Doing frogs and elephants

Or how atypical moving bodies affect and are affected by predominantly able-bodies

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With help of the Deleuzian moving body concept this paper seeks to further insight into how bodies with a different kinesiology are affected by and affect other bodies. Based on fieldwork among fifteen, congenital neuromotor impaired young adults and the lifelong experience of the author with a movement disorder. I first discuss how expectations of people and in particular the body-images of disabled people are affected by our constant enmeshment with other bodies. Secondly, two basic bodily practices which informants have learned in paediatric physiotherapy – the frog and the elephant – are described to introduce the different body kinesiology of neuromotor impaired people. Thirdly, it is shown how the different bodily practices of informants affect encounters with able-bodied people. The focus is on how the ambiguity of the visibility of movement disorders disrupts encounters. This is followed by a description of how informants try to avoid or resolve disruptions in encounters. In the final section the author compares the employed embodied perspective to social political models of disability.

[movement disorders, bodily practices, moving body concept, social interaction, disability studies, reflexive ethnography]

To date there is not much written about what it means to be and have a body with a different kinesiology in a world dominated by able-bodied people. Most sociological and anthropological literature about the body has not the active, moving body as its focus, and, if it does, it concentrates on the embodied experience of sports (Howe 2004; Peace 2010) and arts such as dancing of the able-bodied (Spencer 2009; Thomas & Ahmed 2004; Turner 2001).

In the disability studies literature bodily experiences of people with physical impairments are also not a primary focus. Most studies focus on the psychological and emotional consequences of living with an acquired disability or the social and physical barriers that prevent or make difficult the pursuit of life goals. This may be due to
the dominance of the social-political model of disability that sees disability as an outcome of discriminatory and oppressive practices, and strictly separates disability from impairment (Hughes 2009; Shakespeare et al. 2002). Nonetheless, there are some studies that focus on how embodiment informs interactions between able-bodied and disabled people. One is Robillard’s autobiographical Meaning of a disability (1999) that looks at social interaction from an ethno-methodological perspective. Another one is Howe’s (2009) research note on his experiences with impairment in the pub.

In this paper I explore how our constant engagement with other bodies affects our body images and responses to embodied agents we encounter in everyday life. I hope this may further insight into how embodiment contributes to understanding ourselves and others. Because most people are unfamiliar with the body kinesiology of people with neuromotor impairments such as cerebral palsy and spina bifida, I will describe in detail two basic bodily practices of disabled people that occasionally cause confusion and embarrassment in encounters between able-bodied and motor impaired people: the ‘frog’ or squat and the ‘elephant’. These bodily practices have been taught to most informants as young children in paediatric physiotherapy to get from a lying position or a sitting position to a standing position. Understanding and heightened awareness of how our constant entwinement with other bodies affects our responses to differently-abled bodies in encounters may reduce the negative (normative) inferences people make about disabled people.

I will discuss in this paper: (1) the moving body concept and its implications; (2) how enmeshment of bodies affects body images of disabled people; (3) how “frogs” and “elephants” and other atypical bodily practices of informants acquired in paediatric physiotherapy disrupt encounters when applied in a non-medical context; (4) the ways informants seek to avoid or resolve disruptions in the flow of interactions; (5) how the Deleuzian perspective relates to common approaches to disability.

Fieldwork and the author’s lifelong experience with neuromotor impairments

In 2001-2002 I collected the life stories of young, Dutch adults with congenital, visible motor impairments for my master thesis in social anthropology (Mogendorff 2002a). I was born with a common movement disorder and wanted to know how others lived with and were affected by their impairments. As it turned out, most informants had a form of either cerebral palsy or spina bifida, two non-degenerative neuromuscular conditions that tend to affect muscle coordination and body movement (for that reason these conditions are also referred to as movement disorders). Fieldwork consisted for the better part of open-ended interviews with fifteen informants and participation in an online community for young adults with chronic illnesses and/or physical impairments in which most informants took part. During face-to-face sessions informants and I did not only talk, we also showed, explained, admired, discussed and tried out auxiliary devices. From demonstrations and the try-out of informants’ devices I gained insight in the rich diversity of the everyday bodily abilities and practices of
informants, such as insight in ways to navigate stairs, transport drinks and food, use wheelchairs and other mobility aids. It did give me a feel for what is the normal body habitus of people with neuromotor-impaired bodies. In addition to fieldwork I draw in this paper on my own lifelong experience with a movement disorder.

