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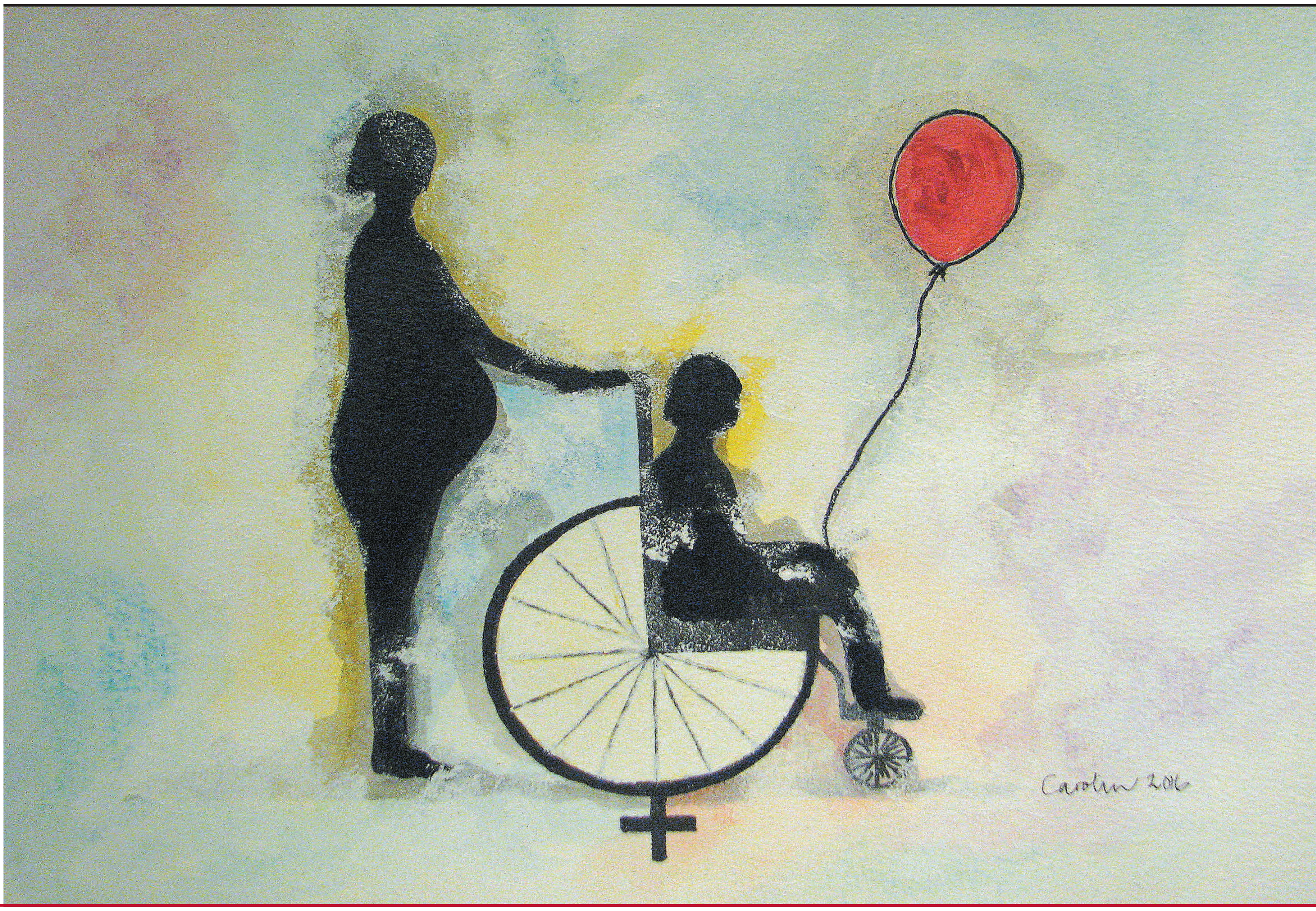
Carolin Ahlvik-Harju

RESISTING INDIGNITY

A Feminist Disability Theology



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Painosalama Oy
Åbo 2016

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Everyone has their own personal life story, but every life story is shaped by greater cultural narratives, society, history, circumstances, experiences and relationships. I never foresaw that research would become my career path, but – unsurprisingly – life does usually not turn out the way we plan. More than an important chapter in my personal life story, this thesis is an outcome of me being invited to be part of a creative milieu that has allowed me to flourish as a person, thinker and writer. It has indeed been a rocky road – one that I would not have dared to walk on if it were not for the many people who have believed in me, given me their input, time, support and encouragement. For this I am deeply thankful.

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Åbo, a sunny day in October 2016
Carolin Ahlvik-Harju

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PART I

1 Introduction

1.1 Background

When I was five years old I met a girl with profound intellectual disabilities for the first time in my life. As I recall our encounter it was one of confusion, fascination, consternation and affirmation. Confusion – because of her being so different from anyone I had ever met. Fascination – because she behaved differently and she had a strange and yet beautiful body. Consternation – because I saw how other people looked down at her and reacted anxiously upon her presence. Affirmation – because I, despite my funny toes, realized that I look like most people. For the first time I was presented with the great paradox of disability as otherness: people with disabilities are *not desired* in this world because they are too different, but at the same time they are *much needed* because they make the presumed normal people feel normal. The values of modern liberal societies are characterized by independence, individualism, success and productivity, and in such societies people with disabilities are, like other "weak" citizens, viewed as an economic and human burden. Because people with disabilities are presumed to place a burden on both families and the society, and because they are presumed to suffer greatly from their disability, modern biotechnology has come to be a highly desired way of dealing with the fear of disability. And despite efforts worldwide to increase the political rights of people with disabilities, they remain invisible and unimportant to many.[1]

Ever since I was five years old, people with various disabilities have been neither invisible nor unimportant in my life. In fact, there is no doubt about what, or rather who, my greatest inspiration for writing this thesis has been: the people with disabilities who have crossed my path over the years, either in real life or through their stories in books and the media. Especially the people I have helped care for in various care homes, and the wonderful lads in the L'Arche community who I was fortunate to live with in my early days as a doctoral student, have

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[1] Newell 2010, 172; Vanier 2010, 21.

had a huge impact on my research and writing. Little did I know then, in the beginning of my writing process, when my interests were directed at analysing the concept of human dignity in ethical theories on prenatal screening, that the life stories of people with disabilities would become a primary resource not only for my own personal inspiration, but as a material and a methodological resource as well. Little did I know then, that my dissertation would become a contribution to an inter-disciplinary field of research, for which I have found no better description than *feminist disability theology*.

The journey into this fascinating research field has truly been one of new discoveries and unexpected encounters, as any good research project ought to be naturally. Not only have I discovered a whole new world of research material, but different ways of doing theological research too. What originally was intended to become a monography turned instead out to be a thesis with four individual articles. Each article represents, in one way or another, the process of discoveries that I have made along the way, and perhaps it is only now when the thesis is done that I see what an immense resource disability as both a concept and human experience is in approaching a wide range of important questions.

Although it became apparent already in the process of writing my first article, one thing that keeps surprising me still after writing three more, is how disability truly is at the core of many medical, political, cultural and theological discourses – implicitly or explicitly, either by its presence or absence, by its mentioning or by leaving it out of the conversation. In various mainstream bioethical theories, as well as in many theological and feminist approaches to human being, human dignity, embodiment, health, and reproductive issues, disability stands out as the representation of the unpredictable, the unstable, the unexpected, and the *undesirable*.

Hence, disparaging the so called eugenic logic[2] that tells us that the world would be a better place if disability could be eliminated is at the

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[2] The expression *eugenic logic* springs from the eugenic ideology and practices that emerged in 19th century, which is more extensively discussed in the chapter *The Normalcy Narrative.* At this point I want, however, to point out that the eugenic logic refers not merely to the eugenic ideology of a particular historical time, but precisely to the persistent view of disability that emerged with the eugenic movement, which

core of this thesis. This is exemplified not least through the practice of prenatal testing and selective abortion, which reveals that the birth of a disabled child is commonly seen as the ultimate sign of catastrophe. It is revealed on a structural level in society, in dominant systems of representation, and in the cultural narratives that not only shape the material world but inform our human relations and shape the sense of who we are. It is revealed in the discourse about reproductive health in which it is apparent that a mother with disabilities per definition is viewed as an unfit mother. And the very same eugenic logic can also be found in the Christian tradition; particularly in the most common criteria for being created in God's image, which is the ability to reason. In all of these, in some sense separate discourses, one thing stands out as a common denominator, namely that disability is placed outside of notions of normality, outside of what is desired. Especially vulnerable to such marginalization are people with profound intellectual disabilities.

I could have followed through with my initial plan to critically analyze a couple of bioethical theories and constructively articulate a viable alternative position on prenatal testing. This would have been a well-motivated task because of the rapid emergence of new biomedical technologies, such as new elevated methods for prenatal screening, which surely raises many questions about how and on what grounds we are to make use of such technologies within health care today. However, the many stories of people with disabilities evoked me to take a different route. In one of the books that has had immense influence on my research, *Feminist Disability Studies* (2011), Alison Kafer writes:

> There are stories of people embracing their bodies, proudly proclaiming disability as sexy, powerful, and worthy; tales of disabled parents and parents with disabled children refusing to accept that a bright future for our children precludes disability and asserting the right to bear and keep children with disabilities; and narratives of families refusing to accept the normalization of their bodies through surgical interventions and the normalization of their desires through heterocentric laws and homophobic condemnations.

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makes sense of and legitimizes marginalisation of people with disabilities. See Garland-Thomson 2012; Grue 2010.

> These stories deserve telling, and the issues they raise demand debate and dissent.[3]

A common approach within feminist theory is to embrace voices from the margins in theory. Feminist theologian Karin Sporre (1999) discusses this as a calibration of ethical priorities between voices or perspectives. She proposes:

> [W]e can make a choice, we can choose to act, so that the one who is designated inferior or subordinate to us can have an interpretative privilege. We would then have an obligation to listen while that person, she or he, talks and gives word to personal experience, perspectives and knowledge of a particular societal practice. We can listen, and the one to whom we listen may through the attention receive a face.[4]

This dissertation is about giving people with disabilities a face, and it is an invitation to imagine the world differently. The life stories of people with disabilities have revealed to me that disability is truly everywhere in culture as both a generative concept and a fundamental human experience, and therefore I believe that disability has an important meaning-making and knowledge-producing potential. I believe that before we go into further ethical analyses of practices or ideologies that serve to uphold a eugenic logic, we need to have faces on those who are most vulnerable to become the victims of such logic.

1.2 How to Speak of Those who cannot Speak?

While it is true that the people with disabilities have been my greatest inspiration for writing this thesis, it is also true that the very same people are the reason to why I have struggled greatly with my choice of a career in a highly intellectual milieu. More than once have I thought to myself: what good can *writing about* these people do and who am I to do so? Who am I to suggest that a good life is not depending on the ability to reason? How could I suggest that communication goes far

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[3] Kafer 2011, 237.

[4] Sporre 1999, 535.

beyond words, when my own success is dependent on my ability to write? How can I propose that an unorthodox body with chronic pain can teach us something important about human existence, when I have a highly functioning and painless body myself?

Nevertheless, the stories about the people that have both touched my heart profoundly and triggered my philosophical thoughts are not familiar to all. Along the way I have heard countless times: "This is so exciting. You need to write about this. It needs to be heard!"[5] Stanley Hauerwas, whose theological thinking has been greatly inspired by people with disabilities, has many times decided to stop writing on the subject of intellectual disability.[6] Reflecting on this he says:

> People who really care about the mentally handicapped never run out of things to say, since they do not write "about" the mentally handicapped precisely because they do not view the mentally handicapped as just another "subject." They write for and, in some sense, with the mentally handicapped. To be able to write for and with the mentally handicapped requires that you know people who are mentally handicapped. By "know" I mean you must be *with* the handicapped in a way they may be able to claim you as a friend.[7]

In this quote Hauerwas captures my own ambition: my wish is to write this thesis *with* those friends of mine who have not got a voice of their own – especially not in the academic context. I have found in the philosophical, ethical and theological literature disturbing accounts of disability. Many negative positions on intellectual disability have been formed in the absence of any representation either by people with disabilities or by their families and friends and found their way into health care and policy decisions through the field of bioethics,[8] and one of the purposes in this thesis is to point at the devastating consequences of such positions. If I, who *know* people with disabilities, do not write about/with them, then who will?

There are challenges, however, in such a project, and to avoid some of the pitfalls one has to take some precautions. Eva F. Kittay (2010) has

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[5] The beautiful Norwegian words of my college Anne Marie Rösting Strand are forever etched in my mind: "Det trenger å bli hørt."

[6] Hauerwas 2004, 13.

[7] Hauerwas 2004, 13. Italics in the original.

[8] Kittay 2010, 397.

identified two of these as *epistemic responsibility*: know the subject that you are using to make a philosophical point; and *epistemic modesty*: know what you do not know.[9] While there is a risk in actually knowing your subject, either by familial bonds or through friendship, that the philosophical conclusions are in some sense blurred by the personal engagement, one can wonder what the alternative is. One example can be drawn from an article on speciesism and moral status, written by Peter Singer (2010), in which he considers the views of parents to children with intellectual disabilities on his proposal of a graduated view of the moral status of humans and nonhuman animals. He demonstrates only two examples of which one is optimistic, the parents praise the characteristics of their son with Down syndrome, and one which is negative and the parents in hindsight would have chosen not to intubate their disabled son at a point when they did have the choice to keep him alive or let him die.[10] Singer concludes:

> I don't have enough data to venture a conclusion as to which view is the more prevalent among parents of children with disabilities, and even if I did, that would not resolve the ethical question one way or another. Rather, we should consider parental choice as a factor in its own right, and one that ought to have an important role in decisions about whether to prolong life or whether to end it.[11]

In Singers writing, there is a strong presupposition that people with intellectual disabilities are non-persons because of their presumed lacking ability to reason, but for anyone who actually *knows* people with intellectual disabilities it is quite obvious that he knows little about these people. His empirical examples do no hold up.[12] And if this, as in the example above, is the best he can do to take into consideration the actual experiences of others there is a level of arrogance in his argument that is far worse, in my opinion, than being *too close* with the subject of philosophy. In his account the epistemic responsibility is truly far away. And what is equally bad in the argumentation of Singer is that

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[9] Kittay 2010, 401. In article 4 I elaborate on the concept of *epistemic modesty* in a discussion about the meanings of being created in God's image.

[10] Singer 2010, 340-341.

[11] Singer 2010, 341.

[12] Kittay 2010, 402-403.

he does not acknowledge his own ignorance. As Kittay points out: "they do not know what they do not know, nor do they appear to take any concrete steps to rectify the situation, because they presume that they have nothing to learn that is of moral significance."[13]

It is important here to note the nature of the questions posed. If one is to make moral statements concerning people with disabilities, then one has the responsibility to pay attention to the people with disabilities and the people who know them. While the question of who is entitled to write on the issue of disability has been one of the key questions within disability studies,[14] one does have to recognize that dealing with different intellectual concepts and ideas demands a certain level of cognitive ability to provide ethically and philosophically sound views. Individuals with (profound) intellectual disabilities simply lack the necessary competence to do so.[15] While such a statement might sound harsh, I believe the more important question is exactly how research on the issue of disability should be done.

Traditionally disability research has been part of the problem of discrimination and oppression, which, as Simo Vehmas (2002) suggests, has promoted the problem rather than solved it. He explains this to be due to the fact that the research has been conducted by people who have the power, that is people who are nondisabled, over those who do not, that is people with disabilities. If one is to break this oppressive tendency, one has to place oneself as a researcher to the service of disabled people.[16] Vehmas asserts:

> Researchers should thus adopt an emancipatory research paradigm which requires, for example, the adoption of a social model of disablement as the epistemological basis for research production, undertaking such a research that will be of practical benefit to the self-empowerment of disabled people, and developing control over research production to ensure full accountability to disabled people and their organisations.[17]

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[13] Kittay 2010, 405; See also Vehmas 2002, 21.

[14] See *The Academic Context.*

[15] Vehmas 2002, 21.

[16] Vehmas 2002, 21-22.

[17] Vehmas 2002, 22.

Hence, academics should join people with disabilities in their struggles to confront and overcome the oppression they face. I will return to the methodological considerations later in this chapter and in more depth reflect upon the ways in which I have tried to conduct my research in a respectful and meaningful way for people with disabilities.

Lastly, as will become apparent in this thesis, the issue of *who is disabled* is entangled with the question of how to speak of people with disabilities as well. While the emergence of the social model of disability has been crucial in reimagining disability identity itself, the sometimes rigid rejections of disability identity and/or the social and political narratives of disability risk losing track of practices and narratives that reimagine disability as an occasion for demanding equal access to inclusion and participation in society. Even though it will be argued in this thesis that the category *disabled* needs to be rethought, it needs also to be recognized that the *political* category of disability, as it functions in society today, ignores the reality that most people with disabilities who identify or are identified as disabled are excluded from life-sustaining and life-giving resources in the social and institutional spheres. People with disabilities can but do not necessarily suffer more from their disability than any other people do in general, but the conditions for human suffering are increased when people do not have the resources they need.[18]

Hence, viable moral reflection on the issue of disability can thus require one to, on the one hand, *be with* the disabled, and help the world accept the disabled on the other. I will conclude this section with a quote by Kittay in which she reflects on her dual role of a philosopher and mother of a daughter with multiple disabilities:

> My daughter, Sesha, will never walk the halls of academe, but when what happens within these halls has the potential to affect her, then I as an academic have an obligation to socialize academe to accept my daughter.[19]

As I think of the horrible destinies some of my disabled friends have experienced, I cannot keep silent. I can, and should, continue to be with

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[18] Hauerwas 2004, 19-20; Garland-Thomson 2014.

[19] Kittay 2010, 398.

them, but I am also obliged to do what I can to change such future destinies. I believe I can and should speak for those who cannot speak.

1.3 The Research Field

The issue of disability has thus far primarily been discussed within the social sciences, and the nature of the research has been mostly empirical. In the anthology *Arguing about Disability* (2009) it is pointed out that even though most of the research on disability has been conducted within a sociological framework, the social theory of disability still remains insufficient. Among philosophers, on the other hand, disability has mainly been discussed in relation to issues of abortion, euthanasia and justice. Although this thesis falls under the traditional philosophical topics as well, I have wanted to take into account the lack in many philosophical accounts of disability, namely the larger contextual factors, such as social, cultural and theological aspects. Hence, it appears as if disability studies research lacks essential dimensions of the complexity of the phenomenon of disability, while philosophers have frequently ignored the empirical realities and facts about disability, which in both cases has tended to stereotype disability in certain ways. This means that progressive and innovative disability research needs to provide both descriptive and normative dimensions of disability.[20]

Another important aspect, but sadly rather *absent* aspect, of disability research has been that of gender perspectives. Even though gender can be argued to be one of the most important dimensions influencing and shaping services and supports for people with disabilities, it is an aspect often unrecognized. Now, this is not only an issue with regards to important aspects being left out, but also about disability theory as such. Feminist theories have been grappling with

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[20] Vehmas et.al. 2009, 1. Though there are a few scholars who aim at providing philosophically and empirically sound views on disability, in the Nordic context the social science perspective is still the most influential. In a recent book, that entails some interesting and valuable contributions, the philosophical (and theological) viewpoints are missing. See *Childhood and Disability in the Nordic Countries. Being, Becoming, Belonging* (2015), edited by Rannveig Traustadóttir, Borgunn Ytterhus, Snaefrídur Thóra Egilson and Berit Berg.

similar issues as those concerning disability for decades and can therefore provide important insights, methods and perspectives to disability research, so that the wheel will not have to be invented all over again.[21] Precisely for this reason I take a feminist perspective or a feminist approach as crucial in disability research in general, but in this thesis in particular.

