

Introduction: Where are the missing bodies?¹

Disability Studies in the Netherlands

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In this introduction we discuss the different forms of doing Disability Studies represented in this special issue. Fortunately, there are also shared concerns. The introduction outlines some of these concerns, such as the place of Disability Studies in academia, the tension between interdisciplinary and disciplinary approaches, the style and language of Disability Studies and what this makes of the person with a disability, the notion of citizenship in health care and its values for Disability Studies scholars, the discourse and practice of Quality of Life, and, finally, the relationship of Disability Studies with biomedical practice. Of special interest in the different contributions is the question how the body may be brought back in into Disability Studies.

[Disability Studies, body, quality of life, The Netherlands]

It's a strange thing with academic disciplines. On the one hand they provide the promise of building on work that's done before, hence making us believe in some form of 'growth' of a body of knowledge and a 'home' where researchers speak the same language. Disciplines are ways to get funding and point out ways to respectable scientific careers. On the other hand, disciplines may be conservative, introverted bastions that prevent innovations to take place. The home of one, may be an inhospitable, even *disabling* place for 'strangers'. Disability Studies is or has been one such stranger within the disciplinary order of the sciences (together with other forms of 'diversity studies' such as studies into gender, race, queer studies, and so on). And, as strangers go, Disability Studies is not a coherent field or subject when we put the different orientations from different countries together. Disability Studies is a young field. Discussions about what should and what should not belong to it are part of the way in which researchers try to define and establish it. If anything, the *diversity* within Disability Studies will become clear in this special issue. The reader will be treated to different forms of doing Disability Studies, different tastes, and different arguments for doing so. Fortunately, there are also shared concerns.

Questions and concerns

One of the questions the authors in this special issue ask is whether Disability Studies should become a discipline in itself. This question is as such difficult or impossible to answer, because Disability Studies are dependent on other disciplines, hence the different methods, empirical and theoretical approaches used. What *is* needed for a field like Disability Studies to develop, is money and colleagues. Money to fund research, and colleagues to develop a body of knowledge. One of the reasons for making this special issue is that on November 6 2009, Disability Studies was launched as an organisation in the Netherlands. This organisation was initiated by the largest Dutch financier of research into health care (ZonMW), and the organisation 'Handicap + Studie' (Handicap and Education), an organisation that aims to help people with disabilities to find their way into the Dutch educational system. The Revalidatie Fonds (Rehabilitation Fund) is also a partner. Their mission is to build a structural program for research and education in Disability Studies in the Netherlands.

Before this date, Disability Studies in the Netherlands operated in the wild, outside of a Disability Studies home. This means that Disability Studies research was done, but scattered over the country and the departments (see Van Wijmen & Kool 2009 for an inventory). There were no official programs for sponsoring Disability Studies research, even though there have been active disability movements in the Netherlands since the seventies (Jacobs & Van Houten 2005). Researchers engaging in Disability Studies worked in different places, fitting their research into other projects.

With the launch of Disability Studies in the Netherlands there is hence something to celebrate, as well as something to fuss about. We may celebrate opportunities to engage in Disability Studies, and argue about how this should be done. What and who should this new field be about? How to relate to the differences within it? What research to fund, and what colleagues to organise? This special issue articulates some of the questions that are of interest here, and provides some examples of 'doing' Disability Studies. With this special issue we hope to stimulate the debate, but not by arguing about what the right discipline is or whether one paper belongs to one discipline or another. Instead, the contributions address different *questions* and *concerns*. Yet, as we will see, we can identify general concerns that run through all disciplinary differences. One particular issue that is addressed in this volume is the place of the *body* within Disability Studies – or should we say: the body's surprising absence?

