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Humanity as a Contested Concept:
Relations between Disability and 'Being Human'

Editors

Paul van Trigt, Alice Schippers and Jacqueline Kool

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Editorial

Humanity as a Contested Concept: Relations between Disability and 'Being Human'

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Abstract

This editorial presents the theme and approach of the themed issue "Humanity as a Contested Concept: Relations between Disability and 'Being Human'". The way in which the concept of humanity is or must be related to disability is critically investigated from different disciplinary perspectives in the themed issue, which is, moreover, situated in the field of disability studies and related to discussions about posthumanism. The argument is made that humanity is a concept that needs to be constantly reflected upon from a disability studies perspective. Finally, the contributions of the themed issue are briefly outlined.

Keywords

ableism; disability; humanity; posthumanism

Issue

This editorial is part of the issue "Humanity as a Contested Concept: Relations between Disability and 'Being Human'", edited by Paul van Trigt (Leiden University, The Netherlands), Alice Schippers (Disability Studies in Nederland, The Netherlands) and Jacqueline Kool (Disability Studies in Nederland, The Netherlands).

1. Theme

What does it mean to be human? This question is discussed on an almost daily basis although not always explicitly. Discussions about medical technologies, doping, old age, human rights, and animal rights highlight how concepts such as human and human dignity are contested. Furthermore, they reveal the role played by implicit norms around humanity and its related concepts. Our themed issue will explore and stimulate these discussions by investigating how, by whom, where, and why the concept of humanity was, is, and can be used. This means that we do not investigate what humanity really is, but how and why the concept of humanity is or can be constructed in different situations (cf. Asad, 2015; Mol, 2012).

Humanity is often taken for granted, in both daily life and scientific research. In this project we critically approach the concept of humanity through a disability studies perspective. Humanity and disability are (possibly) related in numerous ways. Historically, as argued by Hans Joas (2013), development of the notion of individual human dignity was linked to processes of defining groups (including the so-called 'feeble minded') as those that must be included in the human species. Today, we often observe that discourse about human dignity and borders of the human race are determined by the notion that disability leads to reduced quality of life. Also, recent debates about human enhancement are often related to people with disabilities who, for a considerable period of time, have been using devices to 'enhance' their human bodies (cf. Harnacke, 2015).

2. Approach

By addressing relations between humanity and disability, our themed issue will not only contribute to understanding the ways people with disabilities are and were included in and excluded from the concept of humanity. It also makes a contribution to the ongoing debates in the field of disability studies about the value of a posthuman approach and the plea for a posthuman disability studies (Goodley, Lawthom, & Runswick-Cole, 2014; Vandekinderen & Roets, 2016). The development of the multidisciplinary field disability studies since the 1970s would be unthinkable without the social model of disability. With this model, in which disability is in the first place a social construct and problem created by society, activist scholars tried to replace the medical and individual model of disability. Meanwhile, the field is enriched by other models and approaches (Winance, 2016).

Recently, Rosi Braidotti's book *The Posthuman* (2013) inspired scholars to argue for a posthuman disability studies. Goodley et al. (2014) have argued that disability studies is 'perfectly at ease' with the posthuman in criticizing the ideal of humanity that was 'implicitly assumed to be masculine, white, urbanized, speaking a standard language, heterosexually inscribed in a reproductive unit and a full citizen of a recognised polity' (Braidotti, 2013, p. 65). They appreciate Braidotti's aim not only to 'destabilise humanist man', but also to look for alternatives 'in response to the oppressive nature of humanism' and to rethink 'our relationships with our environments, our world and human and non-human inhabitants of our planet' (Goodley et al., 2014, pp. 343–345).

We have no need to position ourselves as posthuman disability scholars, but we are inspired by the aim to 'destabilise humanist man'. Therefore, we investigate humanity as a contested concept and we approach humans as embedded in a network of relations between humans and non-humans. Of course this approach is not reserved to the posthuman approach. In the last decade, disability studies in general have tended to contest 'the normativity of the Western autonomous subject' in favour of 'the notion of relational autonomy', which 'designates the idea that autonomy is conditioned by the social relations in which individuals are embedded' (Winance, 2016; cf. Meininger, 2011). The family and similar biological and social units, for example, have been explored as an intersection of the individual and the group in terms of what makes us human and how we ascribe meaning (Zuna, Brown & Brown, 2014; Solomon, 2012).

As will become clear in our themed issue, we tend to understand the posthuman condition as one in which we constantly reflect on humanity rather than as a condition beyond humanity. In that sense we think the concept dis/ human of Goodley and Runswick-Cole (2014) is very helpful. This concept can be used to (a) dis the human because 'disability has the radical potential to trouble the normative, rational, independent, autonomous subject that is so often imagined when the human is evoked', but also to (b) assert the human, because people with disabilities 'seek to be recognised as human'. This is in line with disability studies as dis/ability studies, that on the one hand acknowledge the struggle to be able with a disability and on the other hand criticize the ideal of ableism and rethink 'ideas that we might have taken for granted' (Goodley & Runswick-Cole, 2014, pp. 2–4). Dis/ability studies recognize the norm and seek to trouble the norm.

Relating our themed issue to posthumanism has also to do with our ambition to contribute from a disability studies perspective to research that lacks such a perspective. We not only want to add disability to mainstream analytical categories like gender, class, and race, but also address the intersection of these categories (cf. Erevelles, 2011). The research tradition of posthumanism enables this and allows disability studies to be part of a broader movement that develops alternatives for the often dominant 'humanist man' (cf. Braidotti, 2013; Butler, 2015). This themed issue is a result of a project which was initiated and managed by the foundation Disability Studies in the Netherlands and in which we give a broader perspective by working with a mix of scholars from inside and outside the field of disability studies.

We want our issue to enrich the ongoing debates in at least two ways. In the first place, our choice to investigate humanity as a contested concept enables the development of a balanced assessment of the way this concept stimulates or not the inclusion of people with disability. As has already been mentioned, we understand the posthuman condition as one in which we constantly reflect on humanity, rather than as a condition beyond humanity. Secondly, the issue is innovative in approaching humanity as a contested concept from a broad range of disciplines (including cultural analysis, care ethics, health science, theatre studies, history) and with different, explicitly explained methods. With the reflection on humanity and our methods we try to take into account objections to posthuman and critical disability studies concerning normativity and methods (Vehmas & Watson, 2016).

3. Content

We start our issue with two contributions that address the ways in which humanity and related concepts like equality are or can be used to in- or exclude people with disabilities. In their commentary Gustaaf Bos and Doortje Kal (2016) discuss whether and, if so, how the idea of equal humans stimulates the inclusion of people with severe disabilities. Fiona Budge and Harry Wels (2016) discuss in their article the desire to be included in humanity and explore how space can be created in society for and by people with an intellectual or developmental disability. These two pieces show, each in their own way, how the usefulness of the concept humanity is highly determined by specific contexts.

In the following three articles we explore how normative notions of humanity can be criticized or dismantled.

In the third article Sofia Apostolidou and Jules Sturm (2016) show how fat subjects were problematized by both biopolitical and posthuman standards. Carolien Hermans (2016) argues in the fourth article how the dance of people with disabilities enables new ways of being human. Alistair Niemeijer and Merel Visse (2016) argue in the fifth article that auto-ethnography enables the integration of (private) experiential knowledge of an illness or disability into scientific debates about (public) care, which is often based on 'normal' humans. These three articles show how dominant concepts of humanity can be challenged.

In the last two articles alternative approaches to humanity and disability are explored. Lieke Kuiper, Minne Bakker and Jacques van der Klink (2016) present in the sixth article a framework to investigate which values and conceptualizations of humanity play a role in the position of people with disabilities in the labour market. In the last article, Paul van Trigt and Susan Legêne (2016) develop, inspired by Actor-Network Theory, a new interpretation of historical photos of people with disabilities in the colonies beyond the dominant humanitarian narrative. In so doing, they underline the most important insight of this themed issue: disability not only contests humanity, but teaches us how humans are related to each other and to non-humans—whether we like it or not.

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Conflict of Interest

The authors declare no conflict of interests.

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Paul van Trigt is postdoctoral researcher in the ERC-project Rethinking Disability: The Impact of the International Year of Disabled Persons (1981) in Global Perspective at the Institute of History, Leiden University. After the defence of his PhD-thesis (2013), he was lecturer political history and has worked from different angles on disability in collaboration with societal partners and researchers from the Netherlands and abroad. He has published about the modern history of the welfare state, human rights, disability and religion.

Jacqueline Kool holds an MA in Theology and was trained as a social worker. She is one of the founders of Disability Studies in the Netherlands and currently serves as the organisation's knowledge manager. She has served as a writer, trainer, and consultant in the disability advocacy and policy fields in the Netherlands for over 20 years. Kool's work centres on disabled people's belonging and participation, and representations of the disabled body. Her work reflects a commitment to integrate theoretical perspectives with the lived experience of disability.

Alice Schippers, MSc, PhD (interdisciplinary social sciences), has been general director of Disability Studies in the Netherlands since 2009 and has worked for twenty years in policy, management, research, and higher education in the disabilities field. She also holds a coordinating senior research position at the Disability Studies unit of the Medical Humanities department of the VU University medical centre in Amsterdam. Her publications are on community support and (family) quality of life. She is chairing the International Special Interest Research Group on Quality of Life of the International Association on the Scientific Study of Intellectual and Developmental Disabilities and is the incoming Vice President for Europe of IASSIDD.

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Commentary

The Value of Inequality

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Abstract
Over the last two decades, inclusion and participation have become leading policy concepts within the Dutch chronic care and social welfare sector. People with an intellectual or psychiatric disability ought to get a chance to participate in, and belong to, the mainstream of our society—on the basis of equality and equivalence. Although on an international level this pursuit has been going on for at least five decades, it still raises all kinds of questions and debates. What does it mean if we want people with intellectual and/or psychiatric disabilities to participate in our society? Based on which idea(l)s about humanity do we define equality and equivalence? And by doing so, how much space is left for individual differences? In the following dialogue the two authors navigate the tension between similarity and difference in thinking about—and working towards—more space for marginalized people. In an attempt to withstand the contemporary dominance of equality thinking, marked by a strong focus on tenability and autonomy—and by extension an increasing climate of taboo around vulnerability and dependency—both authors stress the importance of recognizing and valuing difference, while discussing encounters between people with and without a severe intellectual and/or multiple disability.

Keywords
dependency; (in)equality; encounter; reflection; relational otherness; responsive ethics; severe intellectual and/or multiple disability; space for difference; suspension; vulnerability

Issue
This article is part of the issue “Humanity as a Contested Concept: Relations between Disability and ‘Being Human’”, edited by Paul van Trigt (Leiden University, The Netherlands), Alice Schippers (Disability Studies in Nederland, The Netherlands) and Jacqueline Kool (Disability Studies in Nederland, The Netherlands).

1. Introduction

Over the last two decades, inclusion and participation have become leading policy concepts within the Dutch chronic care and social welfare sector. Encouraged by various government documents and programs, people with an intellectual or psychiatric disability are no longer relegated to the margins of our society, but ought to get a chance to participate in and belong to its mainstream—on the basis of *equality* and *equivalence* (Ministerie van WVC, 1993; RMO, 2002; RVZ, 2002; Taskforce Vermaatschappelijking, 2002; Tweede Kamer, 1995). This rather drastic, idealistic and practical transformation of our chronic care and social welfare sector was legally founded in 2015, by means of four acts: the *Community Support Act* [Wet maatschappelijke ondersteuning], the *Chronic Care Act* [Wet langdurige zorg], the *Participation Act* [Participatiewet], and the *Youth Act* [Jeugdwet].

Although on an international level this pursuit has been going on for at least five decades, instigated by the appeal for *normalization* (Nirje, 1969) or *social role valorization* (Wolfensberger, 1983), it still raises all kinds of questions and debates. What does it mean if we want people with intellectual and/or psychiatric disabilities to participate in our society? What does this participation demand from both civilians with and without disabilities?

How do (local) governments, institutions and companies relate to this? Based on which idea(l)s about *humanity* do we define equality and equivalence? And by doing so, how much space is left for individual differences?

In the following dialogue the two authors navigate the tension between similarity and difference in thinking about—and working towards—more space for marginalized people. The immediate reason for a joint publication on this topic is that Kal, while reading several drafts of Bos' dissertation on encounters in 'reversed integration' settings (formerly sheltered institutional sites where people without intellectual disabilities become neighbours of the original residents), sometimes felt dissatisfied about the way he framed and interpreted the position of *difference*, both in practices and in policy documents. This resulted in discomforting arguments and feelings of mutual alienation.

The authors chose to write this paper in the somewhat unorthodox form of an open, critical dialogue (see Abma, 2006; Smaling, 2008). A dialogue of this kind offers the opportunity to explain each of the authors' own perspectives before comparing them—through *informative friction* (see Kunneman, 2005) and *intertwining* (see Waldenfels, 1990)—in order to develop their thinking about working towards more space for difference.

The leading question, in their joint pursuit through these *swampy lowlands* (see Schön, 1987), is not so much which focus should be preferred—either similarity or difference—but mainly the possibility of one of those getting the upper hand. In an attempt to withstand the contemporary dominance of *equality thinking*, marked by a strong focus on tenability and autonomy—and by extension an increasing climate of taboo around vulnerability and dependency—both authors stress the importance of recognizing and valuing difference, while discussing encounters between people with and without a severe intellectual and/or multiple disability.

2. Responding to Otherness

Gustaaf Bos: I would like to start by saying a few things about the responsive character of our actions towards other people. According to the German phenomenologist Bernhard Waldenfels (1990, 2004) every single encounter with another person starts with an uncontrollable *bodily response*: we see, hear, smell, feel, or taste 'something' about the other, before this perception enters our consciousness. Waldenfels states that this preconscious, pre-reflexive perception of the other causes a confusing, conflicting experience, in which we are at once both connected with and separated from ourselves: our bodily self is responding while our consciousness is struggling to keep up. According to Waldenfels the 'something' to which our attention—preconsciously—turns is always that in which the other differs from us.

Waldenfels typifies this response to the otherness of the other as the nucleus of human behaviour. In doing so he rejects contemporary thinking about human interactions, in which the self is portrayed as an autonomous, rationally and individually acting agent. In Waldenfels' responsive phenomenology we do not decide a priori and/or on the basis of rational arguments how we will relate to another person, but first of all we undergo our body and that which triggers our senses, before we react (and reflect) consciously on that which touched us. It goes without saying that the aforementioned bodily response is everything but 'pure' or 'natural'— it is instead intertwined with our previous (learning) experiences and the contexts, people and cultures in which those experiences are embedded. This interdependency however, does not make our response any more controllable. Ergo: the otherness of the *Other*, in the sense of Lévinas (1969)—a concrete person in a physical, social, communal, cultural and historical context—puts me in motion before I know it.

Perceiving otherness is, according to Waldenfels, no neutral business, on the contrary: the otherness of the other might trigger and fascinate me as well as frighten and push me off. No matter how we subsequently react to this person, the unusual, the unfamiliar, the strange, attracts us and confuses us, disrupts us, puts us out of our comfort zone. During the fieldwork I did for my dissertation *Responding to otherness* [Antwoorden op andersheid][1] (Bos, 2016), about what happens in encounters between neighbours with and without (severe) intellectual disabilities, I heard many personal stories about this confusion and disruption. The stories came from participants without intellectual disabilities, and depicted an experience that I frequently shared (Bos, 2016, pp. 61–67).

Waldenfels points out that we find it extremely difficult to let this confusing otherness be, to leave it *alien*. Many of us cannot accept that the difference between the other and ourselves is fundamentally unknowable. Often we equate this otherness and the other, and then stigmatize and try to avoid it. Even if we are indeed trying to connect with the other, we rather focus on shared characteristics and we usually do not pay attention to that which separates and confuses us (see Walmsley, 2001, 2004). However, by doing so we tend to—at least—lose sight of the otherness of the other, and—in the worst case—*violate* it (by means of romanticizing or ignoring it).

Mostly we do not seem to realize that the contemporary search for and identification of similarities and common ground between people with and without disabilities is only credible if everyone involved has the opportunity to contribute. At this point tension arises when it comes to people with a severe intellectual and/or multiple disability. How do we understand if there is some degree of mutual involvement in the search for what we share? To what extent are people with severe disabilities able to get involved in a search of any kind for that matter? How can we determine if there is any involvement and/or contribution? And which position and

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[1] See English summary on http://dare.ubvu.vu.nl/handle/1871/53873

meanings do we grant in this search to the personal differences, which are often perceived as more prominent than the similarities?

The *responsive ethics* from Waldenfels (2010)—which stresses the recognition of the unknowable and inerasable differences between the other and ourselves—strengthens my conviction that we should plead for more space for otherness. Specifically, the acknowledgment that the perspectives and life world of people with a severe intellectual disability—with whom verbal communication is (practically) impossible—are fundamentally unknowable for people without intellectual disabilities, forces us to give continuous thought to our responsibility for the way in which we attach form, content and meaning to how we respond to them. Why are we doing what we are doing? How much space do we—individually and as a society—offer persons with severe intellectual disabilities to manifest themselves? Which position are we willing to take in order to give them more space? And what form of relationship do we want?

Waldenfels' ethics taught me that, when I want to interpret my (inevitable, preconscious bodily) response to the otherness of the other, I have to acknowledge that this response refers primarily to myself, my familiar concept of man and worldview, my expectations, preferences and fears—*in relation to the other*. After all, in every part of my response to the demand of the other unfolds our relationship and the way I connect with the other. Thus my response is part of something that happens *between* us. There, literally between our bodies, is the leeway, the freedom we have; it is there we can shape our relationship. There, by means of my body, I can relate to the otherness, and try to do right by someone.

3. A 'Passible' Performance

Doortje Kal: For some reason, the above-mentioned encouraged me to dig up an old abstract of a paper from my archive that my brother, philosopher Victor Kal, wrote: *Jacques Derrida and messianity* (Kal, 2004). I am particularly triggered by what you write about Waldenfels' recognition of the unknowable and inerasable character of the difference between the Other and ourselves. You argue that this unknowable and inerasable character of this difference forces us to give continuous thought to our responsibility for the way in which we shape our position towards the other, especially when it comes to people with a severe intellectual and/or multiple disability.

Perhaps I can even deepen this thought with Derrida. In my dissertation *'Setting up camp': Preparing a welcome for people with a psychiatric background* [Kwartiermaken. Werken aan ruimte voor mensen met een psychiatrische achtergrond][2] (Kal, 2001; see also Kal, 2012) I 'use' Derrida (1998), especially in the chapters on *hospitality* and on *normative professionality*.

Derrida's philosophy is labelled as 'deconstructionist thinking' and is thus related to postmodernism, whereby some define it as 'relativism'. Derrida passionately and persistently resists the accusations that in his work there is no space for *responsibility*, and that deconstructionism is irrelevant from a moral and political perspective. Insofar as deconstructionism generally aims to undo exclusion, it sticks with the emancipatory ideals of modernity!

However, in deconstructionist thinking the criterion or standard to which we measure or examine this emancipation is not considered to be at our disposal unthinkingly; rather it is about a justice that is not to be seen. As a consequence, we have to postpone the activist attitude that marks modernism. This encompasses a passive moment. At first, one cannot bring the new, or the otherness (the space for being other) to be by oneself, and certainly not just like that. In order to welcome difference, otherness, we have to first know how the other will feel welcomed. Inclusion, citizenship and participation do not seem to be adequate terms to make the people you refer to feel at home. However, neither do we feel at home with Wilfred, whom you describe in your dissertation (Bos, 2016, pp. 72–73), literally strapped to his bed—and in my opinion we should never feel at home in his situation.

Derrida says that a passive moment does not mean that deconstruction is without activity. In the last chapter of your dissertation you refer to this—following the Dutch philosopher Richard Brons (2014)—as a *passible performance* (Bos, 2016, p. 310; see Lyotard, 1988). A passible performance is a specific sensitivity to feel with, and respond to, the other—not aimed at bringing some kind of activity to this world, or even to rearrange it. Rather, the target of passibility is primarily to uncover the pretentious, apparently closed and definite character of texts and notions (and, I add: practices!) as being premature and not tenable. The effect of deconstruction lies in that the space which was sealed is made accessible. For *what* this space is made accessible stays open. The activity, which is produced by deconstruction, has a transient nature. The current norms are temporarily suspended, in order to find out whether or not they need a transformation or supplement. Meanwhile, the *high justice*—as far as I am concerned, the battle against exclusion, and working towards more inclusion, towards humanity—is not suspended. On the contrary: the aforementioned suspension of active involvement following certain norms takes place in the name of the latter. Or, as Derrida puts it: the given right is deconstructable, but justice is not.

For me, this means that your plea for space for otherness, your emphasis on our responsibility in the way in which we treat the other, is still in need of a more detailed interpretation—starting from this non-destructible justice.

Gustaaf Bos: Could you elaborate a little on this non-destructible *high justice*? I am especially interested in what defines whether or not something is constructible.

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[2] See English summary on http://www.kwartiermaken.nl/english/summary-kwartiermaken-doortje-kal

On what basis is this high justice immune for Derrida's deconstructionism?

Doortje Kal: As far as I am concerned your attempt—listening to the story of the illiterate other, who cannot speak but deserves to be heard—is an example of this higher justice. In the meantime, you demonstrate that the network of chronic care practice (and policy) needs deconstruction and reflection as well in order to facilitate a more valuable and righteous life for those who are unheard.

At this point I remember a remark that I made in the first chapter of my dissertation (Kal, 2001, p. 22), *A question of difference*, where I emphasize the tension which is given with the quest for the *normalisation of the unknown, the alien* (with 'normalisation' I refer here to ceasing the exclusion of 'the strange other'). Making this tension a central issue, I argue, always happens against a background of the eternal dilemma between a radical stand, which is doomed to stick in powerless purity versus a feasible activity that may compromise and whereby one—for the benefit of results—may concede what one is challenging. I then illustrate this with an example of me categorising people with a psychiatric background. Admittedly, such labelling might lead to stigmatization, but denying and moving past their otherness leads to exclusion as well. Ergo: it is about enduring this tension, about not avoiding it, but relating to it (see Boumans, 2013).

Gustaaf Bos: If I get what you mean, I think you now touch upon a paradox between 'thinking about' and 'working towards' space for marginalized people. If I focused solely on developing rational and cognitive knowledge, I would come to the conclusion that it is impossible to know the other, and thus to really make space for him. And, subsequently, this would lead me to believe that there is no point in trying to make more space. Therefore, we are in need of ideals and ethics.

If I understand you correctly, you advocate a deconstruction of current exclusionary structures, logics, and practices (à la Derrida), in order to create (temporal) open space for reconsidering the underlying norms. In this *open space*, we should—appealing to *high justice*—reflect thoroughly on how we may contribute to the inclusion and participation of people who are different and extremely vulnerable.

Although I attach a high value to your aim and commitment, I also question your argumentation. In my view, an appeal to *high justice* regarding participation and inclusion is not self-evident. High justice may be undeconstructable, but the operationalisation of concepts and movements like *inclusion* and *participation* surely can be deconstructed.

Doortje Kal: Indeed, that is exactly my point!

Gustaaf Bos: And if the struggle against exclusion is awarded the predicate *high justice*, do you think there are other concepts and movements, which earn this predicate just as much?

Doortje Kal: Without a doubt! *Human dignity* maybe? We resist incarceration, isolation, strapping, because it is *inhumane*. We must keep looking for *dignified* alternatives.

4. Striking Inequality

Gustaaf Bos: Do not get me wrong, I do not intend to devalue the importance of societal hospitality and tolerance towards people who are different and extremely vulnerable. But I do claim that the way we—as a contemporary society, and as researchers and advocates of a more inclusive society—approach this pursuit, tends to evade the otherness and the lifeworld of people with a severe intellectual and/or multiple disability. By strongly emphasizing the similarities and communality, we are at risk of entrenching ourselves ever deeper in an unreflected presumption that the perspectives and ideals of people with an intellectual disability resemble those of people without disabilities. Moreover, that they all share our needs, dreams and motives. However, in doing so, we seem to forget about the striking differences in lifeworld and the asymmetrical positions of power (see Young, 1997).

Doortje Kal: At the same time, we should never dispute that they feel the need for a worthy life. However, what is dignified for them is not automatically clear to us. If people themselves are asking to be tied up, it is a real challenge to find worthy, 'desired' alternatives for them.

Gustaaf Bos: Amen. The confusion and alienation I often experienced during interactions with people with a severe intellectual or multiple disability in reversed integration settings—as well as my inability to attach satisfactory meanings to these encounters, in order to *understand* them somehow—made me critical towards the aforementioned emancipatory equality focus. Time and again I was astonished, enchanted, frightened, surprised and/or fascinated by so much otherness. During these encounters as well as afterwards, incomprehension and insecurity were reigning. Extraordinary experiences such as those I describe with Karel (Bos, 2016, pp. 139–140), Willem (p. 115) and Wilfred (pp. 72–73) made—and still make—me fundamentally doubt much of what hitherto was familiar to me. They forced me to question my view on man, my worldview, lifeworld, motives, expectations, and ideals—and thus changed my perspective on who I am. I could not help but recognise that all this prickly and provocative otherness cohered with my singularity, with who I was, with how I saw the world and myself.

Doortje Kal: Can you elucidate how? How did you see the world before and afterwards?

5. Prickly, Relational Otherness

Gustaaf Bos: I am glad you asked. These three encounters instigated an ever-growing doubt in me about the recognisability of the perspective of the other. I had begun my research with the intention of imagining the issues and worries of stakeholders with and without intellectual disabilities as correctly as possible—whether they could express themselves verbally or not. Due to my encounters with people like Karel, Willem and Wilfred it struck me that, as a researcher, I always performed from my own perspective. Although this perspective is inevitably shaped by interaction with others, I could never extract myself from it. Thus, I could never truly and fully represent another person's perspective. I would literally never be able to take the stand of another or walk in his shoes, simply because he is already (physically) in that position. And because Karel, Willem and Wilfred barely used verbal communication, I became more sensitive to the skewed power relations between them and me—especially in the academic and policy world, wherein words, sentences and texts are the mightiest machines to produce and spread knowledge that counts (see Deleuze & Guattari, 1987; Jackson & Mazzei, 2013). I could cope with those machines and have access to them; unlike Karel, Willem and Wilfred. This rendered me—and all verbally proficient people in their environment—a more powerful position than them.

If I was to say anything for a verbally non-proficient person, I could only do so when I kept an ongoing dialogue with him, in all modesty, respecting all doubts and through explaining my own motives and intentions.

The world and my position therein regarding other people became less manufacturable, less self-evident, and at the same time less open-ended than I assumed in the prelude to my doctoral research. At the start in 2010, I had been quite sure for instance that mutual encounters and connections potentially meant an improvement of anybody's quality of life. Subsequently I deemed interactions and relations between neighbours with and without intellectual disability desirable—and with my research I hoped to contribute to their (further) development. Throughout my two-and-a-half-year fieldwork however, I gradually reached the conclusion that I had failed to take the difficult, uncomfortable, painful and frightening aspects of difference sufficiently into account. For some stakeholders with an intellectual disability for instance, my sheer (often superficial and observing) presence appeared to be so threatening, that they responded to it by rejection or aggression, whereas others cowered frightfully every time I looked at them for a moment or greeted them while passing by. Because I had not spent any thought on the possibility of such undesirable encounters, which do not enrich the life of the people involved, but rather make them feel less happy, or even threaten their personality, I had failed to make enough space for the individual otherness of some stakeholders with an intellectual disability. I had falsely presumed that all the persons involved in my research would like to know the people in their neighbourhood sooner or later, because their life would benefit from it (Bos, 2016, p. 66).

My growing doubt about something I had deemed self-evident—i.e. not necessary to prove—before these encounters took place, forced me to make more space, and spend more time and attention to interactions with persons who were most radically different in my view. But while doing this, I far from gained more insight into the motives, expectations and ideals of those others, nor did I knew more about what these people with a severe intellectual or multiple disability really wanted. As a result, the growing doubt, insecurity, confusion, fascination and unease made me feel obliged to raise awareness amongst policymakers about the inerasable and unknowable character of the otherness of people with a severe intellectual disability—at the same time emphasizing the *relational* aspects of this otherness.

Here, Waldenfels (2010) is helpful again. In his responsive ethics, we can try to relate to the other in a fitting way, if we recognize that our (initial) response to him undeniably refers to something about ourselves in relation to this person. What does my doubt, confusion, fascination, et cetera tell us about who I am, how I look, how I live—and about the durability thereof? Moreover, how do these ways in which I bring order and attach meaning to my perceptions, experiences and emotions relate to the possibilities I see for contact with these fellow human beings?

In my opinion, we should try to find answers to questions like these, if we really want to make more space for the otherness of people with severe intellectual or multiple disabilities, and if we want to counteract exclusion in a broader sense—in everyday life as well as in policy documents. To what extent are we providing space for inerasable, unknowable, confusing, provocative, and prickly otherness when we try to include everybody on the basis of mutual similarities? Additionally, what and who do we still exclude, even if we strive for full-fledged inclusion?