As for the theological study of the human condition, accounts of the changing and deteriorating body have been widely ignored. There is a prevalent perception within theological research that chronically ill and people with disabilities want to be cured at any cost. Furthermore, if one takes a look at the Bible and much writing in the Christian tradition it is sometimes hard to tell the difference between how women and people with disabilities are spoken of. Usually the body of women have been viewed as corrupt and carnally evil, and because of her eating from the tree of knowledge, the woman is usually considered responsible for sickness, deformities and disease. Throughout the Christian tradition women have thus embodied a similar unwholesomeness to people with disabilities. The feminist exploration of power relations, and analysis of gender and sexuality, and the emphasis on experience-based theology is thus highly relevant for people with disabilities. Because there are so many disabling effects of patriarchy, feminist perspectives need to be actively incorporated in the analysis of what it means to be human, and in the discourse about disability. Likewise feminist theology would be more complete if it would analyse the disabled *bodies* more, because the tendency within both secular and theological feminism is to speak of an idealized and independent body, or of a too fluent gender, which risks that not all women (people) feel welcome in the feminist struggle for equality.[22]

An issue concerning the study of biotechnologies is that theology is frequently regarded to not be as relevant as the natural sciences or applied ethics, since theology is commonly thought to have different aims and purposes. This is the case both within the discipline of theology, and outside. Within theology it is sometimes suggested that theological thinking is weakened by being engaged in science, and outside theological reflection it is sometimes regarded as second hand

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[21] Kristansen & Traustadottír 2004, 19; Garland-Thomson 2011, 13-14.

[22] Freeman 2002, 171-175; Bê 2012, 427-428; Powell 2015, 116-117.

knowledge.[23] However, I will argue that a theological account of human being provides a truth-dimension to the discourse that is relevant for ethical considerations, and that theological ethics can provide a wider moral framework than that of secular ethics. Methodologically philosophy and theology can also bring different dimensions to the discourse, as they do not rely upon falsification and verification. Especially a narrative approach allows for the cultural dimension of science to enter the discourse. It can further be argued that theology cannot afford to ignore questions arising within the natural sciences if it wants to say something relevant in the scientific age of the twenty-first century. This does not mean that theology has to be applied to particular issues, but the way theology emerges it needs to take the scientific context into consideration, just as it needs to take into consideration other cultural contexts such as feminism and disability.[24]

What can be said, still, with regard to this study of disability is that even though it is a growing field of research, it remains quite small and fractured in the Nordic context. In Finland, which is my own specific context, the first professorial chair in disability studies, received by Simo Vehmas, was established as late as in 2013, thanks to the disability organizations that have funded the post at the University of Helsinki. This implies something about that the issue of disability has not yet gained as much popularity in the Nordic context as in the Anglo-American world. While some disability research has been conducted previously as well, it has not been properly organized and therefore remained a shattered field. What remains an almost inexistent field of research in all the Nordic countries, however, is the intersection between theology, disability studies and a feminist approach,[25] and a

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[23] For an interesting account of the emergence of bioethics, the jurisdictional struggle between science and theology, and the retreat of theologians from bioethics, see *The History and Future of Bioethics. A Sociological View* (2012) by John H. Evans.

[24] Dean-Drummond 2001, xv-xvi, 208-213.

[25] To my knowledge Linda Vikdahl, Inger Marie Lid, Arne Fritzson, Susanne Rappman and Björn Nalle Öhman are the only theologians in the Nordic countries who have explicitly written in the issue of disability from a theological perspective, but none with the specific focus of this thesis. Nevertheless, Öhman who wrote his doctoral thesis *Kropp, handling och ritual. Hur förstå religion och personer med grava funktionshinder?* (2008) at my own department of Theological ethics and philosophy of religion has greatly inspired my own writing, not least through his own personal commitment to working with and living close to people with disabilities.

specific focus on *people with profound intellectual disabilities*.[26] Therefore this thesis is intended to fill some of this void. In the chapter *The Academic Context* I will more extensively present the main characteristics of the fields that I take this thesis to be a contribution to.

1.4 Purpose of the Study and Task(s)

Much of our physical, social and cultural sphere is designed in ways that propagate patterns of harmful exclusion[27] of people with disabilities, not least due to the prevalent medical reductionist view of health and human being. The purpose of this thesis is therefore firstly (1) to *identify* such patterns of exclusion and expressions of a reductionist view of human being that places disability on the margins of humanity or mentions it merely for the purpose of defining the outer boundaries of anthropological definitions. Secondly (2), the purpose is to *challenge* and *constructively* reimagine the normative ableist conceptions and representations about human being that render possible undignified responses to people with (profound intellectual) disabilities.

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[26] Simo Vehmas does currently (2014-2018) lead an innovative research project, funded by the Academy of Finland, that is concerned with understanding the lives of people with profound intellectual and multiple disabilities (PIMD) in terms of well-being and a good life. The project is a comprehensive ethnographic study by researchers who either live with, or otherwise are deeply involved with people with profound intellectual disabilities. http://www.aka.fi/en/about-us/media/press-releases/2014/Research-into-culture-and-society-receives-21-in-funding-from-the-Academy-of-Finland/

[27] In much literature the concept of exclusion is used parallel to social exclusion, which refers to the ways in which individuals are at risk of being cut off from full involvement in the wider society. An important feature of the concept of social exclusion is that it addresses the *mechanisms* of exclusion, and focuses on a broad range of factors that prevent individuals or groups from having the same opportunities that are accessible to the majority of the population. As e.g. Anthony Giddens describes social exclusion it does however not cover all the forms of exclusion that I discuss in this thesis, and therefore the concept of marginalization is sometimes used to encompass these. I here think of exclusion of certain perspectives in the ethical discourse, and of exclusion from common conceptions of human existence and experience for instance. See Giddens 2001, 323-331.

The comprehensive *task* is to *explore and analyse mainstream discourses* about human being that tend to reduce important ethical questions to abstract principles and thereby discard the complex moral intuitions, emotions, and visions that are embedded in concrete moral situations in the social, cultural, political, medical and religious sphere and harshly marginalize different forms of lives as unworthy. In order to challenge normative assumptions about human being, various aspects of normality, health and embodiment are *critically discussed, evaluated, and both conceptually and constructively renegotiated*. Although I incorporate narratives of and about people with disabilities in the analysis, it is important to bear in mind that the task at hand is *not* empirical. The character of the task is *normative* in the sense that I aim at articulating an explicitly inclusive concept of human being and human dignity.

The dissertation is divided into two parts with an additional appendix. *Part II* includes four articles that were written as independent articles on the concept of disability in relation to human being, embodiment, health and human dignity. In each article I explore the different themes and can be read separately. However, taken together they answer to the overriding purpose and task of this thesis. Two of the articles (1 and 2) have been published prior to dissertation, while the other two (3 and 4) are reviewed and accepted for publication in 2017. The articles employ different reference systems and different forms of spelling due to preferences of the publishers and editors. Since article 4 is originally written in Swedish, the appendix entails a translation into English.

In *Part I* the interdisciplinary academic context and the methodological considerations are outlined, after which I discuss *four cultural narratives* that I have identified as harmful patterns of exclusion. In these narratives I also point at a counter-narrative that is key in my constructive task. In the discussion of these narratives I have incorporated the main points of the individual articles. At the end of Part I, a final chapter with a concluding discussion of the main questions and arguments is posed, and lastly some prospects for future research are highlighted. In the following the secondary tasks of this thesis will be presented in the order that the articles occur.

Article 1 has the title “Disturbing bodies. Reimagining comforting narratives of embodiment through feminist disability studies,” in which I discuss and challenge the cultural narrative – the normalcy narrative – that makes the able-bodied, rational, male subject the normative standard in society. More precisely the task is to critically discuss how the normalcy-narrative has worked as a motif for social marginalization and oppression through e.g. selective abortion, eugenic programs and sexual violence, and I propose a counter-narrative of embodiment that can work to widen imaginations of "the normal body".

In *article 2* with the title "Theology as a liberating gatekeeper of reproductive health. Towards a relational conception of health through critical reflection on ableism" the aim is to, from a theological perspective, discuss the concept of reproductive health. The task is firstly to problematize the conventional medical understanding of health in the Western context, and secondly to widen this view by combining the insights from theological hermeneutics and so called experience-based narratives about mothers with disabilities.

In *article 3* with the title "The invisible made visible? The ethical significance of befriending people with disabilities" I discuss the practice of prenatal diagnosis in the Nordic countries in light of the question about what it means to be a human being with intellectual disabilities. The purpose is to show how the introduction and implementation of prenatal testing is fraught with expressions of a narrow and capacity-oriented view of human being, and how widening this view is crucial in the striving for an inclusive society where all people are perceived to be of equal worth. With the goal of reaching a widened understanding of human being as well as morality, I contrast the narrative of prenatal testing with one about befriending people with disabilities as manifested in the international organization of L'Arche.

Article 4 with the title "Det är gott att du finns. Människovärde, Guds avbild och människor med grava kognitiva funktionsnedsättningar" ("It is good that you exist. Human dignity, the image of God and people with profound intellectual disabilities"), is about reclaiming relevance in the principle of human dignity as based on the idea that human beings are created in God's image by approaching it as a value commitment. The task is to present a theological constructive argument based on experience-based narratives about profound intellectual disabilities, described in light of the Christian narrative of creation in order to achieve a relevant concept of the principle of human dignity on both a conceptual and a practical level.

1.5 Methodological Considerations

Thus far I have touched upon some of the problematic issues that occur in the theoretical battlefield of disability, theology, and ethics. Already the outline of the purpose and task reveals some of the methodological considerations in this thesis, since the implementation of various methods and approaches are viewed as an essential part of the research task as such – not least the incorporation of experience-based narratives in the theoretical analysis. I have, however, not collected these narratives through empirical studies, such as interviews or ethnographic studies, but they are already documented narratives of and about people with disabilities obtained from different sources. Note also that the theoretical analysis refers to specifically an *ethical analysis* since this is a dissertation in theological ethics. This means that the methodological considerations concern questions regarding the moral sphere of human life. I do not ascribe myself to any specific ethical theory or any single method. Instead I want to make room for different moral intuitions, and propose the talk of the right, the good and the meaningful, and by *descriptive interpretations* propose a view that can impact on people's thinking and actions,[28] as well as theories on disability. An important feature of this enquiry is the argument that integrating disability as a category of analysis and as a system of representation will widen, challenge and transform assumptions and values in the intersecting research fields this thesis concerns.[29] In the following chapter I will present the broader academic context and the intersecting research fields, while in the present chapter I will outline the key theoretical premises.

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[28] See Kurtén 2016, 11-37, in particular 34-36.

[29] Sporre 1999, 34-37; Garland-Thomson 2011, 15.

1.5.1 A disability hermeneutic of human being

An important question in this thesis is: what does it mean to be human? This question has been widely discussed within ethics, philosophy, theology, medicine etc. The answer to such a question will inevitably rely on what view one has on human being. In light of the purpose of this thesis an important methodological consideration is to decide on a solid theoretical platform that distances itself from a reductionist view of human being. However, as Ragnar Holte (1984) proposes, there is a relevant distinction between *methodological* reduction and *ontological* reduction, of which the latter refers to the claim of being able to describe and explain a phenomenon, such as human being, completely. In this thesis disability is never understood as an ontological category and therefore any ontological reduction must be rejected. The former on the other hand, methodological reduction, implies that one recognizes that an issue can never be completely resolved since different perspectives will lead to different outcomes. The ontological reduction of human being actualizes the important question of what one is *expecting to see* when exploring humanity. For example the language of gender, nationalism or race tends to cover other deeper assumptions about the well-being of society being dependent on uncovering the threat that broken and deviant bodies and minds pose.[30] Brian Brock writes:

> It is therefore not far-fetched that to claim that the polarity between the able and disabled humanity underlies the whole range of prejudicial attitudes that have been resisted by activists over the last hundred years, misogyny, racism, and nationalism being the most prominent views which rest on deeply held beliefs that the bodies of women, other races, or other cultures are somehow deficient, intrinsically misshapen, or lacking some basic capacities.[31]

From a disability perspective the persistent belief that some people are "broken" demands that the methodology reveals and challenges this cultural tendency to classify some people as less human. The medical and psychological sciences have established their definitions as default accounts of the category of disability and therefore the

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[30] Brock 2012, 1-2; Holte 1984, chapter 3, especially 43-46.

[31] Brock 2012, 2.

strategy is to read beneath, between, and against the ableist assumptions that underlie such anthropologies. Though there might be other hermeneutic tools that could reveal important aspects of human being, I have throughout the four articles applied what might be called a *disability hermeneutic,* which means that the analysis takes its starting point in the human experience of disability.[32]

While this thesis is formally conducted within the department of systematic theology it is however important to note that much disability theology is described as practical theology, or at least resonates with the general ethos of practical theological enquiry. Disability theology is also *contextual* to the extent that it emerges from theological reflection on the specific form of human experience that is the experience of disability. Furthermore, because disability theology entails the task of challenging the able-bodied hermeneutic that has guided theological thinking through the whole Christian tradition, and because the Church in her theology has been largely influenced by the values that spring from dominant cultures, a *hermeneutic of suspicion*[33] is guiding the enquiry of the disability hermeneutic. The purpose of applying a disability hermeneutic is thus about expanding normative accounts of human being, but also to place disability at the very centre of the anthropological, ethical and theological enquiry so that the question does not remain merely about inclusion but about the centrality of people with disability in theory and practice. On the other hand one must be careful too to not objectify people with disabilities by assigning them a categorical theological function that highlights the general limitation for human being.[34] Elizabeth L. Antus asserts:

> The task ahead for Christian theologians interested in reworking theological anthropology centered around disability will be able to listen and revise, all the while remaining comfortable with the indeterminacy and messiness of overcoming best-case anthropologies.[35]

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[32] See part I and II in Yong 2007; Swinton 2011a, 264.

[33] The phrase *hermeneutics of suspicion* is originally coined by Paul Riceour and is about attempting to decode obvious or self-evident meanings that are hidden or unflattering.

[34] Swinton 2011b, 273-277; Antus 2013, 244-246, 61.

[35] Antus 2013, 261.

Hence, the first premise for the analyses in this thesis is a disability hermeneutic, but in order to avoid the risk of objectifying people with disabilities the second methodological consideration concerns the usage of experience-based narratives or personal narrative stories.

1.5.2 Personal narrative stories and the feminist approach

In the *Background* I suggest that experience-based narratives about people with disabilities and encounters with them are used in this thesis as both a material and a methodological resource. This means that the narratives on the one hand are used as data about human being intended to capture personal and human dimensions of experience. On the other hand, the stories are used as a *narrative analysis* method, which means that the analysis occurs throughout the research process, rather than being a separate activity carried out after the data collection. It can also be pointed out that narratives are used on two separate levels. *Experience-based narratives* inform the analysis, but it is the *cultural narratives* that I argue can be reimagined through personal stories.

There are many different approaches to narrative studies, depending on the analytic strategy and/or form, of which biography, autobiography, life stories, and personal experience stories are a few examples.[36] Since people with profound intellectual disabilities is a group of particular interest in this thesis, I have had to rely upon the stories about them told by those who live close to them.[37] Venla Oikkonen (2013) suggests one fruitful method of narrative analysis to be one that captures the rocky road between structure and context, and she argues that narrative analysis in this sense differs from other methods of analysis, such as discourse analysis. Whereas discourse refers to the specific vocabularies through which we make sense of the world, narrative covers both the vocabularies in narratives and the

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[36] Drummond & Brotman 2014, 537.

[37] In *En gåtfull verklighet* (2000), Ragnar Furenhed tries to give answers to how it is possible to communicate with and about people with profound disabilities, and articulate something significant about their lives and their life quality. Through interviews with parents and care takers he shows in a most respectful way that it is possible to say something about such lives, although it involves the risk of misinterpretation.

underlying logic of those narratives.[38] Naturally, the choice of narratives are in the hands of the narrator and researcher, and therefore reveal something about the character and context of the researcher as well.[39]

Hence, the choice to incorporate narratives as a methodological resource is *firstly* (1) connected to what I have previously referred to as *epistemic responsibility*. In much moral philosophical and ethical research that dominates the field, people with disabilities are excluded from theory. While many of these theoretical approaches are useful tools in various ethical situations, I argue that the boundaries of ethical considerations must go beyond discussions of rights, utility and capacities in order to respond properly to the issue of disability and dignity. The absence of a disability perspective in ethical theory points at the need for a certain kind of academic activism. What this implies methodologically can be referred to as a "methodology of intellectual tolerance," which means the intellectual position of tolerating what previously has been regarded incoherent. This method allows conflict and contradiction, it does not avoid difficult questions and it accepts provisional answers. It seeks equality but claims difference. The method of intellectual tolerance writes new stories and recovers traditional ones, and in this endeavor the experience of disability is crucial.[40] To use experience-based narratives is thus a methodological tool for practicing a responsible ethical analysis of disability and as an expression for academic activism.

Feminist theorists have long proposed a strong critique of the mind-body dichotomy and the intellectual disparagement of the body that are both prevalent in the history of Western thought, which highlights the importance of transcending the body. Feminists have also argued that the dominant forms of Christian theology have strengthened ancient views of the body by representing the body as a major source of the desires and weaknesses that lead to sin, and overcoming the body as an essential ingredient in moral perfection. What feminist theory has not done, however, is to recognize that much of the appeal of philosophies of life recommends that some form of transcendence of

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[38] Oikkonen 2013, 297-298.

[39] See Morberg Jämterud 2016, 43.

[40] Keith & Keith 2013, chapter 6; Garland-Thomson 2011, 40-42.

the body lies in the rational desire to make one's happiness, or at least one's sense of self, independent of illness, pain, and weakness. The reason for this is proposed, by e.g. Susan Wendell, one of the first to theorize on feminism and disability, to be due to feminist writing distancing itself from the negative body.[41]

Hence, the *second* (2) argument for implementing experience-based narratives as a methodological resource springs from the growing interdisciplinary field of feminist disability studies in which a number of scholars focus particularly on disabled women's experiences. A feminist disability approach fosters complex understandings of the cultural history the body, and by analyzing the ability/disability system it goes beyond explicit disability topics such as illness, health, eugenics, reproductive technologies etc. The feminist disability approach has revealed that disabled women are often in a disadvantaged position to both disabled men and non-disabled women, and that their experiences have remained largely invisible. Neither has the perspective of disabled women been properly attended to in either the women's movement or the disability movement.[42] The feminist disability approach thus reveals both the importance of cross-breeding feminist and disability concerns and the importance of attending to stories rarely heard.

The feminist narrative analysis method is characteristically reflexive in that it requires from the researcher to engage in the material resources and in the analytic processes in a *transformative* way. In a sense one could say that the researcher joins the subjects in the stories in a process called "restorying." As Drummond & Brotman (2014) point out: "the act of "restorying" requires an acknowledgement of the participation of the researcher in the creation of the research."[43] The approach thus involves reflexivity, which can be understood as an awareness of oneself acting in the social world. This approach is somewhat similar to the approach among so called "I-Thou-philosophers," who explore human existence from the standpoint of dialogical relationships.[44] In the context of feminist-informed research

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[41] Wendell 1996, 165-166.

[42] Bê 2012, 363; Wendell 1996, 5; Garland-Thomson 2011, 16; See also chapter *Disability Studies*.

[43] Drummond & Brotman 2014, 537.

[44] Holte 1984, 73-74; Buber 1994; Illman 2004. While Martin Buber is internationally the most influential philosopher of dialogical relationships, in the Nordic (Swedish)

methodology, however, the notion of reflexivity is primarily used to address the role of the researcher within the research process and urges for a critical reflection upon the very nature of the research. The feminist approach emphasizes the collaborative, non-exploitative relationship with the subjects in the narratives greatly.[45]

The experience-based narratives of people with disabilities reveal that the truth about disability is not found primarily in theories, but in various descriptions of experience, whether found in blogs, newspapers, autobiographies, or in conversations with people with disabilities or those who live close to them.[46] None of the four articles have been written without a narrative methodology, and by combining my own personal stories with the stories told by others, the act of "restorying" has required a consistent reflexive approach. At several occasions I have had to distance myself from personal opinions and experiences, in order to stay true to the stories told. From a research-ethical point of view it has also been of importance to not use personal stories for uses they were not intended. Both article 1 and 3 include personal stories of mine, but they are used for the purpose of introducing the reader to the theme of the article, not for analytical purposes. I argue that the incorporation of these stories is vital to any research that concern ethical, philosophical or theological questions about reproductive technologies or human being itself, and in this particular thesis they are vital for the description of the greater cultural narratives of normalcy, parenthood, dignity and friendship.

