Inclusion of persons with disabilities in Flanders. A 'participatory' research project on personal narratives, the representation of persons with disabilities in the media and political participation of persons with an intellectual disability.

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Preface

This book is the result of a compelling journey.

It all started with the demand of the Policy Research Centre on Equality Policies ('Steunpunt Gelijkekansenbeleid') of the Flemish Government to collect research material in an attempt to evaluate the inclusion of citizens with a disability in Flanders. An important reference framework for this question is the Convention on the Rights of Persons with Disabilities, formally ratified in 2009 by Belgium. This question spurred us, Disability Studies at Ghent University, together with the Department of Sociology at the University of Antwerp, on to conduct a doctoral research on this theme.

At the same time, the video work of the Turkish artist Kutluğ Ataman was exposed at Bilbao's Guggenheim Museum (Küba, 2011). Ataman spent more than two years getting to know the inhabitants of Küba, a neighborhood in Istanbul, and filming them talk. Forty of these monologues were shown on 40 television sets. It was an island of many narratives. The viewer walks through these, haphazardly chooses which subject's story to listen to and leaves with unique experiences and an understanding of what the story of *Küba* is. His work served as a source of inspiration for our research, as he highlights the importance of -sometimes contradictory- voices and and lets us think about and search for various 'entrances' to study complex phenomena.

In this dissertation, we examine some critical fundamentals of inclusion of persons with disabilities: personal narratives of persons with disabilities, the representation of persons with disabilities in the media and the political participation of persons with an intellectual disability. Each chapter underlines the importance of participation of people with disabilities at every step of the process. Besides, we provide a way to debate some of the issues that arise in doing inclusive research. Hence, this doctoral research is as much about process as end result. Beside this dissertation, a website has been created with a video-collection of personal narratives of persons with disabilities talking about inclusion/exclusion (www.zondergrenzen.be). Via various entrances, the viewer can choose which research material to look and in what order.

Before continuing, we want to give a quick background of the main basic assumptions underlying this dissertation which we listed at the beginning of the research process, and is in parallel with the UN Convention on the Rights of Persons with Disabilities: (a) research results should support the promotion and protection of the full and equal enjoyment of all human rights and

fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity; (b) persons with disabilities are no longer viewed as 'objects' of charity, medical treatment and social protection, rather as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society; (c) disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on a basis of equality with others; (d) we want to have respect for difference and accept persons with disabilities as part of human diversity; (e) we believe that full and effective participation and inclusion are important to empower individuals and to enrich society; (f) all activities (also research) should include the participation of persons with disabilities in parallel with the slogan: 'Nothing About Us Without Us'.

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This dissertation could not have been accomplished without the support of many people. Working as a researcher was a slow maturation process. During the past five years, these people inspired and encouraged me time and again.

In particular, I owe much gratitude to:

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The other members of the guidance commission, Professor Eva Brems, Professor Maria De Bie and Professor Mieke Van Houtte. Your constructive and critical reflections sharpened my view and nourished my desire to keep on searching.

The colleagues at the Department of Special Needs Education. I really felt supported in the past period and this was heartwarming for me. I'm very thankful for companioning me in my research process. In particular, I want to thank my companions of the *Jardin*. Being able to share the struggles, doubts and enthusiasm in the whole process was relieving. I feel incredibly privileged to have you all as close colleagues and friends. Besides, I want to express my gratitude to Stephanie Claus, Karima El Boujaddayni and

Suzanne Verkuijl for their good support while replacing me when I was on maternity leave. And finally, Susan, as an 'outsider' from the Department of Communication Sciences, you felt as a really close ally. Thank you all for your presence in a variety of forms.

All the colleagues, students, practitioners and organizations in the field with whom I worked the past years: Professor Hilde Van Den Bulck and other colleagues of the University of Antwerp, Professor Pieter Verstraete, Onze Nieuwe Toekomst, GRIP, UNIA, VRT, Demos, Han De Bruijn and the Flemish Department for Equal Opportunities, the Diversity Unit of the Flemish Government, Wouter Coppens, Ruben Boidin, and others. I hope this work can bring fuel for further dialogue and projects.

This research project could not have been realized without the support and funding of the Policy Research Centre on Equality Policies (Steunpunt Gelijkekansenbeleid). Many thanks for the confidence and the opportunities to work closely with many interdisciplinary and interesting researchers and inspiring discussions on equality, human rights and intersectionality.

All the persons who shared their experiences and stories with me…

Let me begin with Sofie. When you came across when I was a student, it seemed like a coincidence at the time. Now I understand I would never have entered the process of a doctoral program and this dissertation without you. Companioning you, experiencing injustice in your fight for inclusion and actively standing in the wind, was a huge lesson and important facilitator for my work.

Besides, I want to thank all the people of Our New Future (Onze Nieuwe Toekomst). I experience intensively how powerful the appeal of self-advocates is and how much wisdom you receive in actively listening to it. From I was a student, you made small ruptures in my everyday live. This organization offers me a space where I can learn and work together through trial and error. I'm always very pleased to receive encouraging support from all of you.

Lastly, but of very great importance, all my gratitude to all the participants of this research project. In the beginning, I couldn't see how to do research and make video narratives without being intrusive. How could I avoid an unbalanced representation? How could I make sure people didn't get alienated from the research? For what higher interest would I be filming stories? What if people were not always aware of the presence of the camera

and even less of the impact of its images? Then… you started to encourage me. If I had such scruples, some of you said, it was a good sign. I shouldn't think, certain of you said, that just because you have a disability, you were going to let the camera use you as tools or you were going to be passive sideliners. You played with concepts, categories, the camera and the editing. You decided what to show and what not. You encouraged me to use your stories and to bring it in public.

The processes we engaged with were complex, ungraspable and still ongoing. We were working a lot together, interpreting situations, images and stories. I learned to see with new eyes and to stick to the concrete when I was thinking about inclusion. While working together, there was often no preconception of what to do. This resulted in many ways of sharing something, all of incredible value. I realize that a lot of what we did came down to building a relationship of trust and to listening very carefully. In this dissertation, I have been talking a lot about the relationship with you, and that is no coincidence. I believe that is the actual subject of the research. Rather than doing research about, I've done research with and thanks to you. This research is about what connects us to the other, and about what the other can reveal to us about ourselves.

My family and closest friends. You were very supportive on all fronts. I got a great help with the practical correction of this dissertation (thank you papa, Jacqueline, Sarah and Inge), but also with the pats on my back, home made cinnamon rolls, encouraging words, last-minute babysitting, etc. My friends get a special place in my heart: when we are together, incredible things happen. Thank you to my parents, for always supporting me in the choices I made and for making me feel safe to dive in somewhere.

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Chapter 1

Introduction

Abstract

In this general introduction, disability is conceptualized from a Disability Studies perspective, with attention for the paradigmatic developments over time. Moreover, the research theme of this dissertation is situated in a broader societal and theoretical context. We discuss how the research is embedded in the human rights perspective, with special attention to the United Nations Convention on the Rights of Persons with Disabilities and the capability approach of philosopher Martha Nussbaum. In order to build towards a comprehensive understanding of the evaluation of inclusion of persons with a disability, we connect with the Disability Rights Promotion International (DRPI) model, focusing on three key areas: individual experiences, media and systems. Following this DRPI model, we formulate our central research aims and questions. Finally, the research design and methodology of the different sub-studies are described, together with some ethical considerations. We conclude with a brief outline of the thesis.

1.1 Defining disability?!

The question of defining 'disability' occurred frequently during the research period and remains knotty, which shows its remaining complexity. The interpretation of the concept is evolving over time and subject to major paradigm shifts. In the growing tradition of Disability Studies, 'disability' is defined as a fundamentally social, cultural, political and relational phenomenon (Barton, 1996; Davis, 2002; Taylor, 2003; Danforth & Gabel, 2007; Devlieger, Pfeiffer, & Rusch, 2003). Opposed to clinical, medical or therapeutic understandings of disability, Disability Studies concentrates on how disability is defined and represented in society. From this perspective, disability is not an essential characteristic that exists in the person so defined, but a construct that finds its meaning in social and cultural contexts (Taylor, 2003). Yet there have always been many ways of conceiving disability. Constructing 'models' of disability and debating their existence and prominence has been an enduring obsession in the past decades.

The medical model is rooted in an emphasis on clinical diagnosis and thinking in terms of restrictions, deficits, curing, treating, rehabilitating and segregating people with disabilities. "In Disability Studies, the disability-as-deficit notion is referred to as a clinical or medical model and is rejected as the basis for understanding the lived experiences of disabled people because it tends to pathologize difference and rely upon expert knowledge to remediate difference" (Gabel, 2005, p.2). As a reaction, the social model of disability identifies disability as a form of social oppression (Finkelstein,

1980). Oliver (1990, p.32) points out that "it is not the individual limitations, of whatever kind, which are the cause of the problem, but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization". Without denying oppression and marginalization of persons with disabilities in society, disability is far more complex. Interpreting disability only from a social perspective, disregards the body and cognitive abilities (Barnes, Oliver, & Barton, 2002; Marks, 1999; Turner, 2001). Without ignoring the social aspects of disability, a more complete understanding of disability as social concept is needed, and a recognition of individual experiences of the body over time and in variable circumstances (Crow, 1996).

Consequently, we draw on a postmodern version of Disability Studies where multiple models of disability (medical, social, moral, etc.) are considered to have their own expertise and right to exist. From this perspective, rather than elevating one dominant model, different models can be combined. We recognize the existence of the different understandings and readings of disability (Goodley & Runswick-Cole, 2012) and undertake critical reflection of both positive and negative sides of each perspective. Shakespeare and Watson (2002, p.19) explain: "For us, disability is the quintessential post-modern concept, because it is so complex, so variable, so contingent and so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is multiplicity, a plurality." Disability cannot be conceptualized in dualistic thinking (in terms of 'or'), but rather in thinking in terms of 'and', it constitutes as sites of fluid construction and creativity rather than determination.

In this vein, the intersectional theory offers us a good framework in this study, which prevents us from slipping into the trap of essentialism and assuming that people fall into one or two categories while realities are much more complex (Jacob, Köbsell, & Wollrad, 2010; Raab, 2007). This intersectional framework stresses the need to connect disability to gender, age, sexuality, income, and other vectors of power; and perceive them as mutually constitutive processes. It provides important insights into the complexity and multi-layeredness of people's lives and situations and can help us unmask the taken-for-granted knowledge that only reinforces hierarchies/exclusions. In promoting this openness, we want to challenge the naivety of believing in a reality that exists *out there* and the tendency of certain representations and grand narratives to masquerade as universal and objective truths. Disability has no essential, fixed or true meaning. Hence, we seek to question the archetype of the autonomous, independent, able-bodied citizen and embrace the radical potential of disability to trouble and reframe narrow conceptions of what is conceived as 'normal' and 'human'

(cf. Goodley & Runswick-Cole, 2014). Throughout the dissertation, we elaborate more on this intersectional approach, especially in chapter six and in the conclusions.

1.2 A Human Rights Perspective

1.2.1 Human Rights for Persons with Disabilities

This dissertation is entrenched in the human rights discourse. People with disabilities are part of the biggest minority group in the world, constituting around 15% of the population (World Report on Disability, 2011). Despite their high number, they seem invisible in most policy domains and with regard to the participation in society. For centuries, people with disabilities have been discriminated, excluded, mistreated, neglected, abused and institutionalized (Stiker, 1999). Dominant notions about bodily differences and about what it means to be human classify certain bodies as the norm, and define those who fall outside the norm as 'Other'.

Without assuming that recent trends, such as deinstitutionalization and inclusion (Bjarnason, 2011; Chenoweth & Stehlik 2004; Edgerton 1993), have solved all the problems, it is true that during the last 40 years there has been growing attention for the situation and human rights of persons with disabilities in society (Bérubé, 1996; Landsman, 1999; Rioux, Pinto, & Parekh, 2015; Taylor & Bogdan, 1989; Wolfensberger, 1972). On the international political forum, a major step towards promoting and protecting human rights of persons with disabilities is represented by the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This Convention is a legally binding international human rights treaty which aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (CRPD, article 1). Its general principles, as set out in article 3 of the Convention, provide a clear path for the international development agenda and include: non-discrimination, full and effective participation and inclusion in society, respect for difference and acceptance of persons with disabilities as part of human diversity and humanity, equality of opportunity, accessibility and equality between men and women – just to name a few. The Convention "embodies a 'paradigm shift', from the charitable and the medical approaches to disability to one which is firmly rooted in human rights" (OHCHR, 2013, p.1). 'Participation' and 'full inclusion' of persons with disabilities, is both a general principle of the CRPD, cutting across all issues, and a specific obligation of States

Parties anchored in article 4(3) of the Convention. These human rights standards "require free, active and meaningful participation in matters of public affairs, and participation is a necessary element for overcoming the exclusion of persons with disabilities in development planning and national programming" (OHCHR, 2013, p.3). Besides, States Parties have the obligation, as a matter of law, to involve and consult with persons with disabilities and their representative organizations in the development and implementation of legislation and policies to implement the Convention, and more generally in all decision-making processes affecting their lives. States Parties must also ensure that persons with disabilities and their representative organizations are involved and participate fully in monitoring the implementation of the Convention at the national level.

The Convention opened for signatures in March 2007 and entered into force in May 2008. Quite a few countries have signed and ratified this Convention. By now – begin November 2016 – 160 countries have signed the Convention and 168 countries have already ratified the Convention. Belgium signed the CRPD and the Optional Protocol on 30 March 2007 and formally ratified it on 2 July 2009. It came into force at the national level on 1 August 2009. For Belgium, this is a key event towards the recognition of the rights of people with a disability. From the moment a country has ratified the Convention on the Rights of Persons with Disabilities, it has the obligation to respect the content of the articles of the Convention. In practice, this means that it must adapt its entire legislation (laws, regulations, implementation decrees, etc.) to conform to the Convention. Similarly, any new legislation must respect the content of the Convention. Although the signing and the ratification of the Convention was an important step, as it shows Belgium's adherence to the principles of the Convention and its will to enforce them in the future in its own laws and regulations, the next steps will be even more important: Belgium will have to implement the Convention practically to the benefit of all persons with disabilities.

In this doctoral thesis, human rights and Disability Studies meet in the persuasion that human rights and social justice are of fundamental significance for Disability Studies. Van Hove and colleagues (2012) provide a working model for what Disability Studies can look like within the university curriculum. They reframe disability not as a problem but as an opportunity for dialogical action and reflection. Here, Disability Studies becomes a fundamental social project with a human rights discourse at its heart:

> "With Disability Studies, we join the human rights discourse. The UN Convention on the Rights of Persons with Disabilities ratified by Belgium in 2009 is an important guide for the way we support and

> encourage people. We are not in the position to say what is "reachable" (Barton and Oliver, 1997). Inclusive education and living are part of a human rights approach to social relations and conditions. The intentions and values involved relate to a vision of the whole society of which education is a part. Issues of social justice, equity and choice are central to the demands for inclusive education. Inclusive education is concerned with the well-being of all pupils, and schools should be welcoming institutions." (Van Hove, De Schauwer, Mortier, Claes, De Munck, Verstichele, Vandekinderen, Leyman, & Thienpondt, 2012).

This human rights approach is one of the central elements of the research, teaching and action at Disability Studies at Ghent University, where the resistance to change from an old-fashioned expert position to a human rights perspective seems to be a central challenge (Van Hove, et al., 2012). Instead of thinking about exclusion and parallel systems, this human rights perspective forces those involved to think about support systems for full participation and 'reasonable accommodations'. Hence, the UN Convention on the Rights of Persons with Disabilities is an important contextual framework for this study and a guide for the way we do research, approach, and work with people. The focus is not on the juridical dimension, but concerns a search for adapted methods, ethical positioning and the development of a diversity of strategies for the realization of a collective and individual learning in order to respect disability rights and to challenge oppression in a disabling society. Besides, this research supports the promotion and protection of the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and wants to promote respect for their inherent dignity. In addition, based on this human rights-based approach to disability, we want to abandon the idea of persons with disabilities as 'objects' of charity, medical treatment and social protection. Instead, persons with disabilities are 'subjects' with rights and active members of society, capable of claiming those rights and making decisions for their lives based on their free and informed consent. In this vein, our research activities include the participation of people with the label of a disability, as we engage in bottom-up research ventures that are inclusive towards them, in line with the United Nations Convention on the Rights of Persons with Disabilities.

1.2.2 Capability Approach

On the theoretical level there has been quite a shift as well, as illustrated by the capability approach of philosopher Martha Nussbaum (2006, 2009, 2010).

Disability rights and the capability approach are both frameworks to study social justice. Disability rights offer a framework for formal entitlements to primary resources (Nussbaum, 1997; Sen, 2005), while the capability approach can be considered as a framework to examine how people can make use of and transform these resources and commodities into concrete 'functionings', paying attention to the role of pedagogy and the concrete contexts of people. As such, rights and capabilities complement each other in a fundamental way.

Based on the work of Amartya Sen (1992, 1999), Nussbaum develops a 'capability theory', a theory of justice that questions what citizens should be able to do and be in order for a society to be just. Regarding persons with a disability, Nussbaum starts from the notion that they, if we truly regard them to be citizens of equal value, pose a challenge to philosophical theories of justice. Even the extremely broadminded social contract theory of John Rawls fails to hide the fact that the citizens that enter in a social contract with the state are expected to have a set of skills considered necessary for participation in the political life of the community (Stark, 2007). In contrast to the capability approach, Rawls' approach to social justice emphasizes the distribution of primary social goods based on fairness and equality of opportunity (Ruger, 2004). His theory is based on a view that conceptualizes people as equal, free and reasonable (Rawls, 1999). Such a conceptualization may exclude individuals who deviate from the 'norm' and have unique needs as a result (Benbow, Rudnick, Forchuk, & Edwards, 2014). Hence, Nussbaum argues that this Rawlsian theory is a deeply flawed basis for addressing questions of justice for persons with disabilities and cannot be sufficiently extended to deal with them. Sen continues that "the primary goods approach seems to take little note of the diversity of human beings. … If people were basically very similar, then an index of primary goods might be quite a good way of judging advantage. But, in fact, people seem to have very different needs varying with health, longevity, climatic conditions, location, work conditions, temperament, and even body size. … So what is being involved is not merely ignoring a few hard cases, but overlooking very widespread and real differences" (Sen, 1980, p.215).

A key question within this capability approach is: "What does a life worthy of human dignity require?" (Nussbaum, 2011, p.32). The main answer of the capability approach to this question is that human development should aim at increasing individual wellbeing and human flourishing by enabling access to the resources people need in order to choose and achieve what is important to them. The concern is based on what a person can do or become, conceptualizing human wellbeing as the substantive freedom -or capability- individuals have to choose and lead lives they value and have

reason to value. Capabilities are "notions of freedom in the positive sense: what real opportunities you have regarding the live you may lead" (Sen, 1987, p.36). These capabilities or "the abilities to achieve" (Sen, 1987, p.36) are closely linked but different to 'functionings', understood as achievements or outcomes that "reflect the various things a person may value doing or being" (Sen, 1999, p.75). Nussbaum (2011) suggests, at a bare minimum, 10 central capabilities, such as bodily health, control over one's own environment and affiliation with others. She says that this list might not be exhaustive, but nevertheless she argues that these capabilities are necessary components for "what people are actually able to do and to be, in a way informed by an intuitive idea of a life that is worthy of the dignity of a human being" (Nussbaum, 2006, p.70). According to Nussbaum, capabilites that should be supported by all democracies are:

1. Live the normal length of a human life.
2. Have good bodily health.
3. Have protection of bodily integrity.
4. Imagine, to think, and to reason (senses, imagination and thought).
5. Have attachments to things and persons outside ourselves (emotions).
6. Form a conception of the good and to engage in critical reflection about the planning of one's own life (practical reasoning).
7. Live for and in relation to others (affiliation).
8. Live with concern for and in relation to animals, plants, and the world of nature (other species).
9. Laugh, to play, to enjoy recreational activities (play).
10. Control one's environment:
    a. Political: being able to participate effectively in political choices that govern one's life; having the rights of political participation, free speech and freedom of association.
    b. Material: being able to hold property (both land and movable goods); having the right to seek employment on an equal basis with others.

The capability approach acknowledges the diversity among people and the impact this has upon the individual's ability to make equal use of the same resources and goods in society, as well as the unique needs that arise from such diversity (Robeyns, 2005). It is recognized that people do not possess equal abilities to make equal use of the same recourses. Resources have no value in themselves, but only in connection with human functioning, i.e. for what they actually can do and are for people (Watts & Ridley, 2012). So, the focus of the capability approach is to inquire into the needs individuals have for resources and their diverse abilities to convert resources into valuable functionings. Hence, the starting points of the capability approach are the various concrete situations of people in our society, rather than the integration of persons within the dominant normative institutions of our

society. The theory neither based on metaphysical and ethical doctrines about the good life, nor looking for consensus, but takes into account differences, plurality and openness to values of personal conceptions about the good (Mitra, 2006). Hence, the capability approach provides a fitting lens to answer questions around inclusion and exclusion and to understand experiences in the lives of persons with disabilities concerning this theme, with particular emphasis on justice, uniqueness, fairness and dignity.

1.2.3 Monitoring Human Rights: DRPI

Keeping in mind this human rights approach, we contemplate on how we can evaluate disability rights and the concepts of participation and inclusion of persons with a disability in Flanders. It is true that since the preparatory of the UN Convention on the Rights of People with Disabilities, the concept of 'participation' has gained ground and different ways are explored on how disability rights and 'participation' can be monitored. For example, the World Report on Disability (WHO, 2011) and other studies examine barriers and 'enabling environments'. In this WHO-report, instead of ascribing disability to individual functional limitations or impairments, society is seen as an important contributory factor in disabling people. Although this concept of full participation in society is becoming increasingly important and represents a key goal and vision for many stakeholders, research on inclusion, exclusion and participation of persons with disabilities in society is scarce, certainly starting from the perspective of people with a disability (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). Besides, Verdonschot et al. state that a lot of research does not clearly define participation, is seldom based on a theoretical framework, and restricts the study to limited aspects of participation.

Within this dissertation, we want to look critically at the intangible concept of participation because for several reasons. First, the concept is often not clearly defined (Verdonschot, et al., 2009): if we want to 'participate', we need to participate in what and to what extent? Second, the concept of participation sometimes acts as a synonym for austerity measures (Halvorsen, 2016) and is defined as a normative conception of citizenship (Roose & De Bie, 2007). Participation is often considered as an activation strategy and put forward as the key marker to recognize people as responsible citizens (Cox, 1998). Third, the concept is not easy to measure and there remains a critical need for participatory research that involves people with diverse disabilities and participation experiences in the grounded conceptualization of participation 'from within' (Hammel, Magasi,

Heinemann, Whiteneck, Bogner, & Rodriguez, 2008). Last, as Nussbaum states, participation is not a given status that a person can reach, but an active process that is shaped by trial and error and that requires interaction and support. It would be restrictive to lock participation into a notion that emphasizes *either/or*, *one* or the *other*, you are *in* or you are *out*.

It is clear that one questionnaire, one audit or one data collection method is not sufficient to build towards a comprehensive understanding of the rights of people with disabilities and the discrimination they face. In this research, we connect with the Disability Rights Promotion International (DRPI) model, a global collaborative model to establish a comprehensive, sustainable international system to monitor human rights of people with disabilities. Through partnerships with people in various fields from a number of countries, DRPI recognizes the many tasks needed to be accomplished in order to move toward a holistic monitoring of disability rights. To capture the depth and scope of the inclusion and participation of people with disabilities, DRPI has adopted three broad areas to investigate (cf. Figure 1).

Monitoring Individual Experiences
what people with disabilities tell us about their lives

HOLISTIC APPROACH

Monitoring Systems
what governments have or do not have on their books to protect, promote and fulfill the rights of people with disabilities

Monitoring Media
what the media says about people with disabilities
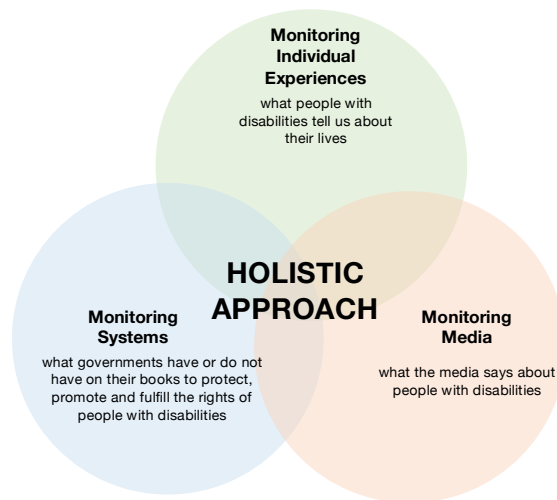
Figure 1: DRPI's holistic approach to monitoring (Rioux, Pinto, & Parekh, 2015)

DRPI uses a holistic approach to monitor disability rights, focusing on finding the facts in three key areas: individual experiences of persons with disabilities; media coverage of disability; and systemic measures taken to protect and promote disability rights (laws, policies, programs) (cf. http://drpi.research.yorku.ca).

- Monitoring *individual experiences* involves fact finding with respect to alleged individual violations of the human rights of people with disabilities. Monitoring human rights violations against people with disabilities will raise awareness of the nature and extent of violations and provide facts and evidence for advocacy efforts and improved government policies and laws.

- Monitoring *media* involves tracking media imagery and coverage of disability. The media have a powerful influence on the way disability is perceived and on the attitudes of the public towards people with disabilities. It is important to document myths and stereotypes perpetuated by media portrayals of persons with disabilities and also to highlight effective reporting of disability issues.

- Monitoring *systems* involves studying legislative frameworks. While laws may protect human rights, they may also violate human rights in some instances, either through a discriminatory provision or through silence on the rights of people with disabilities. Documenting the way laws violate or protect disability rights, and how relevanty laws are implemented and enforced, will inform struggles for legislative reform. Monitoring systems also involves tracking case law before the courts and statutory human rights bodies. Compiling and analyzing disability cases will generate evidence of how courts and other decision-making bodies, such as human rights commissions, address issues related to disability rights, interpret and enforce relevant laws, and use human rights law. Beyond laws and their enforcement, a broad range of government action has a direct impact on the lives of people with disabilities. Analyzing and documenting general government policies, programs, services and practices that violate human rights – either directly or indirectly – will provide evidence and awareness for change.

In order to paint a picture of the current situation faced by individuals with disabilities, human rights monitoring has been broken down into these areas to find discrete pieces of knowledge. The facts in each of these three key

areas tell us one piece of the story and, when combined, they provide a more complete picture of the inclusion of persons with disabilities. In this dissertation, we plug into this DRPI model and collect and report on information in each of the three areas. We will look at inclusion of persons with disabilities in Flanders from these three angles.

1.3 Research aims and research questions

As stated in the preface, the study originally aimed to present the empirical outcomes of a situation analysis of the inclusion of persons with disabilities in Flanders. However, throughout this dissertation, it became clear that following a straight course in this complex matter was impossible. Unique life stories and collaborative moments of research called us to step back from our certainties, listen to multiple perspectives and reflect on processes underlying this research. These reflections provided us handles for illuminating several perspectives and scrolling through complexity and coherence, without wanting to represent *the* truth or a consensus.

Therefore, the aim of this study is twofold. First, following the DRPI model, we want to examine the inclusion of persons with disabilities in Flanders through three dimensions: by focusing on a) personal narratives of persons with disabilities, b) on media representation of persons with disabilities, and c) on a concrete project of political participation of people with intellectual disabilities. Second, we want to reflect on research processes underlying this research. Consequently, both empirical outcomes on and contemplative reflections on research processes are described in this dissertation.

In our dissertation, we use broad and open-ended research questions because of the complexity and abstraction of the research theme. This minimises the risk of *a priori* cutting of meaningful information, as unanticipated answers can be extremely valuable. The specific questions the studies aim to answer are:

> RQ1. What do persons with disabilities tell us regarding inclusion and participation in Flanders? (chapter two & chapter six)

> RQ2. How are persons with disabilities represented in Flemish media? (chapter three & chapter four)

> RQ3. What can a concrete and local project regarding political participation of people with an intellectual disability in Flanders tell

us about structural success factors and barriers regarding inclusion and participation? (chapter five)

RQ4. How can we map complicated subjectivities in doing Disability Research with people with disabilities? (chapter two, chapter six & chapter seven)

The three broad areas of investigation, namely individual experiences, media, and systems are represented in the following Venn diagrams.

Monitoring Individual Experiences
what people with disabilities tell us about their lives

HOLISTIC APPROACH

Monitoring Systems
what governments have or do not have on their books to protect, promote and fulfill the rights of people with disabilities

Monitoring Media
what the media says about people with disabilities
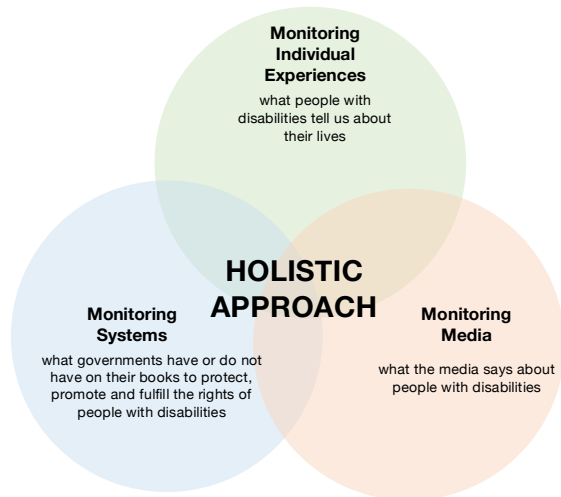
Figure 2: DRPI model (Rioux, Pinto, & Parekh, 2015)

Personal Narratives

RQ1
c.2,c.6

Complicated Subjectivities in doing Disability Studies Research

RQ 4
c.2, c.6, c.7

Political Participation

RQ 3
c.5

Media Representation

RQ 2
c.3, c.4
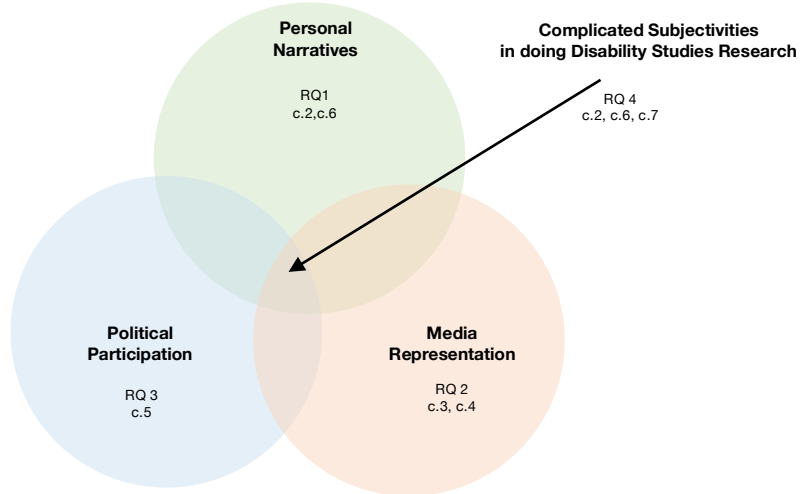
Figure 3: Study design

1.4 Study design

The research is subdivided into three studies, in parallel with the first three research questions. The fourth research question is answered through personal reflection on research processes underlying this research. More concrete details about the methodology can be found in the corresponding articles as depicted in figure 3.

1.4.1 Study 1: Personal Narratives

In the first study, personal narratives are collected to map the subjective stories of people with a disability concerning their inclusion and participation. Within this narrative research, 383 persons with disabilities were interviewed in Belgium and the Netherlands (339 in Flanders and 44 in the Netherlands) to grasp their personal experiences concerning inclusion/exclusion, including 202 men and 181 women, from a variety of background, age, abilities, and experiences. A questionnaire was composed with open-ended questions grouped under several themes that provided space for participants to discuss issues important to them. The questionnaire concerns two main questions: (a) 'give examples of moments or situations where you had the feeling that you were taken into account, that you were included, that people took you seriously'; (b) 'give examples of moments or situations where you felt discriminated against or oppressed'. All the interviews were video recorded, producing more than 500 hours of footage. Students of Ghent University and the University of Antwerp were called upon to assist with recruiting participants and interviewing them individually at a safe place of their choice. 'Viewing days' were organized, to open up the possibilities for participants to contribute to the research process and to interpret and analyze data. Besides these events, ideas and concerns were addressed through a continual dialogue and different meetings where both researcher and participants express views and together define meaning-making. Regarding the analysis of the (Flemish) narratives, it became clear that this was not a linear process. Important common patterns cutting across the multiple variations throughout the narratives were identified by the researcher, the participants, the supervisor, colleagues and students (Patton, 2002). Findings were then explored in depth and discussed. We used a retroductive coding process and analysis (Emerson, 2004), which involves an analysis that employs procedures that are simultaneously deductive and inductive. Retroduction implies "moving back and forth between narratives and theory, modifying original theoretical statements to fit into the narratives part and using pieces of narratives relevant to the emergent theoretical

concepts" (Emerson, 2004, p.458), a *plugging in* of theory with data (Jackson & Mazzei, 2012).

1.4.2 Study 2: Media Representation

The second study seeks to obtain insight into the representations of persons with disabilities in the media. We conducted two sub-studies for this research line. In the first sub-study, we investigated *who* is represented in different media. We obtained a baseline measure of disability, gender and age distribution across different sources of print media. A quantitative content analysis of sixteen magazines and seven newspapers during ten years (2003-2012) was conducted (n=14,529 articles). The second sub-study examines qualitatively *how* people with disabilities are portrayed, using a one year-sample (2012) of these data (n=184). By means of a participatory framing analysis, we tried to understand the dominant and alternative conceptualizations (frames and counter-frames) related to disability in the media.

1.4.3 Study 3: Political Participation

In the third study, a follow-up study is carried out to investigate the political participation of people with an intellectual disability in Flanders. This third study functions as an extreme case study in the conceptualization of inclusion and participation. We started with a participatory baseline study to explore the political participation of persons with an intellectual disability with regard to their involvement in political discussions in Flanders. These findings led the Flemish self-advocacy movement 'Our New Future' (ONT vzw, Onze Nieuwe Toekomst) to set up a concrete and local project to make sure that barriers to participation can be tackled. A participatory follow-up study of this concrete project was organized, in which a dozen of persons with intellectual disabilities in different local participation projects and their advisors who give them support were followed. Experiences and perspectives were gathered through multiple sources of data, making use of a variety of qualitative adapted methods; e.g. photo voice, portraiture, observations, case studies and interviewing. Following the cycle of action research (Bogdan & Biklen, 2006), much attention is given to critical success factors, strategies and barriers that support or hinder the participation.

1.4.4 Ethics

Our research reality -i.e. conducting research on participation, working with the lived experiences of persons with disabilities and establishing research collaborations with co-researchers with a disability- asked for continuous ethical considerations. Working as a researcher was a slow maturation process and several struggles went along with this. What was I going to look at? How could I include voices of persons with disabilities without organizing it 'in a hurry'? Whose voice is it really and is it mine to give? How could I find the right 'language touch' that helps to keep the research process transparent for all researchers and participants? How could I make sure that -due to research engagements- co-researchers with disabilities do not get alienated from the research process? How can I report about such a research process? For what higher interest would I be filming the vulnerable stories of people, intruding into their privacy, often not always aware of the presence of the camera and even less of the impact of its images? What am I going to do with the stories I will hear? Am I running the risk of reducing them or of assuming that they refer directly and unproblematically to *the reality*? Where shall the audience go with them? How to respond to emotional disclosures, sometimes with legal implications?

