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# Voiceless subjects? Research ethics and persons with profound intellectual disabilities

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**ABSTRACT**
This paper discusses possibilities of designing ethical research practice in relation to people with profound intellectual and multiple disabilities (PIMD). We will argue that in the case of this group of people, research ethics is about ethically justifiable research aims, design, methods, and practices that are based on the recognition of their equal worth as humans. We argue that the turn to emancipatory methods in disability studies has effectively excluded persons with PIMD as they implicitly assume that research participants have the kind of cognitive and communicative capacities that persons with PIMD lack. Their exclusion from disability studies is further reinforced by the theoretical tradition of the field that has emphasised the material arrangements of society, as well as the ableist cultural ideologies as key factors contributing to disabled people's social exclusion. It is problematic to apply these approaches to individuals whose lives are marked by insurmountable impairment effects. Research ethics should take into account potential disparities of cognitive ability and power between researchers and research participants. Using an ongoing ethnographic study about the lives of persons with PIMD as an example, we describe in detail what positioning research participants as moral subjects could mean in practice.

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## 1. Introduction

Disability studies as a discipline has grown out of a need for alternative forms of knowledge concerning disability and disabled people. The discipline is characterised by its close relationship to the disability rights movement, sharing a political commitment to disclose and eradicate social discrimination faced by disabled people. In order to implement this political commitment, new approaches to research practice have been sought after recognising how *research on disability* has in its part marginalized disabled people by producing knowledge *on* them and not *for* them. Disability studies has aimed at developing an alternative research paradigm which not only is inclusive but also aims to empower disabled people. In order to change the social relations of research production (Oliver, 1992), disability scholars turned to critical social research traditions to develop an 'emancipatory research paradigm' for disability studies. (Barnes, 2003; Barton, 2005.) Whilst all research in the field of disability studies cannot be characterised as emancipatory, there is a strong consensus among the discipline about its political aim of promoting social justice by listening and representing the 'voices' of disabled people. We would argue that disability studies, or any social scientific research that examines morally and politically marginalized groups of people, should include an ethical commitment to consider the

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wider implications of research – not merely issues to do with research practice but also what kind of understanding the research produces and promotes about these people.

Considering the drive towards empowerment of disabled people within disability studies, we have been astonished by the fact that people with profound intellectual and multiple disabilities (henceforth PIMD) are virtually missing from key theoretical and methodological discussions, as well as from empirical studies in the field. It is thus reasonable to argue that people with PIMD are probably the most marginal group of disabled people both in society and in research (see Boxall & Ralph, 2010). This group is the last to benefit from the changes in the policy and service system that have followed from the political recognition of disability rights. People with PIMD are still often living heavily institutionalised lives. At the same time as their societal positioning calls for academic attention, they have been mostly neglected by disability studies. It seems that whilst emancipatory research paradigm with its emphasis on self-empowerment has made some disabled voices heard, it has not been able to offer alternative approaches to include those who are the most silenced. As Barton (2005, p. 325) notes, there is a need to pay more attention to 'the extent to which we are aware of and able to engage with some voices', particularly voices of 'those individuals who do not communicate through speech'.

This article has twofold focus. Firstly, we explore reasons for the marginal position of people with PIMD in disability studies, and analyse what kinds of challenges the inclusion of this group presents to the discipline, and the dominant understanding of ethical research practice. We agree with Tuffrey-Wijne, Bernal, and Hollins (2008, p. 188) that it is actually unethical to exclude persons with PIMD from research that could provide insights about their subjective experiences, and about how to promote their well-being. Secondly, we look into the possibility of designing and forming ethically sustainable research practice that would include people with PIMD. This will be discussed in the context of our ongoing ethnographic study *Profound Intellectual and Multiple Disabilities and a Good Life* (Academy of Finland grant number 275988).

Our general approach to research ethics has been strongly influenced by feminist research and feminist ethics of care that stress the quality of the research relationship in terms of respect, equality and reciprocity (e.g. Kittay, 1999; Skeggs, 2001). We also share a processual view of ethics with its focus on the ethical sensitivity of the researcher and ongoing critical reflection throughout the research practice (e.g. Christensen & Prout, 2002; Paju, 2013). We will analyse later in this paper how these general positions and principles materialise in our current research project.

