

Looking in a mirror

Creating space to explore identities as persons with impairments

Karen Mogendorff

In this paper I examine how informants and I made sense of each other. The two central questions are: (1) How do impairments affect informants self-image? And (2) How do informants perceive me as a 'one of their kind' anthropologist?

To address these questions I will: (1) reflect on how I think my background affected the way I presented myself to and interacted with informants; (2) explore how sense-making is accomplished in actual encounters – the emphasis being my own sense-making; and (3) offer 'new' insights on conducting fieldwork among 'people of the same kind' as the researcher, and how these interactions may enrich our understanding of disabled persons' lived experiences. To connect these three levels of sense-making, I will employ the concept of intersubjectivity.

[intersubjectivity, establishing rapport, auto-ethnography, researcher-subject relations, anthropology of disability, impairments, native anthropology]

Making sense of shared experiences with informants or intersubjectivity between the researcher and the informant is considered paramount to gaining anthropological insights. Without intersubjectivity, understanding another's point of view seems virtually impossible (Van der Geest 2007). Intersubjectivity is defined here as the outcome of an interpersonal, multi-way process informed by personal and socio-cultural views held by both the anthropologist and the informant (Collinson 2005). Intersubjectivity is embedded within socio-cultural contexts, where the anthropologist tries to make sense of her informant *and* the informant tries to figure out the anthropologist (Paerregaard 2002). Age, skin colour, clothes, sex and other social characteristics relevant to a specific socio-cultural setting may influence how informants view the anthropologist. Informants place anthropologists in categories and in cultural roles that result from enculturation processes. Furthermore, how informants judge the anthropologist will in turn determine the kind and amount of information they disclose to a particular anthropologist (Okely 1992; Paerregaard 2002).

During her fieldwork in Northern Ireland, Margaret Steiner – a blind anthropologist – recalls how she and her informants had a difficult time making sense of each

other. This process of mutual sense-making informed the kinds of interactions Steiner had, and therefore shaped the kinds of insights she gained from the relationships she had with her informants.

Reflecting on her fieldwork Steiner acknowledges that her resistance to stereotyping as a 'Yankee', blind person and a Jew made it difficult for informants to understand her. Informants' inability to easily place her within commonly held stereotypical categories ultimately affected their behaviour toward her (Steiner 1995: 11):

Yet there were those who remained suspicious. The difficulty lay in the fact that villagers could not easily place me in pre-existing categories or roles... My status as a stranger symbolised most saliently by my blindness, meant that people were always trying to fit me into roles with which they were familiar, creating the illusion that they knew what I was up to, while I, for my part, deliberately strove not to conform to stereotypes. The paradoxical attempts at masking and sense-making meant that we were often engaged in palpable gamesmanship. Not surprisingly, my blindness was a central feature to this gamesmanship.

Steiner's experience not only demonstrates how informants' sense-making of an anthropologist impacts what they confide in her but also reveals that the process of sense-making itself may be a valuable source for anthropological insights. Furthermore, Steiner suggests that the way she presented herself to her informants might affect their relationship, and, as a result, intersubjectivity may or may not be achieved. Therefore, it seems worthwhile to not only reflect upon actual interactions between the anthropologist and her informants but also to explore the anthropologists' background, in so far as it is likely to influence interactions with informants.

In this paper I will try to explicate how informants and I tried to make sense of each other. I examined how informants' impairments affected their self-image and how informants tried to make sense of me as 'one of their kind,' since I, too, have impairments. I am simultaneously familiar and unfamiliar to my informants.

Specifically, this paper will: (1) explore how I think my biography affected my presentation towards and interaction with informants; (2) look at *how* sense-making and establishing rapport is accomplished in actual face-to-face encounters (the emphasis being on my own sense-making); and (3) offer 'new' insights on conducting fieldwork among 'people of the same kind,' particularly on the experience of living with impairments. Furthermore, to connect the three levels of sense-making as described above, I use the concept of intersubjectivity.

Finally, I hope to contribute to a wider understanding of the social processes among people with impairments. Many studies about people with impairments focus on the problematic nature of encounters between the able-bodied and persons with impairments, neglecting the fact that impairments do not necessarily constitute a negative basis for social interaction (Albrecht et al. 2001; Ingstad & Whyte 1995; Gorter 1983; Gorter & Janssen 2002).

The concept of intersubjectivity

As mentioned above, intersubjectivity enables anthropological insights, involves social interactions, and embeds itself within socio-cultural contexts. For the purpose of this paper, which seeks to understand how shared experiences of disablement and adaptation between anthropologists and disabled persons offer a different perspective on disabled selves and the meaning of disability, a more precise definition of intersubjectivity is necessary.

Intersubjectivity is a complex, multidimensional and elusive concept with many implicit and few explicit definitions. Intersubjectivity appears in different forms in various phases of the anthropological research process. Furthermore Vysma & Tankink state that intersubjectivity can be used in at least two distinct ways: as a noun and as an adjective. Used as a noun, intersubjectivity denotes “an emotional reality characterized by the conviction/sensation that the ‘I’ understands and is understood by the other.” As an adjective intersubjectivity betrays its own fleeting nature; it is constantly lost and regained (Tankink & Vysma 2006: 251).

In this paper my use of the concept intersubjectivity is largely limited to the preparation and fieldwork phase. Furthermore intersubjectivity operates on the intra-psychic, inter-corporeal and social-sense level. The emphasis here lies on its inter-corporeal sense.

