my visits at the house of Margaret and Victor. Charlotte, one of Felix' support workers, was present on the first day I worked with Felix.

> I introduced myself to Charlotte, explained why I was here and mentioned the consent forms. Charlotte asked Felix if he wanted to talk about the research now or shower first. Felix indicated that he wanted to shower by walking towards the stairs. The bathroom was upstairs. Prior to this chat, when I was talking to Victor, he explained that Felix' parents usually sign on behalf of Felix. I said I would prefer to let Felix try to sign the paper himself. (Field notes)

The field notes reveal one way in which Felix communicated his desires (e.g. walking towards the stairs as he likes to shower). Sometimes he used one or two words to communicate with people, but he mostly engaged in non-verbal communication. For example, when he greeted someone he liked or knew, he touched their hand gently and looked at them, maintaining focused eye contact. After Felix got to know people better and trusted them, he occasionally gave them 'blessings', as his workers called them. A blessing was a gentle kiss on the forehead.

Inside the living room at Felix' place, there was a computer on a desk, located in a corner close to the veranda. Throughout the field research, I often saw Felix spending time at this computer and watching music videos on YouTube. Felix returned to this corner of the room and listened to songs when he needed time and space to himself. Inside the living room, when Felix, Charlotte and I were in this space, I could speak to them about the research.

> After Margaret und Victor had left the house that morning, Charlotte, Felix and I talked about the consent forms. We spoke about what it means to take part in the research. Felix gave me a blessing and smiled at me when I explained the research to him. He said 'Yes' when I asked if he wanted to take part. I

> assisted him in writing his name onto the form. I got the impression that he was comfortable with the thought of me spending time with him. (Field notes)

It remains unclear how much Felix understood in that moment (e.g. purposes of my upcoming visits, reasons for doing the research), but it seemed that he understood that I was going to spend time with him for several weeks and would like to learn more from him. Margaret and Victor were his legal guardians and they had provided written and verbal consent prior to the study, but as a disability researcher, it was my ethical obligation to check if Felix felt comfortable in my presence (Rogers & Ludhra, 2012). I had the impression he did, but I also had the impression that he did not fully understand the details of the study. The quiet and private space of this situation (e.g. living room, desk space and computer, not many people around) supported me in the process of receiving initial informed consent from him, and seemed to support Felix in focusing on my presence and getting to know me. At this point, I had already spent half of the day with Felix and had acquired some understanding of what might influence his moods and communication.

Due to his high level of support needs, multiple people typically surrounded Felix. I benefited from the relationships Felix had with third parties, such as his parents. They helped me to get in contact with Felix and his workers. I needed to draw on a critical lens, however, in thinking about their influence on Felix' responses to the research process. Margaret had helped me to access Felix and his workers. She could imagine her son being involved in the study and mentioned at some point that Felix had been involved in research studies before. I relied on her relationship to Felix to involve him in the research. She trusted her son's capacity to participate in the research. In contrast to Margaret, Victor was sceptical of his son's capacity to consent to the research. I encountered Felix in a more unprejudiced way. Perhaps the fact that I did not have a specific view and/ or set expectations of him helped me in taking this approach. I felt this approach also affected obtaining consent from Felix and finding out about his communication preferences.

Observing the person in the absence and presence of research participants

Another key learning emerged from my reflections about observing the person in the absence and presence of other research participants. Thomas was a young man who lived in a flat with four people with disabilities. His worker Luke assisted him and his flat mates with activities to live in the flat. Luke was always present when I observed Thomas. I only spent time with Thomas in the absence of Luke when I conducted an interview with Thomas towards the end of the fieldwork, which formed part of the observation. In this single interview, I wanted to learn more about Thomas' view of his living and support arrangements as well as his relationship to Luke.

Thomas did not use full sentences to express himself, but he could initiate conversation, for example, by making vocal noises and maintaining eye contact with people or approaching someone and saying a word that Luke (but not always me) understood. Thomas worked with a communication facilitator named Robert who was not involved in the support that Thomas received at the flat. When Robert and Thomas worked together, they met either at Thomas' day program or at Gerda's (mother of Thomas) house. Robert assisted Thomas in putting his thoughts and feelings into writing on a laptop. For the interview, Robert assisted Thomas by holding his wrist so that Thomas could type his answers to my questions into a Word Document. This interview happened at Gerda's house, which was near Thomas' flat. It was quieter and more spacious there.