The article has three main sections. First, we will introduce briefly our research project. Secondly, we will discuss the design of research including people with PIMD, especially in relation to their marginality in disability studies. This section unpacks the subtext of our project's theoretical and methodological choices. Third section of the article concentrates on the practice of doing ethnographic research with people with PIMD. We will demonstrate how we have worked to put our ethical commitments into practice during our fieldwork. We will especially concentrate on issues concerning (1) the creation of relationships and trust with our research participants, and (2) constructing interpretations during the fieldwork about our participants' communication, interests, and well-being.

## 2. People with PIMD and a good life

Our research project was initially motivated by the philosophical debates about the moral status of people with PIMD. In these debates, some prominent philosophers such as Singer (1993) and McMahan (2002) compare such individuals to nonhuman animals; they claim that these people are psychologically comparable to pigs and dogs, and can reach the level of well-being of that of a contented dog (McMahan, 2002, p. 153). It is striking how casually these kinds of remarks are made, without any use of empirical evidence. On the other side of the debate, there are philosophers like Eva Feder Kittay (2010) who has a daughter with PIMD, and who appeals to her personal experience and knowledge to refute the claims made by Singer, McMahan and others. In other words, these ethical debates are often informed by personal experience, anecdotal evidence, or by mere gut feelings. This made us realize that there is actually hardly any empirical research being done in disability studies on adults with

PIMD. As a result, we wanted to set a research project that would examine, in the light of empirical data, what makes a good life for people with PIMD.

It should be noted that PIMD is by no means a clear diagnostic category with a consistent terminology. However, it is usually agreed that it involves significant cognitive difficulties, with little or no apparent understanding of verbal language, little or no ability to care for oneself, and usually associated medical conditions (WHO, 1992, p. 230). We utilized this definition when we sought for participants to our study. However, in our view WHO'S definition captures only partially the complex nature of PIMD. We aim for a more nuanced approach with the help of various theoretical accounts such as the capabilities approach (Nussbaum, 2006; Vorhaus, 2014) and (critical) realism (Bhaskar & Danermark, 2006; Vehmas & Mäkelä, 2009) in order to cater for the individual and social aspects related to PIMD.

We produced our data through ethnographic fieldwork in 2015–2016. The fieldwork was divided in three phases, in which altogether six research participants with PIMD were followed, individually by one researcher (Reetta and Sonja as field researchers). Overall, the fieldwork took place in five group homes and two day activity centers (both from public and private/non-profit sectors) as well as in one vocational school.

The fieldwork was carried out by following one participant with PIMD at a time in their group homes, day centers, and other contexts of everyday living. Each participant was followed for a period of 3–4 months during which the researcher followed them for two days a week, during different times of the day. In addition, we interviewed family members and caring staff of the participants (altogether 20 interviews). The interviews focused on interviewees' views about the lives and well-being of our participants. The aim was to take into account different perspectives, and in this way, increase our understanding about the participants' individual histories, needs and interests. We also collected key textual documents concerning our participants' care and services (e.g. individual care plans issued by municipal social services and care plans made by the institutions).

In order to recruit participants, the project first went through an ethical review of the University of Helsinki ethical review board. Already at this stage we felt uncertain how to apply the general ethics guidelines provided for social research in Finland (Finnish Advisory Board on Research Integrity 2009) to our participants, especially concerning informed consent. Whilst the guidelines do provide instructions on how to proceed when research participants are under-aged, they do not touch on the issue of how to proceed in cases where participants of age are not able to understand the information provided or have no means to communicate their will about it.

Whilst the social research ethics guidelines ignore people with PIMD, the ethical guidelines monitoring medical research, more specifically the Medical Research Act (488/1999), do address the issue. Somewhat surprisingly, regulation of medical research provides a more holistic perspective to informed consent than is usually the case in social sciences. In the case of a research participant with PIMD, a written consent is required from a next of kin or other representative close to the participant. Furthermore, consent should also be evaluated from the point of view of research participants, and the possible stress or harm caused to them.