First, I reflect on my own initial ambivalence towards being a person with impairments in relation to my own personal history. To some extent, my introspection and subsequent practical preparation for fieldwork can be characterised as becoming aware of my own ‘disabledness’. Furthermore, the narration of my biography offers some clues regarding the possible impact of my personal history in my encounters with informants.

Second, I show how intersubjectivity is achieved inter-corporeally during encounters with informants. I emphasize the efforts required to reach mutual understanding, particularly focusing on my attempts. To be more concrete, I define intersubjectivity in the inter-corporeal sense as the perception that researchers and / or informants have in understanding each other and in being understood by the other both cognitively *and* emotionally. Intersubjectivity appeals to the human need to know and comprehend, and to be known and understood by others. Intersubjectivity is found in an *Aha Erlebnis*, a moment that is shared or reciprocal. Verbal cues indicating that one understands the other or is understood by the other include phrases such as, “You have it too!” or “Yes, of course!” Furthermore, mutual understanding may be revealed in one’s ability to laugh or to be comfortably silent with another. I focus on my strategies to reach mutual understandings with informants.

These reflections, in turn, allow for ‘new’ insights that arise slowly over time through reflections on multiple and multi-sensory encounters with numerous informants and colleagues within diverse settings, yet specific socio-cultural contexts. These understandings are social in the sense that they emerge from long-term relationships with people with impairments and from participating in the disability community.

Finally, understandings gained from fieldwork may impinge on the anthropologist's private life, changing the anthropologist's personal views on impairments and the experience of disability and changing relations with family members and friends. Some of these social aspects of intersubjectivity are discussed in the last section of this paper.

Making sense of self: Impact of the biography of the anthropologist on fieldwork relations

When I told people in 2001 that I wanted to study the self-image of young adults with congenital, visible motor impairments, people responded to my topic in different ways. My family's initial response was unenthusiastic: "You aren't going to act the disabled now, are you?" [In Dutch: *Je gaat je nu toch niet gehandicapter opstellen dan je bent?*]. My parents raised me to focus on my abilities and *not* on my disabilities.

Teachers cautioned me not to become over-involved with my informants. Doing so was considered to be a veritable risk because not only did I share a common cultural background with future informants, but also I shared congenital, visible impairments with them. My advisors, on the other hand, stressed the potential benefits of these commonalities.

I was unsure about the implications of these divergent responses. Truthfully, over-involvement was not my main concern. My worries were of a different nature: I doubted whether or not I actually shared enough with my informants. "Am I disabled enough?" I wondered. I do not consider myself disabled, despite being aware of the fact that the society at large views me as disabled. After all, it is visibly obvious that I *have* impairments. Having impairments, however, is not the same as *being* or *feeling* disabled.

I do not feel disabled – most of the time – because I can do most of the things I *want* to (in my own way). I used to think that my impairments made little difference to anyone for various reasons, one being my 'twin-ness.' My twin sister and I are identical. Most people have difficulty in telling us apart, even though my twin sister does not have visible impairments. If people have trouble distinguishing us, then why would my impairments matter? Or, so I reasoned.

Strangers would almost always ask questions about our 'twin-ness' but they rarely asked about my visible impairments. While our 'twin-ness' was a source of endless curiosity and therefore, I presumed, important, my impairments seemed not to be. They never attracted the same level of attention. This only gradually changed when my twin sister and I left home to study at different universities.

In addition to my social and personal identity as a twin, my upbringing also made me doubt that I was disabled enough. My parents had always stressed that I was different from *others*. With others they meant people with mental or multiple disabilities. To stress this difference between *them* and me seemed significant.

During my early childhood it became apparent that I developed in some ways differently from my twin; my doctor told my parents that I was not only physically

impaired but also mentally retarded.¹ My parents disagreed. Although other doctors later confirmed that I was *not* mentally retarded, it still infuriated my parents when strangers occasionally treated me as if I was mentally retarded.

As a result, my parents stressed my normality and distinction from others with (mental) disabilities. “You are not like *them*,” I was told. My parents left me with the impression that there were others who were disabled in a way that was incomparable to my own situation. They told me that I should not take it personally when people spoke to me as if I was stupid. These strangers were people who were brought up with wrong ideas or so my parents explained. “*They* don’t know any better, but *you* do,” they told me.

This explanation was good enough during my childhood. In fact it was a perfect adaptive strategy to counter social barriers.² This attitude prevented me from feeling bad or disabled when strangers treated me as if I was retarded. They only demonstrated *their* shortcomings, not mine, or so I thought. After all, *I* knew better.

I mostly ignored the negative inferences strangers made about me; I usually forgot them as well. Their opinion didn’t matter. People who knew and cared for me, I reasoned, knew better. So for the most part I did not feel disabled during my childhood and adolescence.

Later as an adult, when I decided to conduct research among people with impairments, I was aware of the fact that even people who know me and care for me sometimes treat me differently than others in (less than subtle ways). Sometimes I even found myself in situations where I felt disabled, but I still believed that my impairments did not make much of a difference – for better or for worse. Therefore, I was, at the start of my research project, not sure I shared enough with the so-called ‘disabled.’

To add to this, I was sceptical about there actually being people for whom the negative societal images of the disabled rang true. For me, the negative societal images of people with impairments were far removed from my daily experience.

