Chapter 3

A closer look at ‘wheelchair’ ethnography

Ableism and the insights disabled scholars generate with—not despite—their impairments and disabilities

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Introduction

Ethnography offers unique barriers and opportunities to disabled anthropologists and sociologists. On the one hand, ethnography—the home discipline of ethnography—has the stereotypical image of toughness and daring that does not sit well with disability. Anthropologists are supposed to do research far from their home and comfort, studying less well-off cultures through participant observation (Kloos, 1987; Hammersley & Atkinson, 2000). On the other hand, ethnographical ontology and epistemology offer unique opportunities to disabled anthropologists and sociologists: it recognizes that scholars’ positionsality in research mediated through gender, age, sexual orientation, ethnicity and disability affect researchers’ interests, access to the field, analyses and findings (see also Harding, 1992). Disabled people deviate from the norm and, as such, are optimally situated to expose and analyze taken-for-granted everyday ableist sociocultural practices (Mogendorff, 2010). If disabled anthropologists and sociologists engage more in reflexive ethnography—a reflection on and analysis of one’s own lived experiences as a researcher in interaction with others (Davies, 1997)—insight may be increased into how knowledge is produced through lived bodies and what disabled scholars have to add to the literature (Davies, 1997; Engelstäd, 2005). Despite these benefits, relatively little is published about disabled academics’ careers from an ethnic life course perspective (Roulstone et al., 2003; Shah, 2005) and, to my knowledge, next to nothing about disabled anthropologists’ and sociologists’ work lives (Kasritz & Shuttleworth, 2001).

This contribution is about the role and function of disability in the careers of disabled anthropologists and sociologists and how they, with their lived disabled bodies, produce insights relevant to academics and beyond. Insights that may also play a role in countering ableism. Ableism is a set of beliefs, processes and practices that produce—based on abilities one exhibits or values—a particular understanding of oneself, one’s body and one’s relationship with others of humanity, other species and the environment, and includes how one is judged by others.

(Wolbring, 2006: 252–253)

A reason for the paucity of literature on disabled professionals from an ethnic perspective in general and disabled academics in particular is that disability and impairment tend to be treated as career killers in the employment and disability literature, the media and disability law and regulations (Sandens, 2006; Stone et al., 2013; Williams & Mavin, 2013). In the dominant discourse, disability is equated with unproductivity, passivity and tragedy (Haller, 2000), images that do not fit conceptualisations of the ideal worker (Foner, 2012). However, in recent years several qualitative studies—generally conducted by disabled academics—have critically addressed the barriers and opportunities disabled high-flyers face, for example, see Roulstone et al. (2003), Shah (2005), Foster and Wess (2007). Reflexive disability ethnography specifically may shed light on careers of disabled scholars who deploy their own lived experience of disability as a resource to better understand and help redirect the deeply ingrained culture of ableism.

In this chapter, I draw upon the disability career literature and on what disabled anthropologists and sociologists, myself included, have disclosed in order to explore how the lived experience of impairments and disability affect careers and what disabled anthropologists and sociologists with and through their bodies have to contribute to the literature. Situated disability disclosure may increase insight and appreciation of what disabled ethnographers have to add. But, as discussed later in this chapter, there are ableist processes at play in academia that make this far from easy: the disappearing disability phenomenon and the ‘I am afraid you cannot take it experience.’

When it comes to other disabled anthropologists’ and sociologists’ experiences, I limit myself here to what they published about their lived experience of impairment and disability in relation to their work lives. There are many disabled scholars who choose NOT to publish about how impairment and disability affect their work. Disability disclosure may affect careers (e.g. see Waterfield et al., 2010), or discussing personal experiences does not fit into their ideas about ‘objective’ research (Harding, 1992; Hammersley & Atkinson, 2000). However, I do not need to restrict myself to solely published material when it comes to my own experiences as a congenital non-neuroimpaired inspired anthropologist and non-Western sociologist.