We adopted this wider, more holistic approach to informed consent. This implied a focus on the wellbeing of our research participants as the major concern during the fieldwork; we needed to plan the fieldwork practice accordingly and constantly evaluate our participants' wellbeing during the fieldwork. Thus, following examples from previous international studies including participants with PIMD (e.g. Cameron & Murphy, 2007; Cocks, 2006), our solution was to combine proxy consent with a continuous process of assent.

Our access to the field and to our research participants was gained through a three-tier process of negotiations. In order to gain formal access to the research contexts the project had to apply for a research permit from the municipal offices of social services. This allowed us to approach different care provider organisations, which had different practices concerning research permits. The organisations then guided us to their local units, where we would negotiate with the local level managers, and gradually with the care workers working with our research participants. At this point, the care workers were asked for verbal consent. All interviews were preceded with signed written documents of consent (with one signed copy remaining with the interviewee).

In general, this process of negotiations proceeded surprisingly smoothly, with most of the places immediately welcoming us. Also the family members of our key participants were positive towards the research project. In our view, this easiness of access was probably due to the lack of research on people with PIMD: those contacted seemed to immediately recognise the importance of the project in terms of making this group visible in research – some even explicitly stated that finally someone is doing research on this group. Out of all contacted and asked to participate in the research only one person, a care worker in one of the research units, declined to participate. In this particular case our fieldwork in the unit was carried out when she was not at work.

We initially approached our participants with PIMD through their close family members or their closest care workers (in cases where family ties were loose or non-existent), and a written proxy consent was asked from a next of kin of our research participant with PIMD or a care worker working closely with him or her (see Clement & Bigby 2013; Nind, 2008). In order to take seriously the willingness of our key participants to participate, during the fieldwork we constantly paid attention to whether the participant seemed comfortable with having the researcher participating in his or her everyday life (Cocks, 2006; Tuffrey-Wijne et al., 2008). In order to interpret how the participant with PIMD felt about our presence, we had our interpretations of their responses checked over by their care workers and possibly also by their family members (Cameron & Murphy, 2007; Nind, 2008). We were prepared to withdraw at any time should it seem that a participant was disturbed by our presence. This did not, however, prove to be necessary.

## 3. Designing research focusing on the lives of people with PIMD

Disability studies has traditionally concentrated on examining various social, structural and cultural practices and mechanisms that exclude disabled people from social participation. In the materialist/Marxist tradition, the focus has been on the material, mainly economic factors that have placed disabled people onto the fringes of society (e.g. Oliver, 1990). Various social constructionist and post-structuralist accounts, on the other hand, have mainly produced genealogies and cultural analyses exploring the origins of ableist, discriminatory and oppressive ideas and values (e.g. Goodley, 2014). Since the focus in virtually all theoretical traditions in disability studies has been on societal and cultural factors, individual experiences and properties, such as impairments and their role in people's disablement have often been ignored (Vehmas & Watson, 2017). Unsurprisingly, intellectual disabilities (especially PIMD) have been at the margins of disability studies because they involve the kinds of serious, all-inclusive impairment effects that cannot be explained merely by social arrangements (Chappell 1998; Shakespeare, 2006; Vehmas, 2010).

Methodological developments in disability studies have not facilitated the inclusion of PIMD and the related concerns into the mainstream of disability studies. Considering the wider debate about emancipatory or partisan research (e.g. Hammersley, 2000), and the position taken by disability scholars in the debate (e.g. Barton, 1999; Oliver, 1992), it is easy to understand why people with PIMD have become invisible in the discussion concerning methodologies of disability studies. For example Oliver (1992, p. 111) called for a strict commitment to emancipatory research in which 'researchers have to learn how to put their knowledge and skills at the disposal of their research subjects'. This implies not only that the research should be designed in the best interests of disabled people, but that disabled people should be in charge of research, defining the new emancipatory research agenda (see Disability & Society 1992).