Still, many people assume that the negative images of people with impairments were true. This discrepancy between lived experience and commonly held beliefs seemed a perfect starting point for doing research among people with impairments – ‘at home.’

Some thoughts about doing research ‘at home’

Doing research among people with the same cultural background is often referred to as research ‘at home.’ ‘Home’ bears connotations of social and emotional familiarity. I found this characterization to be problematic because I was socially unfamiliar with others with disabilities. I might *be* one (a disabled person), but I had never really met one (another disabled person). By ‘really’ I mean that I had occasionally seen and talked to others with impairments but I had never talked to them about the experience of disability. In fact, I had hardly ever talked to anyone about my impairments.

I also did not feel a special bond with others based on shared impairments. I did not grow up with people with impairments nor with role models who had impairments,

nor socialised in disability etiquette. Negative public images of people with disabilities did not help either, as Zola (1982) observed, it is hard to build a positive identity off of an illness or disability.

However, I thought that I would share some experiences with my informants – albeit mostly negative ones – after reading relevant literature prior to my fieldwork. But I was certainly not feeling ‘at home’ among people with impairments. Rather I needed, to some extent, to be convinced that I shared something more with my informants other than some superficial features, such as physical impairments.

Preparation

To minimize the risk that I would ask insensitive questions, or too much, I read relevant literature and wrote my own answers to every topic on my list. I also systematically recorded in a diary the episodes and encounters during which my impairments seemed to play a role. All of these preparations made me aware of the impact my impairments had on my own life. It was not the first time I actually thought about my impairments, but it was the first time that I examined how my impairments influenced the way I thought, my relationships with others, the choices I had made in my life and the kinds of activities I pursued.

It turned out that my impairments did, in fact, affect my life in more (subtle) ways than I had previously thought, but not necessarily in a negative way. As a result my awareness of disabling barriers and adaptive strategies grew, which was significant when reflecting on my personal experiences and encounters with others with impairments.

A disabled anthropologist faces familiar others eye-to-eye

During my fieldwork I interacted for the first time in a meaningful way with people who had congenital, visible motor disabilities. To my surprise, it turned out that having impairments in common with informants was more important than I imagined. Sharing impairments prevented our impairments from becoming disabilities in a social sense, as so often occurs in encounters with able-bodied people³. When all people share impairments they become the rule rather than the exception. Having impairments enabled us to create a space for us to talk and think about impairments differently than if I was not a person with impairments. This space made it possible to look differently at ourselves and our experiences of disability within the broader society.

Context or situational meaning of shared impairments in encounters

Sometimes you notice that friendships with people with impairments run more smoothly. Just because you need to explain less. (..) With able-bodied friends it takes a while. Especially if they are conservative, negative about what you can do (an informant).

Impairments become disabilities in encounters with able-bodied people for multiple reasons. Generally, able-bodied people have difficulty assessing what someone with physical impairments can or cannot do. Usually able-bodied people know that something is different but judging what this 'otherness' means is an entirely different matter.

Frequently, able-bodied people over- and under-estimate the abilities of persons with impairments. Knowledge of the practical consequences of disorders and impairments in daily life is not part of the cultural capital for most people. Because of this knowledge gap, many people with impairments often feel obliged to inform or educate able-bodied people and many able-bodied people feel tense in encounters with persons with impairments (Gorter 1983; Albrecht et al. 2001; Mogendorff 2002b).

Informants felt less obliged to explain to me what kind of disorder or chronic illness they had because I shared impairments with them, as the above-mentioned epigraph illustrates. Interviews with a disabled researcher offered them the rare opportunity of exchanging information and ideas about disorders, impairments, disablement and adaptation, transforming impairments from something negative to something positive, at least for a short while. Our exchanges tended to take place on a more or less equal basis and were to a greater or lesser extent reciprocal in nature. I was not a researcher who was temporarily part of their world.

Informants

Fifteen informants participated in this research project which was conducted in 2001. They were relatively young, between 18 and 31 years-old, Dutch, and had congenital, visible motor impairments. There were also many differences among the informants (cf. Mogendorff 2002b). The purpose of this research was to explore how impairments affected the self-image of young adults with visible, congenital motor disabilities.

My encounters with informants varied in frequency, duration and proximity (face-to-face, internet, telephone). I visited all informants at least once in person. In this paper only face-to-face encounters with six different informants are discussed.

Encounters between a disabled anthropologist and her informants

[I]nsight follows from personal experience. You can only understand the experience of others if you have suffered in a similar fashion. Good ethnography must be based on empathy (Kuper 1999: 215).

Although Kuper's quotation might not be universal—one does not necessarily need to have suffered in a similar way to understand another's experience – it nevertheless carries a grain of truth. Sharing similar experiences with informants can enhance our understanding of informants' experiences as long as these experiences are not bothersome to the researcher and he or she is able to reflect upon these experiences.

Shared experiences certainly helped me during my fieldwork, although I was initially sceptical about the benefit of sharing impairments with informants. I still do not think that impairments alone are enough to base a good relationship on.

Sharing impairments with informants turned out to be an asset because several informants expressed that contact was easier with people with impairments, as the following discussion demonstrates:

Researcher: Are relationships with people with the same disorder different from relationships with people with other disorders?