Functions and features of reflexive disability ethnography

Most anthropologists and sociologists who do study disability are non-disabled and disabled anthropologists and sociologists tend to be marginalized within the discipline (Kasritz & Shuttleworth, 2001; Reid-Carringtonham, 2009). Disabled anthropologists and sociologists who have published about how disability informs their
life and work are few, but they argue that researchers should become more open about how research is generated phenomenologically in and through lived disabled bodies by engaging in reflexive ethnography (Seymour, 2007; Howes, 2009). A complicating factor is that disability disclosure may both aid and harm disabled academics' careers: it does not help one to get a job or a promotion (Pearson et al., 2005; Sarcy, 2009), but it may go a long way in:
- creating rapport and understanding with colleagues and research participants (Foster and Wonn, 2007; Mogendorff, 2007, 2013);
- acquiring accommodations that allow one to participate (Mogendorff, 2002);
- creating the possibility that one is being accepted with one's particular difference (Roussone et al., 2009);
- helping debunk crippling images of disability.

Advantages and disadvantages of disability disclosure depend on context, it matters greatly what is disclosed when, where, how and to whom.2 Disabled anthropologists and sociologists, as a rule, do not draw attention to their own lived experiences of disability in their academic writing, nor in face-to-face encounters as employees of universities, it is mostly irrelevant for the business at hand. In academic texts the primary focus is on the analysis of informants' experiences, and, as employees of universities, disabled academics strive to pass as an ideal worker, as 'not really disabled', mainly because passing as normal is rewarded and accentuating difference is not (Mogendorff, 2002; Youse, 2012).

Another reason for the relative paucity of the literature on reflexive ethnography has to do with different traditions and practices in ethnographic writing and publishing. In confessionalist ethnographies readers gain insight into how ethnographers did come by their insights in interaction with informants, literature and colleagues. In the still popular realist ethnographies, the author is the all-knowing storyteller who presents his or her results but reflects little, if anything, on their personal role in the production of knowledge and insights (Van Maanen, 1988). This lack of reflexive writing suggests that the ethnographer's impact on the research done is negligible; what is unhelpful further is that reflexive ethnographic accounts are presumably harder to publish. It is not easy to demonstrate how personal experiences of ethnographers are of wider academic or theoretical interest (Barett, 2014).

The reflexive disability ethnographies published by disabled anthropologists and sociologists that I collected over the years are mostly written by disabled or chronically ill, American, male and arrived sociologists born in the 1970s-1980s: Frank (2002), Karp (1995), Kimmel (2012), Michalko (1999), Murphy (1993), Nighot (2001), Robbins (1999) and Zola (1992). These autoethnographies are very diverse about the extent to which they show disability awareness, the level of reflection and to what extent the authors incorporate the experiences of other disabled or chronically ill people in their analyses. One may even question to what extent they are autobiographies, memoirs, reflexive ethnographies or autoethnographies, but that they all tell a story, sometimes unwittingly, of how one can function as a disabled academic.3 I did not find reflexive disability monographs written by disabled female anthropologists and sociologists, although I did find autoethnographies – broadly defined – written by female academics in other disciplines. Disabled female anthropologists and sociologists, however, have in articles reflected upon how the lived, embodied experience of impairment or disability affected relationships with research participants and enabled the generation of insights about and at home, for example, in Colligan (1994, 2003), Deegan (2001), Mogendorff (2007, 2013), Seymour (2007).

Reflexive ethnography is considered to be a specific form of anthropology 'at home' in that the main focus is on the ethnographers' own experiences. Traditionally, anthropology at home has a lower status within anthropology and non-Western sociology than research abroad. Immersion in another culture for an elongated time period through participant observation purportedly provides a culture shock that enables the fieldworker to critically interrogate taken-for-granted ideas and practices that shape life in the researched culture and makes it possible to examine cultural biases in one's own native culture (Hammersley & Atkinson, 2002). A culture shock that is presumed absent or less profound in anthropology at home. The culture shock is also conceptualised as a vécu de passage, the transition that turns a student into a professional (e.g. see Kloo, 1987; Shuttlesworth, 2004). By extension, anthropology at home is seen as not quite the 'real' thing, although not all anthropologists of note share this view (Brathwaite, 2004). Moreover, Mughal (2015) has argued that anthropology at home is just as methodologically and ethnographically demanding as doing research abroad. Additionally, Van der Does (2007) maintains that reflexive ethnography conducted by insiders is the most engaged form of participant observation that allows for the deepest immersion. One may only participate to the fullest in one's own life and know it totally, whereas our understanding of others' experiences remains always partial and contested.

