

## RESEARCH

# Non-disabled Ableism: An Autoethnography of Cultural Encounters between a Non-disabled Researcher and Disabled People in the Field

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This article describes situations where preconceptions about disabled people were made apparent in a non-disabled researcher's thoughts, words and actions in the course of fieldwork for a qualitative study into the lives of disabled young adults. The article uses these experiences as entry points to discovery and analysis of cultural ableism. It draws on critical theory and insights from the social model of disability and takes an autoethnographic approach to highlight the researcher's preconceptions and her process towards a more nuanced understanding of disability.

**Keywords:** Autoethnography; Ableism; Sexualities; the Social Model; Disabilities

## Introduction

The sun was shining and people in summer clothing were streaming in and out of the grocery shop. They were speaking to each other happily, some carrying shopping bags. A bus went by. Everything was normal. But, that was outside. That was before I entered the hospital. Inside, everything was quiet. I walked past many closed doors. Now and then a nurse hurried past me. Somewhere, something beeped. Hospital sounds. Hospital smells. I heard voices, and prepared for someone coming towards me. But when they rounded the corner, I was startled nonetheless. I think I stopped completely. I saw someone in a wheelchair, and most of all the strange contraption he had around his head. I had never seen anything like it. It was a gigantic helmet of some sort, and it looked as if metal spikes went straight into his skull. He hung limply in the chair. He drooled and mumbled. His eyelids quivered. I realised I was staring. I felt scared. Shaken, because it suddenly hit me that *this is how some people live. This can happen to a human being*. I did not know how to behave. I tried to pull myself together. A woman was pushing the wheelchair, chatting gaily. She said my name. She smiled. She behaved like everything was normal. But it was not! She was wheeling around a man with spikes in his brain. His eyes were so empty that it looked like he was barely alive. Did he understand what was happening around him? Was it possible to speak to him? Was he in pain? My heart was racing and my palms were sweaty. Grief, confusion, uncertainty, anxiety, inadequacy: there was a barrage of emotions inside of me. 'Now it is important that I play along', I thought. 'Now it is important to pretend that everything is normal.'

The excerpt above describes my first moments of fieldwork for an ethnographic study into the daily lives of young adults who had experienced a major traffic accident. Until then, I had never worked with disability, neither practically nor theoretically. However, I had always cherished diversity, and the prospect of making a useful contribution to people who might be considered different from normative standards had motivated my choice of research area. I identified with values that Norwegians tend to claim as their own, as members of what we collectively understand as 'an innocent, humane, tolerant, anti-racist and peace-loving society that is committed to helping the needy' (Gullestad 2005, 43 in Mainsah and Prøitz 2015, 176). This rather self-satisfied perception was to be challenged in the course of fieldwork, and – as the excerpt above illustrates – the challenges started right at the outset. I was startled to find myself struggling with emotional distress as I faced the very first unusual person I was to interact with in the field, and there was plenty more in store for me. At the hospital, many social conventions, i.e., the understandings that are collectively taken for granted and that inform people's behaviour (Eriksen 2010, 49–50), were unknown to me. I felt inadequate and anxious because my cultural background had not provided me with the range of resources I needed to handle encounters with disabled bodies.

Hastrup (1992) has beautifully described anthropologists' discovery of cultural differences in the field as anthropological 'astonishment'. Among the things that astonished me in this fieldwork was that so much of what I knew about disability were unquestioned cultural assumptions that exposed me as an ableist. Here, I take the concept of 'ableism' to mean the unintentional discrimination of disabled people through 'a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human' (Campbell 2009, 5). How I was caught up in such an ableistic network became apparent in many of the questions I asked and several of the choices I made during fieldwork. However, experiences from encounters with study participants – in the form of conversations, confrontations and corrections – compelled a self-reflective process that made me aware of (at least some of) my prejudices. As I came to acknowledge my biases, I started to use them as analytic turning points.

The goal of this article is to discuss subtle forms of cultural ableism from my position as a non-disabled representative of the majority society. I am looking to trace both my own cultural ignorance about disability and the processes of reorientation and maturation that occurred as my preconceptions were challenged.