Informant 1: A little bit. But that's because it is easier to laugh with people with the same disorder. That's all. As someone starts than you can laugh at him.

Researcher (nods): Then you know better what the disorder is about. But having a disability yourself doesn't mean automatically that you understand other disabilities? (I am a bit sceptical here).

Informant 1: No.

Informant 2: I do think there is more understanding for each other.

Informant 1: For instance, as someone starts because the dog barks than you can make a joke about that, but you can only do that if you have the same disorder [In Dutch: aandoening]. But I do think that you can also understand other disorders more easily. The hard of hearing people [of Jopla] also noticed that we [the members with motor disabilities] were considerate of them.

Informant 2: Maybe we are more considerate than most. We have a couple of good friends with impairments; we want to be considerate of them. We take more trouble than most, I think. That brings a lot of nice things. You get more contacts, and you accomplish more.

Informant 1 (to me): You soon pay attention when you interact with others with impairments. (He seems to try to reassure me a bit).

In this discussion, I distanced myself from my informants by questioning the assumptive benefits of sharing impairments with others. Informants responded to me by insisting that in time I would be convinced otherwise.

Although I was sceptical, I reinforced informants' beliefs on the positive aspects of our commonality; I revealed by my choice of words and actions that I was generally well-informed, although I was not conscious of my own knowledge at first.

For example, when informants didn't mention adaptations during discussions on auxiliary devices at home, work or school, I drew upon my own experiences to prompt informants in recalling their use of adaptations:

Researcher: Do you use adapted learning materials?

Informant (thinking aloud): Only a laptop...For the rest, no, not really. No, that is not totally true.

Sometimes they did enlarge study material. When I had difficulty reading the reading material they sometimes enlarged it [the letters] for me. So, they did that for me [teaching staff].

Researcher: When I used a wheelchair for a while, I had a set of books at home and a second set at school.

Informant: Oh yes, wait a minute! I did have that too, indeed! That's right. I did like that a lot, you know. You should have seen how much books they had to carry with them! [other students].

This informant had, like me, difficulty carrying heavy stuff. I never saw him carry heavy loads firsthand but was quite sure that it was a problem when I noticed his mobility devices and observed him at his home. In the above quotation this informant confirmed my speculation, which indicated a moment of mutual understanding or intersubjectivity.

Still, I was not privy to everything my informants did. My ignorance, however, was sometimes helpful in that informants were glad to help a fellow 'crip'⁴ out. During one of my first interviews an informant remarked:

Informant: And of course I have Wajong. (In response to my question, "What special arrangements she used.")

Researcher: What's Wajong? (I had never heard of Wajong before)

Informant: You *don't* have Wajong?

Researcher: No.

Informant: Oh my, we need to educate you (laughs). Wajong makes your life easier. It is a social benefit for people with congenital impairments...

During other times, however, shared impairments made it difficult to elicit responses:

Researcher: Can you tell me more about your encounters with able-bodied people in public places?

Informant (grins): Well, you know, the usual.

Researcher: Yes, but I would like more about your experiences...

Informant: Well... Okay. But I am sure you know most of it already.

In this instance, the informant seemed confused: Why was I asking him things I already knew or should know? Assumed mutual understandings can be a hindrance for eliciting information.

On some occasions, it seemed necessary to stress my own or the other's unique subjectivity to obtain desirable answers. In fact, I had to carefully balance my identity as he 'ignorant' researcher interested in the life experiences of people with impairments with my (ascribed) identity as the well-informed peer.

Corporal realities that help establish intersubjectivity

An informant who had the same kind of disorder but different impairments as me commented upon my appearance while discussing his impairments:

Informant: You know, you have it too [scoliosis]; it is in the way you walk.

Researcher: Well, I don't know. (His remark made me feel uncomfortable. My initial thought was: 'I don't want this; I don't want to be made more disabled than I am. But I am not sure, I didn't have scoliosis. I didn't know what scoliosis was.' So, I asked, 'What's scoliosis?')

Informant: It's a deformation of your spine.

Researcher: (Great! I thought.) Okay. (And then I moved on to another topic.)

When I later recalled this interview, I wondered whether he was reaching out to me or was trying to establish common ground. Maybe he was figuring out for himself how much I was like him, and subsequently, to what extent I could understand his experiences? After the interview I visited my general practitioner to verify whether or not I had scoliosis. To my relief, I did not.

Strikingly enough, all informants commented on my impairments in relation to their own, and sometimes even referred to my impairments during conversations. Informants were uninhibited in their questions about my physique. This was in stark contrast with how classmates or teachers inquired about my impairments. Teachers or classmates would typically say something to the effect of: "I hope you don't mind me asking, but I was wondering, what do you actually have?" Often a look of embarrassment or discomfort accompanied their questions. They often shuffled their feet, or avoided direct eye contact. Conversely, informants frequently asked about my impairments differently from able-bodied people. In fact, they often articulated unabashedly their observations on what I could and could not do. For example, common phrases included: "You have it too!" or "I can see/ hear it." or "You do it too, you know." "I noticed when you came back from the toilet / climbed the stairs", etc. Sometimes I disliked it when informant remarked on the way I walked (as in the aforementioned example), however, often I did not mind because comments helped me make better sense of my own and others' impairments.