6. A Scramble Around the Pulpit

Doortje Kal: Here I completely agree with you: our response to the strange other does indeed refer to something about ourselves, our order, our meaning. This made me think about the metaphor of the *musical chairs* with only one chair—a pulpit—from the Dutch sociologist and philosopher Harry Kunneman (1996). Everyone wants to occupy the pulpit as long as possible, thereby forcing his way of looking, thinking and speaking—his interpretation—onto the others. Each discourse however, excludes alternative logics and ways of expressing oneself; hence there is always a scramble around the pulpit. Some people however, do not dispose of a language that is appropriate for the pulpit; they use an inappropriate idiom in the view of others. Therefore, they have no access to the pulpit.

Kunneman points out that Lyotard (1988) coined the word *contravenity* for this situation of aphasia. Lyotard makes an appeal to give voice to the injustice that cannot be articulated within the confines of a dominant discourse. I think that you tried to respond to this appeal in your dissertation—without knowing exactly, or even by a long way, what/which injustice the people involved would like to address.

7. Responsive Trust

Gustaaf Bos: Ah, this metaphor is very helpful, thank you. According to Waldenfels, our efforts to community and connectedness should not be justified by the starting point of equality and/or bridgeability, but rather by the recognition of relational otherness. *Responsive trust* is a crucial concept here; the conviction that we can do justice to a confusing other even though we will never be able to give a complete, adequate and definite response to his demands. How to develop and shape this trustful responsive attitude in the best possible—i.e. the most righteous—way, is in my view particularly dependant on an ongoing dialogue between the people involved. Bearing in mind of course, that the other might not be able to express himself in your preferred communicational style—and vice versa.

Doortje Kal: I totally agree with the previous. You nicely summarized that I hope that deconstruction will lead to further reflection on existing exclusionary structures. As I mentioned before, in my dissertation I talk about *suspension* when it comes to this; suspension in order to find out how hospitality might be meaningful for the 'strange other', a person whose movements in our society (which is dominated by economic performance) do not go without saying. Subsequently, in my view, this suspension should also concern reflections on the conceptualisation and implementation of inclusion, participation or citizenship ideals. Applied to your research context: how can we prevent these concepts from passing by the radical otherness of people with a severe intellectual and/or multiple disability?

As you know, for policymakers, thinking in terms of equality and citizenship has an emancipatory background; after all there was a time that we thought that people who were different were best off in forests or dunes, that our society could (or needed) not harbour these 'deviants'. I sincerely think that it is important to recognize that many 'deviants' share ideals like autonomy, participation in mainstream society, and belonging with you and me. That is why I think it is unjust of you to dismiss our government policy at this point so firmly. That the conditions for the implementation of this policy are created abominably, or even reduced, is another issue.

Gustaaf Bos: For the record: I only criticize and reject the dominant policy focus on equality and equivalence when it comes to people with a severe intellectual and/or multiple disability.

8. A Person is Never Strange on His Own: An Interpersonal or Societal Approach?

Doortje Kal: That being said, I do agree with the question you raise about the exact benefits of the deinstitutionalization policy, or even the reversed integration policy, for people with severe or multiple disabilities.

You demonstrate how very different many people in reversed integration settings are—and how this otherness confuses you. A cumulating doubt, you write, about everything you had regarded as self-evident, forced itself upon you. As a matter of fact, this is exactly the aim of suspension and deconstruction: reflection on the/your/my/our normality, which does not make space for the abnormal. But, you say, I could not find out—no matter how hard I tried—what would help the people involved.

However, besides the inerasable and unknowable character of this otherness, you also stress its relational makeup. The other is so different, so dissimilar *compared to* me (and my singularity, my familiarity). In Waldenfels' vocabulary: we are alien to each other *due to* each other; a person is never strange on his own. The perceived otherness always refers back to the perceiver as well.

I think that one of the main differences between us is that you—in line with Waldenfels—deploy this reflection very individually, whereas I do this with a rather societal scope. You thoroughly reflect upon the meanings that 'normal' individuals attach to the confrontation with so much otherness: people who mutilate themselves and others, who must be protected against themselves, tied up, medically sedated, isolated—perhaps even more so in reversed integration settings than in the total institutions of the past (because of the presence of 'normal' others).

Waldenfels' responsive ethics suggests that we can only begin to relate to a strange other if we recognize that our response to him undeniably says something about ourselves in relation to the other. You state that we have to be aware of this if we really intend to make space for the otherness of the other, and thus want to fight exclusion. I agree with you on this. At the same time, I want to stress that you and I are also part of a world which co-shapes us, and which we (are trying to) co-shape towards a world, a society that both recognizes and welcomes dissimilarity, no matter how complicated the consequences—consequences I also draw attention to in my work (see Kal, 2012). All this based on a *responsive trust*—and this is where we meet again—that a confusing other should not to be avoided but accepted.

Throughout my work, I never hide the fact that a 'normal' person might get hurt when he enters foreign territories, when he literally *alienates* himself. It is evident that normality cannot stay the same when encountered with otherness.

As you well know, I was quite involved with *To Flourish*, the dissertation of the Dutch psychologist Janny Beernink-Wissink (2015). Just like your dissertation, hers is about people with a severe intellectual disability, as well as serious behavioural problems. The pearl of her dissertation is the description of a radical change in the life of Anja, who from an existence dominated by a regime of safety (you call this 'the focus on what may go wrong', Bos, 2016, p. 168) came to live a flourishing life due to the interventions of Beernink as a behavioural therapist. Just like you, Beernink writes critically about the dominant care system and arrangements.

In the end, she thinks, Martha Nussbaum's *Capability approach* can also be meaningful for people with severe disabilities, precisely because this approach consequently connects individual capabilities to the context (i.e. *external capabilities*, Nussbaum, 2006). Beernink illustrates how a meagre institutional environment in Anja's case leads to serious behavioural problems, which in turn resulted in deprivation of freedom, leading to even more behavioural problems, et cetera.

In your fifth chapter you also sharply analyse how the culture of an institution (i.e. system) colonizes the *lifeworld* of both original and new residents (and indeed yours as a researcher), and undermines the 'capabilities' of everyone involved. Furthermore, you, unlike Beernink, put more emphasis on the necessity of reflection—on yourself as a researcher, stakeholder, 'normal person' in that abnormal context. What does that add to what we know?

I think that both of your stories are necessary. On the one hand it is good to stress Beernink's effort to let people flourish (more)—with an eye for dilemmas and difficulties. On the other hand, it is good that you (sometimes rather extensively) identify and give thought to what it does to a 'normal human being' to be confronted with so much otherness, pain and sorrow; how we tend to flee, to avoid all of this.

I think that the recognition of difference, dissimilarity, leads to the recognition that not everything can be bridged, but certainly a part is bridgeable, connectable. That is something you illustrate again and again very nicely, for example where you describe your encounter with Betsy (Bos, 2016, p. 198).

9. Making Space for Encounter by Moving Backwards

Gustaaf Bos: I totally agree with you when you say that it is possible to connect the *own* and the *alien*. However, with this the otherness of the other is not bridged! Inspired by Waldenfels (2004, 2011), I argue in my dissertation that there is an abundance of options *between* self and other, but that with that the other is still not known. At most—and this often is very valuable!—something happens in an interaction between self and other.

With regard to encounters with people with a severe intellectual and/or multiple disability, the crux of the matter is that participants without disabilities are responsible for the content of the interaction. That is, the latter determine in most cases what happens; success or failure depends on their efforts, their voices. Their perspectives are decisive because the perspectives of the participants with severe disabilities remain largely unknown and because the balance of power between them is inevitably skewed. In my view, there has to be a lot more awareness about this, because nowadays we think and quite often say that our efforts are in line with what people with severe disabilities want, while in many cases we do not know what they wish for and/or cannot satisfy what we think their needs are. More than anything, we *interpret* what they want, basing their life and the shaping of it on our values, capabilities and limitations. This might be painful and difficult to acknowledge, but in my view this is what it is.

Precisely this inerasable difference had to be the starting point for us to think about, and work towards more space for otherness. This space might be in staying with the other *despite* not knowing. In my dissertation, I illustrate that working on this space can be done through humour, playfulness, listening, sensing, and without (too many) words. Making space is attending to the personal (stories) while interacting.

Waldenfels (2010) states that a (policy) starting point from which everybody is—or should be—equal, mistakenly neglects that in human interactions and relations, there is never a 'ready-made we'; every family, population group, congregation, class and community is a 'broken we' at best. He warns that the denying of this communal brokenness might function as a fertile breeding ground for a tyrannical societal system that does not tolerate deviation. Therefore, when we perceive something that (or someone who) is strange to us, we should avoid treating this a priori as a problem to be solved, but rather as a stimulus which keeps waking us from *the sleep of normalisation* (see also Waldenfels, 2011, p. 164).

That the way we cope with interpersonal differences—as an inevitable consequence of the unknowability of the otherness of another person—will always be imperfect and will always chafe, does not mean that we might as well do nothing. On the contrary: recognizing the brokenness of our efforts forces us into an ongoing rethinking and reflection. Hence, the insufficiency we experience when trying to do justice to another person is the driving force behind a permanent searching, responsive-ethical attitude (see Irigaray, 1974).

Of course, the fundamental unknowability of the other's perspective applies to human relations in general, but it becomes extra apparent in relation to people with whom we cannot negotiate verbally about meanings—which is by far the most common way of sharing perspectives in our society. If we, in spite of this, act as if we fully understand such a non-speaking other—and literally try to speak in his place—we will figuratively step on his toes.

According to Waldenfels, there is only one just way to speak for another person, and that is to take a step back, creating space for the other through suspension of our ideas, our ways, our preferences—and in this case our very verbal and cognitive drive. From this perspective, the space for encountering the other only opens up if we are willing to move backwards. Between our bodies; that is where it has to happen. However, I can only make it happen there when I realise that the creation and conditions of this space depend on my willingness and ability to renounce a mainly verbal and cognitive approach to communication; to suspend my tendency to immediately attach meaning to what I perceive.

As far as I am concerned this is a big challenge: to what extent are we able to connect with each other in a meaningful way and also with satisfaction, without a dominance of verbality and cognition? How can we relate to each other and to people with severe intellectual and/or multiple disabilities if we omit words? What will happen to us if we do? Which barriers will we face, but also: which opportunities will we discover? And what can we learn about/from such non-speaking others, about ourselves, and especially about ourselves in relation to these others—when we do not automatically start to talk in a mutual encounter, but consider how we can respond best to the way they present themselves to us?

10. A Re-Evaluation of Dependency, Vulnerability and Solidarity

I suspect that we will start to think in a different, more small-scale way about inclusion and participation if we take people with a severe intellectual and/or multiple disability—the most vulnerable, least articulate, least heard and therefore least understood—as a reference point. And I propose wholeheartedly that we do this for a change!

On the fringes of existing (policy) narratives and practices, we should introduce another story, another approach. It goes without saying that I fully back your focus on the societal responsibility to make space, but in my view this starts with a readiness to get to know one another on an interpersonal level—human to human. Too often, I miss the appreciation of the necessity of personal engagement and the involvement of everyone's individual ethics in contemporary thinking and debates on inclusion, participation and citizenship.

Do not forget that I, with my dissertation, wrote a critique based on the personal, situational and temporal stories from people involved in reversed integration settings. For most people to whom I spoke between 2010 and 2013, the lack of space for otherness was a *concrete* central issue. I do not claim that my findings are generalizable, but I do try, on the basis of these *personally*, *situationally* and *temporally* dependant narratives, to invigorate the dialogue about the precarious position of difference in the *grand narrative* of inclusion and participation.

I most certainly do not do this to dismiss the last twenty-five years' government policy without question. However, I do think that in the year 2016 the said policy still pays unjustifiably little attention to the unknowability of the perspectives of people who cannot speak (for themselves)—and subsequently to our responsibility, as individuals, care institutions, policymakers, and society as a whole, to create relational space for them. *Space of encounter*, in the words of the Dutch ethicist Herman Meininger (2013). Policymakers appear to be blind to the fact that in order to try to respond adequately to the *unarticulated* demands of others, all parties need to be open-minded, attentive, and ready to slow down or go the extra mile.

The big question, then, is which shared storyline—one that is adjusted to the personal characteristics of all protagonists and to contextual features—would get us involved in meaningful encounters with people whom we might try to evade at first glance. A strong focus on autonomy and self-determination misses the point here (see Reinders, 2008, 2010). It would be better to try to bring people (with and without disability) together, and connect them with each other through a *re-valuation* of dependency, vulnerability and solidarity—something you advocate for in your work too. In this encounter, the personal stories of the most vulnerable people should take a central role; the other participants should relate their stories to these. That is not to say that the personal narratives of the people who want to get acquainted and connected with the vulnerable protagonists, should not be shared; they might inspire other people to do the same thing (see Bos, 2013).

Much listening to, and moving with, the other is needed; much imagination and empathy—in order to prevent us from automatically (and a priori) interpreting these stories through the lens of dominant ideals, or current policy narratives. If we do so, we will continuously be provoked to think in new, critical ways about existing orders of normality and deviation (see Kristeva, 1991; Meininger, 2008, 2013). Subsequently, what might happen in the encounter with another, will never be fully predictable nor completely up to us.

Doortje Kal: There was a time that I thought (and said) that people with a psychiatric background were an interesting point of reference to me, because for them contravenity—not being able to *verbalize* what is going on, because the words of the *others* are not theirs—is such an influential phenomenon. But one could also claim that people with mild intellectual disabilities fall between two stools, because they belong nowhere due to that label 'mild'. And one could take an even broader scope, by saying that in our society as a whole the space for vulnerability is waning.

However, if people do not want to be reduced to their vulnerability and want to get a chance to flourish in what they are good at, this should not result in an increasing taboo of vulnerability—something that seems to be the case nowadays. This is, however, putting the cart before the horse; only in a society with space for vulnerability, can people be truly empowered, to use a popular idiom.

I heartily support your appeal to give also—and more often—a voice to the unheard and inarticulate. Besides, you think the whole movement for inclusion could learn something from that. Maybe you can elaborate a little on that?

11. 'Listening Out' Personal Stories of Inarticulate Protagonists

Gustaaf Bos: Well, I think that everyone who supports or advocates *inclusion*, *participation* and *citizenship* could learn a lot from what happens in encounters with persons with a severe intellectual and/or multiple disability. They could also learn a lot from the aforementioned themes—such as dependency and vulnerability—which are pivotal in their life and that of their relatives.

In summary, trying to find out what is *good* and important in the life of what might be the most vulnerable, most marginalized people of our society not only demands sharp eyes and sensitive ears, but also a lot of patience, time, perseverance, engagement, trust and the ability to suspend judgement. Put in another way, it demands our willingness and ability to *listen out* the personal stories of inarticulate protagonists, without foreknowledge about details and storyline. That is both exciting and challenging for many of us, especially since we tend to have a preferred and dominant storyline in mind. How do we approach this area of tension?

Doortje Kal: At the same time, this does not mean that I find community projects that encourage marginalized people (with mild disabilities), such as *We are here* [We zijn er] unworthy of our support[3]. I have underlined this before: in my view it is not about either/or, but about and/and! There is no final answer to these questions. How do we make fair policies and equitable institutions, and how do we make sure that the work is right and has positive results? The murkier the questions, the more important the moral quest for answers (see Kunneman, 2013).

How do we struggle with dignity, and how do we accomplish informative friction? In *swampy lowlands* (see Schön, 1987) it is sometimes hard to get, and stay, close to each other—and the two of us have experienced this in our discussions throughout the years. However, this is no reason to move exclusively on high grounds, or to avoid *prickliness*.

First of all, you confronted me with the work of Waldenfels. He underlines the *relational* aspect of being different—one is no other on one's own—once more. You especially made me think about the inevitable tension, arising when you stay with the other, the other to whom I almost unbearably differ, and from whom I perhaps would rather walk away because I feel incapable.

I hope that our never-to-be-abandoned quest for encounter, connection and inclusion—also, or especially, on the micro-level you have investigated—is of value; first for the people involved, and secondly the broader context (which I am a part of!). In *Responding to otherness*, you show encouraging examples of this. All in all, you strengthen me in advocating *being different*, in spite of the criticism I sometimes get for that categorization.

Gustaaf Bos: I am glad to hear that! Your open, virtually all-inclusive way of thinking encourages me to keep in mind the great effort, engagement and conviction of so many who pursue the citizenship ideal. Besides, you often remind me of the positive effects that thinking and working from a position of equality—a citizen in a democratic society—may have on an individual level. With reference to that, I find what you said about 'powerless purity' versus 'a feasible activity that may compromise and whereby one—for the benefit of results—may concede what one is challenging' quite helpful. Working on an ideal that contributes to a better place in our society for marginalized people—although it may sometimes yield the opposite of what you aim for—is preferable compared to doing nothing because it may sometimes yield the opposite of what you aim for.

Encounters with people with a severe intellectual and/or multiple disability are not a matter of perfection, but of relation; they consist of a personal intention to do right by and connect with the other. May the beautiful poem of an anonymous poet on the endpaper of Dutch ethicist Hans Reinders' *Receiving the gift of friendship* (Reinders, 2008) inspire many people to keep working for more of these spaces of encounter:

> Blessed are you who take time to listen to difficult speech for you help us persevere until we are understood.
>
> Blessed are you who walk with us in public spaces and ignore the stare of strangers, for we find havens of relaxation in your companionship.
>
> Blessed are you who never bid us to 'hurry up', and more blessed are you who do not snatch our tasks from our hands to do them for us, for often we need time—rather than help.
>
> Blessed are you who stand beside us as we enter new and untried ventures, for the delight we feel when we surprise you outweighs all the frustrating failures.
>
> Blessed are you who ask for our help, for our greatest need is to be needed.

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Article

"I Am Human Too!" '*Probeerruimte*' as Liminal Spaces in Search of Recognition

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Abstract
This paper explores the Dutch concept '*probeerruimte*'[1] in relation to the statement 'human as a contested concept', a highly relevant topic in disability studies. *Probeerruimte* encompasses the idea that people need space to 'try things out', a liminal space that facilitates personal development. It was conceived in a context where institutional practices exerted restrictive control over the lives of people with learning difficulties, denying them rights to self-determination and personal growth, rights that are integral to experiences of 'being human'. The concept emerged about 20 years ago, and was revived during two studies conducted in 2014 and 2015. The studies, commissioned by Disability Studies in Nederland (DSiN), explored perceptions of social inclusion. Study findings reveal the significance of associated concepts, inclusive of connectivity, citizenship, liminal spaces, and 'risk taking'. Of critical importance is the need to challenge hegemonic practices that all too often disempower people with learning difficulties, remove their rights and, relegate their status to below citizenship. This paper addresses the relevance of *probeerruimte* for people with learning difficulties, from their perspectives, and examines how institutions can facilitate this process. Opinions from 'all people' involved in the conversation are used as data so as not to 'label' or make too strict a distinction between people with or without learning difficulties. The authors affirm the need to create *probeerruimte* to facilitate varied ways of existing. Ideally these ways of existing will promote opportunities for people with learning difficulties to engage in meaningful spaces, affirm their rights to citizenship and recognise their humanity.

Keywords
citizenship; disability; learning difficulties; *probeerruimte*

Issue
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1. Introduction

This article explores the concept '*probeerruimte*' (the literal translation of this Dutch word is 'trying space') in relation to the theme "human as a contested concept". The contested nature of humanness is perhaps no more relevant than in studies related to 'cognitive disability' (Goodley & Runswick-Cole, 2016; Goodley, Runswick-Cole & Liddiard, 2015; Kittay & Carlson, 2010). The 'disability' lens facilitates a critical look at what it means to be hu-

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[1] *Probeerruimte* is not a regular word in Dutch language and cannot be found in a Dutch dictionary. It is however, cited regularly in Dutch literature related to Health and Development. It is pronounced 'pro-beer-row (as in rhyming with 'cow') mte'.

man, both in terms of honouring our humanness and in recognising how disconcerting our humanness can be (Goodley, Lawthom, & Runswick-Cole, 2014). Confrontations with cognitive disability challenge our perceptions of what it means to be human, as philosophical conceptions of humanness are predominantly determined by the ability to reason. Inherent to disability are notions of 'restriction' in various domains, including restrictions in expressing rationality, taking risks, and having opportunities to try things out. *Probeerruimte*, as the literal translation implies, centres on creating space to try things out. Significant to recognise here are multiple meanings of 'space,' inclusive of physical and psychological space to develop interactions and/or a space between people. *Probeerruimte* has connotations with "*geographies of disabilities*" as described by Hall and Kearns, in terms of ''opening space'' (2001, p. 237). It encompasses the notion that people should be given space to 'try things' necessary for personal development and growth. Implicit to trying things, however, is the 'taking of risks' and recognising the formative impacts this has on experiences of being human. Risks entail opening, negotiating and even losing our space to others, in the endeavours people make to be recognised as human. Often persons with intellectual, psychological or physical restrictions are denied this space which at times elicits the protest "We are human too!!" This protest was echoed in interviews, among people labelled as having 'learning difficulties', in recent studies commissioned by Disability Studies in Nederland (DSiN). Findings from these studies contribute to our exploration of the term *probeerruimte* and its relevance for the statement "human as a contested concept" (cf. Bourke, 2013). It is beyond the scope of this paper to discuss a wide range of disabilities, so discussion is restricted to people labelled as having moderate to mild learning difficulties.

The article is structured as follows: the background provides a short description of research contributing to this paper. This is followed by an explanation of *probeerruimte* and an account of the positive and negative associations with the literal translation of *probeerruimte*. After this comes a discussion about the closely related concepts 'space and place' and 'risk taking'. Next is a brief discussion of the significance of *probeerruimte* for people with learning difficulties and their perceptions of what it means to be human. Before the conclusion, there is a short discussion about the need to challenge hegemonic practices that serve to perpetuate the ways in which being human is contested. The paper concludes with reflections on the central concepts that emerged in the studies.

2. Background

Two research projects, commissioned by DSiN, were conducted in 2014 and 2015 to explore perceptions of inclusion and participation, primarily among people with learning difficulties living in The Netherlands. The first project evaluated a 'Buddy Project', designed and implemented by DSiN, that aimed to increase meaningful participation of disabled people in a disability conference in held in Amsterdam at the end of 2013 (Budge, Schippers, Kool, Miranda-Galarza & Van Hove, 2016). The second project explored perceptions in regard to inclusive and collaborative research and programme development, specifically in relation to the development of a National Disability Programme (NPG) (Budge, Ebben, & Van Hove, 2015). Although the projects were based in The Netherlands, some participants involved in the research lived outside of The Netherlands.

DSiN has been working towards ensuring the full and meaningful inclusion of people with disabilities in the development of a National Disability Programme. These efforts involve the notion of 'trying a new space' as people with learning difficulties are encouraged to engage in spheres such as programme design and development and decision making situations, which are usually dominated by people without learning difficulties. In these two studies a total of 31, individual and paired[2], semi-structured interviews (cf. Green & Thorogood, 2013) were conducted; six were with people with learning difficulties. In addition, six focus group interviews (cf. Rabiee, 2004) were held that engaged 12 participants with learning difficulties. During the second research project *probeerruimte* emerged as a concept needing more exploration in disability research. To support this demand, further interviews were conducted to gather more information. Two more focus group interviews, involving seven people with learning difficulties, and five individual interviews with people without learning difficulties, who are closely involved in the disability arena, were conducted. DSiN is a relatively small and cohesive disability group. Participants in these studies were people with whom DSiN has an ongoing dialogue. All participants willingly agreed to participate.

3. *Probeerruimte*

The term *probeerruimte* emerged around 20 years ago, and was coined by the Dutch developmental psychologist Willem De Ruiter following a visit he and some colleagues made to the US with the aim of learning what was happening for people with learning difficulties. In the US, they witnessed a close alignment between efforts by people with disabilities for inclusiveness, and the civil rights movement. Coinciding with this was an institutional paradigm shift in The Netherlands with mission statements of various organisations claiming the need for 'freedom', 'independence', 'exercise of choice', 'autonomy' and 'inclusion'. This shift was supposed to herald a move toward opening spaces for people with learning difficulties to exercise choice and autonomy. The aim

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[2] The decision to 'pair' some interviews was determined by the need for assistance with communication, both in terms of language, as the primary researcher does not have a good command of the Dutch language, and comprehension.

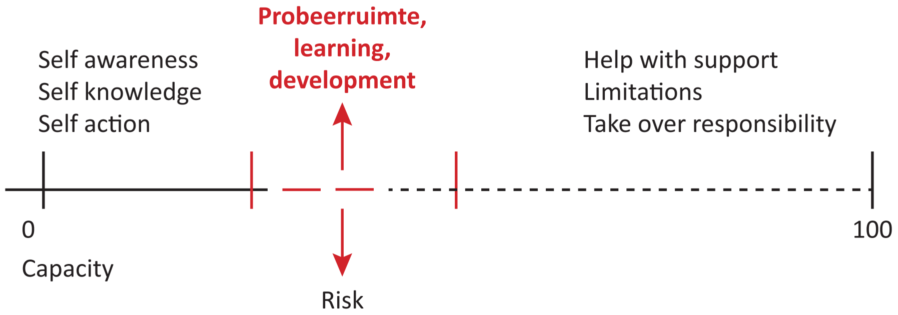

Figure 1. Learning, development and risk. Source: Personal communication (De Ruiter, 24 February 2016).

was to encourage freedom from restrictive institutions where people lived in conditions of tight control and coercion (Smit, 2012). Prior to this shift people with learning difficulties, living in such institutions, were not accorded the same civil rights as other citizens (European Intellectual Disability Research Network, 2003).

A close look at the current situation of people with learning difficulties in The Netherlands shows that the impact of this 'shift' has been variable. Despite the 'good' intentions, shifts toward independence, freedom, and exercise of choice, has occurred more for people with physical or sensory impairments than for people with learning difficulties and mental health needs. The latter groups still mostly live in institutionalised settings (Schoonheim & Smit, 2007; Townsley, Ward, Abbott, & Williams, 2009). This is possibly related to the resistance of institutional staff working with people with learning difficulties. De Ruiter observed this more than two decades ago. He described how staff reacted with incredulity at this shift and voiced comments such as "the people I work with cannot choose for themselves" (personal communication, 24 February 2016). Staff were concerned that such independence would be too risky and endanger people who were assigned to their care. Thomas (2007), a disability scholar, maintains this 'concern' is reflective of a misguided, yet widespread assumption that people with impairment are rendered dependent and as such are in 'need of care'.

In response to such concerns De Ruiter conceptualized the term *probeerruimte*, linking the term strongly with the notion of 'personal development' (personal communication, 24 February 2016). He maintains the term is about creating spaces where people are able to try and do things for themselves, and highlighted the importance of being able to 'exercise influence' as prerequisite for human development. Importantly, exerting influence may be over the self as well as others. The following anecdote highlights one of his compelling reasons. A number of years ago, when working with people with learning difficulties, De Ruiter and his colleagues were asked to 'babysit' some people who were living in an institution, while the 'carers' who usually worked with these people, went out for the evening. De Ruiter and his colleagues agreed to this request and were given an extensive and detailed list of what was to happen—who could sit where, next to whom, what and how people would eat, and so forth. De Ruiter felt this was absurd as he was confident the people 'assigned to his care' would know perfectly well what the routine would be. The list was put aside and indeed everyone was able to clearly indicate what needed to happen. They were able to exercise their own choice and in doing so demonstrated self-determination.

It was evident the regular staff who sought help with 'babysitting' had been exercising regulating power. This scenario resonates with the exercise of bio-power (Foucault, Bertani, Fontana, Ewald, & Macey, 2003), which facilitates an institutionalised form of dependency. People categorised as 'abnormal' become recipients of treatment, care and/or welfare as they are compelled to follow institutional norms. Relevant here, is the elaboration of Rose (2007). He describes 'bio-power' where authorities intervene in a semi-rationalized way to impinge upon the uniqueness of *human existence*, both at an individual and a collective level.

Consequently, facilitating *probeerruimte* is primarily about ensuring spaces are created where people are able to exercise choice and challenge the restrictive and regulatory practices of 'professionals' in the provision of 'care'. De Ruiter cautions that it is necessary to determine if risks outweigh the benefits when creating space for exercising choice and freedom. The opportunity for net benefit should govern when, where and how much support is needed. It is not a static space but rather a space where boundaries are constantly changing as depicted in the diagram above (Figure 1).

