



A Phenomenological Methodology for Inclusively Researching the Views and Experiences of Autistic People with Profound Learning Disabilities

Ned Redmore 

INTRODUCTION

Autistic people with profound learning disabilities have historically been situated as ‘voiceless subjects’ (Mietola et al., 2017, p. 264), understood as incapable of contributing their own perspectives and widely excluded from representing themselves within research or their related academic fields (Redmore, 2023c). The tools with which to conduct research with people from this group are underdeveloped (Simmons & Watson, 2014, p. 148) and the ways in which they can be ethically and meaningfully included in research continues to be an imperative question within inclusive research fields (Gjermestad et al., 2022).

‘Autistic people with profound learning disabilities’ is a term I use to refer to people with a diagnosis of autism and severe/profound learning disability, autism and complex or high support needs, or severe/profound learning disability (but not autism). As I have argued (Redmore, 2023c), people with these diagnoses share characteristics, needs, ways of being and life circumstances, and separating them in research according to diagnostic labels is unjustified, exacerbating their marginalisation from research. I adopt identity-first language in reference to autism as it is contended that it reduces stigma (Bottema-Beutel et al., 2020), though, in contrast, use person-first language

N. Redmore (✉)

The Open University, Faculty of Wellbeing, Education and Language Studies MK7
6AA, England

e-mail: ned.redmore@open.ac.uk

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in relation to learning disabilities, as it is the term most commonly adopted in research conducted by, or in partnership with, people with learning disabilities (e.g., Brownlee-Chapman et al., 2018).

Although autistic people with profound learning disabilities are often defined through deficiencies and incapacities, they are a heterogeneous group with diverse competencies and communicative abilities (Vehmas & Mietola, 2021). The term ‘non-verbal’ pervades the way this group’s communication is described (e.g., Koegel et al., 2020), yet their communication is complex, including vocalisations, body language, facial expressions, ‘emotional and sensory expressions’ (Gjermestad et al., 2022, p. 11), and limited use of Makaton¹ and picture/visual communication. To those close to them, family members, support staff, friends and peers, they regularly express their views, characters and experiences, which, over time, develops dialogues and shared understandings (Nind, 2018).

Exploring the perspectives and experiences of autistic people with profound learning disabilities requires interpretation, presenting risks and challenges relating to the authenticity of voice. This group have had their ways of being rebuked by researchers (mis)interpreting their psychologies, experiences and values (Vehmas & Curtis, 2017), though this does not remove the significant need to increase their participation in research (Redmore, 2023c). The epistemic risk of misinterpretation, argue Vehmas and Mietola (2021, p. 33), should not suppress the moral obligation to ‘represent these voices’.

Research methods to involve autistic people with profound learning disabilities have thus developed, now including collage and narrative diaries (Ridout, 2016), talking mats (Stewart et al., 2018), multi-modal approaches (Doak, 2018), photo-voice (Cluley, 2017), close participatory observation (Gaudion, 2015; Goode, 1994; Mietola et al., 2017; Simmons & Watson, 2014) and life-story work (McCormack, 2017). Such methods have created dialogue and meaning-making opportunities between researchers, autistic people with profound learning disabilities and their wider communities, yet their representation remains marginal within the broader learning disability and autism fields (Palmer & Walmsley, 2020; Redmore, 2023c).

Paradoxically, this marginal position is highlighted by frameworks for inclusive autism research (Chown et al., 2017) and learning disability research (Walmsley & Johnson, 2003) which exclude autistic people with profound learning disabilities through requirements of them being leaders, owners or instigators of research (Nind, 2013). Outside of these specific frameworks, inclusive research is also used as an umbrella term that covers several approaches involving leading and active roles for community members, such as emancipatory or participatory research. However, people with learning disabilities have voiced a preference that *all* such approaches be termed inclusive as this has a clearer statement of intent (Seale et al., 2015, p. 488). Adopting the

¹ Makaton is form of sign language that uses straightforward and figurative signs to communicate key content or meaning.

term ‘inclusive’ over other terminologies, as I will do in this chapter, can thus be seen as an initial step in developing accessible research opportunities (c.f. maximising participation in chapters 5, 14, this volume) for autistic people with learning disabilities.

The exclusionary nature of the learning disability framework led Nind (2019) to turn towards a more expansive idea of ‘doing research inclusively’. At the heart of doing research inclusively is the concept of *dialogue*; the ethical need for researchers to develop shared understandings with autistic people with profound learning disabilities through the ways in which they communicate, express themselves and participate in the world. Others have added to this (e.g., de Haas et al., 2022; Gjermestad et al., 2022), and a number of elements for researchers seeking to do research inclusively now exist.