I agree with the arguments of Van der Does (2007) and Mughal (2015). Based on my own experience with disability ethnography at home, I would like to add that the 'home' in disability ethnography is relative. One may argue that the majority of disabled ethnographers is not totally at home in mainstream ableist society; nor are they typically born into a minority disability culture. As such, disabled anthropologists and sociologists are well-situated to research their simultaneous familiar and strange native culture.

Reflection on one's own experiences in relation to others' is not easy; it requires that one observes and analyzes oneself as an outsider, that one can alternate between involvement and detachment in order to generate insights into how one's lived experience relates to one's peers' experiences and how one is affected by culturally deeply ingrained abelism. Insights that allow disabled anthropologists and sociologists to be successful researchers through academic publishing and to act more informed in one's personal encounters with others. In keeping with this, disabled anthropologists, sociologists and disability scholars account for what they
did to ensure that they were both sufficiently involved and detached from disabled informants to conduct a sound analysis (e.g. see Shah, 2005; Mogendorff, 2002; Seymour, 2007), or the authors simply perform an analysis informed by their lived experience with impairment and disability (Collignon, 1994; Denzin, 2003; Howes, 2009; Mogendorff, 2010).

From an inclusivity perspective, gained awareness of how one’s own and others’ behaviour is affected by ableist culture is a first step in adapting one’s own behaviour in less ableist directions. For instance, doing disability research as a disabled anthropologist helped me over the years to (see also Mogendorff, 2013):

- let go of some ableist notions I had internalized in early childhood about bodies like mine;
- to acknowledge, understand and to take better care of my body’s specific long-term needs;
- and to value my body as a differently abled body.

**Disabled ethnographers’ careers and contributions: the impact of responses to lived differently abled bodies**

Disabled professionals who are gainfully employed have supposedly ‘overcome’ or ‘conquered’ their impairments at least they may have jobs but not careers (Wilson-Kovacs et al., 2008; Williams & Marvin, 2015). A problem with ‘overcoming’ which disabled professionals may learn the hard way is that it generally involves doing things the able-bodied way uneffectively, even if it requires a disproportional amount of effort and discomfort. For instance, late disabled medical sociologist Irving Kenneth Zola, who walked with a brace, started using a wheelchair at airports after 20 years of travelling to and from conferences only to realise that he had previously assumed that for him pain and fatigue was a normal component of travel. He concluded that overcoming is not the same as integrating (Zola, 1996). Paying attention to how one’s differently abled body one may execute academic tasks optimally may make disabled scholars more efficient and effective.

However, given that the wheelchair has become the symbol of severe impairment and disability, neuroscientists and academics who can walk may opt not to use a wheelchair at airports (and other places) and accept the discomfort that goes with it, particularly when they are travelling together with an able-bodied colleague to keep up appearances of ‘not really being disabled’ (see also Frank [2002] on keeping up appearances in a totally different context).

Disabled professionals are inclined to (re)direct their career ambitions towards work or occupations that are objectively compatible with their impairments and in which they may follow their interests, use their talents and achieve personal and professional goals (Shah, 2005; Williams & Marvin, 2015). For instance, Wendy Seymour redirected her career towards the sociology of embodiment when her physical condition worsened and the corporal demands of her former job as a health professional became too much (Seymour, 2007). In keeping with this, Berhold (2008) found that educational level is a better predictor of employment success than the severity of professionals’ physical impairments. Perhaps this finding may in part be explained by the idea that with higher educational level, work tends to become less physical in nature (Foster & Fish, 2006) and problem-solving skills of employees increase, including disability management skills (Shah, 2005).