According to Van Hove[3], "*probeerruimte*, evokes association with 'liminal spaces', 'borderlands', 'margins', 'de-territorialisation' and 'lines of flight'" (personal communication, 15 December 2015). *Probeerruimte* needs to be a space where trust is engendered and reciprocity is cultivated. It is important to note that efforts to elicit change, in regard to the creation of *probeerruimte*, should be initiated by people with learning difficulties. As Thomas states "the struggles for independent living (or integrated living, as it is sometimes called)

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[3] Professor Geert van Hove has been professor in Disability Studies and Inclusive Development at the University of Ghent, Belgium, since 1993 and currently is appointed as the Chair of Disability Studies at the VUmc, Department of Medical Humanities, Amsterdam, The Netherlands.

waged by disabled people's movements in the US and the UK, have proved to be much more successful routes to change than attempts to reform professional practice" (2007, p. 99).

4. Negative and Positive Perceptions of the 'Literal' Word *Probeerruimte*

There were both negative and the positive perceptions of the literal word *probeerruimte*, specifically the notion of 'trying', for some of the people with learning difficulties whom we interviewed for this study. In one of the group interviews it was evident that some members bordered on being 'offended' about the literal meaning of the word in relation to their experiences. *Probeerruimte* is not a regular word in Dutch, and for these people it was a 'new' and unrecognisable word. They considered it too 'weak', feeling it did not reflect spaces where their strength and autonomy could be recognised and exerted. The implication of 'trying' was considered almost patronizing, as is evident in the following quotes: "it [*probeerruimte*] doesn't tell me much. If I want something, I don't need a *probeerruimte* for it"[4]; "it doesn't work for me"[5]; "*probeerruimte* is not really a good word"[6]. Better words should refer more to issues like 'connection'[7], 'meeting'[8], 'strength development'[9], 'own strength'[10], 'not client, but a citizen'[11]. During the discussion, however, it became clear from comments regarding the need for a space where choice and autonomy could be exercised, that their perceptions resonated with the intent of the word as described by De Ruiter. This led to further discussion about how participants would like to express this need. Preferences in the group were for a word that would convey their desire to 'convince' others of their strength and power. In light of this we asked them to consider what the positive aspects of *probeerruimte* could be, as in what spaces are needed for personal growth and self-actualisation? In response, the following ideas were offered:

> "It should be meeting space—a place where disabled and non-disabled people can meet." (Jeanette[12])

Jeanette stressed the importance of 'coaches'[13] and 'managers' in this encounter, expressing a desire not to parse the distinction between people with 'learning difficulties' and people without 'learning difficulties'.

Expanding on this line of thought, Jeanette, went on to say:

> "It is an important space for connecting with others…[where] we can 'share' with others and in doing so raise awareness [about people with learning difficulties]."

Acknowledging the need for personal growth and self-actualisation, another group member contributed the following:

> "Efforts towards inclusion need to be 'two ways'… we need to use the UNCRPD to claim our rights." (Harro[14])

Ideas of connectivity and creation of meaningful networks with others were identified as central to how *probeerruimte* should be conceptualised. Meeting others is not enough. It needs to be a space where 'connection' occurs.

Implicit is a demand for appreciation of diversity and diverse ways people have of being in the world (Cockburn, 2007). Frequently, when people with learning difficulties experience difficulty with expression, it is less related to lack of opportunity and more related to obstructed communication. *Probeerruimte* should be a space where obstructions are removed. This idea is supported by the following statements:

> "It should be a place where we can think for ourselves." (Henk[15])

> "It should be a space where things happen 'with us' and not 'over us.'" (Henk)

> "It should be a place of support but not control." (Harro)

Many of the concepts mentioned above resonated with another interviewee, Anneke Wignand, a woman who works with people labelled as 'schizophrenic'. Anneke considers *probeerruimte* central to her work and affirms the idea of it being a place of connectivity. For her the core of *probeerruimte* is:

> "To be known and to know people."

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[4] Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Het [*probeerruimte*] zegt mij weinig. Als ik iets nodig wil, heb ik daar geen *probeerruimte voor nodig*'.

[5] Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'k Kan er [*probeerruimte*] niks mee'.

[6] Original quote in Dutch from focus group interview Wolvega, 28 January 2016: '*Probeerruimte* is niet echt het woord'.

[7] Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Verbinding'.

[8] Original quote in Dutch from focus group interview Wolvega, 28 January 2016:'Ontmoeting'.

[9] Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Ontwikkelkracht'.

[10] Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Eigen kracht'.

[11] Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Geen cliënt, maar burgers'.

[12] Jeanette, is a person with learning difficulties and worker in a Disabled Person's Organisation (DPO) in The Netherlands.

[13] The terms 'coach' and 'managers' are given to support people, without learning difficulties, working in the DPO where Jeanette also works.

[14] Harro is a person with learning difficulties working in the same DPO as Jeanette and Henk.

[15] Henk is a person with learning difficulties working in the same DPO as Jeanette and Harro.

Anneke is convinced the state of ‘being unknown’ restricts opportunity for growth. As such she extended her understanding of *probeerruimte* to encompass the idea of a space of recognition where people are encouraged to try things in the presence of people who are open and accepting. She emphasised the need for:

> “An open and accepting space where opportunity is created.”

In her analysis of relationships with others, Latimer (2013), makes a distinction between ‘alongsideness’ and ‘being with’. Alongsideness implies being in a proximal position, where connections are intermittent and partial, whereas ‘being with’ is more encompassing. ‘Being with’ builds relationships. The art of dwelling amongst different kinds is important for substantiating identities (Latimer, 2013). *Probeerruimte* should facilitate such exposure and in doing so help in the formation of self-identity.

Dwelling among different kinds includes encounters with something or someone other than humans. Latimer (2013) provides rich descriptions of two radically contrasting encounters people can have. One involves animals the other cigarettes. Both encounters demonstrate the opportunity to be alongside a non-human other and enjoy undemanding relations that facilitate pleasurable experiences and connectivity. She describes how these encounters inhabit, invade, move and traverse us and in doing so help to constitute us. These moments of connection, whether it be with an object such as a cigarette or an animal, provide opportunity to order our worlds. Our identities are punctualised by the demands of relations to both human and non-human others. *Probeerruimte* needs to facilitate opportunities for these encounters.

5. Space and Place

The notion of connectivity is related to the concepts of ‘space’ and *probeerruimte*. Hubbard and Kitchin assert “the articulation of interrelations brings space into being” and they highlight the ‘dynamic’ nature of space “it is not a neutral container, a blank canvas…filled in by human activity….[It is] inherently caught up in human relations, both socially produced and consumed” (2010, p. 40). Furthermore, place is perceived as a particular ‘type’ of space, constituted by lived experiences of people, essential for the expression of belonging and the development of identity (Cameron, 2005; Hubbard & Kitchin, 2010; Parr, 2000). Edward Hall asserts place is essential for people with learning difficulties, claiming “people with IDs[16] are more likely to be deprived, to not be in employment, to be in poor health, to be absent from mainstream spaces…and to sense a low valuing of their lives” (2010, p. 48). It is in the mainstream spaces that the myriad of emotions that constitute ‘self’ (desires, anxieties, passion and love) are able to negotiate ‘symbolic geographies of everyday life,’ and where people develop prerequisite skills for sustaining self and a relationship with the world (Hubbard & Kitchin, 2010). Inherent to this discourse is the notion of ‘liminal space’ an ‘in-between’ space that according to Hjalmarson “is a point more than along the way to somewhere else. It represents anti-structure to structure, chaos to order” (2009, p. 12). Importantly, it is a space where transformation takes place and much of the transformation is due to the removal of control that occurs. Significantly, for people with learning diffculties, ‘other people’ need to relinquish ‘control’ as without this the ‘self’ remains incoherent. Liminal space, almost by definition is a space where self needs to become coherent. Spaces where ‘self’ is constituted are spaces that render us vulnerable as we negotiate unfamiliar and new territory.

The notion of vulnerability brings us to the critical role that ‘risk’ plays in regard to *probeerruimte*. It is a space to ‘let go’ as trust is generated and people can assume ‘ownership’ for their own actions. Indeed, as alluded to previously, it is a ‘risky’ place, a positively risky place, where there is a willingness to be vulnerable.

6. Risk Taking

Probeerruimte, and the notion of ‘trying’ something, entails taking risks (De Ruiter, personal communication, 24 February 2016). Risk taking involves abandoning notions of ‘certainty’ and beginning to cultivate trust. Trust is a relational concept in contrast to certainty, a more concrete and mechanical concept (Brueggemann, cited in Hjalmarson, 2009). Of importance here is the notion of ‘relational autonomy’. Anneke Wignand, observed that *probeerruimte* must also encompass connectivity as it should be a space where networks are established and worlds are widened. Widening of our worlds, and establishing new relationships, inevitably involves taking risks.

Robertson and Collinson identify ‘facilitating positive risk taking’ as “an essential capacity for health and social care staff” (2011, p. 147). Effectively, it is constructed around managing potential danger by facilitating autonomy and providing positive opportunity for personal growth and development (Robertson & Collinson, 2011). Scholars, exploring the topic of risk, caution against solely negative perceptions of risk and also advise making a distinction between ‘risk behaviour’ and ‘reckless behaviour’ (Ravert & Gomez-Scott, 2015). Lupton and Tulloch affirm that “some degree of voluntary risk taking is seen as positive for purposes of personal gain…or self-actualization, or simply as part of the human project” (2002, p. 331). They go further asserting that “risk [is] an inevitable part of everyday life, pervading everything” (2002, p. 325). Integral to decisions about whether or not to take a risk or embrace an opportunity is the central notion of self-determination which is reflected in the fact that individuals make very different choices (Donaldson & Kymlicka, 2011). Risk-taking is suggestive of open spaces where people, who are rendered vulnerable, are

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[16] This is a direct quote and IDs refers to Intellectual Disabilities.

able to demonstrate strength and influence. As Budge et al. infer, the ability to exert influence is related to the idea that "people with learning difficulties do not want others determining if they are 'competent'" (2016, p. 7). As stated before, people with learning difficulties need the opportunity to exercise the same rights as other citizens, including the right to self-determination, thus ensuring their humanity might be recognised.

7. Learning Difficulties, Being Human and the Importance of *Probeerruimte*

For many within disability studies, particularly intellectual disability studies, contestation about the state of being human is related to human rights and specifically citizenship (Cockburn, 2007; Curtice, 2010; Frawley & Bigby, 2011; Jinnah, 2006; Meininger, 2013; Mertens, Sullivan, & Stace, 2006, cited in Laliberte Rudman, 2014; Redley & Weinberg, 2007; Siebers, 2007; Taylor, 2013). Inherent to this line of thought is the idea that being 'awarded' citizenship status is one of the ultimate confirmations of being considered human. Some discourse, in this arena, explores the extent to which moral personhood and a 'life worth living' can be attributed to people with learning difficulties (Taylor, 2013). Who and what determines a 'life worth living'?

This question leads us to challenge prevailing ableist ideas that 'having a disability' precludes human well-being and agency. This is troublesome and may lead to dire consequences, for instance, denying rights and recognition of personhood to people entitled to citizenship. This is a real concern among people with learning difficulties, who participated in the studies conducted by DSiN, as echoed in the following comment:

> "Ik ben ook een mens"—"I am human too." (Niels[17])

In one of the focus groups an animated discussion about rights to citizenship took place with one member emphatically claiming:

> "Imagine if the situation turned around and everyone else became 'clients' and we 'citizens'"? (Harro)

This concern was echoed by another of our participants:

> "People with learning difficulties need to be included at all levels, we are all citizens of our countries….We must not be treated as third or fourth rate citizens." (Robert[18])

Captured in these statements are beliefs that *probeerruimte* needs to be a space where influence is exerted, strength is displayed, rights are claimed, connections occur and self-determination is revealed. These beliefs resonate with ideas that were offered when questioned about what it means to be human.

Being human was closely aligned with notions of citizenship, and citizenship has everything to do with affirming rights and membership of a community (Donaldson & Kymlicka, 2015). Importantly, as with the description of *probeerruimte* offered by De Ruiter, eligibility for citizenship is not contingent on linguistic agency or rationality, but rather on being empowered to participate. Understandings of participation need to go beyond exercising individual autonomy and extend to embracing the notion of 'dependent agency' where 'autonomy' is exercised through the establishment of relationships. This was eloquently described by a participant with learning difficulties in a group interview, when asked about what it meant to be human. With pleasure he described the following:

> "Being human has to do with being able to bring pleasure to others. I live close to elderly people and I can see how happy they are when I visit them and offer them help." (Michiel[19])

Implicit in this description is the idea that 'being human' embraces reciprocity and, as with understandings of *probeerruimte*, having the opportunity to exert influence and establish meaningful relationships.

These lines of thought were linked to experiences in institutions and denial of opportunity to 'think for themselves'. This line of argumentation was offered in support of notions about what it means to be human. Clearly, a strong thread existed between ideas of citizenship, being able to make decisions and feeling human. Perhaps more than for others this notion of citizenship is a contentious issue for people with learning difficulties. Historically, people experiencing learning difficulties have been relegated to the status of second class citizens. This status has usually been attributed to their lack of linguistic skill and lack of reasoning power (DeShong, 2010; Donaldson & Kymlicka, 2011; Goodley & Runswick-Cole, 2014; Latimer, 2013; Siebers, 2007; Wolfe, 2009). Reasoning about citizenship should be turned on its heels. Eligibility for citizenship should not be determined by prerequisite skills such as linguistic ability, rather citizenship should be determined by membership of a society. As Donaldson and Kymlicka assert: "Citizenship is not a prize awarded to those who pass some test of cognitive "normalcy" or linguistic agency, but it is a political status owed to all who are members of a society" (2015, p. 20).

8. Challenging Hegemonic Practices

Power struggles dominated by hegemonic practices drive many of the issues identified in this paper. In their study about the marginalisation of local communities in the

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[17] Niels is a person with learning difficulties and works for a DPO similar to the one where Henk, Jeanette and Harro work.

[18] Robert is a person with learning difficulties, the first person with a learning difficulty to address the UN and a NZ 'People First' Advocate.

[19] Michiel is a person with learning difficulties and works with the same DPO as Niels.

Great Limpopo Transfrontier Conservation area, Spierenburg, Steenkamp and Wels attest to the impact of power struggles over levels of participation, asserting "communities first have to live up to rigid standards and requirements set by the international conservation authorities, before they are considered 'fit' to participate" (2006, p. 18). Some of our participants expressed similar difficulties stemming from the status of 'client'. As with the local communities Spierenburg et al. (2006) observe, conditional benchmarks and status are clearly determined by hegemonic standards, for instance, rigid standards for cognitive ability, linguistic and reasoning skills. Challenging these standards, the study participants proposed this disempowered 'client' status needs to be replaced with the status of citizenship determined by their membership in a shared society, and as citizens, they must be accorded the rights of participation.

In much the same way, prerequisites of autonomy and independence have determined eligibility for citizenship. Discrediting claims for citizenship on these grounds is an issue that resonates with scholars busy with the rights of children and animals (Donaldson & Kymlicka, 2015). Animal theorists, along with disability and child theorists, argue that we need to creatively consider ways to engage the subjectivity of our co-citizens and seek ways to engage their varied ways of existing, including the ways in which we and they connect with others.

Study participants considered the opportunity to connect with others, and specifically to be treated the same as others, a human attribute, inferring the need for access to human rights. As is echoed in the following statement:

> "We need to be respected as citizens and have our rights honoured….We need to be more than citizens on paper, you can't learn to swim from a 'paper.'" (Harro)

Siebers (2007) affirms this, and asserts that our membership to humanity is highly dependent on a sense of political belonging. Elaborating on this, Siebers draws on Hannah Arendt, highlighting "[the]deprivation of human rights is manifested above all as the deprivation of the status of being human" (2007, p. 1). Within many contexts the right to claim citizenship is contingent on the exercise of certain 'abilities' including a minimal knowledge of a language (Benhabib, cited in Siebers, 2007). It is problematic for people with learning difficulties when access to citizenship is determined by certain abilities. The concern is exacerbated when it extends to possibilities for extinction of particular groups that may be deemed unfit for membership of the category human. Arendt drew attention to the circumstances that determine the fragility of eligibility, "a highly organized and mechanized humanity will conclude…for humanity as a whole it would be better to liquidate certain parts thereof" (cited in Siebers, 2007, p. 3). This concern was echoed by some people in this study:

> "Alarm bells are going off…in regard to euthanasia and sterilisation processes….Euthanasia is fine so long as it is a choice made by 'self' but there are major concerns that euthanasia decisions are being made for people with disabilities." (Martin[20])

A woman with a physical disability and living in The Netherlands affirmed this concern:

> "I think and write a lot about pre-natal testing…because I really feel now we have this negative eugenic….If you look at the Third Reich it was a state decision and now it is a personal decision….We make the mistake of thinking if it is a personal decision it is good, that it is a free decision, but that is a mistake….The effect is the same, it is exactly the same as in the Third Reich." (Marie-Jose[21])

These concerns were unequivocally linked to perceptions of what it is to be human:

> "People with intellectual disability have been a deeply oppressed group of our society, they have been the butt of eugenic policies…and I think the Euthanasia law…in The Netherlands is incredibly dangerous for disabled people….One reason is that their voices have to be heard….You know you have to turn around this view that they are not real humans….It is only in hearing their voices that their humanity will be seen and recognised." (Martin)

Inherent here is a desire to impose order. Imposing order is closely related to the practice of 'othering'. Of particular concern for disability studies are the mechanics of 'othering' and the practice of making comparisons to prove exceptionalism. This is dangerous ground as comparisons tend to work negatively in order to degrade the other (Latimer, 2013). The practice of 'othering' has engendered in humans a stance that is oppositional and aggressive leading to exclusive practices and at times violent exclusions (Latimer, 2013). *Probeerruimte*, offers a space where recognition of a person's 'humanness' can occur.

Posthumanist theories make an appreciable counter to the arguments offered above, challenging the ease with which distinctions are made between 'human' and 'non-human' categories (Goodley & Runswick-Cole, 2016; Haraway, 1991; Latimer, 2013; Reeve, 2012). Linking this to disability, Goodley et al., assert, "Critical disability studies…are perfectly at ease with the posthuman because disability has always contravened the tra-

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[20] Martin has a spinal injury and uses a wheelchair. He is a Senior Lecturer in the School of Social Work at Massey University, NZ where his specialist area of teaching is Disability Studies and Social Policy.

[21] Marie-Jose is a Gestalt therapist and writer in the field of disability, illness and medical ethics. She has a progressive muscle disease.

ditional humanist conception of what it means to be human" (2014, p. 342). The ease with which critical disability studies embraces posthumanism, and inadvertently perceives 'human as a contested concept', is related to the discomfort disability studies has with conceptions of 'humanity'. This discomfort has been fed by unease with eighteenth and nineteenth-century classical portrayals of humanity, and more recently, based on modernist and capitalist hegemonic constructions ascribing the status of 'human' only to white, masculine, urbanized, heterosexual citizens, 'speaking a standard language' (Goodley et al., 2014). They further assert, in contexts that weave capital, technologies, and communication through real and virtual spaces, the ideal of a rational, independent, solitary and able-bodied human subject is rendered unrealistic, if not fictional (Goodley et al., 2014).

9. Conclusion

This paper has juxtaposed the Dutch term *probeerruimte* and the statement 'human as a contested concept' exploring the term and searching for its relevance to notions of being human. *Probeerruimte*, as conceived by its author, De Ruiter, is a space where people who are usually subject to institutionalised and restrictive rules and regulations, are able to try out new things and, in doing so, are able to develop as human beings. He points out an important aspect of 'trying' is the exertion of influence. 'Exerting influence' presupposes a relational context where one can exert influence over another and manipulate situations in a desired manner. Inherent to a relational context is the notion of connectivity which, for some participants contributing to this paper, was significant for *probeerruimte*. The term was portrayed as a place where it is important to know and be known, to be recognised. The relational aspect of *probeerruimte* linked significantly to understandings of what it means to be human, where establishing relationships is pivotal.

For some people with learning difficulties, whom we interviewed, denial of what has been conceived of as *probeerruimte* is akin to denying their human rights and status as citizens. Eligibility for citizenship is central to understandings of what it means to be human and a number of our participants were emphatic that being awarded the status of citizenship ensures they have the same rights as others. Instances of the troubles 'marginalised' people have in claiming citizenship, drew attention to restrictive hegemonic practices that establish rigid exclusionary standards. Citizenship should not be contingent on linguistic skills or rationality, rather, by virtue of membership to a society, citizenship it should be accorded as a right. Although the complex topic 'inclusive citizenship' (Curtice, 2010) is clearly beyond the scope of this paper, we want to reiterate the huge significance of this broader issue for further contextualisation and conceptualisation of *probeerruimte*.

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Conflict of Interests

The authors declare no conflict of interests.

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Fiona MacLeod Budge has a background in Occupational Therapy and Medical Anthropology, her research and academic publications have mainly focused on the value of inclusive and participatory approaches in both disability studies and health promotion efforts. She has her own communication and advocacy consultancy and frequently delivers training to people working with so-called 'marginalised groups'. The most recent course focuses on developing research and advocacy skills of disabled people.

Harry Wels was trained as an anthropologist. His research and academic publications have mainly focused on organisational and management processes in (private) wildlife conservation in South and southern Africa. Since his 'animal turn' a couple of years ago now, he tries to include the 'non-human other' in his fieldwork and in interpreting human-animal configurations in wildlife conservation. Rethinking what it means to be human in this context has been an enduring intellectual challenge for him.

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Article

Weighing Posthumanism: Fatness and Contested Humanity

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Abstract

Our project on fatness begins by turning attention to the multiple cultural instances in which fatness has been intrinsically linked with notions such as self—neglect and poor self—management. In Foucauldian terms, we analyse the fat subject as a failed homo economicus, an individual who has failed to be an "entrepreneur of himself, being for himself his own capital, being for himself his own producer, being for himself the source of [his] earnings" (Foucault, 2008, p. 226). From this perspective, we analyse instances of collective hatred towards fat subjects as direct results of the biopolitical triplet of responsibility, rationality, and morality. Morality is our bridge into the field of posthumanism, in which, as we demonstrate, these biopolitical imperatives also apply, reinforced by the field's fascination with prosthetics and enhancement. Where, by biopolitical standards, fat subjects have failed to manage themselves, posthuman subjects find themselves guilty of not responsibly, rationally, and morally manipulating themselves to optimal productivity. Using criticism that disability studies scholars like Sarah S. Jain and Vivian Sobchack have voiced about posthumanism, we demonstrate the ways in which, within posthumanism, all subjects can be found as lacking when compared to their potential, enhanced posthuman version.

Keywords

biopolitics; disability studies; fat studies; posthumanism; prosthesis

Issue

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1. Introduction

> "The writing of the posthumanist condition should not seek to fashion 'scriptural tombs' for humanism, but must, rather, take the form of a critical practice that occurs inside humanism, consisting not of the wake but the working-through of humanist discourse." (Badmington, 2003, p. 20)

When Neil Badmington (2003) suggests that we adopt a critical practice inside humanism, he hints at the possibility that posthumanism must prove itself worthy of performing such critical practices without falling into the trap of reproducing the pitfalls of humanist discourse. The following essay attempts not only to expose the danger of such pitfalls for posthumanism, but also offers ways of reflecting on contested humanity by way of engaging embodied theories. The (fat) body here does not serve as an object of study, but rather as an agent that reveals the objectifying effects of neoliberal biopolitical discourse. Fat bodies thus become part of a critical way of theorising human life from a posthumanist perspective. The fat body's relation to posthumanist theory is specific in that it poses a conceptual problem to the posthumanist's critical stance towards human embodiment and bodily enhancement. The fat body, similar to, yet different from, the generic "disabled" body cannot be enhanced by technology, as technology is widely understood, but only by moral discipline and self-management. While prosthetic enhancements are seen as an external "solution" to disability, the fat body needs to employ internal, moralized technologies of discipline, such as diet and exercising, in order to comply with productive normativity. Our argument in this article is that bodily enhancement (technological as well as moral) is at the core of not only humanity, but also of the seemingly critical and potentially more inclusive post-humanity. Also, that the concept of the fat body, with the help of a critically informed discourse on disability and bioethics, helps to reveal and hopefully contest the dependency of *all* humanity on this core.

The overall aim of this paper is to bring critical posthuman theories into productive dialogue with current social and cultural trends towards bodily "uniformity" in the name of human enhancement. This attempt not only serves as a critique of public discourses and practices by way of analysing popular websites and online forums on "fat hatred"; it also aims to bring to the fore that our contemporary bodies are subjected to a powerful machinery built on neoliberal, moralistic, and rationalist cultural ideologies that target specific bodies more than others. Motivated by a critical disability studies critique of social inequality on the basis of bodily ability, we take the marginal field of fat studies as a conceptual bridge between the discourse around typically marginalized bodies and the more general problem of the body for the constitution of all humanity or post-humanity.

The first case study used in this essay is an image taken from a website called *Health Fitness Revolution* (HFR)[1] (Figure 1). What is first presented to the viewer of the homepage of *HFR* is a series of rotating images that function as links to articles promoting fitness, physical activity, and healthy nutritional habits. Articles with titles like "You Are What Your Father Eats", "Healthy VS Unhealthy Diet", "How to Live to 100", "Best Foods to Fight Fatigue", "Best Foods for Alzheimer's Disease", and "The Benefits of Biking" follow each other in a succession which, for all stated purposes, is not explicitly about or against fatness. These articles are focused on passing down the wisdom of well-being and recipes for longevity, strength, fitness, and even mental health. If anything, dieting and nutrition are props to the sacred mission of healthy living. We have chosen this website as representative of the many dedicated to the ongoing 'War Against Obesity' initiative in the United States. The article on which we have chosen to focus, titled "Tips for Overcoming a Weight Loss Plateau", delivers advice on how to successfully continue one's diet, the key word here being continue. This article targets people who are already dieting: sound, rational *homines economici*. If application of economic to social models is to work, its subject must be a rational *homo economicus*. The reader of this article is thus not addressed as potentially being a fat subject, but instead as a properly functioning individual, dedicated to maintaining his or her good health, and by extension, his or her capital. We would like to dig a bit further into what this assumption—that the visitor of the website is already a well-functioning *homo economicus*—reveals about the mechanisms that produce the knowledge (and thus rationality) allotted to this subject as his or her primary mode of operation.

The image accompanying the article (Figure 1) depicts two men standing next to each other, one of them muscular, holding gym weights and an apple, and the

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[1] http://www.healthfitnessrevolution.com

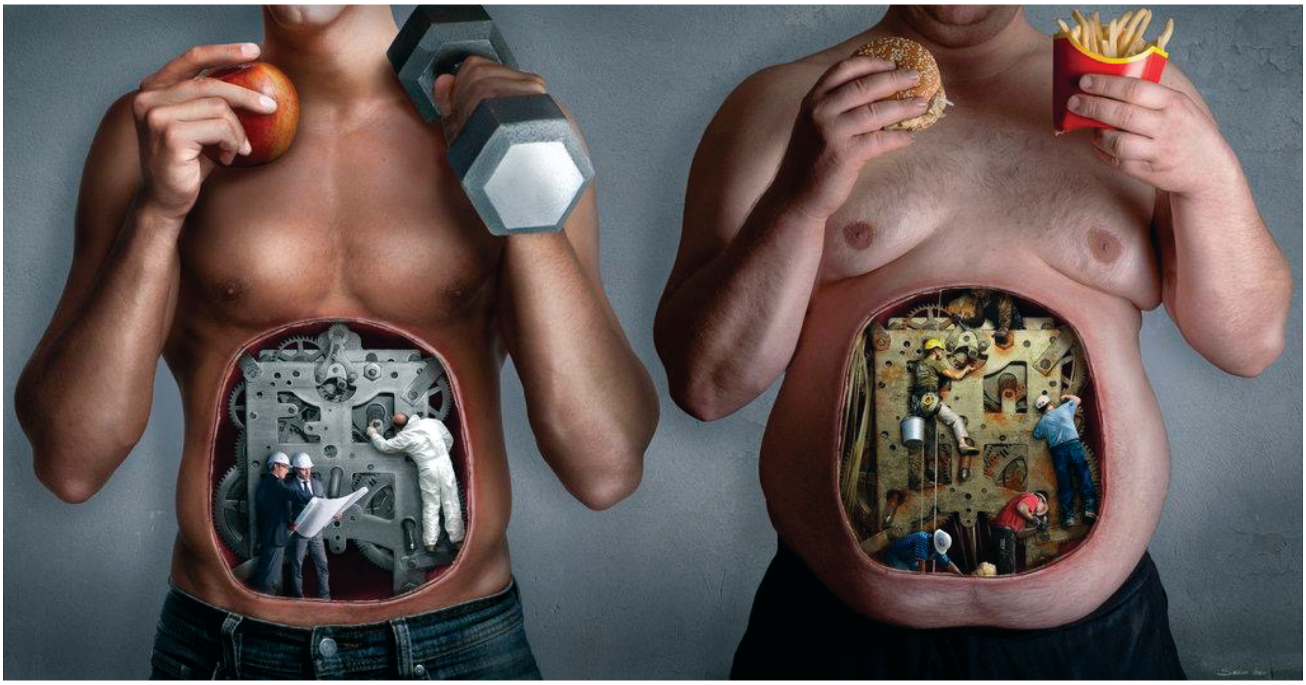

Figure 1. *HFR* "Tips for overcoming a weight loss plateau" (30 May 2016).

other overweight, holding a hamburger and a package of fries. Both of the men's abdomens are hollow, and inside their bellies one can see a machine and a construction crew. The muscular man's machine is made of shiny silver. His construction crew is comprised of two well-dressed men consulting a diagram and a worker, clad in a white uniform and propped up on a ladder, tinkering with some cogs in the centre. The machine in the fat man's abdomen, on the other hand, is rusty and appears dirty and neglected. The working crew is comprised of four men not in uniform, their attire dirty and worn.

