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Autor: Mogendorff, Karen

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SPECIAL ISSUE

COUNTERING ABLEISM IN KNOWLEDGE PRODUCTION

Empowerment of Subaltern People and Reproduction of Epistemic Hierarchies

Karen Mogendorff

Abstract

Participatory action research (PAR) employs co-researchers to further epistemic justice for and empowerment of subaltern people. This methodological reflection discusses how user-led PAR with disabled people challenges ableism – hegemonic notions about normate bodyminds – in knowledge production. I draw on my experiences as a disabled anthropologist and as a facilitator of Zeg het ons! PAR projects – the Dutch version of Ask me!, Zeg het ons! seeks scientific recognition and counters ableism by empowering co-researchers to deploy their experiential disability expertise in quality-of-life research. PAR may contribute to de-ableization while partly reproducing epistemic hierarchies. PAR requires experiential and theoretical knowledge on how to deploy positionalities, institutional and interactional arrangements to be successful. More attention for experiential and practical knowledge in academic outlets could help.

Keywords: *ableism in knowledge production, inclusive research, disability hierarchies, empowerment, anthropology at home; disability studies, experiential expertise*

Introduction

This methodological paper discusses how inclusive research – participatory action research (PAR) with disabled people (Bigby, Frawley, and Ramcharan 2013) – seeks to challenge ableism – hegemonic notions and practices with regard to normate bodyminds [1],[2] – in anthropological knowledge production (Durban 2021, 2).

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[1] The term normate was first coined by feminist disability sociologist Garland-Thomson in 1997 (p. 32). The normate is the cultural ideal image of the white able-bodied and able-minded male in his prime who serves as the standard almost everyone tries to live up to.

[2] The origins of the concept bodymind are unclear / contested, but the concept rejects the Cartesian dualistic notion that the body is not affected by the mind and vice versa. Physical conditions tend to affect specific mental or cognitive processes in a way that creates difference but not necessarily impairment. For instance, the physicality of people with Down Syndrome tends to be affected alongside their cognitive capacities. Moreover, whenever people in encounters ascribe intellectual disability to people with physical disabilities,

PAR seeks to challenge existing power and knowledge hierarchies by employing subaltern such as disabled people as co-researchers who are empowered to use their experiential knowledge in research (Knevel, Wilken, and Schippers 2022). Ableism is not only of interest to disabled people. Non-disabled people also suffer from ableism, they also struggle and fail to live up to the ideal of the normate bodymind – the icon of the able-bodied and able-minded white male in his prime (cf. Campbell 2009).

This paper is informed by my experiences as a disabled anthropologist and as a facilitator of Zeg het ons! PAR projects – the Dutch version of Ask me!, Zeg het ons! prides itself at being the first validated inclusive research project in the Netherlands. It was introduced in 2000 by social workers and scholars as a promising method to promote inclusion and better quality of life of people with intellectual disabilities (Zomerplaag 2003).

I will deploy disability as an analytical lens in a similar fashion as gender may be used as an analytical tool (Ginsburg and Rapp 2020). Feminist standpoint epistemology explains the value of disability as an analytical lens as follows (Harding 1992; Mogendorff 2021): what one may know and understand partly depends on one's standpoint – the positionalities one has vis-à-vis others. Positionalities may be ascribed or claimed depending on how one is perceived to relate to the normate bodymind around which everything in society – including academic knowledge production – is organized. What one may experience and know may differ with age, gender, ethnicity, and ability (Harding 1992). Through their differently-abled bodyminds disabled people experience and relate to people, places, and circumstances in ways their non-disabled peers do not readily, enabling them to produce new insights and approaches to problems and methodology (Burke and Byrne 2021). This is also true for people with intellectual disabilities who are perceived in academia as the least likely to contribute to academic knowledge production (Knox, Mok, and Parmenter 2000, 50).

Deploying (dis)ability as an analytical lens means taking disabled people seriously as knowers and knowledge producers who do not only voice their knowledge and concerns (testimonial epistemic justice) but also get the opportunity to incorporate disability knowledge and expertise in knowledge production (hermeneutic epistemic justice) (Baillergeau and Duyvendak 2016, 407 f.; Fricker 2017; Kuper, Chin-Yee, and Park 2020). Inclusive research tries to bring about both forms of epistemic justice.

Before I get into how Zeg het ons! seeks to challenge ableism, I will discuss (1) the relationship between PAR, anthropology, and disability, and (2) ableism in anthropology.

PAR, anthropology, and disability

Participatory action research (PAR) is a form of research that: (1) challenges hegemonic knowledge and power relationships by employing subaltern people with experiential expertise as co-researchers (Baum, MacDougall, and Smith 2006); (2) may be classified as advisory, leading and controlling collaborative group depending to what extent PAR projects actually share power with subaltern people (Bigby, Frawley, and Ramcharan 2013, 3); (3)

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the bodymind is treated as a monolithic whole. Thus, there is also an empirical basis for the concept.

seeks to address through concrete action issues that really matter to subaltern people (Baum, MacDougall, and Smith 2006); and (4) is informed by the Foucauldian understanding that power / knowledge results from institutional arrangements and is exercised through interaction (Baum, MacDougall, and Smith 2006; Foucault 1980 [1972]). PAR with disabled people or inclusive research seeks to counter ableism through empowerment, increase disabled people's quality of life, and promote inclusion of disabled people and their ways of knowing in society. Inclusive research has become popular in the subfield of intellectual disability studies since 2005 (Bigby, Frawley, and Ramcharan 2013).