And, as Murphy (1990), Kimerling (2002) and Robillard (1999) noted, severe physical impairment is compatible with the academic career business of writing and publishing. However, careers in the social sciences are increasingly defined as boundary-less and precarious, researchers achieve tenure or permanent contracts less often than before (Baruch & Hall, 2004). The latter is certainly also true for disadvantaged employee groups such as disabled scholars.

What may reinforce the marginalised position of disabled academics in ethnography is that disabled anthropologists are less likely to be encouraged to conduct fieldwork abroad. Traditionally, anthropologists are supposed to engage in fieldwork far away from home and comfort, studying less well-off cultures through participant observation. Anthropology’s, admittedly, stereotypical tough and during public image does not sit well with the hegemonic sociocultural notion of disability as inability and vulnerability. The sartorial and junior anthropologists may not seriously consider doing fieldwork abroad, simply because they or their teachers find it hard to imagine that they conduct fieldwork in ‘exotic’ places in a wheelchair or with some other assistive technology, particularly if they have had a sheltered upbringing (Mogendorff, 2011), or have had their competency regularly questioned by able-bodied people, teachers included. In qualitative sociology, this may be slightly different, in that doing fieldwork at home is much more common than in anthropology.

Back in 2001, as a neuroscience impaired student of anthropology, I did not have a particular interest in studying ‘exotic’ communities and considered with Mary Douglas (2002) studying Western cultures as relevant and worldwide. However, I did not seriously consider doing research abroad mainly because I lacked travel experience and self-confidence in the matter and was not encouraged to try it anyway (but I have travelled to South-East Asia since then).

In hindsight, I underestimated the specific opportunities developing countries for disability management offer and I underestimated my corporeal abilities due to lack of opportunity to discover and try out my physical boundaries (see also Sundby [2008] on the consequences of overprotectionism). It certainly did not help me that the most positive remarks I received about my atypical walking style and motor abilities were: ‘it is not as bad as we thought it would be’ (able-bodied students with regard to the distance I walked during outings), and, ‘it looks difficult (the way you walk) from teachers). Some disabled anthropological students have been discouraged to do fieldwork abroad for their own good. If being impaired or disabled in familiar surroundings gets already classified as difficult, it is not surprising that doing fieldwork in unfamiliar less equipped surroundings may be considered a bridge too far. Often it is not so much about active discouragement
but lack of encouragement to do as one's able-bodied peers and conduct fieldwork abroad. Discouragement and lack of encouragement may be understood as abject practice, particularly if judgements are not informed by careful exploration of the specific possibilities of individual disabled students.

The situation is somewhat different for disabled ethnographers with senior status, they may be considered unto to continue doing fieldwork but found capable of supervising students (Murphy, 1990; Robillard, 1999). Also, they can, at least in part, fall back on intellectual and sociocultural capital, contacts and standing they acquired within the university before the onset of severe impairment or disability (Robillard, 1999; Kimerling, 2012).

The disappearing disability phenomenon and 'I am afraid you cannot take it' experience

The negative impact of the disability stigma and stereotypes on careers may be somewhat mitigated by what Seymour (2007: 1193) - a disabled embodiment sociologist - coined as the disappearing disability phenomenon: 'despite clear and visible manifestations of disability, the person with a (high-status) job is seen as not really disabled'. Ruth Benedict is arguably the best example of this phenomenon in anthropology. Every anthropologist knows about Benedict's contributions to anthropology and status as a key anthropologist, but not everyone knows that she had a congenital hearing impairment (e.g. see Mead, 2005).