It was an interesting experience to see Thomas in this environment as up until then, I had only observed him in company of Luke and his flat mates. In his flat, he often stood next to a window looking outside with, what I interpreted to be, an unanswered longing in his eyes. To me he often seemed to feel excluded, sad and misunderstood. In company of Robert, I had the impression that he felt happy and satisfied. Throughout the interview, I could see that Thomas was concentrating on what he was trying to express. It was a strenuous activity for him, not only in terms of finding the right words for his thoughts and feelings, but also in terms of navigating his responses via Robert.

Thomas had published poems with the supported typing method and I had read some of them in preparation. In the interview, I asked him what 'gentle thoughts', the name of one of his poems, meant to him. 'Gentle thoughts are very confidential, even intimate; thoughts one does not share with everyone', he explained by typing his response.

> *Deborah:* With whom can you share gentle thoughts? Anyone? For example, Robert or mum?
> *Thomas:* Is typing for several minutes, then Deborah reads the response, 'practically, it is only possible with Robert, but mother and sister are feeling the most with me.'

By using Thomas' poems as a starting point to talk about his thoughts and feelings, I learned that poetry was his way of communicating his most intimate thoughts. Having worked as a participant observer for several weeks in this setting prior to the interview had enabled me to learn about his interest in poetry. This was a learning I used to access his experience and shift some control over the research process to him which increased his level of research participation. Depending on a communication facilitator to express these intimate thoughts put Thomas in a very vulnerable position. He revealed his feelings not only in my presence, but also in Robert's presence. In the interview, we also spoke about his poem 'From Me'.

> *Deborah:* I read your poem 'From Me' and wanted to ask what you mean when you use the words 'All Alone'. Do you mean that you are feeling alone?
> *Thomas:* Grinds his teeth and types, 'Of course, I am all alone with myself, very alone'.

In the absence of Luke, in the presence of Robert and in a space where Thomas seemed to feel comfortable and safe, I could access his inner thoughts and feelings. This had not been possible to this extent during the fieldwork conducted at Thomas' flat where his flat mates and Luke were present. In the interview, Thomas confirmed the impression I had received about him being isolated and feeling alone when I observed him at his flat.

Robert was not involved in Thomas' day-to-day activities and only met Thomas once a week at Gerda's place. Observing Thomas in presence of Robert revealed something about Thomas' relationship to Luke and his flat mates. Thomas did not share this type of intimacy with them – from my perspective, I wondered if this was because he did not receive the necessary communication support he required to express himself. I had observed Thomas in presence of Luke and his flat mates for four weeks and had not accessed his inner world until the day of the interview, when I observed him in absence of Luke and his flat mates. It was then when I realised that he had a deep understanding of what other people said. He just did not respond in ways that others were accustomed to.

As I reflected on this limitation, I noticed that it was related to my dependence on Robert and Gerda to organise this interview meeting, but it was also influenced by the ways in which the people in the ethnographic field, including myself, had adjusted the research environment to the communication preferences of Thomas. The research environment was Thomas' living environment and it was not inclusive of his communication preferences. Appropriate adjustments, such as consulting and including Robert or Gerda, who were familiar with the supported typing method, more in the observation research at Thomas' flat, might have supported Thomas to express himself through adequate communication support, such as assistive technology.

Balancing views on research participants

The third key learning emerged from reflections about personal struggles in balancing views on research participants. In the context of the SWR study, this struggle included that I sometimes paid more attention to the support worker or third parties than to the person with intellectual disabilities. I sensed the risk that I was relating to them more if the person with disabilities had communication support needs. This tendency to do so usually came through in my field notes, which revealed that I had focused on one person more than the other by writing more about them. Although I always had the intention to build rapport with the person with communication support needs first, I realised that I had to make regular adjustments to balance my view and to shift observational focus on the person with communication support needs.

In Lachlan's setting, for example, I felt particularly challenged in working towards a balanced perspective on Lachlan and his support worker William. Lachlan had Down Syndrome and was living with his long-term friend Paul who also had Down Syndrome. William was their support worker and he was often making jokes.