The moving body concept and its implications

Moving bodies are first and foremost phenomenological or lived bodies (Kosut & Moore 2010). The lived body unites experience and matter, self and person (Thomas & Ahmed 2004; Thornquist 2006). This connection allows for the treatment of bodily practices as a source of knowledge in its own right. It enables people to reflect on and – if necessary – modify their bodily practices. The lived body concept may also in part explain how people’s experiences and histories are expressed in bodily ways and how bodily practices shape encounters (Thornquist 2006). Still, this lived body concept is rather self-contained. It does not fully capture the dynamic nature of how bodies are affected by other bodies and things in daily life. The Deleuzian concept of the moving body may be of use here. In Deleuzian terms a moving body is multiple and constantly engaged with other bodies and/or entities: “the body is a moving assemblage that finds itself enmeshed with other assemblages” (Thomas & Ahmed 2004: 216). Important for the purposes of this paper is that Deleuze and Guattari (2004: 309) view movement as imperceptible by nature: “Perception can grasp movement only as the displacement of a moving body or the development of a form. Movements, becomings, in other words, pure relations of speed and slowness, pure affects, are below and above the threshold of perception.” People perceive what the moving body does, not the movement itself.

The Deleuzian moving body concept is a relational view of the body in which entwinement of life and world is central: as embodied agents we are intertwined or enmeshed with others and things as we go about our activities and projects (Sandberg & Dall’Alba 2009). Moreover, our enmeshment with different assemblages is our primary form of being in that we connect and disconnect constantly with other bodies and things to engage in bodily practices – arrays of habitualized movements – such as cooking and walking. Embodiment, entwinement and shared know-how are preconditions for engagement in practices and for making sense of our world, ourselves and others, blurring boundaries between individual and social levels of analysis and diverse dichotomies and opposites (ibid). Shared know-how is not necessarily consciously or voluntarily acquired as the “that finds itself enmeshment with other assemblages” part of the Deleuzian body concept indicates. Which is not to say that enmeshment with others and things is always or totally devoid of agency but rather that what we interpret as agency is limited by factors as embodiment. People have agency in that they are able to direct their actions in different contexts responsive as they are to the diverse circumstances, possibilities and needs of themselves, others and things. However, our bodies are not always able to do what we want them to do. Physically disabled people know this as no other. For instance, as a child I sometimes
tried to explain my failure at walking as everybody else to curious strangers with: “My feet do not always do what I tell them to do, they do not listen.”

Agency or our ability to direct our (bodily) actions is furthermore constrained by our constant entwinement with others and things. We often have limited control over the bodies and things we find ourselves enmeshed with and how encounters shape our expectations and images of ourselves and others. Or as Guattari and Deleuze put it: “we cannot avoid to affect and to be affected by others and things” (Deleuze & Guattari 2004). Through billboards and advertisements, for instance, we are constantly confronted with images of slim, young women with big breasts. Some people may reject the dominant beauty ideal these images represent but this does not mean that they are not affected by them. Critical individuals are likely to realize that the majority of people they encounter do not conform to this beauty standard. However, by doing this they still use the dominant norm of female beauty as an evaluative standard. Likewise our understanding of what bodies can or should do under different circumstances is formed by our prior exposure to and experiences with our own and other bodies.

A last factor important for understanding encounters between disabled and able-bodied people is temporality (Simpson 2009). Not only do we move our bodies moment by moment (Deleuze & Guattari 2004: 310), temporality is also a factor that structures and informs our inter-actions with others (Sacks 1992). Our enmeshment with others and things is sequentially organized and informed by our past experiences. Sequence one finds in the structure of talk and movements of bodies. Talk is sequenced in that one person’s gestures and symbols calls for a specified response in another person. For instance, when someone asks a question, s/he expects to get an answer from the person s/he is addressing (Sacks 1992). Bodily practices are also sequenced. For example, when we decide to come out of bed to take a shower, we need first to get from a lying position to a sitting position to a standing position (or transfer to a wheelchair) before we are able to walk or roll to the shower. In these, ordered flows of conversation or bodily action social meanings are constructed, reconstructed or disrupted (Simpson 2009). Furthermore, the flow of interaction is very much directed by the habits and knowledge people have acquired during the life course. For instance, people project their generalized other – a generalized set of expectations based on prior enculturation and experience – on their encounters in the present. Moreover, when expectations based on prior experiences are not met, the flow of interaction is disrupted, something interactants are inclined to resolve or avoid in the future (Simpson 2009).