Disability in academia

The issue opens with a reflection on the field of Disability Studies from a science studies perspective. Stuart Blume and Anja Hiddinga list four concerns: (1) Disability Studies' relation to the *disability movement*, (2) the importance of *developing a body of knowledge* that is paradigmatic for Disability Studies and may provide a common language, (3) the traditional and undesirable *embeddedness* of Dutch Disability Studies *within health care*, and (4) the relation of Disability Studies to the *parent disci-*

plines and ways to be taken seriously as an academic field of study. The authors point to parallels with the development of feminist studies. There was a comparable discussion of relating feminism to other disciplines (see e.g. Strathern 1991). Should feminist studies interfere with their home discipline (gender studies should be practised everywhere) or should a separate space for feminist studies be cherished (organise it separately)? The authors argue that the *social model* should not be thrown overboard. The best way to continue Disability Studies as a recognisable field is to integrate, both empirically and theoretically, the critiques formulated.² Although the authors are sympathetic towards the attempt to 'bring bodies back in', they warn for *collusions* with medical and rehabilitation models. Disability Studies, according to Blume and Hiddinga, and with them, many disability scholars, should keep a critical distance from biomedicine and rehabilitation medicine.

Bodies, art and citizenship

Jacqueline Kool is not convinced that a good relation to the disability movement is a safeguard against disembodied visions of the world. In embracing the social model, the disability movement has made bodies absent as well. Kool argues for a flexible use of models that are ready to hand, but, most of all, for *nomadic thinking*, a kind of thinking that progresses beyond old established (disciplinary) boundaries, providing new words and a new language. This new language should enable us to connect individuals to environments, suffering to society and bodies to the world.

Jacqueline Kool's contribution has an interesting shape, not uncommon in Disability Studies or expressions of people from the Disability Movement. Literary texts, poetry, art and imagery are used to engage with Disability Studies in experimental ways. These artistic experiments are about telling stories, articulating experiences by making visible and palpable what it means to live with disability. These expressions question the very category of disability.

This strand in Disability Studies is about using art to express insights in the position of people with disability in society, or give expression to experiences for which words are lacking.³ The discussion whether or how artful ways of expression could belong to an academic endeavour such as Disability Studies is one such disciplinary question that we may ponder about. What strikes, however, is that people with disability have found their ways and expressions in the arts more easily than in academia. What to make of this?

Petra Jorissen moves us into a slightly different genre in her reflections about identity and the body. She talks about the ways she has been living her body, as a child, as a rebellious young woman, as a disabled person or a person-less-disabled-than-others, and as all the confusing combinations of these. Her story shows how complicated it is to discern what these identities are, who is aware of them and who should deal with them. Also, it points to the cruelty of reducing people's complex experiences to one identity.

Sue Thompson, Tom Shakespeare and Michael Wright analyse how people with restricted growth experience their identity over the course of their life. They show



Allison Lapper: proudly pregnant or sadly disabled? The statue is from Marc Quinn and has stood on Trafalgar Square in London for a couple of years.

society that makes participation so difficult. Sabine Ootes and her colleagues are surprised by the lack of conceptual unity of the term *citizenship* in mental health care. They analyse publications of one of the leading Dutch journals in mental healthcare to argue that the concept functions in very particular ways nevertheless; it may both unite people with and without mental illness as citizens, but also allows for arguments about special treatment.

Silke Hoppe explores how people with MS experience their illness as a disease that can be made visible or may be concealed. She argues that these possibilities for discretion could be used strategically in relations with people without disability. However, her analysis also shows that in many cases even when it is disclosed, illness can remain invisible to others. Visibility and invisibility play a role in Karen Mogendorff's contribution as well. Mogendorff explores the concept of a 'moving body' for the case of neuromotor impaired people and shows that taking (learnt) body movement into account might help to understand problematic social interactions. She argues that attending to the body and how it changes over time might help people to deal with frictions in social encounters.

how identity is fluid and changeable over the course of a life. The question remains how to *influence* it, and how to reconcile the wish to be integrated in society on equal terms with others, with experiences of exclusion, dependency and isolation. This contribution presents an example of Disability Studies in the shape of qualitative research into peoples' experiences. Narratives that relate people's experiences are analysed in order to give voice to stories that are often unheard, but also provide reflections on what it means to live in a society as a person with a disability. Who can join in, in a society, who cannot? And on what terms does this happen?