Inclusive research has adopted these 'stringent demands of emancipatory research' (Walmsley & Johnson, 2003, p. 50) when developing research methodology which would truly give 'control to people with learning disabilities and be accountable to them' (ibid., p. 52). Inclusive research methodology was originally used during the 1980s and 1990s, and it has since gained a strong footing in intellectual disability research, whilst staying at the margins of disability studies. Its key principle is the inclusion of people with intellectual disabilities as equal collaborators in all stages of the research process, including control over the outcomes of research (Nind, 2014; Walmsley & Johnson, 2003). These aims of extensive participation and collaboration have manifested in a focus on individuals with mild or moderate intellectual disabilities who have been able to take part actively in the research process. At the same time the main body of methodological texts concerning inclusive research does not discuss how these ethical commitments and innovative methods can be applied to research involving participants with PIMD (Simmons & Watson, 2014; Ware, 2004). This has lately been recognised also within the field of inclusive research as some authors have critically highlighted these exclusionary effects (e.g. Nind, 2014) and presented examples of those few existing studies that have developed research methods to include people with PIMD (e.g. Cluley, 2016; Seale, Nind, Tilley, & Chapman, 2015).

Interpretations of emancipatory research that require giving research participants complete control over the research process effectively exclude persons with PIMD. Whilst this is rarely acknowledged by the proponents of emancipatory research, cognitive impairments often impinge upon an individual's ability to participate in the research process. Especially in the case of persons with PIMD, the idea of them being in charge of a research process is far-fetched. There is therefore an urgent need for further discussions about the possibilities of doing ethically and politically justifiable research which acknowledges power imbalances between researchers and participants.

We agree with Murphy and Dingwall (2001, p. 339) in their view that '(t)he ethics and politics of ethnography are not clearly separable. Questions about the right way to treat each other as human beings, within a research relationship, are not wholly distinct from questions about the values which should prevail in a society.' Our key ethical commitments in our current research project follow from how we position this group. The recognition of their personhood and inalienable worth as fellow humans is the fundamental foundation of this project. We have knowingly put ourselves in opposition to mainstream philosophy that questions the equal moral worth of these people who allegedly lack the cognitive capacities necessary for personhood (see Kittay, 2010; Vehmas & Curtis, 2017). We are with philosophers such as Kittay (2005, 2010) and Nussbaum (2006) who have challenged moral philosophy's one-sided focus on rationality and autonomy, and who have called for the recognition of human embodiment, vulnerability, and interdependence as the overarching features of all humans. Their work provides grounds for positioning persons with PIMD as moral subjects. This has thoroughgoing repercussions for a research endeavour. Firstly, it enables to think their lives in terms of social justice. Secondly, it has implications for research design and practices in terms of creating research relationship based on mutual recognition and respect.

We also believe that Iris Marion Young's (1997) notion of 'asymmetrical reciprocity' is a useful moral framework for developing research practices in studies concerning persons with PIMD. In this outlook, ideal communication starts with mutual recognition, where the other person is seen to have equal moral worth and an irreducible perspective that ought to be considered. However, moral respect also entails recognition of the differences between communicative subjects. According to Young (ibid.), the relationship between participants of a communication situation is always asymmetrical as each of them is distinguished by a particular history and social position: 'when privileged people put themselves in the position of those who are less privileged, the assumptions derived from their privilege often allow them unknowingly to misrepresent the other's situation' (ibid., p. 48). Acknowledging the irreversibility of the perspectives of communicating subjects is therefore an essential element of moral respect.

Young calls for moral humility: acknowledgement that one cannot know in advance how other people feel and judge (see also Kittay's (2010) view on epistemic modesty). This means that one should listen carefully to others expressing their needs and views and be willing to learn something new from them. This is all the more important when research participants are subject to harmful stereotypes and have little means for challenging other people's views about them. The ideal of asymmetrical reciprocity is in line with the practices we developed in our study.

## 4. Research practice with people with PIMD

### *Constructing research relationships: respectful presence and interaction*

During the initial negotiations to gain access to our research contexts and research units we first visited the contexts and shortly met our research participants, and then later discussed with care workers in order to get their consent to participate in the research. For both Reetta and Sonja, who were doing the fieldwork, these initial visits were their first contacts with the research participants – and with people with PIMD in general. In the negotiations with the care workers we emphasised that we must rely on their experience and guidance in how our key participants should be approached and what their preferred ways of interacting with others are (see Boxall & Ralph, 2010; Simmons & Watson, 2014).