1.5.3 God-talk and human experience

An important issue in theological ethics today is the question of the religious versus the secular. Tage Kurtén (2016) writes:

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context John Cullberg is a largely ignored theologian of the twentieth century who emphasized the dialogical thinking in theology. One study that has actualized Cullberg's thinking in our age is Robert Lemberg in *Jag, Du och Verkligheten* (2000).

[45] Drummond & Brotman 2014, 537.

[46] Cf. Wendell 1996, 7.

> In the search for a rational, common for all humankind, basis for ethics much of modern moral philosophy imagines the foundation for the common for all humankind to be non-religious, as secular.[47]

It has been argued that religious foundations for morality have in modernity become highly exclusive of people who do not consider themselves religious, and it has been argued that a secular point of view would be more "neutral" in moral deliberations. However, while religious foundations are indeed laden with ideological content, so too is the secular, Kurtén asserts. From the perspective of the Christian narrative of creation, the religious can be argued to be common for all humankind since God, according to this narrative, has induced the whole creation and thus all human beings with a common morality. In this line of thinking ethics and moral considerations are beyond the religious and the secular, and this enables a holistic thinking that allows us to hope for a mutual agreement between people about the good, the right and the meaningful, if we are only willing to listen to each other's viewpoints.[48]

In this thesis (especially in article 2 and 4) so called God-talk is highly relevant, and in light of Kurtén's account above, God-talk can be understood as the talk about human life and human nature. Following the feminist theological tradition I view human experience as essential to any talk about God. Despite vast suspicion against feminist theology that draws on women's experience as a basic source of content and criterion for truth, human experience can be said to be both the starting point and ending point for all hermeneutic reflection. The early feminist theologian Rosemarie Radford Ruether namely claims both Scripture and the Christian tradition to be codified by collective human experience. Experience thus includes experience of the divine, of oneself, of the community and the world in an interacting dialectic. She further proclaims that the uniqueness of feminist theology is not really about experience as such, but about its use of particularly women's experience, which has been almost entirely ignored in much theological reflection. The use of women's experience is therefore first and foremost a critical force, as Radford Ruether puts it, exposing classical

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[47] Kurtén 2016, 30. Translation my own.

[48] Kurtén 2016, 33-34.

theology and its codified traditions as based on male experience, rather than on universal human experience.[49]

To challenge previous accounts, feminist theologians have developed *a critical principle* which suggests:

> Whatever denies, diminishes, or distorts the full humanity of women is, therefore, appraised as not redemptive. Theologically speaking, whatever diminishes or denies the full humanity of women must be presumed not to reflect the divine or an authentic relation to the divine, or to reflect the authentic nature of things, or to be the message or work of an authentic redeemer or a community of redemption.[50]

While such a principle is not new within Christian theology, the uniqueness of the feminist account lies in that women claim the principle for themselves – they claim themselves to be subjects of authentic and full humanity. As the male human experience has been the norm for authentic humanity, women have been condemned for sin and marginalized in both original and redeemed humanity, and this is argued to have distorted the theological paradigm of *imago Dei* – the idea of human beings as created in the image of God. When the image of God is based on male humanity against or above women, the whole idea of *imago Dei* becomes an instrument for oppression rather than redemption and liberation.[51] Radford Ruether underlines that the critical principle of feminist theology need not only challenge the male dominion, but reach for an inclusive concept of human being that affirms the humanity of all genders, social groups and ethnicities – and although not mentioned, I would add people with various abilities as well. The critical principle of feminist theology is thus at the core of God-talk in this dissertation, and the key for keeping together God-talk and human experience is argued to be a focus on *some elements* that are crucial to human beings. By exploring important elements in human life, I believe we can make sense of God-talk.[52]

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[49] Radford Ruether 1983, 12-13; See also Beattie 2006.

[50] Radford Ruether 1983, 18-19.

[51] The issue of *imago Dei* is extensively discussed and problematized in *article 4*.

[52] Radford Ruether 1983, 18-20; Henriksen 2014, 13. Henriksen further articulates six (a-f) normative guidelines for understanding the relation between God-talk and human experience on pp. 13-14.

Therefore I suggest that the conditions for speaking about God are given along with the existential and experiential conditions of being human. To speak about God is however to speak about much more than a personal experience of the world: it is speaking about the world from a *specific* perspective that I argue can provide increased understanding and orientation in life, and it can help make sense of human experience. While a religious basis for morality can be understood as exclusive, I do, in line with Jan-Olav Henriksen (2014) maintain that it is the task of theologians to at least try to make sense of Christian beliefs to those who would not consider themselves religious.[53] In a recent article he further proposes that religion should be treated as a cultural resource that "contributes to specific practices, which primarily enable personal orientation and transformation,"[54] and he argues that such a view of religion can further serve to challenge the widespread notion in the Nordic countries that religion is primarily a question about belief, which is a position that usually addresses religion as a cognitive proposition.[55]

I will thus argue in this thesis that a theological account of human being and morality that take the critical principle of feminist theology into account can enable a vision for more inclusion, more justice, more liberation, and perhaps most importantly a more solidary world. Now, against the presentation of the disability hermeneutic it is also clear that God-talk in this thesis will be explored from the particular perspective of the human experience of disability. By bringing these two perspectives together I wish to on the one hand strengthen the constructive arguments in this thesis and highlight the common ground I have found between a feminist and a disability perspective.

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[53] Henriksen 2014, 14-17.

[54] Henriksen 2016, 37.

[55] Ibid.

2 The Academic Context

In the chapter *Methodological Considerations* I have proposed that I adopt an explicit disability perspective in the theological and ethical analysis. By doing so I have at the same time situated this thesis in a borderland between broadly three different research fields. Hence, the academic context for the thesis can be said to unfold in a triangular framework of *disability studies*, *disability theology* and *reproductive ethics*.

In the first part of this chapter I will give an outline of disability studies, in particular the approaches that I have found plausible for the specific context that I am situated in, and for the questions posed in this thesis. Since a distinct disability perspective is found too in theological research and in bioethics, particularly reproductive ethics, I will then describe some of the characteristics of *disability theology*, and *reproductive ethics* that are relevant for my aims.

2.1 Disability Studies

Disability studies is a multidisciplinary field of inquiry designed to study disability as a social, political and cultural phenomenon. The origins of disability research can be traced back to the organizations of people with disabilities who raised their voices in the late 1960´s together with other previously excluded groups, such as minority ethnic groupings, women, and lesbians and gay men. What disability activists in the US, the UK, Scandinavia and other Westerns countries wanted was a change in the way disability was understood, from an individual medical problem to a political one. The most important goal of this movement was that disability should no longer be viewed as a personal problem of the individual's body in need of cure by health and social care professionals, but as a politically and socially constructed problem with focus on the disabling barriers faced by people with impairments. From its political and early theoretical formulations in the late 1960´s and early 1970´s it is today regarded as an academic discipline in its own right with established research programs worldwide, and with several international academic journals.[56]

The development of the discipline has generally three key elements: 1) the idea that disabled people are a marginalized and disadvantaged part of the population; 2) the idea that disabled people is a minority group in society, and 3) the idea that disability should be articulated as a social rather than a medical problem. The third point is what has become termed *the social model of disability*, in which disability is described as a social discrimination rooted in institutional, personal and interpersonal processes of exclusion and oppression.[57]

Because of its close connection to people with disabilities and their political movements and organizations, and by moving between various disciplines, disability studies has today become an arena for international and multidisciplinary research. The emergence of this field has not only posed an intellectual challenge to the way disability has been understood, but has too resulted in the establishment of a whole new paradigm around disability. The ideas that have grown out of disability studies have together with disability activism impacted largely on the work of international organizations, such as the United Nations (UN) and the World Health Organization (WHO), and on the work in national governments and third sector organizations.

As disability studies has grown, new ideas and concepts have emerged, both from within the discipline and from the outside, to challenge the key tenets of the discipline. Since the 1990′s disability scholars have also begun a critique from the outside of first-wave disability studies by pointing to the need to go beyond the initially frequent economistic arguments and their correctives by critically analysing ableist structures in society and culture, as well as normalcy and the construction of disabled people as categorically “other”. What both present scholars and first-wave scholars have in common, though, is the concern for the consequences of exclusionary societies and the impact this has on people with disabilities.[58]

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[56] Vehmas 2002, 12; 2009, 2; Roulstone et al. 2012, 3; Egilsson et al. 2015.

[57] Roulstone et al. 2012, 3-4.

[58] Roulstone et al. 2012, 4; Vehmas 2009, 2; Shakespeare 2010, 266-267.

2.1.1 The Nordic relational approach to disability

Disability studies is a mix of many different theories and practices. The wide range of perspectives should not be confused with theories, but viewed as "particular knowledge positions from which to address and refute disablism."[59] Hence, the various perspectives might have similar goals, but take different routes depending on the context of the scholars. For instance, in different geographical locations very distinct responses have emerged. Concepts of dis/ability play a central role in contemporary understandings of normality, the body and intelligence, and it is therefore important to recognize the national and historical times in which new disability studies perspectives emerge. In North America the responses have traditionally been articulated from the perspective of what is known as *the minority model* or *the cultural model*. The former has sprung out of the American Black civil rights and queer politics demands for raised social status, while the latter has been keen to connect analyses of disability studies with transformative ideas of feminism, queer and critical race studies. In the UK the social model has been dominant, whereas in the Nordic countries a wholly different approach has emerged.[60]

The approach in Nordic disability research is commonly referred to as *the relational model*, which focuses on the relationship between the disabled person and the environment. The three main assumptions that the Nordic relational model rests on are: 1) disability is a person-environment mismatch that occurs because the environment is not adapted to accommodate the whole range of people; 2) disability is situational or contextual, thus specific impairments can become disabling or not due to concrete situations; and 3) disability is relative, as the cut-off point in impairment-based definitions of disability is to some extent arbitrary. Hence, disability is understood to occur as a result of complex interactions between the individual and the socio-cultural, physical, political and institutional aspects of the environment.[61]

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[59] Goodley 2011, 10.

[60] Goodley 2011, 10-16. For a more extensive account of various approaches, see Dan Goodley's *Disability Studies: An Interdisciplinary Introduction* (2011).

[61] Mallett & Runswick-Cole 2014, 20-21; Outside the Nordic context there are scholars who have developed similar approaches and who explore disability as relational.

Nordic perspectives on disability have challenged the dominance of British-centric approaches in the global North. Characteristic for Nordic disability research is the interdisciplinary approach. Since the 1950´s, the Nordic countries have expanded disability services in ways that are praised worldwide, and perhaps therefore Nordic disability scholars are less connected to the Disabled People's Movement than elsewhere. Instead, disability studies is developed within the context of welfare policies, strongly influenced by the principle of normalisation.[62] This philosophy is aimed at promoting community participation of people with disabilities. The early normalisation principles informed the beginnings of self-advocacy, which is a movement that remains a strong component of Nordic disability activism today, even though the human rights perspective of the UN Convention of the Rights of Persons with Disabilities (UNCRPD) (United Nations 2007) has come to replace the principle of normalisation as the foundation for disability policies and practice. Nevertheless, while it was more of a guiding philosophy than a service technique, normalisation can still be said to have marked a drastic departure in terms of professional and policy values with respect to, in particular, people with intellectual disabilities.[63]

The relational approach is common in all of the Nordic countries, but there is no uniform Nordic *understanding* of disability. The Nordic approach is rather a family of ideas reflecting common underlying ideologies, principles and definitions, both in scholarship and policy. One important difference between the Anglo-American models and Nordic approaches to disability springs from the difficulties involved in translating the *language* of the social model into the Nordic

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Jerome Bichenbach, who has been a consultant with the World Health Organization (WHO) on disability issues, has contributed largely to the field of disability research in writing about disability quality of life and the relationship between disability and wellbeing. Tom Shakespeare is another established disability scholar who has written about disability beyond the social model in e.g. *Disability Rights and Wrongs* (2006).

[62] The principle of normalisation refers to the idea that disabled people should be able to lead "normal" lives, and instead of various special arrangements such as institutions, they are to be integrated into society with everyone else. During the 1970´s and 1980´s a significant liquidation of care-institutions took place, after which people with disabilities to a greater extent have access to a home of their own. For a more extensive account of this process, see Bengtsson 2004, 75-77; Egilson et al. 2015.

[63] Goodley 2011, 16; Bengtsson 2004, 75-76; Mallett & Runswick-Cole 2014, 20.

languages. The distinction between "disability" and "impairment" does not translate well into Nordic languages, and this linguistic difference has played its part in explaining why a relational model of disability has driven and been driven by empirical research in the Nordic countries. The relational model has been developed in various ways and is still very much under development. Nevertheless, the complex and situated interaction between individual aspects and the environment is at the heart of the Nordic understanding of disability, and this view is widely adopted by scholars in the Nordic countries and forms the underpinnings for much disability research.[64]

An important context for disability research in the Nordic countries has been The Nordic Network on Disability Research (NNDR), established in 1997, which is an interdisciplinary network of researchers using social, historical, cultural and environmental approaches to disability research. The main activities of this network have been to organize research conferences, publish a scholarly journal,[65] and encourage research cooperation among the Nordic countries, as well as to initiate and support links with international researchers and disability activists with similar interests.[66]

One essential aspect in the activities of NNDR has been the feminist perspective, although few men adopt this perspective. Feminist research has a well-established position in the Nordic universities, and a feminist or gender analysis is frequently incorporated in much research within a variety of fields. However, despite an increasing emphasis on diversity in Nordic feminist thought, disability has not been one of the issues explored by Nordic feminists. Disability has with only a few exceptions been ignored by feminist researchers in the Nordic countries.[67] Feminist disability scholars Kristjana Kristiansen and Rannveig Traustadóttir state:

> In light of feminist claims for supporting diversity, recognition of the importance of impairment as a part of human existence continues to be ignored, overlooked or dismissed by the vast majority of Nordic

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[64] Mallett & Runswick-Cole 2014, 20-21; Egilson et al 2015.

[65] *Scandinavian Journal of Disability Research* (SJDR) in which article 1 in thesis is published.

[66] Kristiansen & Traustadóttir 2004, 19; Mallett & Runswick-Cole 2014, 20.

[67] Kristiansen & Traustadóttir 2004, 20-23; see note 69.

> feminist scholars, and disability remains invisible on the agenda in mainstream Nordic feminist research.[68]

It has been argued that disability studies has failed to adequately theorize the experience of disability from a gendered perspective and that it needs to engage more with feminist perspectives. Although the Nordic countries have focused extensively on gender equality, only a few researchers have examined the intersection of gender and disability.[69] It will be important to take gendered aspects into consideration in future research, such as disabled girls' and women's experiences of mothering, abuse and violence.[70] This thesis should be viewed as a contribution to the discipline of disability studies, and in particular as a part of the ongoing development of the Nordic relational approach. My approach is however largely inspired by the cultural model as well, most prominently evident by my extensive use of Rosemarie Garland-Thomson's work, and because of the disturbing lack of recognition of important intersections between feminist and disability perspectives I have chosen a feminist approach in this project. Particularly articles 1 and 2 are contributions to this void in Nordic feminist research.

2.2 Disability Theology

Disability theology refers to the inquiry of thinking about disability in theological terms, or to the exploration of issues relating to disability in the Christian tradition and teaching. Key issues are how disability is understood in light of the doctrines of creation and providence, the person and work of Christ, humanity (theological anthropology), the church (ecclesiology), salvation (soteriology), and of the last things (eschatology). The goal in disability theology is, however, not only to

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[68] Kristiansen & Traustadóttir 2004, 21.

[69] The intersection between disability and gender has in the Nordic countries primarily been studied by Karin Barron, Ingunn Moses, Kristjana Kristiansen and Rannveig Traustadottir. For an overview of the central contributors, see *Gender and Disability Research in the Nordic Countries* (2004) by Kristiansen, Kristjana & Rannveig Traustadóttir.

[70] Roulstone et al. 2012, 4.

understand these issues, but to undertake a thorough intellectual conversation that challenges traditional understandings of disability.[71]

There is no extensive body of literature on Christian theology and disability, which reflects the fact that people with disabilities have been, and continue to be, on the margins of society and scholarly interests. In this sense people who consider themselves Christian are no different than the rest of the society. The literature that does exist, however, comes mainly from North America and the UK, and much of this material is highly influenced by the disability-rights approach, which promotes equal opportunities and rights for people with disabilities. The aim of this research is in large to challenge and change existing practices in the church, but in theology as well, and a common assumption among these scholars is that the leading forces of the struggle for change are from outside the Christian community. Therefore, it is commonly suggested that the change must come from the outside as well. Hans S. Reinders points out, "[g]uided by the core values of liberal democracy, the disability-rights literature often presents "theology" and "church" as objects of resistance rather than agents of change."[72]

What seems to be the case among many theologians who are committed to the disability-rights approach is that they often forget to ask what a distinctively theological perspective might bring to the struggle for inclusion. Neither do they ask how the disability-rights approach relates to the basic notions and practices of the Christian tradition. The task of considering how concepts of the human and divine are formed raises important issues with regards to theological method. Hence, the methodology for conducting disability theology is of special importance.[73]

People with disabilities have long had to deal with the negative attitudes that have been shaped by biblical references to the blind, the deaf, and the lame. Although the contemporary notions of disability would be foreign to the biblical writers, it has been an important task for disability theologians to challenge traditional readings of the Bible, as well as examine the history of the church's beliefs and practices

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[71] Yong 2011, 5; Yong 2007, 21.

[72] Brock 2012, 1; Reinders 2008, 159-160.

[73] Reinders 2008, 160; See also Betcher 2007.

regarding the categories of persons today regarded as disabled – because these views are essentially present in much popular Christian imagination.[74]

Disability theologian Amos Yong (2007, 2011) has identified what he believes are the main elements in the Christian history that continues to inform the theology of disability affecting not only the Christian communities, but the wider society as well. Such theology is characterized by three basic notions: 1) that disabilities are either ordained or permitted by God for God's purposes, hence the view that there are no accidents in creation, hence the question "why me?" 2) that people with disabilities are encouraged to hope and trust in God's plan for their lives, hence the strong belief in God's desire to heal people with disabilities either in this life or in the life after this, hence the belief that suffering is God's instrument that leads to repentance or nurtures holiness; and 3) that the church and society are to meet the needs of people with disabilities, hence they are viewed as recipients of divine favor and objects of charity.[75]

These basic notions do naturally not occur in a vacuum, but are embedded in a culture that perpetuates the belief that some people are "broken" or deviant, and in which it is proclaimed that notions of freedom, self-determination, and equality are at the core of a just society, and in which normalcy is seen as a condition for citizenship. So while many disability theologians have aimed at re-reading and re-telling the Christian tradition in light of contemporary notions of disability (usually stemming from disability studies),[76] the most important task of disability theology today, I suggest, is the inquiry of *what it means to be human*. As I will argue in this thesis, recognizing people with disabilities as fully human is the basic foundation for any

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[74] Yong 2007, 20-27; Reinders 2008, 164. For an extensive account of traditional biblical readings of disability, as well as to common notions in tradition of the church, see PART I in *Theology and Down Syndrome. Reimagining Disability in Late Modernity* (2007) by Amos Yong.

[75] Yong 2007, 38-40; See also Reinders 2014; Swinton 2007.

[76] Brock 2012, 3-5; Betcher 2007, 1-24. Perhaps the most ambitious project of such an undertaking is the reader *Disability in the Christian Tradition* (2012), edited by Brian Brock and John Swinton, in which the authors pursue the constructive task of exposing and commenting on theological insights and ideas in historical scripts ranging from Aquinas to present day theologians with the hope of enriching contemporary thinking about the issue of disability.

plausible deliberations in ethics, anthropology and theology. Any other question of creation, salvation or ecclesiology, for example, relies on our answer to the question of human nature in relation to the divine.