The metaphors in this image suggest that if you eat well and exercise, your body will function like a well-oiled machine. By making the 'right' choices, you supply your body with the 'right' crew that will make effective, well thought-out, rational decisions in the maintenance of your body-machine, keeping it in the best possible condition. The key word is maintenance. As depicted in the image, the machine already appears to function well, needing only minimal tinkering from the worker. If, in contrast, one makes the wrong choices, one's body-machine will be neglected, rusty, and low-functioning. The workers in one's own body will operate under no instructions from a knowledgeable, rational authority. Instead of maintaining an already functioning machine, these workers scatter over its entire width and appear more as though they are trying to salvage it from total destruction.

In what seems an almost too literal representation of the Foucauldian subject-machine, the successful *homo economicus*, represented by the muscular torso, demonstrates the correct management of this man's capital. His machine, his ability to work, which "cannot be separated from the worker himself" (Foucault, 2008, p. 224), is given proper care in order to ensure that the human capital in question will be at a maximum. The fit man also serves to represent the image's imagined visitor and target audience, the economic subject who has incorporated this valuable knowledge and has accordingly responded "in a non-random way, in a systematic way" (Foucault, 2008, p. 269). Systemic here means rational, or rationalistic, as in Val Plumwood's critique of the neoliberal market logic (Plumwood, 2002, p. 14).

Rationality, or rationalism, is a central notion in the self-management of the *homo economicus*. The ability to adjust and respond to information provided ensures that the *homo economicus*' enterprise functions under the best possible regulation. As Thomas Lemke explains in "The birth of bio-politics: Michel Foucault's lecture at the Collège de France on neo-liberal governmentality" (2001),

> "Awarded with 'absolute' liberty regarding the maintenance of themselves, neoliberal subjects must now prove worthy of this gift, by demonstrating their best possible behaviour in their management of their lives. According to Foucault, this neo-liberal homo economicus 'becomes a behavioristically manipulable being and the correlative of a governmentality which systematically changes the variables of the 'environment' and can count on the 'rational choice' of the individuals." (p. 13)

Thus, the neoliberal *homo economicus* is left to operate in a field of seemingly endless freedom, unaware of the fact that all of his supposedly informed and rational manoeuvres are the direct results of a specifically framed 'regime of truth', where 'truth' is formed and authorised in particular manners.

The websites we will analyse in this essay are examples of the kinds of places where that 'truth' about embodied rationalism is generated and distributed. The websites themselves base their arguments on specific biomedical narratives about fatness. They also function as a bridge between scientific discourse and the public under the promotion of the state. However, it is not the responsibility of any state to enforce rational conduct on its citizens; the state is only there to provide them with the knowledge needed for them to conduct themselves in the expected rational way.

Current literature within fat studies has taken up the analysis between the individual fat body and the neoliberal machine. Scholars such as Paul Campos (2005) and J. Eric Oliver (2006) have taken critical stances to analyse the current epidemiological obesity discourse. These critical approaches are centred on debunking commonly held medical 'facts' about 'obesity' and analysing obesity as a social rather than a medical issue. However, by insisting that we employ the terms 'obesity' and 'obese', such work errs on two levels. In criticising Campos for substituting "good" science with "bad" science, Michael Gard (2008) points out how these scholars continue to uncritically subscribe to a problematic, positivist ideal of health morality, and Charlotte Cooper, in "Mapping the Field" (2010), comments on the "scientific" distance this body of work seems to have from its fat subjects—fatness remains a topic that needs to be discussed and spoken for by removed, "objective" experts. This article instead wishes to continue the approach outlined in the *Fat Studies Reader* (2009), edited by Esther Rothblum and Sondra Solovay, where, in close dialogue with fat activism, fat scholars speak for themselves, politicising, theorising, and analysing through their embodied experience as surviving subjects within neoliberalism. The analysis that thus follows will do its best to avoid any notion of a detached, medical view, and instead dive into the examination of the object in a constant dialogue with our own embodiment.

The image of the fat man's torso in the picture delivers a powerful message: the body is a machine for which the subject is responsible. Faced with the freedom of choosing between apples and fries, working out and burgers, the subject finds two separate paths: the first is the path of rationality and responsibility, which will guarantee optimal results for the body-machine—results that will be reflected both on the inside (the shiny machine itself) and on the outside (the muscular body which is directly proportionate to the condition of the machine). The second path is the antithesis of the first—on this road, the subject fails to embody neoliberal rationalism in several ways: the fat torso betrays the systemic laws of efficient and goal-oriented labour, and the workers in the fat body work without a plan, lacking scientific, technocratic methods. He fails to succeed as a neoliberal working subject, and fails to fulfil his public function by potentially creating a threat to the functioning of the larger "machine" of society. Here, fatness becomes the signifier not only for the dysfunctionality of the individual body, but also for the rationalistic world providing this body with (failed) opportunities. The image of the fat man functions as a cautionary tale for the website's visitor: this is what will happen to your machine, your capital, your role in society, as well as your humanity, if you neglect your economic responsibilities as a neoliberal subject.

Nevertheless, it would be short-sighted to identify the website's visitors entirely with the image of the fit man, and to position the fat man as only a cautionary figure. If that were the case, the website itself would be redundant. In a more nuanced metaphor, we think it is possible to claim that there are three planes of existence within which the visitor, the fit man and the fat man, reside. Drawing from religious imagery, we would say that on the left side of the image lies Heaven—a productive, well-adjusted, rational, well-functioning neoliberal Heaven. Even the colours of the left side of the image, the steel-coloured whiteness, and the shiny machinery seem to suggest this. On the right side lies Hell—dumpy, grey, rusty, malfunctioning Hell. And right in the middle, right where the visitor is unconsciously positioned, lies Purgatory. The visitor is most likely not as shiny, muscular, or fit as the man on the left. However, based on the tone and the content of the article that accompanies these images, the visitor is also not assumed to be the lost cause that is the man on the right. Instead, the visitor is trapped in Purgatory, standing at the crossroads, repenting for old sins, and thus his inability to enter Heaven, but not having yet committed the penultimate crime of forsaking self-management, and so not quite in Hell. Which road will the visitor choose: the one that offers a shiny, nutritious apple? Or the other, which presents a greasy, unhealthy hamburger? The religious undertones of such a reading of the image inevitably bring us to the question of who might be the 'priest' of this 'religion', as well as what this 'religion' actually entails. In the following parts, we will utilise Nikolas Rose's theory on pastoral power in order to explore the first part of the question, about the neoliberal religion's priest.

2. Pastoral Power and *Homo Economicus*

In *The Politics of Life Itself* (2007), Nicholas Rose writes about pastoral power that it

> "is not organized or administered by 'the state….It takes place in a plural and contested field traversed by the codes pronounced by ethics committees and professional associations, by the empirical findings generated by researchers, the attitudes and criteria used by employers and insurers, the tests developed and promoted by psychologists and biotech companies, the advice offered by self-help organizations, and even, one might add, the critical perspectives contributed by religious organizations and sociological critics." (p. 73)

When trying to identify which organising field of pastoral power *HFR* uses, our first reaction was to identify it as a 'self-help' organisation. The website does not posit itself explicitly as such. It does not pose as a help manual; it proposes a 'revolution'. We believe that this perception of the website's disposition has to do with the tone of a subtext that posits the website as there to "help you help yourself". What is, however, important about pastoral power and its practice is that it is relational, not unidirectional. Using human reproduction as an example, Rose describes how,

> "[Pastoral Power] works through the relation between the affects and ethics of the guider—the genetic counsellors and allied experts of reproduction who operate as gatekeepers to tests and medical procedures—and the affects and ethics of the guided—the actual or potential parents who are making their reproductive decisions, and their networks of responsibility and obligation." (2007, p. 74)

Thus, the website's decision to position its visitor as an already properly functioning, rational subject can be interpreted as a strategic move in the practice of pastoral power. The website "pretends" that it is not there to lecture, but to have a friendly conversation between equals. Pastoral power enables the creation of a series of microtechnologies, which—unlike the sovereign power model, which requires a knowledgeable lecturer and a submissive receiver—place participants on a reciprocal level.

As pastoral power is two-directional, we cannot speak of one of its ends without taking into account its other. However, we would argue that, in the example of the *HFR* website, the perceived 'pastor' of the interaction is the main focus. Although we could extract a number of observations about the website's visitor through the way the website is designed, he or she does not have a direct voice in the discussion. For that reason, we decided to offer a second case, an online community called *Reddit*. Using this community, we will explore what happens when the authority shifts from a perceived 'expert' to the 'general public', and explore the different kind of divisions that this shift creates.

Reddit is an online platform comprised of hundreds of forums, called 'subreddits', all of which have been created and are continuously moderated by users. Material in the subreddits is also user-generated; users can post links to articles, images, and videos, or submit an original text of their own writing. Every subreddit has its own theme, its own rules, its own etiquette, and, often, its own Wiki page. One can usually find the rules and Wiki page, as well as links to previous, archived posts that could prove useful for a new user in the sidebar of the page.

The subreddits we will analyse here form a constellation, within which all contributions are explicitly dedicated to fat hatred, approached from different angles. Users can choose to share stories of how ridiculous fat people are in *fatpeoplestories*, they can share examples of fat people's lack of rationality in *fatlogic*, or—if they just want to let it all out—go for *fatpeoplehate*. Some would argue that Reddit is a particularly harsh place, and that the explicit hatred expressed in those subreddits is not indicative of the rest of society. We would instead argue that *Reddit* is nowhere near the harshest place in the Internet world. Places such as *4chan*[2] and *Stormfront*[3] take the proverbial cake and eat it before *Reddit* has even had time to lift its fork. We argue that *Reddit*, as a democratically functioning platform where anyone can express anything, simply allows its users to be more explicit about the assumptions under which they operate in everyday life. From the experience of one *Reddit* author as a fat person, the only difference between the attitude of *Reddit* users to the ones the author encounters in everyday life is the opacity with which the assumptions are put to use. While in everyday life these assumptions function in a polite subtext, the anonymity of *Reddit* brings them to the surface in all their explicitness.

On the sidebar of *fatpeoplestories*, one can find the rules of what constitutes a good 'fat people story'. This is the first place where we detected an interesting dichotomy, 'Hamplanets vs fat people'. According to the sidebar, "This sub is a place for you to tell us about hamplanets in your life and your relationships/encounters with them. Remember that hamplanet is not just about the weight, but also the hamentality—rudeness, entitlement, fatlogic, etc. Not all fat people are hambeasts but all hambeasts are fat people". This issue is further explored by the users of the subreddit. In a submission appropriately titled "Hamplanets vs fat people" (2013), user KangK brings up a quote by Roald Dahl, which would not normally be expected to appear in a place dedicated to fat hatred. The user's submission reads:

> "If a person has ugly thoughts, it begins to show on their face. And when that person has ugly thoughts every day, every week, every year, the face gets uglier and uglier until you can hardly bear to look at it. A person who has good thoughts can never be ugly. You can have a wonky nose and a crooked mouth and a double chin and stick out teeth, but if you have good thoughts it will shine out of your face like sunbeams and you will always look lovely. (Roald Dahl, *The Twits*, 1979)
>
> I feel like this quote is relevant when we distinguish between fat people and hamplanets. After all, so long as the fat person doesn't have absurd logic or a ridiculous sense of entitlement, we don't consider than [sic] hamplanets, do we? They are not the people that we are criticising." (KangK, "Hamplanets vs fat people", n.d.)

User MCprofK replies: "I love this subreddit, but I must be honest that some things that it stands for aren't entirely clear from the start. Now, I won't try to speak for the entire sub, but this is our opinion. Fat people are disgusting. But this is the thing....To me, to be truly a 'fat person' you have to have the fat mentality, or simply not realize it at all, and accept none of the guilt" (MCprofK, "Hamplanets vs fat people", n.d.).

Let us make the distinction between 'hamplanets' and fat people more comprehensible. According to this approach, there are fat people, and they are deemed repulsive. However, there exists a hierarchy in how repulsive they are: to be deemed a 'hamplanet', he or she must also be characterized by self-entitlement and rudeness, and afflicted by *fatlogic*. The standing definition of *fatlogic* in the *UrbanDictionary* (n.d.) reads:

> "The astounding mental gyrations obese people use to justify their size. Fatlogic never, ever includes eating too much and exercising too little.
>
> *'Fatlogic insists that five triple cheeseburgers doused with mayonnaise are balanced by a diet soft drink.' 'I'm not fat, I'm just large-boned.'*
>
> *'I have a condition; I gain weight for no reason at all.'—Said when finishing the fourth bag of cookies before noon.*"

Whereas in everyday life fat people are concernedly reprimanded for their health-choices and self-management, here, in the seeming safety of the internet, the advisory tone is crystallised into an underlying question: where is your *logic*? Since the pastoral power exercised by the websites, specialists, dieticians, doctors, and diet bloggers have made the dangers of fatness entirely clear, 'hamplanets' *must* be operating under a completely different set of rules, a warped and greasy logic that prevents them from seeing things clearly. It stops them from utilising the information supplied to rationally manage themselves and adjust, adapt, and manipulate themselves to ensure the worth of their capital, enjoy the benefits of self-regulation, and, by extension, offer these benefits to the rest of society. Here, we would like to point out how claiming the existence of some inherently negative qualities that fat people share—qualities that function as the reasons for any hatred expressed towards fatness—echoes fat persons' failure to properly regulate themselves, this time as social beings, while allowing the

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[2] www.4chan.org

[3] www.stormfront.org

hater to relinquish all responsibility for his or her "attitude". Like the website in our first analysis, the users of this site would have us believe that the focus is not even on fatness itself. It is on all the repercussions that come with being fat. On the other websites, the repercussions were framed in terms of health. Here, they are framed in terms of being hideous. Interestingly though, the distinction between 'hamplanets' and fat people does not enjoy unanimous support. The highest upvoted comment in the submission reads:[4]

> "To me, anyone who let's go of themselves to become obese has a problem, regardless of how pleasant they are. I can't hold them to equal esteem as I would other people, the same way I wouldn't hold someone who doesn't bathe and shave very highly. Taking care of yourself is a good indicator of how you deal with other situations, people who don't care about themselves are less likely to care about other standards." (KangK. "Hamplanets vs. fat people", n.d.)

Following this logic, by allowing themselves to get fat, people demonstrate how little they value the gift of freedom and self-regulation that neoliberalism has given us. By allowing their bodies to get fat, fat people have demonstrated their failure to rationally govern themselves, and should subsequently be ready to relinquish any claims to respect since they have already committed the ultimate act of disrespect towards themselves and, ultimately, towards humanity.

3. Managing the Body and Manipulating the Body: Bioethics and Posthumanism

In light of such neoliberal tendencies of self-enhancement, we wish to position posthuman theories, as well as their related technological practices aimed at human enhancement, in a critical, and possibly more complex, relationship to cultural conceptions of embodiment, such as fatness. One field of research, which promises to keep an overly one-sided trend towards human enhancement in check, is bioethics. Bioethics, as the term suggests, studies the critical relations between new developments in the "bio-sciences" and philosophical, as well as political and practical, questions of value, dignity, and care. In *Bioethics in the Age of New Media* (2009), Joanna Zylinska defines bioethics as a response to developments in biotechnology and medicine that raises "philosophical questions about the constitution of the boundaries of the human and human life, as well as considering policy implications of such developments for government bodies, health care institutions, and other social organs. It is thus always already a clinically driven 'expert discourse,' which can then be applied to 'real-life cases'" (p. 5).

However, despite bioethics' potential to keep certain technological developments and translation to everyday practice in check, critical bioethicists warn against the field's biased approach to notions of embodiment, human norms, and political goals. Zylinska explains that what binds differing approaches to bioethics is that they all embrace a sense of normativity, which is "filled with positive content" (p. 5); they call for universal and applicable moral judgements on the basis of "the rational human subject that can make a decision and that is seen as the source of this decision" (p. 5). The universalizing and normative standards of bioethical theories therefore seem to hide the fact that bioethics has become an integral component of neoliberal regulatory practices. In *When Species Meet* (2008), Donna Haraway even argues that bioethics "acts as a regulatory discourse after all the really interesting, generative action is over" (p. 136).

However, following Zylinska's timeline, bioethics also seems prescriptive, not just descriptive. It seems to generate a discourse that does not simply regulate the morality of what already exists, but dictates a type of morality of both the present and the future. In its role of regulating medical discoveries regarding the body, bioethics operates under the assumption that manipulating the body through science is an imperative, not a choice. When theorists such as Peter Singer go as far as to support "the distinction between a 'human being' and a 'person,' with only the latter, characterised by rationality and self-awareness, being worthy of ethical respect" (Singer quoted in Zylinska, 2009, p. 13), the 'person' in question is expected to be self-aware and rational, and thus to rationally *choose* to make use of current or future medical science to achieve the best possible results for his or her health. This assumption shows the existing relationship between rationality and morality within the field of bioethics itself. An irrational subject who would refuse to use these technologies would also fail morality, and therefore would not be worthy of ethical respect or 'personhood'.

The "hamplanets" of *fatpeoplehate* would directly fall under Singer's categorisation of 'human being', thereby falling outside 'personhood', as they have failed to demonstrate a sense of rationality and, by denying the guilt of their condition, have not exhibited self-awareness. We would like to stress here that Singer's differentiation between person and human being is a distinction in degrees that will necessarily create the likelihood for subjects to fall outside of both, which is how humanity is contested too—albeit in dangerous ways. Thus, by eventually failing in both of Singer's categories, fat subjects are logically "not worthy of ethical respect". Or one could see the fat subject's position somewhere between neither/nor, where both 'neither' (quite a person) and 'nor' (quite a human being) have been imbued with specific meanings. On this background, *HFR* assumes that a responsible, rational, and moral subject must maintain her or his position through an active attempt to sustain her or his good health. What happens,

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[4] Depending on whether a user agrees or disagrees with a comment they can either upvote or downvote it by clicking the orange or the blue arrow next to it.

though, if we take the moral responsibility of an already unattainable super-health and stretch it to its logical conclusion? Earlier, we mentioned the irreducibility of striving for what is 'good for you'. Here, constant technological innovations that target human enhancement irreducibly and seamlessly lead to a striving for what is 'even better for you'. And this irreducibility comes with its own extended morality. Zylinska explains the work of John Harris, a renowned supporter of human enhancement:

> "Harris posits the need for enhancement as a universal 'moral imperative' and seems to have a very clear sense what this 'enhancement' actually means. His 'better people' will be more intelligent, more beautiful, but also 'longer-lived, stronger, happier, smarter, fairer (in the aesthetic and in the ethical sense of that term)'—in other words, 'more of everything we want to be'" (Harris quoted in Zylinska, 2009, p. 14)

Human (prosthetic) enhancement is thus positioned as merely the next step to which the trifecta of responsibility, rationality, and morality should aspire and comply. What we aim to highlight here is that bioethics does not merely function as retroactive (or even passive), as Haraway seems to suggest, but as pro-active and influential on the discourse at-large. Technology, science, and their medical consequences are decidedly placed as the most important factors in identifying who passes as a human being. Bioethics is therefore not only concerned with *current* practices, but is also instrumental in imagining future advancements and their moral implications. This imagined future, to some degree, takes place within posthumanism, a field that, while distinct from bioethics, shares many of its concerns and imageries. Both bioethics and posthumanism are concerned with what counts as personhood; bioethics works to delineate it, and posthumanism to expand it. Both fields share a fascination with technological advancements and a relation to the body; bioethics is more focused on regulation, and posthumanism on anticipation. A fundamental difference between the two fields is that bioethics seeks to categorise, while posthumanism aims to destroy boundaries and blur distinctions. However, even within the field of post humanism—and with all of its critical good intentions—notions of responsibility, rationality, and morality continue to hide behind many celebratory anticipations of prosthetic bodily enhancement and cyborg embodiment. We would like to thus venture into this field and problematize the areas in which such biopolitical narratives are reproduced in posthumanist discourse, using fatness as our shining "b(e)acon". Our main focus will be on prosthesis as both metaphor and materiality, and the ways in which, as demonstrated by Harris, it becomes a societal imperative (Harris quoted in Zylinska p. 14). The fat body, as mentioned in the introduction, here serves as the limit case[5] for both posthuman theory and a project of contesting humanity. The concept of prosthesis, as inspired by the works of Jain (1999) and Sobchack (2006), signifies both human enhancement and inhuman differentiation between bodies termed "worthy" or "unworthy" of human life.

Before we continue with our analysis around fatness and posthuman bodies, we feel the need to outline our understanding of what posthumanism is and how bodies and prostheses function within it. There seem to be as many definitions of posthumanism as there are articles about it, and the same is true for approaches to the concept of prosthesis. In *Discipline and Practice: The (Ir)Resistibility of Theory* (2004), Herbrechter and Callus identify as many as six impossible things before breakfast—six types of post humanism—while articles such as Damien Broderick's "Trans and Post" (2013) indicate the tensions that exist within the discipline itself, with representatives of different branches of posthumanism attempting to delineate their approaches and distance them from or position them against those of others.

Our own understanding of posthumanism is informed by several texts, the central of which is Katherine Hayles' volume *How We Became Posthuman: Virtual Bodies in Cybernetics, Literature, and Informatics* (1999):

> "What is the posthuman? Think of it as a point of view characterized by the following assumptions….First, the posthuman view privileges information pattern over material instantiation, so that embodiment in a biological substrate is seen as an accident of history rather than an inevitability of life. Second, the posthuman view considers consciousness, regarded as the seat of human identity in the Western tradition long before Descartes thought he was a mind thinking, as an epiphenomenon, as an evolutionary upstart trying to claim that it is the whole show when in actuality it is only a minor sideshow. Third, the posthuman view thinks of the body as the original prosthesis we all learn to manipulate, so that extending or replacing the body with other prostheses becomes a continuation of a process that began before we were born. Fourth, and most important, by these and other means, the posthuman view configures the human being so that it can be seamlessly articulated with intelligent machines." (pp. 2–3)

The body becomes "the original prosthesis", a body to be manipulated by the subject, according to her or his wishes—a body to be fused, extended, and imbued with social meaning and function. In this sense, we find that there is a definite overlap between what is expected of a *homo economicus* and a posthuman subject regarding their bodies. Where the *homo economicus* is expected to rationally *manage* his or her body in order to secure his or her well-being, the posthuman subject is expected to *manipulate* his or her body in order to remain faithful to the ongoing evolution of prosthetic embodiment.

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[5] A case that tests the theory as well as humanity because of its extreme/special relation to both.

Whereas the *homo economicus* should aspire to maintain his body in the best *possible* condition, the post human subject should now aspire to expand the body to the best *imaginable* position by allowing the inclusion of cybernetic mechanisms. Management refers to reality, to the existing means and resources and their allocation, while manipulation extends management to the realm of possibilities and imagination.

In her article, "The Prosthetic Imagination: Enabling and Disabling the Prosthetic Trope" (1999), Sarah S. Jain argues that the ways in which the trope of the prosthesis is theorised promotes "the notion that the prosthesis compensates for some sort of physical disability—although this disability may be in relation only to the realm of the possible rather than a handicap in the way in which it is classically conceived" (p. 33). Thus, no matter how alluring the idea of a posthuman subject without boundaries may be, it seems that, in many of its appearances, the trope of the prosthesis does not truly transgress or eradicate, but instead reinforces and multiplies the restrictive expectations that surround the neoliberal subject.

As Jain further explains, when used uncritically, the trope of the prosthesis entails two dangerous assumptions: first, that a disabled or non-able body is inherently flawed and needs correction, and, second, that all bodies are potentially disabled when juxtaposed with their posthuman, enhanced possibilities. In this manner, the biopolitical body-machine relation stays firmly in place. The body is still subjected to the same kind of imperative that demands its placement under constant moral, rational, and responsible social imperatives. In the biopolitical context, Skrabanek speaks of super-health (1994, p. 42), and *HFR* positions its viewer between a frumpy Hell and a shiny Heaven. This narrative is present in many prosthetic imaginations, where subjects find themselves not only morally responding to the realm of the possible but also to that of the imaginary. The end result in both cases is a subject with a body machine that requires constant modification. If we were to follow Singer's distinctive logic of the human being versus the person, both *homo economicus* and the posthuman subject would find themselves in a position where they have to *earn* their right to ethical respect while simultaneously struggling to remain within the human category.

Homo economicus is, then, the condition for the human subject, while the enhanced body becomes the condition for the posthuman subject. When the prosthetic imagination is allowed an uncritical and central role in posthuman embodiment, it comes to reinforce the same boundaries posthumanism wishes to transgress while simultaneously strengthening neoliberal narratives that oppress the body. Again, the posthuman subject needs to be rational and recognise its insufficiency compared with its prosthetic capabilities. It must be responsible, and take action towards achieving its potentiality. Finally, it must be moral, as morality requires one to combine rationality and responsibility. If it seems we are vindictively rubbing our hands together, it is because—metaphorically—we are. Return to our reading of the *HFR* image and its positioning of the viewer as neither in Heaven nor in Hell. Now add posthuman fantasies to the mix, and we get a highly satisfying procedure when the aim is to blur categorical boundaries. With prosthetic enhancement at the centre of current bioethical discussion, Jain's argument demonstrates how easily the perceived viewers of *HFR* can slip from their comfortable Purgatory straight into Hell if they fail to adapt and rationally respond to this renegotiation of neoliberal ideology. In the health/fitness versus illness/fatness schema, viewers can feel confident in their responsibility, rationality, and morality. This time, however, when responsibility, rationality, and morality are expanded *ad infinitum*, where do viewers find themselves on the human vs. failed human scale?

In *The Fat Studies Reader* (2009), Marilyn Wann describes fat/fatness as "a floating signifier, attaching to individuals based on a power relationship, not a physical measurement" (p. xiv). In this paper, we attempted to paint a prosthetic nightmare. We took the theoretical characteristics of the prosthetic trope, turned them around, and demonstrated how they can be applied in imagining a prosthesis that renders the body, and thus the subject, not more, but less human. By positioning fatness as itself a kind of "prosthesis", we intended to point out how—if we add posthumanism to neoliberal ideals—a fat subject can crumble beneath the weight of her or his now supersized, double failure. As *homines economici*, fat subjects fail to optimally manage themselves; as posthuman beings, they fail to adapt to the ever-growing, accelerating capabilities of the human body. Unlike most prosthetic narratives, the fat body as prosthetic embodiment is no longer something that makes the body faster, stronger, and more productive, thus 'improving' it, but something that hinders its productivity and reflects negatively on its owner's ability to successfully manage and manipulate the body's own place in the category of the human.

4. Conclusion

In conclusion, we will attempt to paint a hopefully less nightmarish image of contested humanity by proposing an outlook for the development of different strands of embodied theory that take seriously the impact critical versions of posthumanism and disability theory may make on dominant bodily beliefs and practices. We want to ask what, if anything, could a critical posthumanist and disability studies approach inject into the just painted nightmare? Certainly the most productive theoretical contributions to challenge neoliberal biopolitics have come from critical engagements with marginalised embodied experience and subjectivity, such as in feminist, queer, critical race, and disability studies. However, as recent trends in interdisciplinary humanities research have proven (new materialism, critical posthumanism), an engagement with the non-human, material, animal, planetary, and ecological entanglement of human bodies with the world is similarly crucial to a critical discourse of human life.

What this paper attempted was a dialogue between embodied human difference and more-than-human material practices (technologies) as they have been powerfully incorporated into neoliberal ideology. What remains to be further explored and—hopefully—critically embedded in a future body-politics is a discourse that contests more concretely what Astrida Neimanis has described as “a neoliberal, individualistic reproductive imaginary of commodification and amnesiac bioscientific progress” (2014, p. 109), which fosters discrimination against bodily difference and is primarily focused on preservation of the self-same. A counter-discourse will need to take a critical stance towards all-too-human, rational, technical, progressive, and linear expressions of human futures, and take seriously a more-than-human, affective, transcorporeal, elusive, and messy imaginary of embodied lives.

Fat studies, disability theory, and a critical take on posthumanist theory are but a few ways to sketch a more inclusive future for those who contest not humanity as such, but a neoliberal propagation of seemingly humane cultural practices.

Conflict of Interests

The authors declare no conflict of interests.