It became clear that these everyday ethical issues that arose in the doing of research could not be addressed in procedural research ethics. Although I do not wish to totally dismiss the role of professional codes in guiding ethical research practice, these 'ethics in practice' (Guillemin & Gillam, 2004) reminded me to be both mindful and active in protecting and respecting the rights and wishes of research participants. These unpredictable, often subtle, yet ethically important moments that came up in the field did not strictly fit under procedures or universal principles, but required relational ethics (Ellis, 2007). It involved acting from the heart and the mind, acknowledging my interpersonal bonds with others, and taking responsibility for actions and their consequences. It implied not holding on to static principles, but instead giving the story back, listening closely to what participants were saying, in an unfinalized dialogue, and remaining open to changing minds. It also implied an enduring reflecting on my own position, bringing myself in, together with my own story and mutual entanglements with others in the research. More concrete ethical precautions and thoughts are outlined in the next chapters, especially in chapters two, six and seven.

1.5 Outline of the thesis

This dissertation is a compilation of several manuscripts that have been submitted for publication, are under review, or are published. To make each of these manuscripts self-containing, the content of these chapters may

overlap. Some of the research questions are answered in several chapters, but above all, in the conclusions.

The next chapter after this, *chapter two*, focuses on the collected personal narratives on the inclusion and the exclusion of persons with disabilities. It highlights the importance of storytelling and personal narratives in research and underlines their performative and de-regulatory power.

Chapter three reports on the first part of the media study that discusses the media representation of persons with disabilities. In this study, we investigated who is represented in different print media, analyzing a range of magazines and newspapers during the period of ten years.

Chapter four describes the second part of the media study that addresses the way people with disabilities are represented by means of a framing analysis. Our aim is to understand the dominant and alternative conceptualizations (frames and counter-frames) related to disability in media.

Chapter five looks at a concrete and local project on political participation of people with intellectual disabilities. This study takes up the challenge of political rights and explores the political participation of persons with an intellectual disability and its structural success factors and barriers.

Chapter six brings in the intersectional framework in our research. In this chapter, we draw on the narrative study of this dissertation and reflect on intersectional research processes and emerging complexities and contradictions in personal life stories. We seek to challenge dominant assumptions about disability and try to deal with complexities and intersections of individual lives when people are talking about inclusion and exclusion.

Chapter seven addresses the basic assumption 'Nothing About Us Without Us' and reflects on some collaborative research processes in this research. This chapter puts a particular emphasis on the different modalities voice can have in the field of inclusive Disability Studies research.

Lastly, the *final chapter* attempts to present main empirical and contemplative conclusions and seeks to make sense of some central concepts of this thesis.

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Chapter 2

The Performative and Deregulatory Power of Stories[1]

Abstract

This chapter discusses some research findings of working with the narratives of people with disabilities on inclusion and participation. It shows us why stories are important and how working with stories as a researcher in Disability Studies can make a difference. The emphasis here is on the performative and deregulatory power of narratives, in relation to the work of the Turkish video artist Kutluğ Ataman, showing how closely art and Disability Studies can be intertwined with each other.

2.1 A narrative world

The world lives in and thrives on stories. Every human being has a part in all kinds of great and small stories, individual and collective, historical, fictional, realistic and surreal. As human beings we live in a world where we tell each other stories and in which we construct, are constructed and are 'told' through narratives. We interpret events and the world, by treating them as movements in a story and by searching for the story behind it or (re)constructing it. At the same time, we delve deeper into our own story and that of the other, developing new narratives together. In philosophical anthropology, this led to the development of narrative reflections on personal identity, among others in the work of authors as Hannah Arendt (1958) and Paul Ricoeur (1985). According to the narrative identity theory, stories are fruitful metaphors for describing one's personal identity, but people also actually derive and construct their identity through life stories (De Mul, 2000).

In the past decades, contemporary artists increasingly started to use storytelling in their work, and Kutluğ Atman is a perfect example of this. This contemporary Turkish artist uses video and film to give people a platform and portray them, or 'to stage speech' (Çavuş, 2011). Ataman starts from actual, specific stories that shape a person's life. According to this artist, narratives act as an anchor in our life - they are an undeniable necessity for life. We need narratives to look at the world and understand it: "If narration or story had not been present in human life, then human life would not exist at all. Storytelling is required by the human mind, it is just inevitable" (Çavuş, 2011). He argues that man needs narratives to construct life and give meaning to it. Ataman starts from the idea that a person is like a meshwork of narratives and that's why he uses storytelling as a starting point for all his artworks. He is not interested in capturing or representing reality or searching for deeper truths about people's lives. Instead, Ataman wants to understand how individuals fictionalize, reconstruct and manipulate reality. By allowing

hundreds of people to tell a story into a camera he wants to show the viewer, who is also the co-narrator, how identity is (re)constructed through the various stories, hallucinations, lies and testimonies he films. 'Identity' is a keyword in Ataman's work, in which he tries to break free from the existing, fixed categories and dichotomies, showing instead how the individual can reproduce and manipulate 'identity' in infinite ways. By documenting stories, Ataman wants to focus on identity as a complex phenomenon, highlighting differences within a community and openly discussing them (Peeters, 2006).

By working with narratives about the inclusion and exclusion of people with the label of a disability, we had the extraordinary opportunity as a researcher to become the viewer and co-narrator of countless stories in which people shared their heartfelt experiences in front of a camera. However, the speed with which the study was launched and with which we hoped to work through the stories was soon tempered by the nature of the stories themselves. Each of the images and dialogues originated in front of the video camera and forced us to slow down and stop, hesitate even. It soon became clear that storytelling can pack tremendous power and can knock down ideas that seem cast in stone with one well-aimed punch.

2.2 Performativity as a force

While listening to the different stories of people with disabilities, we soon realized that these are not a simple, neutral and transparent reflection of past experiences. While people tell their story, we gain access to their personal stories and reconstructions or transformations that start to take place in front of the camera. The stories are not static and clean, but instead are constructed and bring about something, like a performance would. People shape their own story, as is the case with Margreet, a 60-year-old woman, who describes herself as a retired kindergarten teacher and a Chiro (ed: Flemish youth movement) girl at heart. Margreet was diagnosed with fibromyalgia and chronic fatigue syndrome. On camera, Margreet literally rebuilds her life, reshaping as she moves through her narrative. As the narrator of her story, Margreet has an impact. She communicates with the intention to include the listener, here a student whose mother is a good friend of Margreet, in her narrative. As a result, the story is placed in a context, it is told at a particular time, by a particular person, to a particular person, in a particular setting. Margreet's story will change, depending on the context and time. Ultimately, however, Margreet always chooses what she wants to show and which aspects of the story she will (or will not) highlight. What she shows in front of the camera is variable, just as she does in her own life. Margreet shows that being different can be a positive thing, even

emphasizing this difference and defending her right to be different. She sings a personal 'protest song' before the camera ("*I'm no different than my neighbor, I don't like fuss, I am happy with my life, I'm average, I admit ... I don't give up, I don't give in, I always go all out, and sometimes I fall down, but who cares*") and while singing it, she completely identifies with the singer of this song. Margreet purposefully chose this anthem, as she calls it, and spent weeks rehearsing it in the run-up to the recording. She pulls out all the stops and wants to break free from fixed structures. She uses diversity in a positive way. At another point during the same video recording, Margreet takes a different approach to difference, when she tells us that she always goes shopping on the other side of the country so people will not recognize her in her wheelchair. She does not want to show her limitations, her disability to friends. At a later stage during the recording, she identifies with inspirational people with a disability in a television program. Hence, what Margreet shows us is variable and has been very strategically selected. Her 'identities' change, influence each other, are contradictory, and depend on time and the setting. It show how she reconstructs her own story and life while telling it. This supports the situation in which she can be who she wants to be, it contributes to her own survival. In this way, both the listener and the narrator are set into motion.

In other words, talking is a performative process, a form of action. It is not just about the world, but it also brings about something in the world. The notion of performativity is often associated with a linguistic act, whereby 'saying something also involves doing something', such as getting married or declaring war. In other words, performative utterances do not describe anything, not even an action. Here, the act of talking becomes an action. The emphasis is not on representation, but on the activity (Austin, 1961/1970). This performative aspect of stories prevents us from seeing narratives as closed and complete, they cannot be pinned down and fixed. The narratives instead reveal elements of spontaneous revelations, fabulation and imagination because they are continuously constructed. As a result, stories reveal their full extent before the camera. This makes us pay attention to complexity, contradictions, and a changing context in which people continually change and evolve.

In this context, it is interesting to consider the work of Judith Butler in which she states that (gender) identity is alternately appropriated and relinquished depending on the purpose of the moment (Butler, 1990). Due to its performative nature, gender cannot be conceived as an essential identity, but as something that is subject to and can change over time and depending on the place, despite the fact that gender tries to keep up the appearance of a solid identity. The content is not fixed, but is portrayed through actions, or "a

set of actions that are repeated within a very strict regulatory framework" (Butler, 1990, p.33). In this process of repetition, these actions are continually re-established and reconfirmed, and thus are produced and reproduced as a norm. In other words, Butler says that gender is established in a performative way.

In line with Butler's analysis of performative gender identity, disability can also be considered as a culturally constructed phenomenon, as a practice that originated in history and culture, which has a normative effect, which is produced and reproduced by performative processes. Individuals obtain disability by citing and repeating cultural norms regarding disability. Following this interpretation, disability identity is thus shaped by a performative act. It does not contain an invariable essence, but is created as a result of the subject's positioning. In this respect, difference can be considered as a construct and a continuous process, or as Dear et al (1997) state, difference (and therefore also disability) may be considered as a social and spatially constructed phenomenon in which various types of differences are continuously produced and reproduced by social and/or spatial boundaries.

The narrative construction of identity which come to the fore in Margreet's story offer an interesting perspective on constructs of disability. Based on the story, we can gain an insight into complex 'identity' constructs of people with disabilities and we can see how disability can be assumed, appropriated or switched off as an identification. The story shows how Margreet strategically and deliberately uses disability stereotypes and shows the active subject position that she adopts in the process of identity building.

One way of better understanding the performative power of stories is to look at the work of the artist Kutluğ Ataman, in which the concept of performativity takes on different meanings: the vigor of language, identity as a perpetual construction based on stories and self-staging, and the impact of his artwork (Peeters, 2006). Ataman points his camera at certain individuals and brings the personal subjective experiences of people to the fore. In *The Four Seasons of Veronica Read,* 2002, a British woman is portrayed who talks about her passion for the amaryllis flower that fills her small apartment. In *Stefan's room*, 2004, Stefan Naumann talks about his obsession with tropical moths of which he has amassed an enormous collection. Both narrators in these artworks discuss their experiences and activities in great detail, with an inexhaustible passion. The result is a seemingly endless monologue, in part because of the way Ataman has edited it. Veronica Read, for example, talks a lot about the characteristics of the amaryllis flower, about her gardening activities, about the diseases and pests that may affect

the bulbs, about how she must carefully pollinate them. She swiftly switches from one topic to another without pause. As a result, the viewer does not feel as they are watching a documentary or an interview with mutual dialogues, but instead are witnessing acts of self-revelation and self-construction, individuals who give meaning to their own existence in front of the camera. Stefan excitedly describes how caterpillars transform into butterflies, he talks about transformation, change, about how insects can become different. At the same time, Stefan almost reinvents himself by talking, and we see that he is undergoing a process of 'becoming' (Deleuze & Guattari, 1987) while he speaks. His language is not passive or a transparent representation of reality, but performative, and inventive even. The complex process and the transformation that Stefan undergoes, is also apparent in Ataman's video installation. Several video screens have been suspended around the viewer in an almost claustrophobic manner, thus creating an atmosphere of neurosis and obsession, and, at the same time, the impression of something that will soon hatch, as a metaphor for Stefan's inner world, which runs parallel to the transformation of the moths with which he shares his life.

In *Never in My Soul*, 2001, Ataman projects the story of Ceyhan Firat, who discusses life as a transsexual person, on six screens. It soon becomes clear that everything in her life is more complex than it seems. Firat tells us how she was abused by her father and by the police, about her relationship with her clients, her flight from Turkey to Switzerland. The way in which she stages her life in relation to the various contexts and gazes (that of Atatürk's lay state, that of modern Istanbul, of her Swiss surroundings, and the gaze of us as western art spectators) means Ataman has to adopt a more complex strategy (Peeters, 2006). Ataman portrays her in various guises on multiple screens and interweaves the original interview with a *re-performance* of what she says. It is a series of self-stagings in a variety of contexts that multiplies the possible differences in observation. The video installation thus highlights the complexity of identity and creates "a parallax view", as the artist calls it (Anton, 2003, p.16), that is similar to the parallax situation in which Firat finds herself.

Ataman succeeds in bringing the performative conception of identity into view by dwelling on the confusing multitude of stories and the emotions they evoke in those who tell them. In *Women Who Wear Wigs*, 1999, in which four women explain why they wear a wig - a well-known journalist who has cancer, a former political dissident who spent years fleeing, a Muslim student wearing a wig instead of a veil and a transsexual prostitute who is also a human rights activist - Ataman paints a picture of four women who live a concealed life or who do not conform to the dominant ideals of the visible body. They see the wig as an instrument that allows them to appear, and thus live, according to their beliefs. Ataman shows four different stories of

people who have in common the motive of the wig, as stories that continually evolve and which overthrow conventional social categories and relations.

This continuous transformation is also apparent in the stories of people with a disability. In these narratives, people show how they constantly change and look for ways out of the prevailing fixed frameworks, how they are constantly evolving and stage and reconfigure their lives in relation to various discourses. As a result, we can no longer refer to delineated, discreet differences. Difference thus becomes an ever-changing concept, an ever-changing reconstruction of one's own narratives, which constantly change and evolve depending on various contexts and the things that people experience in their lives (Massey, 2005). Intersectional thinking (Crenshaw, 1989) ties in closely with this, as fixed categories and oppositions can be broken through and can be seen as rather relative. The banning of the simple binary oppositions is also central to Atamans work and his "*metamorphic montage*" (Demos, 2010) allows him to portray processes of transformation and *differenciation*, which can be linked to the "*method of AND: this and then that*" as coined by Gilles Deleuze (2005):

> *It is the method of BETWEEN, "between two images", which does with away all cinema of the One. It is the method of AND, "this and then that", which does away with all the cinema of Being = is. Between two actions, between two affections, between two perceptions, between two visual images, between two sound images, between the sound and the visual: make the indiscernible, that is the frontier, visible. The whole undergoes a mutation, because it has ceased to the one-Being, in order to become the constitutive "and" of things, the constitutive between-two of images.* (pp. 174-175)

By focusing on this performative aspect in the analysis of narratives, on moments of spontaneous invention and fabrication, we pave the way for inconsistencies and de-regulation, which will be discussed further below.

2.3 De-regulation and points of entanglement

By working with narratives it soon became clear that none of the narratives represent uniform reflections or descriptions. Instead, these stories can confuse the viewer, leaving them with more questions than answers. The story of Timmy, a young man with a visual impairment, is a good example of this. The interviewer is very interested, listens carefully and really makes an effort to listen to the story, but then asks: "So how do you type? Do you use

a special keyboard?", at which Timmy looks straight into the camera and says dryly, "I touch type, just like you probably". (Ed: in Dutch the expression for touch-typing is "blind typen"). The interviewer is briefly embarrassed, turns silent and then has to search for her words for the next question. His answer to her question "How do you swim? What's it like in the pool?" is equally straight-forward, "I swim to the other side and back". Again the interviewer is stumped. Timmy's no-nonsense answers make her stutter (Allan, 2010) and have a disruptive effect. His story mixes up customary meanings and undermines her pre-established ideas.

Narratives are very important for adapting or even overturning the preconceived views and expectations that we all have. Taking the time to listen carefully is vital in this framework, which requires an enormous openness and an awareness of our own views and judgments or prejudices. While we have an opinion about everything, make statements, want to capture everything and classify it in categories, this requires us to have an openness about things we do not know yet, requires to relinquish concepts and start from scratch. It requires to allow confusion and to constantly think and rethink things while listening. Narrative research reveals the impact of our own prejudices to us, whereby we always expect other things and repeatedly stumble into other frameworks. In that sense, the narratives do not merely convey us to the experiences of inclusion and participation of persons with disabilities, but they also require us to participate and engage in self-analysis: it is about all of us and about our attitude to differences and diversity.

Ataman is also skilled at using 'disrupted' lives to unsettle dominant social categories and relationships. He uses the camera to search for simple, dignified perspectives and takes a lot of time for all the interviews, just like listening also requires a lot of time. Each time, the multiplicity of stories and voices evokes specificity and complexity. The disruption of experiences, not only of the people in Ataman's video installations, but also of the viewer, is key here. His works ask questions that are closely linked to, for example, a country like Turkey, and emphatically overturn certain fixed notions in this regard. The spectators are confronted with narratives that transcend a simple concept, also in part due to the considerable length of the videos, the complex narrative structure and the loops of the visual material, making it impossible to see where the video starts or ends. The viewer himself thus becomes a storyteller, fill in lacunas and makes connections with his or own narrative, or as the French philosopher Jacques Rancière put it (2007, p.279): "We don't need to turn spectators into actors. We do need to acknowledge that every spectator is already an actor in his own story and that every actor is in turn the spectator of the same kind of story". Ataman also explains how

he deliberately gives the viewer the opportunity to integrate what is offered in their own narrative: "By making *semiha b. unplugged,* 1997*,* almost eight hours long – it's about an entire life, after all - I wanted the audience to have to return to this piece again and again without ever being able to see the whole thing, and to be forced to make their own Semiha out of the fragments that they do see" (Anton, 2003, p. 16). In this story of Semiha Berksoy, a former Turkish opera singer, Ataman zooms in on contradiction, allowing the viewer to constantly gather new insights about this woman. Her story and performance highlight the perpetual change in her character, confusing the viewer. As a result, early assumptions shift in unexpected directions. Contradiction opens the subject to plurality and multiplicity, which caters to a more complex interpretation of identity. In that sense, Ataman runs counter to the concept of identity as defined in the Eighties and Nineties, in which minority groups were recognized, but often in highly simplified forms and categories (Demos, 2010). This led to stereotyping and the essentialization of difference, a harnessing of subjects in a straitjacket of a particular social category. Ataman's video installations challenge this polarized thinking, as for example in his work *Turkish Delight*, 2007 in which the artist points the camera at himself, mocking his 'exotic status' as a Turkish artist. Ataman appears on a gigantic screen, belly dancing, scantily dressed in a golden outfit wearing a woman's wig, looking slightly plump and crude, and dancing to traditional music. This portrait intentionally is toe curling, embarrassing and almost unbearable to watch. It undermines the stereotypical Western views of Turkey, while the artist shows how disguise and transformation can lead to the disruption of dominant social categories.

2.4 In conclusion: what narratives can teach us

The above research findings reveal the powerful position of researchers and their strong assumptions, which come into play when working with narratives, but also the fact that narrators are not just passive respondents.
Although we are trying to engage in critical reflection on disability and participatory research methods in the field of Disability Studies, we researchers are confronted with our own preconceptions, which are formed by the prevailing theoretical narrative about disability, or in the words of Oliver (1990) 'the grand theory of disability', where pathology and deficit thinking come strongly to the fore. Looking back at the stories of Margreet and Timmy, we should ask ourselves some questions: how do we researchers contribute to the construction or deconstruction of labels? Did these stories fulfill our expectations about disability? How do we portray these narratives? When do we decide to stop the camera, and how does this decision contribute to maintaining or opposing the grand theory of disability?

If we examine the interactions that occur in the stories more closely, we notice how these people play with the concept of identity, undermine the created constructs and resist our preconceived opinions. These 'counter-narratives' of disability challenge the dominant 'grand narrative'. We must thus also put the power and influence of researchers into perspective, because otherwise we run the risk of underestimating the power and influence of the narrators, which in turn would only strengthen the grand theory which sees people with disabilities as passive, incompetent and uninformative. The narrators therefore are never passive respondents, but can undermine, strengthen and construct research.

When working with and analyzing narratives as direct representations of the world, the risk exists that the performative and deregulatory aspects remain invisible in specific situations. What someone does by not saying certain words does not become visible, and words are analyzed as a story about the world, not as a story in the world (Pols, 2009; Riessman, 1990). The advent of postmodernism led to concepts such as truth being strongly questioned and to the proclamation of the end of the 'grand narratives', as Ataman shows in his work. His video installations express the production of several stories or truths, the truth of construction and contradiction and the truth of fiction. On the one hand, he can suspend the 'grand narratives' with the endless loops of his videos, the spatial design of his work, the multiplicity of stories and encounters that are linked to specific lives, demonstrating our inability to fully understand the subjects. On the other hand, he ensures that the viewer can move in and out of the monologues and is not a passive witness, but instead helps co-develop assumptions and stories. That said, this does not mean that we should succumb to a post-modern relativism and argue that there is no truth to the stories in this study or in Ataman's work. The narrators tell stories in which passion, desire, imagination and affect are reflected, which give meaning and structure to their lives and form a truth in itself. These elements are the driving forces behind *becoming* (Deleuze & Guattari, 1987, pp. 300-301), they allow movement and transformation, and have the ability to move and be moved (1987, p.261). In this context, Diedrich (2005, pp. 238-239) describes *desire* as "productive forces, creating other subjectifications, other knowledges and other futures". Michel Foucault, meanwhile, argues in "The Politics of Truth" that "truth ... is not defined by a correspondence to reality but as a force inherent to principles and which has to be developed in a discourse ... something which is in front of the individual as a point of attraction, a kind of magnetic force that attracts him towards a goal ... that emerges from the desire to constitute the self rather than discover it" (Foucault, 2007, pp. 163-164). Isn't this what we recognize in Margreet's song and in Timmy's witty humor, namely the truth of affect, construction, experiences, perceptions and desire?

Like Ataman, we should bear in mind that everyone is defined by stories. Any analysis of a story is formed by and subservient to a story. The researcher or the viewer is never fully aware of the stories in which he or she plays a part. He is both an insider and an outsider within a system with constantly shifting boundaries. There are no objective criteria for analysis, which means we also need to incorporate our own story as a researcher. Our own story, position and response are part of the assemblage and helps determine the tonality of the greater picture at every stage of the process. Besides this own story, performativity, tensions and paradoxes must also be given a chance in research. They must be seen as something positive, just like Ataman demonstrates that multiple positions and perspectives are possible. In the encounter of these different, at times conflicting stories, other cross-connections can be made. We can change perspective, shift the roles and create movement, new opportunities and new meanings. As a result, narratives can provide openings for plurality, contradiction and multiplicity and we can tap in to their potential for resistance in order to disrupt the prevailing standards.

This argument can be framed in and is undoubtedly influenced by the theories of Deleuze and Guattari (1987/2004) for the most part, as well as Braidotti (1994, 2004), which consider subjects as nomadic – as wavering and therefore always in motion. The nomadic subject actively seeks out movements and transitions, comes and goes, packs up and leaves, and constantly undergoes transformations (Braidotti, 2004). Nomadism dictates that all we can do is sway along on the waves of our being – being as becoming, as *devenir* (Deleuze & Guattari, 1987). A complex and multi-layered subjectivity is then created, which is unstable and mobile, a permanent and dynamic *becoming*. This complex subjectivity consists of transitions, shifts and changes, without any essential unit. Man never adopts a permanent identity and configures himself differently depending on the context and the people. The subject, in other words, is fragmented, fragile, multiple (Braidotti, 2004). From this nomadism we learn that "our relationship to reality is not borne by a fixed point that is outside the world, but instead by reality itself" (De Kesel, 2006). Consequently, we researchers must allow the undermining, decentering and deconstructing effect of the elusive differentials of reality to our logical thinking. This requires a different mindset, a different way of thinking according to Deleuze (1986, p. 54), "which you must call nomadic, a nomadic *nomos,* without individuality, definition or measure". When we try to record narratives, we run the risk of capturing the stories of Margreet and Timmy in a totalitarian representation or a representation that we try to subdivide according to a certain logical way of thinking. If we follow Deleuze's analysis, however, we can understand narratives as dynamic processes, which allow us to break through and

overwrite established categories (Braidotti, 2004). We never pin ourselves down, but continually move forward and make progress. Whereby we discover that stories can transform and that the subjects also continually change while they speak. Whereby we create the space for new worlds in the form of improbable encounters with unexpected sources of real experiences and knowledge. Whereby we embrace disruptive encounters and steer clear of easy dichotomies or chronologies. Whereby we realize that the many differences and breaks that narrators incorporate in their stories relate to our own experiences as well as those of the other.

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Chapter 3

Toward a More Balanced Representation
of Disability?
A Content Analysis of Disability Coverage
in the Flemish Print Media.[2]

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[2] Based on Goethals, T., Mortelmans, D. & Van Hove, G. (2016). Toward a More Balanced Representation of Disability? A Content Analysis of Disability Coverage in the Flemish Print Media. *The Journal of Human Development, Disability and Social Change (Thematic Issue: 'Social representations and Disability: shared perspectives on the meaning of a concept').*

Abstract

Even though there is a complex relationship between media coverage and the public, the media have a powerful influence on the way 'disability' as a phenomenon is perceived and on the process of attitude formation. Hence, it is important to document the depiction of people with disabilities and the myths and stereotypes perpetuated by portrayals of persons with disabilities. This chapter reports on a quantitative examination of the extent and nature of the coverage of people with disabilities in the print media in Flanders, the Dutch speaking part of Belgium. Seven newspapers and 16 magazines between January 2003 and December 2012 were content-analyzed.

Key findings include a sorely limited coverage, or even total lack of representation, in certain media sources. The study also discovered interesting correlations between gender, age and type of magazine on the one hand, and the type of disability on the other. Analysis also revealed that print media focus on certain disabilities. In addition, the results showed that, looking over the ten-year time span, some events have more influence than others on the evolution of the quantity of coverage.

This chapter concludes with a discussion of these findings and their implications, from the perspective of Disability Studies and with reference to Cooley's concept of the looking glass self. It is argued that media representation on disability reflects certain broader ideologies and socio-political processes shaped by basic exclusionary social frames. Yet, the media do more than hold up a mirror to basic mindsets and frames. As the media function as mechanisms for strengthening and entrenching the social order, they transmit hegemonic conceptions and play a significant role in the on-going construction of disability discourses.

3.1 Introduction

The mass media are a useful source of information about current and historical norms and values, public opinions and attitudes on disability. The content itself especially reflects dominant discourses about disability. This is not to say that media content is a mirror image of the realities of disability identities in the social world. The world we inhabit is a world of representation and constructions of disability have no essential, fixed or true meaning against which coverage and distortion can be measured (Hall, 1997). In line with the intersectional framework, we believe that disability constitutes as sites of fluid construction and creativity rather than determination. Opposed to the great binary aggregate abled/disabled, reality is far more complex and the social world cannot be neatly divided into binary categories (Jacob, Köbsell, & Wollrad, 2010; Raab, 2007). Hence, the media

do not just represent the reality that exists *out there*, nor do they simply reproduce or distribute knowledge, but they are active producers of knowledge and construct and constitute the very core of our social existence (Kunz & Fleras, 1998) and dominant discourses on disability.

Besides, the mass media play a major role not only in reflecting generally held public attitudes and perceptions on disability, but also in shaping them (Auslander & Gold, 1999; Mutz & Soss, 1997). There are, of course, a number of factors other than press coverage that can influence public opinion on a subject such as disability, ranging from personal experience to historical and political views. Media studies suggest a complex relationship between coverage and the public, but there are evident correlations between increased coverage and growing public priorities (McCombs & Shaw, 1972; McLeod, Becker, & Byrnes, 1974). The media not only provide information but also help to create or reinforce ideas about disability and what it means to be human. As Auslander and Gold (1999) state, the media have an influential role in 'news gatekeeping'. Besides, "the amount of media coverage an issue receives is related to the importance placed on that issue by individuals in society, regardless of any measure of the issue's objective importance" (p. 421). Moreover, Siperstein (2003) points out that the public's perception of capabilities of people with a disability have a major influence on their ideas on education and work for people with a disability, and more generally, on the public's perceptions on inclusion and participation in society. Consequently, a correct media representation contributes to the ways in which people think about inclusion.

Taking into account this nuanced and complex view on disability, media and the public, and in line with the UN Convention on the Rights of Persons with Disabilities which gives explicit attention to the correct representation of people with a disability in the media, we want to introduce this first baseline measure study, as the first of a two part study.

This media study is conducted to establish a baseline of disability portrayals in Flemish print media through a quantitative content analysis of magazines and newspapers. During ten years (2003-2012), the portrayals of people with disabilities by seven Flemish newspapers and 16 Flemish magazines were systematically analyzed, examining how the media represented people with disabilities. In the work presented here, this study seeks to obtain a baseline measure of disability, gender and age distribution across the different sources of current print media. Because media character portrayals and demographics of people with a disability may influence the public's perceptions of social reality (Gerbner, Gross, Morgan, & Signorielli, 1994; Shrum, 1999), establishing sound baseline measures of media character demographics is a necessary step in conducting research on representation and perceived social reality. As we do not believe in the existence of a single

representation, different print media were analyzed, ranging from popular to quality press and from targeted to specific audiences to oriented on specific themes.

Despite the ratification of the UNCRPD in Belgium and the fact that 15% of the population are classified as having a disability (World Report on Disability, 2011), the inclusion and participation of people with a disability in Flanders is among the lowest in Europe (FRA, 2010; Vlaams Ministerie van Onderwijs en Vorming, 2014). As mentioned, a series of factors are assumed to play part in the process of inclusion, however, there is a lack of research into how people with a disability are culturally represented in the Flemish media. The existing content analytical work done on Flemish media has focused on the representation of social minority groups other than people with disabilities, or solely on the depiction of people with a disability in the television news (Vissers & Hooghe, 2010). A clear underrepresentation and an emphasis on people with physical disabilities were two of the main findings of this last study. Although these studies are important steps in examining media content, there is still much left to discover, including a more basic study of representation. This study here represented was designed to fill this gap and seeks to examine a baseline measure of disability, gender and age distribution in the depiction of persons with disabilities in the print media.

3.2 Methodology

This study examined articles on disabilities and people with disabilities published in seven newspapers and sixteen magazines in Flanders, Belgium, over a ten-year time span between 2003 and 2012. All of the issues for this period were surveyed, including each section and article. Data from the newpapers were gathered through Gopress, an electronic news archive that contains all the articles of Flemish newspapers. Because the other media chosen was not included in this online archive, we conducted a manual search in the magazines, collected from the Belgian legal deposit. Although there is a legal requirement that copies of publications need to be submitted to this repository, a small number of copies were missing.

Articles were accepted into the study sample if they included a reference to disability in general, or to a specific disability or chronic illness which incurs disabilities. The selected articles could relate to a broad range of disabilities and conditions which lead to disability, from any cause and at all levels of severity. That reference could appear anywhere in the article: in the headline, text or accompanying image.

Articles were then examined as to the extent of coverage and by the way they related to the year of publication, the demographics and the type of

medium (popular newspapers, lifestyle magazines, celebrity and gossip magazines, news and opinion magazines, age-oriented magazines, quality newspapers, other). The coded demographics included gender (men, women, mixed), age (child, adolescent, adult and mixed) and type of disability (non-categorical, acquired -, multiple -, auditory -, intellectual -, physical -, visual impairment, chronic health conditions, autism, behavioral problems, learning problems). Two coders were trained to code the data independently and compare and discuss discrepancies.

Since some periodicals were published daily, some weekly and some monthly or as a quarterly, all study results are weighted in such a way that the data are defined on the same scale. Where instead of each article contributing equally to the final result, articles from weekly and monthly magazines contribute more than articles from daily newspapers.

3.3 Results

The reading of the seven newspapers and 16 magazines of the period 2003-2012 yielded 14,529 articles containing some mention of disability.

With regard to the evolution of media coverage across time, Table 1 shows that a relatively continual stock of messages including disability can be distinguished in this ten-year time span. The years 2004, 2005, 2006 and 2011 illustrate this constant undercurrent, with a percentage of about 9.5%. This does not mean that disability is fairly represented in the media; this number only shows the percentage of found articles in those years over the total amount of articles containing mentions of disability in the period 2003-2012. The years 2007 (12.68%) and 2003 (12%) are characterized by the largest number of representations of disability, with a 3% increase compared to the undercurrent. This can be explained by the attention on the European Year of People with Disabilities in 2003, the adoption of the Convention on the Rights of Persons with Disabilities by the United Nations at the end of the year 2006 and the European Year of Equal Opportunities for All in 2007. These augmentations fade out relatively quickly. The amount of articles in the years 2009 (10.91%) and 2010 (10.27%) also slightly increased, possibly influenced by the Belgian ratification of the Convention on the Rights of Persons with Disabilities on July 2, 2009. Again, this can be considered as a short-term effect because we see a decrease in representation over the last years of the ten-year time span. In 2012, the representation declines strongly below the undercurrent (7.61%). Despite the influence of events on a political level, other events such as the Special Olympics or Paralympics do not seem to affect the amount of messages in a year.

Table 1. The weighted distribution of articles by the year.

Year	Percent (%)
2003	12.00
2004	9.52
2005	9.58
2006	9.75
2007	12.68
2008	8.34
2009	10.91
2010	10.27
2011	9.35
2012	7.61
Total	100.00

As shown in Table 2, far more articles about disability are published in the popular press, with popular newspapers (35.01%) the highest, followed by lifestyle magazines (27.27%), and celebrity and gossip magazines (15.95%). The popular press covers a much larger amount of articles about disability (78.23%) than all the other media types combined. Strikingly, only 4.87% of the articles on disability came from quality newspapers. Even the celebrity and gossip magazines score higher (15.95%) than the quality newspapers and news and opinion magazines combined (12.66%).

Table 2. The weighted distribution of articles by the type of medium for the period 2003-2012.

Type of medium	Percent (%)
Popular newspapers	35.01
Lifestyle magazines	27.27
Celebrity and gossip magazines	15.95
News and opinion magazines	7.79
Age-oriented magazines	6.78
Quality newspapers	4.87
Other	2.32

In line with expectations, the majority of the articles focused on adults with a disability (70.6%), more than twice the proportion of articles that focused on children, adolescents or a mix of ages (Table 3). Only in the teen celebrity magazine ('Joepie'), do we see more adolescents than adults with a disability, which seems logical as this magazine mostly targets teenage customers. Remarkably, in some cases children and/or adolescents with a disability remain out of sight, even in children and youth magazines. Also, in news and opinion magazines, children are strongly underrepresented. When we found articles on children with a disability, most of the time they were published in newspapers instead of (weekly or monthly) magazines. The articles on children referred mostly to general disabilities and on individuals with intellectual disabilities, autism, behavioral problems and learning problems, which concerns the created connection between children on the one hand, and learning and education on the other hand. Considering all these facts, the overall focus on adults with a disability in the print media is extremely manifest.

Concerning gender, Table 3 shows us a slight emphasis on male representation (47.94%) compared to the amount of women with a disability in the print media (42.89%). Noteworthy is that articles about physical impairments involve more men, while news about chronic health conditions includes more women. In some newspapers and magazines, there is a strong and unbalanced focus on men with disabilities (like in 'De Tijd', 'P-Magazine', Glam*It, 'Flair'). In two of the cases, this was expected because this media focuses on a male audience or is economically oriented. In other -mostly female orientated- media we found slightly more women with disabilities than men (like in 'Joepie', 'Story', 'Goed Gevoel', 'Libelle', 'Dag Allemaal', 'Klap').

Table 3. The weighted distribution of articles by age and gender for the period 2003-2012.