This chapter presents a phenomenological methodology which, it is argued, incorporates several elements of doing research inclusively (see also Chapter 14, this volume). The purpose of this methodology is to explore the experiences of autistic people with profound learning disabilities, so that issues or topics can be researched in ways relevant to their perspectives. The chapter is presented as follows:

1. An overview of elements of doing research inclusively with autistic people with profound learning disabilities.
2. A discussion of phenomenology and the framework of Lifeworld Fractions (Ashworth, 2016), a tool for analysing experiences.
3. An overview of thinking phenomenologically while doing phenomenology (Berndtsson et al., 2007), a process to introduce theories and methods relevant to participants’ experiences.
4. A reflection on how I shared perspectives with Ben, an autistic adult with profound learning disabilities, about how I could research inclusively with him.
5. The methodology illustrated through a research study into service culture (Redmore, 2023a) involving Ben.
6. A discussion of how the methodology promotes the involvement of autistic people with profound learning disabilities, as well as its limitations.

Doing Research Inclusively

A key notion of inclusive research is meaningful participation for those people with whom the research is concerned: ‘Nothing About Us Without Us’ (Charlton, 2000, p. 14) (c.f. Chapters 4, 8, 10, 19, 21, this volume). For autistic people with profound learning disabilities, ‘being-with’ is central to meaningful research participation, referring to researchers embedding themselves in the day-to-day lives of people from this group to create dialogue, share experiences and develop understandings of their lives and contexts (de

Haas et al., 2022; Mietola et al., 2017; Morris, 2003). It is a process which, over time, can enable researchers to challenge the etic perspective, that of the clinical outsider, and gain the emic perspective, that of the attentive insider (Gillman et al., 1997; Goode, 1992).

Taking ‘being-with’ as a central starting point for doing research inclusively enables other key elements to follow. *Dialogue* and trusting relationships can begin to form (Nind, 2018) as researcher, participants and those around them begin to learn of and from one another. This requires an openness to all forms of communication, expression and engagement and the minutiae of the contexts in which they occur: the people, the spatial and temporal details, the activities, the sensory landscapes (Simmons & Watson, 2014, pp. 155–156). In these situations, voice and its meanings can be seen as mediated, dynamic and relational, suggest Skarsaune et al. (2021) and Gjermestad et al. (2022), both drawing from Teachman et al. (2018). Similarly, Van Goidsenhoven and De Schauwer (2020) refer to ‘voice without subject’, something that emerges through the ‘intra-action’ between researchers, autistic people with profound learning disabilities and those people embedded in their day-to-day lives. No matter the terminology, required is a commitment to developing meaning and understanding through an open, measured and time-committed process.

An openness to all forms of communication necessitates an openness to a broad array of methods and methodologies. This is an element of the inclusive autism and learning disability fields more broadly (Fletcher-Watson et al., 2019; Seale et al., 2015), a need for ‘flexibility, responsivity and creativity’ (Brownlee-Chapman et al., 2018, p. 891). As researchers learn how autistic people with profound learning disabilities express experiences and views within their day-to-day contexts, so researchers must adapt our approaches accordingly. For example, Simmons’ and Watson (2014) drew from multiple methods, theories and methodologies to explore the lifeworld of Sam, a person with profound learning disabilities. Adapting and reimagining traditional research approaches can extend and enhance dialogue, encouraging participation that otherwise may be inaccessible (Nind & Vinha, 2014).

Working with autistic people with profound learning disabilities, researchers are at risk of elevating their own perspectives without consideration for their positionality and preconceptions. Some researchers seek to tackle this issue by consulting with those close to participants, family members, support staff and so on (e.g., Simmons & Watson, 2014; Van Goidsenhoven & De Schauwer, 2020), reflecting on interpretations of communication and experience with those who’ve developed understanding over many years. In such cases, the interpretation becomes shared and mediated across research processes: note-taking, fieldwork, analysis, dissemination and so on. Interrogating preconceptions and interpretations can also be methodological in nature, Andrews et al. (2019) for example utilise a framework to redirect interpreters to aspects of experience they may not have yet considered. Such processes can support those close to autistic people with profound learning

disabilities, as well as researchers, to challenge embedded assumptions and bring about new interpretations.

It is argued that this chapter's methodology enables, to greater or lesser extents, the described ways of doing research inclusively. This methodology uses the phenomenological framework, lifeworld fractions (Ashworth, 2016) and draws from the approach 'thinking phenomenologically while doing phenomenology' (Berndtsson et al., 2007), both of which are described below.

Phenomenology and Lifeworld Fractions

Phenomenology is concerned with the study of experience, its structures and meanings. It emanated from philosophers such as Merleau-Ponty and Husserl who sought to challenge the positivist perspective that dominated science, arguing that positivism was dishonest (Merleau-Ponty, 1962, p. 11), taking for granted the 'subjective element' that guides 'everything in the world we call organic life' (Husserl, 1970, p. 6). A phenomenon is a thing or event, and a phenomenological approach aims to understand the meaning of a phenomenon through how we experience it.