> Lachlan asked me, 'how old are you?' I said, 'well, have a guess'. William leaned over to Lachlan and whispered '42'. Lachlan repeated '42'. We all laughed. (Field notes)

After working with Lachlan and William for a while, I started wondering whether the joking was part of William's personality or whether it was a response to my presence. Either way, I noticed that I had paid more attention to William than to Lachlan. I enjoyed that William was being charming towards me.

> I asked Paul if he has sugar in his tea. Paul said ‘yes’. William heard this and said ‘Paul doesn’t, but will say yes to a pretty face’. He explained that Paul only has sugar in his cereals. (Field notes)

Lachlan did not speak in full sentences, said single words very quietly, and stuttered sometimes. During the fieldwork, William interpreted Lachlan’s speech for me, asked follow-up questions and provided contextual information, so I could find out more about Lachlan. Both men had worked with each other for five years and this form of communication support from William seemed to have been in place for a while. Lachlan often relied on people he knew, like William or his mother, and who were familiar with his communication preferences to be heard by others. As a participant observer, this issue became clearer when I became aware of my own dependence on William to understand Lachlan.

Throughout the fieldwork, William continued making jokes and over time, I realised that the banter between William and me was an expression of an emotional attachment. In my field notes, I had paid more attention to his actions and words than to Lachlan’s. I was reciprocating the flirting. After a while, I also started to get the impression that William changed and added activities to the support schedule due to my presence. I sought clarification about this in supervision meetings.

> I felt uneasy about today’s observation. I hadn’t slept well and felt bad as I had paid more attention to William than to Lachlan on the previous fieldwork days. I was concerned about the flirtation between William and me. I had brought this up in supervision. Afterwards I knew that I needed to have a chat to William. I felt anxious about this. (Field notes)

After I came to this realisation, I explained to William that he does not need to feel that he must explain everything to me, as it was part of my job as a researcher to find out how Lachlan and he worked together. I gently reminded him that I would be joining them both in the activities that Lachlan usually does and emphasised that it is important that the support schedule does not change due to my presence. William seemed understanding when I mentioned this concern and I did get the impression that his behaviour as well as mine changed slightly for the remainder of the fieldwork.

This example shows that my emotional attachment to William got in the way of taking and maintaining a balanced and relational view on both men. This view enables participant observers to pay equal attention to and generate balanced perspectives on people and their relationships (Lutz, 2020). I had enjoyed engaging in a playful exchange of teasing remarks with William and it seemed that he had a similar experience.

It is important that participant observers are aware that they can develop different types of relationships with their research participants involving different feelings. Ongoing critical reflections with supervisors or colleagues can support them in noticing this risk and adjusting their behaviour so that people with communication support needs maintain the focus of observation.

Discussion and conclusion

This article dealt with ethical considerations I experienced in using participant observation in my research with three people with communication support needs. To write this article, I analysed field notes and reflections on ethical tensions and questions emerging in relation to those tensions that were part of the data I gathered for the SWR study. I share these findings from my use of the participant observation method to consider how I and other researchers can manage and learn from them in light of their commitment to facilitate research participation for people with communication support needs in the research process. These key learnings have implications for ethnographic fieldwork with people with communication support needs.

The first key learning from these reflections targeted the influence of third parties in observation. The views these third parties hold on the person's capacity to be involved in the research influenced the person's opportunities to express their preferences regarding their involvement in the study. Felix' mother was confident that Felix could indicate if he felt comfortable being involved in the research, whereas his father did not seem to have this confidence in Felix' capacity. Third parties can act as facilitators in that they can support researchers in interpreting the person's communication and may bolster the process of building trusting relationships with the person, as stated elsewhere (Lutz et al., 2016). They can, however, also introduce barriers in that they may have fixed views and set expectations about the person's communication and this may influence the researcher's decisions and the person's behaviours. With this in mind, participant observers should venture carefully into ethnographic settings and critically consider the role and impact of third parties on the person's research participation. They need to continuously check if the person with communication support needs feels comfortable sharing information in the presence of third parties assisting them to communicate. This finding is linked to the second key learning, which also provides indication that the person's communication can vary across research settings dependent on the people surrounding them.