To sum up, the Deleuzian moving body concept may prove helpful in understanding how bodies with a different kinesiology take effect in encounters between able-bodied and disabled people. The usefulness of the concept lies in that it avoids dichotomies such as humans versus non-humans, deliberate versus non-deliberate action, voluntary versus involuntary effects. Moreover, the concept makes it possible to avoid oppositions such as mind and body, past and future.

The temporality implied in the moving body concept helps to elucidate how bodily practices learned in the past may affect present encounters. Moreover, by connect-
ing with other bodies and things we get to know our own, individual bodies and start ascribing meanings to them. The temporal and social nature of body movement could explain why body images of disabled people may change when people start to interact with differently-abled bodies and how these body images and expectations of the body disrupt encounters of embodied agents.

**Enmeshment with bodies: Impact on body images**

Impaired children learn through exposure and inter-action with able-bodies that their bodies are considered deviant by most people. This they first and foremost know conceptually: they know they are seen as different but they do not experience it that way because they lack the embodied knowledge of an able body. This is illustrated by the fact that people with congenital, motor impaired bodies have often an able-body-image, in particular when they have grown up surrounded by able-bodied people, or as an informant put it:

> I don’t have a mental image of myself as handicapped (...) When I look in shop-windows I think: Oh God, is that me? (see Brenninkmeijer 1997; Seymour 1998: 41 for similar citations).

The informant in the quotation has no lived experience of an able body and therefore does not know how her body is different from able bodies on an embodied level. Her body is normal to her, in the sense she is her body. Her response to her body’s reflection in shop-windows indicates that she has modelled her body-image on the able bodies she is constantly surrounded by. However, when she sees her moving body she is acutely reminded of the fact that her body may feel normal but does not live up to dominant, able-bodied norms. Another informant is even more explicit about the impact of growing up surrounded by able bodies on body-image:

> When you are a child and you never encounter disabled children and you only see people who walk normally, how should I know that people could see it [how I walk]?

Likewise, when one finds oneself enmeshed with other physically, impaired bodies for some time body-images may change as my own experience illustrates. Before fieldwork my mental body-image was a likeness of my identical twin sister’s non-impaired body. Over time when I had had regular contact with disabled peers and less contact with my twin sister this image changed; my body-image started to resemble my mirror-image. Furthermore, I started to fall and stumble in my dreams as I do when I am awake (cf. Murphy 1990). I always remember because I wake with a start whenever this happens.

My and informants’ experiences demonstrate how engagement with other bodies affects body-images and how relations between bodies shape conceptions of our own and other bodies. Moreover, generalized expectations of the body modelled on
able bodies may in part explain the disruptive power of differently-abled bodies in encounters.

Before discussing how informants attempt to prevent and resolve disruptions, I will introduce two bodily practices most informants did learn in paediatric physiotherapy as young children: “the frog” and “the elephant”. This description is intended to give an impression of what kind of bodily practices disrupt encounters in non-medical settings and how informants made sense of these bodily practices. The latter is important to understand the embarrassment informants feel when their differently-normal bodies disrupt encounters with able-bodied people.

**Frogs and elephants: Bodily practices learned in paediatric physiotherapy that disrupt interactions in non-medical settings**

Basic bodily practices such as walking neuromotor impaired infants do not necessarily learn by themselves or easily; for them it is hard work that requires discipline and coordination, power and balance training. Still, disabled children who eventually learn to walk usually do not manage to walk the same way as their able-bodied peers. Instead they develop their own particular habitus: the ability to use their bodies without conscious thought or effort (Mauss 1979). However, over time people need to modify habituated body practices due to changing social or physical circumstances (Crossley 2005; Spencer 2009). It is people’s ability to reflect on how and to what purpose they use their bodies that enables them to tailor their bodily practices to their needs (ibid). People often start to reflect on basic bodily practices such as walking when their body fails them (Robbillard 1999) or – in the case of neuromotor impaired children – when they get negative feedback on their bodily practices from others as the following citation of an informant illustrates:

> When I was a child they [physiotherapists] said: “you walk well.” Back then I thought I walk normal. Of course they meant that I walk well for someone with my disorder. But as a child you don’t make that connection.