In another instance, when I laughed at an informant's joke, she exclaimed, "You have it too! It is in your voice. Your vocal tone changes when you get emotional." I had, in fact, noticed her observation before she mentioned it while listening to recorded interviews. My voice indeed changed with particular emotions, but I was never sure if this change was related to my disorder or to something else. Other people's voices changed as well when they were emotional. However, the change in my voice was more pronounced at times. The informant who had observed my vocal change helped me better place my own observation.

In fact, I learned a lot about the boundaries of my disorder and impairments, as did my general practitioner. Interestingly enough, informants' views on what was part of my disorder and what was not differed from those of my general practitioner.

Timing and significance of remarks on our physical and functional similarities

Informants usually commented on my appearance when they first laid eyes on me and when we broached topics on medical histories. Informants remarked on how I was different or similar to what they had imagined I would look like, especially if they

knew that I shared their disorder. One informant, for instance, said, “I thought you had the same disorder as me. It is similar, but also different” (we had the same kind of disorder, but different subtypes).

He sounded somewhat disappointed, which confused me. Why did it seem so important for this informant and others to establish how much we were alike in terms of impairments / disorder?

Later, while thinking about his disappointment, another informant’s comment came to mind: “When I became a member of Jopla I hoped to get to know others like me. Others who not only have comparable impairments but also have an academic education. Sharing impairments is not enough. But there are not that many members of Jopla akin to me. When I saw your call for participants on the website I thought maybe...”

Apparently informants seem to welcome people who can not only understand their *experiences* in general but can also relate to their particular experiences as someone with specific impairments.

Similarities of disorder and/or impairments was a strong predictor of the extent to which we could ‘compare notes’ about physical abilities, operations, auxiliary devices, etc. Comparing notes changed the interviews by making them more reciprocal. These exchanges of experiences were not only verbal in nature, but were also non-verbal. We demonstrated to each other what we could do, and sometimes even tried out each others’ auxiliary devices.

Looking in a mirror

One informant did have the same disorder *and* impairments as me. She even walked almost exactly as I did. Our first encounter was incredibly strange. When I first saw her, it was like looking into a disability mirror; her impairment literally mirrored my own. Where my right leg was affected, her left leg was affected. Seeing her for the first time produced strange feelings yet excitement at the same time. There I was, 24 years-old, and for the first time, I saw someone right in front of me walk just like me! Of course, I knew there were others like me before her, but I had never met one who... We hit it off right from the start, not only because we shared a particular gait but also, even more so, because we were both university-educated, female, twenty-something, and as I later learned, (unconsciously) in search of someone with impairments like ourselves.

This encounter lasted for four hours and evolved beyond just talking. At one point, we found ourselves sitting on the floor, because this informant was demonstrating how we stand up differently from able-bodied people. Up until that point, I had not been aware that we stood up that differently from able-bodied people (cf. Mogendorff 2002b). After showing me how we got up from the floor, she continued to demonstrate other bodily postures, and asked me to follow suit. As requested, I demonstrated in turn what I was capable of.

We then began to compare similarities and differences in our physical abilities. For instance, we discussed our past operations. Even though we had been in different hospitals and had had different surgeons and procedures, it turned out that we went

through the same operation. Furthermore, we discussed physical therapists, auxiliary devices, physical and social barriers; how family members coped with our impairments; and the particularities of the impact alcohol had on our walking abilities.

All of these exchanges were very informative for both of us because we not only explored similarities but also differences that we found in unexpected places. For instance, we underwent the same operation, but we ‘discovered,’ by comparing our experiences, that the same operation can be performed in several different ways though still serving the same purpose. We also learned that while having the same disorder and types of impairments, we faced to some extent different practical problems. For example, I am not able to walk with dinner-trays in big open spaces, whereas this informant could. But she could not ride escalators, whereas I could. Because of our similarities, however, making comparisons became possible. In the end, I realized that it was often productive to exchange personal experiences with informants.

But sometimes it was even better to keep silent.

Knowing when not to ask

Interviewing has a lot to do with asking the right questions in the right way at the right moment. But maybe it is more important to know when not to ask questions. This is a major dilemma for ethnographers: What if you want to know more about informants’ views on sensitive subjects? At the start of my research I was anxious about asking potentially insensitive questions, the kind of questions able-bodied strangers tend to ask. Not only would being insensitive prevent me from finding answers to what I was looking for, but I also wanted to avoid doing to others what others have done to me.

How then do you get the answers you need? The answer seems to be a mix of patience, silence and luck. Some information was offered to me because I was savvy enough not to ask for it. For instance, the field notes from my second visit with an informant reveal how restraints are sometimes good:

When I arrived at the home of a female informant, she was talking on the phone. Her boyfriend was still in his pyjamas eating breakfast. Did I like some breakfast as well? I declined but gratefully accepted a mug of strong black coffee and sat down. We (her boyfriend and I) waited for her to finish her telephone conversation. She was clearly excited about something.

When she put down the receiver she exclaimed radiantly: We are getting ourselves a bed! Finally we can sleep together.

Me (smiling): Naturally, you want to sleep together; you live together.

She: It is really difficult to get an adjusted two-person bed. They don’t have any; you have to hire a specialist to adjust a two-person bed to your needs. Can you imagine?!

Me (incredulous): Really? They don’t have adjusted two-person beds?

She: Yes! Isn’t it stupid?