Variable	Percent (%)
Age	
Child	16.11
Adolescent	8.29
Adult	70.60
Mixed	5.01
Gender	
Men	47.94
Women	42.89
Mixed	9.18

In most cases, articles are non-categorical, focusing on general disabilities and not on specific identified groups or individuals with disabilities. As expected, these general announcements are peculiar in newspapers, as newspapers intend to bring general information to the public and keep people well-informed on important events. When concerning the most frequently depicted disability, most prevalent, by far, were articles that dealt with physical impairments (28.8%). The popular male magazine 'P-magazine' leads this physical oriented tendency. The second most frequent depicted disabilities were intellectual disabilities (22.4%) and chronic health conditions (19.3%). Remarkable is that articles focusing on people with intellectual disabilities appear almost only in newspapers. Auditory impairments, autism, visual impairments, behavioral and learning problems are clearly underrepresented in our sample (under 9%). Articles on behavioral problems are more common in lifestyle magazines, while articles on visual impairments can be found mostly in the only religious magazine ('Kerk en Leven') we analyzed. Across time, no meaningful trends concerning types of disability in the media can be observed.

3.4 Discussion

A first striking finding from this study is the **sorely limited coverage, or even total lack of representation**, of certain persons with disabilities in some Flemish print media sources. For example, children and/or adolescents with a disability remain out of sight in certain children and youth magazines. For the young readership of these magazines, children and/or adolescents with a disability are virtually non-existent. Even though the Flemish government has pointed to the importance of the correct representation of people with a disability in the media and despite the substantial difference with the number of children and/or adolescents with a disability in the real world population, this group remains close to being invisible.

This finding mirrors the reality that **children with and without disabilities share few or even no collective activities**, notwithstanding Belgium agreed to develop a more inclusive system with the ratification of the UN Convention on the Rights of Persons with a Disability (2006). Flanders in Belgium still has an extensive network of segregated services and special schools for children with a disability (Vlaams Ministerie van Onderwijs en Vorming, 2014). In this dual educational system, there are very few opportunities and support for children with special needs in the mainstream educational system and

society. With the highest percentage of students in segregated special schools in the European Union, Flanders has opted more than other countries for segregated settings in education: 5.2% of the total student population attends special education (NESSE, 2012). This tradition of exclusion in education is also visible in our manner of representing children with disabilities in the media.

These findings on the lack of coverage of people with a disability in the media endorse previous international works (Donaldson, 1981; Henderson & Heinz-Knowles, 2003; Saito & Ishiyama, 2005) and reflect that people with disabilities continue to be strongly underrepresented in the media, which adds to the notion that people with disabilities are not fully part of society. This clear underrepresentation falsely implies that people without disabilities are the standard and impedes the struggle of people with a disability for position in social space.

When examining what influences the quantity of disability coverage in the print media, it can be stated that, looking over the long-term span from 2003-2012, **political events have a clear influence**. In particular, this concerns the adopting and ratification of the UN Convention on the Rights of Persons with Disabilities and the European Year of People with Disabilities. Unfortunately, these effects are short-term as the amount of articles on disability recede the year following the event, despite the persistent number of human rights abuses and discrimination towards people with a disability in Flanders (Belgian Disability Forum, 2014; Hardonk et al., 2013). Looking at other big events that could possibly have an influence on the quantity of coverage of disability in the print media, such as the Paralympics or Special Olympics, no clear connection can be observed. This finding can be connected to earlier research claiming that the coverage of the Paralympics and Paralympians is minimal (Tynedal & Wolbring, 2013; Schantz & Gilbert, 2001) and reflects the invisibility of people with a disability more generally in our media.

What strongly determines the representation of certain groups of persons with disabilities is the degree of **visualization**. Print media rarely depict people with certain disabilities, focusing instead on people with **physical, intellectual and chronic health conditions**. This might be a result of the inherent nature of print media as the medium requires visual images. For example, auditory impairments, autism, visual impairments, behavioral and learning problems are regarded as relatively difficult to portray. In contrast, people with physical, intellectual or chronic health conditions are much easier to depict and dramatize (cf. Haller & Ralph, 2001; Saito & Ishiyama, 2010). The emphasis on people with physical impairments confirms earlier studies

(Auslander & Gold, 1999; Haller & Ralph, 2001; Saito & Ishiyama, 2005), which is not surprising in light of the importance of images in print journalism. Besides, since no clear evolution can be observed in the quantity of articles of certain groups of persons with disabilities over time, it can be presumed that categorical **lobby groups** have no clear influence on the amount of articles in the print media concerning the group of people they represent.

In line with other important findings of this research, such as the higher prevalence of found articles in the popular press, the interesting correlations between gender, age and type of magazine on the one hand, and the type of disability on the other, we can interpret the media as a **Looking Glass Self.** This concept was coined by Cooley in 1902, pointing out how our self-image is shaped by society. The Looking Glass Self has been the dominant metaphor in sociology for the development of self-conception. Cooley argued that our self-concepts are formed as reflections of the responses and evaluations of others in our environment. Interpreting our findings, we can argue that media can also be compared to a Looking Glass, shaped by assumptions in society and reflecting underlying societal opinions and traditional power relations. Nevertheless, a right balance must be found between the idea of the media using intentional media strategies and the idea of the media mirroring societal assumptions. Without wanting a unilateral focus on media as a reflection of society, but as well as being an influence on it, and without forgetting the impact of social and citizen media, the concept of the Looking Glass gives us the possibility to interpret some findings on a more abstract theoretical level.

First, an important and remarkable finding of this study is that far more articles about people with disabilities come from the **popular press**. In quality newspapers and news and opinion magazines, a great lack of coverage of people with a disability and disability related themes is detected.

The higher prevalence of messages about people with disabilities in the popular media indicates in a painful way that **people with disabilities are positioned more in the lower educated target audience of these media**, which reflects powerful underlying societal relations and distributions. In particular, the finding reveals the poignant looking glass of the educational barriers that persons with a disability have and their limited connection with the social world of higher educated people. These limited educational opportunities and disparities in education for people with a disability have been ongoing for generations (Vlaams Ministerie van Onderwijs en Vorming, 2014; World Health Organization, 2011).

Moreover, this result is striking as quality media attempt to be diverse and politically correct, reporting on social exclusion and diversity, whilst concerning disability, they fail to cover an adequate representation of it.

Besides, the higher amount of articles about people with disabilities in the popular media can be explained by the fact that popular media, in particular, cover more local and personal information and news. People's lived stories and individual accounts of experience are mainly provisioned in popular journalism, as these media emphasize the particular and personal experiences of individuals at the expense of relating those particularities to more general institutional and structural processes (Sparks & Tulloch, 2000). Although today some shifts in thinking about disability can be tracked, **disability remains peripheral** to the larger political agenda. This can be illustrated by the sidelined and unclear position of disability in the Flemish Government's policy documents (Homans, 2014; Gatz, 2014). Disability is often seen as a matter of a singular personal experience, not relevant to the social and political debate. Recently, disability is increasingly being addressed within a broader human rights context, also in the media, for example by the reporting on the waiting lists for support for people with disabilities. However, disability is situated more within the local agenda than within a larger discourse in respect of human rights. Hence, it is more evident that disability is mainly covered in local popular media, as it is unfortunately not yet embedded in a broadened political discourse on disability in terms of rights and inclusion. The media miss the bigger picture on disability, which is in line with reporting on more general social issues in quality press.

In addition, disability coverage in popular press can be explained by the general prevailing **melodramatic framework** of this media, because of its emphasis on human drama, emotions, scandal and personalities. Their concern is to bring news and reach the public by using and evoking emotions, and people with disabilities can be qualified as perfectly fitting this frame. This eliciting of emotions in portraying characters with a disability in the media is in line with findings in qualitative research where the following dominant stereotypes are detected: the supercrip, the victim, the maladjusted burden, and the evil threat (Nelson, 1996), which add up to a spectacle of otherness, and evoke emotions of pity or admiration (cf. Hayes & Black, 2003).

Second, another surprising result is that **media about physical impairments involve more men, while reports about chronic health conditions include more women**. These findings can be associated with underlying gender ideologies of men and women regarding dual breadwinner roles, prescribing earning for men and homemaking for women. This gendered approach leads

to the notion that men belong to the public and woman to the private sphere. Femininity is often perceived as belonging to the private realm, so women's disabilities are represented more as internal and individual and less visible. Meanwhile, according to this breadwinner model and private/public dichotomy, men act more within the public realm and move freely between the public and the private realm. The association between masculinity and the public is demonstrated in the exteriorization, where the bodily difference is not a private but a public and visible matter. These norms about gender are reproduced regularly throughout the media. Pompper (2010), for example, found that masculine portrayals often emphasize health and fitness. Hence, reporting by the media on people with disabilities, even if sympathetic, seems to be shaped by the fundamental exclusionary social frames that build on the dichotomous understanding of masculine/external/public/political versus feminine/internal/private/ apolitical.

Third, noticeable is the finding that articles on people with **physical impairments** are most common in magazines where **physical beauty** is the main emphasis, while articles about **behavioral problems** are most present in **lifestyle magazines** where behavior and lifestyle predominate. The first emphasizes sexuality and the importance of physical attractiveness, setting unrealistic ideals for the body and making direct statements about beauty. The latter contains articles about health, fashion, decorating, food, and wellbeing, covering ways to improve and get more out of your life.

The distribution of articles on physical impairments and behavioral problems has a visible connection with the core topics of the magazines they are represented in. In particular, the scientific metaphor of matter-antimatter can be used to clarify this distribution. This concept suggests that for every particle of matter created, an 'antiparticle' exists with opposite charge. They are defined as polar opposites and serve as mirror images of the particles that make up everything in our everyday world. Where images of the body present idealized versions of beauty, representations of individuals with physical differences are omnipresent. Where discourses surrounding 'the good life/the good mother/the good partner' are framed and discussed in magazines as if they are monoliths shared by the whole community, more articles about behavioral problems are depicted. The media continuously demarcate between the norm and the deviant, between the 'acceptable' matter and the 'unacceptable' antimatter, the *dis* and the *able*, as opposites, and as the antithesis of one another. By establishing clear boundaries between the able-bodied and those who deviate from the norm, the image of the ideal able-bodied person becomes illuminated and reinforced. This distribution mirrors traditional disembodied experiences and dominant constructions of norms that "necessarily hierarchizes and ranks the two

polarized terms so that one becomes the privileged term and the other is suppressed subordinates, negative counterpart" (Grosz, 1994, p. 3). By over-presenting normative selves as the only way to live and by creating a visible distance between the (dis)abled, the status of what it means to be a human is constantly defined. Since we live in a culture that constantly defines this dominant image normalcy, the presence of disability urges us to think about conceptions of the human (Kittay & Carlson, 2010). At the same time the status of human is frequently denied in the lives of people with disabilities. As Goodley and Runswick-Cole (2014) argue, becoming dis/human is a response to the ambivalent state we find ourselves in relation to the human: disability recognizes the norm whilst simultaneously troubles, reshapes and re-fashions ideas about the human that we might have taken for granted. Dis/ability's disruptive potential urges us to think again about normativity and the condition of the human.

Besides the matter-antimatter metaphor, the eroticization of the disabled body (Garland-Thomson, 1997) can also be a possible reason for the depiction of people with a physical disability in beauty-oriented magazines.

Besides this distribution of articles on physical impairments and behavioral problems, articles on **visual impairments** are found mostly in the only **religious** magazine included in this research. This cannot be connected by the matter-antimatter metaphor, but can serve a more practical interpretation as most of the Flemish organizations for people with visual disabilities are situated in the catholic pillar and Catholicism has had a tight grip for a long time on supporting people with visual disabilities. Visual impairment also has a rich Christian iconographic connotation: from a historical point of view, the blind beggar and the blind prophet or seer - famous for his clairvoyance - are major archetypes for people with a disability. Eventually, a more pragmatic editorial reason may also be the case, although the editorial office objects this argument.

Finally, as opposed to adults, the articles on **children** with disabilities mostly refer to general disabilities, **intellectual disabilities, autism, behavioral problems and learning problems**. Children with disabilities get a peculiar status in the media and are related to other types of disabilities than adults. First, it can be claimed that there is a link between children on the one hand, and on learning and education on the other. This result reveals the dominant looking glass on educational beliefs, where children's academic performance is emphasized (Marcon, 1993). A distinguishing characteristic of education today is the emphasis on outcomes and qualification (Biesta, 2011). It is believed that the extent to which children achieve their educational goals determines the achievement in other domains and is mirror of the success of

their future life. The increasing amount of pressure that parents, teachers and society are putting on young children as little emperors to succeed academically, is very influential on our educational mindset and is visible in the media.

Second, the specific types of disabilities related to children in the media, in particular intellectual disabilities, behavioral problems and learning problems, are consistent with the classification of special education in Flanders. Particularly, these three types of disabilities correspond to the largest groups in the Flemish special education system (Vlaams Ministerie van Onderwijs en Vorming, 2014). In Flanders, diversity is approached by teaching students with disabilities in segregated settings and homogeneous groups. Normalization and the attainment of the educational standards is emphasized, especially for students with learning problems, intellectual disabilities and behavioral problems. This categorical thinking poses a vivid debate and can be observed in the media.

Third, connection can be made with qualitative research on the experiences of parents of children with disabilities. Although further research is needed, it could be argued that the stories on children with disabilities in the media are examples of experiences of the moral force of social order parents have when going out in public with their children, where 'unusual behavior' can embarrass or disorientate 'normal' members of society and subvert the social norms of acceptable behavior (Ryan, 2005).

Lastly, concerning the higher representation of children with autism in the media, Stevenson, Harp and Gernsbacher (2011) argue that when envisioning the disability of autism, a child is more likely portrayed, rather than an adult. According to the authors, autism is predominantly considered a childhood disability. Children with autism have continually been seen as having a condition that is characterized by a broken self, uncontrollability and exceptional talents, that is so non-normative (Sarrett, 2011) it is attractive for media portrayals. Moreover, the infantilizing discourse of autism is characterized by dual stereotypes: either uncontrollable, aggressive, or violent children who cause great stress to their families and carers, or unhappy and often unloved and poorly treated children that evoke pity (Jones & Harwood, 2009).

3.5 Conclusion

Since the press has, among other factors, an important role in reflecting and shaping public attitudes towards people with disabilities, and since the Flemish print media serve as an important source of information for the public about the society, an underrepresentation or an incorrect representation of people with a disability in the media has major impact on public perceptions and attitudes towards people with disabilities in our society. In Flanders, many people rely on the media as a crucial source of information, beliefs and values. Because of the marginalization of social minority groups from mainstream society, many people rely almost entirely on the media for their information about people with disabilities. The relationship between the public and these groups is largely filtered through the values, assumptions and perceptions covered in the media.

Besides, the UN Convention on the Rights of Persons with Disabilities emphasizes the importance of a correct representation and encourages all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the Convention. Moreover, in 2014, the UN Committee noted with concern "that persons with disabilities in Belgium are portrayed in the media mainly as persons with a disability rather than as citizens who participate fully in society" (CRPD, 2014, p. 3), and ordered the Belgian media to "take account of diversity in their code of ethical conduct and provide them, and all relevant professionals, with appropriate training and awareness-raising to ensure better representation of persons with disabilities in the media" (p. 3).

Starting from the insight that media coverage is a key element in the process of attitude formation, and from the clear instructions for Belgium based on the UNCRPD framework, the findings of this study indicate biases and stereotypes in the press that have characterized its coverage till now.
Although this study found a relatively continual stock of messages including disability over the years, which indicates a permanent minimal attention to the issue in the media, a lot of socio cultural-driven biases are discovered in the media reporting on people with disabilities. Remarkably, this study found a number of significant differences between the types of media studied; sometimes a total lack of representation, but generally, the media content reflected underlying dominant societal ideologies that can be problematic as they promote the status quo, reinforce stereotypical attitudes and obstruct change for people with disabilities. When people with a disability are represented in the media, the messages do not have the potential to play a role in facilitating social change and altering public perceptions consistent with the framework of the UNCRPD. The disability-as-deficit notion (Gabel, 2005) has a central place, which is in line with the Flemish policy of

approaching, orienting and classifying people on the basis of their labels. Besides, the studied articles are constituted on ideas of normalcy and perfection, together with binary and hegemonic perceptions on disability and gender. The representations of people with disabilities are often placed opposite to the idealized norm and seem to be shaped by fundamental exclusionary social frames.

This study provided important discoveries about representation in the media and underlying perceptions in relation to disability and intersections with other social categories. Due to the numerous sources analyzed and the integral and systematic way in which they were analyzed, we could precisely measure the quantity of media coverage. However, the approach does not provide insight in how people with disabilities are represented. Further research will be conducted on the same sample in order to investigate the quality of media representations.

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Chapter 4

I'm Not Your Metaphor. Frames and Counter-Frames in the Representation of Disability.[3]

Abstract

Media function as an important arena for the negotiation of difference and normalcy. When it comes to disability, powerful ideas about disability are articulated in and circulated through media. This study examines, by means of framing analysis, how media portray disability and people with disabilities, in a sample of Flemish print news and entertainment magazines. The aim of this study is to understand the dominant and alternative frames related to disability looking at which aspects of reality are selected, rejected, emphasized, or modified in the production of a media text. Participatory analysis of the articles from sixteen Belgian magazines over a one-year time span (n=184) reveals a number of frames and counter-frames. Results indicate that media tend to perpetuate and reinforce the stigma of the disabled as 'the Other' and disability as one of the most frightful obstructions in one's life, while counter frames underlining the notion of the disabled being different but not 'abnormal' are relatively absent. Such negative media image of disability may have repercussions for how we approach and make sense of phenomena relating to disability in the real world. Recognizing this perceptual lens of framing means that it is possible to think about how to reframe disability and what it means to be human.

4.1 Introduction

The media, and more specifically print news and entertainment magazines, serve as valuable sources of information, beliefs and values. Powerful ideas about disability and 'normality' are circulated through the media and are deeply embedded governing assumptions in culture itself. Without exaggerating the importance of media, the representation of disability in the media plays a major role in molding the public perception of disability. Besides, a fair portion of disability-related material in media is negative and offensive and social exclusion is the daily experience of many people with disabilities (Ellis & Goggin, 2015). Disability, then, is a key concern in media.

In Flanders, as elsewhere, media are a vitally important arena for citizens to get information about disability. Despite the ratification of the UN Convention on the Rights of Persons with Disabilities, there is still an extensive network of segregated special services. Because of this two-track system (i.e. special and regular as two distinct systems), many people in Flanders rely almost entirely on the media for their information about diversity and disability.

There is little research into representation of people with disabilities in Flemish media. Existing work done has focused on the representation of social minority groups other than people with disabilities, or solely on the depiction of people with a disability in the television news (Vissers & Hooghe, 2010). Notwithstanding Disability Studies is booming and the pioneering work of authors as Cumberbatch and Negrine (1992), Pointon and Dacies (1997), Riley (2005), Haller (2010), Ellis (2015), Ellis and Goggin (2015), there has been much less work in the area of disability and media around the world. Available research papers are lacking or cluster around particular aspects of disability and media.

Our study is designed to fill this gap and builds further on a large quantitative content-analysis (Goethals, Mortelmans, & Van Hove, 2016) where we investigated *who* is represented in different print media, analyzing 16 magazines and 7 newspapers, during the period of ten years (n=14,529). As the second of this two-part study, this paper examines on a qualitative way *how* people with disabilities are portrayed, using a one year-sample (2012) of these data (n=184).

4.2 Framing as in inroad to study media representation

Framing originates from the field of social psychology (Barlett, 1932) and refers to the way in which the media and the public represent a particular topic or issue (Reese, 2001). According to Entman (1993), framing fundamentally involves selection and salience: "to frame is to select some aspects of a perceived reality and make them more salient in a communicating text, in such a way as to promote a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation for the item described (p.52)". The framing of a message is embedded in a repertoire of symbols and world-views that its members use as a toolkit to attribute meaning to issues they are confronted with (Gamson & Modigliani, 1989), a common ground within a given culture based on values, archetypes and shared narratives (Van Gorp & Vercruysse, 2012).

In this paper, we seek to develop an understanding of the presence of disability in a sample of Flemish print news and entertainment magazines. Our aim is to understand the dominant and alternative conceptualizations (frames and counter-frames) related to disability by means of a framing analysis, that indicates which aspects of 'reality' are selected, rejected, emphasized, or modified in the production of media texts. The way information is transferred to its public comes through various forms of

communication, all of which is framed. Framing defines how media coverage can shape public opinions -without implying that audiences are homogenous and passive- by using specific frameworks to help guide the public to understanding. This is not to say we can speak about a simple and fixed reality: disability has no universal, essential, fixed or true meaning against which coverage can be measured (Hall, 1997). Nevertheless, these images are loaded with ideology and by examining media frames, several trends appear which highlight how media sources are able to influence public perceptions and attitudes.

The categories as used in the work of Clogston (1990) and Haller (1998) can offer a productive entrance to organize a first step in applying framing theory to disability. These colleagues developed models of media representation of disability, which fit into either a traditional or progressive category. The traditional categories include the medical model, the social pathology model, the supercrip model and the business model. In the medical model, disability is presented as an illness or malfunction. Persons who are disabled are shown as dependent on health professionals for cures or maintenance. In the social pathology model, people with disabilities are presented as disadvantaged and must look to the state or to society for economic support, which is considered a gift, not a right. In the supercrip model, the person with a disability is portrayed as deviant because of 'superhuman' feats (i.e. ocean-sailing blind man) or as 'special' because they live regular lives 'in spite of' disability (i.e. deaf high school student who plays softball). In the business model, people with disabilities and their issues are represented as costly to society and businesses especially. Making society accessible for disabled people is not really worth the cost and overburdens businesses, i.e. accessibility is not profitable. The progressive categories include the minority/civil rights model, the cultural pluralism model and the legal model. In the minority/civil rights model, people with disabilities are portrayed as members of the disability community, which has legitimate political grievances. They have civil rights that they may fight for, just like other groups. Accessibility to society is a civil right. In the cultural pluralism model, people with disabilities are presented as multifaceted people and their disabilities do not receive undue attention. They are portrayed as non-disabled people would be. In the legal model, media explain that it is illegal to treat disabled people in certain ways. The UN Convention on the Rights of Persons with Disabilities and other treaties or laws are presented as legal tools to halt discrimination.

This entrance leads us to our main question of this study, i.e. an understanding of the dominant and alternative conceptualizations related to disability by means of a framing analysis of the Flemish print media. In

answering this question, the study aims to make a contribution for Haller's and Clogston's proposition of central frames and the continuous development of a set of frames to communicate disability.

4.3 Thinking about media through dis/ability: a theoretical concept

Although framing serves as a central inroad to our analysis of media representation, in this study we also reflect on the emergent theory of the *DisHuman studies* (Goodley & Runswick-Cole, 2014) and its relation to media. In this approach, we ponder upon the vital question what it means to be human and in what ways disability enhances these meanings. The presence of disability -in the media and beyond- invokes discussions about the human (Kittay & Carlson, 2010). It unpacks, troubles and disrupts dominant notions of what it means to be human. It '*disses*' the human, which means that it has the radical potential to trouble and reframe the normative representation of the subject that is often depicted when the human is evoked. This is the *dis* in the dis/human approach. It conveys that the presence of disability, eg. in media, offers us exciting new ways of thinking about humanness and normality. As Braidotti (2013) argues, humanist conceptualizations of the human are often narrow, normative and rigid. She posits that "at the start of it all there is He: the classical ideal of *Man*" (p.13), referring to a universal model of the human as the idealist figure of da Vinci's *Vitruvian Man* as an exclusionary hegemonic cultural model (white, European, male, handsome, able-bodied, …). Those outside this archetypal humanist ideal are considered less than human or inhuman. The presence of disability in the media can also affirm some typical, common sense normative human categories whilst, simultaneously, demanding new ways of thinking and '*disses*' these conventions. For that reason, we join with the dishuman position that acknowledges the disruptive potential of disability to trouble these dominant notions and demands we question what counts as human.

Beside recognizing that dis/ability has the potential to destabilize normative, taken for granted assumptions about what it means to be human and what it means to be able, thinking in dishuman ways involves at the same time the recognition that a regular normal human being is desirable, especially for those people who have been denied access to the category of the human. At times, desiring and respecting the human is necessary. Everybody seeks to be recognized as human and wants, from time to time, to embrace the able or the normal. Above all, claiming the norm has pragmatic and political value, thinking about human rights, citizenship, law, morality etc.

Accordingly, here we extend our analysis to consider how the media enables *and* limits disability by their constructions as simultaneously both 'different from' and 'the same as' other people. We think about 'sameness' and 'difference' (c.f. Devlieger, Rusch, & Pfeiffer, 2003) in the depiction of people with disabilities and how these representations function to include or exclude. Put differently, we question the ways the presence of disability in the media honor the humanness inherent in dis/ability alongside its disruptive potential.

4.4 Framing as a method: methodology

Sample

The sample in this study consisted of print media content concerning disability, which comprised coverage from sixteen Belgian magazines between January 1 2012 and December 31 2012 (n=184). This included a range of magazines: celebrity and gossip magazines, news and opinion magazines, lifestyle magazines and age-oriented magazines. All of the issues for this period were surveyed, including each section and article. Data from one magazine was gathered through Gopress, an electronic news archive. Because the other media sources were not available in this online archive, we conducted a manual search in the magazines, collected from the Belgian legal deposit. Articles were accepted into the study sample if they included a reference to disability in general, or to a specific impairment or chronic illness which incurs disabilities. The selected articles could relate to a broad range of disabilities and conditions which lead to disability, from any cause and at all levels of severity. That reference could appear anywhere in the article: in the headline, text or accompanying image.

Frame packages

Conducting a framing analysis results in an overview of frame packages (Gamson & Modigliani, 1989; Van Gorp, 2007; Van Gorp, 2010), composed of a core frame, framing devices and reasoning devices. A core frame represents the implicit cultural phenomenon that defines the package as a whole. Framing devices serve as manifest elements in a message that function as demonstrable indicators of the frame, such as vocabulary, metaphors, catchphrases and depictions. Lastly, reasoning devices display the causal reasoning that may be evoked when disability is associated with a particular culturally embedded frame.

In our study, each frame package is composed of the following elements: the central frame, the underlying cultural motive, the specific issue or problem definition, its causes and consequences, the moral values that are involved and the possible actions that can be taken. Besides, manifest framing devices that may trigger the latent causal reasoning are included, such as metaphors, choice of vocabulary and visual images. In addition, we included elements like the framing sponsor -the journalistic choice of which expert gets voice in the media text- and the initiator -the person or thing that is suggested to initiate the course of proposed actions. As a result, a range of frames can be distilled which give possible frameworks to problematize an issue; often accompanied with some counter-frames who deproblematize the issue and give an alternative for the dominant conceptualizations of disability. A single text may perform more than one frame, or combine both frames and counter-frames.

Participatory framing analysis

Conducting a framing analysis is not a linear process. The multiple 'selves' of the analysts, with their own mental constructs, life experiences and history (familial, cultural, ideological, and educational) may interfere with each other and the identification of the frames. A way of monitoring this interferences is by conducting a participatory framing analysis. We define this process as an *iterative, dialogic and cross-expertise analysis*.

Figure 1 Dialogic iterative cross-expertise analysis
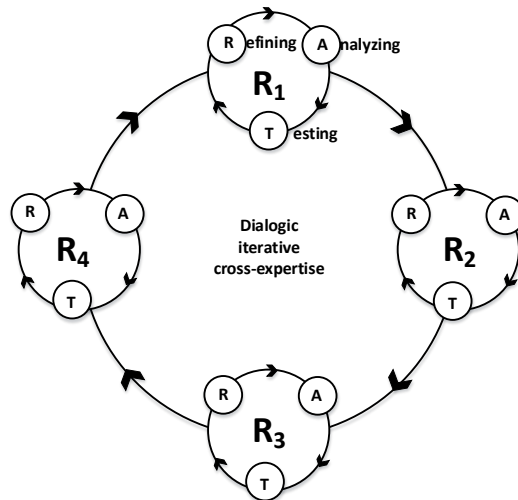
Cross-expertise. Four of the six authors (marked as R1-R4 in the diagram) coded the data. They can be defined as a group of people with different (however not in a dichotomizing or essentialist way) functional expertise, knowledge and experiences {dis/abled, non/academic, Disability Studies/Sociology/Communication Sciences}. Each of them did the coding of the majority of the data independently. There were regular moments of feedback during which possible divergences were discussed. Combining these expertises, gave us different perspectives and theoretical platforms from which to interpret and analyze. As well, it allowed the researchers to capture more out of the data since they balanced each other out. This cross-expertise analysis reminds us of the Greek concepts of Aristotle called *phronesis, techne and episteme (The Nicomachean Ethics,* 1976)*.* These are all of great importance, and Allan (2008) emphasizes the importance not to dismiss *phronesis*, variously translated as practical wisdom, practical judgement, practical ethics, or prudence. *Phronesis* concerns ethics, a deliberation about values with reference to praxis. It goes beyond analytical, scientific knowledge (*episteme*) and technical knowledge or know how (*techne*). More than anything else, *phronesis* requires specific experience (Flyvbjerg, 2004), on which Aristotle says:

> *Prudence [phronesis] is not concerned with universals only; it must also take cognizance of particulars, because it is concerned with conduct, and conduct has its sphere in particular circumstances. That is why some people who do not possess theoretical knowledge are more effective in action (especially if they are experienced) than others who do possess it. For example, suppose that someone knows that light flesh foods are digestible and wholesome, but does not know what kinds are light; he will be less likely to produce health than one who knows that chicken is wholesome. But prudence is practical, and therefore it must have both kinds of knowledge, or especially the latter.*
> *(N.E., pp. 1141b8–27)*

Conducting a framing analysis without a variety of perspectives and interpretations seemed dangerous to us: nobody would notice if we were wrong. So why not involve the interpretations of people with the label of a disability, who are personal experts in reading media articles on disability for decades? By transcending this problem of relevance by anchoring the results in the context studied, we leave the idea of having a privileged position from which the final truth can be told and further discussion arrested. As Nietzsche (1969, pp. 119, §3.12) says: "There is *only* a perspective seeing, *only* a perspective 'knowing'; and the *more* affects we allow to speak about one thing, the *more* eyes, different eyes, we can use to observe one thing, the more complete will our 'concept' of this thing, our 'objectivity', be"

Iterative. The framing analysis was characterized by its iterative design processes. On the individual researchers level (R1-R4), a cyclic process of analyzing, testing and refining was conducted. Each researcher individually read the research material, marked key terms, read again, filled in some fields in the frame package overview, read again, refined, etc. This involves a constant to and fro of reading, reflecting, writing and reordering in a circular rather than a linear way. The material itself asked for this approach, because media frames are often hard to identify (Matthes & Kohring, 2008). Framing analysis requires starting from a simple structure, evaluate it, and continue to improve on it. Also on the level *in between* the researchers, an iterative process was desired and implemented. Individual researcher accounts were evaluated and compared to others, changes and refinements were made, material was reviewed again and frame packages were created and regrouped. This process was repeated until a logical and coherent whole, based on all of the devices, could be created and for the time being, no new frames could be detected. Through these iterations, misunderstandings or inconsistencies are made evident early so it was possible for all the researchers involved to react to them. This study can therefore not claim a definitive truth, but can only be reconceptualized as one utterance in an ongoing dialogue.

Dialogic. The collaboratively-constructed meaning in this study resulted in findings as part of an ongoing conversation rather than represented as an individual product. All the researchers participated in both face-to-face, Skype and email conversations. We met regularly to generate understandings through conversation. Between meetings we encountered new ideas which may be relevant, and these were dropped again in the ongoing dialogic conversation. In contrast to the 'lone researcher' metaphor, every frame package in this study can be seen as iterations of past conversations. We are convinced that taking participation seriously is in reality very complex, especially when conducting research with a co-researcher with the label of a disability. Discussions about the representation of disability were always at work in the daily conversations with this co-researcher. What was essential to these dialogues was the intensity, the conscientiousness, and the continuous process of shared searching and asking a thousand questions to each other. A lot of what happened came down to listening very carefully. In that way, anyone learned from each other. Involving a researcher with a disability implied exchanging stories about lived and very concrete experiences regarding the representation of disability, regarding 'sameness' and 'difference'. These experiences were so sticked to the concrete, that they served as eye-openers. They showed us ambivalence and questioned the ways the presence of disability in the media can honor humanness inherent in dis/ability alongside its disruptive potential. We

believe that these processes has made our study more rigorous and open for complexities, than if we had used the methods we had been accustomed to using as individual researchers. *"I'm not your metaphor"* can therefore be considered as a good title of this paper, as a result of this intensely felt cooperative research process.

4.5 Results

The framing analysis revealed nine dominant frames and three counter-frames. Table 1 (cf. Annex) shows the twelve frame packages, each composed of a central frame, a cultural theme, a specific definition of the issue, its cause and consequence, the moral evaluation that is involved, the possible action that can be taken and the initiator who is suggested to initiate these proposed actions. The last three columns of the table show some manifest framing devices that may trigger the latent causal reasoning in the people's minds: the framing sponsor (the journalistic choice of which expert gets voice in the media text), the used metaphors and choice of vocabulary, and the visual images. All the frames are ranked by extent, starting with the most dominant ones (cf. table 1 in Annex). Dominant frames include:

1. *Suffering and fear of degeneration.* This frame, which is also the most dominant one, postulates that disability equals suffering and degeneration. Having a disability means nothing more than a fatal catastrophe. Persons with disabilities are lost in advance and extremely fearful for the future. There is misery everywhere and that is also manifest in the pitiable visuals which focus on the impairment (often children and family portraits), the loss, the pain, sadness and suffering.

2. *The heavy burden of care.* The second dominant frame involves those around the person with a disability: the carers have to bear a load without any reciprocity. In this frame, not the person with a disability is affected (like in the first dominant frame), but rather those close to them. The efforts needed to care for someone with a disability are emphasized. This often leads to dreadful headlines as 'Autistic grandson source of great concern to grandpa', where the carers must sacrifice and receive hardly any gratitude or recognition.

3. *Faith in science; variant: human enhancement.* According to the third dominant frame, disability is seen as a medical and individual deficit, with a pathology that can be described in scientific terms.

The used jargon is medical and persons with disabilities are reduced to the status of patients or cases. Their impairments are determining and have to be cured to approximate the ideal of 'normality'. In extreme, the variant of human enhancement can be revealed, where the oversimplified improving of human characteristics by biotechnology is depicted and persons with disabilities are reduced to a defect in the genes.

4. *The goer; variant: the hero.* The fourth dominant frame postulates that it is the individual duty of persons with disabilities not to give up and to overcome the disability. Acts of commitment and perseverance are highlighted, and people with disabilities are called inspirational solely or in part on the basis of their disability. This inspiration porn (Young, 2012) depicts the acts of persons with disabilities just living their lives into superficial stories in order to make the reader feel good. The extreme end of this spectrum includes superheroes with disabilities, outrageously admired for their courage, determination and superior abilities.

5. *The helpless victim.* Another common frame is that of the helpless victim. Persons with disabilities are represented as helpless objects of pity or sympathy, that are chosen to be bullied and therefore must be protected or be more assertive. This frame depicts disabled characters whose disability is used by the author to earn sympathy from the audience.

6. *The lurking monster.* This frame involves the idea that disability is an intruder that is always on the lookout and strikes unexpectedly. Disability is represented as a monster that takes away everything a person has built. The victims must give up every dream and are no longer able to participate. The solution lies in a combative attitude and arming oneself against this evil. What is striking, is the remarkable amount of pictures 'before' and 'after' an accident, so the difference and loss of the person's successful life is clear.

7. *Charity.* The charity frame concerns a tragic portrayal of persons with disabilities. They serve as icons of pity, in need of care, not capable of looking after themselves and in need of charity in order to survive. The focus is on the benefactors who fulfill their moral duty to help others, people with disabilities are reduced to recipients of charity. In the data of our study, people with disabilities are not given a voice and not portrayed, only the benefactors and their noble charities are speaking and depicted.