2.2.1 Theological anthropology and disability

Theological anthropology is the study of how human being and nature is related to God. However, the conceptions of humanity in the field of theology are dependent on the methodological considerations that usually are driven by different moral concerns. Although the literature in disability theology is not extensive, Hans S. Reinders (2008) has managed to distinguish at least four different approaches to disability: "a theology of liberation," "a theology of access," "a theology of community," and "a theology of being human." Each of these approaches represents different strategies, and they all have different concerns.[77]

The theology of liberation[78] follows the paradigm of the disability-rights approach in many ways, especially through what can be referred to as the anthropology of liberal citizenship. This includes the recognition of the lived experience of people with disabilities, a critical analysis of social theory of disability, and an emancipatory perspective. The primary concern is here to identify theoretical insights that can enable Christian symbols to be transformed. For this purpose, the minority model of disability is commonly implemented as the framework for theological reflection. Because of the strong focus on self-representation, which is a key concept in the minority model, the theology of liberation is lacking in relevance with regards to people with intellectual disabilities. However, because the social-symbolic order of the able-bodied are assumed to produce the inequality and injustice toward people with disabilities, this must be viewed as a necessary tool to overcome those barriers.[79]

While the liberatory approach first and foremost appeals to people with disabilities declaring themselves a minority group within the

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[77] Reinders 2008, 160.

[78] The main character in this approach, also commonly regarded as one of the pioneers in disability theology in general, is Nancy Eiesland. Although not extensively, her work is incorporated in this thesis as well, especially in article 2 and 4.

[79] Reinders 2008, 165-167; Eiesland 1994, 19-29.

society as a whole, *the theologies of access* are more about appealing to religious communities as such. A concern in the access approach is also social justice, but the relation between subjects and objects of inclusion-exclusion is not as noticeable. Instead they are characterized by at least three other features. Firstly, the emphasis is more pastoral than systematic, and the way of reasoning is more narrative than critically analytic. Secondly, biblical exegesis is important, and in particular the stories and passages that deal with disability as a concept or people with disabilities. The key task in theologies of access is to remove the barriers created by scriptural sources or by the ways these sources have been used. Third, because access is the main concern, these theologies are strong in offering practical suggestions and ideas for how to make inclusion a reality in the church.[80]

The other two theological approaches to disability are slightly different in perspective than the former, and more in line with the perspectives brought forth in this thesis. On the one hand they focus more on intellectual disability, and on the other hand disability is not primarily understood as a social construct that needs to be theologically rethought in order to liberate people from a particular negative identity. The strength in these approaches is rather that intellectual disability is viewed as an integrated and given part of the human condition. In *the theology of community* approach, the main purpose is to question the belief that the existence of people with disabilities poses a problem to the world. Ultimately this is a critique against the liberal idea that we are the authors of our own lives, since in such a paradigm the lives of people with intellectual disabilities make little sense as fully human lives. Instead the analysis is built upon the idea that the Christian narrative shapes a society that allows us to appreciate the presence of people with disabilities and view *all* human life as a gift.[81]

In *the theology of human being* approach, the worth of human beings is the main concern. The traditional way of exploring this issue is

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[80] Reinders 2008, 181-182; Yong 2011.

[81] Reinders 2008, 192-205. The theologian that most explicitly works from this perspective is Stanley Hauerwas, and his writings are frequently incorporated in this thesis. However, Hauerwas is focusing strictly on Christian communities, which I do not take this thesis to be limited to. For an overview of the disability theology of Hauerwas, see *Critical Reflections on Stanley Hauerwas' Theology of Disability* (2004) edited by John Swinton.

through the doctrine of *imago Dei*. In the Christian context, different interpretations of the idea that human beings are created in God's image is what makes human beings significant and valuable. In the theology of human being approach, a presumption is that diversity is inherent in the human condition and if embracing human diversity does not include profound intellectual disability, this must imply that there is a boundary precisely between what we can and what we cannot embrace. In the context of theology, implying a boundary to human diversity and presenting criteria for drawing that line implies an assumption about knowing what God's will actually is. The questions that follow, then, are related to the issue of the worth of human being as such, and whether worth is grounded intrinsically or whether it comes from elsewhere through the care of others or through God.[82]

In the concluding discussion at the end of Part I, the theology of human being approach might stand out as the approach that is primarily incorporated in the analysis in this thesis. One of the tasks set out is namely to capture the human condition in such a way that profound intellectual disability can be viewed as inherent in it. For the purpose of resisting the indignity and the de-humanization of people with profound intellectual disabilities, getting to the core of the worth of human being requires an analysis that rests upon embracing the wide diversity that exists among human beings, without presenting criteria for what is fully human. Nevertheless, my account should not be limited to the theology of community approach, nor the theology of human being approach, because not only is the entire field of disability theology quite limited, but the specific Nordic context and the Nordic relational model of disability is also considered as theologically relevant. The separate articles will therefore reveal the *explorative character* of the thesis and the different thoughts and approaches that have emerged along the way.

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[82] Reinders 2008, 37-38, 207-213. The main sources for this approach are referred to especially in article 4, in which I discuss the image of God as the basis for human dignity, but appear too in article 2 and 3. The two theologians that have been mostly influential in my work are Hans S. Reinders, John Swinton, Deborah Beth Creamer, Jean Vanier and Tom Reynolds.

2.3 Reproductive Ethics and Disability

Since the international project to sequence the human genome, and due to the fast development in molecular biology, the knowledge of disabling conditions has expanded immensely. The technological revolution in the field of artificial reproduction combined with liberal abortion laws create the opportunity to decide if and under what circumstances people with disabilities come into existence. Since there is no cure or treatment for most disabilities, especially intellectual disabilities, one can argue that the ethical issues concerning reproductive technologies are essentially about the very lives of people with disabilities.[83] Are we to welcome children with disabilities in this world? If not, why is this so? What are we to make of the information that genetic testing provides? Erik Parens and Adrienne Ash assert:

> [T]he discovery of abnormal or incorrect sequences has led primarily to the development of genetic tests that can reveal whether a person, embryo or (in the usual case) a fetus carries an abnormality or "mutation" associated with disease or disability.[84]

The tests are constantly becoming more secure, profitable, and available to the general population.[85] And as the tests become more easily available, so does the attitude within both the medical and the larger society change so that prenatal testing is viewed as a natural and self-evident part of good maternity care (article 3).[86]

The bioethical and medical literature of the last decades shows evidence of misinformation and stereotypical thinking about what

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[83] Reinders 2000, 37; Parens & Asch 2000, 3.

[84] Parens & Asch 2000, 3.

[85] In article 3 the various systems of implementation in the Nordic countries will be discussed. Since the writing of the first article the development of the practice of prenatal testing has continued, and new methods and regulations have emerged. Particularly in Norway prenatal testing has been widely discussed since 2014. In The Norwegian Knowledge Centre for the Health Services research report "Non-invasive prenatal test (NIPT) for identification of trisomy 21, 18 and 13" (2016) the new methods and regulations are discussed. In the article "Non-invasive prenatal testing: a review of international implementation and challenges" (2015) the international implementation of the new non-invasive prenatal tests is further outlined.

[86] Cf. *The Parenthood Narrtive*.

disability means for individuals, families, and society. It is common among health professionals and bioethicists to believe that health status[87] is what determines the chances of having a good life for people with disabilities, largely ignoring the role of societal factors for human well- or ill-being. While such a presumption might too be related to the fear of society not being able to adapt to and accept the presence of people with disabilities, it appears legitimate to suggest that the prevention of the lives of people with disabilities is considered morally good, or at least permissible, on the grounds of relieving suffering. Since this view has had a dominant position in informing the ethical debate, the tendency to withhold the wide range of questions about the good life for human beings has led to the conclusion that genetics and improved methods for screening ultimately is an issue about reproductive choice and freedom.[88]

However, as will be problematized in this thesis, for some people the practice of prenatal testing is not so self-evidently good, and there is another story to be told. Since the early 1970's people within the disability community have become more and more critical of the dominant medical paradigm. Through difficult struggles with health professionals and the surrounding communities many discovered that their lives changed in a positive direction once they started looking at themselves as human beings with gifts and potential. And so through the struggle for recognition of potential a new paradigm developed along the medical one, namely the paradigm of normalization,[89] which enabled people with disabilities to be potential participants in social life. With this new paradigm the social services and caring institutions have changed massively in many countries, not least in the Nordic welfare states.[90]

Despite the occurrence of the normalization paradigm that indeed led to increased rights and opportunities for people with disabilities, the implications of genetic science and technology actualizes some serious ethical questions for people with disabilities. How can some be granted new rights and opportunities, when the very same kind of

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[87] In article 2 I problematize common notions of health, and argue for a different account of the concept from the perspective of theology.

[88] Parens & Asch 2000, 5-8; Reinders 2000, 1-2, 21; Glover 2006, 38-43.

[89] See also *The Normalcy Narrative*, and articles 1 and 2.

[90] Reinders 2000, 2; Saxton 2000, 150.

people are to be prevented from existing? It appears as if we are confronted with two completely different worlds here.[91] Hans S. Reinders highlights this controversy:

> The first message says: "Since you're here, we're going to care for you as best we can," but the second says, "But everyone would be better off if you were not here at all."[92]

While these two questions are rarely part of the same discussion for bioethicists, there are many within the disability community who are worried about the relation between them. Although there is no one uniform position on prenatal testing in the disability community, there is a predominant critique against prenatal testing and selective abortion among these people. This critique starts with the presupposition that life with a disability can be valuable and valued. The disability critique is thus framed by two broad claims: prenatal genetic testing followed by selective abortion is *morally problematic*, and it is driven by *misinformation*. This does not necessarily imply that prenatal testing and selective abortion are *morally wrong*, but for sure that the practice is deceptive and need some serious questioning and discussion. Before moving on to some key points with regard to these claims it is worth mentioning that basically all the major work in the disability critique of prenatal testing emerges from people who are also committed to a pro-choice, feminist agenda. Hence, the disability critique does not spring from a position that women should not have the right to exercise reproductive choice, *per se*. The problematic aspect is, as has been described in *the Parenthood Narrative,* that not only should women have the right to choose if and when, but also what kind of child they have,[93] and with the right to abortion there is a risk of women exercising this right in immoral ways.

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[91] Reinders 2000, 2-4; Parens & Asch 2000, 5-10; Swinton 2007a, 1-6.

[92] Reinders 2000, 4.

[93] Mills 2011, 72; Parens & Asch 2000, 3-4, 12; Saxton 2000, 150-153.

2.3.1 The disability critique[94]

The first claim about prenatal testing as morally problematic springs from the idea that selective abortion expresses negative or discriminatory attitudes about both disabling traits as such and about the people who carry them. This is what has come to be known as the *expressivist argument*. At the core of this argument is that the idea of identifying unborn children who would be disabled and choosing to abort them because of this identification sends a hurtful message to people who live with the very same traits.[95] As John Swinton (2007a) points out, this is a very unique form of stigmatization because it is aimed at the ontology itself of a human being – the DNA – as opposed to stigma rooted in social or psychological that in principle are changeable.[96]

Many people with disabilities experience daily how they are overlooked because of some single trait they bear and they worry that prenatal testing will repeat and reinforce the very same tendency of letting one trait stand in for the whole.[97] Because ultimately that is what prenatal testing can reveal: one single (undesirable) trait, which then is presumed to be enough for aborting a foetus that would otherwise be wanted. In any other context than disability this is by most people found to be morally problematic. For instance, sex selection is highly criticized by women's rights supporters. Hence, one of the biggest challenges to disability oppression is precisely that people with disabilities have to fight for their right to be born.[98]

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[94] For a comprehensive of various perspectives about the disability critique of prenatal diagnosis and selective abortion, see *Prenatal Testing and Disability Rights* (2000) edited by Erik Parens and Adrienne Asch. To this date this is the most comprehensive work on the theme.

[95] Mills 2011, 72; Parens & Asch 2000, 12-13.

[96] Swinton 2007a, 6-7; See also Saxton 2000, 160-162.

[97] In article 1 I discuss more extensively how people with disabilities have to balance the dual experience of constantly being both invisible and hypervisible.

[98] Mills 2011, 72-73; Parens & Asch 2000, 14; Saxton 2000, 150-151.

Both within and outside the disability community there are opposing voices towards the expressivist argument.[99] Nevertheless, as Catherine Mills (2011) points out

> [I]t is worth asking whether this is in fact the appropriate register for the broader idea that the expressivist critique seems to grasping at, this is, that the social significance of prenatal testing is inseparable from apparatuses of discrimination against people with disabilities.[100]

Discrimination is not simply a matter of individual beliefs about people with disabilities, but is too a matter of the conditions of truth production that is the very foundation for those individual beliefs (articles 1 and 3). The normalcy-narrative shows that modern Western culture is characterized by demeaning disability, which inevitably takes the form of discriminative practices in social, political and cultural life. Reasons for avoiding the birth of a disabled child involve passing negative judgements on lives characterized by similar traits, in a similar matter as decisions people make in other spheres of social life, intentionally or unintentionally affect other people's lives. Therefore we need to ask in what ways using prenatal testing may affect the social position of people with disabilities.[101]

Another argument suggesting that prenatal testing is morally problematic is referred to as the *parental attitude argument.* The critique is posed against the parental attitude that a child can be perfected by their parents,[102] and against the belief that prenatal testing can reveal what kind of child prospective parents are expecting. Essentially the critique is proposing that no parent can guarantee perfection for their

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[99] James Lindemann Nelson and Eva Feder Kittay can be mentioned as two scholars who object to the expressivist argument. For an overview over their key arguments see Parens & Asch 2000, 14-17; Mills 2011, 73-74.

[100] Mills 2011, 74.

[101] Mills 2011, 75; Reinders 2000, 66-67.

[102] Within ethics the new possibilities of genetic choice have led to the emergence of a view called *procreative perfectionism* or *procreative beneficence*, which means that prospective parents should aim to have children who presumably will have the best chance of a good human life. Commonly this argument is posed together with the argument of reproductive freedom. See e.g Glover 2006, 52-53; also Savulescu 2001, 413-426.

child, disabled or not, then it would become clearer that we should turn our attention to attitudes about *parenting* instead of the disabling traits of the children. It is suggested that good parents would, or should, care about what ever child they receive. The worry is that the attitudes towards parenthood, and ultimately towards human beings, are changing through reproductive technologies like prenatal testing, and that children are increasingly viewed as commodities instead of gifts. But again, this view is not uncontested and the most important critique is that reproductive freedom and autonomy is of superior significance to whatever problematic aspects there are in parental attitudes, and that the issue is essentially not about perfection of the child, but about the potential flourishing of the child.[103]

The third claim of the disability critique is that prenatal testing depends on misconceptions of what life is like with a child with disability. Connected to this claim is the question of whether disability can be regarded as one part of human diversity. At the core of the disability critique is among any other argument that the stories of people with disabilities are not heard in the public debate or in the ethical considerations.[104]

Advances in genetic technology appear to bring relief from many forms of impairments and illnesses, and in some cases this is most certainly true. However, these technologies also bring with them social side effects that are often hidden from the public imagination, and these effects leave people with disabilities with questions about their own value, worth and dignity. Therefore reproductive technologies, such as prenatal testing, present great challenges to our understandings of the validity and authenticity of the humanness of people labelled disabled.[105] Therefore the issue of disability should be right at the centre of the reproduction ethics debate. Therefore, the stories of people with disabilities should be heard.

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[103] Parens & Asch 2000, 17-19; Reinders 2000, 69-70; Glover 2006, 29-36: Cf *The Parenthood Narrative.*

[104] Parens & Asch 2000; Saxton 2000, Reinders 2000; 2008.

[105] Swinton 2007b, 192.

3 The Cultural Rationale of Disability

To most able-bodied people disability is a clear matter. A disabled person is someone with a dysfunctional body or mind. A disabled person is a special case. A disabled person is someone who is pitied. A disabled person is someone who able-bodied people generally feel awkward around, someone who makes it through life with the help of government funding and state services, someone few able-bodied persons would want to switch places with. Disability is simply an undesirable error in humanity.[106]

People with disabilities are usually perceived as a small minority group in society[107], which is an assumption that can easily be proven false e.g. by a report from the *World Health Organization* (2015) which shows that there is actually over a billion people, about 15% of the world's population, that have some form of disability, and another 110-190 million adults that have significant difficulties in their bodily functioning.[108] While such reports and statistical facts may cause a few to raise surprised eyebrows, they are not likely to remove the sense of unease people with disabilities commonly give rise to among people regarding themselves as normal. In fact, such reports might even *reinforce* the sense of unease. Knowing that the probability of becoming disabled is a real possibility for anyone might cause anxiety in a similar matter as the death of a close friend usually makes one think about the limitations in life.[109] Hence, there is a side to narratives about disability that touches upon how we as human beings create and understand meaning, values and make sense of ourselves.

In contemporary liberal societies people identify themselves with culturally given patterns of meaning; they inscribe their lives into these patterns and live accordingly.[110] As will become apparent in this dissertation, I believe that the common assumptions about disability are largely a result of the cultural meanings that have been ascribed to disability. More precisely: In line with many disability scholars I view

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[106] Davis 1995, 1-2.

[107] Betcher 2007, 6.

[108] http://www.who.int/mediacentre/factsheets/fs352/en/. Accessed 20.1.2016.

[109] See article 1.

[110] Reinders 2000, 197.

disability as part of a historically constructed discourse and ideology of thinking about the body. Disability is a social process that involves everyone who has a body, which then implies *every* human being. Hence, the concept of disability regulates not only the lives of people with disabled bodies, but also the lives of those who perceive themselves as *normal*.[111] Disability scholar Lennard J. Davis writes:

> [T]he very concept of normalcy by which most people (by definition) shape their existence is in fact tied inexorably to the concept of disability, or rather, the concept of disability is a function of a concept of normalcy. Normalcy and disability are part of the same system.[112]

The connection between the concept of disability and the concept of normalcy is in relation to liberal values a theme that pervades all four articles in this dissertation, and this is frequently referred to as the *normalcy narrative.* As I will argue, the normalcy narrative stands in a dominant position in Western societies and culture, especially with regards to the body, health and what is perceived as the good life. The prevalent assumption about disability as an error follows a persistent binary thinking of e.g. able/disabled, healthy/sick, strong/weak, that in a wider context is part of an ideology of control and a politics of power and fear.[113]

As one begins to untangle the threads of the normalcy narrative it becomes clear that disability, and by default normalcy, has a place in at least three broad historical traditions in Western thought and institutional practice: the religious, medical-scientific, and political traditions.[114] These three historical traditions are to some extent all relevant in this research project. Since this thesis is conducted within theology, the (mis)representation of disability in the religious (Christian) tradition is pressing. Because the practice of prenatal testing is used as a case to actualize some urgent questions about disability, the medical-scientific traditions receive much attention as well. Although this thesis is not one in political or social theory, prenatal testing has

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[111] Davis 1995, 2.

[112] Davis 1995, 2.

[113] Davis 1995, 4-10; Cf. Betcher 2007.

[114] Garland-Thomson 2012, 342.

clear political relevance. In addition my view of politics involves not only the activities of government or formal-interest groups organizations, but all aspects of institutional organization, public action, social practices and habits, and cultural meanings insofar as they are potentially subject to collective evaluation and decision making.[115] Therefore this dissertation undoubtedly speak into the political discourse as well.

A running thread in this thesis is my critique against a reductionist view of human being, which I claim create harmful patterns of exclusion of people with disabilities in much of our physical, social and cultural spheres. In my research the strong cultural rationale of disability occurs in various relevant cultural narratives that largely shape our sense of selves, how we perceive others, and what we regard as a good life. These are identified as "the normalcy narrative," "the parenthood narrative," "the dignity narrative," and "the friendship narrative." In what follows I will discuss these narratives in a broader historical, cultural, ethical and theological context on the one hand, and as they appear in the articles on the other. Hence, this is where the essential discoveries and content of the articles are discussed.