And later the same informant says:

> As a child you go to hospitals where doctors tell you we can only do something about it [your impairments] when you are full-grown. As a child I interpreted that as: I will be okay, I really thought that I would walk normal as I was full-grown. (…) I told myself as a child when I am eighteen I will be operated and after that I will walk like everyone else. 9

Only years later when their bodily practices are misunderstood by able-bodied children, informants do realize that they were wrong as young children. Perhaps they walked well in comparison to other children with movement disorders, but not in comparison to able-bodied children.
The frog and the elephant are basic bodily practices taught in paediatric physiotherapy to children with movement disorders. These practices occasionally disrupt encounters outside the semi-clinical context. Basically, sitting like a frog is standing up or sitting down by squatting: bending or stretching the knees and moving downwards or upwards (see also picture 2, the squat-to-standing exercise). Squatting is also done by able-bodied people as part of power training often in combination with weight lifting. Children and adults with cerebral palsy, spina bifida or other movement disorders are less likely to be able to use dumbbells while squatting. They may only be able to squat by their own with help of their hands and arms, doing an adapted frog. None of the informants was able to do the frog without hand support. However, a frog done with hand support enables one to perform some bodily practices independently such as sitting or transferring to a chair (for more details on squatting see Dan et al. 1999; Van Voskuilen 2006). Another, easier practice for getting into sitting or standing position is ‘doing the elephant’. Standing up elephant style entails getting on all fours from a side-lying position. Lying on the back one bends the knees and roles over with arm-support. When one is subsequently standing on all fours in the elephant-stance (see picture 1a) the hands are placed on a chair or a table for leverage when available. Next one leg is (manually) brought upward till the sole of the foot makes contact with the ground (see picture 1b). From this position one pushes oneself upwards into a standing position. People who cannot stand may use a modified elephant to get from a lying to a sitting position. The elephant comes in handy when one is not able or too tired to do a frog to stand up or to sit down. If one learns frogs and elephants at a young age than these practices are performed as part of the body habitus. In contrast, the frog and the elephant are generally not recognized by able-bodied people as regular bodily practices. The constructed, ‘special’ status of these bodily practices becomes apparent when informants act as models to educate therapists-in-training. The following fragment is part of a storied account about being a ‘model’:

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Once or twice I have even been ‘used’ as a living patient for physiotherapists-in-training. So that the therapist could demonstrate to his students how specific exercises are done in practice. Or how the elephant-stance is done (getting up on all fours). That is still the way I stand up; I cannot do it any other way.

The above citation does show that the elephant stance is a bodily practice that may be the only way people with a different body kinesiology are able to stand up by their own. And that it is a practice that needs to be taught to physiotherapists-in-training and disabled children alike, demonstrates its constructed nature.

Moreover, bodily practices serve social and communicative ends. When motor impaired children go to school they find out that it is not only important to be able to perform certain bodily practices, but that one should also be able to walk, sit down, and stand up in tacitly agreed-upon ways.

How bodily practices of disabled people disrupt encounters with the able-bodied

The impact of bodily practices becomes apparent when one considers responses of people to practices that are unfamiliar to them. The following fragment describes how the frog performed by an informant is perceived by an able-bodied girl who witnesses the informant sitting down (K is the interviewer and author, I is the informant):

I: In high school I thought that I sit down on the ground normally. What I did was first place my hands on the ground then sit down. A girl said then: Oh I thought that you were going to lie down on the ground. Because indeed I placed my hands first [on the ground].
K: How do they [the able-bodied] do that normally?
I: Well, they really… you should watch them (…) From standing they directly sit down cross-legged.
K: Really?! I always use my hands.

In this fragment the able-bodied girl’s confusion is resolved when the girl comes to understand that the informant is sitting down and not lying down as she first thought. Obviously, she is not familiar with the frog as a practice for sitting down. The fragment also illustrates the confusion of two, motor impaired people who use a combination of the frog and elephant for sitting down, about what constitutes a normal moving body. They realize that their normal way of sitting down is not necessarily evaluated in the same way by able-bodied peers. The following citation demonstrates that bodily practices may be evaluated negatively by able-bodied people:

Elementary school wasn’t really fun. Back then a girl said to me: “you just walk that way because you want attention.” Right then I wanted the floor to open and swallow me.

First this fragment shows that responses of able-bodied people to informants’ different body kinesiology may cause embarrassment. Secondly, it demonstrates how bodily
practices that deviate from dominant norms or expectations are made accountable in encounters (Sacks 1992: 172-80). People who enact deviant bodily practices are likely to be asked to explain them and risk negative judgment and action.