After this we talked a bit more about the stupidity of care providers who don’t take into account that people with impairments want to live a normal life like everyone else

(such as sleeping together). Then the ADL-assistant⁵ came in to assist her boyfriend in getting ready to go out. We switched to other subjects. Shortly thereafter, she said:

I am glad you didn't ask about our sex life. A lot of people ask us how we do it, you know.

Me (quietly): I, too, am often asked the same kind of question.

She throws me a sharp look and says kindly: Yes, I can see that.

And later, when we are discussing the pros and cons of having children as women with impairments, she comments (while smiling):

You know what? I will tell you how we do it.

Sometimes you get more than you ask for.

In this situation, the behaviours of able-bodied people impacted our conversations. My behaviour toward my informant was favourable in contrast to the behaviour of able-bodied people who sometimes ask upsetting and insensitive questions. This is a common experience for the majority of those with impairments and their partners.

However, experiences with able-bodied people are not always a source of annoyance; sometimes they become a source of mirth as well. Laughing together with my informants is the final way of establishing rapport and/or mutual understanding that I discuss in this paper.

Laughing together at the responses of able-bodied people

Humour may be an important strategy for coping with negative life experiences and a tool for establishing rapport, especially if the humour is nearly exclusive to the in-group members. The ability to make others laugh implies you share some understanding or outlook on life with them. Exchanging 'funny' experiences with informants about encounters with able-bodied people strengthened my relationships with them, particularly when emphasizing what *we* have in common at the expense of able-bodied people's ignorance. This was the case in the following exchange:

Informant: Yes, then it is all right. They [children] don't notice anymore [that you have impairments]. It is sometimes even fun. For instance there was a boy – I don't know how old he was –he came up to me and said: "One of your legs is too long." That's what he said! I found that grand; normally people say: "Your one leg is too short." But he said: "Your leg is too long." That, I do like.

Researcher: Yes (smiles). There was also some girl who said to me: "Does it hurt?"

Informant: (Laughs).

Researcher: Or, "How clever that you can walk that way!"

(Informant and researcher both laugh.)

Informant: Things like this are funny. What happened one time, which was also funny... My one leg is far shorter than the other one. I wore boots, just boots from one pair (there is

a great difference in the size of her feet) and the boot on my left leg just hung there. A boy with his father passed me. The boy was looking at me. I saw him turn his head to look at me. And my boot was loose and turned all the way. My toes pointed in opposite directions. One foot pointed forward, one foot pointed backward. "What is that?" the boy asked his father. His father: "I don't know, just walk ahead." He didn't know what to do [the parent]. What could he have said about something like that? (Informant laughs).

To my surprise and delight I discovered in interactions like this that informants understood why I thought encounters with able-bodied people were sometimes funny. This strongly contrasts with my experience of trying to laugh with able-bodied people about funny disability-related exchanges. Able-bodied people tend to be unsure about how they should respond to anecdotes similar to the ones we told. Are they allowed to laugh? Or should they be shocked?

For this reason, I think laughing together about the responses of able-bodied to impairments is a group coping strategy in dealing with negative societal images of people with disabilities that operates alongside individual adaptive strategies (For a discussion on individual adaptive strategies, see Mogendorff 2002a).

Examining moments of mutual understanding

So far I have discussed how I, as a disabled anthropologist-in-training, tried to establish rapport and come to a mutual understanding with my informants. I began by discussing my personal biography to the extent I thought it relevant to the way I presented myself to and interacted with informants. This process requires further elaboration.

My ambivalence as a disabled person prevented me from assuming that I already knew a lot or anything at all about living with impairments. Consequently, I asked about things that were supposedly known to everyone with impairments. Informants were sometimes confused by my obvious questions: Why was I asking about things I already knew about?

However, most informants were aware of the fact that I had not grown up among others with impairments, and therefore that I was ignorant about some things. After all, most of them (but not all) also did not grow up with 'peers' either or knew from personal experience the significance of getting to know other people with impairments.

Intersubjectivity was reached by sharing experiences and doing so shows that I recognized, understood and acknowledged their experiences. This was accomplished in several ways: (1) by prompting informants to recall memories by discussing my personal experiences of living with a disability; (2) by avoiding insensitive questions that able-bodied people often ask; (3) by recalling personal memories to make informants laugh (and to strengthen our relationship); and (4) by being a willing listener; and (5) by sharing personal experiences with and answering inquisitive questions from informants, making the exchanges more equal and reciprocal. Finally, sharing experiences was also a way to find out how my own experiences related to theirs.

Of course, these ‘strategies’ also have limitations. Using one’s own experiences only works well when there is a genuine match in the underlying mechanism between informants and researcher that helps constitute the experience of living with impairments. Actual experiences, however, do not need to be the same.

I did not consider these ‘strategies’ prior to starting my fieldwork; they are *not* strategies in the sense that they were all planned in advance. However, before I began, I self-consciously avoided asking insensitive questions, even though I realised that this was risky. It was risky because there is absolutely no consensus on which questions qualify as being insensitive, particularly since this depends on context and personal preference. By avoiding questions, however, one might miss valuable data as well.

Sharing personal experiences was also something I planned to do in my fieldwork. From everyday experience, I knew that it is easier for someone else to share experiences (especially negative ones) by revealing some first. I usually did this in a few short sentences, which is how I displayed trust, which in return made it easier for others to trust me and return the ‘favour.’ This strategy may only be safe to employ when three conditions are met: (1) you are in the ‘same boat’ as your informants, sharing their vulnerability or making yourself vulnerable to informants, and (2) using your own experiences is based on sincere interest in knowing about theirs, and (3) you are not too ‘needy’ in sharing experiences about yourself. If you are, you run the risk of rambling on too much about yourself.