A problem with the disappearing disability phenomenon is that it sustains domanice-negative images of disability. If success continues to require disability in the public eye, evidence of successful disabled professionals will, by itself, do little to weaken the strong association between disability and inability. For various reasons it is quite clear that disability really disappears and causes to affect careers, although it may seem so at first, particularly when individual disabled anthropologists' achievements and sociologists' standing equal those of their able-bodied contemporaries. Studies show that disabled professionals in senior positions face problems similar to members of other disadvantaged groups who have managed to land a senior position (Seyre, 2009). They may encounter a pay-gap, a glass ceiling — one is given less opportunity to further develop and prove oneself as one's able-bodied peers — or a glass cliff — one is given assignments with an elevated risk of failure (Williams-Kovacs et al., 2003; Rousseau & Williams, 2004; Williams & Mavin, 2015). Moreover, the disabled anthropology and sociology professors who, according to Seymour (2007), are subject to the disappearing disability phenomenon' mention in their monographs instances of when I call the 'I am afraid you cannot take it' experience. Ruth Zola (1982) and Murphy (1990) describe how some colleagues became less critical of their work because they assumed that they had so much on their plate already with their conditions, colleagues, etc. When questioned about it, he would say 'I am afraid you cannot take it'. It is, according to Zola (1982) — and I agree with him — one of the greatest disservices to any academic. Critical constructive feedback helps one to grow and prosper.

The 'disappearance' and subsequent reappearance of disability may have to do with sociocultural beliefs about disability in general combined with individuals' feelings of unease in the actual presence of disabled colleagues. My experience with a facility manager at a university where I was employed for several years, demonstrates this:

A university building was several times renovated while I worked there. During renovation, disability access accommodations such as the ramp at the building's entrance were blocked. Information about temporary changes in accessibility were not included in the standard briefings about the renovation on internet. Every time the entrance ramp was blocked, I felt obliged to point out to the facility manager that this may pose a problem for some disabled employees, students and visitors, although I did not need to use the ramp myself. I also advised him to include accessibility information in the renovation briefings. In response, the facility manager would tell me to my face without batting an eye: 'No disabled employees work here'.

I was surprised by this answer the first time I heard it. I did know for a fact that there were various students and employees who used the entrance ramp, although I did not know them personally. I also knew that the facility manager did know at least one visibly disabled employee, I had caught him staring at several occasions at my legs and feet — I have an in-toe walking style typical for my neuromotor condition. He had also offered me once unneeded help with some minor task, which I had politely declined.

I decided to change tack, after the facility manager's last statement - given that I was not a ramp user myself and asked the facility manager: 'What about disabled students and visitors who are unexpectedly confronted with a closed off ramp?'

Facility manager: 'They can be carried inside, or they can call for help.'

I did not think, that he really believed that it would work the way he claimed. Calling at the bottom of the stairs leading up to the entrance was not possible, there was no bell. And people who could carry wheelchair users up - and downstairs were certainly not literate about. I concluded that the facility manager did not consider building accessibility during renovations his problem or responsibility.

From my experiences, as with Murphy's and Zola's, it may be concluded that disabilities that appear to have disappeared may pop-up unexpectedly in interactions between disabled and non-disabled employees. And that the 'disappearance' of disability is likely to reinforce ableism.

Insights from engaging with and reflecting on one's disability experiences

Ethnography is informed by standpoint ontology and epistemology, what one sees, experiences and knows partly depends on one's standpoint (Harding, 1992; Howe, 2012).
from each other. In my experience, the added value of doing disability research 'at home' lies partly in the recognition, companionship and reciprocity found in fieldwork encounters between disabled researchers and (disabled) informants.

For example, when I conducted life history research interviews with young adults with neuromotor conditions not unlike my own, informants would occasionally request extra time in between sessions because I made them think about their lives in ways they had not before, and they wanted to process things first. Informants were curious about my lived experiences of disability. Their questions were of the type: 'Do you have that too?' And: 'How do you...?' or 'What do you think about that?' Some of these questions appeared to be a test - mostly posed by activist informants - to ascertain whether I had not internalised an ableist take on disability, but mostly they hoped to learn something from me and my research. Practiced lived through acquired knowledge about how to handle mundane everyday tasks to ensure that one can live a life in agreement with one's own preferences was most valued by informants, as well as an understanding and appreciation for the informants' own smart solutions. Research can be a mutual learning process without compromising the quality and independence of the research.