Of key importance in the cited example is that the able-bodied girl implies by the way she phrases her accusation that the informant is able to walk like able-bodied people, otherwise the accusation “you just walk that way because you want attention” would be unfair. By its nature the accusation also signifies how the addressee needs to refute the moral judgment: provide an inability account. A response such as: “This is the only way I can walk” would serve this purpose. However, in this particular example the informant is too embarrassed to defend herself. In the following narrative another informant provides an inability account with help of her teacher after a negative evaluation of bodily practices she performs (running and boxing):

Well you know, people already think the weirdest things about you only because you walk a bit different. Once, that was in elementary school, a man from the acting academy visited [our school] to make a video. We went to the gym to do some exercises, to warm up. We had two boys in class who enjoyed acting a little bit weird. In the gym we were standing in a circle. We were asked to run forward one-for-one pretending to be boxing. Those boys ran forward and started to act like idiots. When it was my turn to run forward and pretend to be boxing it was: “act normal!” [In Dutch: doe eens normaal!]. I cried then. Back then I was nine or so. I don’t cry that easily but I kind of liked him [the man from the acting academy], he seemed such a nice person. It was unexpected and in front of the entire class. Our teacher explained then that I couldn’t do it any other way. He felt very bad about it, said he didn’t know, and apologized.

The above example also shows that kinetic deviance is not readily accepted, but is treated as accountable in social interactions with able-bodied people. Obvious from the two previous citations is also that the informants as children found it difficult to defend themselves against negative inferences of others. Perhaps because they were too hurt and surprised by others’ responses. Most people need to belong, to identify with a group. The strong feelings of embarrassment of informants may therefore indicate that their sense of belonging is threatened. Thirdly, the examples illustrate that the disruption in interaction takes place at moments that informants start to move. At such moments able-bodied people start to realize that their initial classification of someone as able-bodied based on prior enmeshment with primarily able-bodies needs to be adjusted. This is a highly ambiguous experience for the disabled people involved. The ambiguity here is that neuromotor impaired people one moment may be treated as able-bodied and the next moment as disabled.

In the following section I will provide a short auto-ethnographic narrative about the use of a disability arrangement in public buses. The narrative serves to demonstrate how the moment by moment ambiguity in the perception of movement disorders is a disruptive force and a resource in encounters.
Ambiguity in the perception of movement disorders as a disruptive force and resource: The case of the seat reserved for disabled people

As a student I went to high school and university by bus. When I travelled alone I usually sat in the seat reserved for disabled people. A seat every Dutch bus is equipped with. Usually this seat is located directly behind the bus driver. As a general rule passengers are not allowed to exit the bus via the entrance. However, travellers occupying the seat for disabled people are – as a tacit rule – entitled to exit the bus via the entrance on the assumption that its occupants move more slowly or have poorer balance than able-bodied travellers. So, the seat reserved for disabled people has clear benefits for travellers with movement disorders. Despite that, I prefer to sit at the back of the bus. Why? My occupation of the seat reserved for disabled people occasionally confuses fellow-passengers who enter the bus after me. There is no problem when I enter the bus; as long as I am walking it is apparent to everyone in the bus that I am entitled to sit in the seat reserved for disabled people. It is when I sit in the seat reserved for disabled people that my right to sit there is sometimes contested; then it is not visible to the untrained eye that I am entitled to use disability arrangements.

Many times I have listened to people talking about me while occupying the seat. Their conversation usually goes as follows: “Nowadays, youngsters have no manners, don’t you agree?” The addressee responds with something like: “Yes, we were taught that it is polite to stand up for elderly people and handicapped persons.” This is sometimes followed by a long pause and ended with the statement: “Well, it is none of our business.” Whenever this happens, I give no indication that I have heard my fellow passengers. However, when I leave the bus I do not exit via the entrance but walk past the people who sit behind me. When I am past them I briefly make eye contact with them. Usually they smile uncomfortably or they turn red in the face. In response I smile broadly at them and wish them a good journey before leaving the bus at the back.

It is rare but more embarrassing when someone enters the bus who is entitled to sit in the seat reserved for disabled people while I am occupying that seat. Once, a lady of about forty with crutches and a leg in a brace demanded in a loud, angry voice that I immediately vacate the seat reserved for disabled people. I did not say a word; I just stood up. The moment I put my left foot before my right foot she turned bright red in the face and stammered: “I will sit in another seat” and quickly moved away.