Whilst relying strongly on the information and advice given by people working with our participants, we still had some general principles concerning interaction that we held on to: for example, always greeting our key participants verbally (and with touch if preferred) when arriving to the context, interacting with them (verbally or by touch) in situations (moments, spaces) where casual interaction is commonly expected, thus respecting their right to be included in 'normal' interaction and communicative community. We knowingly tried to avoid relying on predetermined, unchallenged diagnostic categorisations that lump together those with the same diagnosis without considering the multiplicity of their experiences and capacities. Instead, we aimed to develop our practices according to what we learned about the individual preferences of our participants in the course of getting acquainted with them (see Christensen & Prout, 2002; Klotz, 2004).

> I go to Ella[1] to say hello, kneel down next to her on the floor, touch her hand and say 'Hi Ella, how are you?'. Ella turns her face towards me, takes hold of my hands and claps my hands together. Then takes my hand to her lips, and from there to her face, pressing my palm against her face. She then lifts her gaze towards me and smiles. Starts clapping with my hands again, then lets go. (Fieldnotes, 'Greeting Ella', spring 2015)

In order to further enhance our ability to communicate and interact sensitively with our profoundly disabled, non-verbal participants, we also acquired consultation on Intensive Interaction methods. Familiarising ourselves with these methods enabled us to attend the subtle and unique interaction initiatives of our participants and respond to them. This way, we were able to build one-to-one relationships with our participants and to develop an understanding of their non-verbal communication and preferences instead of relying exclusively on the views of people close to them.

Previous studies with non-verbal participants have underlined how understanding about individuals' modes of communication and preferences concerning interaction can only be built over time, through sustained presence and participation in their lives (e.g. Davis, Watson, & Cunningham-Burley, 2008; Pockney, 2006; Simmons & Watson, 2014). By taking time in observing the interaction of our participants with other people in different situations as well as their responses in these situations, we gradually learnt to adjust our participation to their preferences and thus construct forms of interaction which would take into account their personal ways of interacting and communicating (see Klotz, 2004). Some of the participants seemed to want to keep distance to us, and we respected this by staying in the background and participating in their activities only minimally. However, others seemed clearly to enjoy close, even physical contact, such as clapping hands, sitting on our lap, or hugging. We responded to the participants' interaction initiatives whenever we could, and interacted with them in ways they preferred.

> I'm sitting on a sofa in the living room and writing notes. Sebastian rolls his wheelchair towards me, stopping in front of me. He sits there a while making repeatedly some of his characteristic utterings, slapping his thigh with his hand, his gaze wandering around, sweeping over me occasionally. I start echoing his utterings. He then grasps my hand firmly, and takes my notebook and throws it to the floor. I rise to pick up the notebook, then return to the sofa. Putting the notebook aside, I bend slightly towards Sebastian and look at him. His head jerks slightly and he lifts his eyebrows, looking enlivened. He rolls a bit closer still in order to pat my thigh with one hand. I pat him back, and on we go, patting each other in turns a long while. In the midst of this patting game Sebastian smiles cheerily and smacks his mouth as if giving me a flying kiss. (Fieldnotes, Sebastian's grouphome, autumn 2016)

We felt that it was crucial for us to learn to recognise our participants' initiatives as well as how they signaled different physical states (being tired, agitated etc.). With some of our participants interpreting their preferences concerning interaction felt easy, like with Sebastian in the above extract, as they were keen to get in contact with others. But with some the process of learning to interpret their expressions and gestures took weeks or even months. We also considered that our participants' preferences concerning interaction might vary in different times and places. For example, we paid attention to any signals suggesting that otherwise sociable participants wanted to be on their own.

Despite the experience we gained during the fieldwork of our participants' means of communication, our interpretations remained partial and situational. We also confronted repeatedly moments when we were uncertain of how to interpret our participants' actions (see Boxall & Ralph, 2010). For example interaction with Ella, who was often seeking physical contact with people around her, sometimes turned into action that could be seen as self-harming.