Two contributions engage with the notion of *citizenship*, the idea that people, regardless of their disabilities should be enabled to participate in society. They are citizens among other citizens. Or are they not? Annette Hendrikx and her colleagues analyse the experiences with participation of people with brain damage. The authors show what it is in the Dutch

Mariët Veen and her colleagues analyse employment for people with disabilities. They uncovered that private enterprising may be a way into a labour market that is otherwise difficult to conquer for people with disabilities. They interviewed successful entrepreneurs about their experiences and show that many of them seem to entwine their specific disability with the identity of their company. To them, entrepreneurship provides the kind of flexibility that they felt they needed as a disabled. But of course these are the voices of entrepreneurs who are *successful*.

Quality of life and who to include

The one year anniversary of Disability Studies in the Netherlands was celebrated by a conference organised in December 2010. Here, yet different ways into Disability Studies could be witnessed. The conference was about Quality of Life, a concept coined within biomedical research and adopted by social scientist in Disability Studies. The concept serves to make the experiences of people with disabilities central in research. The conference blurb:

To promote the Disability Studies approach in The Netherlands the conference will focus on a key concept in mainstream academic approaches to disability, namely 'quality of life'. It raises the question of how this concept can be used in a Disability Studies perspective. [...] It presupposes that persons with disabilities possess a quality of life that is defined foremost by the appropriation of their own life-story. This involves active contribution of persons with disabilities.

At the conference it became clear that Quality of Life (QoL) is a quite loose concept, allowing for different methodological approaches, quantitative as well as qualitative. Alice Schippers paper in this issue shows how the concept may be used. Notwithstanding the novelty of using *quantitative* research within Disability Studies, QoL may be used in these types of research. This, proponents argue, may be all the more convincing to decision makers who should do something about the position of people with disabilities. In contrast to this, Dick Willems is concerned with what happens if Disability Studies would switch to quantitative methods. He shows that people with chronic heart disease interpret QoL questionnaires in very different ways, making the results ambiguous. Willems pleads for *listening* to people instead of *measuring* them.

The place of people with disabilities and the disability movement in Disability Studies research is another theme of interest in Disability Studies discussions. During a workshop in the Netherlands (see below), Tom Shakespeare explained some of the controversies they had had about this in Great Britain. The question was whether people with chronic disease should also be included in Disability Studies, or that Disability Studies should stick to its original target group: people with disabilities. This turned out to be a disciplinary fight as well, between disability researchers such as Mike Oliver, who insisted that Disability Studies should address issues like exclusion and poverty, and medical sociologists such as Michael Bury and Ruth Pinder, who

address the meaning of being ill and the narratives about that from the people concerned. At stake was the *political relevance* of Disability Studies.

Disability Studies in the Netherlands explicitly include people with chronic disease. One of its slogans is that no Disability Studies research should be undertaken without having those concerned participate as researchers. Fortunately, this slogan is not taken too rigidly. Ruud Hendriks engages with people who are not mainstream subjects within Disability Studies: people with dementia. They cannot be researchers, but they can be articulated as subjects, Hendriks states. In a gripping tale he relates his first experiences as a clown for people with dementia. He asks what this makes of the clown as well as of the person with dementia. While introducing a new target group for Disability Studies, Hendriks also experiments with new methods within Disability Studies: auto-ethnography.

Bodies back in – biomedicine back in?!

The other event that led to the composition of this special issue, was the workshop organised by the guest editors on December 16 2009: *Distributed bodies: Practices of disability and chronic disease*. The contributions in this special issue came out of this workshop. The blurb positioned the workshop as exploring the boundaries of Disability Studies:

The social model has been pivotal to create awareness for the social position of people with disabilities. But there are also effects that are being debated. One of these debates is about the exclusion of the body and its ailments. With the stress on handicapping situations, the body and its specificities seemed to have disappeared from social theory. This is problematic, because differences between people with different disabilities or between disabilities and chronic diseases are not explicitly discussed within in Disability Studies, whereas ‘true discourse’ about the body is exclusively delegated to biomedicine.