8. *Carpe Diem.* This frame transmits the message that persons with disabilities and those around them look for happiness and comfort in the little things of life. The idea here is that life is too short to grieve or to worry. Although the focus is no longer placed on the

catastrophe and the sad side of disability, in this study we group this frame as a dominant one as the involved media articles presume the simplified idea that individuals are responsible for their own happiness and must ignore obstacles or worries to have a decent life. The complexity of disability as a phenomenon, reflecting the interaction between the person and the society in which he or she lives, is neglected in this case.

9. *Mind-body dualism.* According to this frame, a human being is made up of a material body and an immaterial soul, as two distinct parts. Here, a disability is a pathology that deprives a human being of his mind. Having a disability means acquiring a new (or no) identity and personality, becoming 'a half-fool', and ending up in your own world. Metaphors of plants, darkness and empty shells are used to contrast with the reason and intellectual capacities.

Counter-frames include:

1. *Human rights.* In this counter-frame, the notion of disability is conceptualized within a rights-based discourse. People with disabilities become politically active against social forces of ableism, claiming human and civil rights. This frame affirms that all human beings, irrespective of their disabilities, have certain rights that are inalienable. From this perspective, equal access for people with disabilities is a human rights issue of major concern, and concrete policy actions must be taken.

2. *Disability creates opportunities.* The capabilities, expertise and value of persons with disabilities are central in the next counter-frame. Potential is recognized and persons are portrayed as active members, making decisions for their lives and adding value. Disability is evaluated positive and the idea is claimed that society is blind for the expertise and added value of people with disabilities.

3. *Interdependence.* In the last counter-frame, interdependence between people, irrespective of their disabilities, is the main theme. Reciprocity, mutual learning and benefits for both people with and without disabilities are central. There is a focus on solidarity and warm friendships, with a lot of shared dreams, fears and laughter.

What has been described so far does not mean that every source uses only one frame. According to the analysis, several of the frames are combined. None of the counter-frames was the privilege of single sources; they were always a result of a combination with one or multiple dominant frames. Moreover, as can be seen, the examples of the used metaphors and the

voice of vocabulary is less detailed when moving to the counter-frames, as these alternative representations are not common in the analyzed media texts.

4.6 Discussion and conclusion

Analyzing media text from different media magazines offered insights into dominant and alternative frames related to disability. An inventory of dominant frames was developed, together with alternative counter-frames that may offer 'new' perspectives regarding disability.

Framing analysis of the media discourse revealed nine dominant frames and three counter-frames. This unbalance, characterized by the relative absence of counter-frames, confirms the one-sided and negative image of disability in media (Ellis & Goggin, 2015). The accent is above all placed on suffering, caring, fixing and overcoming the disability. The results from the analysis indicate that most of the images rely on the frames of '*Suffering and fear of degeneration', 'The heavy burden of care', 'Faith in science; variant: human enhancement', The goer; variant: the hero',* These dominant frames can partially be connected with the medical model, the social pathology model and the supercrip model of disability as defined by Clogston (1990) and Haller (1998). Nevertheless, the inventory made in this study complement their previous propositions of central frames regarding the representation of disability. New frames emerged (e.g. *'The lurking monster', 'Carpe Diem'*, …) and existing frames were refined (e.g. '*Suffering and fear of degeneration'* and *'Faith in science; variant: human enhancement'* as elements of the medical model on disability).

The evaluations made in the most dominant frames of this study remain grounded in traditional dichotomous thinking. The public is proned to an oversimplified binary way of perceiving persons with a disability. Disability is narrowed in two extremes. On the one hand, the frames rely on the prejudice that persons with a disability are disadvantaged, weak, dependent on and in need of help from nondisabled people. On the other hand, they build upon the prejudice of the disabled person as heroic and inspirational. Disabled persons are able to perform feats normally considered not possible for persons with disabilities or can live a 'regular' life in spite of a disability. They can display ordinary or extraordinary achievement and this is framed in terms of heroic courage and inspirational achievement, often referred to as inspiration porn (Young, 2012). The impairment begets extraordinary willpower and must be successfully overcome if only the person would try

hard enough. This perception does not challenge the cultural and environmental burdens, but demonstrates that they can — with sufficient willpower — be overcome (Clogston, 1994; Harnett, 2000).

In these two extremes - the helpless and the inspirational – disability is represented as a problem located in individual bodies, to be cured or to be overcome. "When disability is seen as the largest component of a person, much of what is unique and human about him or her is obscured" (Kunc, 2000, p. 25). This normative thinking/individualization focuses on what is *not* there, on what is missing, on deficits (Veck, 2009). In that way, structural and systemic causes of disability are obscured in media representation.

Besides, both the two extremes objectify people with disabilities. They are not represented as real persons or subjects, but as objects. The observing audience is assumed not to have an impairment, and there is little ground for identification with the person. The depictions of disability are connected to the maintenance alienating modes of relating, which may deprive persons with disabilities of the recognition of subjective experience and personhood. It seems that the journalists kept the readers at a distance by exaggerating the people's struggles to fit normative notions of what it means to be human. This normalizing process closes off potentialities to affect and to be affected (Davies, 2014). What is central in the media discourse, is fear towards to monstrous others (Shildrick, 2002), and the abjection of them, to shore up a sense of the reader's own normality.

Where do hybrid identities fit into these representations? According to Goodley and Runswick-Cole (2014), disability challenges our narrow conceptions of what constitutes the human. It allows to trouble and question traditional conceptions of normality and humanness. However, the results of the analysis reveal that the most prominent media-frames do not question hegemonic ideologies, but rather confirm them. Portrayed people are forced into normative and binary extremes, that catch us all up in the active differentiation between insiders and outsiders, 'us' and 'them', leading to social exclusion of those who are not seen fitting in appropriate normative categories. Analysis proved that the segregated, inferior and 'less than human' position of disability (Goodley & Runswick-Cole, 2014) is still very often taken for granted, instead of granting them opportunities to break up the narrow boundaries of what is conceived as normal and human. By allowing a dis/human position in media representation, we can remain more vigilant to complexities, hybridity and ambivalence. By transcending boundaries of dis/abled, self/other, us/them, complex conceptions of disability can be retained. The Other, like the Self, has many faces and should be recognized as a diverse and complex entity – a citizen, an expert, an object of love and desire, a potential enemy and victim, a model for identification, an object of care and hospitality, a subject with agency, a person-in-relation-to-others, … Unfortunately, these complex assemblages

of the human are not offered in media. Similarly, the world cannot be divided in frames/counter-frames as bad/good. Complex assemblages of frames and counter-frames where subjects are allowed to tell their own stories is needed to challenge and deconstruct social prejudices.

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Annex

Table 1. Dominant and counter-frames in media-analysis.

Frame	Cultural theme	Issue	Cause	Consequences	Moral evaluation	Possible solutions / actions	Initiator	Framing sponsor	Metaphors, choice of vocabulary	Visual image
9 DOMINANT FRAMES										
Suffering and fear of degeneration (n=27)	Struggle, suffering, fear.	Disability causes a complete catastrophe. PwD are lost in advance, and are uncertain and are extremely fearful.	Defeatism. Disability means degeneration, a disaster.	PwD are suffering in agony, they have to undergo, they have fear of the future.	Disability means suffering, is very negative and pathetic. Fear of degeneration.	Struggling, prostration, praying, hoping, resignation.	PwD and their family.	/	"Suffer, misery everywhere, a pool of pain, misery and fear, every day is a fearful day, the sword of Damocles above your head, horrible decline, the distress of the illness, ..."	A lot of images of children and family portraits. Usually unhappy and with medical treatments. A remarkable amount of pictures 'before' and 'after' an accident, so the difference and loss is clear. Focus on the disability.
The heavy burden of care (n=20)	The reciprocity of relationships is essential.	The real victims of disability are those around the person with a disability, heavy burden, sacrifice.	PwD lose autonomy or behave inappropriately. Others have to do everything in their place without getting anything in return.	Collateral damage, the carers must sacrifice, risk of isolation and institutionalisation.	Disability means suffering for the family who must sacrifice, costs outweigh the benefits, feelings of guilt because of the heavy burden.	Potential institutionalisation, environment need more support.	Family carers.	Psychologists psychiatrists.	"Autistic grandson source of great concern to grandpa, grandfather doesn't know a way out of a problem, the life of father M. is completely dedicated to his son, parents sacrifice themselves, ..."	A lot of family pictures with PwD as passive members. Portraits of unhappy people.

Frame	Cultural theme	Issue	Cause	Consequences	Moral evaluation	Possible solutions / actions	Initiator	Framing sponsor	Metaphors, choice of vocabulary	Visual image
Faith in science; variant: human enhancement (n=15)	Belief in medical improvements and miracles. Disability is a medical affair, a defect, a mistake in the genes. Science can overcome limitations of the body, can enhance the human condition.	PwD are ill and should be treated as patients. They are impaired and in need of curing.	New scientific breakthrough	PwD become patients or cases. They disappear behind the diagnosis and are examined and cured.	Belief in medical science and human enhancement. PwD can be saved through curing.	Curing, managing the illness or disability, approximate the ideal of "normality", medication, medical research, prenatal screening, experimenting, DNA technology.	Medical professionals.	Medical professionals	Medical jargon: "disease, illness, impairment, diagnosis, treatment, cure, deviation, gene defects, patients, medication, fixing, …"	Brains in a test tube, DNA, pictures of surgery and other medical treatments.
The goer; variant: the hero (n=13)	Struggle, perseverance, the individual duty not to give up.	Deterioration can be conquered by commitment and perseverance. PwD are inspirational, brave, heroic and have distinguished courage and abilities.	There is too little attention to the brave acts of PwD.	Individual: PwD draw satisfaction out of their inspirational role / Societal: PwD and their heroic acts serve as social role model.	Individual duty not to give up.	Moral duty not to give up, individual courage, dedication and vigor, individual commitment and responsibility. Disability must be overcome. The pursuit of the good.	PwD + others who nominate them as inspirational personalities.	/	"Refusing to give up, combative, overcome your disability, iron man, every setback is an opportunity to fight back, fight the devil, fighting spirit, miracles, very stubborn, …."	Heroic pictures, PwD in combat and sweating.

Frame	Cultural theme	Issue	Cause	Consequences	Moral evaluation	Possible solutions / actions	Initiator	Framing sponsor	Metaphors, choice of vocabulary	Visual image
The helpless victim (n=11)	The innocent victim that must be protected and be more assertive as archetype.	PwD are easy victims.	PwD are fragile and too weak to defend themselves.	Individual: PwD feels vulnerable and not belonging / Societal: PwD are chosen to be bullied.	PwD are fragile and potential victims, they deserve protection and must be more assertive.	Protecting PwD + PwD have to be more resilient.	Others must protect + PwD must be stronger.	Psychologists, psychiatrists.	"Impaired and bullied, I did not dare to come out of my house, …"	Portraits of unhappy people. Black and white photography. Anonymous faces.
The lurking monster (n=10)	Disability is a demon, constantly lying in wait and striking unexpectedly.	Disability means a tragedy, it is frightening and steals a person's successful life.	Disability lurks around every corner.	Disability takes away everything you've built, one must give up every dream and is no longer able to participate.	Disability as a monster to be fought and combated. Focus on negative impacts, arouses pity.	Arm yourself against this evil demon and warn others.	PwD and their family.	/	"The curtain falls, we were attacked on the eve of our retirement when our dreams shattered, defence against terrible suffering, …"	A remarkable amount of pictures 'before' and 'after' an accident, so the difference and loss is clear. Unhappy people. Pictures of people confined to bed.
Charity (n=9)	Selfless commitment, charity.	PwD deserve pity and care.	People learned to care unconditionally, also for PwD.	Benefactors fulfil their duty.	Moral duty to help others. PwD as recipients of charity.	Charity, fund-raising.	Benefactors.	/	"We support a good cause, raising money, the smile on the face of those people making all efforts well, etc."	Pictures of benefactors (princesses, private companies, celebrities, etc.)

Frame	Cultural theme	Issue	Cause	Consequences	Moral evaluation	Possible solutions / actions	Initiator	Framing sponsor	Metaphors, choice of vocabulary	Visual image
Carpe Diem (n=6)	Seize the day, optimism, carpe diem.	Life is not always what we had hoped for, but PwD and their family can also enjoy life.	Today is the day, life is too short to grieve or to worry.	Live from day to day, enjoy the present and don't think about the worries of tomorrow.	The norm to enjoy life.	Learning to find happiness in the little things in life.	PwD and their family.	/	"Take each day as it comes and enjoy it, happiness is in the little things around you, every 26th of September we open a bottle of champagne to celebrate I survived, every day counts, etc.".	Pictures of sunny beaches and smiling faces.
Mind-body dualism (n=5)	Mind and body are distinct natures, a person is made up of a body (material) and soul (immaterial).	Disability means acquiring a new identity and personality.	Disability changes people's minds.	PwD end up in their own world, obtain a different personality.	Having a disability defines the person completely. Acquiring another personality is in opposition to ideals of autonomy and individuality.	Revolt or euthanasia.	Medical professionals.	Neurologists.	"I became a half-fool, another man, his new soul, formerly a gentleman and now nothing, a plant, no master in your own head, …."	Dark, rainy, foggy pictures. PwD as passive and not capable to participate.
3 COUNTERFRAMES										
Human rights (n=9)	All human beings, irrespective of their disabilities, have human rights.	The importance of equal rights for PwD.	Problems arise if one does not respect human rights.	Whether or not equal rights for all.	Believe in equal rights for all. PwD are seen as subjects with rights, who are capable of claiming those rights.	Concrete policy actions, demonstrating the importance of equal rights.	Policymakers.	Advocacy organisation.	"Waiting for equal opportunities, our country urgently must pull up its socks, …."	No focus on the disability.

Frame	Cultural theme	Issue	Cause	Consequences	Moral evaluation	Possible solutions / actions	Initiator	Framing sponsor	Metaphors, choice of vocabulary	Visual image
Disability creates opportunities	Cost-benefit analysis of what provides value and opportunities within society.	PwD offer opportunities, expertise and value.	Society can learn from PwD, society is blind to the capabilities and expertise of PwD.	Individual: PWD feel valued / Societal: PwD add value and knowledge.	Recognizing potential and value. PwD as active members, making decisions for their lives and adding value.	Make use of the opportunities, expertise and knowledge of PwD.	Society.	/	"His expertise means an added value, the wise man or woman, they respect me for full and that gives me energy, …."	No focus on the disability. A picture of a wheelchair as art.
(n=7)										
Interdependence	Interdependence between people, irrespective of their disabilities.	Interdependence, solidarity and warm friendships between people with and without disabilities provides a mutual understanding and benefits, a win-win situation.	PwD are active members of society, but are sometimes too little encouraged or given the opportunity to fill in these active roles.	Individual: PWD feel valued / Societal: society benefits of this mutual understanding.	Interdependence, friendship, warmth, reciprocity.	Mutual learning, knowledge and experience.	People with and without disabilities.	/	"Jeffrey enjoys working with Wouter, part of the family, get to know each other as human beings, they are making plans together, …"	Hand in hand, working together, laughter.
(n=4)										

Chapter 5

Political Involvement of Persons with Intellectual Disabilities - a Qualitative Research Project in the Dutch Speaking Part of Belgium[4]

Abstract

Although over the past few decades there has been growing attention to the situation and human rights of persons with an intellectual disability in society, there is still hesitation on many fronts. This research takes up the challenge of political rights and explores the political participation of persons with an intellectual disability with regard to their involvement in political discussions in Flanders, the Dutch-speaking part of Belgium.

Based on this participatory research, it can be concluded that the political participation of persons with an intellectual disability in Flanders has not yet been achieved. Suggestions are made to consider political participation as a rhizomatic conception where difference is an integral part of relationships, and it is with and by these relations that participation can be achieved (relational citizenship).

5.1 Introduction

Throughout history people with an (intellectual) disability have been discriminated against, mistreated, neglected, abused and institutionalized (Stiker, 1997). Without assuming that recent trends, such as deinstitutionalization and inclusion (Bjarnason, 2011; Chenoweth & Stehlik, 2004; Edgerton, 1993), have solved all the problems, it is true that during the past 40 years there has been growing attention to the situation and human rights of persons with an intellectual disability in society (Bérubé, 1996; Landsman, 1999; Taylor & Bogdan, 1989; Wolfensberger, 1972). For instance, at the international political forum we recently saw the United Nations Convention on the Rights of Persons with Disabilities (go to http://www.un.org/disabilities/) put to a vote. Quite a few countries have signed and ratified this Convention. By now – begin November 2016 – 160 countries have signed the Convention and 168 countries have already ratified the Convention. In its 50 articles, the Convention aims to support a paradigm shift in approach from charity to rights, to describe these rights and their wide area of application as clearly as possible, and to establish a link with rights as anchor points that can be incorporated into projects concerning development cooperation. In regard to the right to political participation, article 29, 'Participation in political and public life', is particularly relevant for the work reported in this chapter.

On the theoretical level there has been quite a shift as well, as illustrated by Martha Nussbaum (2006, 2009, 2010) who modifies the social contract theory of Rawls. Based on the work of Amartya Sen, Nussbaum develops a 'capabilities theory' that starts from the notion that people with an intellectual disability, if we truly regard them to be citizens of equal value, pose a challenge to philosophical theories of justice. Even the extremely broadminded social contract theory of John Rawls does not manage to hide the fact that the citizens that enter into such a contract with the state are expected to have a set of skills considered necessary for participation in the political life of the community (Stark, 2007). Tisdall (1994) points out, however, that assumptions about the fundamental competence and skills required for participation in political life are "arguably based on exclusion as well as inclusion" (p. 3) and some groups are inevitably left out. To counter exclusion, Nussbaum develops an alternative that uses 10 central capabilities, or substantial freedoms, that all governments should guarantee to their citizens. According to her, the capabilities that should be supported by all democracies are that people are able to:

1. Live the normal length of a human life.
2. Have good bodily health.
3. Have protection of bodily integrity.
4. Imagine, to think, and to reason (senses, imagination and thought).
5. Have attachments to things and persons outside ourselves (emotions).
6. Form a conception of the good and to engage in critical reflection about the planning of one's own life (practical reasoning).
7. Live for and in relation to others (affiliation).
8. Live with concern for and in relation to animals, plants, and the world of nature (other species).
9. Laugh, to play, to enjoy recreational activities (play).
10. Control one's environment:
    a. Political: being able to participate effectively in political choices that govern one's life; having the rights of political participation, free speech and freedom of association.
    b. Material: being able to hold property (both land and movable goods); having the right to seek employment on an equal basis with others.

(For our subject, we pay special attention to the final capability.)

The capability approach uses the idea of a threshold (Nussbaum, 2010): for each important entitlement there is an appropriate level beneath which it

seems right to say that the relevant entitlement has not been secured and, as a result, human dignity is bound to be compromised.

At this point we move to the most controversial step, namely one of the motives for our research project. In concrete terms, when Nussbaum evaluated the situation of people with a disability she found mixed results: although in many western countries progress had been made in a number of areas (for example, people with an intellectual disability were often accepted in mainstream education, and many specific support services for people with a disability were up and running), she still saw hesitation on many fronts. This was partly through budgetary reasons, and partly because persons with an intellectual disability were often still regarded as charitable cases instead of citizens with rights. This spurred Nussbaum to call for going one step further. Now she proposed taking the most controversial step of all: giving people with intellectual disabilities political and civil rights on a basis of genuine equality (Nussbaum, 2009, p. 350; 2010, p. 94). Nussbaum tried to illustrate this by considering the right of people with an intellectual disability to vote, or the right to serve on a jury.

In this chapter we take up the challenge as formulated by Nussbaum and we explore the political participation of persons with an intellectual disability with regard to their involvement in political discussions. In this study, political participation means that they participation in municipal, provincial and national policy bodies and politics. We don't refer to participation in councils for service providers, or in specific NGOs for persons with an intellectual disability.

5.3 Research context

Flanders, the Dutch-speaking part of Belgium, ratified the UN Convention on the Rights of Persons with Disabilities in July 2009. Ratification as such means that a country is obliged to follow the Convention articles and report regularly on the country's progress regarding citizens with a disability. The reports are coordinated by the administration of Equal Opportunities Flanders, together with the Flemish Minister of Equal Opportunities. In 2010 the Minister initiated a study on 'participation in political decision-making by persons with an intellectual disability in Flanders'. During one year a part-time researcher (second author) conducted this research project, under the supervision of the first author and in very close collaboration with Our New Future, the Flemish self-advocacy movement of people with intellectual disabilities, and in the spirit of 'Nothing About Us Without Us' (Charlton,

1998).

5.4 Problem definition and research questions

A recent report by the EU Fundamental Rights Agency (FRA, 2010) compared member states on the subject of the political rights of persons with an intellectual disability. In this report, Belgium is classified in the category of countries where there is exclusion from the right of political participation in decision making by persons with an intellectual disability. This shows that persons with an intellectual disability in Belgium, and Flanders as a part of Belgium, clearly have to be considered as a minority group – a minority group whose political rights are in jeopardy. Proceeding from this conclusion and the introduction of this chapter, the following research questions were included for our study:

- What is understood by participation in political decision making?
- How many persons with an intellectual disability were participating in the political decision-making process in Flanders at the start of the research trajectory (baseline measurement)? Where are they participating?
- Who are the various persons involved in the participation in political decision making by persons with an intellectual disability? What are their experiences, views and needs?
- What resources are currently made available by the administration to make it possible for persons with an intellectual disability to participate? How are these existing opportunities for participation functioning?
- How can participation in political decision making be inclusive and meaningful for persons with an intellectual disability? How does that translate into practice?

5.5 Research methods

In this research project various methods and were used, which we will briefly discuss below.

Participatory research (Garbutt, 2009; Gilbert, 2004)

The entire study was developed in close collaboration with the Our New

Future (ONF). This happened in various ways. Members of ONF – persons labeled as having an intellectual disability – were part of the steering committee of the study. They were involved in drafting the research questions and the questions for the interviews, took part in conducting the interviews, were actively involved in passing on the feedback from the first results of the study to the key members of ONF, participated in interviews and focus groups, and were involved in converting the research report into accessible language for persons with an intellectual disability.

Baseline measurement

In the first phase of the study, a baseline measurement was carried out. This was to determine how many people with an intellectual disability in Flanders participate in political decision making. Using purposive sampling (Bernard 1995), an email was sent to 15 organizations, selected by the researchers because they were sure that if people were participating politically, these organizations would know of them. The two umbrella organizations of all Flemish provinces and municipalities were also contacted, since they had the most extensive knowledge of the local political decision-making processes in Flanders. Finally, a letter was sent to all Flemish political parties. To gain an insight into the situation in the French speaking part of Belgium – the Walloon provinces – the Walloon self-advocacy movement 'Vous et Moi' was contacted, as were the Walloon colleagues of 'Inclusion Flanders' (AFrAHM). This was an attempt to introduce the other part of the country in a 'negative case analysis' (Mertens, 1998, p. 182). The following questions were given to these organizations:

- How do you understand participation in political decision making, and at what level do you think this participation is situated?
- How many persons with an intellectual disability that currently participate in political decision-making procesess do you know, and to what extent do they participate?
- Do you know of any colleagues we could write to and ask this question? In this way a snowball sampling process was generated (Bernard, 1995).

In-depth interviews

In the second phase of the research, several in-depth interviews were conducted with those involved in participation in political decision making. In the first instance, these were persons with an intellectual disability who participated in political decision making or were interested in participating in

the future. In addition to these persons, seven staff members of organizations for persons with a disability that were involved as professionals in political decision making, six persons from another minority groups who were involved in political decision making (e.g., hands-on experts on poverty and social exclusion within federal public services), and 10 advisors of persons with an intellectual disability were interviewed. These advisors are what ONF members call 'coaches' or volunteers who provide support to ONF members who are involved in community activities. Coaching has to be considered as the necessary support persons with intellectual disabilities need to show and realize their potential. Examples of concrete coaching activities in political decision-making processes are translating inaccessible language, making sure that persons with intellectual disabilities get enough time to think and make decisions, making sure people get accessible information and enough time to prepare for meetings, etc. During the interviews, the focus was on what kind of support is seen as being beneficial to make participation in political decision making more effective.

Focus groups

In addition to the interviews, three separate focus groups were set up for persons with an intellectual disability, advisors and policy makers (Adler & Ziglio 1996). Five persons with an intellectual disability, four advisors and five policy makers attended these groups. The focus groups with advisors and officials were primarily conducted online. Participants were given the opportunity to comment on propositions and questions that were put forward, with topics such as support needs, structural coaching solutions, representation and the preservation of the self-advocacy movement agenda within political decision making.

Analysis of research material

The research material was analyzed using a thematic analysis method, following the model as developed by Braun and Clarke (2006). They propose to work in the following steps: data familiarization, initial coding generation, search for themes, theme definition and labeling, and report writing. In the following part of the chapter, the results are grouped in five robust themes.

5.6 Results

(1) With regard to defining political participation, it was noticeable that the organizations that were consulted gave very different answers. Most

organizations stated clearly that they position the participation in political decision making on different levels. Some organizations indicated explicitly that participation in decision making is also positioned at the level of services (residents' associations and consumers' associations). One of the organizations even talked only about this level, and not about the broader political level. Some organizations saw participation in decision making also at the organizational level, e.g. taking part in working groups in an organization for persons with a disability. No organization gave us a clear description of participation in decision-making as defined in this study.

(2) Regarding the baseline measurement, only three persons with an intellectual disability were found who participated in politics in the Dutch-speaking part of Belgium: one person was involved in the Consumers' Council of the Flemish Community, one took part in an advisory body for persons with a disability at the level of a city, and one was a committee member in a policy-making organization for persons with a disability. In 2010, Flanders had 6,161,600 inhabitants. The World Health Organization (WHO) estimates that 1% to 3% of the population has an intellectual disability – so the potential number of persons with an intellectual disability who could participate in politics lies between approximately 60.000 to 185.000.

(3) From the experiences of persons with an intellectual disability and their advisors it was obvious that conditions for participation could easily be made clear. They are considered to be minimal structural preconditions and are listed below:

- Persons with an intellectual disability would like to have equal influence on topics to be discussed in the political arena. In order to obtain a better participation, it is essential that they can also determine agenda items for meetings.
- An accessible location where the meeting takes place is a minimal precondition, either by public transport or by other means (often, a location near an accessible railway station is preferred).
- The stress for persons with an intellectual disability would be reduced if clear and easy to understand symbols were used at the location where the meeting is held (e.g., lift, signposts, information boards, emergency exits, etc.)
- Attending meetings would be much easier if accessible publications are made available. The invitation, preparation, report, additional documents and presentations could be made available on request. Each document could have a brief summary as introduction. By adjusting the typeface, using plain and simple language, introducing

pictograms and photographic material, offering a digital version, avoiding unnecessary embellishments, etc. many items could be made easier to understand without affecting the actual content.

- Participation actually begins with the invitation, which could include a clear indication of the time and place, the route description and map in simple language, a clear list of points on the agenda, full details of the contact person, asking what kind of support will be needed, identifying the points on the agenda that indicate the points where the input of the persons with an intellectual disability would be appreciated, etc. These are important signals for persons with an intellectual disability to tell whether or not they are taken seriously as active participants.

- Essential documents for the meeting (limited in number and pages) should preferably be sent 10 days before the day of meeting. It must be taken into account that not everyone has access to a computer and internet and that persons with intellectual disabilities may need support in reading and understanding the documents prior to the meeting.

- Participation would be made easier for people with an intellectual disability if the language used during the discussions would be calm and easy to understand, without complicated words and jargon.

- Time is an extremely important aspect for effective participation by people with intellectual disabilities. Time is needed for planning, thinking, talking things through, consulting with others, developing strategies, formulating opinions, and achieving, in this way, full participation in the decision-making processes. If participation is taken seriously, a different timetable is needed.

- It is best to avoid scheduling meetings in the morning, evening or at weekends. Many persons with an intellectual disability are dependent on the availability of professional staff members of the organizations who give them support. Travelling to meetings, nearly always by public transport, could take quite a long time.

- The meetings should not last too long, and there should be a few breaks in the meetings for the persons with an intellectual disability and their advisors. There should also be an option to take a 'time-out' in a meeting, so that members with an intellectual disability could briefly consult their advisor or others.

- It would be better if the meeting has a limited number of agenda points and if the discussions have a clear structure.

- It is very important to announce fairly in advance if the meeting date is changed. In this way, respect is shown for the fact that persons with an intellectual disability participate voluntarily and need time for preparation and planning.

- It would be easier to secure political participation on a structural basis if some kind of remuneration is made available for the persons with an intellectual disability and their advisors. This remuneration sometimes clashes with existing regulations regarding disability grants, however, it could be used to meet the expenses incurred and could provide some compensation for their time working as volunteers.
- The meetings could become safe environments if there were no major unexpected changes in the length of the meeting, the persons sitting around the table, the points on the agenda, etc.
- It would be easier to maintain concentration in a meeting by avoiding distractions, such as requesting that mobile phones be turned off during the discussions.
- Active participation is only possible with tailor-made and continuous coaching (see 5).

(4) The interviews and the focus groups revealed some sticking points and pitfalls of political participation. These sticking points showed that participation is not just a matter of structural technical adjustments, but also involved -and perhaps mainly- a shift in attitudes and foundations. Many participants in our study remain unconvinced that persons with an intellectual disability are 'allowed' to participate 'for the right reasons'. They believe that participation was in name only. We will let them speak for themselves:

> *Sometimes organizations do it to make them look good. We have to watch out for this.* (person with an intellectual disability)

> *I have the feeling that they are using people, just as a beautiful sign board. To engage people with an intellectual disability, seems to 'be cool'.* (advisor)

> *Perhaps they want us to join, so they can get more grants.* (person with an intellectual disability)

In spite of all the progress made in international principles and declarations, there are still many persons with an intellectual disability in our study who point out that the danger of people 'speaking for them' (see Alcoff, 1991) still exists.

> *That is why I don't want to join an organization I don't know anything about, because you could end up being one of their numbers that they show off about or use, and they may not*

> *consult you at all. I'm not saying it's everywhere like that, but in some organizations it is true that they don't consult you but they do use you, you see.* (person with a disability)

During the entire study the question kept cropping up at what level people are 'allowed' to participate. Some interviewees (without intellectual disabilities) would like to see restrictions in the subjects and decision-making levels that people with an intellectual disability were allowed to participate in. They argue that persons with an intellectual disability cannot share in political decision making when it concerns complex questions and would therefore opt for the alternative of involving them in matters that are 'less complicated'.

> *We know from experience that we are misled sometimes. We are invited to attend a meeting. But we just sit there and are not allowed to say anything. This may suit the organization, but not us.* (person with an intellectual disability)

> *It should be more than just being there. Did he really have a say? Did they really listen to him?* (advisor)

Many of the participants gave examples of the fact that persons with a disability are often seen as 'a homogeneous group'. The possibility of diverse experiences and opinions around the table is obviously not apparent to everyone.

> *Sometimes they say that 'the consumers' have been consulted, but then you find that you sit there only with people who have a physical disability, because the building is accessible. So, those are then almost the only ones that take part, because the others need an interpreter or an advisor. This means you have such a limited representation and then they say 'the consumers have been consulted'.* (policy maker)

A striking fact emerging from the research data is that persons with an intellectual disability often had to 'fit in' the structures and objectives that are decided from above. People have the feeling of being 'held hostage' in the system and don't have a channel to make their voice heard. They are only given the chance to participate within a given system and are hardly ever involved in setting the agenda.

> *We don't set the agenda. The agenda is set from above. If we ask for something to be put on the agenda, they don't pass it*

on. It is only one subject. I want to discuss various subjects. Inclusion, for example. (person with an intellectual disability)

The dubious title of 'consumer', given to persons with an intellectual disability, raises quite a few questions among our research participants. A 'consumer' has the role of 'using the system', not the role of (contributing to) decision making. This name already raised suspicions that persons with a disability are forced into inferior positions. Attention is also drawn to the danger of wrongly redefining the philosophy of self-advocacy. In that way, very few opportunities are created for the self-advocacy movement to develop, and for people with an intellectual disability to actually be involved and heard.

(5) From all the findings it emerged that coaching is the central, vital link in the chain if political participation to be successful. There seems not only a need for more opportunities for people to participate, but careful consideration should be given to ways of supporting them in this. Coaching seems to be a relational matter rather than a technical one, and needs to be flexible and on request. Not every person with an intellectual disability needs the same level of support and on the same areas, but coaching must be suited to individual needs and according to the context. In line of the idea that there is no such thing as a standard program for coaching, it is imperative that there is open communication regarding the need for support. "What do you need?", is a simple but crucial question.

I think that the only rule that works is to go in dialogue on things together. It is important to reach an agreement on certain matters, on what you like and what you don't like. It may be that a person hates it when he sits in a meeting and has to whisper something in my ear, making it obvious that he doesn't understand. What do you do then? What the person wants is always the most important thing. (advisor)

Coaching people with an intellectual disability is a relational matter where reciprocity, mutual respect and trust are key.

With coaching... There must be a connection. It must click. (person with an intellectual disability)

It is difficult to say how much input, percentage-wise, should come from the advisor and how much from the person he

> *coaches. This will also change all the time. And it also depends on the subject matter. If the subject matter is something you have talked about a few times already, than you shouldn't do too much as an advisor. You should take a backseat. If it is something completely new, you should definitely be on the ball.* (advisor)

Coaching a person with an intellectual disability is different from assisting in practical daily life activities: it is about thinking, interpreting moments and situations, and deciding together.

> *Support is not just about hands and feet. People who say something like 'I get it, all you do is write things down'. If that is your approach to coaching people with an intellectual disability, you'd better not bother at all.* (advisor)

An advisor should be alert all the time and be encouraged to look further than his/her own perspectives, to create the space and opportunities for persons with an intellectual disability to develop (more) self-determination. The support must always be in control of the self-advocate. The advisor should not take over, but facilitate and make possible. The advisor must always question his/her *raison d'être*.

> *Sometimes you hear things in a meeting that are not right. The person you support sometimes doesn't understand. That's why it is important that as an advisor you know the person very well, so that you have a good idea of what the person would or wouldn't agree with, without making assumptions because that could be tricky, of course. But there are moments when I will say 'you will have something to say about that, don't you remember, in that meeting last time you told them what you thought?' This is more like jogging their memory. Instead of saying 'this is what you think about that'. It would also be no real participation if I did not intervene on these occasions.* (advisor)

> *A good advisor sits next to the person. And if there is a difficult word, the advisor must explain what that word means, if we ask him. An advisor should not take things out of your hands. They should not always be the first to speak. Advisors have to make time too. Time to properly prepare for meetings, for example.* (person with an intellectual disability)

> *It is quite difficult for me to hold back sometimes. Because I have opinions too and occasionally I would like to say something too. But I am there for him.* (advisor)

Sometimes the pitfall of 'taking over' loomed, because others often address the advisor instead of the participant with an intellectual disability. Therefore it is crucial that an advisor always stays in the supporting role.

> *As an advisor you find that people often address you and ignore the person you are supporting. You should put a stop to this pretty quickly. If they start talking to me I'll say: 'it's those five there that you want to speak to.' (...) Knowing when to keep your mouth shut, Knowing when to create an opening for people so they can take the initiative, knowing that you can ask certain questions to facilitate discussions or certain matters... These are the things I find very important.* (advisor)

Because coaching means striking a balance all the time, it is extremely important that you assess one another honestly. One of the basic principles of coaching is to make sure that you both have a say about the support being offered.