Although PAR is compatible with anthropology's core business of representing and enabling a diversity of subaltern voices, disabled voices have been underrepresented in both action anthropology – a form of PAR that dates back to the 1950s – and in mainstream anthropology (Ginsburg and Rapp 2020; Shuttleworth 2004). The human rights "nothing about us, without us" movement and disability studies are the most important drivers of inclusive research from the 1990s onwards (Hartblay 2020; Oliver 1992). Within anthropological academic boundaries, the study *of* disability is still largely confined to medical anthropology (Durban 2021; Hartblay 2020; Shuttleworth 2004). But since the 2000s, there is increased recognition in (medical) anthropology that disabled people are not only good informants, but may also be excellent co-researchers who as experiential experts bring a perspective and insight to research, policies, and practices that non-disabled researchers and professionals lack (Oliver 1992; Van der Geest 2007, 11). Van der Geest (2007) argues that a strength of reflexive ethnography and participatory research is that anthropologists may more fully engage in participant observation in their own lived experience than they possibly can in informants' experiences.

PAR is also driven by efficacy arguments: science funded with public money should benefit society (Knevel, Wilken, and Schippers 2022). However, studies found that most non-participatory research has not structurally improved subaltern peoples' life conditions, health, or societal position (Bennett 2004, 19). PAR is believed to be able to help decrease the science-society gap (Bigby, Frawley, and Ramcharan 2013). But that is questionable given that many insights from PAR do not reach academia. Particularly, user-led PAR such as Zeg het ons! that is conducted outside of academia is not published in scientific journals (Bennett 2004; Rubinstein 2018; Stapp 2012). This may in part be because co-researchers and academics do not easily find common ground (Bennett 2004). Van der Geest (2010, 105–108) who encouraged Dutch medical anthropology students to engage in research with representatives of disability organizations as co-researchers in the Netherlands, found that students' master thesis interests did not match the practical research questions provided by 15 patient organizations. Answering questions such as: Is the training for experiential experts effective? does not necessitate anthropological inquiry. Van der Geest's (2010, 105–108) matching-attempt resulted in only one collaborative research project.

To summarize, PAR is increasingly popular in the human rights movement and across the social sciences, including anthropology. It may, however, be unrealistic to expect that advocacy organizations formulate research questions of immediate anthropological relevance. Conversely, anthropologists-in-training may not be optimally situated to direct participatory research projects that address both practical research questions and anthropological concerns. Perhaps experienced researchers in close collaboration with advocacy organizations may be more successful in combining different questions and concerns. Depending on the study's purpose, setup, and population a specific epistemic tradition of PAR may be more relevant than another.

Ableism in (anthropological) knowledge production

This contribution focuses on how PAR may challenge ableism in knowledge production. But what is ableism and how does it manifest itself in anthropology? Durban (2021, 2) citing a conversation between Talila Lewis – an influential community lawyer and educator on intersectional social justice – with negatively racialized people defines ableism as follows:

> *A system that places value on people's bodies and minds based on socially constructed ideas of normalcy, intelligence, excellence, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism, and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily (re)produce, excel, and "behave."*

Thus, countering ableism in anthropology is much about the deconstruction of beliefs, systems, and practices regarding normate bodyminds and, as such, can be understood as a specific form of intellectual decolonization. Intellectual decolonization is understood by Moosavi citing Mbembe as: "dismantling the global Apartheid in higher education" (2020, 333). Moosavi (in Mbembe 2020, 333) mentions disability only in passing, but he discusses mechanisms, e.g. tokenism – the semblance of inclusion is created without real inclusively – that perpetuate marginalization of both Southern and global disability scholarship (Meekosha 2011, 667). People are marginalized or subjugated through a valuation system that negatively judges people who deviate in ability or appearance from the white, abled-bodied and able-minded male norm promoted by a combination of systemic ableism, sexism, ageism, capitalism, and colonialism. The focus is here on an -ism that recently attracted attention in anthropological discussions – ableism in knowledge production (Durban 2021; Hartblay 2020; Mogendorff 2021).

Ableism does not affect all disabled people to the same extent. Disability hierarchies in academia mirror hegemonic societal ableist rankings, e.g. physical disability ranks higher as a presumed less severe disability than intellectual disability (Deal 2003). The latter may translate in increased stigmatization and ableism of people with intellectual disabilities. Disabled people may also internalize ableism; they hold ableist attitudes towards people with other disability types or may consider themselves as less capable than their non-disabled peers (Campbell 2009). Ableism also tends to be systemic and omnipresent: it plays a role across the life course and in every sphere of life. For instance, over-protectiveness – a form of ableism in particular disabled children encounter – may lead to lack of development of skills and capacities that present-day society asks of its citizens (Mogendorff 2011, 67–69).