In contrast, elderly people usually do not make a fuss when they notice that I occupy the seat reserved for disabled people. They just move to the closest available seat. When I stand up for elderly people they usually say: “Please sit down, I will ask someone else” or “Please sit down, I can stand better than you do.” In the more than twelve years I travelled by bus four or five days a week I had only to sit in another chair once. On that particular occasion I vacated the seat reserved for disabled travellers for a man in his eighties or nineties with walking difficulties at the request of his son-in-law.

What my narrative has in common with the earlier discussed examples is that the differently moving body is a disruptive force in encounters. In the bus narrative I am treated as an able-bodied person until I start to move my body, only then it becomes
apparent to others that I have a movement disorder. The discovery that I am not able-bodied disrupts the encounter.

Different from the earlier examples of informants, the discovery of my impairments does resolve the initial disruption caused by the imperceptibility of my disability status while seated. Because I am using a facility created for disabled people, the first disruption originates in that fellow passengers suspect me of abuse of disability arrangements. This misinterpretation is resolved when my moving body communicates clearly that I am entitled after all to use facilities for disabled people. However, this resolution also creates a new disruption. It makes abundantly clear that my fellow passengers have wrongly accused me of improper behaviour. The latter tends to embarrass them. Another difference between my narrative and the examples of informants is that informants were more embarrassed than the able-bodied people they encountered, whereas in my bus narrative the onus of embarrassment did lie with passengers who accused me of improper behaviour. Put differently: the ambiguity in the visibility of movement disorders is in my bus narrative a disruptive force but also a resource. When I move my body I clearly communicate to fellow passengers that they have wrongly accused me of improper behaviour (resolution), which is embarrassing to them (a new disruption) (cf. Hoppe 2010).

To sum up, in this section I have described how children with a different body kinesiology learn alternative bodily practices as the frog and elephant and how they make sense of them. Ironically, disabled children learn later – when they interact with able-bodied peers at school – that their particular way of moving is not considered a valid, alternative way of moving around but a source of confusion and embarrassment. Moreover, my bus narrative of brief encounters in one context illustrates how the moment by moment ambiguity in the visibility of movement disorders has not only the power to disrupt but also the power to resolve disruptions.

How disabled people try to avoid or resolve disruptions in encounters

How do people with a different body kinesiology try to prevent or resolve disruptions in encounters? From a Deleuzian perspective there is no one catch-all solution. Not only have people limited agency over their own moving bodies and the bodies they constantly connect and disconnect with they have also limited control over how they respond to and are affected by other bodies. Of course the latter does not prevent people from trying to resolve disruptions (Simpson 2009). Moreover, embodiment and entwinement do not only limit people’s agency in encounters, they also make it possible (Sandberg & Dall’Alba 2009).

As this paper has demonstrated, disruptions in encounters between disabled and able-bodied people are caused by ambiguity in perception of movement disorders and a lack of shared know-how of the kinesiology of bodies. Informants and many other disabled people are aware that most able-bodied people do not know what their movement disorders entail or what challenges and opportunities movement disorders pose in everyday life. This they have learned from numerous encounters with able-
bodied people in the past. Depending on the situational context, informants act on this understanding in different ways. They may address the lack of shared know-how by explaining to others in detail what it means to function in a society that is ill-adapted to people with a different body kinesiology. Often, however, they do not have the time or inclination to provide detailed explanations to strangers; they generally just want to go about their business. To be able to do just that disabled people need to respect the limitations of their bodies and deal with physical barriers. Also stigmatization and social barriers may hinder them in their activities (see also Mogendorff 2002ab).

Respecting the limitations of their bodies and avoiding stigmatization disabled people routinely accomplish by staying at home when tired and by minimizing bodily movements. For instance, people with an asymmetrical walking style prefer sitting over standing or walking because they have impaired balance and lack walking efficiency. Moreover, as we have seen in the previous section, people’s movement disorders are less perceptible to the untrained eye when they are seated. Therefore sitting down is for people with a different body kinesiology a comfortable way to avoid stigmatization. The limitation of the seating arrangement is of course that one cannot remain seated forever. Effectively one can only delay the discovery of one’s different body kinesiology. For instance, when a neuromotor-impaired woman visits a bar and has a drink seated at the bar it happens that a guy shows interest. Sometimes this interest abruptly ends when the woman stands up, sometimes not. One may conclude from this that avoiding discomfort and social barriers is not that easy after all.

Moreover, informants are willing to undergo some physical discomfort to look ‘normal’ and, with that, avoid social barriers. For instance, minimization of the use of disability aids such as wheelchairs not only helps to avoid social barriers but also impedes wheelchair users’ freedom of movement (Mogendorff 2003). Also disabled people may use inconvenient hand or foot orthoses to appear able-bodied. A problem with these normalization practices is that its practitioners may appear to be just like everybody else while in fact they are more impaired in the sense that they can do far less than when they do not ‘hide’ their differences.