Berger (2001) also mentions this strategy as being characteristic of the auto-ethnographic method. This may sound a bit calculating, but if all goes well, the sharing of one’s own experiences is a spontaneous affair; it does not need to be done by design. Still, it is sensible to think in advance what you want to disclose and what you do not.

From mutual understanding to ‘new’ insights

The experience of intersubjectivity in this fieldwork was instrumental in gaining new insights, because it made sharing and comparing similar experiences with other people with impairments (e.g. comparing notes about operations and therapies) possible. Intersubjectivity also helped me deal with social barriers (for a more extensive description of strategies to deal with social barriers, see Mogendorff 2002a). This sharing of subjectivity made it easier to place individual experiences of living with impairments in Dutch society in broader perspective.

Doing research among other people with impairments also convinced me that I shared something more than impairments and experiences of disablement and adaptation with informants. We also shared to some extent a similar outlook on life that is, at the same time, different from many able-bodied people. I was only convinced of this fact when I noticed that informants responded differently than able-bodied people to my impairments as well as to my attempts at sharing funny anecdotes of disablement.

Insights are thus gained from comparing and contrasting experiences between informants and able-bodied people. By contrasting my fieldwork experiences to my everyday experiences, my awareness of how my impairments impact on my own life

and that of others grew (for an example of a better understanding of how able-bodied view people with impairments, see Mogendorff 2003).

The impact fieldwork had on the anthropologist's personal identity

Comparing and analysing my own experiences with disablement and adaptation with others' experiences whenever they occurred during and after fieldwork also set in motion a process that ultimately resulted in a shift in my personal identity. I went from 'having-impairments that are-not-really-a-part-of-me' to integrating my impairments into my personal identity in the same way that other identifiers are part of my identity, such as being one-half of identical twins, Dutch, a woman, etc. This has made me more self-confident since I am more aware of myself and how others respond to me in *any* encounter. I have also come to realize how my impairments collectively with other characteristics make me unique. I try to make most of what life has to offer, including my impairments⁶.

My body has become a 'tool' for understanding life's experiences and the world I live in (for similar experiences, see the work of another disabled anthropologist Colligan (1995, 2001)).

Furthermore, sharing impairments has positive aspects alongside the negative ones, precisely because they have helped shape friendships with people with impairments, including former informants. To state that impairments are not exclusively negative is to challenge dominant societal views on impairments and disabilities.

If one compares my view on the significance of impairments in my life before and after my fieldwork, then it can hardly go unnoticed that my personal background had an impact on my relations with my informants and therefore made it easier to achieve intersubjectivity. The relationships and insights gained from this research also affected how I thought about the role impairments played in my own life. This influence might signify that intersubjectivity is cyclic in nature, in addition to being intrapsychic, inter-corporeal and social.

The need for and to create space for...

The dominant view on impairments is that those afflicted by them should compensate for these shortcomings or at least not draw attention to these imperfections, particularly in reference to bodily functions. Able-bodied people often display some discomfort or 'action-shyness' (In Dutch: *handelingsverlegenheid*) when they are confronted with impairments. What should they say? How should they act? As a result, able-bodied people ask inquisitive or inappropriate questions of persons with impairments, making them feel disabled (Gorter, 1983; Mogendorff, 2002b). Even if able-bodied people do not display any overt awkwardness, their unease might be gauged from their careful avoidance of the subject of impairment and disabilities. For instance, at home, my impairments were seldom mentioned let alone discussed, nor was I encouraged to talk about them. Informants tended to share this experience, remarking on it by saying things like: "My parents accepted me, but I don't think they really accepted my

impairments.” However, informants expressed their wish and desire to be accepted as a person *with* impairments.

In general, the majority of informants felt that they were either treated like they were the embodiment of disability itself, rather than as persons with impairments. Or they felt that people acted as if their impairments were not even there. Even informants commonly believed and acted for a time as if their impairments made little or no difference in their lives. At some point, however, they became aware that their impairments did – or might – matter. And they felt, after realizing this, increasingly uncomfortable when people totally ignored their impairments. As a consequence, some informants became involved with disability organizations, seeking acknowledgement for what and who they were since their families and the society at large failed to acknowledge them as persons with impairments.

The promising prospects of the space among people with impairments

During encounters, the space created in this research by the informants and myself provided to some extent the same needs that disability groups and organizations did. When I realised this, I also understood why in encounters so much emphasis was put on assessing the similarity and difference of various disorders and impairments. Informants were searching for understanding, recognition and acknowledgement of themselves as persons with impairments, as people that matter. Furthermore, drawing from their personal experiences, they knew that this social recognition was hard to find in society. Society offers a very limited framework to articulate and make sense of the lived experiences of persons with impairments.

The space created in encounters during this research provided a ‘place’ to voice and discuss fears, anxieties, problems, needs, dreams and expectations that are rarely voiced elsewhere, at least without being met by some form of pity or disapproval. This was especially true for digital encounters in the Internet community for young people with impairments in which I participated.