Addressing ableism in all its guises is key to rapport building, empowerment, better quality of life, and the effective use of experiential disability expertise in research. Failure to sufficiently address ableism results in alienation of disabled people, the reproduction of ableist views and practices regarding bodyminds, and to a reduced quality of life for disabled people (Oliver 1992). Ableism also perpetuates the marginalization of both disabled anthropologists and disability anthropology as a field of inquiry on its own (Durban 2021; Hartblay 2020). To accomplish what I coin de-ableization[3] of knowledge – changing ability norms in a way that fosters diversity and inclusion – it is necessary to address forms of ableism on the interactional and institutional level in knowledge production.

Experiential disability expertise is rarely acknowledged outside disability and care research. Perhaps partly because, as Durban (2021, 4) notes, disabled scholars may be advised to not disclose their disability; to disclose one's disability is considered a career killer (Durban 2021; Mogendorff 2021). Hiding or downplaying disability and impairment either as an expression of internalized ableism, or for strategic reasons, comes with considerable costs to individual disabled scholars and helps to perpetuate ableism and the ideal of the normate bodymind which is most harmful to disabled scholars, but may also negatively affect non-disabled scholars.

Ableism in anthropology Durban (2021) blames largely on the still hegemonic Malinowskian model of total immersion in a field abroad for an extended time period[4]. This classic model of fieldwork is an ideal to live up to and is more likely to booster a career in anthropology than other valued but less influential research paradigms such as anthropology at home, action anthropology and reflexive ethnography (Durban 2021; Mogendorff 2021). Disabled anthropologists are not readily seen as able to manage the hardships associated with Malinowskian fieldwork, and have been advised to engage in presumably less challenging forms of fieldwork despite examples to the contrary (Durban 2021; Colligan 1994).

Part of ableism in knowledge production is also that disability still gets treated as a master identity – an identity that overshadows everything else including disabled peoples' ability to compete with non-disabled peers in the labour market. In my experience, when colleagues tell you that "your disability is not as bad as we thought", chances are that you have sufficiently "proven" that your disability does not interfere overly much with your work. Studiously ignoring disability and impairment or withholding asked for reasonable accommodations are also expressions of ableism found in academia (Campbell 2009; 2019).

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[3] Ableization was first coined by Bednarska (2011) to describe how ability norms can inform conceptions of aesthetics, gender, and sexuality. I prefer the term de-ableization over reablement as used by Campbell (2019). De-ableization and reablement have in common that they call for a critical examination and adaptation of society's narrow understanding of ability, and, with that, disability. However, the *re* in reablement suggests that we need to return to a prior understanding of ability (re is Latin for return to a prior state), whereas *de* signifies moving away from old and current understandings of ability (de is Latin for moving away from). Moreover, reablement may be understood as restoring ability, which may reproduce dominant conceptualizations of ability.

[4] In the Malinowskian fieldwork model, I was educated myself when I pursued a master degree in sociocultural anthropology between 1999–2002. In the curriculum no attention was paid to disability and action anthropology.

Ableism is generally countered by accepting instead of merely tolerating disability as a form of difference. To accomplish this, it is in practice still necessary to demonstrate that ableist assumptions are untrue and that disability may generate novel insights (Mogendorff 2021). Inclusive research seeks to counter the disempowerment caused by ableism by employing co-researchers. By acting as capable co-researchers, disabled people highlight that ability is a part of disability – although this different ability, or diffability as I call it, is often misunderstood, and as such, calls for a critical examination of the concept of ability. Examining and redefining ability Campbell (2019) calls reabledment, but as explained earlier in this paper, I prefer the term de-ableization and diffability – to enable the development of novel conceptualizations of ability instead of returning to old ability conceptualizations.

Zeg het ons! concepts: Quality of life and empowerment

The inclusive research Zeg het ons! counters ableism – a major cause of diminished quality of life – with empowerment of disabled people. Ableism is already discussed, which leaves the concepts quality of life and empowerment as they inform the Zeg het ons! method to be discussed.

Ask me! is originally user-led PAR developed in Maryland, United States by ARC – a care provider – and People on the Go – an advocacy organization for people with intellectual disabilities. ARC and People on the Go developed a questionnaire with easy-to-read text and visuals informed by the quality-of-life questionnaire of Schalock and Keith (1993) and on Signs of Quality provided by People on the Go (Zomerplaag 2003). The concept of quality of life used in Ask me! and Zeg het ons! is: “quality of life is enjoying ‘the good things of life’ – security, belonginess and self-actualization” (Schalock, and Siperstein 1997, 246). Moreover:

> *quality of life is experienced when a person’s basic needs are met and when he or she has the same opportunities as anyone else to pursue and achieve goals in the major life settings of home, community, school, and work.* (Schalock, and Siperstein 1997, 246)

This definition implies that disabled people do not experience full quality of life as they do not yet have “the same opportunities as anyone else” (Schalock, and Siperstein 1997, 246). Ableism is why disabled people do not have the same opportunities as everyone else. Realizing full quality of life requires changes in multiple life domains: housing, social life, employment, self-determination, education, leisure activities. The provided definition of quality of life tells *what* should be accomplished. The concept of empowerment explains *how* full quality of life may be accomplished.