## Methods

### *Context and empirical data*

This article analyses conversations and interactions that occurred between the study participants and myself in a qualitative study focusing on young adults who had sustained serious injuries in a traffic accident in which they had been drivers of a motor vehicle. The overall aim of the study was to explore how young adults may experience their everyday lives after such an occurrence, including their experiences of rehabilitation, their approaches to motor vehicle driving, and their experiences of un/employment. There were 14 study participants, 12 men and 2 women, between 20 and 36 years of age. Their accidents had taken place between 2 and 15 years before the fieldwork for this study started. Most had been diagnosed with either moderate traumatic brain injury (TBI:  $n = 8$ ), spinal cord injury (SCI:  $n = 3$ ) and/or severe trauma affecting the face, legs, back, neck and/or hips ( $n = 6$ ).

In this study, we used semi-structured interviews and participant observation. I interviewed most participants two times or more, and joined a subset of them in a range of everyday life situations. In line with an anthropological approach, I engaged with the study participants not only as a distant researcher, but to a large degree as myself (Fangen 2011). For example, the study participants and I sometimes met at home (theirs or mine), took strolls together, or went out for dinner together. The purpose of participant observation is to get to know people and gain access to their realities through shared experiences. Personal interaction might promote better or different understandings and interpretations of what is going on in the field than other qualitative data. For instance, the researcher might get a fuller picture of people and their lives than she would have gotten if she had only conducted interviews (*ibid*).

Empirical material consisting of field notes, interview transcripts and diary entries has been produced from the start of the project in January 2013 until today. For this article, I reviewed texts I had written after what I had perceived as particularly significant fieldwork experiences in the sense that they had prompted reflection and insight in an especially effective manner. They were thus akin to what Trigger, Forsey and Meurk (2012) characterise as 'revelatory moments': intense, unplanned episodes in the field that often involve feelings of discomfort and surprise, and that give the researcher new insight. What the revelatory moments discussed here have in common is that they effectively threw light on the ways in which I, the researcher, was trapped in an epistemic framework that draws on clearly ableist assumptions.

Rather unfortunately, I did not discuss the discovery of my ableism with the study participants during fieldwork. On the contrary, I often felt so embarrassed to find myself struggling with the social 'performance' (Goffman 1990 [1959]) of smooth interaction with the Other that I sought to hide my immediate thoughts and feelings in an attempt to minimise the exposure of my prejudices. I did, however, discuss these experiences at length with the co-authors.

### *The authors*

As is always the case, the background and experiences of the authors helped to shape the text and the analysis it mediates. I will therefore give a brief presentation of the three of us. Among the things we have in common is that we speak from positions of considerable privilege. We are all relatively non-disabled persons, born and brought up in an affluent society. We share rather similar socio-political values and tend to emphasise the importance of diversity, inclusion and social justice, both in our work and in our lives. At the same time, we have differences, for instance in terms of age, gender and a range of work and life experiences.

The first author, Rannveig, who carried out the fieldwork for this study, is the person the first-person narrative voice refers to in this text. I am 35 years of age and have often found myself in opposition to normative ideals and in sympathy with people that tend to be considered as 'different'. This might be because I often perceive of myself as somewhat 'different', too. For example, I am bisexual and voluntarily childfree, and I often draw on my experience of otherness both in my personal life and in my research as a social anthropologist.

The second author, Grace, is 63 years of age. She has worked with chronically ill and disabled people for decades, variously as a home-care nurse, a municipal health manager, and a leader and researcher in a rehabilitation hospital. Her academic work draws extensively on insights from cultural studies, critical theory and social anthropology.

The third author, Kåre, is 53 years of age. He is a trained physician with additional degrees in community medicine, public health and social anthropology. His current research focuses primarily on populations that tend to be marginalised in preventative and curative health care, including same-sex attracted men in the African HIV epidemic and immigrant women in European cancer screening and prevention. Kåre does not have specific previous experience in the field of disability research.

Throughout the study period, the three of us have constituted a small 'epistemic community' (Haas 1992, in Moen and Middelthon 2015): a team of co-producers of knowledge who have collaborated closely on the planning and execution of fieldwork, data analysis and writing. All of us have contributed to the ongoing exploration of and reflection on the data, and in bringing the empirical material into dialogue with theoretical work. Recurrent themes in our discussions have been how (dis)ability might be understood from different theoretical angles, why non-disabled people apparently know so little about disability, and how ableism is culturally constituted. In the work on this article, the deliberations in the research team have played an important role in creating analytic distance, since the empirical material is so closely tied up with the personal experiences of one of us.