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Article

Differences in Itself: Redefining Disability through Dance

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Abstract

This paper brings together two different terms: dance and disability. This encounter between dance and disability might be seen as an unusual, even conflicting, one since dance is traditionally dominated by aesthetic virtuosity and perfect, idealized bodies which are under optimized bodily control. However, recently there has been a growing desire within dance communities and professional dance companies to challenge binary thinking (beautiful-ugly, perfect-imperfect, valid-invalid, success-failure) by incorporating an aesthetic of difference. The traditional focus of dance on appearance (shape, technique, virtuosity) is replaced by a focus on how movement is connected to a sense of self. This notion of the subjective body not only applies to the dancer's body but also to disabled bodies. Instead of thinking of a body as a thing, an object (Körper) that is defined by its physical appearance, dance is more and more seduced by the body as we sense it, feel it and live it (Leib). This conceptual shift in dance is illustrated by a theoretical analysis of *The Cost of Living*, a dance film produced by DV8.

Keywords

dance; difference in itself; disability; Körper; Leib; lived body; lived experience

Issue

This article is part of the issue "Humanity as a Contested Concept: Relations between Disability and 'Being Human'", edited by Paul van Trigt (Leiden University, The Netherlands), Alice Schippers (Disability Studies in Nederland, The Netherlands) and Jacqueline Kool (Disability Studies in Nederland, The Netherlands).

1. Introduction

It is a surprising fact that philosophers and cognitive scientists took quite a long time to acknowledge the importance of the body. The devaluation of the body governed most metaphysical thought and perhaps even most philosophical thought until at least the time of Nietzsche. More recently one can see an explicit and nearly universal rejection of Cartesian dualism (Gallagher, 2000). The body has been reinserted into philosophical thinking and it's now widely acknowledged that the body is crucial for our intersubjective being in the world.

If the 'normal' body is now appreciated in philosophical thinking, the disabled body is, however, still negated and ignored within a society of normalization (Foucault, 1980). "Disability is a deeply contested term used to describe individuals (or a people?) that are in a position of difference from a centre" (Kuppers, 2003, p. 5). The term disability is associated with disease, illness, tragedy, and loss. The term is not value-free: alongside the benefits, stereotyping, harassment, and hatred are still commonplace.

Even more importantly, the body of the disabled person is largely absent in Western theatrical dance. The disabled body is marginalized within the predominantly able-bodied dance community. Western theatrical dance has traditionally been structured by a very narrow vision of a dancer's body (white, long-limbed, flexible, thin, able-bodied) and by strict aesthetic structures and representational codes that suppress and devalue bodies that don't fit into normal categories.

This paper addresses the need to incorporate the disabled body in Western theatrical dance discourse, specifically with regard to screendance. For too long the focus has been on idealized bodies that strive for perfect bodily control and that move within the vocabulary of standardized aesthetic movements. It is time to rethink these normative aesthetic standards and to include a diversity of bodies with idiosyncratic movement styles, in order to embrace differences. By deconstructing traditional representational codes of Western theatrical dance and by showing other bodily realities, we can redefine and enrich our notion of the 'normal' body.

Despite its bodily regimes, dance can also provide opportunities to question cultural and normative standards of what a body should look and feel like. In daily life our bodily experiences are hidden below the surface most of the time. In dance however, we share the bodily, that is, we share somatic experiences in a playful, imaginative, and expressive manner.

Dance is a social encounter: it's a place where we share meanings with each other on a bodily level. It's a place where the private and the public meet (Kuppers, 2003). Dance mediates and has the power to construct and deconstruct social meanings; it has the potential to create spaces in which fixed identities and normative standards suddenly become unstable and uncertain. This is due to the fact that dance produces embodied, living knowledge that is always in flux:

> "The intersection of dance and disability is an extraordinarily rich site at which to explore the overlapping constructions of the body's physical ability, subjectivity, and cultural visibility that are implicated within many of our dominant cultural paradigms of health and self-determination." (Albright, 2001, p. 1)

The dance film *The Cost of Living* (2004) by DV8 is an example of this potentially rich encounter between dance and disability. The film is an adaptation of a stage production that takes David Toole, a double-amputee dancer, as its main character. In line with Overboe (1999), I will argue that the lived experience itself offers a radical way to explore disability in terms of differences, subjectivity, and cultural visibility. Watching a disabled dancer like David Toole forces us to see with "a double vision, and helps us to recognize that while a dance performance is grounded in the physical capacities of a dancer, it is not limited by them" (Albright, 2001, p. 1). I will use the terms Leib and Körper (Overboe, 1999) to analyze the way in which, in the dance film, we slowly move away from objectified standard bodies—bodies as efficient machines—to lived bodies that are made of flesh, are real and that are different in themselves.

The following research question is central to this paper: How can we rethink disability within the field of screendance by using the phenomenological notions of Leib and Körper? I will first discuss the theoretical difference between Leib and Körper, two concepts that are embedded in the phenomenological tradition. Then I will discuss how the intersection of screendance and disability can be an extraordinary site to explore these two concepts (Leib and Körper). Subsequently I will discuss three scenes from *The Cost of Living*: in all these scenes we—as spectators—experience a shift between Körper and Leib. In the conclusion, I will return to my research question and discuss how the notion of Leib can draw attention to an aesthetic of difference in dance. An aesthetic that incorporates a diversity of bodies: bodies that tell their own lived narrative.

2. Leib and Körper

Looking intuitively at these two concepts, saying them aloud and listening to them carefully, the concept of Leib has a more personal connotation, while Körper coincides with the objective, anatomical shape of the body:

- A Leib can be imperfect: with scars, birthmarks, fat, wrinkles, a missing leg, a crooked back;
- A Leib is a unit, self-awareness without distance, the familiar without alienation;
- A Leib is the inner-felt, lived body;
- A Leib is the experience of sensing oneself as being sensed (Slatman, 2007, 2009);
- A Leib is a way of being, an existence in the world, while Körper, under the influence of normative standards, becomes a suit in which a human being exists on earth (Wijk, 2014).

The concepts of Leib and Körper both find their origins in the phenomenological tradition (Overboe, 1999). According to Husserl and Merleau-Ponty, Körper refers to inanimate life—the Cartesian res extensa—while Leib indicates the contrary, namely, animated life (Slatman, 2007). Körper is the image of the body. Körper is the body that is seen by others, an object, a thing with physical qualities, while the Leib is the body that I experience, a physical experience of being me. Slatman (2009, p. 120) describes the distinction as follows: "The Körper is the body that is seen, and the Leib is the body that is seeing. My body is not only a thing that can be seen but it is also seeing. It is a Leib because this 'seeing', while entangled with movement and space, is not a (Cartesian) mental way of seeing, but rather an embodied seeing". In other words, a Leib refers to my own living body as I experience it from within, while the Körper refers to the body that is being seen from the outside.

Disabled bodies in our society are often perceived in terms of Körper. By opposing the disabled to the abled (the abnormal versus the normal), the disabled body is reduced to a thing to be looked at, even stared at. Under the gaze of the social other, the disabled body is constructed and filled with pre-existent expectations and by stereotypical thinking. This results in a process of exclusion: the disabled body is reduced to a predetermined subjectivity that leaves no room for the ground-zero experience of the body as a Leib (the body that lives, experiences, and resonates with others). According to Overboe (1999), the concept of Körper reduces the handicapped body to a classification that has a normative effect. The outer appearance of the handicapped body determines its value: from imperfection, a lack of control of the body, and vulnerability, to pain and death, or the heroism of people who have conquered their handicap. In this way, handicapped people are depicted as less human or too human, but rarely as ordinary people who do ordinary things and have ordinary desires (Oliver, as cited in Overboe, 1999).

However, there is more at stake here. Firstly, the normalizing external gaze forces people with a disability to 'have' a body, that is, to relate to their own body as being a Körper. Secondly, everyday routines no longer serve as a way to relate subconsciously to their own body (the body as a Leib) or as a way to sense the body in a pre-reflective state. Daily bodily habits and routines usually force the body into pre-subjective agency—in affects and sensations. In encountering the daily environment, the body responds in ways that are unnoticeable or undetectable by the conscious mind (Berger, 2013). However people with a disability are often forced to relate consciously to daily routines because of pain or the effort it requires to accomplish certain actions (such as taking a shower, going to the toilet, getting dressed etc). Access to the pre-reflective experience of the body is not easy for people with a disability. Although new routines and embodied ways of being may be developed over time, this requires a negotiation between the body and the environment and often forces the embodied experience to become reflective and subjective. Dance can help gain access to purely physical sensations, affects, and embodied intensities (in experiencing the body as a Leib). This is not to say that dance can solve the complex relationship between being disabled and the suppressing forces of the social environment but it can be helpful in tuning in to the inner-felt dynamics of the body as it is lived and experienced.

3. Dance, Screendance, and Disability

Dance is the art form par excellence in which communication takes place on a non-verbal level. In dance we engage with ourselves and with others through the kinesthetic (Daly, 1992; Smyth, 1984). This experience is a first-person experience, that is, we live the movement and as we live it we understand it and give meaning to it. Experiencing self and others—in and through movement—also includes the intentions and affects that flow back and forth between the agents that are involved. Kinesthetic experiences are thus always connected with a sense of self and a sense of otherness.

Foster (2011), Reason and Reynolds (2010), and Wildschut (2003) speak of kinesthetic empathy when referring to the embodied empathic process that takes place within the spectator. They refer to the inner-felt physical sensations that are evoked in the spectator while watching/experiencing the dance performance.

This paper takes *The Cost of Living* as its departure in order to investigate the kinesthetic experiences that are evoked by screendance. Although cinema works differently to live performance events, kinesthetic empathic processes are still at work here. D'Aloia (2012) states that in film the spectator interacts with a series of quasi-bodies. "The film images are celluloid bodies that, nonetheless, express vitality thanks to their movements and their resemblance to human bodies and movements" (p. 95). Kinesthetic empathy is awakened in the spectator "by the film's mediation (in the double sense of keeping separate and putting in contact) between the two lived-bodies, although that of the character is only a quasi-body" (D'Aloia, 2012, p. 980).

In dance films the experience of both our own body and the on-screen body is thus not only visual-perceptual but also empathic and kinesthetic. Kinesthetic empathy is triggered by the expressive properties of film: through the visual, the auditory and through physical and technical camera movements. Furthermore, as Wood (2016) says:

> "The connection between the spectators and performers is affected by embodied imagination and the haptic visuality of the image. The viewers connect to the images on screen through their corporeal knowledge and kinesthetic sensibility to surfaces and gravity." (p. 250)

Three different elements can be distinguished in dance films that evoke empathic, kinesthetic reactions in the spectator: (1) narratives, (2) filmic techniques, and (3) synchronicity in movements (D'Aloia, 2012; Wood, 2016). Firstly, narrative structures are used in screendance to engage the spectator in an embodied way. Through narratives, the spectator relates personal bodily experiences to the bodily movements that are being seen on screen. Secondly, filmic techniques create a visual atmosphere that brings the spectator to a heightened kinesthetic state. Lastly, kinesthetic experiences are evoked by the synchronicity of the dancer's movements. "The spectators participate in the uplifting feeling of the movements and respond in an immediate emotional manner" (Wood, 2016, p. 251). These three elements will be used later in order to analyze several scenes in *The Cost of Living*.

The way in which the spectator relates to disabled dancers on screen is still a point of discussion. One might say that people with disabilities are already being staged in daily life (because of the normalizing, external gaze of the social other). I will argue in this paper that screendance offers possibilities for the opening up of new registers of meaning-making that force the spectator to look and engage differently with disabled people. The disabled body in dance films manifests itself through perceptual experience—not as an object among objects but as a bodily subject (Thompson, 2005), not as a Körper experience but as a Leib experience.

3.1. An Example: The Cost of Living *by DV8*

I will illustrate the difference between a Körper experience and a Leib experience within dance by analyzing three scenes from the dance film *The Cost of Living*. This dance film was made in 2004 by DV8 Films Ltd. Although it was produced some time ago, the film still has not lost its relevance. The film was directed by Lloyd Newson, the founder of DV8 Physical Theatre, and combines dance, physical theatre, and dialogue. The movie is located in Cromer, a seaside resort town, at the end of the summer season. *The Cost of Living* is a dance film in which David Toole, a double-amputee dancer, plays the lead.

> "David Toole, a disabled British dance artist, performs in *The Cost of Living* (2004), conceived and directed by Lloyd Newson, based on his earlier stage production. The film runs for thirty-five minutes and tells a story of two men who are street performers in an end-of-season English seaside resort. The locations are various and shift between urban, rural, domestic, and public sites. The narrative develops around the men's relationship, their encounters with others, their attempts to attract women, their vulnerabilities and insecurities, as well as their tactics for survival." (Whatley, 2010, p. 45)

The director Lloyd Newson states that the dance film is about those people who don't fulfill our societal criteria of success. He asks himself what happens to those people who don't fit in to the categories of success and perfection. Although Toole is the only dancer with an overt physical disability in this film, he is primarily a dancer among dancers. All the characters in the film have their own individuality, their own way of being, and their own autonomy, which make them all slightly different to what is perceived to be the 'normal' or 'the average'. According to Whatley (2010), the film is so powerful because "it is located in bodies and bodily sensation that might be characterized as excessive" (p. 45). The film also blurs the boundary between fiction and reality (another example of binary thinking). Eddie and David are the real names of the main actors. Throughout the film it remains unclear whether the dancers play a character or are 'just' being themselves. The film lasts 35 minutes and is so rich in detail and narrative that just giving an overview would not be sufficient. I would therefore like to focus specifically on three different scenes, which I will henceforth refer to as the ballet scene, the film scene and the choreographic scene.

3.2. The Ballet Scene

The scene occurs halfway through the film. We have seen David and his friend Eddy at the seaside, in their apartment, in a bar, on the street, and together on an autoped, as well as having fun by racing with the wheelchair through the streets and accidently bumping into people.

The ballet scene starts with a close-up of the feet of ballet dancers who are doing exercises at the barre. We hear piano music in the background and the ballet teacher counting 'two-three-four and-one'. The feet move in complete unison. They start with a battement tendu, pushed sideways on the ground, with the right leg, followed by a battement glissé with a petit battement, then move to the left leg using a grand plié. Finally, the feet turn to the other side to continue the exercise. The dancers all wear classical outfits: pink tights, ballet shoes, and a black leotard.

In the next shot we see David Toole outside, on a summer's day, with casual black trousers (cut below the upper part of his legs) and a black shirt, looking in at the windows. They are a little too high so David has to lean with his arms and lift himself up from the wheelchair in order to see what's happening inside. Eddie joins him at the window. David then decides he wants to go in to join the dancers in the studio.

He moves out of his wheelchair and walks on his hands into the studio. The dance class is still going on: some dancers are doing exercises at the barre, others are stretching their bodies and chatting to each other. David moves inside and we see him moving through a mass of pointing legs. The music changes: the violin indicates a change in atmosphere. A different body has entered the space.

Suddenly the dance studio is empty except for David and a female ballet dancer. A dance duet unfolds between David and the classical dancer. It is a modern dance duet in which David and the female dancer move under and over each other in a playful, fluent and soft manner. In the corner we see another female dancer, a silent witness, who is now doing modern exercises. She is looking outside and so completely ignoring the dancing couple. David and the classical dancer move through the studio using the ground, they move in and over each other, stretching, lending and giving weight, and supporting the other. The camera moves to the right and we see another (fourth) dancer stretching his legs.

The female dancer suddenly interrupts the dance duet and walks over to her stretching colleague, leaning informally against the wall while they start chatting with each other. We then see Eddie, who is still an observer from the outside, pointing to David and inviting him to come outside. David leaves the studio. We hear a door opening: a sound that marks the end of this scene.

The scene is very rich in symbols and they will not all be identified here. An important element is the notion of moving inside at the beginning of the scene (entering the studio space) and moving outside at the end of the scene (entering the real world again). This can be interpreted as a movement that indicates a shift between the body as it is perceived from the outside (Körper) to the sensed, internal body (Leib).

When David and Eddie look in at the window (they are literally observers from the outside) at the ballet dancers inside, we see only Körper: idealized bodies that move in unison, with a culturally defined aesthetic. Perfect bodies, perfect shapes that move in a perfect way. Bodies are treated as objects here.

However, when David enters the dance studio (when he literally moves inside) and the violin emphasizes the moment, we suddenly move to an embodied first-person perspective. The change from a classical dance vocabulary to a modern dance vocabulary can be seen as a disruptive symbolic element, as can the abandonment of unison movements; both mark the end of the Körper experience. Bodies are no longer treated as objects but as dynamic entities, always in a process of becoming, open to difference, moving into fields of affectivities. At this moment, as spectators, we are no longer involved in a Körper experience, but we are engaged in an embodied, sensed sense (a Leib experience). The fact that the other dancers in the studio—the silent witnesses—ignore the dance may contribute to this shift. Since the stretching dancers in the studio are not looking, we as spectators are invited to look. However, the way we look at this scene is changed by the (ignoring) attitude of the silent witnesses: apparently the scene is not that important, perhaps it is too ordinary (Whatley, 2010). As a result, the spectator's dominant gaze is interrupted and instead the spectator is invited to use different ways of looking (namely seeing, feeling and sensing). The ignoring attitude gives room to the spectator to come closer, to enter the private, to become intimate.

Filmic techniques such as changing the camera's viewpoint (first filming from the outside to the inside, then only inside and finally filming from the inside to the outside) mark the shift from Körper to Leib and back to Körper again. In addition, filming close to the floor provokes a feeling of gravity and weight in the spectator: this feeling of groundedness stimulates kinesthetic sensitivities in the spectator. Furthermore, the looking away (the ignoring attitude) of the silent witnesses in the dance studio serves as a gateway for the personal and the intimate. Finally, the shift from ballet to modern dance vocabulary can be seen as a movement away from normative, standardized aesthetics towards an aesthetic of differences.

3.3. The Film Scene

In another scene we see David in front of a building on a green field, sitting on the grass, without a wheelchair. He is alone. He has his sunglasses on. We hear the sounds of seagulls flying over. The pleasant, joyful music 'Do you believe in life after love' by Cher is replaced by sinister sounds. The last phrase of the song—'cos I know that I am strong'—resonates in our heads. The cameraman walks into the scene and approaches David in an aggressive and direct way. The deep, sharp shadows of the cameraman fall over David. The cameraman moves in circles around David. The cameraman is too close. He invades David's space, subordinates him. His gaze turns him into an object, a thing to be whipped at. The cameraman stands while David sits on the grass: the scene is shot from above, so that the cameraman looks big while David himself looks small.

The cameraman now enters David's personal space. He touches him but it is not a nice, gentle touch. The cameraman begins to ask David intrusive questions. David in return reacts through movements that are simultaneously vulnerable, avoidant, and compliant.

> "Can I ask you a question? What happened to your legs? Were you born like that? Or did you have them chopped off? Do you have an ass-hole? Or do you shit through your back? How do you go to the toilet? Can you masturbate? Seriously, I want to know. What's this lump on your back? Do you blame God for being born? What are these (touching his stumps)? Are they stumps? Do you have any friends? Have you ever been in a fight? Have you? If you hit me first, it's okay if I hit you back, isn't it? 'Cos you're a man. Do you trust me? 'Cos I don't trust you."

Then the cameraman walks out of the scene. David lies down on the grass.

The gaze of the cameraman places David under observation and causes him to experience himself as an object that is seen by others. In Lacanian terms (Lacan, 1964), David knows that he is being looked at and the gaze here alienates David from himself. The cameraman symbolizes the all-seeing eye that captures him and turns him into an object. The gaze denies his full subjectivity: David is reduced to an object and in this act he becomes alienated from himself. Little details all contribute to this process of alienation: David's sunglasses; the circular movement (the cameraman approaching David, David turning away); the harsh lighting with deep shadows; the whole scene shot from above (making David look small); and David's silence (not answering back). Here we, as spectators, experience the way in which David is reduced to a Körper.

Filmic techniques and narratives (the interrogation) are used in this scene to produce defamiliarization and alienation in the spectator. As spectators we feel uncomfortable and ashamed and not only because the cameraman invades David's space in a harsh and intrusive way, thereby completely denying his lived subjectivity. There is more involved here. Through the harsh interrogation, a narrative is constructed in which we, as spectators, have to position ourselves politically and move away from the normalizing, imposing gaze and towards a gaze that leaves room for the personal and the subjective. As spectators we not only feel shame, embarrassment and discomfort but also feelings of responsibility and guilt are produced. The cameraman serves as a symbol for our society: he is a symbol of the external, normalizing gaze that turns the disabled person into an object and denies him full subjectivity (that is, humanness). In this scene we, as spectators, are forced into feeling responsible for the societal, normalizing gaze that is (this must not be forgotten) created and mediated by all of us.

3.4. The Choreographic Scene

David is alone again. He sits on the grass and takes off his sunglasses. Music starts, an accordion makes a recognizable and human sound. David lifts himself up and does his now ‘typical walk’: moving on his hands, while his back and stumps swing from side to side. This scene is shot on a small hill. Casually dressed dancers suddenly and unexpectedly appear from under the hill, joining him in this dance, in his typical movements. The female and male dancers all move from one arm to the other, dragging their seemingly lifeless legs behind them. This is a powerful scene since ‘difference in itself’ has been taken here as a way to connect bodies. Here we encounter ‘otherness’ as a powerful force, as an aesthetic of difference, as Leibs that move together, as Leibs that celebrate the lived experience. We encounter here a collective of difference, all moving in unison, a sameness that nevertheless has its origin in difference.

The dancers collectively make variations on David’s movements: they roll on the ground, spreading their legs, hopping from one side to the other, then turning again, standing on their feet, swinging their left leg, moving to the ground again, lifting the other leg over the body, sitting with their legs in front of them while walking with their arms, getting up again etc. It is as if they are finishing David’s movements and in our imagination we can see the endless possibilities, the potentialities, of David’s typical walk.

Finally, the dancers move backwards. David by now has disappeared from the scene. The dancers have returned to David’s typical walk: walking on their hands, dragging their seemingly lifeless legs behind them. One by one they disappear under the hill, where they are no longer visible to us, the spectators. David returns and he is the last one to leave the scene.

We see the cameraman walking away with the camera in his hand. He is no longer filming. He looks back and we hear the accordion music at the same time. This scene clearly symbolizes the defeat of the all-seeing eye: subjectivity is restored and the lived experience has been foregrounded. A disabled embodiment and sensibility is validated (Overboe, 1999). We, as spectators, are invited to rethink disability by leaving representation and categorical thinking aside, and by recognizing the lived experience of disabled persons.

In this scene the synchronicity of movements invites the spectators to tune in to David’s private experience of being his body. The synchronicity evokes a feeling of pleasure that subsequently allows the spectator to be “bodily carried away by an escapist flow of movements, while for another it is to feel viscerally involved in an awareness of effort, muscle and sinew” (Reason & Reynolds, 2010, p. 72). The feeling of pleasure raises awareness in the spectator that different self/other relations between spectator and disabled persons are possible and desirable. Furthermore, by multiplying David’s personal movements, an aesthetic of distance as well as an aesthetic of intimacy is created. This double movement of distance and intimacy gives access to pre-reflective experiences, such as physical sensations, affects, and embodied intensities. The synchronicity of movements introduces an aesthetic of differences.

4. Conclusion

At the beginning of this paper, I asked myself the following question: How can we rethink disability within the field of screendance by using the phenomenological notions of Leib and Körper? *The Cost of Living* is an example of how an aesthetic of differences can be communicated in dance: the film deliberately questions the dominant aesthetic of dance by shifting attention away from perfect, fictitious, idealized bodies to bodies that are real, ‘excessive’ and different in themselves.

However, some criticisms should be noted. Firstly, the film (subconsciously) seems to assume an abled spectator. The fact that David is the only disabled dancer among abled dancers makes his position ‘special’ and possibly evokes feelings of pity in the spectator, as well as an acknowledgement of heroism. In both cases, the reality of Toole’s disability is denied: the body is again reduced to a thing.

Secondly, the danger of analyzing *The Cost of Living* in terms of Körper and Leib could easily produce another binary way of thinking. This is not desirable. Slatman (2009) states that Körper and Leib are two interrelated concepts. The body as it is lived and sensed is not closed up in itself but is embedded in the outside world. Images of how the disabled body is looked at (from a societal perspective) thus merge with inner body images. Together they constitute bodily subjectivity. Although for the sake of argument I made a sharp distinction between Körper and Leib, these two concepts are closely interrelated. Its relationship, its difference in itself, constitutes bodily experience. The place where Körper and Leib meet is where an aesthetic of difference can arise.

Thirdly, *The Cost of Living* blurs the boundaries between fiction and reality. However, the film depicts David Toole as more real (hyperreal) than the other dancers. Toole performs his “own narrative, his own authentic biography” (Whatley, 2010, p. 45) while the others play more fictional characters. Although the authentic touch allows the spectator to come close and enter the private and the intimate, it also puts Toole in an unequal position.

Despite its limitations, *The Cost of Living* sheds some preliminary light on how we can shift our attention from a disabled body that is captured in a Körper experience to the opening up of new, radical spaces that invite us to look at each other in terms of subjectivity, the innerfelt, and the reality of our lived bodies. *The Cost of Living* questions the normative aesthetic standard of perfect bodies in dance and invites the spectator to rethink what is perfect and what is not. The film offers us an alternative by introducing an aesthetic of differences.

What I hope to have shown in this paper is that dance can help gain access to the Leib experiences of persons with a disability. A film such as *The Cost of Living* can encourage the acceptance of an aesthetic of differences that gives room to the personal, the sensed, and the lived experiences of disabled people:

> "Rather than an 'equality of rights' based on identity politics, I call for an 'equality of condition' that validates both a disabled embodiment and sensibility. Our physical, mental and emotional manifestations of disability as well as the social, political, moral and physical environment will continue to have an impact upon us. But shifting the notion of an identity which is devalued to a lived experience that is validated causes a change in approach." (Overboe, 1999, p. 23)

Dance can be helpful here. Firstly, because dance is the place where we share and express meanings with each other on a bodily level. Secondly, and more importantly, because dance provides opportunities to establish an 'aesthetic of difference', an aesthetic that communicates embodied selves that live and breathe. Bruce Curtis (1988, p. 18) states that we are all "dancing bodies": we are all bodies that try to let out movements that are joyful, bodies that are vulnerable in themselves, bodies that want to communicate and be intimate with each other on the most basic level, namely by moving with each other. In my opinion, that is what lived experience is all about: the capacity to be moved by movement and be moved to move (Fuchs & Koch, 2014). Dance is within us and between us.

Conflict of Interests

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Article

Challenging Standard Concepts of 'Humane' Care through Relational Auto-Ethnography

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Abstract
What is deemed 'good' or 'humane' care often seems to be underpinned by a standard ideal of an able-bodied, autonomous human being, which not only underlies those 'social and professional structures within which narratives and decisions regarding various impairments are held' (Ho, 2008), but also co-shapes these structures. This paper aims to explore how a relational form of auto-ethnography can promote good care. Rather than being based on and focused toward this standard ideal, it challenges 'humanity' by showing how illness narratives, public discourse, and policy are framed by ethical questions. It illustrates how normative ideas dictate policy and public discourse. It critically questions this constitutive power by shifting attention to the lived experiences of people with chronic illness and disability. By highlighting and reflecting together on the first author's life with a chronic illness and his son's disability, and thereby framing the narrative, it will be argued that, in order to improve care practices, personal illness and disability narratives and the way they interlock with public narrative and auto-ethnographic methodologies should be investigated.

Keywords
auto-ethnography; care ethics; disability; chronic illness; humane care

Issue
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From: Alistair Niemeijer
Sent: Friday 18 October 2014 14:12
To: Merel Visse
Subject: Re: Article auto-ethnography

Dear Merel,

I just wanted to tell you that I have finally read the auto-ethnographic article you co-wrote with Truus, and it made a huge impression on me. On the one hand because it is an account of a fellow researcher, and, as you have pointed out before, not everyone working in academia is willing to tell their own story. On the other hand it is so unique because I have come across so few of these articles before. So many things that were described struck a chord with me, such as the cyclical aspect of having a chronic illness (rather than a linear one) and doing lots of silly things just to 'belong' (remember last conference when I had to sleep on the floor of an empty classroom just to get some rest).

I remember that when I first became ill I had given myself the personal assignment to also create something from this, or to cite the article: 'I'd better do something with it', but in my case also something 'good', whatever that may be. Now, inspired by your article, and spurred on by our other colleagues, I hope to also contribute something, and if you think this is a good idea, I would very much like to involve you (and your expertise) in this. So thanks again for sending me the article, it is very encouraging for me to see that such a unique perspective is actually valued as such.

Best,
Alistair

1. Introduction

This article illustrates and discusses how a relational form of auto-ethnography might promote good care by highlighting the everyday realities of living with a chronic illness or disability. As care ethicists with a strong affinity with Disability Studies, we are always interested in promoting good care and therefore ask whether a relational auto-ethnography on living with illness and disability might contribute towards that aim.