A key phenomenological concept is that of the lifeworld, referring to 'a person's subjective construction of reality' (Kraus, 2015, p. 4). It is the taken-for-granted nature of our daily lives (Finlay, 2011) in which our experiences are embedded with meaning though rarely reflected upon (Ashworth, 2016). Across phenomenology, the lifeworld is considered the structure within which the world appears for any given person (Ashworth, 2006).

Drawing from a range of theory, Ashworth (2006, 2016) defined the lifeworld through eight constituent elements termed fractions. All eight fractions are felt in any experience, some stronger than others. Considering how a person experiences a phenomenon through the scope of the fractions can reveal significant and complex aspects of their lifeworld in a fully formed and expansive manner. To describe the fractions, the following refers to the phenomenon of speaking to a doctor about a minor ailment, a cough:

- Selfhood—How do we experience our identity? Empowered, or a self that lacks autonomy? Disclosing a cough to a Doctor, I may experience myself as a fraud. I am not ill enough, and I fear judgement.
- Sociality—How others affect our experiences, and how we experience relationships. I am inferior to the Doctor. They cast decisions on what I am. How they act and attend to me affects how I experience myself.
- Embodiment—The way we experience our bodies. Do we feel strong or incapable? We may experience aspects of gender, age, disability or ethnicity. My body feels out of place when disclosing a cough, it is not ill enough. It tenses, and a nervous energy grows inside.
- Spatiality—The meaning of space and place. Space is embedded with customs and practices; they feel welcoming or unfamiliar. A Doctor's

office is strange, exacerbated by the ambivalent way they face half towards me, half towards their computer.

- Temporality—How the passing of time is experienced. Our biographies may challenge us or provide a welcomed sense of nostalgia. We experience our histories and our futures. Sitting in a waiting room feels slow, while speaking to the Doctor flashes by. I am confronted by a moment from my childhood.
- Discourse—The discourses we draw from. The way our actions and expressions are embedded in social and cultural contexts. Talking to a Doctor, I perform and exaggerate my cough to conform to the conventions of illness.
- Moods (mood as atmosphere)—The mood of a situation. The experience and feeling of an atmosphere. I experience a cloud of dread when sitting in a doctor’s waiting room, though the cloud lifts as I disclose my ailment.
- Project—The pursuit of what we care for. A situation may make us feel enabled or challenged, proud or angry. Speaking to a doctor, I want to see my cough treated. A caring response elicits comfort and reassurance, and I am not embarrassed for disclosing such an illness.

The fractions prompt people to look more closely at how they have previously interpreted experience, to consider experience in a complex and open way, and to reframe prior assumptions and bring about new interpretations. Andrews et al. (2019) demonstrated this when interviewing parents about the developing sexualities of their autistic children, using the fractions to support them to explore their children’s experiences from fresh perspectives. The fractions thus prompt even those with years of experience of engaging with autistic people with profound learning disabilities to look more closely at how they have previously interpreted experience and so, in this sense, promote elements of doing research inclusively.

Thinking Phenomenologically While Doing Phenomenology

A limiting factor in the approach of Andrews et al. (2019) and others that have used fractions (e.g., Finlay & Molano-Fisher, 2008) is that they are presented as a tool to guide interviews and data analysis, which has limited use when researching with autistic people with profound learning disabilities. To value all forms of communication, expression and experience, and to be able to adapt the research approach accordingly, it is suggested that the fractions be incorporated into the process of ‘Thinking phenomenologically while doing phenomenology’ (Berndtsson et al., 2007, p. 256). This is a theory-led approach that asks researchers to be guided by how people experience a phenomenon so that they can explore it with relevant methods and theoretical perspectives. It involves longitudinal research with people in their everyday lives, adopting methods apposite to how they communicate their

experiences, and introducing theory and adapting foci relevant to their experiences. Theory, argue Vehmas and Mietola (2021, p. 55), enables researchers to ‘see beyond the obvious and push our understanding of the lives’ of autistic people with profound learning disabilities, and so with consideration for its broader approach, this phenomenological-led methodology has potential for doing research inclusively with autistic people with profound learning disabilities.