> I go and sit down next to Ella. Ella moves herself so that she sits right next to me, takes hold of my hand, slipping her fingers in between mine. She's looking at our hands, but doesn't turn to look at me. She suddenly raises her hand (and mine) and hits her forehead with my fist. I tell her 'No, I don't want to hit you Ella', let go of her hand and stroke her hair, but she repeatedly takes hold of my hand and tries to hit herself again. I try to move bit away from her, but she follows right after me, sitting again glued to my side. (Fieldnotes, Ella's group home, spring 2015)

These kinds of incidents kept us aware of the complexity of building ethical practice based on sound interpretations. Especially situations that involved crying, yelling, biting, scratching or hitting, which in the care contexts were often automatically interpreted as negative expressions, were troubling for us. We wanted to respect our participants' right to express a wide range of feelings but at the same time we needed to know whether certain behaviours expressed discomfort towards our presence.

Respecting participants as moral subjects involved also an idea that they have an equal right to privacy. As Kulick and Rydström (2015, p. 6) note, 'for many disabled people, especially those who live in group homes, or who need assistance to do things like bathe and dress, the line between public and private is blurred, and often it is neither acknowledged nor respected.' When negotiating access to our participants, we were aware of these possible challenges concerning privacy – we were after all going to do fieldwork in our participants' homes (cf. Stalker, 1998). In order to be clear about our commitment to respecting privacy of our key participants and their housemates, we brought up these issues already during the negotiations with the care workers. We asked the care workers to guide us to 'house rules' concerning privacy (e.g. knocking door when entering a private room) and to explain us how our participants expressed their wish to be left alone. In these discussions we also defined clear limits to our participation, for example not entering in toilet, dressing or other private activities. During the fieldwork we mostly stayed in the shared rooms and exercised special caution in entering the participants' own rooms.

However, while we accepted respecting privacy as a general rule, we also took into account individual differences and contextual complexities. For example, one of our participants, Frida seemed to enjoy spending time alone in her private room, listening to music or resting in bed. Both Frida's parents and the care workers explained this with Frida's past experience of sharing her room with two other residents when living in a learning disability hospital. For Reetta, Frida's 'own little home' (her father's expression) seemed a very private space, and in a sense this privacy was something that had been defined, at least partially, by Frida.

When spending time with Frida in her room, Reetta paid extra attention to whether and when Frida wanted her to leave the room. However, Reetta felt that since Frida's room was such an important aspect in her life, sometimes a researcher's presence would be justified due to the research interest, as long as this could be done in ways that Frida accepted. Forming ethical practice in these moments, required positioning Frida as a subject with active interests who is capable of communicating her own preferences (see Klotz, 2004).

In addition, we structured our action in relation to the participants according to the principle of reciprocity. In other words, we were keen to contribute positively to the lives of our participants during the fieldwork (see Boxall & Ralph, 2010). One essential way of doing this was to keep company and give extra attention to our research participants. Almost all of their daily activities are organised in groups (group home, day activity centre), where due to the limited number of care staff, the service users only get a very limited amount of one-to-one time with the care workers. Since our participants have very high support needs, they spent long periods of time waiting for care workers to involve them in activities. Our presence made it possible for the participants to have someone there during these times, to watch TV with, to communicate with, or just to 'hang out' with. In some contexts and with some participants it was easier for us to find ways of being 'of use' – the extra pair of hands which makes it possible for our participants to take part in surrounding activities – and thus do fieldwork in a more participatory manner. This, however, required that we already were aware of the general institutional practices, how they were applied individually with our research participants, and also what were our participants' preferences concerning support (see Davis et al., 2008).

> Frida's group is decorating gingerbreads for the coming Christmas party. When others are already finishing, there are still two gingerbreads on Frida's plate. I talk to Frida, ask whether we should still decorate these two. I take a gingerbread in my hand and a tube of sugarpaste in the other, and hold my hands in front of Frida. Frida's eyes are fixed on the gingerbread while I squeeze the tube. I ask Frida did it turn out ok, she reaches her hand out and touches the gingerbread quickly. I take another gingerbread, once again bring it and the tube close to Frida. Frida reaches her right hand forward, stretches her fingers and takes hold of the tube. We stay holding the tube for about a minute together, until she lets go of the tube. I continue by squeezing some sugarpaste on the gingerbread. (Fieldnotes, day activity center, December 2015)

## Building communication and interpretation during fieldwork

Our project's initial commitment was to develop an understanding about the lives of persons with PIMD from their own point of view. This, according to Young (1997), is something we owe to other persons – it is an element of moral respect. We applied this principle by aiming to gain understanding – however partial and fragile – of the things that are important to them and contribute to their well-being.