### **Theoretical approaches**

I use autoethnography, a reflection-based approach that thus far has not been very widely used in disability research. I will therefore present a short review of what autoethnography entails and what it can contribute to the field of disability studies.

Autoethnography is a method, process and product (Ellis, Adams and Bochner 2011) that emerged in the 1980s as academics challenged ideas about truth, objectivity and fact in research. An autoethnographic approach recognises that research cannot escape being influenced by the researchers by whom it is carried out (Ellis, Adams and Bochner 2011). Rather than attempting to hide this fact, autoethnography embraces it. Texts are usually written in first person, they put the scientist's self on the line, and they try to enter culture through thick descriptions (Plummer 2009). In autoethnography, data may include thoughts, feelings and actions, for example, as they emerge under or after conversations or other social interaction with others. The researcher seeks to 'use personal experience to illustrate facets of cultural experience, and, in so doing, make characteristics of a culture familiar for insiders and outsiders' (Ellis, Adams and Bochner 2011). Many autoethnographies are both political and critical and may 'provide a resistance to dominant cultures and dominant voices and narratives' (Plummer 2009, 268).

I write within the anthropological tradition, in which autoethnography has been referred to as 'autobiographical (i.e., confessional) ethnography – texts in which trained observers explicitly address and analyse their personal relations with the natives they are writing about' (Couser 2005, 126). I place myself within 'disability autoethnography', a narrow but independent strand within health studies.

Disabled persons' own range of perspectives on disabilities have not been adequately addressed in academia, and a valuable aspect of disability autoethnography is that it has contributed to a greater representativeness in academic knowledge production. It has also been used as a tool to analyse complex relations of power, such as in Rogers (2009) discussion of sexual surveillance and control. From the position of the mother of a sexually experimenting teenage daughter with learning disabilities, she questions if one has the right, or the obligation, to interfere in the sexual expressions of another human being. Furthermore, disability autoethnography may be an entry point to discover new practices and critique hegemonic discourses. For example, Hendriks (2012) used an autoethnographic approach to explore how professional clowns could use their bodies to communicate with persons with advanced dementia. Fürst (2015)<sup>1</sup> – writing from the position of a patient's wife – showed how the insight of next-of-kin may be given little weight in a biomedical context. These original and insightful academic contributions are examples of knowledge and ways of knowing that, without autoethnography, might not have been brought to the fore because they were produced in ways that do not easily fit with traditional templates for knowledge production.

In addition to its autoethnographic orientation, this article draws on critical theory in its discussion of non-disabled ableism, not least the insight provided in 'the social model' of disability. The Western discourse on disabled people had been dominated for a long time by what is now referred to as 'the biomedical model' when Oliver (1983) theorised these concepts. In the biomedical model, disability is understood primarily as pathology that yields impairment in individual bodies. Consequently, disabilities are first and foremost health problems in need of medical attention, and disabled persons are measured against cultural ideas of normality. The ideal trajectory for a disabled person is, in turn, one that will render her 'cured, treated, trained and changed' (Barnes 2003, 9–10). In the social model, disability is socially created instead of being located as a problem in the body itself (Oliver 2013). Here, disability is the consequence of the gap between individual functioning and society's facilitation. For instance, 'an inability to speak is an impairment but an inability to communicate because appropriate technical aids are not made available is a disability' (Morris 1993, ix in Barnes 2003, 14). Hence, disability may be seen as a manifestation of discrimination that might be treated with equal rights and social justice.

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<sup>1</sup> Fürst does not explicitly position herself as an autoethnographer, but the article has many autoethnographic characteristics.