In general, auto-ethnography might be understood as an approach involving autobiography, self-observation, and reflexive investigation in the context of ethnographic inquiry, thereby connecting the personal to the public (Ellis, 2004; Maréchal, 2010; Visse & Niemeijer, 2016). It differs from ethnography specifically in the foregrounding of the researcher's own (private) experiences and subjectivity, as opposed to attempting to limit these. Indeed, as Denzin (2014) has pointed out, any qualitative inquiry which is aimed at social justice (and a more caring society) should 'develop a methodology that allows us to examine how the private troubles of individuals are connected to public issues and to public responses to these troubles' (Denzin, 2014, pp. 5–6). However, as Ellingson and Ellis (2008) have indicated, 'the meanings and applications of auto-ethnography have evolved in a manner that makes precise definition difficult' (p. 449). In this case, the so-called 'private troubles' are those of the first author. The above email sent by the first author to the second author served as a starting point for a mutual, relational endeavor, as opposed to a solitary, non-cultural (thus autobiographic) undertaking. Both authors are care ethical scholars working at a university department. The first author lives both with a chronic illness and a young son with Down's Syndrome in, what Arthur Frank has so aptly called, *a remission society*, where patients are 'effectively well, but could never be considered cured' (Frank, 2005, p. 163).

According to Pols (2013), when care in society 'chronifies', as might be the case in chronic illness and disability, there is a need for new knowledge and new values to re-orient care. Instead of viewing care and treatment as one-time events provided by professionals or short interruptions in the life of one person that ought to be self-managed, Pols argues that it becomes important to look at how care practices are shaped over time and how these might help people live with their illness and/or disability (Pols, 2013).

The emphasis in care ethics lies in the study of everyday care practices in the context of societies, rather than trying to encompass the totality of (a) society. By eliciting critical events of daily routines of people living with disease or disability and the everyday aspirations of caregivers, these studies can inform us about *why* and *how* what might be conceived of as 'good' emerges, and under what conditions (cf. Klaver, van Elst, & Baart, 2014; Pols, 2013). This entails that the accounts and the representations of what currently might be depicted as 'humane' and 'caring' have to be seen against a background of sound (historical) anthropology describing everyday life. Rather than viewing care as 'humane', we deal with practices in which '(hu)man(e)' is produced relationally (Goodley & Runswick-Cole, 2016). Research geared towards the humanization of practices should thus not be simply restricted to theoretical reflection and clarification but should also aspire to make a practical contribution to fostering specific humanization as both an outcome and a process simultaneously (Visse, 2012).

As these social practices change rapidly under the influence of current (political and socio-economic) realities, this means (re-)interpreting these practices through repeated and meticulous empirical research and connecting emerging insights with theory. Consequently, as we aim to show in this paper, this should be done by mapping and comparing ways of living in such a manner that it leads to knowledge about what it means to be human, which is not only relevant to a particular person, but which might also be useful for what happens to others elsewhere. Ultimately we will argue that the 'classic humanist trope' (Goodley & Runswick-Cole, 2016) of a lone, fully functioning able-bodied thinking subject no longer works as an image of what it means to be (a caring and cared for) human, and is therefore in need of other, richer concepts in order to improve practices of care for people with chronic disease and disability.

2. Contesting an Ableist Ideology

What is deemed 'humane' invariably depends on the historical and cultural dynamics of meanings (of life) and constantly shifting articulations of 'humane' in particular settings. This is particularly pertinent in (institutionalized) care, as neo-liberalist policies have urged more and more people living with illness and disability to take control over their own health and life and act accordingly, as independent users and consumers (Teunissen, Visse, & Abma, 2015). Simultaneously, in recent decades, intertwining ideas of self-determination and well-being have received tremendous support in the disability movement and in bioethics, guaranteeing people with disabilities a voice and protecting them against any patronizing and unwanted paternalism. However, less attention has been paid to the ableist ideology which seems to underpin these ideas, including the social structures which influence any form of decision-making (Ho, 2008).

Moreover, an ableist form of autonomy is often only upheld as a form of negative freedom, i.e. the absence of (extraneous) interference or coercion. It contrasts as such with the (ethical) motives of care professionals to involve or engage themselves with others and it has little room for the value of concrete practices and particular relationships (Hertogh, 2010) and still less for sensitivity to 'the complex conditions that actually support the unique identity of those individuals needing … care' (Agich, 2003, p. 134). Consequently such a negative conception of autonomy is hardly useful in formulating an ethics of (chronic) care and reflects the 'idealized paradigm of choice or decision-making dominating ethical analysis' (Agich, 2003, p. 165).

To seriously consider how somebody experiences life, what challenges he or she encounters and, based on this, to think about what it means to care well for people with (chronic) illness and/or disability, implies approaching 'care' from both a more person-centered and relational perspective. Nevertheless, modern care policies seem to presuppose an 'ideal(ized) client/patient', namely an able-minded, autonomous agent who seeks independence and appropriates care services as such. To be able-bodied and able-minded is indeed often the ideal on which meanings of a good life are constructed (Hertogh, 2010; Ho, 2008). These meanings underlie not only 'the social and professional structures within which discussions and decisions regarding various impairments are held' (Ho, 2008, p. 198) but also the aims and 'consumption' of (institutionalized) care services that co-shape these structures. As Goodley and Runswick-Cole (2016) suggest: 'many disabled people have been denied the opportunity to occupy the position of the modernist humanistic subject: bounded, rational, capable, responsible and competent. Being recognized as having these ideals is understandably a big deal (it is a mark of being considered human after all).' However, this raises an important epistemological question: how can people with chronic illness or disability actually be viewed as (more) human if this concept is underpinned by a deficient yet pervasive, 'ableist' humanistic ideal?

Rather than simply looking for what is 'just' or what is 'humane' in a given practice, we would like to argue here that it might be more helpful to shift the focus to what *matters* to the people whose positions (or in fact, human-ness) are contested. In other words, what people care for and about as evaluative beings (Sayer, 2011). But how can this evaluative knowledge be accessed? Auto-ethnography, as an epistemology and methodological approach, might be one possibility.

3. Accessing the Particular

According to Neumann, auto-ethnographic texts democratize the representational sphere of culture, by locating the particular experiences of individuals in tension with dominant expressions of discursive power (Neumann, 1996). Hence, auto-ethnography has a political dimension: it has the potential to reclaim authentic voices which are often less visible (or audible) than those of people deemed 'more able', by introducing (vulnerable) insiders' perspectives on experiencing living with illness and disability. What people care for and about, what they are responsive to, is often not well defined but emerges from a complex sociopolitical process of relating to each other in everyday situations. We can only thoroughly understand the particularities of these situations and the people involved by looking closely at what happens in particular situations and how people experience these occurrences. In order to be able to distinguish an occurrence and an 'event' (or epiphany, in line with Denzin), we need to become familiar with the setting and embody an insider's perspective. As an outsider, we are not always able to determine what events and situations mean; we do not know whether we can actually label any occurrence as an event. Thus, we would like to propose here a *radical emphasis* on the particular. However, in our view, placing the 'particular' at the center should also involve recognizing the sociopolitical and relational nature of knowledge of 'the particular'.

At the same time, we view auto-ethnography as a mutual endeavor: an epistemological approach and a methodology that allows us to examine dialogically the 'radically particular' (Visse & Niemeijer, 2016). It is only through dialogue (not necessarily verbal conversation, but dialogue in the broad sense of an encounter) that insiders' knowledge and experiences of persons can become known. Through dialogue, tacit understandings become visible and can be reflected on together.

Care ethics has always emphasized the importance of voice and dialogue that enables an inclusive (deliberative and responsive) approach. Despite this attention, there is still a lack of in-depth understanding of how to hear particular voices, perspectives and experiences. It is important to acknowledge here that 'voice' is not a panacea. Equally important (one might say requisite) to expression of voice is an audience: voices have to reach those who are willing to listen and reflect on what they are hearing. Consider for example, the following transcript of a recorded reflection by the first author (who shares his voice with a later potential listener, in this case the second author):

> 'I feel really tired today, even though I have had a relatively relaxed weekend. But it is as if I'm constantly short of breath. It started this morning, something

> didn't feel right, and yes, then you immediately start to worry whether this is a sign that you have been doing too much, or that things are worsening again, because I tend to always interpret these things always in terms of progression or exacerbation. And that can be tiring in itself, because sometimes you just want to be tired without there being a dimension of 'this will have these and those consequences' etcetera. Not just for me, but also my family, friends and even colleagues. This is especially difficult with regard to my work—I am actually recording this at work this moment, alone in my office—because you really want to remain productive, effective even and not burden others with your illness. Recording this at least gives me a sense that I am sort of spending my time worthwhile, but when I am tired like this, it is so difficult to work effectively. You tend to linger with certain things, and of course you actually do less, but you're also somewhat irritated with yourself that you're doing so little, showing so little productivity. But, funnily enough, at the same time, you tend to also be satisfied more quickly with doing anything at all, even if it doesn't count as being productive. Now it is always difficult as an academic to pinpoint exactly the productivity of all that I do. Is this recording actually productive? But of course I have set tasks, such as correcting papers, responding to students' emails, that are waiting and I can't seem to come round to today as I have so little energy.'

The above example gives us an insight into the immediate and personal thoughts of the first author, who mentions the fact that he is tired, but also reflects on how this fatigue is reinforced by feelings of not knowing how to interpret it and on what it means for his productivity as a professional. In a certain sense, one might say that he has internalized an all-too familiar discourse which has been prominent in modern Western society and requires people to manage their lives independently and successfully and act as if their lives were an open project (Giddens, 1991). It is also interwoven into policies that are designed top down, focused on efficiency and productivity, and which lack consultation or deliberation with the people they concern. The above example shows that this individualization discourse affects the perspectives and expectations of all citizens, professionals and institutions, including those with a chronic illness and/or disability. As a result, people find themselves in ambiguous practices dominated by policy perspectives aimed at individualization, which may ultimately lead to a more 'dark and political' side of care (O'Toole & Meier, 2003; Visse, 2012).

4. Relational Auto-Ethnography

At this point it is important to reiterate that we do not view auto-ethnography solely as an approach to gain access to insiders' knowledge and experience (i.e. 'voice'), but as a necessary space in which to enter a dialogical learning process regarding good care that constitutes and articulates voices simultaneously. Auto-ethnography fosters learning processes of self-understanding. For example, ethno-graphing illness entails actively interpreting (mapping out) the meaning of illness in cultural contexts. This interpretive 'act' can be seen as an act of caring for the self by being attentive to one's own needs and preferences, and responding to increased awareness of those needs. However, a relational auto-ethnography would also entail caring for others, and being open to others' perspectives in the construction of one's lifeworld. In line with dialogical hermeneutics, the self and the other are not separated, but closely engaged in a dialogical process where the subject matter unfolds in the dialogue (Gadamer, 1975, p. 396). In situations where self and other are related, the process of self-understanding can be seen as constitutive of the dialogue and vice versa.

Sharing experiences with disability or illness in the context of auto-ethnography occurs between people who are seen as *inter*dependent beings. Only one person articulating experiences while the other person 'captures' or asks questions does not foster a humane practice and might even lead to what Guba and Lincoln (1989) have dubbed 'malconstructions' of people's perspectives. For instance, social activist and critical thinker bell hooks (Gloria Jean Watkins) has questioned the academic's engagement with the Other, and argued that, to truly engage, the academic would have to remove him or herself as 'the expert' at the center of the relation, in order to avoid 'colonization' of the Other's own story:

> '[There is] no need to hear your voice, when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still author, authority. I am still [the] colonizer, the speaking subject, and you are now at the center of my talk.' (Hooks, 1990, p. 43)

Accordingly, *how* people respond to and engage with one another will ideally always occur from a stance of openness to genuinely understanding the other (Gadamer, 1975, p. 390), despite possible conflicts or disagreements. Only in this case can auto-ethnography be seen as a praxis of care (Visse & Niemeijer, 2016). According to Gadamer, the process of accessing and widening one's own point of view is always dialogical. Through dialogue, people articulate, explore, interpret, 'test' and transform their experiences. This does not happen intentionally, but occurs in and through conversation and encounter. This means we cannot control or influence understanding deliberately. We can however, be open to understanding, by listening to the other and being prepared to move into a shared dimension of meaning: 'The prejudices of the individual, far more than his judgments, constitute the historical reality of his being' (Gadamer, 1975, p. 245).

In the context of care, personal meanings, empathic understanding, suspension of judgment, and apprehending the other's reality as a possibility are necessary for auto-ethnography to foster care (Noddings, 1984). For instance, the second author of the article tries to make sense of the experiences of the first author, writing to him the following email:

> From: Merel Visse
> Sent: Saturday 3 January 2015 16:15
> To: Alistair Niemeijer
> Subject: after having read your transcripts.
>
> Dear Alistair,
>
> Intrigued I read your transcripts (1 t/m 6). A few times I lay them aside and picked them up again. Finally today I could see a recurring theme through all of it….Of course, I am writing this with a large disclaimer: this is my interpretation or lens. So please tell me if this does not resonate with you.
>
> When I was reading I was constantly asking myself: who is telling the story? This is Alistair, he is writing in the first person. But then: Yes, but which Alistair? It was as if I could read different selves, or voices from the same one Alistair. Often you start the sentence with 'I'…and then a personal experience is recounted. But then, and you also mention this, you start to evaluate these experiences. It is as if you're an ongoing evaluator.
>
> So I started to wonder: who is this 'self' which is evaluating, or which voice is actually speaking? At times you also write about different positions of this 'self', although these are not always clearly present, but at times you seem to transcend all of these 'selves', reflecting on a certain meta level on how you are telling your story. When you are recounting, you often tend to position yourself (explicitly) in relation to others. Now from a care ethical perspective this is not strange, but you seem to do this very explicitly. Whether you are not 'a burden', or 'a bore', or whether you can 'fulfill certain expectations' etcetera. At the same time you have also mentioned loneliness and intimacy (of which the latter actually seems to point to a warm relation with yourself).
>
> To sum up: perhaps it would be useful to distinguish between these 'multiple selves', each with their own positions (in time, but also with regard to others) and the conflicts between these positions, including the relations and meanings that are involved?
>
> One of the reasons this might be useful is that it could lead to a (care ethical) redefining of for instance 'self-management'….because, as you have shown, self-management would then not make any sense, because there is not simply 1 self.
>
> Let me know what you think!
> Best,
> Merel

An important insight that comes to the fore here is the fact that people with a chronic illness are not simply patients, but also partners, colleagues, consumers, and soliloquists. Once they make a decision concerning treatment or care, we should ask: which self (if not a combination of multiple selves and/or multiple discourses) is making this decision? And how does it contrast with what the other self would prefer? This is in strong contrast with the dominant conceptualization of man and society stemming from liberal political theory, which projects people as individuals who are independent and self-sufficient, and portrays the ideal relationship in more or less contractual terms, where people act as equal citizens within a public realm (Agich, 2003; Hertogh, 2010; Nussbaum, 2006; Tronto, 1993). It is highly questionable whether vulnerable people with an illness or disability, if indeed any of us, meet this idealized assumption of being totally independent and self-sufficient, or whether this is not simply 'a mere fiction' (Kittay, 2011, p. 51). Indeed, should being human be seen not as singular, but rather as polyvocal? If this is the case which self is ultimately responsible? And which self has priority in making 'informed' decisions?

Nevertheless, rational choice and independence is still the predominant approach in dealing with normative issues in care and this has several important implications for people with chronic illness and disability. Firstly, this emphasis on independence leads to a discourse in which ‘the language of rights eclipses other ethical language’, as care is primarily thought of in terms of problems which can be regulated and dealt with by establishing rights (Agich, 2003). However, it may also create a backlash against dependence of any sort, with those in need of care susceptible to the pejorative meanings associated with illness, dependence or disability (Agich, 2003; Hertogh, 2010). This can occur despite the fact that there is a growing interest in patient experiences and patient stories, as the following fragment of a recorded conversation between the authors examines:

> Alistair: what I seem to miss in those patient stories, particularly of those living with inflammatory bowel disease (IBD)—and there is plenty of material, patient blogs and vlogs, several books etc.—is that it often stops at the toilet door. You can never look behind the door. The way experiences are told are in a sort of remote way, sometimes even in third person. So if you tell people more graphic experiences about pooh and diarrhea, which is an integral part of this disease…well then.
>
> Merel: you open up the conversation, because all conventions suggest ‘one shouldn’t talk about these things’...?
>
> Alistair: Exactly, and in public discourse certain diseases seem to be more interesting or more ‘sexy’ to talk about, such as certain forms of cancer tend to be in the media more than other forms, which is not always dependent on the number of people with this illness. For instance, what I find quite remarkable is that my son’s disability is much more well-known than my own disease. When I say that my son has Down’s Syndrome, I don’t really have to explain myself. Yes, of course there are all these misconceived notions and ideas about this disability, but most people seem to have at least a basic idea of what it involves. Whereas when I mention I have Crohn’s disease, half of the time people haven’t even heard of it. Even though the IBD population is much larger! I think this might be related to the somewhat embarrassing aspect of this disease, plus the non-visible aspect. It is kind of an elusive or incomprehensible type of illness. In my experience, many people are always very surprised when they learn I have this illness. I remember when we went to that conference in Stuttgart, when I was still in the midst of a flare up and at some point somebody asked me whether I had the ‘flu...I don’t mind it that much, and kind of understand it, because if you don’t see it, then, well...I realize that when as colleagues you still receive coherent, ‘semi-intelligent’ contributions from me, that this doesn’t match up with somebody who is very ill at that particular moment, maybe the expectation of people is that my contribution would be something less coherent. That in a sense you’re only ill when you’re also ill on an intellectual level, even though you know from your work with Truus that this doesn’t really matter.
>
> Merel: So you are giving the illness a face? Or actually several faces, including the public face, the intellectual side of things, but also the raw side, the so-called ‘dirty’ side of things?
>
> Alistair: I suppose yes you could say, that some of these sides tend to come to the fore more at particular moments more than other sides, but what interests me as a researcher also is which side to focus on.
>
> Merel: I have always had the impression with Truus, but also with other students, that whatever you are going through, there are always multiple parallel processes going on at the same time and you can’t capture these completely but you might gain some access to some, but only if you study this on a very small scale, as opposed to large studies of patient experience.

Auto-ethnography is a way to acknowledge the many sides of the illness experience, both public and private, and to make them visible and known. This is a practice that honors people as capable; for example the first author’s ability to function well as an assistant professor despite his illness. Simultaneously, such a practice also respects people as vulnerable beings, with everyday difficulties such as anxiety about the presence of blood in their stools or explaining to others what it means to live with the disease. They may include raw images of vomit and excrement that are rarely spoken about in connection with the first person, thereby putting the actual materiality of being ill in the foreground, rather than confining it to a (sanitized) medical discourse.

Being ill includes a bodily vulnerability, but also, as the above fragment illustrates, a social vulnerability (Schües, 2014). Social vulnerability refers to the potential of being judged by others, for example when the first author reflects on his capacity to contribute (intelligently and coherently) even though he is in the midst of an inflammation of his disease. Besides this social vulnerability, a person with a chronic illness or disability also runs the risk of being institutionally vulnerable. The first author could, for example, lose his job because people cannot understand the fact that he is capable of certain contributions (sharing his thoughts) but not of others (lecturing to a class). The image of a capable, able-bodied, thinking subject no longer works as an image of what it means to be (a caring and cared for) human. The fragment shows that we should produce more suitable, multiple images that honor both the capabilities and the vulnerabilities of people with chronic disease and disability, rather than viewing these dichotomously. We strongly believe that auto-ethnography has the potential to do exactly that.

5. Conclusion

The relatively young discipline of care ethics has alerted us to the need to reflect on care as practices of care, with a particular emphasis on interdependence, on relations as the locus of discovery of what is good (or humane), and on the particular good of people within a particular context. Care ethics does not depart from a specific norm or principle of (what ought to be) good care, because it does not conceive of good care as something static or a-historical (cf. Hertogh, 2010; Mol et al., 2010) and because the ethical content of practices might itself be comprehended as 'a way to be normative' (Willems & Pols, 2010, p. 163). In fact, the supposedly neutral practice of ethical and moral reasoning as such should not be conceived of as value free, but instead as context sensitive and serving multiple interests (Leget, 2013; Walker, 2007).

In line with this, auto-ethnography as a praxis of care critiques an individualization discourse which involves isolated selves, absolute truths or certainties, and a-historicity. In line with what Merton has termed 'sociological autobiography', which includes 'perspectives, ideas, concepts, findings, and analytical procedures to construct and interpret a narrative text that purports to tell one's own history within the larger history of one's times' (Merton, 1972, p. 18), auto-ethnography tries to focus on factors such as personal meaning, empathic connection and resonation in order to uncover stories about 'embodied struggles' (Ellis, 2013), while being responsive to ambiguity, complexity and difference(s).

Consequently, auto-ethnography has the potential to create space for topics to which access is difficult and to stimulate the emergence of a variety of creative (re-)presentations through a mutual learning process. Of course, we are mindful of the potential pitfalls of auto-ethnography; for example, the discussion of very personal events can lead to a situation of great vulnerability. Also, auto-ethnography can be susceptible to too much introspection, leading even to (self-)obsession, whereby one's own role is given too much priority and there is not the adequate amount of critical reflection or rigor that should accompany sound (qualitative) research.

Nevertheless, we feel that auto-ethnography holds great promise not only in care inquiry and disability studies, but also beyond the specific fields of (academic) inquiry. After all, there is an 'untapped well of personal experience' among all our own colleagues (and students), friends and family. Developing a relational auto-ethnography on illness or disability, with its unique combination of mutual reflection on the personal (evocative, literary and narrative) and attention to both capability *and* vulnerability, is not a question of 'capturing' a patient's voice or story. It is rather both a relational and caring practice itself which entails carefully handling vulnerabilities, listening, being attentive and responsive, and facilitating the exploration of valuable sociopolitical knowledge, whilst at the same time co-creating a fuller picture of someone who is faced with illness or disability, but defined beyond their perceived limitations.

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Conflict of Interests

The authors declare no conflict of interests.

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Article

The Role of Human Values and Relations in the Employment of People with Work-Relevant Disabilities

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Abstract
The aim of this study is to discuss the role of human values and relations in the employment of people with work-relevant disabilities. *Purpose:* Finding and maintaining a paid job is known to be more difficult for people with a disability. The aim of the study is to explore the use which people with a disability make of their private and professional network in finding and maintaining a paid job and the role values play in these relations. This was placed in the context of three complementary perspectives: a perspective that stresses the importance of other than merely rationalistic values, a perspective that stresses the importance of values in work and an interpersonal perspective in which 'the Other' is central. *Methods:* Semi-structured interviews were held with 8 people with a working disability. As well, 4 interviews were held with people from their private network (family and partner) and 4 interviews with people from their professional network (colleagues and employers). All interviews were audio-taped and transcribed verbatim. A framework analysis was used to identify the different values in the interviews. This was done with use of MAXqda. *Results:* The interviews showed that both romantic and rational values and arguments were mentioned by the employers in the context of hiring people with a work-relevant disability; they need to be willing to adjust. The importance of human relations was emphasised in the values mentioned by the respondents when talking about having a paid job. Moreover, 'the Other' played an important role in the employment process of people with a work-relevant disability. People with such a disability asked their private network to help them and to provide emotional support. *Conclusion:* Enabling values and relations had more chance if they were in line with the mission and central value of the organisation. This was one of the first studies on the role that human values and relations play in maintaining a paid job for people with a work-relevant disability. The study gives a first impression of how human values and relations play a role, but more research is needed to provide more detailed insights, for example in different groups (e.g. non-employed people with a disability).

Keywords
disability; employment; human relations; values; work

Issue
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1. Introduction

In December 2006, a new rights based disability paradigm was set with the declaration of The United Nations Convention on the Rights of Persons with Disabilities. Within this paradigm, values such as dignity and human rights of people with disabilities have become more important. This paradigm presupposes a broader perspective on quality of life of people with disabilities; a perspective that goes beyond meeting the basic (care) needs, and focuses on social participation. This social participation could be enhanced via improved access to health, education or employment (Mahar, Cobigo, & Stuart, 2013). Paradigms are important and presumably necessary, but certainly not sufficient for values, and subsequently behaviours, to be implemented in daily practice and (working) life. In the study reported in this article, we investigated values and value perspectives that people with a disability encounter in the workplace, facilitating or hindering their participation.

Maintaining a paid job can be difficult, especially for people with a work-relevant disability. In this article, we consider a disability to be work-relevant if it is a chronic disease, illness or disability, which may or may not be caused by work itself, but in all cases will impact the individual's functioning at work, indicating its relevance considering labour (Borst-Eilers, 1999). Employers generally expect more absenteeism and lower productivity from people with a work-relevant disability (Van Petersen, Vonk, & Bouwmeester, 2004), which can make them reluctant to hire people with a disability (Winsemius & van Houten, 2010). Insight is growing, though sporadically, that, on the other hand, hiring people with a work-relevant disability is one of the aspects of increasing workplace diversity (Ball, Monaco, Schmeling, Schartz, & Blanck, 2005; Muyia Nafukho, Roessler, & Kacirek, 2010). This diversity, in its turn, increases the creativity of the company by having different kinds of people in the organisation. A more diverse workforce attracts new customers and improves the company's or its brand's image (Vries et al., 2005).

Although the importance of work is widely acknowledged, the value of work is often described in terms of practical issues, such as income or daily structure. However, other values than income, such as building and maintaining meaningful relations and contributing to something valuable, play an increasingly important role for present day workers (Gheaus & Herzog, 2016; Van der Klink et al., 2016), and this may count even more for people with a work-relevant disability. Indeed, the disability itself often leads towards a re-orientation on values, in which other values than income and career become important. There is often a need for more resources (like job control) too (Koolhaas, 2014; Koolhaas, Brouwer, Groothoff, Sorgdrager, & Van der Klink, 2009), because people with a disability not only need to cope with their job demands but also with the demands of their condition.

Values of work can be regarded as governing interpersonal behaviour (Bardi & Schwartz, 2003; Maio & Olson, 1995; Taylor, 1989, 1992). Although issues related to the employment or not of people with a work-relevant disability have been largely researched, the role of values and their governing of interpersonal behaviour in the employment of people with a work-relevant disability have not been studied so far. Even so, to the best of our knowledge, there has been no research that inquires the role of the professional and private network of people with a work-relevant disability in their employment. Both perspectives, however, provide interesting insights in aspects playing a role in finding and maintaining a job for people with a work-relevant disability. Therefore, the aim of this study is to gain insight into how human values and relations play a role in the employment of people with work-relevant disabilities.

To achieve this aim we used three complementary but not mutually exclusive theoretical perspectives to approach our empirical data in a framework analysis: a perspective that stresses the importance of other than merely rationalistic economic values; a perspective that stresses the importance of values in work and an interpersonal perspective in which 'the Other' is central.

The first perspective is an overarching perspective that finds its roots in two contrasting societal views from different historical periods: rationalism and romanticism (Berlin, 1999; Van der Wilt, Deinum, & Van Engelen, 2016). This perspective is inspired by the theoretical framework of Berlin. As he saw it, the Romantic revolution involved a rejection of the Rationalistic idea that (1) "all genuine questions can be answered," (2) "all these answers are knowable," and (3) "all these answers must be compatible with one another" (Berlin, 1999, pp. 21-22). This rationalism contrasts with the 'romantic' vision that the world is not organised by geometry but by poetry. Important values and goals cannot be 'discovered'; they have to be created. Romanticism asserts that also other values (driven by what is 'right' in a more moral way) are important and that values can be mutually conflicting (Berlin, 1999). Berlin states: "The notion that there are many values, and that they are incompatible; the whole notion of plurality, of inexhaustibility, of the imperfection of all human answers and arrangements; the notion that no single answer which claims to be perfect and true, whether in art or in life, can in principle be perfect or true—all this we owe to the romantics" (Berlin, 1999 p. 146). In our society, and especially in the economy and the labour market, values have predominantly been derived from a rationalistic point of view (efficiency, cost-effectiveness, etc.). The position of example is apt, because there are recent developments in economy and management that use a broader, 'romantic', value perspective than exclusively rationalistic values (corporate responsibility). Thus, in this broader perspective, the orientation on and the achievement of values that are outside the dominant (mainstream) rationalistic and economic values are central.