Empowerment in Zeg het ons! Projects

Schalock's and Siperstein's (1997, 246) definition of quality of life that informs Zeg het ons! projects is closely linked to the definition of empowerment by Maton and Salem (1995, 631):

> *The active, participatory process of gaining resources or competencies needed to increase control over one's life and accomplish important life goals.*

Participation, control, and self-determination are essential elements in Maton and Salem's definition of empowerment (1995, 631). These elements are accommodated in the structure and execution of Zeg het ons!: by ensuring that the research is controlled by the advocacy organization *LFB-OS*, by employing disabled people as co-researchers, and by implementing research outcomes together with disabled people guided by an action plan.

Foucault's view on power / knowledge as embodied by PAR, implies that successful co-researchership requires active management of power relationships (Baum, MacDougall, and Smith 2006). According to Foucault (1980 [1972]), knowledge and power are exercised through interaction and result from institutional arrangements and practices (Tremain 2015). The latter means that in order to avoid tokenism – the appearance of influence without real influence (Romsland, Milosavljevic, and Andreassen 2019) – in PAR both interactional practices and institutional arrangements need to be adapted. In Zeg het ons! projects and interactional arrangements are purposely designed to empower co-researchers.

Before I discuss how Zeg het ons! co-researchers are empowered by design and in practice, I will introduce Zeg het ons! further and my involvement in it as a facilitator and as an anthropologist.

My role as a disabled anthropologist and Zeg het ons! facilitator, the Zeg het ons! team, co-researchers, and study participants

I was a Zeg het ons! facilitator from 2005 to 2007. Zeg het ons! projects are still conducted today under the name Zeg het zelf! [Tell it to us! in English].[5] In 2005, I applied for the position of Zeg het ons! facilitator at the Dutch advocacy organization for people with intellectual disabilities called LFB-OS. At that point in time, I had done anthropological research with young adults with physical disabilities, engaged in reflexive ethnography, had conducted research with disabled people as a university researcher and had served as an experiential expert on different advisory boards. It appealed to me that as a Zeg het ons! facilitator, I could employ both my scientific knowledge and my experiential disability knowledge to enable other disabled people to do research.

Soon after I was employed as a Zeg het ons! facilitator, I was asked to present insights and findings of Zeg het ons! projects through academic outlets. For the later purpose, I was given

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[5] Zeg het ons! projects protocols and questionnaires were adapted in 2007 in keeping with changes in legislation for service-provision for vulnerable citizens, hence the name change.

access to reports and anonymized data from when Ask me! was first introduced in the Netherlands in 2000 up to 2007. I wrote fieldnotes and memos during my employment as a facilitator. Co-researchers and I spend training and Zeg het ons! research days together. We would have lunch together and hangout in between Zeg het ons! training, interview, and focus group rounds. In-between time allowed for informal talks. I did not formally interview co-researchers as an anthropologist. But as a facilitator, I did conduct evaluative interviews with co-researchers after every single Zeg het ons! interview co-researchers conducted.

Zeg het ons! team and co-researchers

The Zeg het ons! team consisted of a handful of facilitators who mostly had a background in social work. Half of the team in 2005–2007 had also been involved in the adaptation of the Zeg het ons! method in 2000–2003. The facilitator role is a paid 10-hour-a-week job; all facilitators did hold other jobs in advocacy, care, teaching, or consultancy. I was the only facilitator with a visible physical disability and the only one who had been employed by a university and had published in peer-refereed journals. Most facilitators were involved in 3–4 projects per year.

By 2007, 143 co-researchers had worked for Zeg het ons! on 24 projects; 54 co-researchers worked regularly for Zeg het ons!. On average eight co-researchers participated in a Zeg het ons! project. One of the experienced co-researchers had become vice-president of LFB-OS by the time I joined the Zeg het ons! team. Another co-researcher participated in Zeg het ons! team meetings.

Co-researchers aged 20–60 were all recruited by the Zeg het ons! team through local branches of the advocacy organization LFB-OS. Co-researchers lived on their own with support from a service-provider, most of them had been institutionalized earlier in their lives. In the Netherlands up until the 1990s most congenital disabled people were institutionalized or lived with family.

Study participants of Zeg het ons!

Study participants are service-users of care organizations aged 18–60. Most study participants were institutionalized, but in later projects study participants were increasingly living in local communities with support from a service-provider. Per Zeg het ons! project, 30 people were interviewed and two focus groups were conducted with 8–10 people. Study participants are recruited through purposive sampling of the records provided by the service-provider that always participates in Zeg het ons! research. The 30 interviews and focus groups divided over 4–5 days did take place at a service-provider facility. A Zeg het ons! project cycle from acquisition to signing an implementation agreement with the service-provider typically takes close to a year, two years if one includes the site visit a year after the implementation agreement with the participating service-provider is signed.

I will now discuss the adaptation and validation of the Zeg het ons! method. Scientific recognition is important if one wants to influence academic knowledge production.

The Zeg het ons! adaptation of the Maryland Ask me! method: Greater participation but failed attempt to gain scientific respectability?