The second key learning arose from spending time with the person in different relationships and environments. This broadened my perspective on the person's experiences. Observing Thomas in absence of Luke, but in presence of Robert, helped in understanding Thomas' day-to-day living arrangements and his relationship to Luke and his flat mates better, including its limitations regarding Thomas' involvement in his support. I am aware that supported typing has been criticised for not adequately representing the views of people with communication support needs and promoting dependence on the facilitator (e.g. Chan & Nankervis, 2015; Travers et al., 2014). In the interview with Thomas, however, it seemed an effective communication option available to him in expressing his thoughts. When I read the responses he had typed aloud, he confirmed them by nodding, smiling or making a vocal noise, which I interpreted as ‘yes’. An understanding of Robert’s role earlier in the research with Thomas and Luke might have allowed me to collect more first-hand information from Thomas, which could have increased his level of research participation. Participant observers in future studies should be conscious that people can show different traits in different relationships and communicate these differently. At the beginning of the fieldwork, it is therefore important to identify and speak to people who know the person’s communication support needs well and assess how these needs can be best supported in the context of participation in the research. In all three research settings, I had spoken to the person’s parents prior to meeting them. This facilitated my understanding about issues of exclusion and their links to communication barriers. Conversations with people who know the person well can support researchers in creating richer understandings of how to facilitate the person’s research participation.

The third key learning revolved around the struggle to balance views on research participants. This happened when there was a risk of my relating more to other people in the field, such as the support worker, when the person with intellectual disabilities had communication support needs and I had difficulties making arrangements to accommodate these needs. My emotional engagement with William elucidates this inner conflict very clearly. While other disability scholars have discussed and contextualised issues of emotional attachment and involvement in the researcher-participant relationship (e.g. Cutcliffe & Ramcharan, 2002;

Goodley, 1999; Rogers & Ludhra, 2012), its implications for research participation of people with communication support needs have hardly been considered in research studies. Lachlan's communication support needs, his shy and introverted nature, as well as me feeling drawn to William contributed to the fact that I had initially focused on William more than on Lachlan and did not take a balanced approach toward them. Participant observers need to maintain focus on the person as they blend in and capture broader observations to build a narrative of the people and relationships they are learning from. They need to be cautious that this surrendering process does not compromise their ethical sensitivity, by for example becoming too emotionally attached to research participants. While it is natural that the ethnographer may develop personal relationships involving stronger emotions with research participants over time (Rogers & Ludhra, 2012), it is important to be aware of the risk that the personal aspects of the role can affect the observer's balanced and objective view on the research process (Goodley, 1999).

My learning about how each person communicated took time. Within three to four weeks, I was not able to fully understand the communication preferences of Felix, Thomas and Lachlan, but had started to become familiar with them. I relied on support workers and third parties to sharpen this understanding. I often had to leave the research setting at the time I became more familiar and confident in understanding and interpreting the person's communication. Researchers in future studies that include people with communication support needs have to be conscious that developing this understanding about their communication requires time (Boccagni & Schrooten, 2018; Labaree, 2002).

With respect to time limitations, it is important to note that, compared to other qualitative research methods, such as focus groups or interviews, the method of participant observation provides more time to check if the person feels comfortable with the form and style of the research (Lutz et al., 2016; McGrath & Laliberte Rudman, 2019). It allows researchers more time to become familiar with the person's communication preferences (e.g. preferences regarding AAC and assistive technology). This can increase opportunities for people with communication support needs to experience control in research by expressing their views and feelings and noticing that the researcher gradually understands these expressions (Davis, 2000). Experiencing this control can begin to mitigate power imbalances within the researcher-participant relationship which is particularly important due to the intrusive and invasive nature of participant observation (Gans, 1999; Hammersley & Atkinson, 2019; Rogers & Ludhra, 2012). However, utilising this potential requires researchers to remain sensitive and to be open to the person's body language and signs of non-verbal expression (e.g. eye contact, unovert and subtle movements, muscle tension) (Forster, 2020). Building this sensitivity can be supported by engaging in an ongoing critical reflexivity (e.g. journal writing, re-reading field notes, reflexive research discussions) before, during and after fieldwork (Etherington, 2004, 2007; McGrath & Laliberte Rudman, 2019).

It is therefore important that disability researchers are given opportunities to engage in critical reflexivity through authentic peer or supervisory interactions based on trust and confidentiality. These discussions may help in managing difficult and challenging emotions arising in their role as participant observers, building trusting researcher-participant relationships, generating a profound understanding of the person's communication preferences and taking a step back to reflect on emotional attachments and power dynamics within the researcher-participant relationships and the broader research setting (Warin, 2011).