As already pointed out, the notion of 'asymmetrical reciprocity' emphasises our obligation to take into account the perspective of others, and to acknowledge the 'alterity' of other subjects.In research concerning persons with PIMD the differences that must be acknowledged involve not only the *content* of communication, but also the *method* of communication. Whilst Young's communicative ethics emphasizes the particularities of the experiences that are being recounted, it also provides an ethically sensitive way of dealing with the radical differences in the communicative abilities between the researchers and research participants. By definition, persons with PIMD are not able to speak. Instead, they rely on the most rudimentary forms of non-verbal communication (WHO, 1992, p. 230). In relation to communicative abilities, the ideal of asymmetrical reciprocity could be seen to entail a commitment to recognise the non-verbal research participants as communicative subjects (equal in this sense to persons using verbal language) while simultaneously recognising the differences in their communication. This means that researchers are required to take the time and make the effort to learn to understand the individual, non-verbal ways of communication of participants (see Klotz, 2004).

We followed the ideal of asymmetrical reciprocity by discarding to the best of our ability all presumptions about how research participants could and should communicate. Instead, we were committed to learn each participant's individual way of communicating in the course of our interaction with them (see Klotz, 2004). In practice, this required a great deal of help from their 'communication partners', i.e. people who knew them well (Nind, 2008).

> Leo is in his room, lying on his back in his bed. Once in a while he makes a shout, which starts as a low, hoarse noise, and rises in the end quite high. I'm sitting on a sofa in a living room, but I can still hear his voice clearly, as the room is very quiet, and the door to Leo's room is partly open. I'm wondering if being in his room is what Leo really wants at the moment. One of the carers, Anja, pops in to the living room to tell me that '*that* sound means that he is happy, there is a difference, you see'. She is referring to our earlier discussion about another kind of shout, low and steady, that Leo sometimes makes, and about which I had queried her interpretation. (Fieldnotes, Leo's group home, spring 2016)

However, the aim was not to simply adopt the views of care workers and family members; we were prepared to develop differing views about the behaviours, expressions, and aspirations of our participants where that seemed justified. For example, Sonja eventually came to view Leo's challenging behavior in a way that differed from the interpretations of some of his care workers. Many of them thought that Leo's habit of hurting himself, which included biting and hitting himself and banging his head to hard surfaces, was unintentional; these acts were seen merely as uncontrolled symptoms of his condition, often unrelated to the happenings surrounding him. Sonja, however, noticed that Leo often began to hurt himself when he found some situation uncomfortable in one way or another. For Sonja, Leo's self-harming behavior began to appear as a way to express his discomfort or concern, although this conflicted with the initial views of the care workers.

As we gradually became acquainted with the participants and their ways of communicating, we learned to appreciate the richness of expression that bodies retain in the absence of language (see Klotz, 2004). We saw persons with PIMD communicating with us and other people through, for example, facial expressions, looks, touches, utterings, and movements.

> Anna is driving a motomed [=a motorized stationary bike] in the living room. After driving a while, Anna starts to cry. There are no tears, but she opens her mouth and moans quietly, and there is an unhappy expression on her face. It seems to me that she probably would like to stop driving motomed. (Fieldnotes, Anna's group home, spring 2015.)

Although the communication between our participants and the persons around them was not always optimal, we were nevertheless often impressed by the carers' skills in listening and interpreting the residents' non-verbal expressions. When asked how they communicate with their non-verbal care recipients they often replied that it was not exceptionally difficult. However, the carers we interviewed also acknowledged that they were not able to understand *all* their expressions. Awareness of the limitations in their ability to understand the persons they cared for represents a form of humility (Young, 1997) and epistemic modesty (Kittay, 2010) – something that we also as researchers should practice continuously – as it allows their clients to remain partially unknown, and treats interpretations about their needs as constantly evolving.