3.1 The Normalcy Narrative

Although the contemporary understanding of disability as a concept and categorization is fairly new in a historical perspective, and usually described from a Western perspective, there are clear traces of people with disabilities being oppressed throughout history. Through the *Middle Ages* disabled people were subjects of superstition, persecution and rejection. They were associated with evil and witchcraft, and common targets of amusement and ridicule. And though one could perhaps assume otherwise, in large, the story follows the same patterns in the history of Christianity. One explanation for this is found in economy; people with disabilities have throughout history depended on charity, the help of others and later on government funding. Another explanation is that the common understanding of impairment and disability are affected by a deeply rooted fear in culture of the

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[115] See e.g. Young 1990, 9; Leftwich 2004, 13-14.

unknown, the anomalous, and the abnormal.[116] Whether the explanation is found in economy or in a cultural fear, one thing is clear: something radical happened with the *expressions* of oppression against people with disabilities in the eighteenth and nineteenth centuries. This means that if we are to understand why people with disabilities are denied human dignity, if we are to *think differently* about disability, one of the first steps is to understand the connection between a physical impairment and the political, social and multi-dimensional environment that places that impairment in a specific arena of meanings and significations.[117]

3.1.1 A world of norms

We live in a world of norms.[118] We consider what the average person does, thinks, earns, or consumes. We rank intelligence, cholesterol levels, weight, height, sex drive, and bodily dimensions along some conceptual line from subnormal to above-average. Children are ranked in school and tested to determine where they fit into a normal curve of learning and intelligence. There is probably no area of contemporary life in which some idea of a norm or average is not calculated, and therefore it can be stated that in one sense or another, each of us usually strives to be normal. In article 1 I discuss how the body is highly idealized and objectified in Western societies, and that there is a strong social pressure to shape, regulate, and normalize one's body in order to fit the normative standard. I highlight examples of how we struggle to meet the standards of normality in our attempts to control, mould and maintain our bodies, and in so doing I point at how the body in various ways is an important showground for social control, not least in the area of health and appearance. Now, to understand the disabled body, I argue one must turn the attention to the concept of the norm and the normal body.[119]

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[116] Barnes 1997, 20-21; Brock 2012, 1-2.

[117] Barnes 1997, 23; Davis 1995, 3.

[118] I realize that the concept of the *norm* can imply an ethical standard as well, which is not what I intend here. The concept of the norm is here understood in relation to the concept of normal.

[119] Cf. Davis 1995, 23-24.

Because much writing on disability has focused on the disabled person as the object of study, just as the study of race has focused on the person of colour, it appears as a legitimate question to ask why the focus should be on normalcy instead of disability? The suggestion, and at the same time a key argument in this dissertation, is that the "problem" is not the *person* with disabilities, but the way normalcy is constructed to create the problem of the disabled person. For instance, in article 1 and 2 I discuss how societal constraints with regards to womanhood and motherhood have had devastating consequences especially for women with disabilities who are commonly devalued as both women and mothers – simply because of their unorthodox bodies and minds. Hence, not only has the female body been medicalized during modernity, but both women and people with disabilities have been viewed as medically abnormal, which means that sickness is usually gendered feminine. Not only does this affect how other people view or value women and people with disabilities, but also how they end up devaluing themselves. Furthermore, the fact that people with unorthodox bodies are devalued in society is argued to lead to an immense fear of not living up to the standards of embodiment.

Accordingly, the concept of the norm is argued to partly be a social category, rather than a "natural one". In order to understand this mechanism better, I suggest one go back in time when disability was regarded somewhat differently from today. As already mentioned, a radical change was about to happen in Europe when the ideological legitimacy for an intensified oppression of people with disabilities and the social process of disabling occurred along with the industrialization, and practices and discourses that can be linked to late eighteenth- and nineteenth-century notions of nationality, race, gender, criminality, and sexual orientation.[120] In this particular time-period a few things stand out as the very foundation for the normalcy narrative.

A first remark concerns terminology and the entrance of the words "norm" and "normal" into the European languages, which happened as late as in the nineteenth century. The word "normal" and the concept of the norm as "the common type of standard, regular, usual" entered the English language around 1840, and was most likely preceded by the concept of the "ideal", a word that can be dated back to the seventeenth

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[120] Davis 1995, 24; Barnes 1997, 25; Betcher 2007; Giddens 2001, 35-45.

century. While the word "ideal" initially had nothing to do with attainable bodily standards, the emergence of normalcy transformed its meaning into the notion of a positive deviation from the norm.[121]

To find some explanations for the conceptualization of the norm one can then turn to the discipline of statistics, which in the early modern period began as a use of data for "promotion of the sound, well-informed state policy". Statistics was later applied to the human body when Bisset Hawkins defined medical statistics in 1829 as the application of numbers to illustrate the natural history of health and disease. Despite its initial purpose, in France, statistics were mainly used in the area of public health in the early nineteenth century.[122]

3.1.2 The effects of industrialisation

A second aspect is the changing nature of work during industrialization, which I discuss particularly in article 2 in relation to the growing medical profession in the Nordic welfare state context. High speed factory work was not well suited for "slow" people, and as the professional power of health professionals increased the negative effects of the industrialization became evident. Policies of segregating people with disabilities into various institutional settings, and the exclusion of people with disabilities from social and economic life were increasingly justified throughout the eighteenth and nineteenth centuries. Another connection between the emerging notions of the

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[121] Davis 1995, 24: Yong 2007, 86. However, the concept of the ideal was not then what it is today, even though the idea of an ideal body did exist long before this, usually exemplified in the tradition of the nude Venuses. A noticeable fact about the ideal body, then, is that it was viewed as a divine body and not at all attainable by humans. The ideal body could per definition not exist in this world, and therefore there was no demand for human beings to live up to the ideal. By contrast, the grotesque as a visual form was inversely related to the concept of the ideal and its corollary that all bodies are in some sense disabled. In that mode, the grotesque is a signifier of the people, of common life. The use of the grotesque had a life-affirming, transgressive quality in its inversion of the political hierarchy. However, the grotesque was not the equivalent to the disabled, since, it is impossible to think of people with disabilities now being used as architectural decorations as the grotesque were on the facades of cathedrals throughout Europe. The grotesque permeated culture and signified the norm, whereas the disabled body, a later concept, was formulated as by definition excluded from culture, society, the norm. Davis 1995, 24-25.

[122] Davis 1995, 26.

normal body and the industry can further be shown in the fact that the leading members of the first British statistical societies were industrialists or had close ties to industry. The normal as an imperative then became a generalized notion in the mid 1800's when the way astronomers averaged errors in space was applied to human features, and the concept of the average man (*l'homme moyen)* was formulated by the French statistician Adolphe Quetelet. His central idea was that this figurative human was the average of human attributes in a given country, both with regards to a physical average and a moral average construct.[123]

It is crucial to highlight the social implications of this idea, because in formulating the average of man a justification of moderation and middle-class ideology could emerge. Now, Quetelet developed an analogy between the notion of the average man and the term "juste milieu." Davis suggests that Quetelet's thinking and usage of this term was connected to ideology of Louis Philippe's July monarchy, and influenced by the philosopher Victor Cousin who yielded a concept that combined bourgeois hegemony with the constitutional monarchy and who celebrated moderation and middleness. Over time the average man became the model for the middle way of life, and along the way the average became a kind of ideal. Again, it is important to note that this is not just a mere fact or a neutral development, but highly problematic since the average man applied to both *moral* qualities and to the body.[124] This can, for instance, be connected to the fact that women with disabilities who wanted to reproduce were viewed as a biological, social and moral danger to society. This view was upheld by the women's movement during the twentieth century as well, which I problematize in article 2, and which I argue is a prevalent view still today.

Hence, in contrast to the concept of the ideal, the concept of the norm inflicts the majority of the population with the demand to be part of the norm. When this line of thinking became rooted, the symbol of the norm was figuratively imagined as a bell-shaped curve. This curve, the graph of an exponential function, was known as the astronomer's "error-law", "normal distribution", or simply as "the bell curve". The

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[123] Davis 1995, 25-26; Barnes 1997, 23-25; Giddens 2001.

[124] Davis 1995, 26-27.

majority of the population was thus to fall under the arch of the bell curve. As a consequence of this view of the norm, the concept of deviations or extremes emerged. Hence, in a society where the concept of the norm is effective, people with disabilities will naturally be thought of deviants.[125]

3.1.3 The emergence of the eugenic logic

The use of statistics began an important movement, and an interesting fact about the early statisticians is that many of them were eugenicists. Hence, there is an actual connection between the statistical measure of human beings and aiming at improving humans toward the positive extreme. The concrete result of the idea if the norm, then, is that the population is divided into standard and nonstandard subpopulations. And even though the initial aim of statistics was not to create a norm for human beings, both statistics and eugenics bring the concept of the norm into society. By constructing the normal body, the disabled body is by effect created (article 1).[126]

What the eugenic logic did to the bell curve is that it changed form and went from idealizing the middle, to a ranking system that put the "positive" extreme on top. Francis Galton, the most known pioneering eugenicist, who was also the cousin of Charles Darwin, sought to redefine the concept of the "ideal" in relation to the general population through natural selection. He pursued this firstly through creating the idea of a deviant body by applying the idea of norm to the human body itself. Secondly, the normal variation of the body was measured against a stricter template in order to guide what a normal body should be. Thirdly, the revision of the "normal curve of distribution" was changed into a ranked order, and all of these formed a new ideal for human being. In contrast to the classical ideal, [127] which implied no imperative of actually *being* an ideal human, the statistical ideal strictly imposed what people should be like. Hence, the model of the ranked order was pushed by the imperative of the norm, and supplemented by notions

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[125] Davis 1995, 29.

[126] Davis 1995, 30; Grue 2010, 34.

[127] See note 120.

of progress, human perfectibility, and the elimination of deviance, and the cultural vision of what the human body should be was created.[128]

An important aspect of this development is that the eugenic logic was commonly seen as the ultimate hope for social improvement. Once people began to embrace the idea that there are norms and ranks in human *physiology*, the idea that we could increase the intelligence of human beings, or decrease birth defects, no longer appeared unrealistic. Ideas of this sort were widely influential, and the huge impact of eugenic thinking continued well into the twentieth century in Europe[129] as well as in North-America, to such extent that politically and academically influential people could openly suggest that unless birth control was encouraged, it would be the same as to say that the increase of cripples was encouraged by the state.[130] As I demonstrate in article 2, this kind of rhetoric was common among early twentieth century feminists as well.

One serious consequence of the will to optimize the population was that the eugenicists tended to group together all allegedly "undesirable" traits. It was not only people with disabilities that were viewed as outcasts, but they were grouped together with criminals, the poor, and people with mental illnesses, and all these traits were viewed as genetic hereditary flaws. In this way "national fitness" played well into the metaphor of the body. However strange this might sound, the eugenic notion that individual variations would lead to a broken nation was indeed a powerful one. Together with the industrial mentality that aimed at creating "universal workers" with uniform characteristics, the parallel between the uniform worker and a uniform labour product was

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[128] Davis 1995, 33-35; Buchanan et al. 2000, 30-31.

[129] In Sweden the eugenic programs are a good example of how the eugenic thinking was connected to various political viewpoints. Until the 1930's, the movement was centered in the Institute for Race Biology in Uppsala, with a director who later was a confessed Nazi. The work of the institute was focused on physical anthropology, and more precisely on supposed Nordic traits. Though there was some critique posed against the racist aims of the institute when the Socialist Democratic scientists took control over the institute, the eugenic thoughts gained new ground when the planners of the Swedish welfare state were eager for the government to use natural and social science for the purposes of governing the "quality" and quantity of the population. There was simply no room for the deviant and deficient in the modernization of society. See Buchanan et al. 2000, 35; Broberg & Tydén 2005, 15-57.

[130] Davis 1995, 35; Buchanan et al. 2000, 31-32.

drawn.[131] A similar conclusion was drawn too with regards to how mothers were seen as responsible for the "quality" of their offspring.

The traces of the normalcy-narrative can be seen in a wide range of practices in history. In America they had contests of fitter families based on their eugenic family histories, in various places in the world (not least in the Nordic countries) the eugenic sterilization practices are well documented, the very foundation of the Nazi ideology is built upon the eugenic logic, Freud's widespread theories on normal sexuality and sexual development was made possible by the idea of the normal, and today we see its relevance still in the practice of corrective surgeries or biomedical technologies. The normalcy narrative shows up again and again. For this reason a disability consciousness – a disability perspective – can alter the way we see not just people with disabilities, but *all* people.[132] Lennard states:

> [T]he very term that permeates our contemporary life – the normal – is a configuration that arose in a particular historical moment. It is part of a notion of progress, of industrialization, and of ideological consolidation of the power of the bourgeoisie. The implications of the hegemony of normalcy are profound and extend into the very heart of cultural production.[133]

As I have shown, the concept of normalcy does not only touch upon the will to control one's own body, but very much upon the reproduction of new bodies as well.

3.1.4 Discussion

The aim of discussing the normalcy narrative as the dominant cultural narrative of embodiment in this thesis is to show that disability and the disabled body are part of a greater historically constructed discourse and ideology of the body, and that a critical discussion and a reimagination of such narratives is necessary. In article 1 the theoretical basis for the critical discussion and analysis is found primarily among feminist disability scholars who on the one hand address a wide range

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[131] Davis 1995, 35-36; Broberg & Tydén 2005, 60-61; Grue 2010, 34.

[132] Davis 1995, 37-49; Grue 2010, 34-35; Hall 2008, chapter 3 in particular.

[133] Davis 1995, 49.

of feminist issues, and on the other hand make the body, bodily variety, and normalization central to analyses of all forms of oppression.

However, in article 2 I demonstrate that Western feminism has a clear connection to the eugenic ideology in the twentieth century, and that the strong emphasis in contemporary feminism on rights, individual freedom and autonomy, as well as the fear of traditional female roles, weakness, and dependency prove to be highly exclusive of particularly women with disabilities. I argue that feminism in the struggles for women's rights have focused too much on challenging gendered hierarchies and thereby failed to challenge the very structure of oppression, especially with regard to reproductive health issues. In the attempt to challenge contemporary notions of (reproductive) health, normality, womanhood and motherhood I incorporate experiences of disabled mothers in the analysis. I argue that in the context of the reproductive health discourse, the stories of women with disabilities can serve to challenge both feminisms relationship to power, and exemplify in what ways feminism has failed to include all women in theory. This perspective challenges the troping of disability in able-bodied culture as deviance, helplessness, and speaks openly about a form of embodiment often excluded from the conversation in both disability and feminist discourse.

In order to challenge the normative standards of embodiment I highlight three main aspects of embodiment in article 1: *body standards*, *corporeal difference*, and *vulnerable subjects*, all in light of the concept of disability. I argue that the normalcy narrative is governed by a normalcy structure in society and culture, and that the normalcy narrative not only shapes the sense of who we are, but restricts the life of people with deviating bodies and limits the imaginations of those who think of themselves as normal. Prenatal testing and selective abortion is used as an example of the normalcy narrative at play as it is argued to be an important source of expressed notions about what it means to be human and to have a human body. As I have touched upon in this chapter, one problematic issue with normative standards of embodiment is the connection between bodies and people: not only are deviating *bodies* devalued, but the very *people* in those bodies. Because current perceptions of embodiment devalue some people, this makes having a disability a clear disadvantage in society, which in turn leads to an immense fear of not living up to the standards.

In the counter-narrative about embodiment that I propose in this thesis I integrate a feminist perspective and life-stories about people with disabilities on the one hand, and a theological account of health on the other. I argue that narratives of corporeal difference serve the purpose of challenging the political agenda of feminism that claims women to be strong, independent, and controlled, and I maintain that these narratives are crucial in the project of rethinking relations between bodies and selves, subjects and societies. The feminist notion of otherness is discussed since many feminist thinkers maintain that otherness is limited by culture but also that it can be said to limit the culture, and I argue that dominant narratives of otherness hinders counter-narratives to be equally important.

As for the life-stories I also underline that it is of importance *how* they are told. Embodiment does in general have multiple cultural meanings, and especially people with disabilities are simultaneously viewed as invisible and hyper-visible. Therefore, it is argued that we need to avoid telling stories that send a message that serves to legitimize objectification, humiliation and disrespect. Feminist disability theory presses us to ask what kind of knowledge is produced though bodies radically different from the standard. Acknowledging stories about lived, experienced, different embodiments is a first step away from the notion of one standard body and towards an understanding of the link between difference and sameness.

The concept of vulnerability has in recent years been increasingly included in political, philosophical, theological, and critical theories of human being and human embodiment. However, in the normalcy narrative vulnerability and dependency are aspects of human embodiment that we are still taught to ignore. These are symbols of a life not worth living, and therefore people with disabilities who expose vulnerability in society cause great anxiety. On the other hand, disability can also point at the fact that life can be lived with pain. I claim that disability narratives can teach consciousness a certain kind of freedom from the sufferings and limitations of the body, and one step towards accepting pain as a natural part of life is argued to be to deprive it of meaning. Furthermore, I argue that the body is not only vulnerable to life itself, but that it is excessive to its own boundaries in what I call "intercorporeal vulnerability". Based on the thoughts of Margrit Shildrick I explain this intercorporeal vulnerability as to compromise on one's own control by touching another person, a touch that affects both parties. The touch that I intend transcends both the material and the mental as it can involve physical contact as well as simply "being in touch". In this way our being in the world is understood as becoming. The body is changing through every touch. To exemplify what this means I draw on life-stories about people with disabilities who describe their bodily experiences through being in touch with other bodies.

In this thesis I maintain that a theological account of human being and health can bring another depth to the counter-narrative I am proposing. Not only do I argue to include people with disabilities on a conceptual level, but that it is sufficient in changing social practices as well. Aware of the fact that religious values connected to sexuality and reproduction have controlled women's sexuality and made motherhood a "compulsory trap", I point out that a reason for this might be due to the fact that a lot of research and teaching on religion and sex has been constructed from an exclusively male perspective. For this reason, I do find it important to involve a feminist approach in the theological reflection. In articulating a conception of human (well-) being that claims inter-personal relations as both determinant and necessary the arguments are inspired by the Barthian tradition of relational human being, as well as a disability hermeneutics. I argue that when personhood itself is defined in terms of relationality, the health of an individual will always be dependent on the inter-connectedness with other human beings, which is a huge leap away from a self-centred and individualistic understanding of well-being. Just as I in article 1 argue that pain is never the whole of human experience, so do I in article 2 argue that bodily health is not to be equated with the whole of human well-being. Therefore any theological talk of "wholeness" should be treated with caution, since the dichotomy between wholeness and brokenness too often has worked to stigmatize people with broken bodies and minds. I argue that the concept of relationality offers theology a way to re-imagine disability, healing and liberation for people with disabilities in a very concrete way, and that liberation has little to do with a body refashioned and remade.

To be a body is to be unstable. To be a body is to be in constant change. To change is to become. In order to start the journey of becoming, one has to invite vulnerability along. One way of inviting vulnerability along is to get in touch, physically or mentally, with bodies in distress; bodies that seemingly are more vulnerable to life; bodies that have been forced to accept painful sensations; bodies that the normalcy narrative has taught us to ignore. Experience-based narratives of embodiment expand our comforting truths and reveal that there are no given certainties. I believe that re-conceptualizing the meanings of embodiment ultimately is what can lead us to reimagining our comforting narratives of embodiment and hence create a more compassionate and just society.

As mentioned, one example of the possible consequences of the normalcy narrative that I emphasize in this thesis is prenatal diagnosis and selective abortion. Being part of routine maternity care in the Nordic countries, prenatal diagnosis is a major source of expressed notions about what it means to be human and to have a human body. These notions affect most pregnant women (and their partners) in important decisions regarding reproduction, and due to the strong focus on finding foetuses with genetic and chromosomal deviations, people with disabilities are clearly affected by the practice and the values expressed – in one way or another. As reproductive technologies are often discussed in the light of reproductive autonomy – the right to make decisions about one's reproduction – I believe it is important to point out that the will to control our own bodies inevitably will affect our moral judgements with regard to prospective children. In what follows I will therefore turn to the second cultural narrative I have found to create harmful patterns of exclusion of people with disabilities, namely *the parenthood narrative*.