> *And I always ask afterwards: 'how do you think the meeting went? And how did I do? Did I explain everything ok? Did I talk too much? Did you understand everything? Did you say what you wanted to say?' Later on I will informally evaluate everything once more. And we have a few laughs too sometimes.* (advisor)

Furthermore, it seems that advisors need quite a bit time to become familiar with the subject matter, the concepts and structures and the -sometimes implicit- rules of the policy-making meeting, in order to give proper support. They need to think about matters such as: who is sitting around the table, , what are their interests, what strategies can be used, what kind of power structures are at play, etc.

> *The preparation with those advisors, that was not so good. We could not follow the meetings. From the summary you could not figure out what it was about. Because they didn't get it themselves, they could not coach us. So we sort of sat there, looking like dummies.* (person with an intellectual disability)

The interviewees advocate for advisors who are not dependent on a policy-making organization, but on the person himself. This means that mixed interests would be avoided, that the person would have more autonomy within the organization, and that it would be possible to use the advisor for activities and meetings in other settings.

> *I cannot ask my advisor to go to a meeting of another organization. That's a shame. I was not allowed to use her either to translate a policy paper from the minister. I cannot use her for other things to do with politics. The organization decides what she can and cannot do.* (person with an intellectual disability)

5.7 Discussion

From this study we can conclude that the political participation of persons with an intellectual disability in Flanders has not yet been achieved. This conclusion runs parallel with the fact that we have learned through history that individuals who are located at the intersections of race, class, gender and disability were and are constituted as non-citizens and (no)bodies (Gabel et al., 2012) by the society and its institutions that are designed to protect, nurture and empower them (Erevelles & Minear, 2010, p. 127). From a historical perspective, people with a disability are perceived as clearly different from the 'storybook ideal citizens' (Carey, 2009). These latter are seen as citizens that are gifted with trumps such as being able to take rational decisions, to deal with complex information, to participate based on distinct communication, to be independently responsible for own basic needs, and to be independent on a financial and social level.

How can this non-participation (yet) of persons with an intellectual disability be understood and approached?

To start with, there are different ways in which citizenship and political participation is being translated. We have chosen to consider political participation for persons with an intellectual disability as a part of being on the way to the implementation of the UN Convention of the Rights for Persons with Disabilities. Whereas intellectual disability as a phenomenon is increasingly described as a social construction more than a biological fact (Finkelstein, 2009; Goodley & Rapley, 2001), we have the moral duty to take the question of political participation seriously. Although we cannot deny the strong binary thoughts in Belgium about citizenship and the associated

political participation, more and more people with an intellectual disability question this division and accompanying exclusion, and consequently the representation of the ideal citizen.

Sometimes we see a translation of political participation where traditional power relations are not altered but there are only certain linguistic shifts. Goodley (2011) points out the danger that, under the guise of political participation, self-advocacy as a minority movement is confronted with re-colonization through a government/majority agenda.

Besides, Biesta (2011) warns us for a possible second pitfall: the solution cannot simply be found by preparing persons with an intellectual disability, via training or schooling programs, hoping that they, at some point, 'will be allowed' to participate.

In a third possible solution, we follow Bérubé (2003) suggesting that it would be a better option if persons with an intellectual disability participate if they want to, while we change the system. While they participate, they are entitled to receive coaching, structural preconditions are being met, and everyone involved has a more positive attitude needed to achieve real and proper participation. Hence, nothing is preordained and everything is more flexible and negotiable. Through this last option we consider political participation as a rhizomatic conception, where opportunities are being opened based on a non-standardized (not similar for everyone) coaching.

With this latter option, we make a connection with the Deleuzian approach where thinking about difference makes room for the perspective of differenciation (Davies, 2009). Whereas the approaches Biesta and Goodley are cautious about are linked with the view where difference is a dimension of separation, we chose an approach where difference can be considered as a continuum, a multiplicity of fusion (Davies, p. 17). This results in a fluidity of categories (p. 19) and an escape to some degree from the limits of the individual and new ways of becoming a subject (p. 20). Hence, individuals don't have to 'fit in' (Pols, 2004), citizenship and political participation imposes the responsibility not only for the person with an intellectual disability. This process of becoming is located within an understanding of citizenship as a relational concept, where interaction can lead to a political opening, and gives people the chance to consider the collective (Winance, 2007). Difference is an integral part of relationships and it is with and by these relations that participation can be achieved.

"We want to participate but not only to sit there and to vote 'yes' on an agenda of others…" can be considered as a good closing quote (as stated by one of our interviewees) for this chapter.

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Chapter 6

Weaving Intersectionality into Disability Studies Research: Inclusion, Reflexivity and Anti-Essentialism[5]

Abstract

In recent years intersectionality has gained more and more attention among Disability Studies researchers. Using intersectionality as a tool creates opportunities to see how disability is imbricated with other categories of 'difference', such as race, gender, transnationality, age, sexuality, poverty, etc., categories that previously seemed so clear-cut, but are in reality complex, interwoven and embedded in space and time. Despite the notion of intersectionality is not new, methods for integrating intersectionality into Disability Studies research are in the nascent stages. This chapter explores three innovative ways to bring intersectionality into Disability Studies research, namely an inclusive, a reflexive and an anti-essentialist approach. The empirical part of this chapter is based on narrative research about inclusion and participation conducted in collaboration with people with disabilities in the Dutch speaking part of Belgium. While exploring the premises and challenges, we have tried to create new entries into the field of Disability Studies and to raise some vital questions.

6.1 Introduction

Much Disability Studies research has given voice to persons with a disability who are often marginalized by society and given limited, if any, decision-making power. This reputation, however, should be questioned, since a central weakness has been that despite its efforts to be inclusive, the traditional focal points of mainstream Disability Studies research tends to essentialize the category of people with a disability (Erevelles, 2011). People with disabilities are frequently assumed to share the same views, experiences, and priorities, regardless of gender, age, cultural background, sexual orientation, socio-economic status, religion, and other categories of difference. Consequently, primacy is given to 'disability' over other key elements, meaning that the interactions among all determinants are often neglected. Thus, the questions remain whether all people with a disability benefit, and which persons with a disability tend to be excluded from current research projects.

In response to these pressing issues, a growing number of Disability Studies researchers began to engage in intersectional research that explored multiple axes of difference. Continuous calls have been made to direct explicit attention to diversity among people with a disability (Jacob, Köbsell & Wollrad, 2010; Raab, 2007). Despite the fact that some researchers do incorporate other variables in their research, many continue to limit their analysis to comparing people 'with' and 'without' disabilities, producing

binary data. Another pitfall is that they assign prominence to disability and use an additive approach that entails looking at various variables as isolated and dichotomous rather than interactive and mutually interdependent (Yuval-Davis, 2006). Moreover, it is tempting for many researchers not to represent marginalized positions or voices, and design and produce research that tends not to benefit anyone who differs from the privileged 'norm' (Hankivsky et al., 2010). Another important pitfall in much Disability Studies research is that they tend to be inclusive, which is good and essential, but we argue that this is insufficient when conducting critical Disability Studies research. Not infrequently, this inclusive approach is the only focus. We believe that, when we really want to trace back the roots of Disability Studies, this inclusive approach needs to be completed with reflexivity and anti-essentialism, the two other approaches discussed in this chapter. To our opinion, Disability Studies research must be basically critical, embracing intersectionality as an important frame of reference. However, as illustrated above, we see that the concept of Disability Studies is frequently misused as the critical dimension is missing (Goodley, 2013; Meekosha & Shuttleworth, 2009). Consequently, we argue that inclusive, reflexive and anti-essentialist approaches are required for conducting critical and intersectional Disability Studies research.

This chapter will draw on current ongoing research of the authors in the Flemish Disability Studies context, in order to explore the premises and practical challenges of the processes involved in applying an intersectionality paradigm. In this context, we draw on a postmodern version of Disability Studies where different models of disability (medical, social, cultural) are considered and have their own right to exist. We recognize the existence of the different understandings of disability and undertake rigorous critical reflection of both positive and negative sides of each model. In promoting a multiplicity of readings, as Goodley and Runswick-Cole (2012) suggest, we seek to accept uncertainty, and to challenge the tendency of certain grand narratives to masquerade as truths in a postmodern era. Hence, the solution of problems cannot be conceptualized in dual thinking (in terms of 'or'), but rather in thinking in terms of 'and', as for us inspiring feminist researchers and philosophers such as Davies, Braidotti, Deleuze and Guattari as well. We seek to challenge dominant assumptions about living with a disability, and constitute disability as sites of construction and creativity rather than determination; we are thus opposed to the great binary aggregate: abled/disabled. With the latter, we make connection with feminist Disability Studies (Garland-Thomson, 2005), in tending to avoid impairment-specific or medical diagnostic categories to think about disability, and resist falling back on essentialist definitions of disability as inferior embodiment. By considering feminist Disability Studies, we go beyond explicit disability topics such as illness, beauty, genetics, etc. (Hall, 2011), and "reimagine disability", as

Rosemarie Garland-Thomson states (2005, p. 1557).

Having observed the concern about these issues, we hope to provide a source of inspiration by conducting research that is based on an understanding of the complexities of people's lives and situations, and contribute to the development of concrete intersectional methodologies. While overall principles and abstract methodologies have already been discussed in the literature, debates are scarce regarding concrete intersectional methodology and analysis (Simien, 2007; Valentine, 2007). Our objective in this chapter is therefore to contribute to the development of concrete intersectional methods in Disability Studies research, based on three methodological approaches used in ongoing research of the authors, namely inclusion, reflexivity, and anti-essentialism. The three approaches will be exemplified, comments will be provided about the methodological choices, and the importance of intersectionality for understanding the research material will be elaborated. It is important to point out that the approaches do not represent a unified way or one-size-fits-all solution to conduct intersectional research, instead they offer opportunities to demonstrate the different ways in which an intersectional perspective can be applied to Disability Studies research. The common characteristic is that they can bring processes into the research leading to more differenciation and embracing complexities in people's lives.

6.2 Intersectionality

An emerging paradigm for Disability Studies research is intersectionality (Goodley, 2010; Jacob, Köbsell & Wollrad, 2010; Söder, 2009). Intersectionality addresses a central feminist concern about capturing multiple positionalities, placing an explicit focus on differences among social groups (Davis, 2008). It seeks to illuminate various interacting factors that affect human lives and tries to identify how these different systemic conditions varying in place, time, and circumstance cooperate to reproduce conditions of inequality.

Although intersectionality theory emerged in the late 1970s, its roots can be traced back to Black Feminism. Female black pioneers such as Sojourner Truth (1851) used their own lives to illustrate the experience of intersectionality. In Thruth's famous "Ain't I A Woman?" speech, she implied that all too often 'woman' actually meant 'white woman'. Later on, the term of intersectionality was coined in 1989 by Kimberlé Crenshaw, and since then has travelled the world as a promising concept offering understanding

of how different axes of power intersect. The idea has caught the imagination of different disciplines (Sen et al., 2009), and is now recognized as a relatively new research paradigm (Hancock, 2007a) that builds on a number of assumptions regarding interactions of multiple systems at multiple and often simultaneous levels. First, intersectionality moves beyond traditional frameworks that separate social life into "discrete or pure strands" (Brah & Phoenix, 2004, p. 76). People have multiple roles and identities and being members of more than one 'group', they can simultaneously experience privilege and oppression. By no longer considering, for example, 'disability' in isolation from other categories (gender, religion, income, age, cultural background, family status, and many others), dynamic and contradictory power dynamics become more apparent and it becomes clear that no one social category is more important than any other. Second, intersectionality offers us a lens through which categories are viewed as mutually constituting processes. Rather than simply adding categories to one another, intersectionality strives to understand the unique experiences and perspectives at the intersection of two or more social or cultural categories and positions that intertwine as complex, overlapping, interacting, and often contradicting systems (Hancock, 2007b). Third, the concept of intersectionality can be used to analyze how power and power relations are maintained and reproduced. Intersectionality scholars tend to look to the perspectives and experiences of unmarked and unheard groups. In Staunæs' (2003, p. 101) words, "the concept can be a useful analytical tool in tracing how certain people seem to get positioned as not only different but also troublesome and, in some instances, marginalized".

Despite the fact that intersectionality is a topic that has caught growing interest, and produced a plethora of literature on the concept, there is a paucity of academic work on intersectionality from a methodological perspective (Bowleg, 2008; Cuádraz & Uttal, 1999; McCall, 2005). In particular, although the concept itself seems to have provided a solid framework, as Nash (2008) notes, there is a "lack of clearly defined intersectional methodology" (p. 4). With a number of studies undertaken (see, for example, Christensen & Jensen, 2012; Sen et al., 2009), the development of methodological practices has the potential to lead to both theoretical and methodological innovation in Disability Studies research.

6.3 The research

This chapter draws on an ongoing research project of the authors and discusses the challenges of implementing intersectional thinking into

Disability Studies. The key aim of the research project is to examine the inclusion and participation of people with a disability in the Dutch speaking part of Belgium. Whilst people with disabilities account for 15% of the world population and thus comprise one of the biggest minority groups in the world (World Report on Disability, 2011), they seem invisible in most policy domains and have little participation in society. Before starting the research, we drew up a list of basic assumptions, in parallel with the UN Convention on the Rights of Persons with Disabilities: (a) research results should support the promotion and protection of the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity; (b) persons with disabilities are no longer viewed as 'objects' of charity, medical treatment, and social protection, but rather as 'subjects' with rights, who are capable of claiming those rights, making decisions for their lives based on their free and informed consent, and as active members of society; (c) disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others; (d) we want to have respect for difference and accept persons with disabilities as part of human diversity; (e) we believe that full and effective participation and inclusion are important to empower individuals and to enrich society; (f) all activities (also research) should include the participation of persons with disabilities in parallel with the slogan: 'Nothing About Us Without Us'.

Within the research, narratives are collected and analyzed to map the subjective stories of people with a disability concerning their inclusion and participation. 383 persons with disabilities were interviewed in Belgium and the Netherlands (339 in Flanders and 44 in the Netherlands) to develop a picture of their personal experiences concerning inclusion/exclusion. The project was developed through a co-operative methodology (analogous to the framework of Van Hove, 1999) to access the perspectives and experiences of people with a disability, which have been often ignored or overlooked in research (Verdonschot et al, 2009). To map the subjective stories of people with a disability, open-ended questions across different facets of social life were discussed in an interview. The interview concerns two main questions: (a) "give examples of moments or situations where you had the feeling that you were taken into account, you were included, that people took you seriously"; (b) "give examples of moments or situations where you felt discriminated or oppressed". All the interviews were video recorded, producing more than 500 hours of footage. Students of Ghent University and the University of Antwerp were called upon to assist with recruiting participants and interviewing them individually at a safe place of their choice. The interviews lasted an hour and a half on average, were filmed

and fully transcribed. The research population consists of 383 individuals with a disability, including 202 men and 181 women, from a variety of backgrounds, age, abilities and experiences. The formulation of Turnbull & Turnbull (2002) is used to define disability "... the new paradigm of disability is contextual and societal. A person has an impairment that becomes a disability as a result of the interaction between the individual, and the natural, built, cultural and societal environments. Accordingly, research into the natural, cultural and social environments is warranted and is targeted at enhancing enablement and preventing disablement..." Here we understand disability as a social construction that is not a unified, singular thing or a condition people have (Connor, Gabel, Gallagher & Morton, 2008), but a "quintessential post-modern concept, because it is so complex, so variable, so contingent and so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality" (Gabel & Peters, 2004, p. 588). We believe that disability cannot be placed squarely in society as the social model suggests (Oliver, 1990), but needs a more complete understanding of disability and impairment as social concepts, with recognition for individual experiences of the body over time and in variable circumstances (Crow, 1996).

It became clear that constructing an intersectional framework in this research entails thinking carefully about the research methodology. Reflecting on our own research experience, three methodological approaches are described and commented in the following section, namely an inclusive, a reflexive and an anti-essentialist approach.

6.4 The inclusive path

Over the previous few years we have learned a lot from colleagues who we see as 'role models' while talking about inclusive/collaborative/cooperative research projects (Goodley, 2000; Walmsley & Johnson, 2003). In this inclusive approach, the research process and its methodologies must ensure that people with disabilities – about whom, and for whom the research is designed – are involved not simply as research subjects, but play a central role as researchers and research participants. We refer to inclusive research as a term that encompasses a range of research approaches that have traditionally been termed 'participatory' or 'emancipatory' (Walmsley, 2001). In Disability Studies research, the development of inclusive research, where people with disabilities are active participants, is now fairly common; its impact however has been limited (Walmsley, 2001). Inevitably, following an

inclusive approach in research has not been without its critics and presents a number of ethical and methodological challenges: power differences in research relationships are fragile, giving voice can not be organized 'in a hurry', co-researchers with disabilities can get alienated from their own research process, language and reporting can be non-transparent for researchers and participants. However, analogous with our basic assumptions ('Nothing About Us Without Us') and the UN Convention on the Rights of Persons with Disabilities, we highlight the importance and challenge of involving people with a disability in the research; in order to keep the research relevant, honest, and representative; ensuring that the analysis is grounded in the lived experiences of the participants. With all involved in a process of mutual recognition and co-understanding, we try to create a discursive space where we could think and act with one another, doing research *with* rather than *on* or *for* people with disabilities, and co-constructing research where people don't get alienated from the process.

Promoting the engagement of participants in an inclusive debate on issues relevant to them, creates a productive dialogue on developing theory and connects with intersectional theory, participatory methods to achieve social change, and critical engagement with issues of power and structural inequalities (Krumer-Nevo, 2009). In particular, one of the key features of an intersectional perspective, and one which is a common theme in the inclusive approach, is that it involves the creation of coalitions and strategic alliances to alleviate social exclusion, marginalization, and subordination (Hankivsky, et al., 2010). Through the cooperative articulation of experiences and following each other's footsteps, participants and researchers got to know each other's interests and pluralist meanings while at the same time creating new ones. Moreover, in the inclusive approach, all forms of knowledge are valued as sources of data and information. It generally lends itself more easily to an in-depth investigation into the complexities and intersections of individuals' social lives. In enabling the discussion to ground itself in 'real life' where ideas can be discussed and tested against what is known, experienced, and understood (Fine, 2007; Kemmis & McTaggart, 2008), inclusive approaches are therefore particularly complementary to an intersectional perspective. It is key for developing a fully nuanced story and dissolves the distance between those labeled and categorized as 'them' or 'us', which automatically leads to communal activism and resistance in order to cultivate a desired social change.

Within our research project, the inclusive approach permeated different levels of the research process. Our belief that all participants have valuable knowledge to impart based on their personal perspectives and experiences led to different co-operative methods such as the organization of viewing

days and participatory data analysis, the editing of the footage in close collaboration with the participants, the launching of a website with accessible research material and reporting, the participation of representatives with a disability in the advisory committee of the research, but above all, the continuous dialogue and intensive and close collaborative relationships between researchers and participants where opinions, interpretations, and experiences were shared. The participation through the viewing days is felt to be a crucial mechanism to achieve maximal participation from, and dialogue with, the participants within the research project. This dialogue and listening turned the known into the unknown and opens up new modes of knowing and being (Davies, 2014). To illustrate, the researcher wrestled with the fact whether or not – and if yes, how – to use categories such as *inter alia:* age, cultural background, abilities, gender, in the research, without slipping into the trap of labeling people, especially assuming that people fall into one or two categories while realities are much more complex. Participant discussions on this topic during the viewing days, and preferred that some categories of difference should be named and used. They shared the opinion that although it is an ongoing challenge, it is difficult to talk about inclusion and discrimination without talking about people as through they belong in some categories. Beside this, participatory data analysis was also conducted on the viewing days to supplement participants' own analyses. Asking the research participants to help interpret findings brought new perspectives on data. For instance, the researchers' contribution to the analysis was discussed among the participants as the researcher saw the concept of 'role models' as an emerging theme out of the data material. Participants questioned this topic because the researcher had interpreted this theme in a passive way (namely, role models *for* people with a disability), whereas the participants saw themselves not only as recipients, looking up to others with respect and admiration, but also as people who can also be respected and admired *by* others and serve as a role model themselves (for others, with or without disabilities).

Although we have encountered some challenges when attempting to integrate these co-operative approaches into our research (with questions such as: whose voices get heard? Who is included? Who may be silenced within the research?), they provide important lenses for discerning the complexities in people's lives and for contributing to intersectional research. The study benefited immensely from the co-operative analysis and the constant dialogue with the participants, as it ensured that the research process and the findings were meaningful and respected the voices of participants themselves. So, briefly, we believe that intersectional Disability Studies benefits from an the inclusive approach in research as it gives insight in the complexities and multi-layeredness of participants' lives and allows for

the in-depth study of individuals' personal and unique social locations and experiences with power and privilege.

6.5 Reflexivity

Reflexivity is intended here as 'storying' lived experiences and multiple intersections through individual and collective narratives together with continuously acknowledging your own positionalities, experiences, roles, and political and theoretical frameworks as a researcher. According to this point of view, stories of lived experience of both the subject and the researcher are co-constructed and negotiated between the people involved as a means of capturing complex, multi-layered, and nuanced understandings. These lived experience approaches have become increasingly recognized as an important strategy in Disability Studies research (Atkinson, 1997; Booth & Booth, 1996). A leading question in Disability Studies is how to capture and fully include the voices of persons with disabilities and how to provide opportunities for traditionally marginalized perspectives to be heard (Ashby, 2011; Barton, 2005; Garland-Thomson, 2005; Goodley & Van Hove, 2005). Together with the researchers' reflections on how their own narratives are built in relation to both the research and the subject, this reflexive approach has become a topic for discussion for Disability Studies research as positivistic research models are challenged (Rinaldi, 2013; Crooks, Owen & Stone, 2012). Rinaldi (2013), states that engaging reflexively with positionalities and how they affect the production of knowledge can be particularly beneficial in Disability Studies, aiding in the paradigmatic shift from research *about,* to research *by* and *for,* disabled people.

Together with Cole (2009), we believe that intersectional theory can provide major theoretical support for methodological approaches such as the reflexive approach which permit the exploration of multiple and individual experiences, different connections, new questions and alternative understandings. Meanwhile, storying lived experiences can often illuminate hidden complexities, and invalidate simplistic binary generalizations and essentialisms. Elliot (1991) and Titchkosky (2007) argue that lived experiences have the power to disrupt dominant normative accounts of disability; they can illuminate the embodied reality and complexity of experience in contrast with professional and dominant biological models of disability. Taking personal experiences as a starting point, we agree with Hearn (2011) who in his study of men, suggested that it is necessary "to go back from masculinity to men", that is, to allow space for embodied realities and experiences in stead of starting from subject positions. Also Butler

(2011) states that there needs to be a distinction between subjects and individuals: the embodied experiences of real individuals taking subject positions are much more complex than social constructions (see also, Villa, 2011 "Embodiment Is Always More"). Different stories offer data which are open to different readings and interpretations and suggest multiple ways in which disability and other axes of difference might interact. Besides, next to differences between groups, storying lived experiences can take into account intra-group differences, an important feature of intersectionality following Crenshaw (1991, p. 1242). These narratives are helpful in reclaiming the stories of people with disabilities as suitable research material and allow differences among these experiences without the problematic emphasis on the universality of them.

Looking at reflexivity in our research, we can confirm that we concentrated on listening to a diversity of people with a disability in Flanders about their experiences on inclusion and participation in society. Our research material consists of 383 narratives from the participants with examples from their own lives, including their hopes and dreams, the many difficulties they face and their interests. This was one of the research project's goals, as the voice and analyses of persons with a disability are largely absent from research and policy making. As such, they come across as human beings rather than stereotypes, and the findings are grounded in experience.

We argue that the narrative approach we used brings *insider perspectives* and makes room for complexities and embodied realities, illustrating that the method of interviewing allows us to bring intersecting categories into play in order to under- stand processes of power and inclusion. In addition, we have found that one of the best ways to get at the underlying power dynamics contributing to patterns of domination, oppression, and privilege is by raising open-ended questions across different facets of social life. By doing so we have obtained context rich information about power relations and subjectivity. It is for this reason, we acknowledge the arguments of Bowleg (2008) for a 'qualitative stance' of the researcher in order to address the complexities of intersectionality. He developed ideas for conducting intersectional interviews, like Cuádraz & Uttal (1999) who also state that "the method of feminist in-depth interviewing encouraged individuals to explain how they viewed their circumstances, to define issues in their own terms, to identify processes leading to different outcomes, and to interpret the meaning of their lives to the researcher" (Cuádraz & Uttal,1999, p. 160).

We start by looking at the story of Tess, a 50 year old woman with a physical disa- bility who said that she sometimes identified herself as a woman, other times as unmarried, other times as disabled, other times as childless, other

times as having children, and other times as a committed swimming teacher, or all combined together in complex ways. She described the intersection of her identities in ways that makes these not discrete categories, but mutually constitutive and interacting. Seen through the lens of Buitelaar (2006), Tess speaks from different 'I'-positions, she switches positions or combines different positions when she tells her life-story. Recognizing these circumstances as catalytic factors in the life of Tess is essential in understanding the ways in which various forces and events shape the lives of people with a disability. In the words of Prins (2006): the narrative scripts available for these different collective identities modify one another and produce a unique life-story. Prins argues further that narratives tell us how people draw on different categories in the construction of their life-story. She sees 'identity' as a narrative in which we both play the leading role and write the script (p. 281). Categories and their intersections therefore emerge in the way people tell their life-stories. From an intersectional point of view, due to listening to the lived experiences of Tess, this account shows us that disability is imbricated with other categories of 'difference' and that these axes of difference are neither hierarchically ordered, nor static or dichotomous.

Additionally, the narratives from the research project are ambiguous and they confuse and tackle certain stereotypes of people with a disability. They call for engaging reflexively with our own positionalities, and the subjectivity of the researcher, in the ongoing process of situating ourselves and acknowledging, or even making use of, our own filters and presumptions. For example, the interview with Titus, a young man with a visual disability, offers the interviewing student some unsettling moments during their conversation. At a given moment, the interviewer asks Titus how he types on his computer and if he needs a special keyboard for his visual impairment. Titus looks right into her eyes and responds very seriously: "I *type blind (touch typing), just like you do I suppose?"* This answer was very confusing for the interviewer, since it was a departure from the expected content, although the created hesitations and stammerings kept the mind of the interviewer open and responsive, just like when he said to her that he swims right, "right *to the other side of the swimming pool and then back".* The interviewer was disrupted because she expected other answers, but as a result she carefully monitored her own subjectivity. Concretely, reflexivity implies here "a critical consciousness of the discourses that hold us in place, that is, a capacity to distance ourselves from them, at the same time as we are being constituted by them; a capacity to see the work they do and to question their effects at the same time as we live those effects" (Davies & Gannon, 2006, p. 380). This interview highlights our active, and reflexive, interviewers who are aware of what we are bringing to the research, and how findings are affecting our own

perceptions. These accounts also illustrate the strength of narratives because "it privileges the voices of everyday life over the researchers' pre-assumed theoretical perspective" as "researchers do not organize the world in the same way as those whom they are researching" (Cuádraz & Uttal, 1999, p. 168).

To sum up, we highlight the importance of reflexivity in research, the importance of narratives and the analysis of everyday life, and argue that taking this approach as a point of departure has potential for intersectional Disability Studies research. In attempt to unpack some of the complexities and power relations of research, this approach can function as a tool for revealing positionalities and can build a more careful representation of reality, one that is not assumed to be the objective, positivistic truth.

6.6 Anti-essentialism

The anti-essentialist perspective that Disability Studies endorses in various manifestations, is important for what it teaches us about disability and the social construction of human differences generally (Danforth & Gabel, 2007). Throughout history, the impairment label served as the signifier for exclusion, and a pathology where pre-social biological differences are suggested to mark off the 'impaired' from the 'normal'. In this view, social categories and dichotomies (impaired/non-impaired, normal/abnormal) are perceived as 'real' and fixed (Corker & French, 1999; Corker & Shakespeare, 2002; Price & Shildrickn, 1998). From anti-essentialist perspectives, Disability Studies can shed new light on how institutions and researchers use the traditional deficit and deterministic approach to shape interactions and traditional parameters in the theorization of disability. Within the anti- essentialist outlook, "disability theory centers on the interrogation of cultural categories, discourses, language, and practices in which 'disability', 'impairment' and 'being normal' come into being through their social performance, and on the power that these categories have in constructing subjectivities and identities of self and other" (Thomas, 2004, p. 36).

The Deleuzoguattarian rhizome can offer us both a map and a metaphor for the field of (anti-essentialist) Disability Studies, a philosophical concept advanced by Gilles Deleuze and Felix Guattari (1987): "unlike trees or their roots, the rhizome connects any point to any other point, there are no points or positions in a rhizome, such as those found in a structure, tree, or root. There are only lines" (p.9). In contrast, modernist knowledge can be seen as a root tree. "The tree is already the image of the world, or the root the image

of the world-tree...Binary logic is the spiritual reality of the root-tree" (pp.5-6). The rhizome opens up new ways of approaching disabled ways of living and *disability* as a word and concept, and can hold a wide variety of experiences and structured position in moments of precarious productive imbalance (Kuppers, 2011).

Following the intersectional perspective, it is important not to essentialize any group or assume that all members of a single social group share similar experiences, perspectives, and needs (Hankivsky & Cormier, 2009). On the contrary, an essentialist point of view assumes that the experience of being a member of the group under discussion is a stable one, one with a clear meaning, a meaning constant through time, space, and different historical, social, political, and personal contexts (Butler, 1990; Grillo, 2013). For example, the group 'women with disabilities' may vary considerably according to income, ethnicity, religious views, age, and geography and consequently may have very different experiences. Moreover, social categories such as disability, gender, age, ethnicity, class, geography, and so on are flexible and fluid. Following Burgess-Proctor (2006) and Weber & Parra-Medina (2003) in the intersectional perspective, we see that social categories are dynamic, historically grounded, socially constructed, and work at both micro and macro structural levels. Postmodern feminist theory has posited these categories as 'performative' (Butler, 1990). They are constantly re-made or re-written through daily actions and interactions. Meanwhile, a lot of research tries to 'fix' and solidify these performances, for example through a linear analysis. Categories and identities, such as disability, are inherently unstable and dynamic and interact with various other processes. They are not as universal and dichotomous as they look. They are created in relation, and are temporal and contextual. Furthermore, individuals speak from different positions, switch positions, or combine different positions. Telling one's life story thus consists of orchestrating the voices within us that speak from different positions and adjust the narratives for varying audiences (Buitelaar, 2006). Therefore, the concerns of people with a disability can only be properly understood when put within a dynamic context of relations and interactions. This can be likened to Prins (2006), when she makes a distinction between systemic and constructionist interpretations of intersectionality. The first interpretation assumes a more essentialist view on categories which are seen as static and rigid systems of domination. By contrast, the constructionist interpretation adopts a more relational and dynamic view of power where identity is not perceived as a matter of naming, but one of narration. People are both actors in and co-authors of their own life-stories and their positions are not static or given, but sites of constant struggle and negotiation. As such, the conceptualization of social categories involves a process of construction, deconstruction, and reconstruction

(Staunæs, 2003) and asks for a more rhizomatic way of thinking in order to challenge the omnipresent perception of seeing people, society and concepts in linear arborescent ways.

In our research project, the narratives demonstrate no single reality, and consist of multilayered, contradictory, and performative stories in which different categories play a constitutive role. Overzealous focus on extrapolating the data in fixed themes is to commit the error of essentialist thinking and harks back to the positivist tenet that there is a single and fixed reality. So, in our attempts to consider the multiple layers of intersectionality, analyzing the data became more sophisticated than a linear thematic analysis. Viewing the narratives through a rhizomatic structure with multiple entryways, connections from one point to another and without beginning or end (Deleuze & Guattari, 1987), allowed us to step away from understanding identities as essentialized or additive. Instead, it allowed us to see them as open, dynamic and in tactile relation with each other. This way of working is associated with the writing of a rhizomatic text where multiplicity and complexity is allowed (Sermijn et al., 2008). Deleuze (1995) writes of treating writing as a flow, as one flow among others, a flow meeting other flows. In writing 'messy texts' (Denzin, 1997), we tried to avoid linear figurations, simplistic dichotomies, and encourage the reader thinking rhizomatically, refusing "to impose meaning on the reader" (p. 224). As researchers, we had to be vigilant that we didn't pretend to reveal the complete truth, but only a part of the rhizome. Discontinuous, contradicting, and temporary elements from the narratives get a chance to contrast with linear analysis. The purpose is to disrupt and resist the assumed and known, and give attention to the context and the subtle (Leafgren, 2009). Since there are many different readings possible in the analysis (Goodley & Runswick-Cole, 2012), we choose to make public the multiplicity of stories on the website. Just as a rhizome has multiple entryways, we gave people the chance to pick their point of entry. People could chose different pathways, select themes emerging from the stories, or select to view all the stories of, for example, women with a disability, or even decide to view the whole narrative of every person with a disability. By doing this, we try to show many possible truths and realities that can all be viewed, instead of assuming there is only *the* truth. People have to listen and look at the complexity, uncertainty, and the layers of contradiction that emerge when people with a disability tell their lived experience. As such, multiple, fracturing and dissident experiences can be found in a diverse array of examples.

To sum up, we believe that an anti-essentialist approach is useful in terms of providing contextual and detailed accounts that illustrate complex social relationships, dynamics, multiple realities, and contribute to an

understanding not only of non linear relationships between concepts, but also the making of meaning and the processes behind those dynamics. In our opinion, this approach challenges the idea that the social world is neatly divided into categories, and contributes to the deconstruction of essentializing concepts of 'disabled' people in Disability Studies research. It helps researchers to identify, as an intersectional perspective demands, the full range of interlocking factors that affect the experiences of people with a disability.

6.7 Concluding thoughts

It is increasingly recognized that there is a need for intersectional research so that the full range of experiences and perspectives of diverse people with a disability are not obscured. This intersectional framework provides important insights into the ways in which disability intersects with other identities, contributing to unique experiences. However, bridging theory and method is never an easy undertaking, yet, we see great value in making this attempt because intersectional theory can help us unmask the taken-for-granted knowledge that only reinforce hierarchies and exclusions.

In this chapter, intersectionality is addressed as a promising methodological tool to explore complex and interwoven categories of difference. By highlighting a few methodological approaches, namely an inclusive, a reflexive, and an anti-essentialist approach, the usefulness of an intersectional perspective for Disability Studies research is revealed. Inspired by our own empirical research experiences and struggles, the chapter aims to contribute to concrete innovate intersectional methodology and analysis. The three approaches illustrate how they can illuminate complexities of every day life, rejecting the separability of social categories, as they recognize the heterogeneity of people with a disability. By doing so, we aim to elaborate on the emerging, yet undertheorized, paradigm of intersectionality as an innovative frame- work that has the potential to counterbalance essentialist interpretations of the category *disability.*

The questions raised by these approaches expose some of the methodological realities of engaging with an intersectional framework. However, we argue that these approaches have the potential to generate complex knowledge and rectify common misperceptions about people with a disability. They can challenge the common Flemish discourse about 'us' and 'them', in the sense that they can eliminate stereotypes and boundaries. They encourage "a dialogical process where participants negotiate meanings

at the level of question posing, data collection and analysis" and "encourages participants to work together on an equal basis to reach a mutual under- standing" (Gitlin & Russell, 1994 in Bridges, 2001, p. 382). By doing so, the chapter makes reference to the feminist concern about capturing multiple positionalities, where researchers and participants engage in intensive encounters and relationships where values such as trust, openness, involvement, and connection are key concepts (Tillman-Healy, 2003).

Moreover, the three approaches imply an attitude of fundamental "not knowing" (Claes, 2014), an uncertainty that creates space for complexity and ambiguity, an "ignorance that does not show the way, but only issues an invitation to set out on the journey" (Biesta, 1998, p. 505). In Rinaldi's words, by engaging in dialogue we enter "a process of transformation where you lose absolutely the possibility of controlling the final result" (Rinaldi, 2006, p. 184). This dialogue and listening turns the known into the unknown, and opens up new modes of knowing and being (Davies, 2014). This idea of experimentation concerns what is not yet known and demands more than recognizing or representing the truth (De Schauwer, 2011). This 'becoming' (Deleuze, 1994) rests on the capacity to let go of fixed identities and patterns, and to be open to the not-yet-known.