However, this still leaves the problem that research with a 'therapeutic theme' or focus on body normalisation gets more easily funded, then research on social inclusion and participation irrespective of one's health or disability status. Furthermore, most research with disabled people is mediated by or takes place in medical or care institutions informed by theoretical interests and models that have been developed with no or little input of the majority of disabled academics or citizens (Shuttleworth, 2004). The latter makes it not only important to recognise and explicate the contribution disabled academics make, but also to ensure that the funding and organization of research allow for more diversity in views and takes on disability.

Conclusion: towards an appreciation of 'wheelchair' ethnography

The focus of this chapter was on how impairment and disability not only act as a career boundary but are also resources in the work lives of disabled anthropologists and sociologists whether they engage in disability research or not, and how this is both facilitated and constrained by ethnographic ontology and epistemology. I did draw on publications of disabled anthropologists and sociologists in which they explicate the role of impairment and disability in their work lives and on my own experiences as a congenital neuromotor impaired anthropologist and non-Western sociologist to explore the disability-ethnography relationship.

In dominant discourse, disabled academics are considered unexpected workers (Stone et al., 2013), a notion that is both expressed and reinforced by the disappearing disability phenomenon (Seymour, 2007): if one has acquired a high status one becomes 'not really' disabled and differently abled-bodily is ignored.
until it surfaces again in encounters with others who feel uncomfortable in the face of a tangible difference or vulnerability. The reassurance of disability I coined as the ‘I am afraid you cannot take it’ experience and should be understood as a mechanism that helps to consolidate the ablest status quo.

Disabled academics strive to pass as normal workers, and are careful about what they disclose when and where. But as I have argued, passing is not the solution to ableism. Disabled academics need to be valued for their achievements, which they accomplished not despite their differentlyabled bodies, but with and through their lived bodies. This requires disabled scholars to be reflexive and open about how negative and positive impairment and disability experiences helped to generate insight and understanding. We need what I coined ‘wheelchair ethnography’—reflexive ethnography conducted by disabled anthropologists and sociologists who may or may not use a wheelchair.

Change is unlikely to be brought about by thoughtful and reflexive accounts or wheelchair ethnography alone. Addressing forms of ableism in academia, such as the disappearing disability phenomenon and the ‘I am afraid you cannot take it’ experience, as discussed in this chapter, is necessary. Facilitating funding and organization of social research that focuses on how one may live the good life with impairments or disabilities may also help. Last but not least, extra support for disabled talent across the sciences through diversity policies and disability scholarships may increase the visibility, efficacy and appreciation of what disabled anthropologists and sociologists have to contribute, with, not despite, their chronic conditions.

Notes

1 Wheelchair is put in between “because the wheelchair is the socio-cultural symbol of disability in the West. This contribution does not focus exclusively on disabled scholars who use wheelchairs.”

2 Disclosure I consider equally relevant to academic work with visible and invisible impairments. As I have argued elsewhere (Mogendorff, 2020), visibility of disabilities is a relative phenomenon. Invisible impairments in time become glaringly obvious—for example, in misinterpreted body language or misinterpreted behavior—and visible differences do not translate one-to-one into limitations and special needs and, as such, are subject to misinterpretation.

3 See more on the value of different forms of autoethnography in Borrow (2014), Charmaz (2006) and Davis (1997).

4 As far as the relationship between educational level and disability management skills as a specific form of problem-solving has not yet been researched, but it seems plausible.

5 Anthropologists who are well-regarded for their ‘at home’ work such as Mary Douglas generally have proven themselves first by publishing about more ‘intrinsic’ fieldwork.

6 This could be understood as a specific expression of the lowered expectations disabled citizens in general face due to negative stereotyping (Sanders, 2006).

7 Unacknowledged and unwarranted help is one of the social barriers in the social model of disability.

References