### ***Concepts and the risk of exotification***

Let me point out that I find it somewhat challenging to write about encounters with disabled bodies from the position of a non-disabled body. Firstly, this entails a risk of cementing the same discourses of norms and deviance that I aim to critique, because it may easily reproduce the dualistic imaginary in which certain types of bodies are deviant while other are normative. When I choose to describe myself as non-disabled, rather than able-bodied, the aim is to avoid reproducing a non-disabled starting point as norm. I must emphasise, however, that it is still a matter of utterly simplified categorisation when I refer to myself as non-disabled and to study participants as disabled. Both the participants and I have unique functional abilities, histories of injury, and experiences of living in our bodies. The way I use these concepts, therefore, is both imperfect and problematic, and must be understood as a form of 'strategic essentialism' (Petersen 1998, 28) through which the researcher with critical awareness refers to what is understood as a group-level essence in order to enable theorisation. A body as a being in the world is not reducible in the same manner. Disabled persons, just as non-disabled persons, are clearly not a uniform group of people who share the same experiences of disability (Couser 2005; Lid 2013). Moreover, disabilities are diverse and make up a complex field consisting of different groups, identities and struggles for political, economic and social rights (Solvang 2000). For example, diagnostic criteria are continuously being negotiated (Bowker and Star 2000), and the same individuals may have status as non-disabled and disabled in different periods of their lives (Lid 2013). Some theorists rely on a more radical understanding of disability that considers everyone (or a majority) of the population as impaired, highlighting the body's general capacity for illness, exhaustion, ageing and dysfunction (Shakespeare 2014, 51).

Secondly, there is a risk of reproducing a pattern in which disabled people are yet again exotified through a non-disabled gaze, or even a 'non-disabled stare' (Garland-Thomson 2009). Disabled people have been marginalised, objectified and at times colonised (Goffman 1990 [1963]; Stiker 1997), and it is important to maintain critical awareness of this history as part of the effort to avoid reproducing such ideas and practices. In this article, my non-disabled gaze is still a non-disabled gaze, but I hope that it may work to significantly challenge rather than to reproduce exotification when the vantage point is one of conscious self-reflection that takes a critical perspective on normative ideas. Through confrontations with disabled bodies, the gaze may be thrown back towards the non-disabled body, which is revealed as complicit in the production of ableism and thus loses its upper hand. In this way, the non-disabled gaze may take on a different function, as an analytic tool that can help provide access to cultural assumptions, understandings, norms and unspoken scripts that shape society's takes on disabilities. This kind of self-critical gaze will hopefully contribute to discussions of ableism that may encourage so-called non-disabled people to reflect on their own relationship to disability (Campbell 2009; Ellis 2010) and contribute to nuances and knowledge of potential benefit in the field of disability studies.

### ***From individual to society***

I seek to say something about the general, that is, trends at the collective level, by using the particular as a starting point. I do not in any way claim to capture the only perspective,<sup>2</sup> and it is of course not possible to generalise data in qualitative research in the same manner as in quantitative research (e.g., Moen and Middelthun 2015). Though I cannot rule out the possibility that some of my reactions and experiences may be particular to me, I primarily understand them as formed and mediated by ideas and trends in the cultural contexts I am part of. Like Geertz, I understand cultural context here as 'a system of inherited conceptions expressed in symbolic forms by means of which men communicate, perpetuate, and develop their knowledge about and their attitudes toward life' (Geertz 1993, 89). Turning the gaze from the individual to the collective is key to understanding ableism. Doing so enables the capturing of complexities that are overlooked when ableism is only interpreted as prejudices at the individual level. Like racism (Blumer 1958), ableism is to a large extent about group-based positioning since

'the sense of group position is the very heart of the relation of the dominant to the subordinate group. It supplies the dominant group with its framework of perception, its standard of judgment, its patterns of sensitivity, and its emotional proclivities' (Blumer 1958, 4).

What follows is based on this very understanding of ableism. While it is unpacked from the standpoint of the researcher as an individual, that individual is understood to be part of and draw on discursively produced understandings of both disabled and non-disabled bodies. While this may not render my own prejudices any 'better' or less alarming, it clearly expands the scope of the critical analysis.

<sup>2</sup> For example, it has been shown that disabled people are subject to verbal harassment (Ahlvik-Harju 2016) and staring (Garland-Thomson 2009) by non-disabled people. My contribution is not meant as a counterpoint to this, but as a supplement to the ongoing academic debate about the different expressions of ableism by non-disabled people.

## Findings

During fieldwork, I had several experiences that revealed ignorance about disabilities and a propensity to generalise about disabled people based on rather unconscious preconceptions informed by the biomedical model of disability. In the following, I present this discovery and my process towards a more nuanced understanding.