3.2 The Parenthood Narrative

In the world of norms, reproduction is a pressing subject. As I will argue in this thesis, particularly in articles 2 and 3, having children is a vital part of people's lives in today's society and for the sense of having a flourishing life. Hence, values of parenthood and family life constitute desires and commitments for many, and therefore questions concerning reproduction do reveal underlying assumptions about normality, sexuality, social relationships, health and embodiment. These values are, like many other personal values, strongly connected to various institutions in society and to the surrounding culture. Along with the industrialization of Europe, the nuclear family became a necessary "ideal" form for family life. The emergence of liberal ideology with "free choice" at its core has worked to support the thought of smaller family units, and despite the vast variety of family forms that today exist, the imperative of free choice has in relation to family life made the nuclear family the *normal* family form.[134] The right to reproductive freedom and autonomy has an important place in Western political thought, and is thus embedded in any democratic culture. Within this culture the genetic and reproductive technologies are understood as a route towards increased choice regarding reproduction. Genetic knowledge offers potential parents the choice of preventing the conception or birth of affected individuals through genetic counselling, prenatal diagnosis, or progressively sophisticated methods such as preimplantation genetic diagnosis – all practices that are regarded to increase the range of choices, and enhancing reproductive freedom.[135]

It appears to be a common belief that more choices are equal to more freedom. But on the flipside of the "freedom-coin" is the medical, social and political government over people's lives – including their

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[134] Important to note is however that various family patterns that now are imaginable would not have been so only a few generations back. In general people are less likely to marry today than they once were, and those who do get married do so at a later stage in life. Nevertheless, Anthony Giddens point out that more and more people chose to live together and to cohabit. This means that while the institutions of family and marriage still exist and are important, their character has radically changed. One important change is in the expectations of relationships today. In late modernity relationship is something active, and increasingly dependent on collaboration and communication. Nevertheless, traditional family patterns are still the norm and therefore atypical family forms are met with great resistance. See Giddens 2001, 172-173, 178.

[135] Westerlund 2009, 42-43; Lindfelt 2009, 68; Scully et al. 2006, 22; See also Beattie 2014. In the article "Barn, föräldrablivande och meningsmönster" ("Children, conceiving parenthood and patterns of meaning") Mikael Lindfelt discusses the seemingly narrow conditions for what constitutes "the normal family", and highlights not only that the imaginations of the normal family do not entail impairments, but neither does it usually encompass adoptive children or foster children, see Lindfelt 2009, 69; Also Westerlund 2012.

reproduction. The welfare system, health care professionals, and economic systems, for instance, all regulate and inform people's choices and freedom. This is sometimes referred to as "institutionalized individualism" in modern Western societies. At the centre of this idea is that people are to take control over their lives, not least in the reproductive sphere. Whereas trying to control reproduction has indeed been a human activity from far back in history, the conditions for family planning have in the liberal society changed immensely with the emergence of reproductive technologies, as well as with the increased equality between the sexes and the emancipation of people with different sexual orientations. Not only can children be aspired to fit into the normalcy paradigm through various pedagogical practices and therapies, but with reproductive technologies, such as prenatal testing, it is possible to control what kind of children that are being born in the first place.[136]

As I demonstrate in article 3, a consequence of this new technology available is that many women experience an immense pressure to control their reproduction not only in terms of reproducing at the right time in life, but also to have the right kind of child. Before the existence of reproductive technologies, the foetus was assumed to be "normal" until otherwise was proven. That is, abnormality was not looked for but was confirmed usually as late as at the birth. In this sense reproductive technologies have contributed to a slight attitudinal turn with regards to pregnancy itself as the aim of health professionals today is to find out – to control – whether the foetus is "normal" or not. This aim is put into effect by the implementation of prenatal tests. Although there is no formal demand on participating in the prenatal tests that are offered, it is frequently said to be the responsible thing to do both with regards to the society and with regards to the life of the prospective parents, since it is imagined that a society with as few people with disabilities as possible is a sign of advancement and improvement. The pressure to live up to the norm and the normal family is conveyed not least through the shame of being different.[137]

The social pressure to plan and control one's pregnancy is an indication that the normality that surrounds parenthood and

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[136] Hall 2008, 3-4; Gordon 2007, 357; Westerlund 2009, 44-46, 52.

[137] Westerlund 2009, 52-53; Ginsburg & Rapp 2010, 242,

pregnancy is enforced by experts. Despite the growing tendency to be sceptical about authoritative knowledge, I argue that we still live in a time with great trust to experts in general, and the medicalization of pregnancy and parenthood implies that expectations are formed by a system of expertise that is based on authoritative knowledge. In the articles 2 and 3 I argue that the dominance of health professionals as gatekeepers of (reproductive) health, and the system of institutionalized individualism result in diffuse and problematic ideas of parenthood. Surrounded by experts and technological possibilities, prospective parents are overwhelmed with choices and challenges already before a child exists.[138] It seems as if the very concept of parenthood is at stake in this debate. Hence, what is it that constitutes parenthood in contemporary liberal Western societies? The possibility to control what kind of children we have actualizes the question of whether disabled children can/should be part of the family dream. And the issue of sharing one's life with a disabled child is therefore related to the broader issue of *meaning* in contemporary society.[139]

Though there are various ways of understanding meaning, or meaningfulness, in this thesis I am interested in the question of what constitutes life as meaningful. Hence what characterizes a life as meaningful, or what is characterized as hindering life from being meaningful?[140] In life, I suggest, some events bear meaning-making potential, and some do not. Parenthood is here taken to bear such potential, while in liberal culture having a disabled child appears to interrupt the meaning-making potential of parenthood, and by effect hinders *life* from being perceived as meaningful. In order to capture if and in what ways patterns of parenthood are oppressive for people with disabilities, it is a crucial task to explore how we can understand the meaning-making potential of parenthood in a reproductive landscape characterized foremost by control, information and the normalcy narrative?

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[138] Westerlund 2009, 53-54.

[139] Reinders 2000.

[140] Cf. Wolf 2016, 256.

3.2.1 Meaning-making patterns of parenthood

The physical event of delivering a child is usually described as an existential experience like no other, but it is the *becoming of a parent* that holds a key position in many conceptions of a flourishing life as a whole.[141] Mikael Lindfelt writes:

> To have a child is to be linked to the continuous chain of life, to become a part of a social context that in a special way connects history with future, and that can be seen as an expression for an embodied hope.[142]

It would be unreasonable to suggest that family planning and reproduction is entirely in the hands of experts, because the issue is of course much more complex than that. Though it can be debated on why it so, which is also a disputed issue in this thesis, it is a fact that the birth of a child with an impairment is highly stigmatizing in Western countries. As already touched upon in the previous chapter, and as I argue throughout this dissertation: to most people, disability and people with disabilities are spontaneously disturbing and unsettling, and because having a child with an impairment is frequently attributed either to inadequate health practices or to the bad genes of the parents, this is no incomprehensible fact.[143]

In article 3 I discuss the common belief that an impairment of a child would place an economic and/or emotional burden on its parents – a burden that is not part of the family dream, not part of the choice to become a parent. The statistics show that many choose to have an abortion in case of foetal abnormality, usually Down syndrome, which on the one hand reflects the attitude among prospective parents, and the attitude among legislators on the other, as even late-term abortions are permitted in most Western countries *only* in the case of foetal abnormality. And even though there are many stories by parents to children with disabilities that challenge this belief, it is sometimes true that a child with an impairment does cause a lot of hardship on the

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[141] Lindfelt 2009, 68-70.

[142] Lindfelt 2009, 70. Translation my own.

[143] Vehmas 2002, 93-94.

family.[144] In a recently published book about families with "special children"[145] there are several testimonies of what such hardships might look like. One mother says:

> The list of medications that Leo needed during a day admitted to half a page, and some of the medications were to be given four or five times a day. Different problems occurred all the time. At some point the kidneys stopped working and the epileptic seizures escalated over time.[146]

Another mother describes the difficulty in balancing her own well-being with that of her disabled son, and with that of the siblings:

> I never had any time to myself, and the times I would do something I had to make the other siblings take care of Oscar and help out in the home. That led to me having a bad conscience, but I had no other choice. I was still lucky not to become depressed as I got help in time.[147]

In this thesis such testimonies reveal the hardships of everyday life with a disabled family member. But equally important, I suggest, are the stories of parents to disabled children that reveal the hardships of not fitting into a normal meaning-making family pattern,[148] because many of them entail the claim that the biggest difficulty is trying to explain what their life is like and fit into the surrounding community with "normal" families. Hence, the normative context for family life is informed by experiences based on normal family patterns, which makes atypical family forms appear problematic. The risk is, then, that the atypical families are discriminated against, which in turn will lead to an immense pressure to live up to the ideal.[149]

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[144] Vehmas 2002, 94, 100; Solberg 2009, 193.

[145] "Special children" is an expression that I generally find problematic, but I chose to use here because that is how the parents in the book refer to their children.

[146] Henriksdotter 2016, 56. Translation my own.

[147] Henriksdotter 2016, 47. Translation my own.

[148] See articles 2 and 3; Katarina Westerlund discusses the normal meaning-making family patterns more extensively in Westerlund 2012; 2002, 138-145.

[149] Lindfelt 2009, 73; Solberg 2009, 187-189. This is also true with regards to gay and lesbian family forms, although such partnerships usually witness a greater equality and commitment than many hetero-sexual relationships. See Giddens 2001, 192-193.

In contemporary Western societies it is commonly believed that meaning is in our own making, that meaning is to be produced by our own deliberate activity. Hans S. Reinders describes this modern view of the quest for meaning as characterized by activist notions of "giving", "constructing", "inventing", which indicate their displacement in previous notions such as "receiving", "finding", and "discovering". Because people with disabilities, especially intellectual disabilities, are not regarded to be able to act in a meaningful way – i.e. their life has no meaning – it is difficult to comprehend how sharing one's life with them would bear any meaning-making potential.[150]

However, how can people have any idea of what it means to share one's life with a person with disability and care for them, unless one is actually engaged in doing so?[151] As one of the tasks in this thesis is to make visible different narratives and atypical experiences, also referred to as counter-narratives,[152] I will in what follows briefly reflect upon some characteristics of "atypical meaning-making family patterns" to map out a context in which the narratives of families with disabled family members can be perceived as meaningful.

3.2.2 Foundations for atypical meaning-making family patterns

The way we narrate our experiences will define the meaning we ascribe to certain events, such as becoming parents. The problematic issue regarding atypical families is that narratives about parenthood that fit into the normalcy-narrative are the ones receiving most attention in the public sphere, and thereby atypical narratives are privatized and placed outside the meaning-making potential of parenthood.[153] However, not all people find meaning in the exact same way, because there are various culturally given patterns of meanings, and therefore the perspective of the meaning-making of otherness has to be

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[150] Reinders 2000, 193-194.

[151] Reinders 2000, 194.

[152] See *Methodological considerations*.

[153] Note that this is also true in the philosophical debate. E.g. Peter Singer discards experience-based narratives of family life in the discourse about the moral significance of personhood with the argument that they would not resolve the ethical question anyways. Singer 2010, 341.

recognized in the task of de-stabilizing normative conceptions of parenthood.[154]

There are indeed various existential meanings that can be found in the different patterns of parenthood,[155] and the one most relevant for understanding the mechanisms of the meaning-making potential of atypical parenthood is that about community and *belonging*, which implies that the sense of meaning springs from inter-personal relationships. This can be understood in either a historical sense; for example that human beings stand in relationship to earlier communities and/or extended family; or in the sense that the primary meaning-making potential lies in present inter-personal relationships.[156] In this view the need to give and receive care and love are the point of destination for the meaning-making of parenthood.[157]

Placing the very destination for meaning-making in community and belonging is naturally a stark contrast to the liberal values of autonomous choice and freedom, and in the ethical debate about reproductive issues this has been argued to be problematic.[158] If meaning springs from belonging, then individual freedom is at risk naturally, since belonging as a concept presupposes that one in one way or another surrenders to the greater whole. But belonging as the primary meaning-making aspect implies that various communities, fellowships or kinships are expressed in a *positive* heteronomy in which it is possible to live in an intimate relationship with another human being *without* losing oneself. Within feminist bioethics an alternative understanding of autonomy has been developed that is in line with the concept of belonging namely the concept of *autokoenony*,[159] which implies that individuals are subjects who are closely connected with other subjects and therefore in need of them, but nevertheless not

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[154] Reinders 2000, 197; Lindfelt 2009, 74-75, 82-83.

[155] For a more extensive account of these, see Lindfelt 2009, 88-109.

[156] In article 2 I discuss further the concepts of *inter-corporeal vulnerability* as a fundamental essence of human being and what it means to be an embodied being.

[157] Lindfelt 2009, 93; See also "Meaningfulness: A Third Dimension of the Good Life" (2016) by Susan Wolf for an account of meaningfulness as involving both a subjective and an objective condition linked together in proper ways.

[158] Singer 2010, 341.

[159] First proposed by Sarah Lucia Hoagland (1988), and further interpreted and developed into bioethics by Susan Sherwin and Rosemarie Tong.

entirely dependent on them.[160] Belonging can be found either in the two-ness of a couple, or in the greater community of friends, families, or other kinds of smaller communities, and thus constitute "a family of choice", which is a term sometimes applied to gay communities as well.[161] Since families with a disabled child, out of both necessity and choice, have a big family of choice with e.g. assistants, care takers, and therapists, it is clear that the sense of meaning evolves in the wider network of people – the chosen family.[162]

A disabled child does not only represent a disease, but a radical difference, and therefore difference or otherness challenges one of the key purposes of reproduction: the meaning-making potential of parenthood and family life. But the birth of child with an impairment can from the perspective of belonging be viewed as an occasion for meaning-making, precisely because the caretaking of a disabled child demands different and expanded resources than what can be provided by most parents without additional support. The stories of "an unexpected journey to an unknown world" offer a hope in the face of crisis when a disabled child is born, or when an anomalous foetus is discovered through prenatal testing. Studies have shown that there is a direct relationship between the initial efforts of families to reimagine their narratives and the more public actions they undertake to help rescript narratives of inclusion at a broader cultural level. This, however, means that the possibility for imagining a different and perhaps unanticipated social landscape in the sphere of parenthood requires that the stories of atypical parenthood are actually heard. The revelations of the limits of kinship-based caretaking and the need for broader social recognition and resources for people with disabilities offer a foundation for the meaning-making of atypical parenthood, a model for familial inclusion and for social inclusion as well. [163]

From this perspective, then, the link between autonomous choice and freedom is indeed questionable. As has been argued by some, parenthood is essentially unconditional. Berge Solberg states: "You do not become a more autonomous or freer parent by being given the

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[160] Nyrövaara 2011, 94-95; Tong 1999, 41.

[161] Lindfelt 2009, 96-97; Vanier 1998, 39-47, 52; Giddens 2001, 192.

[162] Henriksdotter 2016.

[163] Solberg 2009, 193-194; Ginsburg & Rapp 2010, 239-246; Reinders 2000, 17-18.

choice of throwing away your children when you become tired of them. Again, it is the opposite: good parenthood is good precisely because it is unconditional."[164] What is at stake with regards to parenthood in Western liberal societies is ultimately a question of culture, and as I will argue in this thesis, the benefits of giving and receiving love and care are primarily consequential as opposed to conditional.[165]

3.2.3 God as the source of meaning

In this *theological* thesis the talk of God naturally occurs, and the Christian narrative is implemented in the analyses since I strongly believe that a theological perspective can bring another depth to the ethical, political and cultural discourse about disability and dignity. The arguments put forward in the articles (especially article 2 and 4) are in large based on the concept of relationality, or otherwise expressed inter-personal relationships, and therefore I would like to note here that in this particular context the meaning-making potential is, or at least *can be*, strongly anchored in God.

God can be viewed as a separate category outside the community, but also as an aspect embedded in the inter-personal relationships, as part of the concept of relationality itself. If God is viewed separately from the concept of relationality, it means that God has a prioritized position in relation to other relationships. This means that the meaning-making potential *relies* upon the relationship to the divine. From another perspective God can be viewed as an essential dimension of the interpersonal relationships, and the reactive presence of God is thus visible in the continuous act of creation.[166] This means that the divinely rooted meaning found in interpersonal relationships is dependent on various understandings and descriptions of who God is. One central aspect of the being of God, I propose, is that human beings cannot negotiate the conditions of their existence. It means that God's presence is in everyday life, in the needs, desires and the commitments of people. Lindfelt asserts: "The one who recognizes life as the life of God, reacts in a different way than one who, for example, merely sees the

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[164] Solberg 2009, 197: This argument is further developed in article 2 and 3.

[165] Cf. Reinders 2000.

[166] Lindfelt 2009, 102-103.

symmetrical, mutual love as any other human relationship as a mutual contract of utility."[167]

3.2.4 Discussion

There are many aspects of the normalcy-narrative that can be problematized, and I have here tried to point at a few aspects with regard to *parenthood* that are an important basis for the arguments that I pose in this thesis. I believe it is important to lay out that the question of when, why and how reproductive technologies, such as prenatal testing, are implemented in health care is not merely a question of ethics, but very much about people's lives and what makes people's lives *meaningful*. The conception of meaning as a matter of choice and decision has implications for how people think about the meaning of having children. If we regard children as a means to our own fulfillment, the presence of a disabled child is going to cause a great deal of stress and frustration, not only because the presence of such a child reduces our capacity to control our lives but also because we are committed to a conception of a meaningful life that is inevitably going to make our disabled child look like a failure. One of things that atypical parenthood reveal is that meaning can be defined in terms different from those in liberal culture.[168] The narrative of parenthood is not just about what choices are right or wrong, but about understanding the complexity of the various narratives that shape and inform our lives.

In this thesis parenthood is discussed in relation to disability from two viewpoints: firstly from the perspective of *who can reproduce* and become a parent, and secondly from the perspective of *what kind of children* fit into meaning-making patterns of parenthood. In the articles I show that both of these perspectives reveal harmful patterns of exclusion of people with disabilities, since neither disabled children nor disabled mothers are viewed as desirable in normal family patterns.

In article 2 I incorporate narratives of women with disabilities and their experiences of womanhood, sexuality, reproduction, and oppression, and I argue that through their stories a wider conception of what it means to be a woman and mother, what it means to be human

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[167] Lindfelt 2009, 104. Translation my own.

[168] Reinders 2000, 204.

emerges. I argue that these stories, having received little attention in the discourse about reproduction, expose how many women with disabilities long for motherhood, but are perceived to lack the skill and maturity to pursue it. An important aspect of these stories is that these women are excluded from normative conceptions of both womanhood and motherhood, and since being married and having children have long constituted "normal womanhood," these roles are frequently presumed tickets to "normalcy." Hence, the normalcy structure is here too proven to be highly influential for both gender roles and on the meaning-making potential of parenthood. The stories of women with disabilities make it clear that the traditional female roles, that are strongly rejected by particular versions of liberal feminism, are desirable to many women with disabilities, and I find it pressing to note that there is a huge difference between being discouraged from having children because of a feminist commitment to abortion rights, and because of an ableist discrimination against disabled persons in general.

In order to challenge the normative ableist conception of parenthood I strongly argue that the stories of atypical parenthood need to be recognized in reproductive ethics, but in the wider culture as well. In article 2 I argue that while such experiences can be said to previously have been quantitatively marginal, the prolonged life span of people with disabilities and the increased number of people with disabilities marrying and having children has grown significantly, and thus made relevant their experiences of sexuality and reproduction. It needs to be recognized that motherhood is an *actual reality* in the lives of disabled women's (people's) lives, and that it is an important occasion for meaning-making in their lives. Their presumed lack in ability to pursue parenthood needs further to be problematized, because while it is true that the sense of guilt is oftentimes intensified for mothers with disabilities, due to the disability making a lot of things difficult to undertake, it is however important to raise the question of what the most important part of being a mother actually is? Is it for instance playing around with your child, completing tasks fast, or is it emotional caring, commitment and closeness? Belonging as the primary source for meaning-making points at the relevance of the latter since others can in fact help out with activities, and the home can be built to make everyday life easier. Many of the accounts of mothers with disabilities bear witness of how difficulties can turn into an asset in life. In this sense atypical family forms image a beautiful account of parenthood that can liberate “normal” parents from the increased critical gaze by health professionals who are eager to give medical advice and guidance on reproduction and parenting.