Between 2000 and 2003 the Ask me! method was adapted to fit the Dutch context by NIZW – the former Dutch institute of Care & Wellbeing in close partnership with LFB-OS – the Dutch advocacy organization for people with intellectual disabilities. The aim was to make it more participatory in nature than the original Ask me! project and ensure validity and reliability of the Dutch adaptation of the Ask me! method (Zomerplaag 2003).

In the Ask me! project disabled people were involved as peer interviewers. In Zeg het ons! disabled people's participation was expanded to include (1) member-check and prioritization of interview outcomes, and (2) construction and implementation of action plans to improve quality of life of disabled service-users (Zomerplaag 2003).

As a first step of validation the Dutch translation of the Ask me! questionnaire was assessed with disabled interviewers in different care organizations. Questions with regard to quality-of-life domains such as housing, employment, self-determination, and self-actualization did not optimally fit the Dutch context. Subsequently, assessment findings were used to construct the first version of what was from then on called the Zeg het ons! questionnaire. Multiple cycles of testing, evaluation, and adaptation with co-researchers followed until good validity and reliability was reached. Also, a comprehensive procedural handbook and video was produced for facilitators and co-researchers. Finally, complete control over the Zeg het ons! method was transferred from NIZW to the advocacy organization LFB-OS in 2003.

To sum up, in terms of power/knowledge concrete actions were taken to increase the chance that the research would be taken seriously academically; by validating the method and develop protocols over a three-year period. Additionally, the traditional power-knowledge dynamic in research was modified by enlarging the role of disabled co-researchers and by transferring control of the Zeg het ons! method to the advocacy organization LFB-OS.

In actual practice, careful validation of the Zeg het ons! method was not always enough to ensure that Zeg het ons! was taken seriously academically, as my experience with a university researcher indicates:

> *When I was a Zeg het ons! facilitator, a senior university researcher contacted me. This researcher was in the process of writing a report and grant application for inclusive research. I thought it was a good initiative and agreed to share my experiences with Zeg het ons! with her. After the interview, I never heard back from her although she had promised she would send me the report. Later, I did find out that she had claimed in her successful grant application and in her public communication about it, that she was the first to do participatory research with people with intellectual disabilities in the Netherlands. Zeg het ons! was not acknowledged as a source of inspiration.*

The described incident made me wonder: When does PAR get ignored and when acknowledged? The Zeg het ons! method was carefully developed to meet scientific standards, so lack of compliance with scientific norms is unlikely to be the reason. A factor may be that user-led research by disability organizations without a university partner cannot capitalize on the reputation of the university. Perhaps a collaborative partnership in which academic and advocacy actors collaborate as equal partners would be better at gaining scientific recognition? The answer to that question depends on many factors, but my experience shows that user-led PAR may not always be the best arrangement if one seeks to influence academic knowledge production.

Lack of scientific recognition, however, does not mean that user-led PAR cannot increase insight in how ableism may be countered through empowerment.

The Zeg het ons! method: Empowerment and quality control by design and in practice

In the Zeg het ons! method empowerment and quality control are built in different phases of the research cycle. In the recruitment and training phase, co-researchers are empowered by that they are taken seriously as experiential experts: they have to meet job requirements and receive training, coaching and support tailored to their capabilities and needs. They get paid per interview. Taking experiential experts seriously seems self-evident, but professionals may experience action-shyness [*handelingsverlegenheid* in Dutch] when they need to correct people who do not follow pre-established rules or norms. Ensuring that co-researchers conform to scientific norms did empower and helped to guarantee the research quality. In the data gathering phase, co-researchers and the facilitator welcome the study participants who are interviewed during multiple rounds at the research location. The facilitator introduces Zeg het ons! to the study participants at the beginning of every interview round. This introduction serves to double check understanding and consent and to match interviewer duos with study participants. Co-researchers interview in duos because that way one interviewer may ask the facilitator for help if needed, while the other stays with the interviewee. Also, working in dyads ensures that not all individual co-researchers need to have all required research skills, making the research more inclusive. In this phase, if needed, extra accommodations can be provided for individual study participants.

Subsequently, study participants are interviewed by the duos with the Zeg het ons! questionnaire. During the interview, the facilitator visits with refreshments. The latter is an informal way to check interview progress and to offer assistance if needed. Additionally, the role reversal – the facilitator brings refreshments; the co-researchers are in charge of the interviews – is meant to empower in a subtle way. Shortly after conclusion of an interview, the facilitator evaluates each interview with the interviewer duos. These interview evaluations are a quality control step, but also a moment to collect co-researchers' insights and thoughts on the interview, and to provide coaching when needed.