The inclusive promise of thinking phenomenologically while doing phenomenology is, however, negated by its inaccessibility to researchers without an established phenomenological knowledge base, a challenge only exacerbated by the complex and difficult to access writing so often found in phenomenological works (Dahlberg & Dahlberg, 2019). Furthermore, the approach does not provide a framework to challenge a researcher’s assumptions or direct them to alternative, unconsidered areas of experience and so risks elevating their understandings and perspectives. However, both of these challenges can be addressed by using fractions within the approach. As discussed, they help researchers to reconsider, reframe and open up interpretations of experience. The fractions are also a framework based in a broad range of theory including phenomenology, discourse theory (e.g., Harré & Gillett, 1994) and human geography (e.g., Seamon, 1979), and so, as Dahlberg and Dahlberg (2019, p. 5) note, represent a directory of theories relevant to the exploration of experience. In essence, the fractions can act as signposts to support researchers to explore theories, methodologies and approaches relevant to a person’s lifeworld and day-to-day context. Utilised within the approach of Berndtsson et al. (2007), the fractions can thus enable researchers with different levels of academic experience to promote the elements of doing research inclusively when working with autistic people with profound learning disabilities. An example of this process is detailed below.

Ethics

The methodology is described below by drawing from a study in which I explored day-service cultures from the perspectives of autistic people with profound learning disabilities (Redmore, 2023b). The study was granted a favourable ethical opinion by The Coventry and Warwickshire Social Care Research Ethics Committee (18/WM/0322). All names are pseudonyms.

Sharing Perspectives Across Intellectual and Communicative Capacities

The study initially involved a key participant, Ben, a young autistic adult who attended a day-service three days a week. He primarily communicated through vocalisations and body language. His days were busy, pursuing activities and interests in the service and out in local areas. The service was also busy with between 20 and 30 members and staff accessing it each day.

Ben and the majority of his peers would be considered to have severe or profound learning disabilities, meaning that they had significantly limited capacity to understand my role or the project more broadly, no matter the way in which this was communicated. My perspective was that I wanted to enhance and facilitate participation for Ben wherever possible, to allow him to shape the research focus and direction, though it was not possible to explain this to him. Similarly, asking Ben for his perspective through methods normative to me, i.e. speaking or writing, was impossible not only due to his intellectual capacity but also because he was extremely distressed by direct communication or minute changes to his routine.

Hultman et al. (Chapter 8, this volume) describe the sharing of perspectives in a community and academic group of neuro-mixed researchers, including ADHD:ers and people with acquired brain injury. In this dynamic a disharmony of communicative preferences and abilities existed, including people that spoke at different speeds and used different complexities of language, requiring the development of a shared practice to facilitate meaningful participation. Developing a shared practice with Ben was in some ways very easy, as he had no interest in participating or expressing himself other than through the way he lived every day, involving the schedules and activities that defined his life. Across the eighteen days I spent with Ben, there was almost no direct communication between us other than a nod at the start and end of each day.

Ben did, however, understand that I was not a support worker, as he had specific ways of engaging with them that I was not part of, and over the course of the project, showed a keen interest in what I was there for, observing me regularly and at one point taking and looking through my notepad. In this sense, he could share that he was comfortable and accepting of me and what participation meant for him, and it was subsequently a task for me to ask how this form of participation could enable the exploration of his experiences. This process showed that it is important not to presume the limitations of autistic people with profound learning disabilities in their understanding of research and participation, but rather to learn how you understand one another's roles over the course of researching inclusively.

ILLUSTRATING THE APPROACH

The purpose of the approach was for me to develop a dialogue with Ben in which he highlighted areas of experience important to him, as well as methods and theories relevant to his day-to-day circumstances and that of his peers. The approach required a multi-stage, cyclical process of fieldwork, analysis, fieldwork, analysis and so on. Analytic stages did not represent a final analysis and did not require an in-depth interpretation of the data, rather they prompted me to explore the relationship between Ben's experiences, the day-service context, and relevant theories and approaches. The intention was for Ben's views and experiences to guide the study's development and focus, thus promoting meaningful participation.

As described below, the research began with close participatory work with Ben and broader ethnographic observations of service life. A subsequent period of analysis with lifeworld fractions highlighted areas of experience important to Ben and the broader context of the service community, pointing to theories with which to explore these experiences. By returning to the service and once again being-with Ben in his day-to-day context, I reflected on the analysis and whether it still felt pertinent and plausible, to see if there were aspects of his lifeworld and service life to explore, and to consider the relevance of theoretical perspectives highlighted through the analysis. It was also an opportunity to consider whether the methods being used were appropriate to the way Ben and his peers were communicating their experiences. Over two stages of fieldwork and analysis, the process enabled me to learn about Ben and his peers' experiences and communicative preferences, leading me to understand how I could research service culture through a relevant theoretical perspective and method.

Examples of the analytic method are provided below through screenshots of Nvivo 11, a qualitative data analysis software.

Stage one

Fieldwork

The aim of the initial stage was to observe and learn about the milieu in which Ben, his peers and their support staff lived day-to-day and to develop an understanding of their social and cultural practices. This required me to develop trusting relationships, ensuring any engagement and research activity was sensitive to their etiquettes and circumstances. By coming to know and understand how they lived and responded to their everyday situations, and by sharing in these situations together, I was able to begin to collect evidence of the ways they were experiencing their worlds.