### *Stumbling over wheelchairs*

In my interaction with the study participants, I had several awkward encounters with wheelchairs. The first revelatory wheelchair moment occurred early on in fieldwork, when for the first time I was to have a study-related conversation with a person using a wheelchair, Åge.<sup>3</sup> I had been in touch with him on the phone to schedule the interview, and I knew that he was paralysed. When I stood outside his door and knocked, my heart was racing. This was not so much because I was going to do an interview as I had done that before, but because I was going to interview a paralysed person and was not sure how to behave in this unfamiliar situation. According to my field diary, our encounter started like this:

I heard him call 'come in' and opened the door. I entered a room with no furniture other than a bed and two wheelchairs. A manual wheelchair was parked next to the bed, and a large, motorised wheelchair stood along one wall. Åge was lying in the bed and was looking at me while I – with a growing sense of confusion – pondered whether and where to sit down. There were no chairs in the room! Should I get one? Or wait until he explained where I could find one? Or sit down on the edge of his bed? I waited for him to help me, tell me what to do, when he calmly said: 'Do you not want to sit down?' and made a gesture with his hand. Had I understood him right – that he gestured towards the wheelchair next to the bed? He could not mean that I was to sit there? This turn of events was both surprising and uncomfortable. I felt resistance towards sitting in the wheelchair. I was not sick. There was nothing wrong with me. Uncertainly, I walked towards the wheelchair and gripped its back. I tried to turn it towards me, but it would not move. 'It is the brakes', he said. I think I smiled and said 'oh, ok'. I hoped my voice sounded calmer than I felt. I leaned down and started to mess with the brakes. It did not go well. Bright red and despairing, I pushed and pulled on buttons and levers. Something finally happened, a click could be heard as the brakes were released. I moved the chair a bit back and forth and finally sat down in it. It was awkward. I felt small and uncomfortable, but I smiled at him and pretended that I felt like I had a handle on the situation. He nodded back. I conducted the interview, but did not for one second forget that I was sitting in a wheelchair.

In retrospect, when reflecting on what happened in this situation, it is obvious that I oriented myself in the room from a distinctly non-disabled perspective. I had seen a room entirely without chairs. My preconceptions were made apparent in the encounter with someone who oriented himself based on a different understanding. To Åge, this was a room with two chairs. This was just as obvious to him as it was to me that the room did not have any chairs at all. Åge's gentle gesture towards the wheelchair filled the social situation with this basic insight. At the same time, it both revealed a cultural difference between us and made his understanding of the wheelchair accessible to me. Before his intervention, I had not seen the chair in the wheelchair because wheelchairs were something *other* than chairs to me.

Another significant difference in the way Åge and I saw the wheelchair also emerged in this situation. His vision was richer than mine because where I first and foremost saw what the wheelchair could *not* be used for, Åge saw what it *could* also be used for, namely to sit in. For anyone. I did not associate wheelchairs with their use but with a group of users: a clearly delimited 'them'. I also associated wheelchairs with being 'sick' or having something 'wrong with you'. With anthropological astonishment, I had to acknowledge that these were not characteristics I primarily associated with wheelchairs, but with disabled people, and that these were characteristics I was distancing myself from when I considered wheelchairs as objects I should and could not use.

As my fieldwork continued, my limited view of wheelchairs and wheelchair users continued to be challenged and developed on several other occasions, including in this situation when I met with Hans-Egil:

He sat in a wheelchair and waited for me when I stepped off the bus. He lived some distance from the bus stop, and we headed towards his place together. Or, not quite together – that was not really how it happened. He sped ahead in his wheelchair, and I followed as best as I could. It felt strange, because I have always thought of wheelchairs as a disadvantage. Exhausting, slow, and difficult to manoeuvre, rendering places cumbersome to get to. That is how I had imagined it. Instead, now I was suddenly taking up the rear. Hans-Egil outmanoeuvred the red light and sped across the pedestrian crossing, while I was left on the other side. He had to wait for me several times. Most of the time, he was many metres in front of me. I was jogging along, trying not to lose sight of him. Unlike Hans-Egil, I was sweaty and out of breath when we finally rounded the corner to the building where he lived. Phew. I wish I had a wheelchair.

<sup>3</sup> Åge is a pseudonym, as are all names used on study participants in this article.