The ‘distributed bodies’ in the title referred to the idea that what a body *is* and comes to mean is the result of how bodies shape and are shaped in practices. A body is not a natural entity that exists by itself, outside of social and material ties. The participants in the workshop explored ways to ‘bring bodies back in’ to Disability Studies (referring to work of Arthur Frank and Irving Kenneth Zola). And even: to bring *medical practices* back in, as important practices where bodies are shaped. The challenge is not to take biomedicine for granted as provider of truth about bodies, but as a set of practices that help shape certain *versions* of bodies. Medical practices deserve to be closely scrutinized so we may argue about the consequences of picking one version rather than another, instead of leaving this to ‘the experts’.⁴

This is something different than *colluding* with medical or rehabilitation practices; it means opening up these practices in order to critically reflect on the possibilities these practices offer for living with a disabled body. Medical practices, and maybe particularly rehabilitation practices,⁵ are significant arenas where disabilities and bodies

become social and political entities. In her contribution Amade M'charek focuses on Down Syndrome and how it is done in medical practice for new-born babies, and by the so-called Down Dolls. She shows how one and the same body in medical practice may be shaped into different versions, as various relations between disability and race. Her analysis of the Down Dolls makes clear that the boundary between the social and the medical is neither fixed nor stable. Jeannette Pols argues that when the analysis of medical practices is kept outside of Disability Studies, Disability Studies might miss out on chances to support the development of a particular knowledge; the practical knowledge of dealing with a disabled body on a day-to-day basis. Articulating this knowledge provides interesting ways for people with disabilities or chronic disease into society.

To conclude and to open up

Even if the variety in this collection of paper is wide, it is by no means exhaustive. There is no paper about rights for people with disability. There is, remarkable for an anthropology journal, no paper on the position of people with disabilities in developing countries.⁶ Also, the concern how disability interferes with other differences (sex, race, gender, age) is not addressed at length here. Our attempt was to identify concerns that may productively inform the developments in Disability Studies, in the Netherlands and elsewhere. We hope that this collection of papers will stimulate debates and exchanges within Disability Studies, regardless of disciplinary boundaries. Within the differences and controversies, there are shared concerns, the main one being the concern for the social position of people with disabilities. Disability Studies engages with these positions, be this in a theoretical, qualitative, quantitative, narrative, or artful way, by crossing disciplinary boundaries or staying well within them.

Notes

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- 1 The reference is to Bruno Latour's 'Where are the missing masses?', a paper about the importance of studying material things within the social sciences.
- 2 Within Disability Studies, the social model of disability has been developed and advocated. The social model states that disabilities do not reside in individual bodies, but are the product of material situations, in which the political will to accommodate particular disabilities is reflected. It is the stairs that are disabling to people using wheelchairs, not a particular problem with an individual body. Letting chairs disable people is a political matter.
- 3 The art manifestation 'Niet Normaal' (Not Normal) that was organised in Amsterdam in March 2009 is another example. The artworks all related to the question: what defines the normal and to whose benefit?

- 4 Gender studies have faced comparable problems when sex was distinguished from gender, and gender studies concentrated on the gender side, as if biology was a science in which nature itself speaks (Mol 1990). A parallel argument is made for race: see M'charek 2010 and disability (Moser 2009). The so called 'material semiotic' interpretations approach may be seen as a variety of the social model in disability, this time including the body in the model. (Moser 2009; Pols 2010).
- 5 Particularly in mental health care, rehabilitation practices have been organised as emancipatory practices. American rehabilitation is developed as a counter-story to a medical model of psychiatric illness. Concepts like citizenship and recovery gained pride of place within these practices.
- 6 But see Ingstad & Whyte 1995 and 2007.

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