The initial stage involved nine days (9am–4 pm) of fieldwork over three weeks. Ben was very accepting of me accompanying him and his support worker on his day-to-day pursuits, though he found direct communication distressing. Developing a dialogue with Ben, I began to understand that he disliked direct engagement and instead valued a sociality in which he enjoyed other peoples' presence through observing, listening and sharing situations. I thus chose methods that reflected this preference and etiquette, and which helped to form a body of evidence and understanding over the course of the nine days, they were:

Participatory Observation

This method was drawn from Simmons and Watson (2014) and involved spending approximately 5-hours per-day with Ben, taking fieldnotes detailing the minutiae of his day-to-day life including his communication and expressions, the surrounding contexts, his activity, and how others engaged with him and vice versa.

Ethnographic 'hanging out' Observations

The day-service was a space shared between Ben, his peers and support staff and was the site at which they experienced and contributed to service culture. I was explored this through ethnographic 'hanging out' (Kusenbach, 2003, p. 463) which involved making fieldnotes relating to the practices, activity and customs of everyday life at the service, speaking to and asking informal questions to people and collecting archive material such as support plans.

Reflexivity

I undertook reflexive note-taking throughout fieldwork and analysis to consider what participants were communicating, whether methods could be adapted or introduced to enable stronger dialogue, and whether theories were relevant to their views and experiences. I considered my own position and perspective and how this could be impacting the research approach and process. I am a neurotypical person and former day-service support worker, meaning I had some assumptions and beliefs about day-service life and the experiences of autistic people with profound learning disabilities, such as ideas about the meaning of their relationships with support workers. At times I found myself drawn to areas of life seemingly unimportant to Ben, such as the conversation of support workers, and I explored this in relation to my previous role through reflexive note-taking. I kept in mind the question of how the research topic should be explored in a way that was relevant to Ben and his peers' experiences, perspectives and methods of communication, and attempted to re-focus my perspective accordingly.

These methods led to the development of two data sets, one concerning Ben's experiences and another concerning everyday life for members at the service, the site of service culture. The purpose of the analysis was to explore significant aspects of Ben's experiences and to see how they may have related to the broader experiences and practices of his peers.

Analysis

The first stage of analysis was done through the scope of lifeworld fractions. I did this by coding words, phrases or sections to the relevant fraction or fractions, though this could also be done with visual data, such as photos or video recordings, by coding sections or whole images. Fractions are 'mutually entailed, with overlapping... meanings...' (Ashworth, 2016, p. 23) and so data was often relevant to more than one and require coding as such. An example of fieldnotes coding:

He watches over her shoulder, directing his gaze at her hands and the man behind the counter (sociality and project). The tickets are printed and she shows Ben, clearly stating that we are in screen 4. He nods (sociality, embodiment and discourse).

Each fraction subsequently had a collection of data assigned to it (see Figs. 15.1, 15.2, 15.3 and 15.4):

Fraction	Sources	Individual parts of data
Fractions	0	0
Discourse	9	66
Embodiment	8	33
Moodsness	8	13
Project	9	61
Selfhood	7	34
Sociality	9	87
Spatiality	9	50
Temporality	9	63

Fig. 15.1 An example of the fractions at the end of the initial stage. The numbers on the left indicate the amount of sources (e.g., a day of fieldnotes or a single interview), while the numbers on the right indicate the amount of individual parts of data (e.g., words, phrases or sections)

Fraction	Sources	Individual parts of data
Fractions	0	0
Discourse	9	66
Embodiment	8	33
Moodsness	8	13
Project	9	61
Selfhood	7	34
Sociality	9	87
Spatiality	9	50
Adapting	3	5
creating personal areas	7	17
locating time in space	7	30
project in familiar space	8	28
Space and place	3	6
stillness throughout	7	10
Temporality	9	63

Fig. 15.2 A screenshot of an Nvivo analysis that illustrates six units of meaning within the spatiality fraction