The principle of asymmetrical reciprocity calls for giving voice to research participants, but it also involves an awareness of the dilemmas involved. It emphasises that our understanding of others is always partial, especially in the case of people with very limited communicational and cognitive capacities. It is important to remember that the voices represented in research are always constructions made by the researcher, constructed for research purposes (see e.g. Jackson & Mazzei, 2009; Komulainen, 2007). And indeed, some postcolonialist scholars have questioned altogether the right of the ethnographer to represent 'Others' voices' (Schrock 2013; Visweswaran, 1994). Whilst this is a valid concern, we nevertheless side with those feminist researchers who have argued that representing the stories of 'others', speaking for those who cannot do it themselves, is often necessary (e.g. ibid.; Mietola et al., 2016). We aim to represent participants' perspectives in a way that makes visible the interpretative process through which we have arrived to certain understanding of them.

Finally, it is important to bear in mind that the actions of all parties of care interaction are necessarily affected by policy level decisions and governance. For example, one care worker complained that some decisions made by her superiors had hampered her ability to meet the standards of care and support she had set for herself. In our view, ethically sustainable research means representing this complexity and interdependency of action through analysis which takes into account multiplicity of positions and views (Murphy & Dingwall, 2001; Young, 1997). This does not mean that the ethical commitment to enhance the wellbeing of people with PIMD by building understanding of their lives would be compromised. Quite the contrary; considering the perspectives of differently positioned subjects enables an understanding of the web of social relations where people and their identities are constructed.

## Conclusion

We have been inspired by Paul Atkinson's (2015, p. 172) notion that '(w)ith a very small number of egregious exceptions, *ethnography is among the most ethical forms of research.*'(emphasis in the original). Atkinson defends his argument by approaching ethical possibilities of ethnography from two perspectives. Firstly, he stresses the ethical commitment of the ethnographer as key to ethical practice, especially in doing fieldwork, which 'embodies a personal, intellectual and even emotional commitment to the lives of others' (Atkinson, 2015, p. 172). Secondly, Atkinson considers ethics as linked to the general orientation of ethnographic understanding, ethnography's devotion to 'grant serious attention' to the researched culture, and representing lives of research participants in their 'full complexity, with due regard for the rationality of social action, and with respect for the social actors involved' (ibid., p. 173). In Atkinson's view, ethics should be evaluated in relation to the project's commitment to promote 'interests of social justice' (ibid., p. 183).

Our approach to research ethics follows Atkinson's view, and underlines the interlinked nature of these two aspects – the general commitment of promoting social justice and the personal commitment of the ethnographer towards the research participants. Our commitment to social justice and promoting it in the lives of people with PIMD has not only governed the way we have positioned our participants in the initial formation of the research aim, but also profoundly guides our everyday research practice.

The way empirical data is interpreted produces a particular kind of knowledge which, again, constructs a certain kind of reality. The way disability is depicted in empirical research often has normative implications that ought to be considered because empirical claims direct normative judgments considering disability. As mentioned earlier, when philosophers base their normative arguments on empirical assumptions of people with PIMD being comparable to pigs and dogs, it is only consistent of them to grant persons with PIMD a lower moral status compared to other humans. However, if they used a more nuanced empirical knowledge that would problematize simplistic comparisons between humans and animals, their normative arguments might take a very different kind of direction as well.

There is no absolute neutral ground regarding empirical knowledge, without an evaluative component of some sort. Bearing this in mind, it is only reasonable to require a political and ethical sensitivity from disability scholars as their work concerns (in)directly a group of people who suffer moral and political wrongs (Oliver, 1992; Vehmas & Watson, 2017). Having said that, a commitment to benefit the well-being of disabled people should not risk the integrity of academic research. Finding a balance between these two commitments is especially crucial in research that examines a virtually unexplored terrain – such as the well-being of people with PIMD, and what makes a good life for them.

## Note

1. All names used in this article referring to the participants are pseudonyms.

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