In this space there is no need to downplay impairments or disabilities. There is no need to help others overcome their discomfort with your visible impairments. Having impairments in this space is in many ways norm-al – it *is* the new norm. Able-bodied people are outsiders in this space.

From a long-term perspective, spaces like this – safe havens – might help participants create a positive self-image and confidence through their adaptive strategies as individuals and as a group in countering, and even transforming the negative social responses and images of people with impairments within the broader society. Looking in a mirror could be, but doesn’t need to be, confrontational. To the contrary, it can be a source of peer-recognition and -empowerment. And that is the ‘new’ insight that is ‘born’ or created from mutual understandings.

Notes

Karen Mogendorff is employed by Vilans, institute for long term care and is a researcher on patient-doctor communication at the Radboud Medical Centre in Nijmegen, The Netherlands. She has a background in cultural anthropology and communication studies. E-mail: kmogendorff@hotmail.com

I like to thank Marie Rosenkrantz-Lindgaard and the other participants of the 'Intersubjectivity as tool in anthropology' symposium, Rebekah Park, my reviewers and the editors of *Medische Antropologie* who provided critical or editorial feedback on earlier versions of this paper. I thank Marianne Vysma in particular for her encouragement and helpful comments during the final phase of writing this essay.

- 1 Later I found out that people with my disorder often get initially diagnosed mentally retarded. This also turned out to be true for all informants with whom I shared the same kind of disorder.
- 2 This way of coping with negative responses from strangers to people with impairments can be seen as an example of the strategy 'turning around' [In Dutch: *omkering*] which I discuss in an earlier paper (Mogendorff 2002a).
- 3 For this reason I mostly prefer talking about 'people with impairments' to 'people with disabilities.'
- 4 'Crip' is generally considered to be a demeaning term, but may be used in joking situations among people with impairments. Able-bodied people, however, are ill-advised to use it.
- 5 An ADL-assistant is someone who helps others with daily activities, including eating, dressing, and getting in and out of bed (ADL is shorthand for: Activities of daily living).
- 6 However, I think it is important to stress that my research among people with impairments only *started* this process. The research period was too short to bring about substantial changes in identity and body-image.

References

- Albrecht, G.L, K.D. Seelman & M. Bury (eds.)
2001 *Handbook of disability studies*. California: Sage Publications.
- Berger, L.
2001 Inside out: Auto ethnography as a path toward rapport. *Qualitative Inquiry* 7 (4): 504-17.
- Colligan, S.
1995 The ethnographer's body as text: When disability becomes "other"-abling. *Anthropology of Work Review* 15 (2-3): 5-9.
2001 The ethnographer's body as text and context: revisiting and revisioning the body through anthropology and disability studies. *Disability Studies Quarterly* 21 (3): 113-24.
- Collinson, K.A.
2005 Emotions, interaction and the injured sporting body. *International Review for the Sociology of Sport* 40 (2): 221-40.

- Gorter, K.
 1983 *Handicaps tellen dubbel: Een literatuurstudie naar mogelijkheden de vooroordelen over mensen met een lichamelijke handicap te bestrijden.* 's-Gravenhage: NIMA-WO.
- Gorter, K. & U. Janssen
 2002 *Vrouwen met een lichamelijke functiebeperking in Nederland: Een kwalitatief onderzoek naar hun leefsituatie.* Utrecht: Verwey-Jonker Instituut.
- Ingstad, B. & S.R. Whyte (eds.)
 1995 *Disability and culture.* London: University of California Press.
- Kuper, A.J.
 1999 *Culture: The anthropologist account.* Cambridge, MA etc.: Harvard University Press.
- Mogendorff, K.G.
 2002a Wanneer het vanzelfsprekende niet vanzelf spreekt: Geslaagd omgaan met negatieve beelden over handicaps, fysieke en sociale barrières. *Medische Antropologie* 14 (2): 303-20.
 2002b *Handicap en zelfbeeld: Een studie over jongeren met aangeboren motorische beperkingen in Nederland* (scriptie). Nijmegen: Radboud Universiteit.
 2003 Paradoxen van lichamelijke kwetsbaarheid. Wanneer 'hebben' 'zijn' wordt: Angst, medelijden en 'bewondering' voor mensen met een zichtbare, aangeboren motorische handicap in Nederland. *Medische Antropologie* 15 (1): 9-26.
- Okely, J.
 1992 Anthropology and autobiography: Participatory experience and embodied knowledge In: J. Okely & H. Callaway (eds.). *Anthropology and autobiography.* London: Routledge, pp. 1-28.
- Paerregaard, K.
 2002 The resonance of fieldwork: Ethnographers, informants and the creation of anthropological knowledge. *Social Anthropology* 10 (3): 319-34.
- Steiner, M.
 1995 When an other meets an other: Coming I-to-I. *Anthropology of Work Review* 15 (2-3): 10-11.
- Tankink, M. & M. Vysma
 2006 Intersubjectivity as an analytical tool in anthropological research. *Medische Antropologie* 18 (1): 249-65.
- Van der Geest, S.
 2007 Is it possible to understand illness and suffering? *Medische Antropologie* 19 (1): 9-21.
- Vysma, M. & M. Tankink
 2007 Introduction: The various uses of intersubjectivity as an analytic tool. *Medische Antropologie* 19 (1): 5-8.
- Zola, I.K.
 1982 *Missing pieces: A chronicle of living with a disability.* Philadelphia: Temple University Press.