The opposite of normalization – stressing one’s different body kinesiology – has its own problems and advantages. If one needs auxiliary devices or disability arrangements to live the life one wants, than drawing attention to one’s impairments may be a good strategy. For instance, informants bring along auxiliary devices to face-to-face meetings where their eligibility for disability arrangements is determined. By using the fact that disability aids are not only functional artefacts but also symbols that heighten the visibility of impairments, informants increase their chances to get the arrangements and aids they need. The problem with this is, is that there is a contradiction between the means and the end: disabled people need to visibly stress their impaired status to live a life similar to able-bodied people. This contradiction engenders ambivalence in informants. Moreover, informants have learned the hard way that it is more often than not in their interest to avoid drawing attention to their deviant bodies. The ambiguity or dissonance disabled people experience is even more exacerbated when they realize that in contrast to their lived experience of their bodies, able-bodied people equate visibility of impairments with severity of impairments. A short
exchange between my twin sister who is able-bodied and me illustrates the latter. In contrast to most fellow Dutchmen I use my left foot to brake and accelerate behind the driving wheel. My twin sister wondered why (T= twin sister, K= author):

\( T \): But your left leg is worse than your right, isn’t it?
\( K \): No [I replied surprised], my right foot is worse than my left foot.
\( T \): Oh, but it’s more visible in your left leg that you walk differently than in your right leg.

From living in a body with a different kinesiology disabled people learn that – contrary to common belief – the visibility of disorders says next to nothing about the severity of impairments. The relationship between visibility of a different body kinesiology and disability is not a straightforward one. Differences in experience and knowledge between disabled people on the one hand and on the other hand able-bodied people engender feelings of alienation or ambiguity in disabled people.

Stressing or downplaying impairments are not the only ways informant handle negative inferences of others. Frequently they just ignore undesirable responses of others such as staring. Something informants do not always find easy to do as the following citation illustrates:

People often stare at me and yes I find that… You have people who turn their heads 360 degrees. Then I think: is that necessary? Of course I stare back at them. When they look at me I look back. That does unsettle them. And that I like very much. I also yell at them: “Can you see it!?” That people stare occurs frequently.

The above example can be understood as an attempt of the embarrassed informant to let the able-bodied ‘offender’ feel what he feels by mirroring the offensive behaviour – staring. In situations like this disabled people are entitled to ‘reprimand’ the able-bodied ‘offender’ who was first to transgress a social norm. In my bus narrative in the previous section something similar happened when I responded to the false ‘accusation’ that I had no right to occupy the seat reserved for disabled people. However, disabled people may only reciprocate improper behaviour when it is abundantly clear that the able-bodied person engages in improper behaviour on purpose. The latter means that this strategy can only be used sparsely. More often than not, informants do not stare back at people who stare at them instead they mostly ignore undesirable responses of strangers in chance encounters. Ignoring responses of strangers is often combined with adapting the context or choosing the people one wants to interact with in private life. For instance, disabled people may prefer to: invite people to their well-adapted homes, participate in online communities, or engage in activities with people with impairments such as disability sports to be ‘like everybody else’ (Mogendorff 2002a; Mogendorff 2007; see also Peace 2010). Unfortunately, people more often than not are not free to choose the bodies and entities they interact with. Despite that, if informants have the freedom to choose between alternatives they are most likely to choose the most convenient one: e.g. a restaurant that is easy to reach and move around in is preferred over a similar but overcrowded restaurant.
To sum up, informants try to regulate their different body kinesiology that causes disruptions in encounters in order to prevent or resolve disruptions and accomplish their life goals. This they routinely do by either downplaying their impairments to appear to be like everyone else or by stressing their impairments, e.g. to acquire disability aids. The act of stressing or downplaying impairments is fraught with difficulties. Informants experience stressing and downplaying of impairments as ambiguous, primarily because these ‘strategies’ conflict with people’s norms, beliefs and experiential knowledge of living with a disability. In contrast, ignoring undesirable inferences of strangers or choosing carefully the people one interacts with seems to be less ambiguous and more fruitful ways to deal with disruptions in encounters.