The second perspective can be seen as an elaboration of this: it is based on the values that people should be able to realise with their work and in their work. Throughout the history of philosophy from 'Aristotle to Arendt' people have thought about the value of human action and work. Mostly, at least three aspects are recognised: livelihood (making a living), creativity (creating something) and participation (being part of a community). In this tradition Gheaus and Herzog (2016) recently identified four values people should be able to realise with work, besides income: (1) excellence, (2) social contribution, (3) community and (4) social recognition (Gheaus & Herzog, 2016). Another modern value based framework is the capability approach developed by Amartya Sen (1980, 1993, 2009). In this approach, people should be enabled to realise 'beings and doings people have reason to value'. According to Sen these values are group and context dependent and should not be formulated by experts but 'collected' in the target group in a democratic procedure. In this line, Van der Klink et al. (2016) identified and validated (Abma et al., 2016) seven work values in a population of Dutch workers: (1) the use of knowledge and skills, (2) the development of knowledge and skills; (3) involvement in important decisions; (4) building and maintaining meaningful contacts at work; (5) setting own goals; (6) having a good income; and (7) contributing to something valuable. Values are 'transformed to capabilities if they are important for a worker in his/her work situation and if s/he is enabled and able to achieve the value in their work'. Thus, the context is essential. Within this perspective, in which the value people should realise with and in their work is central, the values Gheaus and Herzog identify are focused on what values should be achieved *with* work (work itself as a capability), while Van der Klink et al stress which values people should be able and enabled to achieve within their work (work capabilities).

The third perspective stresses the interpersonal perspective and is based on the theory of Levinas. After 2500 years of philosophy wherein either the self (egology) or 'being' (ontology) is central, Levinas introduces a totally different point of departure: the Other. A person is not determined by his or her self or by destiny, but by 'the Other'. Levinas' point of view may be elucidated by contrasting it with Sartre's view on the other. For Sartre, the discovery of the identity depends on others because 'I can never see myself as others see me' (Sartre, 1943). The gaze of the other attributes characteristics to me that I cannot determine from myself, but it also 'objectifies' me and with that, I am reduced to a thing that is not subject to change. By that, the other denies me my freedom to act differently, to be different.

As Sartre relates the other to the self, Levinas takes a diametrically opposite starting point by placing 'The Other' in the central position and stating that human behaviour is determined by the responsibility towards 'the Other' (Levinas, 1961). For Levinas, 'the Other' is not knowable and should not be made into an object of the self, as is done by traditional philosophy that puts the self in the central position (from which either other people and the world can be objectified, or the other is considered as threatening the integrity of the self—as in Sartrian philsosophy). For Levinas, the responsibility for 'the Other' as a person is central and unconditional.

From this asymmetric relationship originates an ethical appeal. Ethics thus sprouts from my concern for 'The Other'. Levinas outlines that freedom is predominantly a responsibility: my natural freedom becomes a moral freedom because I am invited to responsibility by the Other.

These three perspectives will be used in order to get insight into the motives for people with a work-relevant disability to work and the motives of employers to hire people with a work-relevant disability (or, in a broader context; the motives of the network to "invest" in people with a work-relevant disability).

2. Methods

2.1. Study Design

An exploratory qualitative network study was executed. This design was used to explore the views, opinions and attitudes of people with a work-relevant disability and their professional and private network, about their roles in the employment of people with a work-relevant disability and their motives and underlying values to do so.

2.2. Recruitment

Eight qualitative, semi-structured interviews with people with a work-relevant disability were conducted. Five people with a work-relevant disability gave permission to interview their private and professional related network as well, which led to another eight interviews. So, in total 16 interviews were conducted.

The eight people with a work-relevant disability were recruited from the networks of Emma at Work (employment agency for people with a work-relevant disability), Disability Studies in the Netherlands, Bartiméus (organization delivering services to visually impaired people) and the FNV (Federatie Nederlandse Vakbeweging), the largest trade union in the Netherlands. Participants were purposefully recruited. Inclusion criteria were: having a work-relevant disability and (experience with) a paid job. The people from the private and professional network were recruited by the primary interviewees (the persons with the work-relevant disability).

All participants were contacted via an e-mail in which the study objective was explained and their permission to be interviewed was formally requested. If they replied to the e-mail, they were subsequently called by phone. All optional participants who were contacted by phone enrolled in the study. During this phone conversation, both the study's objective and their permission to be interviewed were repeated, and an appointment was made for the interview.

2.3. Data Collection

Semi-structured, in-depth interviews were conducted with people with a work-relevant disability and the people from their private and professional networks. Interviews were conducted with the help of a topic list to increase the homogeneity between the topics spoken about in the interviews (Frambach, Van der Vleuten, & Durning, 2013). The topic list was based on intuition and relevant themes suggested in the literature (Leufstadius, Eklund, & Erlandsson, 2009). After each interview, the researcher evaluated the topic list to see if changes were necessary. The information collected from the initial interviews was used in the successive interviews. This led to new questions for the next interview(s), resulting in additional data generation (Van IJzendoorn, 1988). Important themes on the topic list were 'change as a result of getting a paid job', 'benefits a paid job can offer people with a work-relevant disability' and 'getting hired with a work-relevant disability'. The interviews were conducted either at the participants' home, at the office, or another quiet place to prevent disturbance.

2.4. Data Analysis

Based on the three complementary perspectives, a framework was formed to analyse the data. The key elements of each perspective were coded and these codes were assigned to text fragments in the transcripts. This was done with the use of a code book. The codes were noted as a priori codes in the codebook, provided with a separate label, definition and description for each code. The code book was designed by the researchers involved in the analysis, based on relevant literature considering the theories concerned. This led to a framework to structure and analyse the data in the transcripts in a meaningful way (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The interpersonal perspective, based on Levinas, with responsibility for 'the Other' as central theme was covered by three a priori codes: feeling responsible, showing responsibility and claiming responsibility. The society perspective based on Berlin was put into operation by eight a priori codes: being aware of, feeling and acting according to a 'rationalistic' value (cost-effectiveness); the same triptych for 'not-rationalistic' or 'romantic', broader values and separate codes for incompatibility and incommensurability of these different viewpoints. The value perspective, as based on Gheaus and Sen/Van der Klink et al., was covered by 22 codes: the four values of Gheaus and the seven of Van der Klink et al were covered by two codes each: the importance of the value and the achievement of the value.

Each of the sixteen transcripts was analysed by two members of the research team. If a piece of text matched the description of one of the codes in the codebook, that piece of text was assigned to that code. For the analysis of the data, qualitative analysis software program MAXqda was used. In the phase of mapping and interpretation, the relationships between the concepts, typologies and associations with these concepts were explored (Green & Thorogood, 2014). The differences and similarities between the views of the respondents were investigated. Finally, all findings were interpreted.

3. Results

3.1. Participants

The group of people with a work-relevant disability, who joined the study, consisted of six women and two men. They all were in the age range from 23 to 65 years old. They had different kinds of disabilities, illnesses or diseases, but all of them defined their disability as having impact on their work. One person currently did not have a paid job, but had experience with having a paid job (see Table 1). The interviews lasted on average 43 minutes with a range between 26 and 83 minutes.

The people from the private and professional networks of those with a work-relevant disability consisted of six females and two males. They were between 28 and 66 years old (see Table 2).

Hereunder, various aspects of human values and relations in the context of employment are described. Three different theoretical perspectives were used to analyse the data, based on Levinas, Berlin and Gheaus/Sen as elaborated in the introduction. The reporting is structured based on these three perspectives. First, the results of the framework analysis of Levinas will be discussed, followed by Berlin and then Sen. All the results focus on the role of human relations as guided by values, in the employment of people with a work-relevant disability. Representative quotes are given in the text. Clues are added to indicate the source of the quotation (R refers to a person with a work-relevant disability. C refers to people from the private or professional network. See Tables 1 and 2 for more details about the respondents).

Table 1. Demographic information about the participants with a work-relevant disability.

	Sex	Age	Type of disability	Paid job
R1	Female	26	Chronic disease	Administrative assistant
R2	Female	26	Psychiatric disability	Administrative job during the summer
R3	Female	43	Chronic disease	None
R4	Female	48	Sensory disability	Freelancer, CEO, member of several Supervisory Boards
R5	Female	28	Physical and mental disability	Sheltered work
R6	Male	38	Psychiatric disability	Sheltered work
R7	Female	65	Sensory and mental disability	Sheltered work
R8	Male	52	Sensory disability	Psychosocial supporter at the county

Table 2. Demographic information about the participants who were part of the private and professional network of the interviewees with a work-relevant disability.

	Sex	Age	Connection	Paid job
C1.1	Female	46	Supervisor R1	Manager
C1.2	Female	25	Colleague R1	Project coordinator
C1.3	Female	56	Mother R1	Nurse
C1.4	Male	28	Brother R1	Social media agent
C2.1	Female	59	Commissioner R2	Director
C2.2	Male	63	Partner R2	Program manager, strategic adviser
C6.1	Female	36	Head of the HRM department of R6	Head of the HRM department
C6.2	Female	66	Friend R6	None

3.2. Moral Perspective

In this perspective, inspired by the work of Berlin, the central viewpoint is that people in an organisation often cherish a broader set of values than those that are strictly in line with the 'rationalistic' organisational goals (maximise profit and (cost-)effectiveness).

Employers use both rational and non-rational 'romantic' arguments when discussing the employment of a person with a work–relevant disability. This shows that—although both types of arguments seem contrary—they do not necessarily exclude one another. All three employers mentioned the importance of accessibility and inclusiveness. The importance of accessibility is the most expressed 'romantic' value by the employers interviewed. As people with a work-relevant disability have trouble finding and maintaining a job, the employers feel an urge to help them. They feel responsible for the people with a work-relevant disability as well as feeling responsible for society as a whole.

The employers emphasize that people with a work-relevant disability are part of society, a society with a labour market that is not accessible and inclusive for people with a disability. The employers want to contribute to the solution, to change society and make it more inclusive for people with a disability. They acknowledge that a better world starts at home and, therefore. they want to be part of the solution, not of the problem.

> "We have an important role in society in general and want to set an example for society. This means giving people who have fewer chances in life opportunities as well." (C1.1)

Another important value, which played a role in employing people with a work-relevant disability, is the importance of a pleasant working atmosphere. This is not necessarily related to the disability as such, but to the attitude of the employee with the disability. Working hard, being a good colleague and being willing to contribute to the company and its working atmosphere are important reasons to hire and employ someone with a work-relevant disability.

A positive attitude, sometimes rooted in gratitude for getting opportunities and a job, can improve the working atmosphere and working culture, resulting that people from the professional network experience the providing of help to the people with a work-relevant disability less as a burden than as a commitment towards a respected colleague.

> "I think she delivers a positive contribution to the working culture by the way she is standing in life." (C1.1)

However, in some cases the rational argument of cost-effectiveness outweighed the broader 'romantic' values. This implies a hierarchy in which 'romantic' values are restricted to a certain limit value. They can be used to argue for a certain investment in the employee, but this investment is not infinite, neither in time, nor in money. The employers in our sample drew a line under to what extent they could invest in people with a disability. They found it hard to make this explicit, as there is not a strict criterion for the worth of romantic values. However, all the employers stated that there is such an imaginary line, which can change over time and from case to case. Nevertheless, there is a limit.

> "Look, if we needed to invest in a 10.000-euro computer for a task of three months, we would have solved it differently [and not have employed her]." (C4.2)

On the other hand, romantic and rational values can reinforce each other. Sometimes the romantic value of creating a pleasant working atmosphere results in more cost-effectiveness. Supervisors use these kinds of rational arguments to convince their superiors of the importance of 'romantic' values.

> "I think the working culture is determining the way you approach the people you meet, so by setting R1 as an example and learning from her positive attitude we will probably change the way we approach our clients for the better, which will be beneficial for the company." (C1.1)

3.3. Value Driven Perspective

In this perspective, the value people should realise with and in their work is central. The work values as according to the capability approach and the values formulated by Gheaus and Herzog may represent values from an *individual* or personal perspective. For people with a work-relevant disability, several of these values are overtly related to human relations. Not all values will be discussed; hereunder, the focus will be on values which were most frequently mentioned and/or had a striking, different meaning in the group of people with a work-relevant disability. Four of the 'capabilities' (the development of knowledge and skills; building and maintaining meaningful contacts at work; having a good income; and contributing to something valuable), and three of the values of Gheaus will be presented (being part of a community, excellence and social recognition) (Gheaus & Herzog, 2016) .

3.3.1. The Development of Knowledge and Skills

This value not only represents the development or growth in itself, but rather the respondents express that they feel that they were given a chance by their employer or colleague to grow and evolve in their jobs. In general, the respondents express gratitude for the opportunities given by their professional network. To some respondents, getting this opportunity is more important than the actual personal growth or development. This reflects the essence of the concept of capability in which the opportunity to achieve is central and not the actual performance (that can depend on—restricted—choice).

> "My self-esteem has grown, because I got the chance to learn and got some education in the meantime. They do not see me as a hopeless case. That is really valuable to me." (R1)

3.3.2. Building and Maintaining Meaningful Contacts at Work

Being surrounded by other people is described as an important aspect of work by almost all people with a work-relevant disability. Having a paid job gives them the opportunity to meet new people. Making connections gives them the feeling that they are (still) valuable. People who have been unemployed for a certain amount of time, who are living in an institution and/or have a small group of friends or social contacts describe even more benefits of having a paid job than people who had a large private network. They have been feeling lonely for a certain amount of time and the gain of not being on their own but being able to connect on a regular basis was tremendous for this group.

People who have had a paid job for quite some time make use of the connections made. They use their professional network to create new chances. Moreover, they mention that some people from their professional network became part of their personal network as well. Some people were still friends with people who had been their colleagues years before.

> "I: What has having a job given you—what would you not get if you didn't have a job?
> R: Friends" (R2)

The social part of work was recognised as important by the professional and private network of the people with a work-relevant disability as well.

> "You are actually doing something that you like, also aimed at socializing, for example, which sounds very much like getting through the day." (C1.3)

This value seems to be particularly important for people with a work-relevant disability; because of their diminished energy, it is very difficult to maintain a social network beside their work.

3.3.3. Having a Good Income

Remarkably, income was not mentioned by all respondents as a value of work (where this is one of the explicitly mentioned values in work for non-disabled (Abma et al., 2016; Jahoda, 1982)). For these respondents, other values such as social contact, structure or social contribution are the reasons to work. For some respondents, however, their income is of great value. Not so much because of the possibilities it gives them to buy material things, but rather because it gives them freedom and independence. Not relying on the government or partner/parents gives them a feeling of freedom.

> "When I had enough financial security and a cell phone and a credit card, I was able to manage every situation. I did not need my eyes that badly anymore." (R4)

> "To keep that independency, because there were times when I was really depending on my parents, I was not working because of my disease, and that didn't feel well." (R2)

This is in line with how the ancient Greek looked at the relation between work and income. Work performed to earn a living was very low esteemed, not much higher than slavery, but work that served a higher goal like independency or freedom or a societal goal, was highly esteemed (Van der Klink, 2015).

3.3.4. Contributing to Something Valuable

When people with a disability are not able to work, they receive social benefits in The Netherlands. This means a basic income is guaranteed for them. However, earning their own money gives most respondents the opportunity to repay society. Society gave them an income when they were not able to earn it themselves; now they want to contribute to society, by earning their own money and repay it by paying taxes. Besides paying taxes, a contribution is made by producing goods or providing services which are beneficial to others, as pointed out by some respondents. Being able to contribute strengthens their identity and their role in society.

> "[Work means] really doing something for society to get money" (C6.1)

> "[About making sockets] I am really useful for someone else. Socket, well, if you don't have power you can't do a lot of things. Take a kettle, you need a socket. A stove needs power as well. So many things need power. Think about a vacuum cleaner, a fridge, a freezer, a washing machine, you can go on and on and on. If there is no power, if there are no sockets, all those things are not useful anymore." (R6)

The notion that work is more than an economic transaction and should add (other) values for the worker and for society is a reflection of the ancient Greek perception mentioned above and of the broader 'romantic' perspective.

3.3.5. Being Part of a Community

Having someone with a work-relevant disability in the workforce is only possible in a community that is willing to adjust. People with a work-relevant disability do sometimes need some special care. This can imply going on sick leave more often than people without a work-relevant disability, but can also imply taking the elevator instead of the stairs or making sure the hallway is empty to prevent someone with a visual disability from hitting boxes which stand in the way and falling. This need for adjustments means that the other people in the company need to take the person with a work-relevant disability into account. Adaptation has to be reciprocal.

It is normal in a company that people have to take their colleagues into account; however, the people with a work-impacting disability, their colleagues and employers, when interviewed, declare this happens on a more regular basis for people with a work-relevant disability. The willingness to change your behaviour to help someone in the community was seen as an obligation and not as a choice, because you are helping the wider community and not only the person who receives help. Admitting someone into the community means reaching goals as a group.

> "I am not worried about being absent, my colleagues know about it [having a work-relevant disability], if the work that needs to be done is urgent they will work it out. It gives me a safe feeling, them knowing that [needing to adjust]." (R1)

The respondents are, in general, well aware of their dependence on others, also considering their job. Some try to prevent difficulties, by putting extra effort into building a network that could forestall problems. They are conscious about their sometimes fragile position and building a network or safety net can partly overcome this fragility.

> "I: How does such a network arise?
> R: By building it reeeeeeally carefully, investing lots and lots of time, attention, being seriously interested, being careful. Keeping in touch with all those people, remembering birthdays, asking about their wives, that kind of simple stuff, letting them know you exist, on Facebook, on Twitter, on Instagram, whatever, LinkedIn of course." (C.1)

This value shows a divergence of perceptions. From the perspective of the 'community', having a person with a work-related disability as a member can contribute to the diversity and development of the group. From the perspective of the person with the work-relevant disability, however, it appears to be a value on the 'safety level' with the function of a life vest or safety net.

3.3.6. Excellence

Having a work-relevant disability means people have to overcome all kinds of boundaries, every single day. These boundaries imply that working is more of a challenge for them than for their colleagues who do not have a disability. By not giving up hope and keeping their heads up, people with a disability are set as an example for and by their colleagues and employers. Their positive attitude to face every challenge is seen as a contribution to the work in which they excel and that is sometimes deliberately used to change the working climate.

Feeling appreciated for their hard work and being able to influence the company is giving a boost to the self-esteem of people with a work-relevant disability. It makes them more loyal to their colleagues, their employer and their company as well. It therefore strengthens their will to keep working despite all the challenges.

> "It's wonderful to hear colleagues say: 'Gosh, you know, I think about the things I do' or 'I complain less about aches, because you suffer every day.' Wow, those are the things that make me realise one's personality can make a tremendous difference in a department or a company." (R1)

The downside of the fact that being able to keep up, to act 'normal' and not complain, is that some people with a disability have the feeling that in order to be accepted they are not allowed to complain or at least not too much. This can be troubling for some of them. Besides, the type of recognition based on their positive attitude is experienced as difficult and frustrating by some respondents.

They do not want recognition based on their disability, but rather based on their (professional) capacities and work. In their attempt to be 'normal', they sometimes feel uncomfortable to accept this type of recognition.

> "Every time I had to overcome boundaries, because I was young, because I was not able to see well, that made me think: 'Fuck you, I will not play the part you want me to'. I do not like to carry a stigma with me….I did not come this far by pointing at my disability. If I have a problem, I need to solve it." (R4)

For this target group, the value of excellence is not so much applicable to the 'output' of work, the product, but rather to the 'throughput', the mode of carrying it out.

3.3.7. Social Recognition

The fact that people with a work-relevant disability perform in a paid job, leads to different kinds of appreciation by the people surrounding them. First of all, there is the recognition of the boundaries people with a disability have to face by the people from their professional network, as discussed above. Secondly, having a paid job changes the way society feels about people with a work-relevant disability as well. People with a disability often feel less valued based on experiences through their lives of having been bullied or denied a job because of their disability. Paid work changes, for some of them, their role in society. It is important for these people to be acknowledged in their capacities, to be valued as a 'normal' human being, to be part of society.

> "Her bullies are all stay-at-home mums at this point and she is travelling the world, she outranked them all in some way. She did not go to her school reunion. First she did, wanted to go and show them: 'Look here I am, I am having a life of my own'. But they are not worth it." (C4.1)

The interviews show that being recognised as 'having a life of their own', acting and performing like everybody else is an important recognition for people with a work-relevant disability.

3.4. Interpersonal Perspective

In this perspective, being responsible for 'the Other' is central. The definition of 'the Other' is based on Levinas: the Other as a subject that cannot be objectified nor controlled.

Having a paid job can be exhausting for people with a work-relevant disability. This means they explicitly or implicitly demand their private network to take this into consideration. They expect their private network not to exclude them when they do not have the energy to join them or the energy to be cheerful when they get home. Moreover, people with a work-relevant disability ask their private network to spare them and dismiss them from household tasks. They need the support and collaboration of the people from their private network to hold their job. Besides that, the emotional support, the willingness to adjust and the pride expressed by people from their private network gives the people with a disability firmness and a feeling of having a safety net and being able to take a risk and try to excel.

People with a work-relevant disability appeal to their private and professional network to take responsibility and to see their colleague not merely as instrumental but as a source.

This reflects the categorical imperative by Kant but is specifically concordant with the conception of 'the Other' according to Levinas. The interviews show that this conception plays a very important role in the employment process of people with a disability.

> "My mum is a big support, she will always back me up, she is really proud of me. [It influences my work] It makes me feel positive to know there are always people [like mum] happy with my being." (R1)

The professional network needs to accept the person with a work-relevant disability, who in most cases differs from the general workforce, as 'the Other' and take responsibility for him/her. This means the workforce needs to be open-minded to change itself and to accept and adapt to the person with a work-relevant disability. It is therefore necessary that there is a focus on the need to adapt and adjust the work environment to make it possible for the person with a work-relevant disability to become—and stay—part of the professional network. Therefore, it is necessary to focus not solely on the Otherness but ask about the needs of the person with a work-relevant disability and the need to adjust. The focus should be on the need to change the working atmosphere. By being willing to adjust, the person with a work-relevant disability is not only Another but becomes part of the professional network as an 'Other'.

> "Everyone has to take that [R1 being frequently absent] into account, the tasks assigned to her have to be tuned on that [R1 being absent sometimes]….This means her colleagues have to know about it, accept and adjust." (C1.1)

4. Discussion

4.1. Summary of the Results

The results give insight into how human values and relations play a role in the jobs of people with work-relevant disabilities. Both romantic and rational values and arguments were mentioned by both employees and employers in the context of employing people with a work-relevant disability. These values can reinforce each other but can also be incompatible. With regard to specific work values, there seem to be some differences in the appreciation of these values compared with people without a work-relevant disability. Because this was not a comparative study, this observation must be considered with caution. The importance of human relations was emphasised in the values mentioned by the respondents, when talking about having a paid job. The interviews showed that 'the Other' plays a very important role in the employment process of people with a work-relevant disability. People with such a disability, appeal to their professional network for consideration and practical support and to their private network to help them and to provide emotional support. Both networks need to be willing to adjust.

In this article, three different perspectives were used to gain a deeper insight into the value of human relations in work for people with a work-relevant disability. The three perspectives have in common that they all stress the importance of a broader value perspective than a just self-centred economic perspective. They differ in how the individual level interacts with the context. The moral perspective focuses on the morality, on the basis of the acts of the individual in a societal context, the value driven perspective focuses on the values of work for the individual in his or her micro-, meso- and macro context (Van der Klink et al., 2016) and the interpersonal perspective focuses on the responsibility of the individual from and to the individual 'Other'.

We chose these three perspectives because of their complementary characteristics. For the moral, societal perspective, we chose Berlin because he devoted his professional work to 'a strikingly audacious project: to define Western philosophy as a single coherent tradition based upon a faith in rationality, to convince us that such faith is unwarranted—even dangerous—and to advance his own ideas to take its place.' (Sylva, 1999). Our choice for Sen's capability approach was motivated by the increasing importance and influence of this value driven approach in many fields and because of the recent operationalization for work (Abma et al., 2016; van der Klink et al., 2016). The recently formulated values of Gheaus and Herzog were added because of their complementarity. Levinas was chosen because he was undoubtedly the thinker with the most extreme position regarding our responsibility towards the Other, a beacon that is probably unreachable but can show us the direction.

Sen and Levinas both underline the importance of responsibility. For Levinas, this is predominantly an appeal to the individual: your responsibility for 'the Other' is a personal responsibility. For Sen the responsibility is both individual and societal: people have a societal claim to be enabled to achieve their capabilities. Levinas and Berlin also have a common focus on responsibility as a 'romantic' value. For Levinas, this responsibility is a very specific appeal of the individual 'Other'. The employers in our sample stressed that they felt, besides their responsibility towards the individual employee with a work-relevant disability, a responsibility to society too. This is more in line with Berlin. Sen's capabilities might be seen as a translation to a specific context of Berlin's broad scope on values that should not be merely rational. However, Sen would object to the distinction rationalistic versus not rationalistic. In one of his most influential essays, he analyses the economic literature from Smith to Edgeworth and notes that the precise formalising of self-interest as an economic principle is an irrational misconception (Sen, 1977). Sen argues that the 'rationalistic' economic man is significantly worse off because of a failure to recognise the distinction between actual individual preferences and our ethical ideals:

> "A person thus described may be 'rational' in the limited sense of revealing no inconsistencies in his choice behaviour, but if he has no use for these distinctions between quite different concepts, he must be a bit of a fool. The purely economic man is indeed close to being a social moron." (Sen, 1977)

For people with a work-relevant disability, the context seems even more important and relevant. The relationships with their private and professional network play an important role in the meaning that the values of work become relational values. This was found in every perspective.

The relationship between the individual and the concept of 'the Other' is a reciprocal one. People with and without a work-relevant disability feel, answer and ask responsibility of each other. 'The Other', as Levinas describes, is not allowed to be objectified and integrated in the self; you have to leave him or her 'the Other', in the sense that you owe him/her responsibility and respect as a person, a separate identity on its own (Levinas, 1961). The interviews show that the private and professional networks are demanded—and willing—to change and act out of responsibility towards the person with a work-relevant disability, designated as 'the Other'. Our results showed that this 'Other' tries to make a change too, feeling responsible to 'return' or 'repay' by being 'a model employee'. By that, it is meant that being responsible for 'the Other' is conditional. There has to be a reciprocal relationship with 'the Other' to feel responsible for 'the Other'. Here, practice as reflected in our interviews does not meet one of the cornerstones of Levinas' theory: that the responsibility for 'The Other' is unconditional. By imposing conditions on the responsibility for 'the Other', that 'Other' loses its role as the centre of attention. Even the good practices we investigated could not meet the high ethical standards of Levinas. Notwithstanding, the data are in line with seeing 'the Other' as a separate identity and not merely instrumental as contributor to rational goals. As such, the data are in line with Kant's categorical imperative. This imperative was meant as a moral guideline, a practical philosophically based rule. Levinas does not make the claim of a moral imperative. He designates his point of view as 'first philosophy', prior to practical ethics. This leaves the possibility to consider Levinas' description of the Other as a regulative ideal, a beacon, something to strive for with as highest achievable operationalization as Kant's categorical imperative.

According to our material, romantic and rational values can be sometimes incompatible or hierarchical. When the cost to fulfil a romantic non-rational value exceeded a certain limit, the romantic value went down. This confirms the presumption that there is a certain limit to which the romantic value is seen as achievable and that, in the present work, rational values must in the end prevail. Romantic values can have a place but that place is limited by rationalistic borders.

Values such as 'Having a good income' or 'Contributing to something valuable' seem, for people with a work-relevant disability, especially meaningful in the context of the relationships with their private and professional networks. In the case of people with a work-relevant disability, there is a strong interaction between, on the one hand, the private and professional network and society as a whole and, on the other hand, these personal values. The values that guided the relations and, vice versa, were almost all values that were affected by the way other people conceived people with a disability. This seems specific for people with a work-relevant disability.

Besides that, values can have a different meaning for the people with and without a work-relevant disability. Earning an income, for instance, is one of the values identified by people without a disability to work (Abma et al., 2016; Van der Klink et al., 2011). People with a work-relevant disability valued an income more because of the independency it gave, than because of getting an income as value in itself. This may relate to the fact that they would receive a benefit if they did not work, but the independence from others and the pride in being self-sufficient were strong (interpersonal) values in themselves.

The product of their labour is, in contrast to people without a work-impacting disability, not the main indication of the excellence of people with a work-relevant disability. Being able to contribute to the working process, to a company and to society by having a paid job and acting 'normal' and, despite the disability, not being inferior to colleagues without a work-relevant disability is a way of being excellent when you have a disability. Some interviewees with a disability even managed to be excellent at setting an example of how to cope with problems. In general, considering the capability perspective of which '"being" people and "doing" people have reason to be valued' is an important aspect. For people with a work-related disability, it seems the 'being' aspect is more important than the 'doing' identity. Being a 'normal', valuable and valued person is even more important than doing all the things you value.

4.2. Methodological Strengths and Limitations

Semi-structured, in-depth interviews as data gathering method combined with a framework analysis fitted the aim of this study and the research question but, as in every qualitative research, the results are not meant to be generalised. The research population consisted of an appropriate sample of people with a work-relevant disability, which led to a diverse group of people. There were relatively large proportions of females, people with a sensory disability and people with a mental disability. Although the ages of the study population varied, there were three people in their forties, three people in their twenties, but none in their early thirties. Around the age of thirty, people are making decisions about having children or not, therefore important insights may have been missed. Two of the respondents (R3 and R4) spoke about the difficulty of combining a paid job and having a disability. They both derived a different conclusion from this dilemma: R3 decided to stop working and R4 decided not to have children to be able to hold on to her job. It could have been interesting to interview someone who was in his or her early thirties and was deciding if he or she wanted to have children or not.