References

Balcom, S., Doucet, S., & Dubé, A. (2021). Observation and institutional ethnography: Helping us to see better. *Qualitative Health Research*, *31*(8), 1534-1541. https://doi.org/10.1177/10497323211015966

Berger, R., & Lorenz, L. (2015). Disability and Qualitative Inquiry. Methods for Rethinking an Ableist World. Part II: Observational methods: London: Routledge. https://doi.org/ 10.4324/9781315577333

Boccagni, P., & Schrooten, M. (2018). Participant observation in migration studies: An overview and some emerging issues. In R. Zapata-Barrero, E. Yalaz (Eds), Qualitative Research in European Migration Studies. (pp. 209–225). Cham: Springer International. https://doi.org/10.1007/978-3-319-76861-8_12

Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual and Developmental Disability*, *34*(1), 45–54. https://doi.org/ 10.1080/13668250802688306

Boxall, K., & Ralph, S. (2011). Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities*, *39*(3), 173–180. https://doi.org/ 10.1111/j.1468-3156.2010.00645.x

Chan, J., & Nankervis, K. L. (2015). Stolen voices: Facilitated communication is an abuse of human rights. *Evidence-Based Communication Assessment and Intervention*, *8*(3), 151–156. https://doi.org/10.1080/17489.2014.1001549

Cluley, V. (2016). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities*, *45*, 39–46. https://doi.org/ 10.1111/bld.12174

Curryer, B., Stancliffe, R. J., Dew, A., & Wiese, M. (2019). Use of body mapping to explore key family relationships of adults with intellectual disability. *Journal Of Intellectual Disability Research*, *63*(7), 754–755.

Cutcliffe, J. R., & Ramcharan, P. (2002). Leveling the playing field? Exploring the merits of the ethics-as-process approach for judging qualitative research proposals. *Qualitative Health Research*, *12*(7), 1000–1010. https://doi.org/ 10.1177/104973202129120313

Davis, J. M. (2000). Disability studies as ethnographic research and text: research strategies and roles for promoting social change?. *Disability & Society*, *15*(2), 191–206. https://doi.org/ 10.1080/09687590025621

de Haas, C., Grace, J., Hope, J., & Nind, M. (2022). Doing research inclusively: understanding what it means to do research with and alongside people with profound intellectual disabilities. *Social Sciences*, *11*(4), 159. https://doi.org/10.3390/socsci11040159

Dew, A., Smith, L., Collings, S., & Dillon Savage, I. (2018). Complexity embodied: Using body mapping to understand complex support needs. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, *19*(2). https://doi.org/ 10.17169/fqs-19.2.2929

Etherington, K. (2004). *Becoming a Reflexive Researcher: Using Our Selves in Research*. London: Jessica Kingsley Publishers.

Etherington, K. (2007). Ethical Research in Reflexive Relationships. *Qualitative Inquiry, 13*(5), 599–616. https://doi.org/ 10.1177/1077800407301175

Forster, S. (2020). Approaching a person with profound intellectual and multiple disabilities: What do you think, what do you do?. In M. Nind, & I. Strnadová. (Eds). *Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion* (pp. 133–158). London: Routledge.

Gans, H. J. (1999). Participant observation in the era of "ethnography". *Journal of contemporary ethnography*, *28*(5), 540–548. https://doi.org/10.1177/089124199129023532

García-Iriarte, E., Díaz Garolera, G., Salmon, N., Donohoe, B., Singleton, G., Murray, L., ... & Spelman, M. (2021). How we work: reflecting on ten years of inclusive research. *Disability & Society*, 1–23. https://doi.org/ 10.1080/09687599.2021.1907546

Goodley, D. (1999). Disability Research and the "Researcher Template": Reflections on Grounded Subjectivity in Ethnographic Research. *Qualitative Inquiry, 5*(1), 24–46. https://doi.org/ 10.1177/107780049900500102

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry, 10*(2), 261–280. https://doi.org/ 10.1177/1077800403262360

Hammersley, M., & Atkinson, P. (2019). *Ethnography: Principles in practice*. (4th ed.). New York: Routledge.