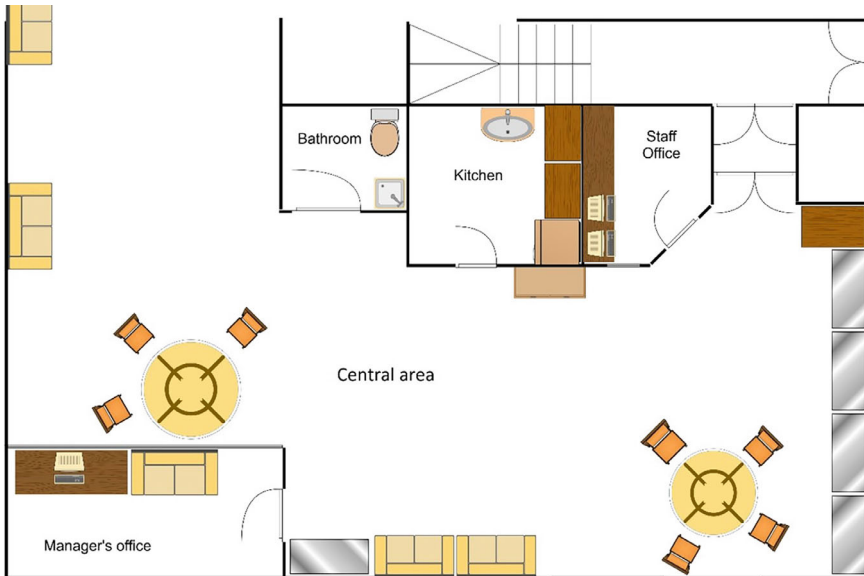


Fig. 15.3 An example of the fieldmap template developed to explore the spatial and temporal character of everyday life within the day-service

I then examined the data assigned to each fraction and suggested ‘units of meaning’, referring to my interpretations of what the experience meant to Ben. To do this, I attempted to orientate my perspective to that of Ben’s and ask of the data: in relation to this fraction, what does this tell me of how Ben was experiencing the situation? I considered the data at hand, as well as insights gained during fieldwork. The below example details an observation of Ben after just arriving at the day-service:

...(Ben) continues watching the person complete the jigsaw. This person is vocalising quite loudly, ‘eeees’, ‘ahhhhhs’ and ‘chup chup’. Emma brings out 2 bottles of squash saying nothing, Ben touches the summer fruits and Emma goes into the kitchen to get him this.

In relation to selfhood, the observation suggested that:

- Ben experienced himself as provided for in that drinks were brought to him.
- Ben experienced a sense of autonomy in the opportunity to choose a drink.

In relation to sociality:

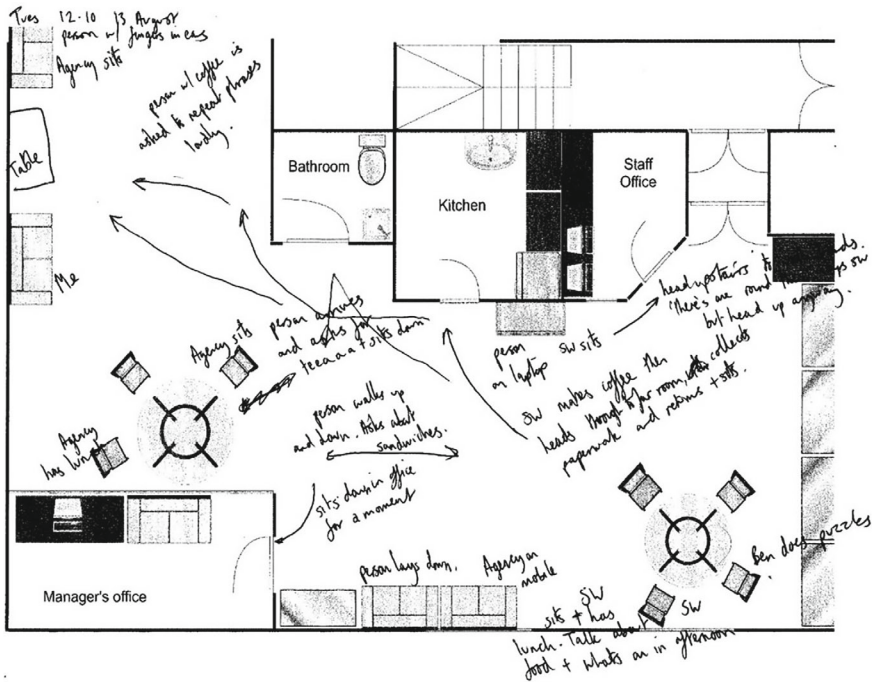


Fig. 15.4 An example of a completed fieldmap depicting ten minutes of activity in the day-service

- Ben was drawn to the activity of others as he observed them.
- Ben viewed support workers as providers (of choice or refreshments).

In relation to discourse:

- Ben expressed his choices through physical direction. He embodied his communication.

As the analysis progressed, units of meaning became more or less decided though never certain, particularly when analysis brought about new or alternative interpretations.

Connecting Analysis to Theory

The analysis will likely have highlighted one or more fractions as significant, which can guide a researcher to explore its foundational theories (see Ashworth, 2006, 2016) and to explore participants' experiences in new, complex and relevant ways. Researching with Ben, three fractions were suggested to be potentially significant after the initial analytic stage: sociality,

temporality and spatiality. The phenomenological works that Ashworth (2006) points to when defining these fractions were thus consulted:

Sociality—the theories of Gurwitsch (1962) and Schutz (1976) and the concept of typification: the prereflective understanding of who others are and how they will act in situations. This prompted a more defined focus for the second stage involving a closer examination of interactions between Ben and his support workers, looking for small differences or similarities in the way he interacted with different people.