In this dissertation I want to challenge the underlying ableist ideology in normative parenthood narratives by suggesting that the experience of disability makes visible that all mothering is shared and relational. Particularly in the context of the health discourse, the stories of women with disabilities can serve to challenge both feminisms relationship to power, and exemplify in what ways feminism has failed to include all women in theory. I argue that the disability perspective on womanhood and motherhood can challenge the troping of disability in able-bodied culture as deviance, helplessness, and speaks openly about a form of embodiment often excluded from the conversation in both disability and feminist discourse. The other valuable purpose for including these stories is as a starting point for the theological reflection. Besides the significance of inviting the voices of marginalized people, narrative studies with mothers with disabilities can offer valuable insights into the embodied, interactional aspects of health and disability.

Hence, the first perspective on parenthood narratives has to do with the parenting role and the question of who is to reproduce. The second perspective on parenthood is discussed in relation to question of what kind of children fit into meaning-making patterns of parenthood. The practice of prenatal testing is discussed most explicitly in article 3, and in the first part of the article I show that the practice is informed by narrow conceptions of what it means to be human. Perspectives are brought to light that have been made invisible in the introduction and implementation of prenatal diagnosis in the Nordic countries as well as in the ethical debate. For instance, the one value that can be pointed out as the superior ethical principle in favour of implementing prenatal testing is autonomous choice in relation to utility and prevention of harm. The question is then what autonomy actually means when the majority of pregnant women feel pressured to participate in the tests? And what does autonomy mean when the genetic counselling concerning prenatal diagnosis often is concentrated on mere medical facts? I suggest that the principle of autonomy is an expression of a narrow conception of life (with limited capabilities), and a narrow conception of morality as well.

As I have pointed out already in this chapter, and as I argue in the article, many parents with disabled children tell stories about quite happy children and quite happy lives, and therefore I propose that the discussion about prenatal diagnosis should be widened from ideas of normality to incorporate happiness, love, friendship and relationship as important aspects of parenthood, and human life in general. I do believe there are valid arguments for and against implementing prenatal screening in maternity care, but I claim there is a moral cost involved as abortion is the main "treatment" available for eliminating disability. I suggest that parenthood ought to be about making possible happy lives for our children, as opposed to merely making possible having medically "normal" children. I problematize whether autonomy, utility, prevention and rights are the best guiding tools for prospective parents and pregnant women to make good decisions regarding their pregnancy and future children? I strongly dispute whether autonomy as a superior value will bring people to a qualitative life, and whether the pursuit to be medically normal leads to happiness?

3.3 The Dignity Narrative

Thus far I have outlined some key features of the cultural narratives of normalcy and parenthood, and I have pointed at some of the challenges that disability poses to understandings of human being and parenthood. One of the biggest challenges that disability presents us with appears to be the question of the *quality of life*. In a society characterized by a eugenic logic conceptions of quality of life do not encompass deviance and weakness. Therefore, disability occurs as a threat to individual autonomy, freedom and the right to live our lives as we please – aspects of what is frequently taken to be criteria for good quality of life. Disability threatens many of those aspects we value about our lives, things that make our lives worth living, things that we believe to bring meaning to our lives. But the disability concept calls into question yet another threat, which is about the very basis for common notions about the quality of life, namely the value of human dignity and the worth of human beings. In a world of norms, the human dignity of people with deviant bodies and minds is threatened, because the dominant cultural narrative of human dignity is based on notions of humanity that clearly does not include people with disabilities, especially people with intellectual disabilities.

The traces of the normalcy narrative and the eugenic logic are thus at the very core of the human dignity discourse. In articles 3 and 4 I discuss the concept of human dignity in a more constructive manner, and I defend on the one hand the moral significance of *people* with disabilities, and an inclusive concept of human *dignity* on the other hand. In what follows I will outline some of the main aspects that I take to be part of what I call *the dignity narrative* – the assumed notion that all human beings are of equal worth and therefore deserve equal respect – and I will highlight the problematic features with regard to people with disabilities and common social responses to them, in particular in the biomedical context.

3.3.1 A historical concept of human dignity

Contemporary understandings of dignity differ largely from historical notions of the concept, and since the historical development of dignity is highly ambiguous depending on the context it is challenging to outline a straightforward background to the dignity narrative. Nevertheless, I will outline some of the key elements in its development. The concept of human dignity has a long history tracing back to the antiquity, the Greek and Roman stoics, the Aristotelian tradition, a number of ancient literary works, and in various religions and cultures. Historically human dignity has served to answer the theoretical question of the place of human beings in the world, and it has implied that human beings are distinguished from the rest of the nature. The term dignity was initially used to express the special position of human beings, while the moral relevance of human dignity – as we tend to think of morality today – occurred later. One could describe this twofold conception as "initial dignity" and "realized dignity".[169] The actual word dignity comes from the Latin words *dignitas* (worth) and *dignus* (worthy). In ancient Greece and Rome dignity was frequently attached to traits such as physical skills and intellectual wisdom, but more importantly so, dignity referred to the elevated position of the ruling aristocratic class in society. People could thus differ in dignity, depending on the degree they were able to manifest these traits, and in this sense dignity could increase or decrease. In practice, human dignity was only applied to very few people, and was therefore not a universal concept at all. In fact, the Roman *dignitas* is a complex notion that goes beyond worthiness. One could be of high rank in society without being regarded as worthy. The essential aspect was that dignity expressed a relation, a position of being over someone else.[170]

The Stoics, Pico della Mirandola and Immanuel Kant are examples of influential theorists of the historical concept of human dignity, that are still of relevance in the current debate. The stoic philosopher Cicero makes a sharp distinction between animals and humans, and it is precisely the rational nature of human being that bestows her with dignity. In the stoic tradition dignity is further connected to a moral virtue: one should live one's life worthy of dignity. The Renaissance philosopher Pico della Mirandola claimed that human beings were created by God to be free to form their own nature, and this is, according to him, the very basis for her dignity.[171]

Without discarding the importance of these earlier philosophies on dignity, the first major theorist of dignity in the Western tradition is generally regarded to be Immanuel Kant (1724-1804). While he is a famous historical thinker, he is considered part of the contemporary thinking about human dignity as well. Influenced by the stoics' idea of the dignity of persons as based on humanity's rational perspective, Kant viewed dignity as an ethical principle inferring that human beings should not solely be treated as mere means, but as ends in

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[169] Also referred to as intrinsic dignity and attributed dignity. See discussion in Morberg Jämterud 2016, 52-56.

[170] Mitchell et al. 2007, 60; Misztal 2012, 102; Sensen 2011, 75-76; Morberg Jämterud 2016, 52-53.

[171] Morberg Jämterud 2016, 71-75.

themselves.[172] The Kantian concept of dignity was closely connected with the human capacity to act morally, which is tied to the faculties of reason and freedom. The Categorical Imperative implied that one has a duty towards oneself not to violate the privilege one has over other creatures. Hence, the principle of human dignity was considered to be a moral principle intended to guide people in their deliberation on moral problems. Yet in a Kantian perspective, dignity is an absolute inner value all human beings possess precisely in their inherent capacity to think and act rationally. While the Kantian view is generally perceived as the secular foundation of human dignity, the capacity to reason has within the Christian tradition also been strongly identified with being in God's image, *Imago Dei*, especially in the early formative centuries of the Christian church.[173]

Thomas Aquinas is one of the most influential theological thinkers regarding dignity. In Aquinas view of man, he points at a hierarchy of the powers of the soul. The highest level of the soul is for him the intellective soul, and this is what ultimately defines human nature and personhood. Although never discussing the concept of dignity explicitly, Aquinas appears to justify human dignity as relying upon personhood. He also relates the idea of *Imago Dei* to the intellectual nature of man. Some theologians have pointed out that Aquinas view on the intellect is that reason is the ultimate good and true, which is God, and hence nothing that can be elevated.[174]

Though the capacity to reason has indeed been defined in various ways from "knowledge" to "self-consciousness" to "self-

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[172] Kant 1987, 73-74. Note that Kant is frequently misinterpreted on this point. Usually the principle is articulated as "human beings should never be treated as mere means but as ends in themselves". But the point is that it is inevitable to be treated as a mean at some point since human beings are always placed within a variety of communities, structures and power-relations. Therefore, the ethical principle of dignity needs to be understood in light of the Categorical Imperative. See Lindfelt 2012, 50.

[173] Sensen 2011, 80-82; Grenholm 2003, 46-47; Misztal 2012, 102; Collste 2002, 14, 145. Examples of influential theologians who have connected reason with the image of God are e.g. Irenaeus, Clement of Alexandria, Origen, Athanasius, Augustine, Cyril of Alexandria and Aquinas. An example of the highly problematic and devastating implications of such a view is how Martin Luther even advocated drowning "feebleminded" children because of their limited mental capacities that he viewed as a corruption of the soul. See Kilner 2015, 178-188.

[174] Morberg Jämterud 2016, 62-64; Collste 2002, 49.

transcendence" to "free will" and "choice," reason has nevertheless been viewed as the primary criteria of being in God's image, or, in other words, as a criterion for human dignity. And considering people who have been perceived as human beings with "little reason" – e.g. young children, women, elderly people, or people with intellectual disabilities – the connection between human dignity and reason can be shown to have been very harmful.[175] Considering the devastating consequences such a view has had particularly on people with intellectual disabilities, an important task in article 4 is to challenge this view from the perspective of profound intellectual disability and show that dignity is instead dependent on other variables in life, such as relationship and the goodness in being God's creature.

3.3.2 A contemporary concept of human dignity

As has been suggested above, contemporary concepts of dignity differ largely from the historical notions, not least in the present emphasis on rights. Up until World War II human dignity was unknown in national law texts, but the violation of the dignity of groups of individuals in the Nazi regime, Hiroshima, Rwanda and other atrocities have called for a new respect for the dignity of vulnerable subjects and a new way of thinking ethics. The contemporary notion has therefore come to refer to an inherent value of human beings, and it has strong moral implications.[176] The United Nations Universal Declaration of Human Rights says that: "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world".[177] Hence, human beings are said to possess an objective and inherent property called "dignity" and this enables people to make rights claims on others. As the declaration is articulated human dignity is ascribed to *every* human being, irrespective of e.g. gender, race, religion, sexuality, or ability. *Human rights law* is also clear about that human rights do not rely upon any individual or group characteristics, but simply being human is

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[175] Collste 2002, 13-19; Kilner 2015, 19-30, 178-189; Mitchell et.al. 2007, 63-65.

[176] Sensen 2011, 72.

[177] The UN Universal Declaration of Human Rights. http://www.un.org/en/universal-declaration-human-rights/ Accessed 27.1.2016.

criterion enough. This is usually called "the standard view" of human dignity. The universality claim is in the human rights system linked to the idea of equality between individuals, which means that no differences between human beings, or the conditions they live in, can legitimize discrimination of any kind. However, as many scholars have pointed out, the actual *meaning* of the inherent dignity of human beings is extremely vague.[178]

Nevertheless, by comparing the historical concept with the contemporary one aspect can be clarified, namely that the historical concept of dignity appears to be more about perfecting *oneself*, whereas the contemporary account is about how to treat *others*. The distinguishing feature of the contemporary concept is that dignity is a value higher than other values. In some views it has a strong ontological focus, and is said to be detected by intuition or as a direct recognition. Hence, it is difficult to pinpoint exactly what human dignity is, but in this view it can at least be said to occur in the recognition of the other. In all views, usually inspired by Kant, the *absolute* value of human beings is argued for. What seems to be clear though is that human dignity has to do with the worth of the human person and that it is inherent in all human beings.[179]

3.3.3 Are all human beings valuable?

Thus far it can be concluded that the dignity narrative informs us that human beings are somehow special and valuable in a morally relevant way. Various expressions for human dignity are "sanctity of life," "dignity of life," "intrinsic value of life," "respect for life," and they all point at the uniqueness of human life. But what does the "realized dignity" actually imply? When utilitarian philosophers, such as Helga

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[178] Slotte 2005, 28-30; Macklin 2003; See also Sensen 2011, 72-74; Egonsson 1999, 9. The human rights discourse is manifold and human rights can be described and interpreted in various ways, e.g. as both a moral and a judicial concept. The focus here is to capture how human rights and human dignity as concepts have been and are used simultaneously, in order to point out the ambiguity that surrounds specifically the concept of human dignity. For a discussion and overview of human rights, see Slotte 2005; 2015.

[179] Sensen 2011, 72-75, 84-85.

Kuhse and Peter Singer[180] or Torbjörn Tännsjö,[181] argue that the abortion of a disabled foetus can be defended on the grounds that its death will lead to the birth of another child with better prospects of a happy life, whose dignity is then realized? The argument is that a disabled infant is not yet a person, and therefore its dignity cannot be violated, but then the *personhood* and *humanness* of the child is at stake instead. Against the backdrop of the historical conception of dignity and within a culture marked by "hypercognition" – the elevation of the capacity to reason – the temptation to define the nature of personhood and humanness according to such criteria is of course convenient. But the events of the Second World War points at the evident tension that exists between the concept of human dignity and normative ethical perspectives, such as utilitarianism, that usually affirm dignity only to the degree it is found beneficial to do so. The idea of beneficence can potentially justify doing anything to certain individuals, no matter how destructive, unless some standard of human dignity prevents that from happening.[182]

According to the utilitarian account, individuals whose existence imposes a burden on the whole must be eliminated to improve the well-being of the whole. This means that while most people believe that all human beings have a higher moral status than non-human animals, there is a prevailing disagreement on the moral worth of human beings that appear to place a burden on others, such as people with profound intellectual disabilities. The general abortion debate actualizes the question of whether a foetus ought at all to be viewed as a subject with dignity or rights, but the case of prenatal testing and selective abortion opens up yet another door relevant for the questions posed in this thesis, namely the question whether *certain* foetuses possess less dignity or fewer rights due to some "undesirable" traits. The case of selective abortion highlights an important distinction in the discussion about human dignity because recognizing that a human foetus has *dignity* does not necessarily require one to recognize the foetus as a being with *rights*. As human dignity is commonly connected to human rights, this distinction calls for reflecting upon the relation between

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[180] See e.g. *Should the Baby Live?* by Helga Kuhse & Peter Singer (1985).

[181] See e.g. *Välja barn* (1991) or *Göra barn* (1991) by Torbjörn Tännsjö.

[182] Collste 2002, 24; Swinton 2007a, 186-187; 2012, 110; Mitchell et al. 2007, 61.

rights and dignity, but also the deeper meaning of dignity as such, and dignity as a moral value. The practice of selective abortion, as assisted suicide too, reveal that there are some dangerous ideas in motion about people's perfection and about the absence of needs that have led to a society inaccessible to those who are vulnerable.[183] The most pressing ethical questions that reproductive technologies give rise to are then: what human lives are desirable? What is the place of disability in a morally worthy life?

3.3.4 Challenges in bioethics

The ethical principle of human dignity is frequently referenced to and prioritized in the biomedical sphere. This is seen in e.g. *The Universal Declaration on Bioethics and Human Rights* (2005).[184] In the 20th century the progress of scientific inventions was rapid, and the discoveries after the World War II, such as the discovery of the DNA-code, raised new ethical concerns. Bioethics as a discipline emerged in a time with many scientific inventions, but also in a time of radical social change.[185]

The principle of human dignity has been vastly challenged, mainly from a utilitarian perspective.[186] A common critique against utilitarian approaches to genetic testing and reproductive technologies, for instance, is that they have similarities with the eugenic ideology in the 18th and 19th centuries. Although the "old" eugenics was about who could reproduce, and the "new" eugenics is about what kind of children that will be born, the presumed weak links in society are to be removed in both cases. Yet only in contemporary society the eugenic practices are presented as exercises of freedom and choice.[187]

In bioethics there are usually two approaches to the basis for human dignity.[188] Either it is rooted in specific characteristics, or in the simple

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[183] Mitchell et al. 2007, 61; Vehmas & Curtis 2016; Swinton 2007a, 185-186; Lid 2015, 1562-1563.

[184] UNESCO: *The Universal Declaration on Bioethics and Human Rights*, 2005.

[185] Morberg Jämterud 2016, 16.

[186] Morberg Jämterud 2016, 81.

[187] Soulen 2006, 110; Cf. *The Parenthood Narrative*.

[188] For an overview of various accounts, see e.g the anthology *Human Dignity and Bioethics* (2009) edited by Edmund D. Pellegrino, Adam Schulman, and Thomas W. Merrill.

fact of being human. The former response maintains that human beings have dignity because of one or more characteristics that are typically human. Usually this view is grounded on the ability to reason, but can also be found in other capabilities such as bodily integrity or in the ability to sense and imagine things.[189] In any case this common view is problematic having people with intellectual disabilities in mind, since they are denied human dignity simply because of their presumed non-personhood. It seems as if the worldview that guides the goals of Western liberal democracies, not least in the medical context, has shaped the priorities so that personhood tends to have a quite specific focus. To be a person means that one has to be able to live one's life autonomously and develop one's potential. Hence, personhood is considered necessary for being important and valuable.[190]

The latter response maintains that human dignity is granted to all human beings that are bound together by belonging to the species *Homo sapiens*. But what difference does it make to be part of the human family? For many evolutionary biologists being human is merely a product of the natural forces, and for many humanists it is nothing more than a factual designator that indicates the value of people without any need for transcendence, and some ethicists claim that there is no moral significance in belonging to the human species at all. Hence, here it comes down to the question of *value* as such, and therefore it is of importance to note that the value of human life has various meanings. For example, economic value can be given to human lives as an estimation of losses and gains of human lives, or of the present value of the expected future earnings for the rest of a person's life. One can also talk about the value of human lives from the perspective of contribution to the welfare of others, or of the instrumental value human beings have to other people. Another is to talk about the value that is attached to the content and fulfillment of life, which usually is referred to as an intrinsically good life.[191]

Common to these different ways of valuing life is that the values are different for different people. The economic value is different for

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[189] See for example Amartya Sen's *Development as Freedom* (1999) or Martha Nussbaum's *Sex and Social Justice* (1999) or *Creating capabilities: the human development approach* (2011).

[190] Swinton 2012, 111, 130; Mitchell et al. 2007, 63-69; Reinders 2006, 122.

[191] Mitchell et al. 2007, 63-69; Swinton 2012, 160; Collste 2002, 25-26.

women and men, the instrumental value depends on a person's contributions and social relations. It appears as if only those lives that can meet the conditions of subjectivity and autonomy are properly called human. And if humanity is questioned in a moral sense, then so too is the dignity of that individual. This means that even if the principle of human dignity presumes an *equal* value, even if human dignity is defined by the way human beings should be *viewed* and *treated*, people who are not recognized as human beings can never possess dignity.[192]

The extensive usage of the concept of dignity creates a chaotic landscape of meanings and therefore it is often difficult to grasp exactly *how* human dignity is, or ought to be, used in various situations. This becomes particularly evident in the bioethical discourse, and which is why bioethicists frequently reject the concept.[193] Debates about selective abortion or assisted suicide, for instance, reveal that the principle of human dignity is claimed as the basis both for implementing and prohibiting practices alike. The confusion that occurs especially in the arena for medicine is however not surprising if one takes a few steps back to look at the broader re-estimation of values regarding medicine, health and the human body that has occurred in Western societies. Traditionally the practice of medicine was placed within a larger moral framework that located bodily health, illness and suffering within a broader conception of morally worthy life, which means that the dignity of human being was previously not equated with bodily excellence. Gradually the practice of medicine has been re-contextualized in an alternative moral vision in which health and physical excellence is at the core. And when mainstream bioethics becomes a product of this moral vision, the whole idea about what it means to respect the life of another becomes blurry.[194]

3.3.5 Discussion

As I have demonstrated in this chapter, the concept of human dignity is a chaotic landscape of views, values and meanings. Therefore, there

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[192] Mitchell et al. 2007, 60-61, 82; Collste 2002, 19, 25-28; Reinders 2006, 122.