In this chapter, we do not want to rely on a strictly 'methods as tools and techniques' approach to research design, and then universalize or represent the discussed approaches as a unified way to conduct intersectional research. Instead, we demonstrate the various ways in which an intersectional perspective can be applied to Disability Studies research, by providing concrete illustrations of how an intersectional framework can be applied to research. It is our hope that our reflections can be a source of inspiration for other researchers striving to work from an intersectional perspective. In order for the full potential of intersectionality to be realized in Disability Studies research, methodologies need to be constantly questioned and improved, so that researchers can take a nuanced approach to power and the fluidity of categories. Here, we consider intersectionality as a chance to abandon Disability Studies research where impairment is the central focus, and we conclude that we have to retrace the roots of Disability Studies where the critical dimension and intersectionality should be an inherent component, and where the three approaches discussed in this chapter, namely inclusion, reflexivity, and anti-essentialism, should be fundamental principles.

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Chapter 7

Researching Together: Voice as a Guide in Research[6]

Abstract

This chapter seeks to explore the many meanings attached to 'voice' in research, with a particular emphasis on the different modalities voice can have in the field of inclusive Disability Studies. The interpretation of the six different perspectives of voice is based on the framework of Lawrence-Lightfoot and Davis (1997) and is contextualized within the work and engagement of the self-advocacy network in Flanders. The combination of these six aspects of voice led to the construction of a particular research design where voice is manifested through the chosen methodology, the various roles and various selves of the researchers and the subjects, the research tools and analysis. Drawing on the ideas and insights from a research project about political participation of persons with an intellectual disability in the self-advocacy network, tensions in the research process are explicated and research choices are discussed.

7.1 Context

This chapter was born out of a critical qualitative study on the political participation of persons with intellectual disabilities in Flanders, the Dutch-speaking part of Belgium. In this study, we attempt to explore and support the political participation of such persons with regard to their involvement in political discussions. Concretely, by political participation we mean the participation in municipal, provincial and national policy bodies and politics, and not in councils of service providers or non-governmental organizations for persons with a disability.

In a recent collaborative research project (Goethals & Van Hove, 2011) it was found that persons with intellectual disabilities want to participate in political discussions and decision-making. Despite this statement, we were unable to find Flemish citizens with an intellectual disability who were 'politically active'. Political involvement, when existing, was limited to getting out a vote during the elections (ironically, the Dutch translation of 'to vote' is 'stemmen' or 'voices'). These findings led to the Flemish self-advocacy movement 'Our New Future' (ONT vzw, Onze Nieuwe Toekomst) setting up a concrete project which started at the beginning of 2012 to ensure that barriers to participation could be tackled. Within this study we organized a follow-up of this project, following a dozen persons with intellectual disabilities and the advisors who support them in different local participation projects. Experiences and perspectives were gathered through multiple data sources, making use of a variety of qualitatively adapted methods, such as photo

voice, portraiture, observations, case studies and interviewing. Following the principles of collaborative research (Gibbs, 2001), much attention was given to critical success factors, strategies and barriers that support or hinder participation.

7.2 The meaning of voice in research

One of the leading questions within Disability Studies is how to capture and fully include the voices of persons with disabilities and how to create opportunities for traditionally marginalized perspectives to be heard (Ashby, 2011; Barton, 2005; Garland-Thomson, 2005; Goodley & Van Hove, 2005). To respond to this need, Disability Studies introduces, *inter alia*, the use of different approaches such as narrative methods and dialogue in research (Booth & Booth, 1996; Goodley, 1996, 2000; Atkinson & Walmsley, 1999; Nind, 2012) *"in order to understand the social production of life, we need people who story their lives to structure and give meaning which lends some insight into the experiences and realities of people as active human subjects"* (Roets, Van de Perre, Van Hove, Schoeters &, De Schauwer 2005, 104f.). However, due to the almost universal and enduring silencing of the voices of persons with intellectual disabilities, it is difficult to see how Disability Studies researchers can give meaning to the different modalities that voice can have in research. As Walmsley and Johnson (2003) state, clearly articulated voices and roles are often camouflaged in inclusive research, making "the research itself becoming blurred and subject to misinterpretation." (p. 201)

At the same time, according to Lawrence-Lightfoot and Davis (1997), voice is everywhere in research: "overarching and undergirding the text, framing the piece, naming the metaphors, and echoing through the central themes." (p. 85) The researcher's imprint is always visible in the choice of theoretical framework, the selection of the research questions, the methodology, the choice and collection of the data, interpretation and assumptions. "The researcher's hand—revealed in the conceptual orientation, the disciplinary lens, the methods and design [and probably in personal disposition]—is certainly present and shaping the work" (p. 86). Pure objectivity with a rigid detachment of the researcher from the 'subject' does not exist, and more and more is replaced in much contemporary feminist research, by an ethic of involvement (Wilkinson & Kitzinger, 1996): "clarifying and being 'up front' about one's stake replaces the notion that one should have no stake." (p. 50)

In considering this ubiquity of voice, an initial and pertinent question concerns the involvement of the researcher. The research project described

in this chapter, where the political participation of persons with intellectual disabilities is studied in the context of the Flemish self-advocacy network, for a number of reasons involves the active association of the researchers instead of the more classical stance of objectivity which researchers in the traditional modernistic approach hold dear (English, 2003). Firstly, the research is imbedded in the self-advocacy movement where vivid dialogue and close collaborative relationships between researchers and self-advocates are an essential and omnipresent feature. Shared participatory knowledge production and collaborative research methods serve here as natural allies of self-advocacy (Atkinson, 2002). Secondly, through working with different narrative methods in this study, Booth (1996) argues that this implies intimate (research) relationships between the researcher and the subjects, and an intertwining of the cultural, political and theoretical background of the researcher in the study. Thirdly, multiple data (voices) challenges the position of the researchers in relation to voice since such data accentuates the movement of language and voice as a performative act that destabilizes the real. Hence, the researchers and participants engaged in on-going, long-term research relationships and conversations within which actions and discourse are shared, openness is negotiated and opportunities created whereby processes of de- and re-construction of alternative truths and identities are strengthened (Braidotti, 1994).

Consequently, conducting this inclusive research on the political participation of persons with an intellectual disability, presented a number of ethical and methodological challenges.

In this chapter, we would like to take the audience from ideology to research reality. The work of colleagues who we see as 'role models' when talking about inclusive/collaborative/cooperative research projects (Goodley, 2000; Walmsley & Johnson, 2003) has provided a solid basis of support in this process. Starting with a concrete research project on the political participation of persons with intellectual disabilities, we took it as a challenge to take a stance as researchers and to examine how we can deal with 'voice' in research and handle the relationship between researcher and participant (c.f. Atkinson, 2005; Tregaskis & Goodley, 2005, for facing similar areas of tension). We will illustrate and discuss some central topics about voice, starting with the conceptual framework of Lawrence-Lightfoot and Davis (1997) who identified six aspects of voice that might be useful for the clarification of the research steps, the search for adapted methods and ethical positioning. Lawrence-Lightfoot and Davis take portraiture—a qualitative research methodology that bridges science and art— as a starting point for exploring subjects' human experiences and complexities within a particular context, so as to identify several ways in which the researcher's and subject's voices are important for the research project. In portraiture, the

making of the portrait is shaped through rich dialogue and collaboration between the portraitist and the subject in an effort to grasp the complexity and dynamics of human experiences. In particular, Lawrence-Lightfoot recommends that the researcher attend to six different aspects of voice: voice as witness, voice as interpretation, voice as preoccupation, voice as autobiography, listening for voice, and finally, voice in dialogue. Similarly, they caution the researcher on the manner of handling all these dimensions of voice in this complex and nuanced balancing act:

"Each of these modalities of voice reflects a different level of presence and visibility for the portraitist in the text, from a minimalist stance of restraint and witness to a place of explicit, audible participation. In each modality, however, the chosen stance of the portraitist should be purposeful and conscious. Whether her voice—always dynamic and changing—is responding to or initiating shifts in dialogue, action, or context, she should be attentive to the ways in which she is employing voice. And although it is always present, the portraitist's voice should never overwhelm the voices or actions of the actors. The self of the portraitist is always there; her soul echoes through the piece. But she works very hard *not* to simply produce a self-portrait." (p. 105)

All of these dimensions of voice introduced by Lawrence-Lightfoot and Davis speak to the research used in this chapter. The research steps will be clarified and discussed through all these six categories of voice. Each layer of voice will be introduced by a quotation from Lawrence-Lightfoot and Davis to define the main aspects of the specific level of voice.

7.3 Voice as Autobiography

The researcher brings her own history—familial, cultural, ideological, and educational—to the inquiry. Her perspective, her questions, and her insights are inevitably shaped by these profound developmental and autobiographical experiences. She must use the knowledge and wisdom drawn from these life experiences as resources for understanding, and as sources of connection and identification with the actors in the setting, but she must not let her autobiography obscure or overwhelm the inquiry.

(Lawrence-Lightfoot & Davis 1997, p. 95)

Lawrence-Lightfoot calls this layer of voice 'voice as autobiography'. In this step it is recommended to share those aspects of the researcher's story that

have direct relevance to the research project. We begin with voice as autobiography because it includes our history far beyond our work as researchers in the field of Disability Studies. As part of our unmasking of our choices and perceptions, we portray a brief overview of the personal and academic backdrop of the first author, as an introduction and invitation to this autobiographical aspect of voice.

I was raised in a small rural village in the countryside, with my two sisters, my father as a doctor and my mother as a medical assistant. Our house was situated on the hillside, and my father's surgery was part of our house. Down the road, there was a big residential institute where a hundred people with disabilities lived. My father was the doctor for all the people living in that institute. As a child, I had no contact with those people with a disability. The only thing I saw was that there was often a specially adapted bike parked in front of our house; it belonged to the people with a disability who cycled up the steep road from the institute to see my father for a medical consultation. My only perception was that those people needed a lot of medical care, and I felt pity for them. Around the same time in nursery class, I had a friend called Iris, and she had a disability. I remember the game of climbing up the wheelchair with as many children as we could, and then Iris would turn in circles really fast. Iris was also my classmate in secondary school. She studied really hard, took the prettiest and most colorful notes, had a lot of fine humor and enjoyed it when we went shopping together after school. In contrast to the people from the institute who visited my father for a medical consultation and who—from my perception as a child— only needed medical care, Iris showed me that she was able to do something, to have preferences and dreams. Years later, I took this experience with me and started my academic studies at the University of Ghent studying Special Education. I also worked as a personal assistant to Sofie, a young woman with a disability. I look back on a warm summer day in the city, where Sofie and I were celebrating the end of the exams with a drink on a sunny terrace. A French family was having a chat with us, and was baffled by the way Sofie answered with 'oui' & 'non', by shaking her head and talking with her eyes focused on her communication book. The family was astonished that Sofie could understand them, that she could understand the French language, and moreover, that she went to a regular school where she learned that language. A lot of people are even more surprised that Sofie is now studying at the University and has a lot of friends. While I was studying and working with Sofie, I also got to know some leading and respected self-advocates within

Our New Future, a self-advocacy group in Belgium, through volunteering as an advisor over the past six years. I discovered everyday life in collaboration and working on several projects on human rights. In sharing their stories, struggles, joys and dreams, we aim to "give voice" as a way to providing an alternative to the dominant discourse of disability and hope to bring positive shifts in beliefs and attitudes of society.
(Tina's research diary, 2012)

A number of 'selves' come together in one person and in this study: the self who is a researcher, the self who was in the same class as a girl with a disability, the self who is an activist, the self who is a mother, the self who is a friend, the self who is a community member… All these multiple 'selves' influenced the research and the voice as autobiography threads through the work, as revealed by the intensity of our dialogues, the nuances of our interactions, the questions we had in store, and our raucous laughter. Based on all these intensive shared experiences and dialogues, the stories of persons with disabilities in this study call up powerful responses within us, shaping our thoughts, interpretations and constructions. By engaging in the on-going process of situating ourselves and acknowledging our own filters, we realized that we conducted this study with the recognition that we live in an inherently 'ableist' society, and so made the choice that one of the primary goals of the research agenda is to bring the perspectives of persons with a disability, who are all too often silenced within the community and within the political decision-making process, to the forefront. Our intention here is to unfold several aspects that are very important for our position today in working as researchers. Being introduced to 'real' persons and the confrontations with different relationships in working with and looking at people with a disability made small ruptures in our everyday habits of thought. These confrontations with the Other imposes becoming and demands the boundaries to become blurred and breached (De Schauwer & Van Hove, 2010). By never-ending learning through working together with people, listening to their stories and actively engaging with Iris, Sofie and many self-advocates, we were afforded endless opportunities for ongoing engagement and becoming. We were privileged to encounter a multiplicity of positions and relations that oriented, attracted and affected us. By going into and out of, and back and forth between these positions and encounters, we continually construct and deconstruct our own understandings. The knowledge and wisdom drawn from these experiences serve as resources for understanding and as sources of connection with the people with whom we work, and must be elucidated for every individual researcher.

7.4 Voice as Witness

> This use of voice underscores the researcher's stance as discerning observer, as sufficiently distanced from the action to be able to see the whole, as far enough away to depict patterns that actors in the setting might not notice because of their involvement in the scene. We see the portraitist standing on the edge of the scene—a boundary sitter—scanning the action, systematically gathering the details of behaviour, expressions, and talk, remaining open and receptive to all stimuli
>
> (Lawrence-Lightfoot & Davis 1997, p. 87)

This component of voice is identified by Lawrence-Lightfoot and Davis as that of the witness. It is used to express the outsider's stance "which looks across patterns of action and sees the whole" (Lawrence-Lightfoot & Davis 1997, p. 87). In doing so, we took advantage of our privileged position as eye-witness, volunteer advisor and researcher in and around the self-advocacy network. Locating ourselves in Disability Studies in Flanders, over the last years we became more sceptical observers of political participation, critical success factors and barriers that support or hinder the participation processes of persons with disabilities. During our participatory observations of self-advocates participating in political discussions and decision making, we were sometimes "able to perceive and speak about things that often go unnoticed by the actors in the setting because they have become so familiar, so ordinary" (1997, p. 88). From a position on the boundary, we were able to witness the flow of conversation and grasp the continual interplay and interactions in which different mechanisms of professional and oppressive powers were at work. We will illustrate this with an extract from our field notes based on an event where Steven and Daniel, two self-advocates from around fifteen other persons with disabilities, were invited by a municipal servant to give their opinions on how the city hall could be made more accessible for people with disabilities.

> *…We move in and out the corridors of an immense building. We pass elevators, staircases, rooms, offices, and a hundred help desks. Everybody is scanning and looking for opportunities to enhance the accessibility of the city hall and its service provision. Steven and Daniel identify particular difficulties regarding the intellectual demands on participating as a citizen with intellectual disabilities, looking for accessible text and signs, scanning the accessibility of the floor plan, checking whether the icons of the elevators and emergency exits are understandable and clear. The municipal servant records scrupulously what she sees and hears from the*

participants, and gives them each time positive feedback. Yet, every time Steven and Daniel give some advice to the city servant, she does not record anything. Nor does she give them any answer of value. Meanwhile she mumbles to others that accessibility for people with intellectual disabilities is not yet an issue. Then, looking back on the event with Steven and Daniel and trying to strike up conversation, I ask them how they felt about it. They answer that they are honored and pleased about it, 'glad that the servant will make a change'. I am surprised because I had the opposite feeling. (Tina's field notes, March 2012)

From our privileged but challenged position of witness and advisor, we witnessed how Steven's and Daniel's voices and opinion were silenced, and their actions disqualified. Different mechanisms of oppressive powers were operating, often in a tricky and hidden way, bringing challenges into focus for self-advocates participating in a respectful way and for our delicate positioning as combined witness, advisor and researcher. In our research these critical events sensitized our queries and influenced our recognition of the fact that people with the so-called label of 'intellectual disabilities' are often denied recognition as citizens, infantilized, and tied into conventional, often subordinate roles. Furthermore, due to these incidents, the complexity of the claims for equality and full participation of self-advocates fascinated us, and will be a source of inspiration for the rest of our research queries. Nevertheless, sharing and verifying our observations, feelings and learning from the activity continues to be an important process in this research step; the views, feelings and experiences sometimes do not reflect the self-advocates opinions and experiences.

7.5 Voice as Preoccupation

With increasing presence in the text, the portraitist's voice as preoccupation refers to the ways in which her observations and her text are shaped by the assumptions she brings to the inquiry, reflecting her disciplinary background, her theoretical perspectives, her intellectual interests, and her understandings of the relevant literature.

(Lawrence-Lightfoot & Davis 1997, p. 93)

This layer of voice is identified by Lawrence-Lightfoot and Davis as 'voice as preoccupation'. In this layer, voice not only seeks to witness the participant's stance, and through new eyes, but also is used as preoccupation, or the "lens through which she [the portraitist] sees and records reality." (1997, p. 93) This component of voice is "more than interpretive description". (1997, p. 93) It is the theoretical framework underlying the work that defines "what she [the portraitist] sees and how she interprets it". (1997, p. 93)

The life trajectories and ideas of self-advocates moved us towards a search for a theoretical framework capable of seeing human subjects as no longer divided from others and grasping the complexities of their identity and actions, drawing on disability activism, Disability Studies and intersectional perspectives. A crucial component in all our research and practice is the dialogical exchange by means of 'modest relations' (Goodley & Van Hove, 2005). The commitment to engage in relationships between people with/out the label of disabilities is central in our perspective on Disability Studies. These intense encounters form the basis of the methodology for this research. They also provide the basis for thinking and practising in terms of possibilities for the multifaceted nature of self-advocacy support (Goodley, 1998) and participation in 'real' contexts. These theoretical resources, in combination with our involvement in the self-advocacy movement, shifted us towards a deeper understanding of the beautifully illustrated work of Martha Nussbaum (2006, 2009, 2010) who in her 'capability theory' (expanding on the work of Amartya Sen) tries to correct the social contract theory of Rawls. Nussbaum takes as a starting point the notion that people with an intellectual disability, if we truly regard them to be citizens of equal value, are a challenge to philosophical theories of justice. Even the extremely broadminded social contract theory of John Rawls does not manage to hide the fact that the citizens who enter into such a contract with the State are expected to have quite a few skills (Stark, 2007). With her theory Nussbaum tries to develop an alternative that uses ten central capabilities which can be seen as substantial freedoms, and which all governments should guarantee to their citizens. The ten capabilities that, according to Nussbaum, should be supported by all democracies are (for our subject we pay special attention to the last capability):

- being able to live to the end of a human life of normal length (life)
- being able to have good health (bodily health)
- protection of bodily integrity (bodily integrity)
- being able to imagine, to think, and to reason (senses, imagination and thought)
- being able to have attachments to things and persons outside ourselves (emotions)

- being able to form a conception of good and to engage in critical reflection about the planning of one's own life (practical reason)
- being able to live for and in relation to others (affiliation)
- being able to live with concern for and in relation to animals, plants, and the world of nature (other species)
- being able to laugh, to play, to enjoy recreational activities (play)
- being able to control one's environment. (A) Political: being able to participate effectively in political choices that govern one's life; having the rights of political participation, free speech and freedom of association. (B) Material: being able to hold property (both land and movable goods); having the right to seek employment on an equal basis with others.

The capability approach uses the idea of a 'threshold' (Nussbaum, 2010, p. 78): for each important entitlement there is an appropriate level beneath which it seems right to say that the relevant entitlement has not been secured, and as a result human dignity is bound to be compromised. When Nussbaum evaluates the situation of people with disabilities she finds 'mixed results': although in many Western countries progress has been made in a number of areas (people with an intellectual disability are often accepted in schools and participate via inclusive education in mainstream education and many specific support services for people with disabilities are operational), we still see hesitation on many fronts (partly for budgetary reasons, partly because persons with intellectual disabilities are often still regarded as charity cases instead of citizens with rights). This spurred Nussbaum on to call for going one step further: "Now we have to take the most controversial step of all: giving people with cognitive disabilities political and civil rights on a basis of genuine equality..." (2009, p. 350; 2010, p. 94). She tries to illustrate this herself by considering the right of people with intellectual disabilities to vote, or the right to serve on a jury.In this context, we take up the challenge as formulated by Nussbaum and explore in the research the political participation of persons with intellectual disabilities with regard to their involvement in political discussions.

In this light of voice as preoccupation, working in the natural environment of the self-advocacy movement felt like a balancing act where we continuously sought to accommodate the theoretical predispositions and the subjects' realities, and tried to reveal the connections (and disconnections) between scientific abstractions and the subjects' empirical categories.

Moreover, our preoccupation with different qualitative research ventures, in terms of being motivated to experiment with more creative ways of capturing the complexity and the richness of the lived experiences of the self-

advocates, also contributed to our interactions with the participants in this research. The enterprise was uncertain: it took us in many directions with sometimes dead ends and it kept us searching and moving. These interactions in the form of interviews, observations, and shared interactive space are aspects of 'voice in dialogue'.

7.6 Voice in Dialogue

With voice in dialogue, the portraitist purposely places herself in the middle of the action (in the field and in the text). She feels the symmetry of voice— hers and the actor's—as they both express their views and together define meaning-making.

(Lawrence-Lightfoot & Davis 1997, p. 103)

In this active positioning of voice in research, we see the developing relationship between the researchers and participants, with their voices in dialogue as an "ongoing construction of the story that happens in the two-way interviews and multivocal conversations" (Chapman, 2005, p. 38). This 'voice in dialogue' has a prominent place in the work within the self-advocacy movement and grows out of our volunteer engagement as advisors of members of Our New Future, informing our work as researchers and providing us a basis for acting and dealing with uncertainties. In this framework of the self-advocacy network, professionals do not take over, but are constantly reminded to engage in a genuine dialogue and to strive for a searching process that respects the complexity of practical and professional knowledge (Van Hove, Roets, Mortier, De Schauwer, Leroy, & Broekaert, 2008). Our encounters are experimental. In Rinaldi's words, by engaging in dialogue we enter "a process of transformation where you lose absolutely the possibility of controlling the final result" (Rinaldi, 2006, p. 184) This dialogue and listening turns the known into the unknown and opens up new modes of knowing and being (Davies, 2014). Parallel to Freire's (1972) contribution of dialogical relationships, self-advocates, advisors and researchers consistently try to establish horizontal and not vertical relationships between the persons involved; based on empathy, respect, tolerance towards diversity and listening to each other's life experiences. Through this joint research and shared experience, we try to embrace and value the insider perspectives and ideas of the self-advocates in a workable dialogue. However, in this balancing act, the researcher's "soul echoes through the piece" (1997, p. 105) from his activist and constructivist position, but he

needs to works "very hard not to simply produce a self-portrait" (1997, p. 105). Hence, we spontaneously strove to foreground self-advocates' long-silenced voices and experiences and tried to create a discursive space where we could think and act with one another, doing research *with* rather than *on* or *for* people with disabilities. They made us look at the world through their eyes and invited us to see their struggles and experiences and, at the same time, our own evolving 'selves' (as described earlier) resonated with theirs, all involved in a process of mutual recognition and co-understanding. Through dialogue, we grew through an exchange of viewpoints between self-advocates, advisors and researcher(s), which dissolves the distance between those labeled and categorized as 'them' or 'us'. We worked as a team and shared laughter and struggles, which automatically led to communal activism and resistance in order to cultivate a desired social change (Freire, 2004). In this way, our research is not neutral and becomes a political act, as illustrated in this sparkling dialogue between two self-advocates, an advisor/the researcher. Reflecting together on the participation of Louisa in a local city council, Steven, Paul, Thomas and the researcher give meaning to and become increasingly conscious of the precarious situation of Louisa:

> *Thomas explains the claims of the city council for the participation of Louisa: 'The council wants that Louisa justifies her value, before she can enter the council. They wonder if Louisa can deliver a useful contribution to the board. They don't give her the right to participate, they first want proof.'*
> *Steven: 'This is barbaric!'*
> *Tina: 'She first has to prove herself before she gets the chance to be heard, to give voice.*
> *Paul: 'We feel put aside, as if we are a group of people who doesn't know anything.'*
> *Steven, pounding on the table: 'We are self-advocates. Do we want to have to prove ourselves in this way? Like they want us to? Or are we doing it our way? They disregard our rights!'*

This example of collaborative reflection was one of the many ways in which the researchers were active by the side of and part of the team of self-advocates and advisors. We held conversations that were often spirited and lively, shared observation notices, gave mutual feedback, conducted group and individual interviews, participated together in the staff meetings, evaluated and refocused the project goals, made together sense of our experiences. Our relationship evolved through the vivid display of our dialogue, ever struggling to find a place of balance and symmetry, and provided meaningful insights into our communal engagements and experiences.

7.7 Voice as Interpretation

> Here we not only experience the stance of the observer and her place of witness, we also hear her interpretations, the researcher's attempts to make sense of the data. She is asking, "What is the meaning of this action, gesture or communication to the actors in this setting?" and "What is the meaning of this to me?"
>
> (Lawrence-Lightfoot & Davis 1997, p. 91)

In this phase, acting as researchers who act and interpret actions, we will lay bare a critical incident about the participation of self-advocate Robert, based on encounters with him and some of his professional support workers. Nevertheless stories like these are able to stir up a multiplicity of interpretations, and we discovered that our research activity provided opportunities to better understand individual and collective politics of resilience and resistance of self-advocates.

> *Robert [a respected member of Our New Future] wants to join the new project of the self-advocacy movement [where local political participation of people with 'intellectual disabilities' is supported]. He notifies that he learnt from the stories and experiences of other self-advocates participating in local boards and that he is interested in more local policy participation. He asks Our New Future to give him an overview of all the local community and policy organizations in his town, so he can have a look. On Tuesday, we get a call from his support worker of the institute where he lives. She asks upset: "What did you do with Robert? He suddenly knocks on the table and says that he wants to participate in the local community board!" Additionally, she states on the telephone that the participation on the local board is way out of Robert's league. "He is not able to do that", she declares. We propose to meet Robert and the support worker two days later. At the meeting, the support workers are in the majority and argue with a series of arguments ("yes, but… no, because") that it is better for Robert not to participate ("you have to be elected in a board like that, not everyone is welcome there, it is far beyond your capacities, you will not understand what they say"). After the meeting, Robert says to the advisor that it is still his dream*

to participate. He shows his interest in the local sports council and together we contact them with some questions. Surprisingly, a little later we receive a positive answer from the sports functionary and we make a call to Robert with this good news. Suddenly, the telephone disconnects. When calling back, we only can reach the support worker, not Robert, who says that we cannot talk to Robert anymore about this. According to her, Robert has to focus on other important things in life, such as his possible relocation.

We are painfully aware of the risk of leaving these research notes open for power takeovers and interpretations of any kind, since we experience here that Robert's human rights, and especially the opportunities to actualize them, are not safeguarded when comparing this incident with the international human rights discourse, in particular with the UN Convention on the Rights of Persons with Disabilities. Mirroring these guidelines, we could say that Robert is denied the opportunity to participate in political and public life on an equal basis with others. What equally strikes us is that any symmetrical and reciprocal dialogue is relinquished and the knowledge and dreams of self-advocates are buried under expert truth and power. Their lived knowledge, resistance, ambition and moments of desire are silenced and disqualified and can be the reason why they feel alienated and excluded. In our eyes, Robert is caught in a politics of segregation and exclusion, and in a taken-for-granted system of professional discourse that tends to control his everyday life. These professional experts deny Robert being grown-up with dreams and desires, and continually create barriers and requirements so it is impossible for him to participate. Although self-advocates like Robert show us that they need interdependent, supportive relationships to be able to exercise their citizenship, support is often considered less important than quality of care (De Waele, Van Loon, & Van Hove, 2005). Traditional notions of independence, self-determination and autonomy are leading principles in many forms of institutionalized care in Flanders in which moments of reciprocal and genuine dialogue are nigh on impossible to ever happen.

7.8 Voice discerning other voices, listening for voice

When a portraitist listens for voice, she seeks it out, trying to capture its texture and cadence, exploring its meaning and transporting its sound and message into the text through carefully selected quotations.

(Lawrence-Lightfoot & Davis 1997, p. 99)

In this final exploration of voice in research activities, the researcher must address and pay attention not only to what actors say with words, but also to what Lawrence-Lightfoot and Davis call "mixed feelings" (p. 100), in particular what they say with body language, hesitations in speech, timbre, tone and silences. When discerning other voices, the researcher makes a critical distinction between "listening to a story" and "listening for a story" (Lawrence-Lightfoot 2009, p. 17), where the former implies a "more passive, receptive stance in which the interviewer waits to absorb the information and does little to give it shape or form" (p. 17); the latter suggests a much more engaged and active role for the researcher in which she or he searches for the story, while creating and moulding it as a constructivist activity, involving action instead of passive observation.

In this research project on political participation, the researchers played an active listener role in the self-advocates' storytelling. In collaboration with these self-advocates and their advisors, the experiences on participating in local policy-making processes were composed, which offered an in-depth understanding of their lived knowledge, the multiplicity of their selves and the complexities of their lives and contexts. In attempting to jointly capture and interpret these glimpses and slices of their lived experiences of oppression and resistance, we understood more completely both others and ourselves. Through cooperatively articulating our experiences and following each other's footsteps, self-advocates, advisors and researchers got to know each other's interests and pluralist meanings while at the same time creating new ones. Self-advocates used, for example, photographs, portraiture, object constellations, poetry, symbols, video and visual metaphors to foreground their voices in a variety of ways. These methods were used as a medium for dialogue and to chronicle the self-advocates' experiences and selves so as to facilitate the story-telling process. They were key for developing a fully nuanced story and co-constructing a narrative that becomes their own. They require, most importantly, time and an absolute commitment to listening, to interpreting the communications and the silences, and to supporting the process of reflection. By holding to the language of the actors and entering their story, *we* co-constructed narrative and together discovered new ideas and worlds, rather than assuming to already know what we were going to find. For example, the experiences of self-advocates about political participation were collaboratively revealed by developing vivid portraits which presented joint research activity and cooperative processes of composing layout, pictures, text and metaphors. A translation of self-advocates stories and worldviews resulted in a shared development of these artistic portraits, and we experienced that some self-advocates were first-class developers of imagery language. Moreover, these portraits were vital illustrations of accessibility and dialogue, for which the self-advocates' aim was to affect

the wider society through presenting their artistic and performative work to a wider audience in an exhibition at the end of October 2012. Self-advocates wanted to create a medium for dialogue and invited visitors to explore their portraits, to make time for confabulation, reflection and on-going interpretation and meaning making. In the collaborative process of composing the portraits, many metaphors were used to illuminate their struggles and wishes. These metaphors had rich connotational meanings and unveil a profound recognition of power dynamics in the field of self-advocacy, participation and support. Simultaneously, they indicate the complexities of people's lives and the contexts influencing them. As it is the researcher's responsibility to watch for the ways in which the actors' movements and gestures speak much louder than words (Lawrence-Lightfoot & Davis 1997), the imaginative thinking of self-advocates offered us ways to elicit these complicated set of dynamics and the various subtle and overt, or sometimes contradictory- meanings. It asked for an engaged position and a listening for meaning, for the 'through' line and for what is genuinely human.

7.9 Concluding thoughts

In this study, it is clear that a variety of voices of the researchers and self-advocates are omnipresent. Multiple and overlapping facets of voice co-exist and are heard through different mediums and texts, framed within the cultural, political and historical context of this research. Along with Lawrence-Lightfoot and Davis (1997), we would like to acknowledge the researchers' political role in making meaning of texts and shaping research being presented to the world. Nevertheless, we do not want to underrate the voice and actions of subjects with disabilities as critical agents and meaning-makers in research. Their lived experience must be honoured and must be seen as revealing counter-narratives towards resisting dominant and oppressive disability discourses (Ware, 2002), challenging hegemonic discourses and enabling us to discover their activist potential and resistance towards modernist misconceptions (de Lauretis, 1987; Goodley, 2007). Both portraiture and Disability Studies recognize that these voices and counter-voices need to be embraced to dispel powerful myths and defy current stereotypes and dominant ableist assumptions (Linton, 1998; Charlton, 1998; Fisher & Goodley, 2007). Similarly, we suggest, together with Reason & Torbert (2001) and Nind (2011), that we need to accept that human persons are agents who act in research on the basis of their own and mutual sense-making and (collective) action, and thus it is no longer possible to conduct research *on* persons, but *with* persons, involving them in each of the

research phases.

The plurality of voices implied a balancing between multiple positions, a messy struggle with tensions and challenges. The processes and different layers of voice we engaged with are complex and interwoven. Working together and actively doing and being involved with people, was interwoven with the work at the university: by reading, discussing with colleagues and working with students. Our need to search for meaning only increased, while our meaning making and knowledge construction also occurred in relational activity, in a continuous process of formulation and reformulation, testing and negotiation (Dahlberg & Moss, 2005, p. 102). Our process as researchers was constructed through simultaneous approaches and withdrawals, choices and standstills, that took us in many different directions. In an ongoing search process we tried to find theoretical concepts and frameworks that could help us to make sense of and re-think what we experienced in working with people, as a witness, and in our own history far beyond our work. These processes are ongoing, never-ending, and ungraspable as a 'whole'. When bringing al the different layers of experiences and voice together, the notion of 'becoming-minoritarian' of Deleuze and Guattari is appropriate, as suggested by De Schauwer and Van Hove (2011), it "can help me to understand how I as a multiple identity am relating to other humans, non-humans and to the world. I can take the freedom to become an 'activist' and 'partner' and 'researcher' and 'mother' all at once and negotiate these different identities in encounters with the Other" (p. 18). Becoming indicates a process that destabilizes solid identities and facilitates a potential creation of entirely new and multiple identities embedded in variable and discontinuous fluxes of living. It leads you away from a stable and universal identification as a researcher, activist, friend, witness, mother and advisor. It gives you endless opportunities to cross borders and categories.

Besides, along with Ashby (2011) and Jackson and Mazzei (2012), we believe that the challenges inherent in an uncritical construction of giving voice are indispensable. While it is important to conduct research that aims to give voice, it is essential to simultaneously problematize the premise of giving voice: "Was I really giving voice? Was it mine to give? Whose voice is it really? Who benefits from the telling? Is spoken voice preferable?" (Ashby 2011, p. 1732) Longing to give voice can cause different strains. It can lead to oversimplified knowledge claims that attempt to offer an authentic essence or voice that is present and stable (Jackson & Mazzei, 2012). It can assume that the experiences and perspectives are inherently distinct from those of others. It can be supposed that the people being researched have no voice and need an external impulse to reveal their experiences. In this way, "it denies that these individuals have their own voice and can (and do)

choose to exercise it, although admittedly people with disabilities are often denied the opportunity to do so" (Ashby, 2011, p. 1732).

Because the research discussed in this chapter implies, among others, a far more interactive process than the classical stance and is no neutral activity, but culturally and politically embedded, we insist on the importance and even ethical-deontological imperative of engaging with questions of voice, power and injustice issues. As a result, as it is unnecessary and even dangerous to assume that there is only one voice; one must be conscious and clear about the myriad ways voices are operating and coexisting in research and of the parts all the actors, including the researchers, play in shaping the research process and outcomes.

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Chapter 8

Conclusions and Discussion

Abstract

In this final chapter, we search for modest yet constructive answers to a complex question.