Temporality—the writings of Heidegger (1962) that concern protention and retention and relate to the future (its potentials, hopes and fears) and the past (its memories). This had some relevance to units of meaning concerning Ben's experiences, in that he was frequently attending to the next stages of the day and assuring that they happened in a particular way. This theoretical perspective was noted in the front of the fieldnotes diary for the second stage of fieldwork.

Spatiality—the 'place ballet' theory of Seamon (1979) which relates to the coming together of 'individual routines... in space and time' (p.58). Ben's experience of his and others' routines seemed significant, and this was reflected in units of meaning. However, Seamon (2002, p. 45) asserts that place ballet is unintentional and accidental and so on reflection this did not appear relevant to a day-service with planned activities and schedules. Further investigation was required to consider the concept in context.

I 'carried' these theories into the second stage of fieldwork by noting key ideas at the front of my fieldnotes diary and by focusing more closely on relevant aspects of Ben's day-service life, such as how Ben and his support workers engaged with each other in relation to sociality.

Stage Two

Fieldwork

I entered this second stage with ideas of what Ben was expressing about his experiences and the surrounding context, methods that were appropriate for his and his peers' communicative preferences, and particular fractions appearing most relevant to their experiences. I remained open to their views and experiences and whether the theoretical insights gained during analysis were still relevant. This was a case of further developing dialogue to explore previous and new possibilities.

The second stage involved six days (8.50am–3 pm) of fieldwork across three weeks. First stage methods continued though with a more defined focus that concerned:

- The ways in which Ben and his support workers interacted, including differences or similarities between support workers and how they sought to anticipate one another (sociality).
- Routines within the day-service and how these related to movement, environment and the activity (spatiality).
- The ways in which Ben looked to the future through planning, direction or action (temporality).

Analysis

In the second stage, spatiality and temporality were again suggested to be significant to Ben and his peers' experiences and the day-service context. Ben viewed schedules and routines as extremely important and prioritised related customs, which were also highlighted in units of meaning concerning the temporal and spatial order of the day-service and Ben's peers. However, contrary to the speculations I made in the first stage regarding the organisation of the day-service, second stage analysis suggested that people's movement and activity happened according to unwritten schedules and showed day-to-day life to be far less scripted than previously thought.

Consideration of the fractions led back to place ballet (Seamon, 1979), which refers to the ways individuals' routines can become experientially inter-related with others when connected to time and space. This creates shared customs and ways of experiencing a place, so if other people's routines change, a person may experience a disturbance of their own. This theory appeared highly relevant to the units of meaning relating to Ben's experiences, the customs of his peers and day-to-day life at the service. Exploring place ballet further identified a study involving a maps method (van Eck & Pijpers, 2017), which involves documenting qualitative, observational data on a bird's-eye view of an area or space over set periods of time. This method appeared as though it could capture aspects of day-service culture in a way relevant to Ben's experiences, the activity and customs of his peers, as well as the broader context of the day-service. Thus, moving to a third stage of fieldwork, I adopted a maps method with a guiding theoretical perspective relating to space, time and place ballet.

Stage Three and Onwards

The first two stages at Ben's service had highlighted areas of experiences important to him and his peers and suggested that a maps method, led by the theoretical perspective of place ballet, would be an appropriate way to explore this further. Thus, a maps method was used in ninety-minute periods across sixteen days of fieldwork, with a map completed every ten minutes.

This final stage produced a data set with a focus on the activity of everyday life at the day-service and its related spatial and temporal customs. I analysed this through theory-driven thematic analysis (Braun & Clarke, 2006) that used

the concept of place ballet (Seamon, 1979, pp. 143–152) as this had been established as an appropriate frame of reference.

DISCUSSION ON THE APPROACH

This discussion reflects on the ways this chapter’s methodology enabled me to meaningfully involve Ben in research about a key part of his life, day-service culture. I do this by drawing from the phenomenological concept of the *while* (Heidegger, 1996) to consider the ways Ben participated, the ways his perspectives were responded to and how his input contributed to the project’s development.

Heidegger (1996) used the term the *while* to refer to the in-the-moment nature of experience. Rix et al. (2020) drew from the *while* as a way to consider the inclusive nature of research, suggesting that, like experience, participation is in-the-moment and requires reflection in order to understand its meaning. They argued that inclusive researchers often position disabled people outside the *while* of research participation, during analysis for example. Participation thus requires reflection and consideration after the fact, including at what stages people could participate, how they could participate, and how this impacted knowledge construction. Below, Ben’s participation in the *while* is considered through three key areas: dialogue, analysis and design.