Co-researchers add value in the data-gathering phase; they are generally best at calming study participants who are often nervous. In some cases, interviewees were asked their opinion for the first time in their lives. The added value of co-researchers during peer interviews, is illustrated by the following episode with a study participant with elevator phobia:

> *At one research location the Zeg het ons! interviews were conducted in meeting rooms on the first floor, on the ground level was a swimming pool. The first floor could only be reached with an elevator, the stairs were closed off with chains. One of the study participants who arrived at the interview location did not want to take the elevator, he did not like cramped spaces that moved up and down. I will call him John [pseudonym]. Confronted with this unexpected situation, I was thinking about moving the interview with John to the swimming pool; it is important that participants feel safe and at ease during an interview. One of the co-researchers that day – Peter [pseudonym] – could not write or read but had excellent social skills. Peter formed an interview duo with his wife who could read and write, but was not as socially gifted as Peter. Peter did go downstairs to keep John company, while I introduced Zeg het ons! to the other study participants and matched them with an interview duo. When I wanted to go downstairs, the elevator doors opened and Peter and John stepped out chatting amiably with one another. I welcomed them and offered refreshments. John seemed at ease and wanted to progress with the interview so I introduced Zeg het ons! to him and John was interviewed by Peter and his wife. Afterwards, Peter accompanied John on his elevator ride down. When he was back, Peter, his wife, and I evaluated their interview with John. Peter and his wife: "John liked to be interviewed by us. By another person with an intellectual disability". Peter: "He liked that I did understand his fears. It calmed him down. I am really good at calming down people".*

The experience of being better at something because of one's skill-set and one's specific positionally made Peter and other co-researchers feel accomplished. Co-researchers liked that sometimes they were better at putting at ease study participants than the facilitators. Or at least that is what they told a social work student who evaluated the 24 Zeg het ons! projects in 2007. Co-researchers also told me: "we learn from their [study participants] experiences". It helped co-researchers to expand their (experiential) knowledge.

Study participants were empowered in that they were encouraged to think about their lives and what they would want from it. If you are not used to decide for yourself on many everyday matters, which is true for many institutionalized disabled citizens, you may not think about what you want to begin with (Atkinson 2004). Study participants mentioned during chats after interviews that they liked to be interviewed by peers without a proxy – a family member or personal assistant – being present. Or as one study participant put it: "You can be more honest if they are not there [proxy]".

In the analytical phase of a Zeg het ons! project, the preliminary analysis is conducted by a facilitator. Subsequently, results are presented, member-checked and discussed during a focus group with co-researchers and study participants. In a second focus group, co-researchers, study participants, and members of the clients' board that represents the interest of service-users of the participating service-provider brainstorm about solutions for the identified and prioritized quality-of-life problems. The brainstorm and the action plan that results from it are guided by questions that represent the individual, organizational, and societal level of empowerment: What can disabled people themselves do to solve identified problems?

What the service-provider? And what should be addressed by society or by LFB-OS? In this last phase co-researchers and study participants exercise and increase their experiential knowledge by thinking together of ways to improve service-users' quality of life. The project is concluded with a festive presentation of the results and action plan by co-researchers, after which an implementation agreement is signed with the service-provider. Subsequently, the implementation is monitored by the provider's client council and the Zeg het ons! team.

To sum up, the Zeg het ons! method affects epistemic hierarchies to the extent that experiential disability knowledge is valued. During the data-gathering phase scientism was dominant with the nuance that disability expertise was with co-researchers firmly inserted in it. In contrast, in the validation, sense-making, and implementation phase disability expertise was valued over scientific expertise. Overall, Zeg het ons! shows that scientific knowledge and experiential disability knowledge may complement one another.

De-ableization in the disabled facilitator-co-researcher relationship: questioning disability hierarchies

When I became a Zeg het ons! facilitator, I did not know how my status as a disabled researcher would affect the facilitator-co-researcher relationship. I do have a common highly stigmatized neuromotor developmental disorder that results in physical impairments, but may also go together with intellectual disability. In early childhood, I was initially misdiagnosed mentally retarded after insufficient diagnostic research. Based on these and other ableist childhood experiences, I suspected that I would have more in common with co-researchers than in this paper discussed disability hierarchies suggest.

As it turned out, my visible physical impairments initially confused some co-researchers at the start of Zeg het ons! projects: my impairments indicated I was one of them, but my role as a facilitator signalled to them that I was a non-disabled professional. Having a visibly disabled facilitator communicated effectively that disabled people can be researchers. Some co-researchers would characterize my membership of the disability category and of the professional facilitator / anthropologist category as: "you are an in-between person" [*een tussenpersoon* in Dutch.] someone who has stakes in multiple worlds. In my case, the world of disability and the world of academia.

The shared experience of impairment-disability seemed in part to equalize and enhance the facilitator-co-researcher relationship. This is illustrated by co-researchers' consideration of and reflection upon the lived experience we shared of being labelled too slow:

> *Walking together as a form of reciprocity and empowerment:*
> *A thing that puzzled but pleased me was that co-researchers would almost always walk with me from the bus stop to the research location and vice versa. Due to my physical impairments, I walk significantly slower than non-disabled people. Non-disabled people almost never*

> *match their walking speed to mine all the way to a destination; they sometimes try, but at some point, speed up and wait for me farther along the route, or they will at some point say "I need to be elsewhere". We then separate ways. As a child, I was constantly urged by family to walk more prettily and faster, at a more "normal" speed. No matter how hard I tried, I never walked fast enough. As a result, I had unwittingly internalized an unhealthy walking speed characterized by occasional anaerobic respiration. People generally do not notice, if I walk on top speed, it still takes me 1,5 times longer to get somewhere than non-disabled people. Given my prior experiences, I did not expect co-researchers to walk with me to the research location. I was puzzled: Perhaps they walked with me because they thought that they could not access the research location without me? When I told co-researchers that they did not need to walk with me because I did not have the key [the door was always opened and closed by an employee of the host organization], co-researchers responded with: "We want to walk with you. You are slow with your legs; we are slow in our heads" (see also Mogendorff, 2013). And: "You do not mind we are slow in our heads you take the time to explain things".*