In the example above, my immediate assumptions about wheelchairs were shaped by culturally prevalent ideas that represent wheelchair users as being only at a disadvantage. Instead, I found that Hans-Egil unquestionably had the more convenient form of transport for the situation, and that he was quick, strong and mobile. With anthropological astonishment, I realised how I had not attributed such characteristics to him, at least not there and then. On the contrary, I had stereotypically reduced him and his window of opportunity to act in the world in line with a pathology-focused biomedical framing of disability. Hence, I had pictured Hans-Egil as sick and lacking in strength.

Two insights emerged from this revelatory moment: first, I came to realise that there are other ways of handling disability than I had access to in my cultural repertoire. Here, this was demonstrated when Hans-Egil operated the wheelchair in a manner I had not predicted. Secondly, I realised how an ableist worldview might make wheelchair users disabled – rather than their bodies or their wheelchairs. The insights of the social model were demonstrated for me as I witnessed Hans-Egil's skilled handling of his wheelchair. Here, the wheelchair user created and experienced a highly favourable interaction between body and terrain. At the same time as Hans-Egil became non-disabled, I emerged as disabled, for I had lagged behind, sweaty and out of breath.

### ***Colliding with sexualities***

Recent research demonstrates that disabled people encounter significant prejudice related to their sexuality (Rogers 2009; Kim 2011; Grønningsæter and Haualand 2012; Sparkes, Brighton and Ingle 2014). For example, disabled people are often assumed to be asexual by staff in health and social service organisations (Grønningsæter and Haualand 2012). With anthropological astonishment, I discovered that I was drawing on similar cultural notions. I will illustrate this with an excerpt from the field notes I wrote after a conversation with Jonas. He had both cognitive and physical injuries.

I talked with Jonas on the phone today and was taken aback when he said he had been separated [from his wife] since we last spoke. It had seemed like he and his wife were doing so well. I was even more surprised when he told me why. He had 'had dessert somewhere other than at home', he explained. It was not the first time he had been unfaithful, but now his wife had had enough. This really hit me, because I must admit that it had simply not occurred to me that this man, who had sustained such major injuries, had a sex life. And it certainly had not occurred to me that he was having sex with women behind his wife's back. How on earth could I have assumed that he was not having sex? The feeling I got during this telephone conversation reminded me of the embarrassing situation I experienced on another occasion when I heard myself saying to Jonas that he was lucky to have married. The look his wife gave me made me realise what I had said. She patiently went on to explain to me that many people with traffic injuries are married. She had a friend with a traffic injury who was a great charmer, she said. He could have whoever he wanted. I remember how utterly foolish I felt. I got defensive right away and tried to cover up my mistake. Said of course I didn't mean it like that, so sorry.

Stereotypical expectations about the sexuality of a disabled person emerge in the excerpt above. I was surprised that Jonas was unfaithful. Unfaithfulness – and actually even a sex life in the first place – was a capacity I did not immediately attribute to a person with 'such major injuries'. My presumptions were clearly reflective of a pathologising view of disability. Also, it echoed the hegemonic, cultural idea that sex is a privilege that belongs to non-disabled, normatively attractive bodies. The wide circulation of notions like these creates barriers for the bodily and sexual expressions of disabled people, in part because exclusionary sexual ideals are imposed on them, and in part because their own entanglement in the same cultural imaginary renders disabled persons themselves at risk of accepting and reproducing those very norms (Sparkes, Brighton and Ingle 2014). Conversely, moving away from ideals that exclude give room for a re-articulation of pleasure (ibid).

During fieldwork, the barriers of sexual exclusion, and the potential of a re-articulation of pleasure, was illustrated for me during a conversation between myself and a study participant with a spinal cord injury. An excerpt from the field diary illustrates how ableism was made apparent, and confronted, in one of our conversations:

I asked Håkon how he felt about not being able to have sex any more. He was quiet for a while. Then he said: 'So ... what is sex?' This simple question overwhelmed me, and for good reasons. It revealed how I had automatically invoked the idea that sex equals penetration. I had basically assumed that he did not have sex because he was paralysed and could not get an erection. In that moment, I realised what an incredibly limited view I had produced of him moments earlier. And of sex. How embarrassing! He said he would open up to me about this topic even though it was a sensitive issue for him, because it is so important that it comes out. He has good sex. He gets pleasure from the visual. Lying near another body is just as pleasurable for him as it was before. He can get an erection when he uses vibrators. He can ejaculate. He does not feel orgasms as before, but he feels desire, pleasure and satisfaction. He said it might well be that he has a better sex life than someone without functional impairments, even though he is paralysed.