The COREQ-checklist was used to ensure all important aspects of this research were reported (Tong, Sainsbury, & Craig, 2007). The research fell short in two of the 32 criteria of this checklist; namely, data saturation and participant checking. Although data saturation was accomplished within the respondents group of people with a work-relevant disability, data saturation was not accomplished within the respondents group from the professional networks nor in the group of respondents from the personal networks of the primary respondents. This could mean that there might be additional values relevant. However, all values included in the framework were mentioned in the interviews, which implies that we gained a broad insight into the meaning of these values and their differences.

Neither the transcripts nor the results were sent to the participants meaning that there might have been an unrectified mistake in the transcripts. Input from the participants might have given some extra information that could have enriched the results found.

To the best of our knowledge, this is the first research on values and relations with respect to people with a work-relevant disability. This makes this research innovative, but also a proper comparison with other studies is more or less impossible.

4.3. Implications and Conclusion

People with a work-relevant disability need adjustments in order to work. The paradigm mentioned at the beginning of this article, secures the rights of people with a disability on these adjustments and on participation. This study investigated which value systems exist in daily working situations that could serve as a matrix for the implementation of these rights. The perspectives we used showed to be useful in structuring and interpreting our data. Employers who valued the romantic value of accessibility, inclusiveness and creating a better working atmosphere as a rational value were willing to take the needs of the people with a disability into account. They felt responsible for the fact that employees with a work-relevant disability could achieve the value of having work and important values in that work. We found that 'enabling values and relations' had more chance if they were in line with the mission and central value of the organisation.

A practical application of this study might use the help it provides us to select the right arguments if we want to introduce a person with a work-relevant disability for employment. With employers that are receptive for only 'rationalistic' arguments, we should choose Sen's strategy of an alternative rationality: it is rational to strive for diversity and a fit of values of the company and its employees and to meet societal standards of responsibility. When dealing with employers that have a broader value perspective, a more direct appeal to the responsibility can be made.

This was one of the first studies on the role that human values and relations play in maintaining a paid job for people with a work-relevant disability. The study gives a first impression of how human values and relations play a role, but more research is needed to provide more detailed insights, for example in different groups (e.g. non-employed people with a disability). Further research can provide more insights that policy makers and the government can use to improve the work participation of people with a work-relevant disability.

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Conflict of Interests

The authors declare no conflict of interests.

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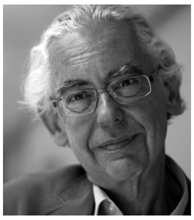

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Article

Writing Disability into Colonial Histories of Humanitarianism

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Abstract

In this paper, the relation between humanity and disability is addressed by discussing the agency of people with disabilities in colonial histories of humanitarianism. People with disabilities were often—as indicated by relevant sources—regarded and treated as passive, suffering fellow humans, in particular in the making and distribution of colonial photography. In the context of humanitarianism, is it possible to understand these photographs differently? This paper analyzes one photograph—from the collection of the Tropenmuseum Amsterdam—of people with leprosy in the protestant leprosarium Bethesda, in the Dutch colony Suriname, at the beginning of the twentieth century. It discusses the way the sitters in the photograph have been framed, and how the photograph has been made and used. The photograph makes it difficult to register agency, but easily reaffirms existing colonial categories. Therefore, this paper also uses another strategy of analysis. By following Actor-Network Theory, focusing on non-human actors, the second part of this paper offers a new and more convincing interpretation of the photograph. This strategy (a) understands agency as a phenomenon of interdependence instead of independence, and (b) approaches photographs as both real and performed. Combining the written history of humanitarianism and disability, it allows new histories of people with disabilities to develop, histories that move beyond the categories of colonialism.

Keywords

actor; Actor-Network Theory; agency; colonialism; disability; humanitarianism; leprosy; photography

Issue

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1. Introduction

With the adoption of the UN Convention on the Rights of People with Disabilities (CRPD) (2006) the world community officially acknowledged that people with disabilities are equal in terms of their humanity and place in society. In general, disability activists welcome the convention because it enables the global inclusion and situational improvement of people with disabilities. With this framing of disability as a human rights issue, disability becomes part of the “humanitarian cloud”, prompting organized efforts on behalf of others based on the notion of a shared humanity (Laqua, 2014, p. 175). Although clouds are flexible, the “humanitarian cloud” is and was often determined by the dichotomy of active (Western) helpers acting on behalf of passive (non-Western) sufferers (Hutchison, 2014, p. 12). This dichotomy is being questioned from a postcolonial perspective—for instance, by Gyan Prakash (1994)—as well as from a disability studies perspective (Meekosha, 2011). “Nothing about us, without us” summarizes the overarching program of the disability rights movement (Charlton, 1998), which emphasizes the agency of people with disabilities. Their intervention requires further reflection with respect to the “humanitarian cloud” around human rights. This is the more pertinent since, as Mark Philip Bradley has argued in the US context, popular American commitment to human rights was often preceded and accompanied by stories and pictures of fellow humans suffering (Bradley, 2014; cf. Musarò, 2015).

In this paper, we link the postcolonial and disability studies perspectives by asking the following question, "How do people with disabilities figure in the history of the "humanitarian cloud", and how can their histories be known? Are these separate histories, running parallel to "mainstream" history, just as a leprosarium was a colony within the colony, or do their histories interfere in and change history at large?" In the historiography about humanitarianism and human rights, people with disabilities receive little explicit attention, which is also the case in (post)colonial historiography. The history of people with disabilities in the (former) colonies is in its infancy (Brégain, 2016). There may be strong reasons for this: since disability, as understood in the West, is not always articulated in the same way in non-Western contexts, it is not certain that a disability approach to history makes sense in histories of colonialism (cf. Livingstone, 2006; Maxwell, 2008). When we follow, however, an intersectional approach—adding disability to our conceptual toolbox as a category like race and gender (Kudlick, 2003)—we may be able to investigate whether and how sources from colonial times depict the intersection of these categories in the making of the colonial context.

If we try to imagine a humanitarian history of disability—in, for example, the case of leprosy (Vongsathorn, 2012)—we will likely find that, because of the dominant perspective of sources, the history depicts people with disabilities as passive sufferers. People with leprosy often entered the colonial archive only as the inhabitants of leprosariums, receiving the benefits of progressive medical research and religious care. Of course, historians have found alternative ways to write about the history of leprosy that undermine this preconceived idea of people with disabilities as passive (Buckingham, 2002), and that support the aim of disability history—part of the emancipatory field of disability studies—to present, represent, give voice to, and restore historical agency to people with disabilities (Kudlick, 2003; Longmore & Umansky, 2001). However, this image of people with disabilities as passive sufferers is hardly undermined by an analysis of visual sources, whereas, in the historiography of humanitarian photography, disability is not addressed (Fehrenbach & Rodogno, 2015; Lydon, 2016).

Here we come across a central problem in colonial history. In a recent article about the representation of human suffering in post-colonial exhibitions, we discussed a Dutch exhibition of photographs that "explicitly show rows of Indonesian rural village (desa) people who have been executed by the soldiers under Dutch command". We saw the potential of these photographs to "trigger debates on law, justice, reparation", but also questioned whether displaying the dead bodies of desa people who had been killed, and thus effectively made the "last" passive victims of the Dutch empire, was a way to leave ethnographic photography behind and acknowledge these people as historical citizens of a postcolonial state to come (Legêne, 2014). We take up this question again—in the case of people with disabilities, whose images figure in the "humanitarian cloud"—and ask, "How can their history be written beyond their image as silent sufferers?"

This paper will explore possible answers to this question through analysis of a photograph of people with leprosy in colonial Suriname. The photograph is part of the collection of the Tropenmuseum—the former Dutch Colonial Museum—in Amsterdam and the Royal Netherlands Institute of Southeast Asian and Caribbean Studies. The photograph—as a historical source—is relevant for three reasons. In the first place, photographs are an important source in the history of the "humanitarian cloud". Visual materials often have been produced and used to serve campaigns for humanitarian relief and human rights. Secondly, this photograph, made in the context of leprosy care in Suriname, enables us to investigate the possible intersection of disability, race, gender and religion, and the multiple affinities and distinctions that put the disabled in their designated place within the colonial hierarchy. Although we focus on leprosy, we do not want to suggest that people with leprosy can represent all people with disabilities in the colonies. However, the case of leprosy is relatively well documented, and is therefore a good starting point for writing disability into humanitarian histories of colonialism. Finally, a photograph from a museum collection in the data cloud helps us consider how historians and museum professionals might intervene in the dominant essentializing and ahistorical reproduction of colonial images of people with disabilities in public histories, for instance by reconsidering the captions that "document"—in the language of their time—these photographs.

This paper investigates whether and how the historical agency of people with disabilities can be recognized in modern visual sources, and what this recognition would mean for writing histories of disability in the "humanitarian cloud" from a disability studies perspective. This paper, therefore, is mainly about methodology, especially because disability history's aim of "granting agency" to people with disabilities (Kudlick, 2013) needs—in our opinion—an alternative. In the first part, this paper analyzes the photograph described above through a method proposed by anthropologist Elisabeth Edwards to investigate colonial photography. Edwards (2001, p. 20) distinguishes three "defining moments" of a photograph: 1) the arrangement of the setting (or the framing), 2) the making of the photograph, and 3) the usage (or the circulation) of the printed image. Such an analysis enables us, as will be demonstrated, to combine strategies developed by scholars like Stoler (2009), Roque and Wagner (2012), Jordanova (2012), and Legêne (2013) to trace the agency of the "colonized". Nevertheless, it appears—as will become clear below—difficult to register agency or break through the silence. Historiography about photography may need other concepts (cf. Edwards, 2016). Moreover, existing categories of (dis)ability seem reaffirmed when we follow the special biography of the photograph in its moments of framing, making, and circulation. Therefore, in the second part of this paper, an additional method is explored: the so-called Actor-Network-Theory (ANT). ANT approaches the research object or actor as embedded in a network of relations between humans and non-humans (Latour, 2005). Moreover, ANT enables us to approach the photograph as both made and real (cf. M'Charek, 2010), and as co-existing with other realities. We apply ANT in a heuristic way when analysing the photograph, and argue that this method has the potential to be used for writing the history of people with disabilities in the "humanitarian cloud" without reaffirming the image of a disabled person as passive and colonized.

2. Description of the "Others" Within

The extensive historical literature about people with leprosy in the colonies provides an essential context for analysing the photograph here discussed. In the quest to locate agency, it is important to know that people with leprosy in the colonial era were—because of their leprosy and the colonizers' fear of infection—"othered" in a way that was beyond the "othering" treatment generally accorded colonised peoples, and in the corresponding humanitarian discourse. They had to live in places that were separated from the rest of society (as "others within", see Roque & Wagner, 2012, p. 15; cf. Stoler, 2009), often referred to as leper colonies. For this case study, we have chosen such a colony: Bethesda, a protestant leprosarium in Suriname, founded in the 18th century, modernized at the end of the 19th century and closed in 1968 (Van Hilte-Rustwijk & Van Steenderen-Rustwijk, 2003; cf. Menke & Menke, 2013; Snelders, in press). Bethesda's history between 1879 and 1928 has been written by Jacqueline Postma (2003).

The photograph we will focus on (see Figure 1), was made between 1897 and 1915. In the picture, we see eleven people on the veranda of a house, on what seems to be a sunny day. Four are white European women, attired in long dresses, two of whom wear a straw hat with a ribbon. Seven people are black, mostly young men, Surinamese men. One of them is standing, like the four women. The other six sit on chairs and benches in a half circle around a piece of leather. Most of them wear an apron and have a tool, shoe, or a bristle in their hands; one of them is sitting be-

Figure 1. Shoemakers and staff at New Bethesda, Suriname, before 1915. Collection H.W. Bosman. Photographer unknown (Augusta Curiel). Photograph Courtesy National Museum of World Cultures (TM-10019121).

hind a shoe stitching machine. One young man, or—better—a boy, has his hand bandaged, and one man is wearing special sized shoes; the boy and the man with the special sized shoes are nearest the camera, and are therefore clearly visible. Seven people are looking in the camera, three are looking in another direction, and one man turns his gaze down. (Collection National Museum of World Cultures. Object nr. TM-10019121. Copy of original dry gelatine glass negative. See also www.collectie.wereldculturen.nl and look for "Schoenmakers in de leprozenkolonie Nieuw Bethesda". The same photograph is in the Image collection of KITLV, (http://media-kitlv.nl) collection number 7655).

Can we understand this photograph as a depiction of agency of the "others within"? As was said, we could recognize the dominant image of people with leprosy who are isolated by exclusion within a colonial context; but is this actually what is at stake in this photograph? In this photograph, the people with leprosy, their tools, and their working materials are center stage. The European women—nurses of Bethesda and, probably, in the middle, the Director's wife—enclose the group. The four women and the man who stands, maybe a supervisor, do not perform a role; they seem there only at the request of the photographer. Their position in the photograph suggests they do not suffer from leprosy. The sitting men re-enact their craft; they seem to stop working only for the moment the photograph is taken. Their position in the photograph suggests they have leprosy indeed. We suspect the photographer has staged the arrangement because a veranda was not often used as a working place, and because the number of men seems more than needed for the number of shoes and the size of the piece of leather, but—in this photograph—the men are working men. So, in this photograph, it is not immediately clear who is the "other" because no act of "othering" can be observed. In fact, we should doubt whether a preconceived framing of people within the colonies as "others" (cf. Stoler, 2009) helps us analyse the photograph.

3. Framing, Making and Circulating

First, we have a closer look at how this picture is framed; that—according to Edwards—is the first defining moment of the photograph (2001, p. 20). The veranda, the garden, and the wall of the house frame the image. The stair, balcony fencing, and wooden pillars indicate that the veranda is above ground level. But we do not see the wider world to which this particular place and particular people belong, which makes clear that Bethesda is a closed off place on the margins of Surinamese society. People with leprosy were expected—or forced—to live apart. Bethesda was a microcosm in itself. The nurses were part of the community, but had more freedom of movement since they were not infected with leprosy. As we turn our attention within the frame of the photograph, the presence of nurses and shoemakers underlines a difference we know from the wider world—namely the difference between white colonizers and black colonised—as well as (we come back to this later) a difference between abled and disabled people. To depict people with leprosy at work, the presence of nurses is—strictly speaking—unnecessary. The nurses are not skilled shoe makers, but they volunteered to be part of this photograph, or the photographer invited them because—without them—the picture would be incomplete. People with leprosy need supervision, the photograph seems to suggest. The nurses' presence within the frame limits our ability to see the shoemakers as independent, to see their agency.

What can we learn about agency from the second defining moment, the making of the photo? The identity of the photographer is unknown. Because of the photograph's quality, and because there exist comparable photographs of other aspects of Bethesda from the beginning of the twentieth century, it seems likely that the management of Bethesda hired a professional photographer like Augusta Curiel—who also made photographs of Bethesda, which circulated as post cards—to make their project visible (Van Dijk, Van Petten-van Charante, Van Putten, & de Jonge, 2007; Weiss, 1915). Regardless, there seems no real interaction between the people in the photograph and the photographer; perhaps the line of vision adopted by all in the composition was under the direction of the photographer, standing at the other side of the veranda. Some people are looking into the lens, some are staring or looking in another direction, and one man turns his gaze down. Although there is little interaction, the moment the photograph is captured could be the moment in which we register—through their looks—the agency of the "others". Like other photographs in the Tropenmuseum, this photograph probably presented a harmonious picture of Bethesda, but the men had—in general—more serious-looking faces than the women, which hints of the situation's forced character. Moreover, the man in front, with his eyes downwards, seems to wish to ignore the whole performance. So in the interaction between photographer and sitters at the moment the photograph was captured, we can register something like the agency of the "other within". The performance seems forced.

The third defining moment is the circulation of the printed image as object or artefact (Edwards, 2001; Edwards & Hart, 2004; Jordanova, 2012, p. 131). The photograph was part of a collection that was donated to the museum by H.W. Bosman from The Hague in 1917 and 1919. The collection, of photographs from the Dutch colonies in the "East" and the "West", is very diverse. So far we could not trace the journey of this specific photograph from Suriname to the collection in the Tropenmuseum, but we can give one example of the distribution of the image at the time of its making and the audiences who saw it, and that might also explain how it entered the museum collection. This photograph was reproduced in the illustrated travelogue *Vier maanden in*

Suriname ("Four months in Suriname", 1915) by H. Weiss, and published by the Dutch reformed publisher Callenbach, with photo clichés made by De Bussy in Amsterdam. The photographs in the collection might have come via De Bussy since various other photographs in Weiss's travelogue ended up in the same collection.

Weiss was a protestant missionary of the Moravian Brothers, and had worked in Suriname in various capacities since 1896, among others as the Director of Bethesda. He returned to Europe when he became ill, but revisited Suriname (and Bethesda) in 1914. In his account of his visit to Bethesda, illustrated with 14 photographs (Weiss, 1915, pp. 61–72) Weiss emphasizes the modern progress visible in the institution, and underscores that today's Bethesda adheres to its policy of voluntary enrolment. The chapter is illustrated by pictures of people with leprosy, including the photograph of the shoemakers (Weiss, 1915, p. 70). Other photographs depict the infrastructure of the place (roads, school, church, houses of the European staff and nurses), the bridge providing entrance to the "lepers village", and a picture of the Steamer "Paramaribo" anchored in the Suriname river off Bethesda. Weiss does not refer to the pictures, but has added short captions to them like "view of Bethesda from the Director's house, or "Our lepers" (caption to a photograph of children climbing a tree). The photograph taken on the veranda is described as the manufacturing of shoes by lepers in Bethesda ("Het vervaardigen van schoenen door melaatschen op Bethesda").

In using this photograph as one of his illustrations, the author probably wanted to highlight one of the activities that make Bethesda "not a place of whining and complaining, no, here people are living together who know that their life, although it is still so painful, has meaning and purpose" (Weiss, 1915, p. 70, our translation). The caption puts emphasis on the working men, producing shoes. In the book's context, the picture makes especially clear how the missionary—from religious motivation—frames the people he cares about as "others" who are supposed to have their own agency within the civilizing mission of both modern medical care and conversion. The travelogue, which circulated among his religious community in the Netherlands, presents the printed image as a materialization of the voluntary internal colonialism of the leprosarium within a strict colonial order (cf. Roque & Wagner, 2012, pp. 10–11). This presentation is unchanged when one reads the caption and explanatory text to the digital image in the Tropenmuseum database.

4. Alternative Interpretation

By looking for the agency of the "other", we have more or less chosen the interpretative strategy that "reads colonial documents [in our case, images] against the grain", which means being critical towards the original intention (Roque & Wagner, 2012, p. 18). Following Edwards (2001), we have tried "to identify in colonial accounts the words, visions and agency of indigenous people" (Roque & Wagner, 2012, p. 18). The result seems disappointing: in terms of framing, the photograph above shows all colonial agency, with slight evidence that the shoe makers are not at ease during the making of the photograph. A copy of the glass negative—inserted as an object in the Colonial Museum collection in Amsterdam—as an image in the normative travelogue of a contemporary leading missionary and as a digitized image in a collections database reinforces what we already know. At best, the analysis is critical towards the people with power and "represent[s] the subaltern [or the marginalized] in a way that is sensitive to their silence" (Spivak, quoted by Legêne, 2013, pp. 238–239). But as we asked earlier, might it be possible to get beyond sensitivity to their silence through a deeper understanding of their agency in photographs and objects? Edwards' method might help circumvent the colonial order with its fixed categories (Legêne, 2013, pp. 241–242). The investigation of visual and material sources in general can contribute to dealing with Gyan Prakash's question of "how the history of colonialism and colonialism's disciplining of history can be shaken loose from the categories and ideas it produced" (Prakash, 1994, quoted in Legêne, 2013, p. 237), and—in particular—how we go beyond the image of silent suffering.

Our disability studies approach makes evident that analyzing a photograph makes one extremely aware of categories. Because we had to describe an image in words, we became aware of the broad range of possible formulations, and therefore the contingency of the categories involved. To quote Edwards (2001, p. 20), "Photography is like ritual or theatre because it is between reality, a physical world, and imagination, dealing not only with a world of facts, but the world of possibilities". However, it also became clear that it is not easy to go beyond the fixed colonial order. By analyzing the photograph's "defining moments", the familiar categories pop up and determine our investigation. Therefore, we will recapture our case study through an alternative strategy; we will draw, inspired by ANT, the attention from the "other" to the non-human actors or things and how they interact with each other and with human actors (cf. Mak, 2012; Mol, 2002).

Let us start by looking at "leprosy" within the frame of this photograph. A disease like leprosy cannot be understood as simply existing, as Annemarie Mol has argued (Mol, 2002; Ruberg & Clever, 2014). What leprosy is depends of the context in which it is enacted. Diseases like leprosy are multiple. At the same time, people regularly use one word for multiple enactments: they enact a disease as a "virtual common object" (Mol, 2002; Ruberg & Clever, 2014). If we look again at the photograph discussed here, leprosy is not clearly visible, but—because of the caption in Weiss' travelogue—we know the whole image is unthinkable without that virtual common object. Leprosy is the common denominator of these humans, their objects, the structures, and nature together. Without leprosy, there is no reason to build a leprosarium, to wear and make adapted shoes, to have nurses. Even though the overall context of Bethesda is religiously informed, all elements of the photograph hang around leprosy; the other way around, all these elements enact leprosy in a particular way, namely as a disease that can cause a disabled body that can still be productive. The non-human actor of the stitching machine is especially important here. In all the "defining moments" (the framing, making, and usage of the photograph) this machine, together with tools and leather, enables the enactment of the disabled body as a productive body. The sewing machine is a call to action.

By putting leprosy center stage, we emphasize the actors' interdependence (Reindal, 1999) and go beyond the questions of how independent or not the actors are, who is an active agent, and who not. The people with leprosy are in need of nurses, and the nurses are in need of people with leprosy. Our emphasis on such relations has similarities with a strategy that "is concerned with the exploration of the actual cross-cultural encounter and material practices in which colonial knowledge is grounded and embedded" (Roque & Wagner, 2012, pp. 19–20). However, we hesitate to use here the term "cross-cultural encounters" because this is not so much about ethnic cultures as about "shared work", with the aim of "compensating for inabilities" (Winance, 2010). Our point is similar to the plea of Roque and Wagner for an "entwined reality" of "indigenous and colonial worlds" (Roque & Wagner, 2012, p. 19), but our hesitation has to do with our reluctance to reaffirm colonial categories (as we did in our first analysis of the photograph). Plenty of images of the productive disabled body from a Western context (e.g. Van Trigt, 2013) make clear that the bodies in this picture are not (only) enacted as white and black bodies (bringing into being the colonial category of race or ethnicity), but (also) as disabled and abled bodies (bringing into being another dichotomy). There is an intersection of concepts at stake here, which was overlooked in our first analysis, and which the missionary wants us to see not as dichotomy but as rooted in common religious views.

5. Agency

We argue that looking for the agency of the people within this picture as "other" is not the best way to interpret this photograph. That does not mean they do not play a role of importance; on the contrary, they are—with other actors—involved in the enactment of the disabled but productive body. This complex embeddedness of actors in networks tends also to be overlooked in the historiography of disability, which focuses on tracing or granting agency. In a recent discussion about medical and disability history, Kudlick (2013, p. 551) states,

> "Even if our subfields share some of the same topics, the U.S. disability history approach will always come back to two core political ideas, both rooted in the disability rights movement: a need to challenge prevailing assumptions about disability, and the importance of granting people with disabilities historical agency."

Kudlick's aim of "granting agency" is comparable with the search for marginalized or "other" perspectives, and is—in our opinion (cf. Van Trigt, 2016, in press)—in need of an alternative. As Galis (2011) points out, the rational, independent modern subject is an important part of the disability rights movement. Independence is the prime goal because people with disabilities are often treated as dependent, in need of care. The past, as sources like photographs also tell us, tends to reflect the dependency of people with disabilities because the dominant focus of the sources emphasizes caring for people with disabilities. Although Kudlick's appeal for agency does not necessarily imply a "rational independent modern subject", it is—as Pieter Verstraete (2007, 2012) has argued—an important characteristic of (new) disability history.

In our approach to visual sources of the colonial past, ANT provides a good alternative, with a many-sided approach, to agency because of the broad range of (non-)human actors that can be taken into account. Actors are always part of a network in which they are related to other human and non-human actors. Agency is part of these relations. Bruno Latour's advice to "follow the actors" (Latour, 2005) means that researchers might only follow the actors in power, but this is not necessarily the case. On the contrary, ANT enables a rich analysis that takes account of a broad range of actors. This approach of agency is, in our opinion, also preferable to approaches that—often inspired by Foucault—criticize the independent subject only by pointing towards ways the subject is governed.

6. Multiplicity

But what, exactly, does it mean that people with leprosy are involved with other actors in the enactment of the disabled, but productive body? This brings us to the question of how this photograph relates to the historic context of lepers in Bethesda, or—more generally—in Suriname. Slightly different from Edwards and Jordanova, we do not want to underline the constructed character of the photograph too much. We have no reason to doubt the (historic) events surrounding the productive body as enacted in this photograph, not only because we know from other sources that shoe manufacturing was an important activity at Bethesda to which people with leprosy contributed (Postma, 2003, pp. 74–75; Van Hinte-Rustwijk & Van Steenderen-Rustwijk, 2003, pp. 18–19), but also because we consider this enactment as one way "to do reality". In this photograph, we see what some people with leprosy are doing a couple of hours a day. In other (in this case, available) photographs and other sources, the bodies of people with leprosy were enacted in other ways (look for lepra/leprosy in the museum collection), thanks to other actors to which they were related and practices in which they took part. The body—

in our opinion—has to be approached as a relational rather than natural object; categories related to the body are unstable (Mak, 2012; M'Charek, 2010). Inspired by ANT, we try to understand reality as multiple, and to approach the body in its multiplicity (Mol, 2002). Bodies and disease have to be enacted, and never simply "are"; "they appear, gain shape and are manifested through a whole range of different techniques, practices and routines" (Mak, 2012, p. 6). The consequence of understanding reality as multiple is that different realities and bodies co-exist (Mak, 2012, p. 6; Mol, 2010, p. 264).

The method we followed in the first part of the paper has the disadvantage—at least in the way we used it—of prompting the historian to construct a "real" context from the "real" looking photograph that tends (unintentionally) to reaffirm existing categories. Alternatively, if the photograph is approached using Actor-Network-Theory (ANT, see Mol, 2010; Latour, 2005), a reality is enacted that is both made and real (M'Charek, 2010) and co-exists with other realities. To put it less abstractly: in this photograph, the bodies of people with leprosy are enacted as productive bodies, whereas—in other photographs—the bodies of people with leprosy may be enacted as ill, or as black, or as sharing religious views with others without leprosy. The ANT assumption that the reality enacted in the photograph is both made and real prevents a simplistic interpretation (as representing a fixed historical context) and enables one to see how reality is constructed without assuming a reality behind the construction. So—for example—in our case study, one might say that the forced character of the performance—as mentioned above in analyzing the moment of making—is not forced or constructed in the sense of being coerced, but forced in the sense of having the people with leprosy stop their daily work and perform that work for distant others.

7. Conclusion

The central question of this article is, "How can we write histories of people with disabilities as part of the history of the 'humanitarian cloud' in a way that goes beyond the dominant image of people with disabilities as marginalized people who suffer silently and have no agency?" We have argued that existing methods that trace the agency of subalterns tend to underline existing categorizations and consequently underline (even if critically) the image of a people who have no unmediated voice in history. Moreover, it was difficult to address the concept of disability through existing methods. Nevertheless, as we argued in the second part of our article, the heuristic use of ANT can help address disability in the history of humanitarianism and overcome the dominant image of people with disabilities as lacking agency. Our case study has shown a practice that should not only be understood through the dichotomy between active and white, on the one hand, and passive and black on the other (Edwards, 2014, p. 173). Instead, it shows how—at the beginning of the twentieth century—some people with leprosy in Suriname were, by manufacturing adapted shoes, enacting their bodies just as did disabled people in—for example—the Netherlands. Therefore, if we look at the intersection of concepts, and we take into consideration the possibility of agency within the network of humans and non-humans, photographs are more than worthy of our investigation. Probably they cannot deliver a final answer to Gyan Prakash's question on shaking loose colonialism's history and colonialism's disciplining of history in its produced categories and ideas. However, photographs have the potential to destabilize existing categories and ideas, since they allow for so many perspectives on the "humanitarian cloud" around human rights. They underline and make visible that approaching the non-human as more than just context, but also as co-constitutive of mutual dependencies, will thoroughly affect the history of the humanitarian cloud.

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Conflict of Interests

The authors declare no conflict of interests.

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