Co-researchers response in words and actions demonstrate empathy and reciprocity informed by the shared experience of disablement. They do know what it means to be constantly judged as too slow and have experienced first-hand the impact of these type of ableist judgments. Co-researchers it seemed, given their own experiences with ableism, made an effort to avoid adopting ableist attitudes themselves. I felt empowered by the co-researchers who walked with me, my low ambulation speed was not merely tolerated but accepted. The fieldnote also shows that experiential experts may help each other to overcome internalized ableism. While walking with co-researchers, I did not have to live up to the normate walking speed I had internalized.

When I did get to know co-researchers better – particularly those I worked with on different Zeg het ons! projects – I noticed how much more we had in common in terms of disablement in addition to the shared experience of being treated as too slow. In the following, I will discuss three related forms of ableism I had in common with co-researchers.

Disabled people are given less opportunity to try, fail or succeed, and learn[6]

It is assumed that you cannot do it anyway, no need to try. For instance, the doctor in charge of the early intervention team that treated me in early childhood told my mother: "you do not want the best for your child" when she refused to follow doctor's advice to enrol me in special elementary school. Instead, my mother with some difficulty, arranged for me to attend the same regular primary school as my non-disabled siblings.

It struck me in co-researchers' stories that they have been given less opportunities to pursue an education or learn new things than their non-disabled counterparts given their limited education. Their stories made me wonder whether some of them could not read or write due

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[6] This phenomenon is related to the social barrier learned helplessness in the socio-political model of disability.

their disability or due to their lack of learning opportunities.[7] Moreover, it was a consistent finding across Zeg het ons! projects that study participants craved more opportunities to learn new things.

Being able to do it, is not good enough[8]

The normate does not only prescribes that you need to be able to do something, you also need to do that something at a certain speed or in a certain way. My parents "punished" me for walking too slowly and putting my feet incorrectly one before the other by requesting that a sibling to walk behind me and tell me to "put my feet straight". I was also put into a stroller by my parents until age 9–11[9] because I was too slow. If I refused to get into the stroller – which was increasingly awkward when I grew, at some point I sat in the stroller with my knees up to my chin – I was not allowed to come along with an outing. As a result, parents of former class mates act surprised when they learn my sister and I are twins: "I thought you were her [my twin sister] younger sister, you were always in a stroller".

Co-researchers were not put into a stroller, but shared the experience of being seen as "thinking too slowly" as discussed previously. Slowness is not only met with judgment; in practice it means that care professionals as proxies took over tasks that co-researchers could and wanted to do themselves. Co-researchers liked that living on their own meant that they could do things their way in their own time. Or as some of them would say: "I am free to do it my way now [I live by myself]"; "Now I can do it myself"; "I want to do it myself"; "I want to learn to do it myself".

Help is generally forced upon disabled people such as me and co-researchers for efficiency reasons, but help is also normative. It signals that the disabled person is doing things in a non-normative way. Moreover, the provided well-intentioned help may disempower disabled people in that it hampers them in developing skills and self-confidence resulting in learned-helplessness and feelings of "never being good enough". And as my stroller experience shows, it may also affect how bystanders view the disabled people concerned.

Being over-protected / monitored[10]

My parents did not allow me to travel to secondary school by bike. I had to go by bus accompanied by my non-disabled twin sister until I was 15, although I did not require and did not

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[7] Segregation of disabled students still exists today in the Dutch educational system. But since 2016 we have in the Netherlands a law that promotes inclusive education of disabled children [*wet op passend onderwijs* in Dutch].

[8] This phenomenon is related to the social barrier "receiving unwanted help" in the socio-political model of disability.

[9] I am not sure about the exact age. There are photos of me sitting in the stroller with my knees up to my chin at least until the age of 9. Granny claims that I was put in a stroller by my parents up to the age of 11.

[10] Over-protection is a social barrier in the sociopolitical model of disability. However, monitoring and surveillance does not get much attention in this model.

get any actual assistance to get on and off the bus. My twin sister accompanied me reluctantly, she wanted to go by bike. When I left home at 18 to study and live by myself and from then on did do everything basically by myself without anybody watching over me, it was quite a transition for me.

Being over-protected / monitored turned out to be a shared experience with co-researchers. Not being constantly monitored is something co-researchers liked and valued: "you are your own man / woman when you live on your own"; "I can decide for myself now what I eat / when I get out of bed / whether I have a pet / how I do things". And: "I am not constantly watched" when talking about the benefits of (assisted) living on their own compared to former institutional life.

Over-protection / monitoring may negatively affect development of skills and self-confidence of disabled people considered normal in current-day society. Additionally, over-protection / monitoring may also be a burden emotionally and financially to those who over-protect and monitor. Moreover, as Foucault has taught us, constant surveillance exemplified by the panopticon may also affect behaviour of the monitored when actual surveillance is absent (Tremain 2015).