In this conversation with Håkon, I realised with anthropological astonishment how I had unconsciously invoked a core aspect of a heteronormative<sup>4</sup> understanding of sex. Unconsciously, I had expected sex to mean penile-vaginal penetration. In such a conceptualisation of sexual practice, some men with spinal cord injuries are excluded from the possibility of a sex life as are lesbians, for example. The discovery that I had mobilised such a conservative and ignorant view of sex was surprising, given that I had been reading queer theory for years and had worked politically for the recognition of women's sexual agency. Queer theory is a theoretical approach that problematises heteronormativity and views sexuality as dynamic, fluid and culturally shaped. My sudden regression to a heteronormative, penetration-focused understanding of sex in my conversation with Håkon suggests that the cultural understanding that defines disabled people as outside of sex is so firmly entrenched that it can trump even a strong academic basis for knowing better.

When my surprising assumptions about sex – and disabled people – were revealed in the question I had asked Håkon, he patiently corrected them. He pointed out to me that sexual pleasure can be actively and creatively explored and enjoyed regardless of other functional abilities. What the social model of disability articulates is exactly this insight: whoever is sexually non-disabled depends on the interplay of bodies and terrain. In other words, it is not a given, but continuously negotiated. To free body and sexuality from narrow normative ideals allows transcendence of imposed limitations, and the discovery of new sexual practices (Sparkes, Brighton and Inle 2014).

### Conclusions

When I started fieldwork for this study, I was unwittingly enmeshed in a web of ableistic notions and non-disabled normative ideals. The cultural taken for grantedness of non-disabled privilege and superiority regularly came to the fore in my encounters with study participants. I saw them as people in a rehabilitation *process* where the ultimate goal was to strive for a return to the body and life they had had before their motor vehicle accidents. It is striking how it did not occur to me at the time that being in the world *with* a disabled body could also be a satisfactory possibility. Furthermore, I was leaning heavily on the culturally shared 'knowledge' that disabled bodies cannot be used as well as non-disabled bodies. For example, it did not immediately occur to me that a body in a wheelchair can function more effectively than a body not in one.

Clearly, my way of seeing disability was largely the result of a gaze through the pathology-focused lens so characteristic of the biomedical project. Far from being limited to the clinic, this lens has helped to shape the overall take on disabled bodies throughout the society in which I grew up. The point here is not that medicine has not been enormously important for the treatment of impairments, but that the biomedical way of knowing has come to dominate our overall take on disabilities and 'the disabled' (Stiker 1997). The understanding of 'them' as infirm sets them apart as different, subordinate and underprivileged (Goffman 1990 [1963]), and allows for the consequences that follows in terms of ableism.

In the field, I found again and again that my focus and my preconceptions were out of touch with the perspectives and experiences of the study participants. These situations were filled with bewildered astonishment and the unique kind of cultural insight which may occur when what is commonly taken for granted by 'us' is questioned through a different approach from 'them' (Hastrup 1992). Some of these moments were quite alarming to me because they revealed that my core values of equality were not always as present in my attitudes as I had thought and wished for them to be. Had it been up to willpower, I would not have been an ableist, but I was in the grip of something stronger than my volition, or rather: that did not provide me with the resources that were needed to break out of the ideational framework that boxed me into the biomedical model of disability.

It is remarkable that I did not have better access to the notions that have challenged, nuanced and critiqued the reliance on the biomedical lens in our ways of viewing disabilities. Various alternative articulations and framings have now been promoted by disability scholars for decades (see e.g., Oliver 1983; Moser 2005; Gibson 2014; Grue 2014). Nevertheless, alternatives are not culturally accessible to the point where they provide non-disabled people with the resources needed to encounter unusual bodies without drawing on ableistic conceptualisations. Hence, we must keep addressing cultural prejudices towards different bodies, and continue to explore and promote alternative ways of knowing to extend our imaginations.

### Declaration of interest

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<sup>4</sup> Implicitly, this entails being based on a traditional and heterosexual worldview, which means that other alternatives are obscured (Grønning-sæter and Haualand 2012).

## Competing Interests

The authors have no competing interests to declare.

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