Dialogue

Inclusive disability researchers have highlighted the importance of having adequate time to create meaningful dialogue (Brownlee-Chapman et al., 2018; Liddiard et al., 2019; Olsen & Carter, 2016). This is particularly apparent when researching with autistic people with profound learning disabilities (Bradley et al., 2015; Goode, 1994; Simmons & Watson, 2014, pp. 151–153), where long periods of engagement enable researchers to attend to ‘actions, sounds and body language, but also to tempo, mood and potential significance of meaning’ (Nind, 2018, p. 116).

Notable in researching with Ben was that it was not just the time spent with him in which dialogue emerged, but the *act* of repeatedly recording the minutiae of events and circumstances shared with him and subsequently reflecting on them through analysis. For example, Ben adjusted his socks at the same time, in the same place each week, and this gained significance because it had been noted down several times previously. Although appearing relatively trivial, Ben committed to this act and its importance was highlighted in each stage’s analysis through relevance to spatial, temporal and embodied fractions. Within the approach’s circular process, I suggest that meaningful dialogue was promoted, where, in the *while*, Ben could draw attention to aspects of day-service life and experience that were important to him, which could subsequently guide the research focus.

Analysis

Inclusive researchers have often struggled to include people with learning disabilities in analytic processes (Rix et al., 2020; Seale et al., 2015; Stack & McDonald, 2014), and this has been entirely unexplored in the context of autistic people with profound learning disabilities. There are significant hurdles in this regard, primarily relating to the knowledge capacities and communicative repertoires of people from this group, but also in relation to ethical questions it can raise: for example, Ben would experience upset if direct questions were asked of him (e.g., through creative methods) or if his usual, day-to-day activities were disrupted.

I undertook analysis away from Ben and the day-service he attended, creating ‘a new source of participation’ (Rix et al., 2020, p. 7). Here, Ben’s fieldwork contributions mediated the *while*, though his participation and input were marginalised. Such marginalisation amplified my perspective, a dynamic that continues in this chapter. The circular multi-stage approach did, however, help to blur the boundaries of analysis and fieldwork, allowing Ben’s perspective to shape analysis and its theoretical perspective, which subsequently shaped fieldwork and its methods.

The place ballet (Seamon, 1979) scope was a direct result of how space and time appeared significant to Ben in the *while* of participation; it had not been considered prior to researching with Ben. Importantly, the process was not tokenistic, it followed the principles of phenomenological research detailed by Berndtsson et al. (2007), which is to be guided by participants’ experiences and circumstances and a relevant theoretical perspective.

Design

Involving community members in the design of research is important if it is to effectively explore salient aspects of their lives and circumstances (Cascio et al., 2020). Using lifeworld fractions provided the space and time in which to adopt and adapt methods in the *while*, in the ways Ben wanted to engage with me. This approach is not novel, merely following appropriate ways of engaging with autistic people with profound learning disabilities in research (Gjermestad et al., 2022). Where the *while* was extended, and where the approach showed innovation, was in how Ben’s perspective led to the introduction of the maps method to explore day-service culture. It demonstrated that to greater or lesser extents, autistic people with profound learning disabilities can contribute to study design and that this can affect how their lives, circumstances and fellow community members are researched.

Limitations

The methodology detailed in this chapter requires an extended period of time, something that may not be readily afforded within the constraints of funders’

expectations. The study's initial stages involved working with a single person and further research is required to understand how involving more would impact a study's timing and outcomes. Finally, ethical questions are inevitably raised around the extent to which researchers can interpret the views and experiences of autistic people with profound learning disabilities and this requires appropriate reflection and scrutiny. Presented in this chapter was an attempt to provide such scrutiny through its discussion on the *while* of participation, though this may be strengthened through formalised reflective processes or frameworks.

CONCLUSION: REFLECTING ON THE APPROACH'S INCLUSIVE MERIT

This chapter presented a methodology for doing research inclusively with autistic people with profound learning disabilities. This methodology incorporated the framework lifeworld fractions (Ashworth, 2016) and the approach thinking phenomenologically while doing phenomenology (Berndtsson et al., 2007). It was suggested that this methodology promotes five elements of doing research inclusively, which was evidenced through research with Ben in which he communicated his perspectives and experiences on important aspects of day-service life and how they should be studied. I suggest this phenomenological approach is useful in researching with autistic people with profound learning disabilities as:

- It helped me to identify perspectives on day-service culture significant to Ben and his peers, which to begin with I was not focusing on, and which are not represented in broader service culture literature.
- It introduced me to relevant theories and ways to research which I otherwise would not have come across.
- The fractions are, to greater or lesser extents, an accessible phenomenological concept, which I used as a PhD student with no previous phenomenological knowledge or experience.
- The extended periods of fieldwork and analysis gave me confidence and understanding in doing research using several methods.

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