The main conclusions of each study are discussed and integrated in accordance with the four research questions. Building on these conclusions, the concluding discussion examines some of the key issues in the debate on the inclusion of persons with disabilities and gives meaning to the central concepts used throughout this dissertation. This takes the form of an interrogation of hegemonic discourses and normative institutional practices that define the mainstream culture of society that serves to include and exclude certain people from participating and belonging on the basis of their differences. Subsequently, we offer an alternative framework by promoting a pedagogy of interruption and we conclude with articulating the significance of thinking in terms of capabilities. Throughout the discussion, we describe some academic as well as societal implications and recommendations of our study for professionals, researchers, policy makers and others.

8.1 Main conclusions

8.1.1 What do persons with disabilities tell us regarding inclusion and participation in Flanders?

8.1.1.1 Accessibility and relational citizenship

Our findings from the narrative study revealed that inaccessibility poses a huge obstacle for participation and is a major aspect that is reflected repeatedly in all the narratives of the interviewed persons with disabilities. People with disabilities experience strong exclusions arising from structural causes in various areas such as housing, income, employment, education and leisure. Participating in society requires effort, time, dedication and motivation of people with disabilities and their network: a range of actions and attitudes that are continuously challenged, not in the least due to the fact that problems affecting one area of life reinforce the experienced difficulties in other areas and cause new exclusions.

People with disabilities systematically experience a lack of access in different life domains and institutions within society and are confronted with obstacles that prevent participation in public life. At the same time, information and

communication are insufficiently accessible and comprehensible. Regarding human rights for persons with disabilities, we find ourselves in Flanders on thin ice. If we want to support participation and inclusion, we must therefore have an eye for all these obstacles. Accordingly, participation and inclusion are extremely difficult to achieve. Accessibility (both technical and relational), in addition to mobility and adequate and qualitative support, must be seen as necessary preconditions for participation.

Along with the demonstrated importance of accessibility in this study, it must be noted that persons with disabilities can participate in society but still get the feeling not to belong. This thin line between exclusion and inclusion shows that 'participation' means more than a purely instrumental concept. It is not about *or* inclusion *or* exclusion, but it takes place in the space in between, where relationships, attitudes and interactions occur. This notion of the *space in between* challenges the dichotomy of insider versus outsider status. Presenting these concepts in a dualistic manner is overly simplistic. It is restrictive to lock into a notion that emphasizes *either/or*, *one* or the *other*, you are *in* or you are *out*. Rather, participation and inclusion are relational concepts and refer to 'being connected', 'being there' and 'belonging' (Biklen, 1992). Participation is a verb, a way of becoming, in which it is not possible to make a division between 'participation' and 'non-participation'. Participation is 'AND', never prone to be completely captured. In this relational interpretation of participation (Pols, 2006), the autonomous and independent citizen does not exist. The concept of relational citizenship does not presume that people move through pre-specified trajectories into their citizenship status as an achievement, yet, everyone in society is a citizen "who simply moves through citizenship-as-practice (Lawy & Biesta, 2006). It is not of central importance to be autonomous; instead, the citizen has to establish and maintain relations with other people (…). To be a citizen (…) is to be connected to other people" (Pols, 2006, p.96). This connection to other people is a crucial component when talking about participation, which strongly emerged in the narratives of this study.

Returning to the central theoretical framework of this study, the capability approach of Martha Nussbaum (2006, 2009, 2010) harmonizes with this relational and dynamic conceptualization of participation. In this approach, it is the task of social policy to create conditions to accommodate everyone's capabilities in specific contexts, in contrast with more instrumental and strict approaches as, for example, formulated by the International Classification of Functioning, Disability and Health (ICF). Nussbaum explicitly starts from the concept of people as social and political beings who find fulfillment in relationships with others (2006). Participation is constituted in everyday social relations, in dialogue, in being together and interacting together. It is

not a fixed outcome where certain rights, duties and standards are determined in advance, but it is constantly the subject of discussion and is formed in the relationships between people. Participation is therefore not a given status that a person can reach, but an active process that is shaped by trial and error and that requires interaction and support.

8.1.1.2 Embodiment

Beside structural barriers, bodily experiences play a crucial role in the inclusion and participation of persons with disabilities. These include pleasures, pain, suffering, vulnerabilities, capabilities, constraints, … and are entangled with participation in social life. The body is more than flesh and bones (Paterson & Hughes, 1999); it functions as a permanent condition of experience and the primary site of knowing the world (Merleau-Ponty, 1945). The narratives in our study illustrate the importance of this sense of embodiedness when talking about participation: e.g. mobility comprises much more than using the public transport; it entails questions on pain, pride, shame, attractiveness, etc. People are embodied subjectivities (Vasterling, 2003), and likewise "disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning" (Hughes & Paterson, 1997, p. 334).

The existence of these bodily experiences challenges the social model of disability, which argues that disability is caused by the way society is organized. Following this model, barriers in society are identified as the main contributing factors in disabling people. According to a strict definition of this model, the contribution of the body to participation is disregarded (Paterson & Hughes, 2000; Shakespeare & Watson, 2001). As the abilities of people are time- and place-bound and depend on external and personal circumstances, the individual situation, needs and desires of each person must be taken into account when supporting participation. When optimizing participation, we particularly need to pay attention to 'speaking embodied subjects' (Merleau-Ponty, 1945) and what it means for them to participate and act in society, realizing that the social model is only one of the available options for looking at disability and participation.

The embodied experiences are often overlooked in today's dominant discourse where the rational, autonomous male, disembodied individual is supposed to make rational choices and ought to be responsible for the success or failure of one's own life project (Beasley & Bacchi, 2000, Nussbaum, 2006). People with disabilities are often perceived as a homogeneous group of active and responsible individuals who must fit into a

top-down organized participation structure, where personal needs and desires receive little or no attention. This dominant participatory ideal is that of the 'shortest path to participation', in which participation is considered as an achievable condition. This prevailing liberal paradigm of 'participation as the shortest path' places a great emphasis on personal responsibility and the success or failure of the goal of participation (Cradock, 2007). Participation is seen as a matter of personal motivation and commitment. In this logic, all social problems appear individual problems, and social duty is left out of the picture.

This neoliberal discourse emerges strongly, with an increasing emphasis on the duties and responsibilities of persons with disabilities, in addition to their rights. This interpretation of participation, however, completely ignores what it means personally for people to participate (c.f. Van Hal, Meershoek, Nijhuis & Horstman, 2012). It ignores the needs and desires of people who want to find a life in relation to oneself, the body, the family, the work, one's own abilities. The discourse is all about duties and rules, whereas following Martha Nussbaum and her Capability Approach (2006), human dignity and the good life should be the basis of social order. This unilateral dominant valuation of participation as 'the shortest path' has unintended effects and results paradoxically in a restriction of participating (c.f. Van Hal, et al., 2012). Hence, the setting up of formal and procedural participation structures and categorical strategies for persons with disabilities provides no guarantee of participation: it ignores the personal bodily variables and the needs and desires of people themselves. In other words, besides the procedural logic participation, other personal logics of participation are operating (see also Mol, 2008). This means that the ideal of participation does not work for everyone and results in social inclusion *and* exclusion.

8.1.1.3 Normalization and individual duty

The narratives of our study correspond to the ideology of normalization and reveal that persons with disability in Flanders take on a lot of individual responsibility. According to Nirje (1980), acting on the basis of this ideology of normalization entails making it possible for people with disabilities to practice "those patterns of life and conditions of everyday living that are as close as possible to, or indeed the same as, the regular circumstances and ways of life of their communities and culture" (p.33). Normalization adherents promotes society's responsibility to provide more opportunities for people with disabilities, but emphasizes also that people with disabilities must make adjustments to themselves – their appearance, behavior, speech – in order to be fully accepted and valued by society (Yates, 1999, p.122). The belief in the

importance of changing the disabled individual to make them more acceptable ignores social causes in favor of individual responsibility and generates the idea that willpower and personal effort to live up to social expectations are considered causes of successful participation. The narratives in our study demonstrate that society towards persons with disabilities is primarily structured and departs from the norm where 'able-bodiedness' is obvious and seems normal. Persons with disabilities are seen as deviating from this dominant standard and have to adapt in order not to be marginalized as outsiders. The problems and the solutions for an equal place in society are conceived as intrinsic to the individual. People with disabilities need to commit themselves and adapt to a problem that actually lies in society. The weight of the adjustment lies with the person with a disability, despite the fact that factors that push people with disabilities in the margin are often beyond their reach. This leads to social and discriminatory conceptions and attitudes that uncritically argue that it is for example better for people to walk instead of rolling, hand writing instead of typing, take classes without assistive technology instead of with etc. (c.f. Hehir, 2002).

A striking finding in our research is that 'the good disabled person' (analogues with 'the good gay', Warner, 1999) is accepted in our society, on the condition that the person meets certain standards. It is based on the idea that people with disabilities want to be like the others, and that they want and can overcome their limitations through correct adaptations. The dominant 'able-bodied' group in society is tolerant, but only within the context where 'able-bodiedness' is the norm. In other words, if you have a disability, it is expected of you that you are committed and adapt to the set agenda. If you do not, you will be seen as someone who does not want to participate and you will not be tolerated. It is one's own personal fault, not society's. As autonomous and active citizens (Masschelein & Quaghebeur, 2005), we have to be able to take care of ourselves, be independent, discover and develop our talents, and prove our capacities in terms of productivity and individual outcomes. This focus on independence and self-mastery "reinforces disability as limitation rather than possibility and thus may contribute to legitimizing the repressive systems that exclude disabled people" (Gibson, 2006, p. 190). Being dependent on others is often seen as a sign of weakness and failure, even though "an ethic of care regards dependence as a central feature of human life and human relationships and interdependency rather than independence as a goal of human development" (Kittay et al, 2005, p. 453). When the human condition is viewed as one of interdependency and mutual relationships, this leads to an understanding of independence as 'partnership'. Departing from a relational view of the subject, independence becomes a two-way responsibility and not solely an individual ability (Reindal, 1999, p. 364).

8.1.2 How are persons with disabilities represented in Flemish media?

8.1.2.1 Baseline study of disability representation

Our first media study examines the extent and nature of the coverage of people with disabilities in print media in Flanders, obtaining a quantitative baseline measure of disability, gender and age distribution across different sources of print media during a ten-year span.

As outlined in chapter three, key findings include a sorely limited coverage of disability, or even total lack of representation, in certain media sources. Remarkably, far more articles on disabilities come from the so-called popular press, and a great lack of disability coverage is detected in the more reputed quality newspapers and news and opinion magazines. This can be explained by the qualification of people with disabilities as perfectly fitting the melodramatic framework of the popular media. This result can also indicate limited educational opportunities for people with a disability and their position in the lower educated target audience of these popular media. Lastly, it demonstrates that disability remains peripheral to the larger social and political agenda and is often perceived as a matter of a singular personal experience, which is mainly covered in local popular media.

Regarding gender, a dichotomous private/public understanding between masculine/external/public/political versus feminine/internal/private/apolitical is detected, as media about physical impairments cover more men, while reports about chronic health conditions involve more women.

Also noticeable in the Flemish media is the clear demarcation between able-bodiedness and disability, between the norm and the deviant, between the 'acceptable' matter and the 'unacceptable' antimatter, the *dis* and the *able*, as opposites, and as the antithesis of one another. By the strong prevalence of articles on behavioral problems in lifestyle magazines, and of articles on physical impairments in magazines where physical beauty is the main emphasis, clear boundaries are established and the image of the ideal able-bodied person becomes illuminated and reinforced.

Moreover, children with disabilities are strongly underrepresented or remain totally out of sight in the media. Their virtually non-existence mirrors the Flemish reality that children with and without disabilities share few or even no collective activities. If children with a disability are depicted, they get a peculiar status in the media, other than the type of disabilities of the

portrayed adults. These kinds of disabilities are consistent with the classification of special education in Flanders and this categorical thinking can be clearly observed in the media. Concerning the coverage of adults with disabilities, the degree of visibility strongly determines the representation of certain groups of persons with disabilities, as the chosen print medium requires visuals. One exception is the representation of persons with a visual impairment, found mostly in the only religious magazine included in this research, which can be explained by historical and iconographical connotations.

Lastly, the results showed that, looking over the ten-year time span, some political events regarding disability have influenced the quantity of coverage. Other events such as the Special Olympics or Overall, it can be concluded that the Flemish media reflect underlying dominant societal ideologies that can be problematic as they reinforce stereotypical perceptions towards people with disabilities. In some cases, persons with disabilities remain even totally out of sight in the Flemish media. Above all, media representations of disability mirror certain broader ideologies and socio-political processes shaped by basic exclusionary social frames. The media is constituted on ideas of normalcy and perfection, together with binary and hegemonic perceptions on disability and gender. Most messages do not have the potential to play a role in facilitating social change and altering public perceptions consistent with the framework of the UN Convention on the Rights of Persons with Disabilities. Yet, underrepresentation or incorrect representations of people with a disability in the media have major impact on public perceptions and attitudes towards people with disabilities in our society, since the press plays, among other factors, an essential role in reflecting and shaping public attitudes towards people with disabilities, and since many people rely almost entirely on the media as a major source of information about people with disabilities.

8.1.2.2 Frames and counter-frames in the representation of disability

The second media study of this dissertation, outlined in chapter four, seeks to obtain insight into the dominant and alternative conceptualizations related to disability in the Flemish media. By means of a framing analysis, we looked at which aspects of reality are selected, rejected, emphasized, or modified in the production of media texts.

With nine dominant frames and three counter-frames, the analysis revealed an imbalance characterized by the relative absence of alternative counter-images, and confirms the one-sided and negative depiction of disability in

media (Ellis & Goggin, 2015). Our results point out that media tend to perpetuate and reinforce the stigma of the disabled as 'the Other' and disability as one of the most frightful obstructions in one's life, while counter-frames underlining the notion of the disabled being 'different but not abnormal' are relatively absent. The dominant frames include: 'suffering and fear of degeneration', 'the heavy burden of care', 'faith in science' (variant: 'human enhancement'), 'the goer' (variant: 'the hero'), 'the helpless victim', 'the lurking monster', 'charity', 'Carpe Diem', and 'mind & body dualism'. The counter-frames include: 'human rights', 'disability creates opportunities', and 'interdependence'.

Examining these frames and counter-frames, it is observed that the accent in Flemish media is placed on suffering, caring, fixing and overcoming disability. Disability is narrowed in two extremes, grounded in traditional dichotomous thinking and a strong normalizing vision. On the one hand, the frames rely on the preconception that persons with a disability are disadvantaged, weak, not able to participate, dependent on and in need of help from non-disabled people. On the other hand, the frames build upon the biased view of the disabled person as heroic and inspirational, displaying ordinary or extraordinary achievements and capabilities in terms of heroic courage and solely or in part on the basis of their disability. Hence, portrayed people with a disability are forced into normative and binary extremes, that make us get caught up in the active differentiation between insiders and outsiders, 'us' and 'them', leading to social exclusion of those who are not seen fitting in appropriate normative categories. These two extremes - the helpless and the inspirational – represent disability as a problem located in individuals, to be cured or to be overcome. They focus on what is *not* there, and obscure structural and systemic causes of disability in media representation. Moreover, these two extremes objectify and essentialize persons with disabilities, with little ground for affect and identification between the reader and the portrayed persons. To shore up a sense of the reader's own normality, fear towards to monstrous others (Shildrick, 2002), and the abjection of them, is emphasized.

The normalizing processes underlying the prominent media-frames minimize potential for questioning hegemonic ideologies and confirm the segregated, inferior and 'less than human' position of disability (Goodley & Runswick-Cole, 2014), instead of granting opportunities to break up the narrow boundaries of what is conceived as 'normal' and 'human'. In line with this dis/human approach of Goodley and Runswick-Cole (2014), where disability has the potential of claiming *and* disrupting the norm at the same time, we observe that the Flemish media must be more vigilant to complexities, hybridity and ambivalence in the representation of disability. A more rich and

hybrid portrayal of the human in the Flemish media is needed to challenge and deconstruct social prejudices, with complex and non-dichotomous assemblages of both frames and counter-frames.

8.1.3 What can a concrete and local project regarding political participation of people with an intellectual disability in Flanders tell us about structural success factors and barriers regarding inclusion and participation?

8.1.3.1 Presumed nothingness

Our findings from the follow-up study on the self-advocacy project on political participation (c.f. chapter five) revealed that people labeled as having an intellectual disability are very often associated with presumed nothingness and disconnectedness. This is expressed by a dominant discourse of intellectual incompetence and perpetual disconnectedness to labeled individuals. Within these theories of thought, the minds, and thus the humanity, of people labeled as impaired are dismissed as irrelevant and their opinion is considered inferior. Consequently, the underlying story of a person labeled as 'intellectual disabled' and struggling for acceptance in political decision-making processes remains uncomfortably relevant. In their recent article 'At the End of Intellectual Disability', Kliewer, Biklen and Peterson (2015) explain the opposite concepts, namely 'presuming connectedness and competence'. These "suggests that we involve ourselves with others *as if* we all make meaning of the world, *as if* we all have a rightful place in valued communities, *as if* we all think, and *as if* we all can continue to deepen and expand in our connectedness with the surrounding world" (p. 23).

In the shadow of the dominant deficit model of disability and closely aligned with the prognosis for the 'intellectually disabled' in the *Diagnostic and Statistical Manual of Mental Disorders (DSM),* this pessimistic fable of intellectual disability and the fragility of connectedness is ever present. According to Kliewer et al. (2015), these culturally entrenched metaphors disguised as science, even when based on an increasingly exposed nothingness, do not exit language easily and have isolating, brutalizing, and dehumanizing consequences. Participants in our study were frequently judged and reduced to irrational or disordered and disruptive individuals that naturally belong elsewhere, unsuitable as participants in policy-making processes. Barriers were created and excuses were invented to prevent people from taking an active position in policy participation, leading to endless trajectories of getting access in advisory boards. Their right to

belong and to participate was never realized without question. Deficit ideology was rarely set aside, and openness to the possibility of learning and contributing was hard to find. People involved considered the political participation of persons with an intellectual disability more as a threat than as a grant. According to Kliewer et al., being open to self-critique, surprise, and learning, along with the ongoing search for new ways of engaging and connecting, is fundamental in the process toward ultimately and genuinely presuming competence.

8.1.3.2 Lack of information

Regarding persons with intellectual disabilities, there is a grave lack of information on human rights and on access to policy-making processes and policy boards. Many persons with intellectual disabilities are struggling to get access to information on their entitlements and experience inadequate or no access to any sources of support to get this information. Due to this lack, people with disabilities cannot participate meaningfully in political decision-making processes. A key barrier identified in the study is the lack of supporters, professionals and lawyers with sufficient knowledge and awareness to fully address these issues facing people with intellectual disabilities.

Frequently, professional supporters appeared uninterested, were uncertain about the issues involved, could not be understood, or provided a buffer between the participants and the available information. Moreover, persons living in institutions or group homes are difficult to reach as they seldom have personal contact addresses like phone numbers, email or mailing addresses. There are no equal capabilities to benefit from the full range of mainstream communication products and services that are necessary to participate equally in society. For example, a lot of persons with intellectual disabilities in Flanders gain little or no access to nor receive the full benefits from a phone, computer and the internet. Indeed, Goggin and Newell (2003) argue that people with disabilities are rarely found in positions of power in organizations that make decisions on internet policy and for this reason the digital divide continues to expand. Nevertheless, uncovering the right information is the base for developing critical awareness of one's social reality. Freire (1972) argues that resistance starts with conscientization, which emphasizes social consciousness at micro and macro political levels. Conscientization is literally learning to perceive social, political and economic contradictions and to take action against the oppressive elements of reality (Freire, 1972). It is a combination of collective reflection and action that occurs at both micro and macro levels of society. Within a process of conscientization, people can learn to see and analyze obstacles in attitudes, culture and discriminatory

practices and critically respond to the culture of silence that is forced on them by a dominant culture.

8.1.3.3 Top-down participation

People's political participation is situated in a socio-cultural context that requires an environment that allows for maximum movement, experiment, interdependence, interrelationships and interaction. Persons with intellectual disabilities show in a variety of ways that they can and want to belong. They are looking for points of contact and connection, want to contribute and be a valued member of policy-making processes. However, persons with an intellectual disability often have to adapt and 'fit in' the top-down structures and objectives that have been decided from above. People have the feeling that they are being 'held hostage' in a system where it is hard to make their voice heard. They are only given the chance to participate within a given system and they are hardly involved in setting the agenda. Often they are given the dubious title of 'user', someone who has the role of 'using the system', not the role of (contributing to) decision-making. This name already raises suspicions that persons with a disability are forced into an inferior position. Yet, when the agenda is closed, the diversity in the group is not able to manifest itself, because their opinions are restricted to a very narrow set of -often only picturesque- items. It undermines the input legitimacy because issues are banned from the discussion (Edwards, 2007). As policy problems are often holistic and transversal, a closed agenda setting and very narrowly defined topics hinder the inclusivity of the event on the input side (Caluwaerts & Reuchamps, 2015).

Formal advisory boards in Flanders are highly institutionalized and are often composed of professional representatives of public institutions and traditional interest groups. A lot of complex technical knowledge and skills are required before persons with disabilities are welcomed to participate, e.g. using formal language and working up-tempo. It is people's individual responsibility to adapt in this top-down participation structure. Under the guise of political participation, self-advocacy as a minority movement is confronted with re-colonization through a government/majority agenda (Goodley, 2011). This kind of participation tends to remain primarily instrumental and tokenistic, merely implying rhetorical change, or actually changes taken-for-granted practices in public services (Beresford, 2010). Beresford (p. 499) continues: "the aim is to draw in the views and ideas of service users to inform and in some cases legitimate, existing decision-makers and power holders, (...) for many service users, it can feel like little more than tokenism or a 'box ticking' exercise rather than meaningful involvement". In that way, participation might work as a camouflage

technique that masks the lack of collective responsibility and accountability for dealing with policy issues, existing power structures and structural inequalities rooted in political-economic structures of society (Roets, Roose, De Bie, Claes, & Van Hove, 2012).

8.1.4 How can we map complicated subjectivities in doing Disability Research with people with disabilities?

8.1.4.1 Intersectionality

Looking at the different studies that are brought together in this dissertation, intersectionality is a central theme. Traditional focal points of mainstream Disability Studies research tend to essentialize the category of people with a disability (Erevelles, 2011) and give primacy to 'disability' over other key elements. However, our research learned that disability is not an isolated and fixed category, but is fluid and imbricated with multiple axes of difference, such as gender, age, sexuality, income, etc.: axes that previously seemed so clearly cut, but are in reality complex, interwoven and embedded in space and time. Examining our own research materials, it is important to note that gender, immigrant status, age, socioeconomic status, etc. do matter in the process of inclusion of persons with disabilities. So many different dynamics affect the personal mechanisms of in- and exclusion, Yet, we argue that exploring multiple axes of difference in research is necessary, but insufficient. Analysis cannot be limited to comparing people 'with' and 'without' disabilities, producing binary data. Neither is an additive approach of intersectionality, where categories are assumed to be distinct pure strands that have additive effects, a solution for exploring various interactive and mutually interdependent variables (Yuval-Davis, 2006). We believe and argue that Disability Studies must embrace intersectionality as an important frame of reference, and in our study, as outlined in chapter six, we explored three dimensions to bring this theoretical framework in research, namely an inclusive, a reflexive and an anti-essentialist approach.

Firstly, encouraging and supporting the engagement of participants with a disability in an inclusive research process creates productive dialogues that provide important lenses for understanding the complexities in people's lives. In this approach, the research process and its methodologies must ensure that persons with disabilities - about whom and for whom the research is designed- are involved as more than just research objects. Inclusive research addresses power imbalances between researcher and researched, and

values the many voices and overlapping subjectivities persons with disabilities have.

Secondly, we highlight the importance of reflexivity in research, intended here as storying lived experiences and multiple intersections through individual and collective narratives, together with the continuous acknowledgement of the researcher's own positionalities and frameworks. Stories of lived experience of both the subject and the researcher can reveal often hidden complexities and invalidate simplistic binary generalizations and essentialisms. They have the power to disrupt dominant normative accounts of disability and illuminate embodied realities and complexities.

Lastly, we advocate an anti-essentialist approach in research to counter the overzealous focus on bringing under research data in fixed themes within a single reality. Through daily actions and interactions, categories are constantly re-made or re-written and work at different levels. Their conceptualization involves processes of construction, deconstruction, and reconstruction. Consequently, it is necessary to think about and to search for various entrances to examine research data and give chance to discontinuous, contradicting and temporary elements. Complexity is the norm and asks for more rhizomatic ways of thinking in order to challenge the omnipresent perception of perceiving the world in linear arborescent ways (Deleuze & Guattari, 1987): "unlike trees or their roots, the rhizome connects any point to any other point (…). There are no points or positions in a rhizome, such as those found in a structure, tree, or root. There are only lines" (p.9). The rhizome has multiple entryways (Zembylas, 2007, p.12) and it "has no beginning or end" (p.25). In contrast, the arborescent root-tree model has a central axis, a unified point of origin, and a given direction of growth (Linstead & Pullen, 2006), which is defined by continuous binary cuts and a vertical hierarchy, enforcing totalizing principles and binary thinking.

With these various approaches for applying a more intersectional perspective to Disability Studies research, we want to encourage others to think deeply about the consequences of a lack of deep engagement with other factors such as race, gender, socioeconomic status,… as intersecting with disability. These approaches can help us unmask taken-for-granted knowledge that only reinforces hierarchies and exclusion, and can bring in processes in research leading to more differenciation and complexities in people's lives.

8.1.4.2 Performativity and de-regulation

By working with and listening to narratives on in- and exclusion of persons with disabilities in our study, it soon became clear that the speed with which we launched our research and with which we hoped to work through these stories was tempered by the nature of the stories themselves (c.f. chapter two). Each of the narratives forced us to slow down and stop, hesitate , and rethink.

First of all, we realized that these narratives were not simple, neutral and unproblematic reflections of a fixed reality that exists *out there*. The stories were not static and clear, but revealed performative processes created as a result of the subject's active positioning. People almost reinvent themselves by talking and they do not take a passive and fixed position, but an active, performative, and even an inventive one. Stories are constructed and reconstructed while telling and listening to them, containing elements of spontaneous revelation, contradiction, modification and imagination. Processes of continuous transformations and becoming are apparent. Constantly evolving subjectivities are portrayed, that are looking for ways out of prevailing fixed frameworks, staging and reconfiguring their lives in relation to various discourses. Allowing these performative and ever-changing reconstructions in one's narratives, prevent us from seeing narratives as closed and complete and helps us to illustrate complex dynamics and multiple subjectivities.

Second, it became clear that storytelling can have a tremendous power and can knock down normative preconceived ideas and expectations that we all have. Narratives can de-regulate, confuse and lead to the disruption of dominant social categories. They open the subject to plurality and multiplicity, which caters to a more complex view of these categories. In this way, narrative research reveals the impact of our own prejudices to us, whereby we repeatedly stumble into other unexpected and not-yet-known insights.

Consequently, as viewers we become storytellers as well, filling in lacunas and making connections with our own narratives. We are both insiders and outsiders within a system with constantly shifting boundaries, and relate to our own experiences as well as those of the other. Our personal story is part of the assemblage and must be given a chance in research. At the same time, we have to realize that narrators are not passive respondents, but have the ability to move and be moved. This requires a nomadic thinking (Braidotti, 1994, 2004) where we do not think in terms of a stable and fixed identity, but in terms of "a nomad, an assemblage that crosses borders and categorizations" (Styhre, 2001, p.8). This thinking considers subjects as wavering and always in motion, and helps us in research to compose

mappings of situated embodied social positions and deal with narratives as open systems instead of totalitarian representations which we try to subdivide in hierarchical and fixed structures.

8.1.4.3 Co-research

To engage with questions of power, injustice issues and complicated subjectivities in our research, we call for collaborative research processes with a clear articulation of the different modalities that the concept of voice can have in research (c.f. chapter seven). According to Walmsley and Johnson, clearly articulated voices and roles are often camouflaged in inclusive research, making "the research itself becoming blurred and subject of misinterpretation." (2003, p. 201). One must be aware of and clear about the myriad of ways in which voice is operating and coexisting in research and is part of all actors, including the researcher, and shape the research processes and outcomes. We took it as a challenge to take a stance as researchers and to examine how we can deal with 'voice' and handle the relationship between researcher and participant. We illustrate this by the interpretation of the six different perspectives of voice based on the framework of Lawrence-Lightfoot and Davis (1997) and contextualize this in the field of inclusive Disability Studies research. We consider it as a good practice to attend as a researcher to these six different aspects of voice: voice as witness, voice as interpretation, voice as preoccupation, voice as autobiography, listening for voice, and finally, voice in dialogue (Lawrence-Lightfoot & Davis, 1997). This plurality of voices implies a complex balancing act between multiple positions and processes. We advocate research where these several aspects and tensions are unfolded and justified.

Through research strategies that involve the participation of persons with a disability, people's agency and views on issues that affect their lives are acknowledged. Yet, we caution against a too simplistic and sensationalized usage of the term 'voice'. In the course of our research process, it became clear that listening to voice is not a straightforward thing to do. The discourse on 'listening to voice' is beset with practical and ethical challenges. It involves reflecting on not simply what one 'hears' as a researcher, but on what one expects to hear, and how these expectations may frame the dynamics of interaction (Komulainen, 2007). It involves reflecting on simplified knowledge claims that attempt to offer stable, authentic and universal essences of 'voice' that are present and stable (Jackson & Mazzei, 2012). 'Giving voice' may involve the risk of presuming that experiences and views are inherently distinct from those of others, or that others have no voice and need externals to reveal it. As a consequence, we are provoked to

negotiate and manifest multiple voices in research and to critically question the construction of 'giving voice'.

8.2 Discussion

8.2.1 The hegemony of normativity

8.2.1.1 A double lack-of-futurity

Based on the findings set forth in the previous chapters and in the conclusions, we became aware of manifestations of ableism as a set of discourses and practices through which anyone who does not accomplish an able body/abled mind is pathologized (Campbell, 2009) or regarded as less than human (Goodley & Runswick-Cole, 2014). These strong, sometimes illegible, hegemonic discourses and normative institutional practices nourish the common-sense assumptions that an able-bodied/abled-minded identity is what anybody would want (McRuer, 2006), and that it is, for example, better for people to walk instead of rolling, hand writing instead of typing, take classes without assistive technology instead of with etc. (c.f. Hehir, 2002). The society towards persons with disabilities is primarily structured and departs from this hegemonic normativity where able-bodiedness/able-mindness is obvious and taken-for-granted. Also in media representation, we can observe a continuous illumination and reinforcement of images of the ideal able-bodied/abled-minded person, with a clear demarcation between the norm and the deviant, the *dis* and the *able*, as opposites. Difference is othered and abjected in a complex illegible entanglement of taken-for-granted discourses and practices (De Schauwer, Van De Putte, Claes, Verstichele, Davies, 2016). Besides, the-disability-as-a-problem-in-need-of-a-solution frame is omnipresent (Titchkosky & Michalko, 2012). In order not to be sidelined as outsiders or abjected as so-called monstrous other (Shildrick, 2002), persons with disabilities have to be cured, to adapt, to exhibit will-power, or to overcome their disability.

Due to this normative stance that activates everyone into the same standard, persons with disabilities are perceived as 'no(t-yet-)citizens' and their disability citizenship rights are directly related to normative, liberal citizenship models. Sepulchre (2016) confirms this embedment of citizenship in narrow neoliberal visions of the productive citizen in her scoping review of literature on disability and citizenship over the last 30 years. This neoliberal interpretation of citizenship consists of universal and transcendental notions

of citizenship, where 'difference' is constructed as 'less-than' (Lister, 1997; Moosa-Mitha, 2005). Neoliberal technologies and discourses largely define individuals in economic terms dictated by the market, serving as *homines economici,* where any form of value, other than economic ones, is inconceivable. Individual freedom, choice and autonomy are highlighted, but within this discursive framing the individualized subject of choice finds it difficult to imagine those choices as being shaped by anything other than his/her own naturalized desire or his/her own rational calculations (Davies & Bansel, 2007). In order to fit the norm, neoliberal selves are necessarily flexible, adaptable, multi-skilled, mobile, able to find and respond to new demands and situations. Individuals, reconfigured and reduced to "individual entrepreneurial actors" (Brown, 2003, p. 38), are responsible for this survival, and dependence on the social is removed (Davies, 2005).

With this neoliberal turn, it is no coincidence that essentialized images of the supercrip versus the helpless victim are so common in the Flemish media. Understandings of disabled persons are depicted as both a site of hope and overcoming disability, as well as a site of disabled suffering and tragedy. Along with this, in *Cripping Neoliberal Futurity: Marking the Elsewhere and Elsewhen of Desiring Otherwise*, Kelly Fritsch (2016) argues that neoliberal material and discursive processes orient and imagine disability as a life without a future, unless capacitated through practices of biocapitalism, such as through cure or body/mind enhancement technologies and procedures. In her analysis of portrayed disabled children, she contends that neoliberal futurity produces the figure of the suffering disabled child, figured as the negation of the future or as a subject with no future, in line with what Kliewer, Biklen and Peterson (2015) describe as 'presumed nothingness'. At the same time, neoliberal futurity produces the figure of the disabled child that is productive and meets the current and future demands of the neoliberal economy, premised on the hope of overcoming disability. This "double lack-of-futurity–disabled children without futures and a future without disability–" has the effect "that some disabled adults become unanticipated lives left to wither while others become capacitated as inspirational, hopeful, and progressive success stories of neoliberal inclusion" (p. 12). In Flanders, we are deeply invested in narratives of suffering disabled people who are presumed as not able to participate, while others are celebrated, enhanced, and capacitated precisely because they display a form of courage to achieve something and can be made fit into the neoliberal biocapitalist promise of the future.

8.2.1.2 Participation paradox

When studying the concept of participation in a more profound way, it becomes clear that it is a slippery concept. Although participation seems to be a good solution to problems of marginalization, the boundaries of participation are both opening up and, simultaneously and paradoxically, narrowing down. In this participation ideology, citizenship tends to equate equality with sameness, leading to a homogenizing tendency which ignores existing power inequalities which lead to the in- and exclusion of certain people from participating and belonging. This neoliberal interpretation of inclusion imposes a blanket norm modeled on those who conform to the 'desirable' citizen, forcing the non-conformist either to adept to the model or accept exclusion. Either individuals meet this norm or they do not. As such, a clear demarcation between participants and non-participants is created, and the plurality that exists among individuals and their different ways of participation is largely disregarded. Likewise, this ideology pays little heed to the daily life experiences of people with disabilities and the different social contexts in which persons have to participate (Reynaert, 2012).

With this participation paradox we can refer to Biesta's (2011) conceptual distinction between citizenship as a social identity and citizenship as a political identity. In a social understanding of citizenship, participation is considered to be established by the individual citizen and is "obtained through identification with an existing socio-political order" (Biesta, 2011, p. 145). In the case of persons with a disability, exclusion is predominantly framed as an individual problem and therefore as something that needs to be overcome by the individual. In this framework, democratic education is interpreted as the preparation of people *for* their future participation in democratic life. Persons with disabilities are seen as 'citizens in the making' (Marshall, 1950, p. 25) and the main focus is on the effective means to bring about 'good citizenship' rather on the question what 'good citizenship' actually is or might be (Biesta, 2011). This idea of participation-as-outcome reveals a strong technical- instrumental orientation of disability rights, seeking to support persons with disabilities in the process towards connecting with the dominant values and norms in society, in conformity with a consensus about the 'good' and 'responsible' citizen. We argue that education *for* citizenship, like education *for* anything else, tends to reduce education to a mere instrument for promoting taken for granted discourses and practices (Biesta, De Bie, & Wildemeersch, 2014). In this ideology, participation is conceived as an outcome, a consensus ideology (Hartman, 1998; Hartman, 2004; Quaghebeur, Masschelein, & Nguyen, 2004), and causes again exclusion of certain people from participating and belonging.