**Concluding remarks**

The benefit of approaching encounters between disabled people and able-bodied people as assemblages of moving bodies that are enmeshed with each other lies in that it helps explain different phenomena such as how body images change over time. This phenomenon is less easily explained with, for instance, the socio-political model of disability. Moreover, use of an embodied approach as employed in this paper avoids the need to explicitly or implicitly ‘blame’ one of the parties involved in encounters as the social-political disability model or human rights approach to disability is biased to do. Socio-political models assume that disability is caused by discriminatory or oppressing practices (Hughes 2009). Discrimination or oppression presupposes entities that deliberately or not discriminate or oppress people with differently-abled bodies. Furthermore, an embodied approach enables us to examine how the corporeal and the social mutually constitute each other while avoiding the pitfall of reducing impairments to individual problems as the biomedical model tends to do. The latter is possible because bodies take in part unconsciously effect; it is pre-personal (see Deleuze & Guattari 2004; Nick 2008). Take, for instance, the problem of acceptance of impairments. The biomedical model conceptualizes lack of acceptance as primarily a problem of disabled people themselves and the social model conceptualizes lack of acceptance of difference as a societal problem. In contrast, in an embodied approach, as employed in this paper, the problem of acceptance is neither presented as an individual nor as a societal problem but as an outcome of situated interactive processes that are not owned by a single party.

Looking at encounters from an embodied perspective also places the significance of visibility of deviant bodies in a different light. Some say it is harder to be visibly different because of stigmatization, others say it is more difficult to have less obvious impairments because people tend to forget to take them into account (Gorter 1983, cf. Mogendorff 2002a). This paper has demonstrated that people with so-called visible impairments may also be misunderstood in social interaction; it is not something that only happens to people with ‘invisible’ impairments. People do not always know the meaning or practical implications of what they see when they encounter someone who moves in a different way than they are accustomed to. This lack of knowledge of what
is normal for different moving bodies seems to originate in part in the unconsciously acquired expectations about what a body may and should do in different situations. Because people tend to be predominantly enmeshed with able bodies, expectations of bodily conduct tend to be modelled on able-bodies. The latter in part explains why disabled people who grow up surrounded by able bodies often have able-bodied body images. It also partly explains why people with so-called visible impairments may and do actively manage the visibility of their impairments to address misunderstandings and embarrassment they occasionally encounter (see also Lingsom 2008). Moreover, an embodied approach of encounters helps to demonstrate that visibility of impairments itself is not as clear-cut as it may appear at face value. A better, understanding of how our bodies constitute human interaction in all its diversity may be necessary for reducing embarrassment in interactions for able-bodied and disabled people alike.

Notes

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1 P. David Howe is a medical anthropologist and sociologist with mild cerebral palsy.
2 Depending on location and severity of the disorder individuals may experience a host of other symptoms. However, impaired muscle coordination and body movement are the most important and common symptoms.
3 The author has translated all citations from Dutch.
4 Most informants did not have the illusion that they could ever walk as able-bodied people do although they were often told that ‘something’ could be done about their disorder as they were full-grown. This vague statement resulted in diverse misunderstandings.
5 The frog and elephant are also taught to adults with acquired movement disorders albeit under different labels.
6 A clip of a normal frog for a child with mild to moderate diplegia can be watched on YouTube. The clip is called ‘Frog pose to stand: bare feet’ and can be found at: http://www.youtube.com/watch?v=YKoGuxd9agI.
7 This is sitting down elephant style.

References

Breninkmeijer, J.H. (red.)

Crossley, N.
Dan, B. et al.  

Gorter, K.  
1983  Handicaps tellen dubbel: Een literatuurstudie naar de mogelijkheden de vooroordelen over mensen met een lichamelijke handicap te bestrijden. ’s-Gravenhage: NI-MAWO.

Hoppe, S.  
2010  Visibility and invisibility in chronic illness. Medische Antropologie (this issue).

Howe, P.D.  

Hughes, B.  

Kosut, M. & L.J. Moore  

Levitt, S.  

Lingsom, S.  

Mauss, M.  

Mogendorff, K.G.  


2007  Looking in a mirror: Creating space to explore identities as persons with impairments. Medische Antropologie 19 (2): 269-87.

Murphy, R.F.  

Nick, L.  

Peace, W.J.  
Robillard, A.B.

Sacks, H.

Sandberg, J. & G. Dall’Alba

Seymour, W.

Shakespeare, T. & N. Watson

Simpson, B.

Spencer, D.C.

Thomas, H. & J. Ahmed

Thornquist, E.

Turner, S.B.

Van Voskuilen, J.