Kolesar, R. (1998). Participant Observation: A research and assessment approach for multiply disabled populations. *McGill Journal of Education/Revue des sciences de l'éducation de McGill*, *33*(003), 253–264. https://mje.mcgill.ca/article/view/8435

Labaree, R. V. (2002). The risk of 'going observationalist': negotiating the hidden dilemmas of being an insider participant observer. *Qualitative research*, *2*(1), 97–122. https://doi.org/10.1177/1468794102002001641

Lees, A., Walters, S., & Godbold, R. (2022). Illuminating the Role of Reflexivity Within Qualitative Pilot Studies: Experiences From a Scholarship of Teaching and Learning Project. *International Journal of Qualitative Methods, 21,* 1–9. https://doi.org/10.1177/16094069221076933

Lutz, D. (2020). *Support work relationships.* Wiesbaden: Springer VS. https://doi.org/ 10.1007/978-3-658-29690-2

Lutz, D., & Fisher, K.R. (under review). Personalising Support through Communication between People with Intellectual Disabilities and their Support Workers. *Scandinavian Journal of Disability Research*

Lutz, D., Fisher, K. R., & Robinson, S. (2016). Sharing the focus: Engaging with support workers to include people with communication needs in research. *British Journal of Learning Disabilities*, *44*(2), 138–145. https://doi.org/ 10.1111/bld.12126

Macdonald, D., Dew, A., Fisher, K. R., & Boydell, K. M. (2021). Claiming space: photovoice, identity, inclusion and the work of disability. *Disability & Society*, 1–29. https://doi.org/ 10.1080/09687599.2021.1925525

Martino, A. S., & Schormans, A. F. (2018). When good intentions backfire: University research ethics review and the intimate lives of people labeled with intellectual disabilities. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 19*(3), 1–18. https://doi.org/10.17169/fqs-19.3.3090

McGrath, C., & Laliberte Rudman, D. (2019). Using Participant Observation to Enable Critical Understandings of Disability in Later Life: An Illustration Conducted With Older Adults With Low Vision. *International Journal of Qualitative Methods*, *18*. https://doi.org/10.1177%2F1609406919891292

Nind, M., & Vinha, H. (2016). Creative interactions with data: using visual and metaphorical devices in repeated focus groups. *Qualitative Research*, *16*(1), 9–26. https://doi.org/10.1177/1468794114557993

Nind, M., & Strnadová, I. (2020). Changes in the lives of people with profound intellectual and multiple disabilities. In M. Nind, & I. Strnadová. (Eds), *Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the Boundaries of Inclusion* (pp. 81–97). London: Routledge.

Robinson, S., Hall, E., Fisher, K. R., Graham, A., Johnson, K., & Neale, K. (2021). Using the 'in-between' to build quality in support relationships with people with cognitive disability: the significance of liminal spaces and time. *Social & Cultural Geography*, 1–20. https://doi.org/ 10.1080/14649365.2021.1950824

Rogers, C., & Ludhra, G. (2012). Research ethics: participation, social difference and informed consent. In S. Bradford, & F. Cullen (Eds.), *Research and research methods for youth practitioners* (pp. 43–65). London: Routledge.

Smith, D. E. (2006). *Institutional ethnography as practice*. Oxford: Rowman & Littlefield Publishers.

Spitzer, S. L. (2003). Using participant observation to study the meaning of occupations of young children with autism and other developmental disabilities. *American Journal of Occupational Therapy*, *57*(1), 66–76. https://doi.org/ 10.5014/ajot.57.1.66

Strnadová, I., & Cumming, T. M. (2014). People with intellectual disabilities conducting research: New directions for inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 27, 1–2. https://doi.org/ 10.1111/jar.12075

Travers, J. C., Tincani, M. J., & Lang, R. (2014). Facilitated communication denies people with disabilities their voice. *Research and practice for persons with severe disabilities*, *39*(3), 195–202. https://doi.org/10.1177/1540796914556778

Vehmas, S., & Mietola, R. (2021). Narrowed Lives: Meaning, Moral Value, and Profound Intellectual Disability. Stockholm: Stockholm University Press. https://doi.org/ 10.16993/bbl

Walmsley, J., Strnadová, I., & Johnson, K. (2018). The added value of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, *31*(5), 751–759. https://doi.org/ 10.1111/jar.12431

Warin, J. (2011). Ethical mindfulness and reflexivity: Managing a research relationship with children and young people in a 14-year qualitative longitudinal research (QLR) study. *Qualitative Inquiry*, *17*(9), 805–814. https://doi.org/ 10.1177/1077800411423196