The political understanding of citizenship, however, is characterized by difference and plurality, rather than sameness (Biesta, 2011). Whether the

social understanding of citizenship tends to see difference and plurality predominantly as a problem, as something that troubles the stability of pre-existing orders in society, and as something that needs to be addressed and to be overcome; the political understanding of citizenship engage with plurality and difference and the underlying concepts and norms that shape our democratic society (Biesta, 2011). We are convinced that as long as citizenship is conceived as an outcome, a status that someone can achieve, it places persons with a disability in the problematic position of not-yet-being-a-citizen and does not recognize the equal value of different ways of being (Taylor, 1998). We do not presume that people move through a pre-specified trajectory into their citizenship status. In this sense, disability rights are too often imbedded in an instrumental conception of human rights, where persons with disabilities are appealed as entrepreneurial citizens, expected to participate actively and to behave like responsible citizens, responsible for the realization of their own rights as 'critical consumers'. They can enjoy their rights as long as they behave like independent responsible citizens (Masschelein & Quaghebeur, 2005; Vandenbroeck & Bouverne-De Bie, 2006), while those who do not fit this mould are paradoxically placed in more precarious positions.

8.2.2 Embracing embodied experiences and intra-corporeal reconfigurations to promote a pedagogy of interruption

In order to unsettle hegemonic discourses that appear to confine contemporary thought regarding inclusion and participation, we propose an engagement with 'embodied experiences', together with the grounding of disability as an 'emergent intra-corporeal multiplicity'.

Through this specific methodological design, used in our research project, we attempt to join a "pedagogy of interruption" (Biesta, 2006), entailing communication between people in society, and challenging, interrupting and resisting common sense knowledge and opposing this with alternative understandings. As such, we open up space for a continuous debate about the actualization of human rights for persons with disabilities. We believe that this debate needs to be framed as a constant movement and as a "being-in-question" (Levinas, 1981, p. 111) of education that functions to prepare individuals to fit into a top-down system. For Biesta, this is part of a pedagogy of interruption that opens up possibilities for "coming into the world as unique, singular beings" (Biesta, 2006, p. 27). This pedagogy of interruption urges to make sure we do not "become immune to what might affect, interrupt and trouble" us (Biesta, 2015, p. 90). Hence, this is a plea for

a joint responsibility for examining discursive practices that reduce some human beings as non-citizens, and for educators not to obstruct difference and plurality, which are central conditions of human action and human freedom (Biesta, 2015).

8.2.2.1 Embodied experiences

Because participation and the actualization of disability rights occur in experiential, embodied, real-world contexts, we urge that practitioners continuously engage with a multiplicity of single embodied experiences. Notwithstanding, together with Holloway and Hubbard (2001), we do not want to dismiss the value of global and collective narratives, yet, we want to add a crucial examination of the fundamentally important role of bottom-up local and situated knowledge, the importance of which has often been ignored or downplayed in society's rush to develop large-scale 'grand' theories or human rights implementation strategies that are organized 'in a hurry' or narrowed to technical-instrumental participation strategies.

Through storying lived experiences and opening up space for 'speaking embodied subjects' (Merleau-Ponty, 1945), it becomes clear what persons with disabilities personally define as 'participation', 'human dignity' and 'the good life' (Nussbaum, 2006), without ignoring their embodied variables, needs and desires to find a life in relation to oneself, the body, the family, the work, own abilities etc. Through this dissertation, it became clear that "the body is the vehicle of being in the world" (Merleau-Ponty, 1945, p. 82), a vehicle that mediates and creates our relation with the world and gives meaning and direction to processes of in- and exclusion. Whereas the unilateral dominant valuation of participation as "the shortest path" (Van Hal, Meershoek, Nijhuis & Horstman, 2012) sets up formal and procedural participation structures and categorical strategies for persons with disabilities, this has unintended effects and results paradoxically in a restriction of participating, because it ignores the embodied, the personal - opposite to procedural- logics of participation (c.f. Mol, 2008). In this ideal, participation is considered as an achievable condition and the underlying normative conception of the disembodied citizen is not questioned.

> 'By definition', a citizen is someone who controls his body, who tames it, or who escapes from it. 'Citizens' owe the ability to make their own choices to the silence of their organs. (Mol, 2008, p. 35)

Embodied experiences start out from the fleshiness and fragility of life, and urges us to no longer marginalize, but face disability. These experiences give

practitioners a better understanding of the playful and ambivalent forms of citizenship, where it is assumed that "everyone in society (…) are citizens who simply move through citizenship-as-practice, from the cradle to the grave" (Pols, 2006, p. 96). Embodied experiences question normative discursive practices, together with constructions of 'sameness' and 'difference', and recognize "that all of us are different in many different ways", and that being "different is the norm" (Lister, 1997, p. 79).

Furthermore, allowing embodied experiences implies opening up for multiple interweaving and complex intersections imbricated with 'disability' (i.e. 'intersectionality' as coined by Crenshaw, 1989), that, according our to study, really do matter in the process of inclusion of persons with disabilities. These axes of difference seem clear-cut, but are in reality complex, interwoven and embedded in specific socio-historic context. In our media study, we observed dichotomous and essentializing categorizations of individuals with a disability, such as being dis/abled, ab/normal: individuals who are, on the one hand, abjected as non-citizens, or individuals who, on the other hand, are in need to fit (and be fitted) in a pre-described indicator. This construction of fixed categories and the clear demarcation between frames and counter-frames in the media contrasts with the complexity of the narratives and experiences of persons with a disability in our study, where the fluidity of categories urges us to critically navigate and challenge the ways in which society construct and pin downs subject positions that we assume to be pre-given, universal and unchanging. When considering this contrast, we are mindful of the fact that many people rely almost entirely on the media for their information about diversity and disability. Engaging with these embodied multiple intersections can illuminate the often hidden complexities and invalidate simplistic binary generalizations and essentialisms.

8.2.2.2 Intra-corporeal reconfigurations

In our research praxis, participants with a disability have radically challenged the ways how differences of persons with disabilities can be devalued as inferior. Despite the ratification of the UN Convention on the Rights of Persons with Disabilities, "disability remains stubbornly outside of what is considered a life worth living" (Fritsch, 2015, p. 46). "The value of a disability-free future is seen as self-evident" (Kafer, 2013) due to the contemporary neoliberal hegemonic social imagination by which "disability has been linked to a life of suffering, unhappiness, dependency, poverty, disadvantage, and

incapacitation" and by which "disability remains stubbornly undesirable" (Fritsch, 2015, p.46). Instead, we believe we must start to examine how we think about difference and sameness. We must recognize the "presumed competence" (Kliewer, Biklen, & Peterson, 2015), involving ourselves with others "*as if* we all make meaning of the world, *as if* we all have a rightful place in valued communities, *as if* we all think, and *as if* we all can continue to deepen and expand in our connectedness with the surrounding world" (p. 23). We believe persons with disabilities must be forced out of the role of 'needy objects' or the role of 'customers', that is etymologically related to 'passive' (Mol, 2008, p. 32). We must recognize that we need each other's help, in policy making, in research, in media production and in our everyday praxis. It is not our intention to simply keep persons with disabilities busy, but to sincerely appreciate their contributions in an intra-active way, adding to the richness of our understandings and exceeding individualized human bodies, as a mutual constitution of entangled agencies (Barad, 2007). Nor is it our intention to engage in the activation approach, maximizing the move of people into the labor force and the economization of social relations and life itself. Instead, we argue to ground disability as an 'emergent intra-corporeal multiplicity' to open up space for desiring disability differently (Fritsch, 2015). In this reconfiguration, the undesirability of disability is challenged:

We come to recognize that disability does not emerge as an individualized human body, but rather is an intracorporeal, non-anthropocentric multiplicity. To desire disability differently through the heterotopic imagination is not simply to allow the current formulation of disability to become desirable, but rather to *radically alter how* we desire disability, in addition to altering what disability is, how it is practiced, and what it can be. (Fritsch, 2015, p. 43).

By thinking in terms of disability as an emergent, intra-corporeal multiplicity we open up the idea that a person with a disability, like any human subject, is transformable, in constant motion, always emergent within the interplay of several ways of being and thinking (De Schauwer & Davies, 2015). Rather than a stabilized, individualized, simplified, biological and undesirable monolithic fact of the body (Kafer, 2013), disability emerges in relation. In this relation, bodies are formed *within*, rather than formed 'across' of 'between' already-formed bodies, in always entangled relations. This notion of intra-action is explained by Barad (2007) as "the mutual constitution of entangled agencies" (p. 33).

Further, as an emerging multiplicity, disability becomes a responsibility of the many, not one. How we make sense of difference and disability is a shared responsibility. While normative discursive practices work to hold those diagnosed with a disability in a static place of otherness, we must disrupt this dynamic, as the agencies involved are multiple (Fritsch, 2015). Disability

cannot be reduced to a singular identity: "it is a multiplicity, a plurality" (Gabel & Peters, 2004, p. 588). It sits at the intersection of mutually constitutive and interacting positionalities, and opens up the subject to plurality and multiplicity, which caters to a more complex view of categories. While the social hegemonic imaginary posits a conception of disability that understands it as an undesirable state of being that must be eliminated or overcome, we must "reckon with the ways that disability is not just something that tragically appears in the world that we most tolerate or include, but rather that disability is an emergence of the world; that is, disability is a practice. As an intracorporeal practice, disability is a life worth living" (Fritsch, 2015, p. 65) in which we set out to think disability differently. In this reconfiguration, a space for presumed competence and desiring disability emerges.

By working with the discursive and intra-active practices through which people and events emerge in all their multiplicity, participation may appear different, depending on the context in which actors are involved in the dialogue. Participation is grounded in relationality and cannot be caught up in the normative order that does not allow for variation and alternative understandings of participation. With this latter option we make connection with Pols' concept of relational citizenship (2006), differing radically from normative citizenship, as it assumes that "everyone in society (…) are citizens who simply move *through* citizenship-as-practice" (p. 96), challenging the dichotomy of insider versus outsider status. Hence, individuals with a disability don't have to 'fit in' (Pols, 2004), nor the responsibility of citizenship and participation is imposed only on them. Participation is not a limited and linear product, but an ongoing process, emerging in relationships as an intra-active entanglement of being.

8.2.3 Creating capabilities: participation as a starting point for pedagogical practice

In line with the concept of relational citizenship (Pols, 2006), we move away from the strong technical-instrumental orientation of disability rights in which the ultimate goal for persons with disabilities in particular is to connect individually with hegemonic societal norms and standards. Disability rights often get narrowed to the integration of persons with disabilities within the dominant institutions of society, with a strong discourse of 'technicalization' of these rights. The debate on disability rights becomes a technical debate on the most effective and efficient way to implement those rights, creating the risk that disability rights confirm existing inequalities rather than that disability rights are able to change them. Rights are then presented as the new norm in policy and practice, without questioning or problematizing this

new norm (Reynaert, 2012). Too often, initiatives to promote inclusion are fed by ideal normative models, rather than by the actual reality and different social contexts in which persons live. These models start to operate in society as the new norm. Either persons with disabilities meet this norm or they do not. Hence, the plurality that exists among persons with disabilities and the diversity of participation processes are largely disregarded. This scenario demonstrates the precariousness and fragility of rights.

Instead of understanding disability rights as 'an end' where the solution to concrete problems is embodied in the implementation of the law, we argue that disability rights must be understood as a starting point for dialogue. The actualization of citizenship is made possible through participative processes and joint action (Freire, 1972), in which democratic education is not interpreted as the preparation of 'citizens in the making' *for* their future participation in democratic life, but as education *from* participation, in which various democratic processes and practices are seen as the very *raison d'être* of education (Biesta, De Bie, & Wildemeersch, 2014). Together with Biesta, we want to approach education in which "the question of what it means to be human is seen as a radically *open* question, a question that can only be answered-and has to be answered again and again- by engaging *in* education, rather than as a question that needs to be answered *before* we can engage in education" (Biesta, 2006, p. 151). Understanding rights as being shaped through participation and participative processes during which the definition and the content of these rights are negotiated (Roose & De Bie, 2007), symbolizes "a demonstration of respect for people (…) as being equal citizens" (Lister, 2001, p. 70). Besides, this approach offers the collective a lens through which the taken-for-granted normative practices and discourses can be questioned. In Biesta's words, we need a shift from a social to a political conception of citizenship, as it opens up space for questioning pre-existing orders in society consolidated as safe, stable and cohesive. From the angle of this political understanding of citizenship, participation may appear in different ways:

> This raises a further important question, which is whether is it indeed the case that we can understand democracy as a particular, clearly defined and clearly definable 'order' that you sign up to – in which case you are 'in' – or that you do not sign up to – in which case you are 'out' – or whether we should understand the very idea of democracy in different terms. I wish to argue that the situation is indeed more complicated and that to simply assume that the 'order' of democracy can be fully defined and determined may actually go against the idea of democracy itself. (Biesta, 2014, p. 2)

In this view, citizenship is not translated as an individual status, but rather as a practice to be realized through various activities and social relationships; a citizenship-as-practice (Lawy & Biesta, 2006). In case of our research, this citizenship-as-practice approach means that we must pay a lot of attention to, on the one hand, the way we approach persons with disabilities and, on the other hand, the search for defining inclusion and participation in dialogue with persons with disabilities themselves. Hence, along with Nussbaum, we argue that rights cannot be seen as isolated and stable elements, as this draws the attention away from the conditions and actual lifeworld in which citizens can participate in the making of society. Disability and the conceptualization of disability rights emerges in relation, in an intra-active, mutual constitution of entangled agencies (Barad, 2007). A pedagogical dimension is crucial to conceptualize human rights as open and ongoing processes, oriented towards the lifeworlds of and in dialogue with persons with a disability. As such, participation and human rights are actualized and constantly renegotiated through interactions in which plurality, contradiction and difference, rather than sameness are vital elements (Roose & De Bie, 2007). From this perspective, human rights are seen as 'capabilities', i.e. people's real opportunities for functioning and choice (Dixon & Nussbaum, 2012). In this capability approach, human rights are situated in the lifeworlds and subjective needs of people themselves, where the question is raised not only with regard to the extent social resources are present, but just as well in how far these social resources enable people to function in a fully human way in relation to others. Nussbaum (1997, p. 284) argues that "focusing on resources does not go deep enough to diagnose obstacles that can be present even when resources seem to be adequately spread around, causing individuals to fail to avail themselves of opportunities that they in some sense have, such as free public education, the right to vote, or the right to work."

As a consequence, besides the necessary structural adjustments for obtaining inclusion, human rights cannot solely be catered with *prêt-à-porter* solutions*,* packed in finished condition and in standardized sizes. Instead, *custom-made* processes, tailored to the usage, customs or tastes of individuals are required, in which human rights are translated in specific situations and contexts. Through enabling opportunities for citizens to enact their citizenship through participation in always open democratic learning experiments, participation processes can unfold as flexible and in motion. Instead of a preset goal, participation serves as a starting point for pedagogical practice. In such a way, participation may appear different, depending on the context in which actors are involved in the dialogue. Capabilities, just as human rights, include respect for moral pluralism (Alexander, 2004). As a result, different interpretations and perceptions

regarding participation, the right to participate and what people think is in the best interest, can emerge.

Allowing the difference in subjective needs for social resources that people need, results in the achievement of more equality in the ability to act and a larger sense of human dignity. Translated to disability rights, this contextual character implies that we must contribute to the creation and distribution of collective resources by which people are supported in the realization of dignified social relationships, including the experiences of persons with disabilities themselves on these social relations. A main barrier to inclusion for persons with disabilities, therefore, may have been the way in which the concept has been dominantly explored and understood.

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Appendix 1

Nederlandse samenvatting

Context en situering van het onderzoek

Binnen dit doctoraat wordt op participatieve wijze onderzoek gedaan naar inclusie van personen met een beperking in Vlaanderen, vertrekkende vanuit een mensenrechtenperspectief. Een grote drijfveer voor dit onderzoek is het feit dat de participatie van personen met een beperking in heel wat domeinen nog steeds erg gelimiteerd is (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009; World Report on Disability, 2011), niettegenstaande zij de grootste minderheidsgroep ter wereld (15%) vormen (World Report on Disability, 2011). Een tweede grote drijfveer betreft de VN-Conventie inzake de Rechten van Personen met een Handicap (http://www.un.org), intussen geratificeerd door reeds 168 landen, waaronder in België op 2 juli 2009. Dit mensenrechtenverdrag bevat bepalingen gelinkt aan inclusie, participatie en zelfbepaling voor mensen met een beperking en beklemtoont dat mensen met een beperking het recht hebben erbij te horen en midden in de samenleving te kunnen leven. Een derde grote drijfveer is de beperkte wetenschappelijke aandacht voor dit onderzoeksthema, in het bijzonder vanuit het perspectief van personen met een beperking zelf (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007; Lloyd, Gatherer, & Kalsey, 2006; Jones, 2007; Verdonschot et al., 2009; WHO, 2011).

Willen we aansluiten bij de meer hedendaagse visie op personen met een beperking, dienen we bij het denken over en onderzoek doen naar participatie dit 'mensenrechtenmodel' mee te nemen. In die zin is onder andere de VN-Conventie een zeer belangrijk normatief raamwerk voor dit onderzoek. Naast dit socio-politiek kader nemen we ook – op theoretisch vlak – het werk van Martha Nussbaum (2006, 2009, 2010) mee als belangrijk framework binnen het onderzoek. Haar capability approach is een specifieke mensenrechtenbenadering ontwikkeld als referentiekader ter evaluatie en beoordeling van het individueel welzijn van personen en het sociaal en maatschappelijk beleid dat hiervoor ontwikkeld wordt. Geleid door deze inbedding in het mensenrechtenperspectief werden enkele basisaannames geformuleerd bij dit onderzoek, overeenkomstig de VN-Conventie inzake de Rechten van Personen met een Handicap en overeenkomstig het kader van Disability Studies (Van Hove et al., 2012):

1. Het onderzoek dient de rechten van personen met een beperking en hun menselijke waardigheid te ondersteunen en te bevorderen.
2. Personen met een beperking zijn niet langer 'objecten' die zorg ontvangen, maar 'subjecten', actieve personen met eigen mogelijkheden en rechten die eigen beslissingen kunnen nemen.

3. Disability ontstaat als een interactie tussen de persoon en de omgeving. Drempels in de maatschappij kunnen participatie in de weg staan.
4. We willen respect tonen voor het anders zijn en personen met een beperking zien als volwaardige persoon.
5. We geloven dat volledige en effectieve participatie en inclusie belangrijk zijn om mensen te laten groeien en om de samenleving te verrijken.
6. Aan alle activiteiten -ook onderzoek- moeten personen met een beperking kunnen participeren (Nothing About Us Without Us).

Onderzoeksdesign

Inclusie en participatie zijn moeilijke en veelzijdige concepten die op veel verschillende manieren geïnterpreteerd en onderzocht kunnen worden. Voor dit onderzoek sloten we aan bij een bestaand model om de mensenrechten van personen met een beperking te evalueren, het DRPI-model (Disability Rights Promotion International) (Rioux, Pinto, & Parekh, 2015), en gingen we tegelijkertijd stilstaan bij complexiteit en meervoudigheid doorheen het onderzoeksproces.

Ten eerste gingen we na wat persoonlijke narratieven van mensen met een beperking in Vlaanderen ons kunnen leren over processen van in- en uitsluiting. Ten tweede bestudeerden we de representatie rond 'handicap' in de Vlaamse media via een inhoudsanalyse en framinganalyse. Ten derde volgden we een concreet project op van een Vlaamse self-advocacy beweging aangaande politieke participatie van personen met een verstandelijke beperking. Tot slot stonden we stil bij meervoudige subjectiviteiten en complexiteit binnen Disability Studies onderzoek.
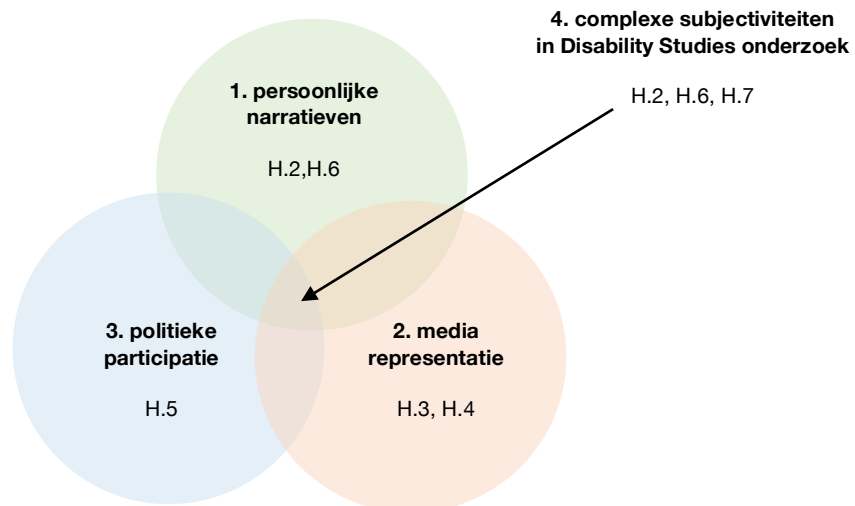
Centrale onderzoeksbevindingen

De eerste onderzoeksvraag betreffende de insiderperspectieven van mensen met een beperking, bracht ons tot volgende drie belangrijke concepten:

- Toegankelijkheid en relationeel burgerschap
  Beperkte toegankelijkheid en mobiliteit blijven heikele punten in Vlaanderen, waardoor deelname van mensen met een beperking aan het maatschappelijk leven in vele gevallen bijzonder moeilijk verloopt. Tegelijk wordt duidelijk dat er weinig rekening gehouden met persoonlijke behoeften en verlangens van mensen in dit proces en met wat het daadwerkelijk betekent voor mensen om te participeren. Inclusie betekent namelijk meer dan deelname aan het bestaande aanbod. Het gaat over verbondenheid met anderen en behelst een dynamisch proces in voortdurende beweging, waarbij steeds op zoek wordt gegaan naar mogelijkheden om samen te leven en leren. Vanuit dit perspectief worden de verschillende manier waarop mensen aanwezig zijn en participeren in de samenleving erkend, in lijn met het concept van relationeel burgerschap.

- Embodiment
  Onderzoek naar het fenomeen 'beperking' en 'inclusie' kan de 'doorleefde ervaringen' van mensen rond lichamelijkheid, handicap, pijn, kracht, etc. niet negeren. Het toonaangevende *hardcore* sociaal model is dus niet voldoende bij het evalueren en ondersteunen van participatie en inclusie, maar dient vergezeld te worden met subjectieve ervaringen rond lichamelijkheid.

- Normalisatie en individuele verantwoordelijkheid
  De samenleving wordt voornamelijk gestructureerd en vertrekt vanuit de norm waarin 'able-bodiedness' vanzelfsprekend en normaal lijkt. Het probleem en de oplossing voor een evenwaardige plaats in de samenleving wordt gelegd bij de mensen met een beperking zelf, niettemin de factoren die hen in de marge duwen of houden veelal buiten hun eigen bereik liggen. Vlamingen met een beperking blijken hierbij veel verantwoordelijkheid zelf op te nemen. De neoliberale, vrije, autonome burger wordt als ideaal naar voor geschoven en het idee van voortdurende inter-afhankelijkheid wordt zelden erkend. Maatschappelijke problemen zijn in deze logica het resultaat van een gebrek aan individuele verantwoordelijkheid, eerder dan een resultaat van meer structurele oorzaken.

Aangaande de tweede onderzoeksvraag rond de representatie van mensen met een beperking in de Vlaamse media kan -in grote lijnen- het volgende gesteld worden:

- De kwantitatieve inhoudsanalyse (n=14.529) zoomt in op een aantal variabelen en leert ons dat mediarepresentatie rond 'handicap' sterk gebaseerd is op bredere ideologische opvattingen en processen gekenmerkt door uitsluiting en traditionele machtsrelaties. Bovendien is er in sommige bronnen een totaal gebrek aan representatie, of staan representaties scherp tegenover een geïdealiseerde norm. De berichtgeving rond mensen met een beperking heeft bijgevolg niet het potentieel in zich om verandering te brengen in attitudes en percepties bij het publiek in lijn met de VN-Conventie voor de Rechten van Personen met een Handicap.

- Bij de framing-analyse ontdekten we een negatieve eenzijdige portrettering van personen met een beperking in de media, gekenmerkt tot 9 dominante frames en 3 alternatieve counter-frames. De frames die gehanteerd worden zijn geworteld in een traditioneel dichotoom denken en laten geen ruimte voor complexiteit, waarbij de portrettering van mensen met een beperking vaak wordt beperkt tot twee extremen: enerzijds als mensen die benadeeld, zwak, afhankelijk zijn en niet in staat te participeren; anderzijds als helden of personen met een uitzonderlijke moed voor hun inspirerende prestaties, waarbij de beperking wordt 'overkomen' door individuele inzet en wilskracht.

Voor wat betreft de derde onderzoeksvraag komen we terug op volgende concepten:

- Presumed Nothingness
  Mensen met een (verstandelijke) beperking worden systematisch onderschat. Men gaat er niet van uit dat ze competent zijn (presumed competence) en hun mening wordt als minderwaardig beschouwd. Hierbij worden heel veel drempels of voorwendsels gecreëerd zodat mensen met een verstandelijke beperking geen actieve rol kunnen spelen bij beleidsbeslissingen, of worden ze expliciet geweigerd. Toegang krijgen tot een lokale adviesraad kon jaren in beslag nemen en draaide vaak uit op een weigering.

- Gebrek aan informatie
  Er is een groot gebrek aan informatie over politieke betrokkenheid en het recht op politieke participatie. Bovendien is de beschikbare

informatie zelden toegankelijk of hebben mensen zelden toegang tot internet of andere communicatiemiddelen. Daarnaast fungeren zorginstellingen vaak als buffer of toegangspoort, waardoor de informatie nog moeilijker -of helemaal niet- bij de betrokkenen terecht komt.

- Top-down participatie
  Politieke betrokkenheid impliceert het inpassen in een top-down georganiseerde participatiestructuur. Mensen moeten zich inpassen in structuren en doelen die van bovenuit bepaald zijn. Ze mogen er zijn, maar er wordt beslist voor hen over wat ze al dan niet kunnen meepraten en -beslissen. Hierbij worden vaak onredelijke voorwaarden vooropgesteld waaraan mensen moeten voldoen, denk aan taalgebruik, tempo of grote hoeveelheden te verwerken ontoegankelijke tekst.

De vierde onderzoeksvraag doet ons stilstaan bij complexiteit en meervoudigheid via volgende drie invalshoeken:

- Intersectionaliteit
  We kijken kritisch naar het concept 'disability' en vullen dit in als een dynamische en complexe constructie. Bij processen van in- en uitsluiting zijn er steeds meerdere maatschappelijke factoren gelijktijdig werkzaam die op een complexe manier met elkaar interageren. Intersectionaliteit biedt een interessante lens bij het onderzoek doen rond 'beperking' en 'inclusie' en laat ruimte voor verschillende assen van ongelijkheid ('axes of difference') die kunnen meegenomen worden in het kijken naar machtsrelaties. Het idee van een statische en essentialistische invulling wordt verlaten voor verschil als een steeds veranderend en continu concept. Hoofdstuk 6 verkent drie manieren om intersectionaliteit binnen te brengen in Disability Studies onderzoek, namelijk inclusie, reflexiviteit en anti-essentialisme.

- Performativiteit en de-regulerende verhalen
  Narratieven hebben een derugelerende werking: ze brengen ons in de war, ont-regelen en halen onze vooronderstellingen onderuit. Bovendien zijn ze performatief: wat mensen ons laten zien als onderzoeker is heel variabel. Narratieven zijn nooit afgesloten en voltooid, niet vast te leggen of te fixeren. Dit terwijl we als onderzoekers vaak de pretentie hebben te veronderstellen dat verhalen op een directe en onproblematische manier verwijzen naar

de werkelijkheid. In hoofdstuk 2 worden deze stellingen geïllustreerd met voorbeelden en wordt bovendien verbinding gemaakt met het werk van Turks videokunstenaar Kutluğ Ataman, wat aantoont hoe nauw kunst en Disability Studies met elkaar verbonden kunnen zijn.

- Co-operatief onderzoek
  We kiezen voor co-operatief onderzoek en streven naar continue dialoog en actieve betrokkenheid van de participanten in alle fasen van het onderzoek, in lijn met de VN-Conventie inzake de Rechten Van Personen met een Handicap. In de relatie tussen participant en onderzoeker staan connectie, wederzijds respect, stem geven en luisteren centraal. In hoofdstuk 7 worden de verschillende manieren hoe deze stem kan inwerken in onderzoek belicht en geïllustreerd.

Discussie

In de discussie wordt stilgestaan bij de kracht van normativiteit, dewelke duidelijk op te merken is doorheen alle onderzoeksbevindingen binnen dit doctoraat en dewelke in- en uitsluiting van bepaalde mensen op basis van verschil teweegbrengt. Als alternatief stellen we een 'pedagogie van de onderbreking' (Biesta, 2006) voor, aansluitend bij onze eigen methodologie in dit onderzoek. Hier benadrukken we het belang van 'doorleefde ervaringen' en 'intra-corporeal reconfigurations (Fritsch, 2015)'. We besluiten met een pleidooi voor participatie als uitgangspunt, en niet als eindpunt, van het (pedagogisch) handelen. Hierbij staat niet de identificatie met en intrede tot de vaste normen van de samenleving voorop, aangezien deze invulling van participatie terug neigt naar in- en uitsluiting. Wel plaatsen we de interactie die tot gediversifieerde en veranderende vormen van participatie kan leiden voorop. Dit sluit aan bij het denken in termen van capabilities (Nussbaum, 2006, 2009, 2010), waar mensenrechten niet verengd worden tot technische en losstaande elementen, maar een aanknopingspunt kunnen vormen om vanuit een concrete context van mensen in te zetten op gelijke mogelijkheden voor een menswaardig bestaan en op die manier een genuanceerder denken over participatie kunnen verwezenlijken.

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Appendix 2

Data Storage Fact Sheets

Data Storage Fact Sheet 1

Name/identifier study: Narative research on inclusion of persons with disabilities - chapter two, chapter six & conclusions
Author: Tina Goethals
Date: 03/11/2016

1. Contact details

1a. Main researcher

- Name: Tina Goethals
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1b. Responsible Staff Member (ZAP)

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

* Reference of the publication in which the datasets are reported:

- Goethals, T. (2016). De performatieve en deregulerende kracht van verhalen. In G. Van Hove, A. Schippers, M. Cardol, & E. De Schauwer. *Disability Studies in de Lage Landen.* Antwerpen-Apeldoorn: Garant.

- Goethals, T., De Schauwer, E., & Van Hove, G. (2015). Weaving Intersectionality into Disability Studies Research: Inclusion, Reflexivity and Anti-Essentialism. *Journal for Diversity and Gender Studies, 2*(1-2), 75-94.

* Which datasets in that publication does this sheet apply to?: all data

3. Information about the files that have been stored

3a. Raw data

* Have the raw data been stored by the main researcher? [X] YES / [ ] NO
If NO, please justify:

* On which platform are the raw data stored?

- [X] researcher PC
- [ ] research group file server
- [X] other (specify): a selection of the visual material is edited together with the participants and stored on the website www.zondergrenzen.be

* Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [ ] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

3b. Other files

* Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: different topic schemes
- [X] file(s) containing processed data. Specify: transcripts from audio files
- [X] file(s) containing analyses. Specify: files with preliminary results
- [X] files(s) containing information about informed consent
- [ ] a file specifying legal and ethical provisions
- [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: files containing basic information about the nature of the data and the way in which they have been collected
- [ ] other files. Specify: ...

* On which platform are these other files stored?

- [X] individual PC
- [ ] research group file server

- [ ] other: ...

* Who has direct access to these other files (i.e., without intervention of another person)?

- [X] main researcher
- [ ] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

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* If yes, by whom (add if multiple):

- name:
- address:
- affiliation:
- e-mail:

Data Storage Fact Sheet 2

Name/identifier study: Research on media representation of persons with disabilities - chapter three, chapter four & conclusions

Author: Tina Goethals
Date: 03/11/2016

1. Contact details

1a. Main researcher

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2. Information about the datasets to which this sheet applies

* Reference of the publication in which the datasets are reported:

- Goethals, T., Mortelmans, D. & Van Hove, G. (2016). Toward a More Balanced Representation of Disability? A Content Analysis of Disability Coverage in the Flemish Print Media. *The Journal of Human Development, Disability and Social Change (Thematic Issue: 'Social representations and Disability: shared perspectives on the meaning of a concept').*

- Goethals, T.; Mortelmans, D.; Van Den Bulck, H.; Van den Heurck, W., De Schauwer, E., Van Hove, G. (submitted). I'm not your metaphor. Frames and counter-frames in de representation of disability.

* Which datasets in that publication does this sheet apply to?: all data

3. Information about the files that have been stored

3a. Raw data

* Have the raw data been stored by the main researcher? [X] YES / [ ] NO
If NO, please justify:

* On which platform are the raw data stored?

- [X] researcher PC
- [ ] research group file server
- [ ] other (specify)

* Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [ ] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

3b. Other files

* Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: coding schemes, framing matrix
- [X] file(s) containing processed data. Specify: SPSS .sav files
- [X] file(s) containing analyses. Specify: SPSS output files, framing matrix
- [] files(s) containing information about informed consent
- [ ] a file specifying legal and ethical provisions
- [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: file containing basic information about the nature of the data and the way in which they have been collected, code book
- [ ] other files. Specify: ...

* On which platform are these other files stored?

- [X] individual PC
- [ ] research group file server
- [ ] other: ...

* Who has direct access to these other files (i.e., without intervention of another person)?

- [X] main researcher
- [ ] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

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* Have the results been reproduced independently?: [ ] YES / [X] NO

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- address:
- affiliation:
- e-mail:

Data Storage Fact Sheet 3

Name/identifier study: Research on political participation of persons with intellectual disabilities - chapter five, chapter seven & conclusions
Author: Tina Goethals
Date: 03/11/2016

1. Contact details

1a. Main researcher

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

* Reference of the publication in which the datasets are reported:

- Van Hove, G., Goethals, T., De Schauwer, E., Gabel, S. (submitted). Political involvement of persons with intellectual disabilities - a qualitative research project in the Dutch-speaking part of Belgium.

- Goethals, T., Van Hove, G., Van Breda, L., & De Schauwer, E. (2016). Researching Together: Voice as a Guide in Research. In T. Buchner, O. Koenig, & S. Schuppener (Eds.), *Inklusive Forschung.*

> *Gemeinsam mit Menschen mit Lernschwierigkeiten forschen.* Bad Heilbrunn: Klinkhardt.

* Which datasets in that publication does this sheet apply to?: all data

3. Information about the files that have been stored

3a. Raw data

* Have the raw data been stored by the main researcher? [X] YES / [ ] NO
If NO, please justify:

* On which platform are the raw data stored?

  - [X] researcher PC
  - [ ] research group file server
  - [ ] other (specify)

* Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [ ] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

3b. Other files

* Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: see methodology section in the articles
- [X] file(s) containing processed data. Specify: transcripts from audio files, transcripts from observations
- [X] file(s) containing analyses. Specify: files with preliminary results
- [X] files(s) containing information about informed consent
- [ ] a file specifying legal and ethical provisions
- [ ] file(s) that describe the content of the stored files and how this content should be interpreted. Specify:
- [ ] other files. Specify: ...

* On which platform are these other files stored?

- [X] individual PC
- [ ] research group file server
- [ ] other: ...

* Who has direct access to these other files (i.e., without intervention of another person)?

- [X] main researcher
- [ ] responsible ZAP
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