These three related forms of disablement co-researchers and I experienced, helped to make intelligible how different ableist practices may reinforce each other and may negatively affect disabled people's development regardless of disability type by fostering inability and marginalization. Sharing experiences highlighted the importance what Zeg het ons! tried to accomplish: creating a safe space to empower disabled people who have been disempowerment through ableism, including myself. Safe space is something that needs to be created because experiences of ableism tend to be non-normate; they cannot be shared with everyone everywhere without risking censure or misapprehension, or, as a child, bullying by non-disabled children (Mogendorff 2007).

Naturally, there were also differences between co-researchers and me particularly with regard to knowledge and academic skills. Or as co-researchers would put it: "you find words for everything"; And: "you are slow, but if you are there everything runs on time"; "You keep things calm" [these last two things were mostly said as the facilitator with ADHD was present] and; "You are an academic but not cold". Academics in general some co-researchers considered cold and distant, as not really caring about their lives.

Finally, my experiences with co-researchers indicate that adopting non-ableist attitudes and practices may help to negate disability hierarchies and may also soften academic hierarchies at least on the interactional level. The circumstance, that I share experiences of disablement with co-researchers made it, I think, easier to gain a deeper understanding of the myriad ways in which ableism affects people's lives. This was accomplished in co-production in informal conversations between disabled anthropologist and co-researchers. That we do not have the same disability type appeared to matter little. The latter highlights that disability hierarchies are ableist constructions and it suggest that disability hierarchies may become more fluid in PAR such as Zeg het ons!

Concluding remarks

This methodological reflection focused on how PAR with disabled people may contribute to countering ableism in (anthropological) knowledge production. I discussed the Zeg het ons! method to explore how PAR seeks to affect ableism in knowledge production through empowerment by design and in practice. The focus on empowerment in Zeg het ons! contrasts with the disempowering ableist practices co-researchers and I experience in everyday life.

A factor to consider when engaging in PAR is that experiential experts and community workers in general have other stakes and interest than academics. At the end of the day, community workers and co-researchers find the difference they made in the lives of subaltern people the most important. It is great if empowering people also contributes to theory development but that is generally not the main goal for them. For academic researchers the opposite is true, career wise contributing to theory comes first, changing concrete life conditions of subaltern people second. This is not to say that, anthropological insights cannot contribute to the quality of life of disabled people, as we have seen, they may create safe spaces to share experiences of disability and ableism. However, anthropology is not going to change the majority of disabled peoples' lives for the better. Particularly not as long as disability anthropology as a field of inquiry faces relative marginalization within mainstream anthropology and answering practical (research) questions is not considered relevant to anthropological inquiry.

Employing co-researchers is an effective strategy to demonstrate that subaltern people can be competent knowledge producers and may add something to the research non-disabled people cannot readily. At the same time, the circumstance that the ability of disabled co-researchers to add to research is still not fully treated as self-evident, signals that there is a long road ahead to ensure that experiential disability knowledge significantly impacts on epistemic hierarchies and mainstream academic knowledge production.

PAR may, however, inspire anthropologists who look for ways to involve subaltern people in their research in a manner that does not only benefit the researcher but also the subaltern people (Bennett 2004, 19). As we have seen in this paper, for the latter experiential experts are essential. PAR can help to gain a better understanding of the emic point of view through co-production: you make sense of experiences, events, and data together. Not only the anthropologist but also to some extent the co-researchers engage in participant observation contributing to novel insights.

What type of PAR is most effective in knowledge production is not answered by this paper. As noted earlier, collaborative PAR may be taken more seriously in academia than non-academic user-led PAR, and as such, may potentially have a greater impact on power / knowledge hierarchies. However, collaborative PAR comes with the risk of "cherry picking": only insights are used that fit into narrowly defined academic norms and practices of knowledge production and, in doing so, partly reproduce the status quo. Non-academic PAR is less confined to academic modes of knowledge production. Although, too eager adherence of non-academic user-led PAR to scientific norms of the neopositivist variety may hamper inclusiveness and methodological innovation in the long run. Also, people involved in non-academic PAR may lack experience in academic publishing to affect academic knowledge production significantly.

Last but not least, I learned that the role of community worker / facilitator can be combined with the role of anthropologist and that in fact these two may enrich one another. This contrasts with the stance in anthropology and my education as an anthropologist that anthropologists cannot or should not be simultaneously researchers and community workers (Goldring 2010). To me one role seemed to flow quite naturally into the other; partly because anthropological techniques may be used to empower subaltern people. Knowledge / power is affected in the facilitator / anthropologist-co-researcher relationship in that empowerment is not a one-way street. The specific added value of PAR is that all involved may learn from each other: in the case of Zeg het ons! about de-ableization, marginalization, and the value of slowing down to question the normate.

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Author

Dr. Karen Mogendorff is a disabled anthropologist and communication scientist with an interest in the uses of experiential expertise alongside other forms of expertise. Currently, she works at the Erasmus Medical Centre in Rotterdam, the Netherlands. Her work there focuses on building an infrastructure for participation of disabled people in medical research.
kmogendorff@hotmail.com
Erasmus Medical Centre