[193] See e.g. Macklin 2003.

[194] Soulen 2006, 104-105; Mitchell et.al. 2007, 58, 63; Lid 2015, 1562.

is, on the one hand, an urgent need to capture human dignity on a conceptual level, and reflect upon its practical implications on the other. This constructive task is one that I have undertaken particularly in article 4.

There, one aim is to constructively articulate an inclusive concept of human dignity in light of the experience of profound intellectual disability. To place the starting point in the experience of what is frequently regarded the outermost boundary of human being is motivated by the purpose of constructing a concept of human dignity that can include *all* human beings. Despite the evident significance of human dignity as a core principle in society, some critics argue that the concept has lost some of its relevance due to it being frequently used synonymously with human rights, and due to the concept being increasingly decontextualized from its theological roots. Additionally, it can be argued that the values of individualism, autonomy, rationality and subjectivity that have come to pervade the Western societies have weakened human dignity as a morally relevant concept. While I in this chapter have outlined some of the key aspects of the broader dignity narrative that comprehends both philosophical and theological perspectives, the purpose in article 4 is to recontextualize human dignity in theology.

Because the ability to reason has been one of the main criteria in the theological tradition for possessing dignity, the starting point for the theological constructive argument put forward is found in experience-based narratives of profound intellectual disabilities, described in light of the Christian narrative of creation. To avoid the risk of articulating a sole abstract concept of human dignity, a second step is to discuss the practical implications of the concept. In order to do so a *disability hermeneutic of love* is implemented as a route towards an understanding of human dignity as a value commitment, and so I argue that an increased significance in the concept of human dignity can be reclaimed.

In article 4 I argue that an important premise for possessing human dignity is recognition of the humanness and of the personhood in all human beings. Because people with intellectual disabilities have frequently been denied their personhood, the first step in the reflection is to explore what aspects of the Christian narrative of creation that enable a view of human being that encompasses the experience of profound intellectual disability. The purpose is not to present the Christian doctrine of creation as such, but to point at some aspects of the Christian understanding of *creatureliness* and the biblical claim that "the whole creation was good". Five such aspects are incorporated in the analysis and they are: dependency, relationality, a future dimension, likeness-difference, and embodiment. The experience-based narratives serve to shed light on these aspects both with regard to human being and to the divine being of God, as any theologically rooted concept of human dignity is based upon human beings being created in the image of God. If we take seriously that human beings are created in God's image, then the argument is that whenever we say something about human experience, we say something important about who God is as well. An important point in the view presented is that just as the being of God is always open-ended and unpredictable, so too is every story about human existence. Therefore the humanness and the personhood of people with poor intellectual capabilities cannot be denied. Therefore their dignity cannot be denied.

The second step of the constructive theological proposal is elaborated on in the second part of article 4, and partly in article 3 as well, in which I discuss the possible implications of an inclusive view of humanity. With the starting-point in Judith Butler's view of the ontology of the body and her view of life as grievable, I argue for a view on responsibility for the well-being of others as *inherent* in the human condition, precisely because human being per definition is understood as being in mutually interdependent relationships. At the core of Butler's view of life as grievable is that life does not have a worth in itself, but that it gets its worth in the specific social context that it is in. To say that someone's life is grievable is to say that (there is a possibility) that someone would grieve in case the life would stop existing. To best comprehend what such relationships look like, in article 4 I attend to the image of the parent-child-relationship in which love is usually the most characteristic feature. Because mainstream accounts of love do not encompass entering into relationship with the one *too* different from oneself, I discuss the concept of love through the lens of a disability hermeneutic. This reveals a love that is a way of being in the world. I describe this as a form of "catalytic relation" between human beings, which implies that love is not primarily about improving the other or doing something for the other, but about being someone in the life of the other. The narratives of people who love people with profound intellectual disabilities are argued to bear a hope of redeeming the sense of worthlessness and sorrow for the life that never came to be.

The Christian narrative of creation further points at a love that does not cease to exist in the face of disappointment, because God continues to love his creation even after the "Fall". I argue that since goodness came before sin, goodness is the primary condition of humanity. While brokenness is argued to be inherent in the human condition, it is important to consider when and how to speak of it. Sin is here understood to appear when people, or systems created by people, act in such a way that the suffering of other human beings increase, and this has therefore little to do with the will of God or some basic sinful feature in only *some* human beings, such as disability. I argue that humanity understood in light of the Christian narrative of creation can enable a response towards other human beings that makes possible a view of human dignity as a value commitment. To recognize people with profound disabilities as human beings with dignity therefore requires a social response that expresses: "It is good that you exist." This kind of response demands wilfulness and effort, and it says that people with disabilities should be loved in spite of the fact that they are a disappointment. In this way I argue that a constructive theological account of human dignity as a value commitment can offer new visions of human existence and inspire to hopeful practices also in the face of people who do not seem to have much to offer.

Consequently, increased relevance in the principle of human dignity relies ultimately upon the social and political networks people live in, how they are viewed and treated, and whether the conditions for people living a decent life are improved. An inclusive concept of human dignity is therefore in the hands of the other, because all human life is. Argumentatively I therefore defend the principle of human dignity as a value commitment that is embodied in institutions and practices, and in small gestures that express: "it is good that you exist." In the conclusion of article 3 I further highlight that the state budgets in the Nordic welfare states are presently getting smaller and smaller, and that the economic motive for prenatal testing and selective abortion is more likely to become more frequently used in the ethical debate, and I argue that if, or when, this happens we need to seriously have taken up the discussion about what it means to be human and what the concept of human dignity actually implies, and I argue that we need to include widened concepts of humanity, solidarity and every human beings' equal worth – at least if we claim to want a fully inclusive society. And perhaps, by stretching our imagination, we will find that not only can we avoid marginalizing people with disabilities, but also experience a richer and more fulfilled life? As I will show in the final cultural narrative – the friendship narrative – human fulfilment is argued to be found in something else but individual freedom, power, autonomous choice, or bodily health, namely in friendship and in our capacity to love others.

3.4 The Friendship Narrative

As I have outlined thus far, people with disabilities have in various ways been neglected throughout history – they have simply not been recognized as fully human and thereby excluded from dominant cultural narratives about human existence, as well as from resources, opportunities, health and life itself. One of the purposes in this thesis is to argue for social change and for the importance of recognizing people with disabilities as fully human.[195] My suggestion is that a counter-narrative is needed to come to terms with the oppressing and discriminating social, political and medical practices that the dominant values and the normalcy narrative make possible and legitimize. At the core of the proposed counter-narrative is one of the main arguments in this thesis, namely that love and friendship do something for a person that rights and autonomous choice cannot. Hence, the concept of friendship is the most fruitful path I have found to widen the narrow conceptions of human being, human dignity, ethics and the good life that I suggest marginalize particularly people with profound intellectual disabilities.

In article 3 I argue that the concept of friendship, and precisely friendship with people with disabilities, can have immense moral significance since I argue there is a transformative structure in an ethical perspective that springs from such friendship, but also that such

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[195] Cf. Swinton 2007a, 218.

friendship can widen a narrow view of humanity. I also disclose throughout this dissertation that narratives as such impact on our views and values, and therefore I stress the need for counter-narratives that reveal that disability need not be a catastrophe, that people with disabilities can be perceived as life-giving, precious gifts that increase the quality of life. Since friendship is at the very center of the constructive argumentative enquiry of this thesis I will devote significantly more space to the friendship narrative than to the narratives already presented. Since parent-child relationships are especially important in this thesis I pose a view on friendship that can fit into these relationships as well. Therefore, a key feature of friendship will be vulnerable love. In what follows I will give an overview over the history of the concept of friendship and then outline the main features of the concept that is the basis for the arguments posed in the thesis.

3.4.1 A brief history of friendship

During antiquity a number of philosophers devoted their philosophical work to the concept of friendship. The words for friendship *philia* (Greek) and *amicitia* (Latin) were used during this time, although their meaning implied close relationships in a much broader sense than the contemporary notion of friendship allows. Philia was the word used by Aristotle (384-322 BC), whose thinking has impacted various notions of friendship throughout history. In philosophical thinking friendship was usually closely connected to the word *eros* – the concept of love that desires something from its object – while it within the Christian tradition was more commonly connected to word *agape* – the concept of love that is sacrificial and springs from God.[196]

Aristotle is thus considered one of the major philosophers of friendship, and his philosophy and ethics have influenced many contemporary notions of the fundamental values of life, such as: friendship, virtue, and the good life, especially as they are formulated in *The Nichomachean Ethics*. The bases of friendship, according to Aristotle, is mutuality, affection, and good will. His view was that

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[196] Österberg 2007, 49-50; Hofheinz 2016, 120; Cf. Kurtén 2016 on the usage of eros and agape in Christian ethics.

friendship is the route towards reaching the higher good for individuals, and that good friendship is best realized among persons that are alike. In fact, he suggested that every kind of change, at least negative change, in the persons or the circumstances around the friendship would threaten the friendship. However, his assumption that something must have the same properties for us to call it the same does not resonate well with a life, or a world, that is in constant change. Now, the Aristotelian concept of friendship could concern relatives and colleagues as well as *chosen* friends, and he does, unlike many other philosophers, not draw a sharp line between friendship and love. Friendship is to Aristotle more about ethics and politics, and is understood as a relationship that helps the individual strive for justice and virtue.[197] Aristotle writes:

> It [friendship] is crucial in our lives. No one wants to live without friends, even if one has all kinds of other good things, do they? Even wealthy, influential and powerful people are regarded to be in need of friends. Because what good does it do to have such wealth, if one does not have the opportunity to do good deeds that first and foremost and in its most admirable form will benefit one's friends?[198]

While Aristotle points out significant aspects of friendship, such as the importance of friendship as a political, ethical and personal resource, it needs to be pointed out that friendship was not possible for anyone but for *free and wise men*, which means that the Aristotelian friendship excludes women, children, slaves,[199] and per definition people with disabilities as well.

The foundation for the European philosophy of friendship was established in antiquity, but the 17th and 18th centuries are commonly regarded as the classical centuries of the friendship discourse. The language of friendship was widely used to describe both equal and hierarchical relationships, and because the concept of friendship bridged the gap between the public and the private, it was considered

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[197] Aristotle 1988, *The Eight Book* in *The Nichomachean Ethics*: See also Österberg 2007, 49-55; Kronqvist 2008, 337.

[198] Aristotle 1988, 220. Translation my own.

[199] Aristotle 1988, *The Eight Book* in *The Nichomachean Ethics*; See also Österberg 2007, 49-55; Kronqvist 2008, 381.

to bear a significant political and meaning-making potential. For instance, people who were convicted of a crime against someone they were friends with, were sentenced to a more moderate punishment since friendship was seen as a proof of a person's goodness.[200]

The concept of friendship continued to be politically important into the 18th century, but lost some of its significance in the 19th century due to resentments among the people and the emergence of the socialist ideology. Whereas friendship had previously been the antithesis to war and conflict, the society was now largely characterized by divisions between groups and classes. The only sphere where friendship remained a central concept was in Christian communities or among the bourgeois. At the end of the 19th century philanthropists and Christians believed that personal commitment and closeness to the weak of the society was the key to improving the world, and the imperative of "love your neighbour" and friendship were frequently used as important expressions in the work for the poor.[201]

In modernity the language of friendship disappeared as a political concept in other political ideologies built upon freedom, rights, democracy, solidarity, welfare, capitalism and economy. According to Eva Österberg (2007) this was due to the power and superiority of the state becoming more prominent. She further points out that today the concept of friendship has gained new significance, because of anti-authoritative, democratic and egalitarian tendencies in society.[202]

3.4.2 A contemporary account of friendship

Österberg, who has written about the history of friendship, believes that the new found interest in friendship is rooted in the increased mistrust against modernity and the organisations of the 20th century. Drawing on Zygmunt Baumann she contends that while we still in many ways live in a modern society, in as much as we have strong nation states and democratic political systems and organisations, we

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[200] Österberg 2007, 183-185.

[201] Österberg 2007, 190.

[202] Österberg 2007, 214-217, 27.

have come to be more sceptical about the ability of the state to resolve issues of individuals.[203]

In contemporary culture, the common notion of friendship is still marked by the Aristotelian intuition that says that friendship is possible only between persons that are alike. This means that when we talk about friendship today, most people understand it to be a phenomenon about *sameness* and *social exchange* rather than *difference*, and precisely for this reason it might be difficult to recognize friendship between a so called normal person and a person with a profound intellectual disability as just that. However, friendship is by most people considered to be something that every human being desires in life. It is commonly viewed as a basic human experience as social beings. Therefore, it is considered to belong to the most important spheres of life. While people usually choose others as their friends based on similar interests, because they belong to the same peer group, have much in common on a temporal level, or because they recognize the other's way of responding to the world, I argue that the concept of friendship needs to be widened to include a different way of being-in-relationship. In Aristotelian terms *true* friendship is about both parties getting the same reward out of it, and any other kind of friendship would be considered unequal and therefore second best, or even untrue,[204] and this is simply not compatible with people with disabilities who often live in highly asymmetrical relationships.

Before moving on to a different account of friendship, I would like to point out another keyword concerning friendship today, namely that friendship is usually based on *choice*, and specifically as a part of people's individual life projects. In Aristotle's ethics this notion is guided by how to succeed in life as a human being,[205] while it in contemporary liberal societies can be said to be about succeeding to "live in a freedom that is shaped by one's own preferences".[206] Hence choosing friends is an activity of *freedom* that contributes to the good life. However, precisely because freedom in contemporary society has largely been turned into an *object* of choice, most people are not capable

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[203] Österberg 2007, 27-29.

[204] Reinders 2015, 340-346; Swinton 2007a, 220-221; Österberg 2007, 43-47.

[205] Aristotle 1988, 222-228.

[206] Reinders 2015, 346.

of perceiving life as good unless it is chosen. In this view friendship is true and good merely in case it is chosen.[207]

Against the presented view of friendship, it is probably not clear how friendship could be a fruitful route towards the inclusion of people with disabilities, since it appears as if the prevalent conception of friendship is placed within the same normalcy narrative as parenthood and human dignity previously discussed. People with disabilities are rarely *chosen* as friends because they are too different from anyone who considers themselves "normal", and further because their social position of being isolated in institutions or group homes makes it further difficult for them to be chosen as friends.[208] Increased political and human rights do certainly bring more fulfillment to the lives of people with disabilities, but friendship brings a moral resource into the debate about reproductive technologies, human dignity and human being that rights and justice do not. Therefore we need to explore in what ways people with disabilities can be included in our lives as friends, and not just as citizens.[209] Jean Vanier writes:

> Justice renders us to open to respect for others. Friendship goes further. Nothing pushes us quite as radically beyond ourselves as friendship. So far, we have spoken of happiness as a subjective and solitary activity that involves an attitude of openness to the world but that makes the subject alone responsible for and the beneficiary of his own perfection. With friendship we see another dimension emerge, giving a new slant to happiness.[210]

In *The Normal Chaos of Love* (1995) Ulrich Beck and Elisabeth Beck-Gernsheim explore the ambiguous nature of personal relationships and family patterns in the ever changing social landscape. They argue that the traditions, rules and guidelines that used to govern personal relationships no longer apply, and that the one thing that love is the one driving force for close relationships in whatever form they take. They suggest that because the world is overwhelming, impersonal and

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[207] Reinders 2015, 347-348.

[208] Andersson et al. 2015.

[209] Reinders 2008, 41-44.

[210] Vanier 2001, 55.

abstract, love has become increasingly important.[211] Hence, to love someone involves regarding life as meaningful, and it seems as if the most important aspect of finding one's life as meaningful springs from personal relationships, whether friendship, family or lovers. Friendship is thus a basic and vital human relationship that forms the social fabric of our lives. We discover our identity through our friendships; we gain our sense of value and place in the world, and learn what it means to participate in community. Friends help us to recognize one another and the world.[212] Just as the concept of human dignity might reach further than human rights with regards to the social responses to people with disabilities (and people in general), so too can friendship, I believe. But because friendship pushes us radically beyond ourselves, as Vanier suggests in the quote above, I believe that the concept of friendship can transform our values, our responses, and the way we treat each other. In what follows I will negotiate a different concept of friendship that sets the foundation for how it is used as a counter-narrative, or counter-logic, in this thesis.

3.4.3 A counter-narrative of friendship

As suggested above, if friendship is to be viewed as a tenable core of the counter-narrative I am proposing it has to be reimagined. It is in this endeavour I argue that a disability perspective, as well as a Christian theological perspective and a philosophy of love is sufficient. In the Christian narrative Jesus's relationships were marked by unconditional acceptance, solidarity with the poor and marginalized, and commitment to others. Since these kinds of relationships – friendships – are at the core of Jesus' being in the world,[213] one could suggest that friendship is the very sign of God's presence in the world,

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[211] Beck & Beck-Gernsheim 1995, 175-176; See also Giddens 2001, 178-179.

[212] Kronqvist 2008, 308-311; Swinton 2007a, 216-217.

[213] Marco Hofheinz argues in "What a Friend We Have in Jesus": Friendship as a Theological Approach Toward the Teaching of the Threefold Office of Christ" (2016) that knowledge of God's will come through friendship. Drawing on Augustine he contends that friendship with God is the very prerequisite for knowledge about God's will. Friendship with God comes, according to Hofheinz, through relationship with God's son Jesus Christ. Hofheinz 2016, 124.

and a sign of God's image in human beings,[214] which is what I suggest in articles 2 and 4. John Swinton writes:

> Human beings are social creatures, made in the image of a social God who is trinity; a God who is love and relationship in essence. God is a community of Father, Son, and Holy Spirit, eternally indwelling one another in a community of love. It is only natural that creatures made in the image of God should seek after relationships in all of their various forms.[215]

Christian friendship thus reveals something different than the Aristotelian notion of friendship. It reveals a friendship that is not based on likeness or social exchange, and therefore makes "second hand" friendships impossible. Jesus chose to befriend the outcasts in society, he was committed to them, he accepted them, he loved them – and this way of relating to the world is central to human existence in the Christian narrative. As Jesus in the service of the foot washing (John 13:14-15) sets the example of a form of authority that should define a community characterized by love, he points at a friendship with a reversed logic. Not only does Jesus introduce a model of friendship that transcends the boundaries of utility and freedom. He also points at a friendship that is based on the principle of grace, and on the shared knowledge that every human being is recognized by God as God's friend, which calls for recognizing the world and others within it in ways that differ greatly from the assumed norm.[216] This concept is thus related to a specific notion of love as well.

In *What We Talk About When We Talk About Love* (2008), Camilla Kronqvist asserts that every encounter with another human being encompasses a compromise of one's own will, at least the possibility of it being compromised, and in this sense love itself limits the freedom of the individual. This means that while love does indeed make claims on the individual, it also creates opportunities to act in ways one could not without love. From this perspective love places the individual in a world in which people *matter*, in which they are precious and meaningful, which in turn allows the individual to matter and mean

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[214] Swinton 2000, 43-44.

[215] Swinton 2000, 44.

[216] Swinton 2000, 47; 2007a, 221; Hofheinz 2016, 126-129.

something to others. Hence love brings in an element of irrationality to the concept of friendship, because love does not fit into rational thinking about what justifies our actions. But the desire to have rational grounds for all meaningful human interaction can also be argued to be an expression of the fear that our lives would otherwise be rendered contingent, and therefore the need to have good reasons for befriending someone is usually defended. But is there not something strangely odd about first having to clarify the qualities of a person – *what* the person is – in order to explain why a person can form relationships with others? As Kronqvist suggests, the things that people commit themselves to in friendship are usually not bound to the characteristics of a person, but are rather aspects of the relationship. It is *in* the relationship that the person emerges.[217] Therefore, no characteristics can take away the vulnerability that is built into every relationship, and in this sense all human beings are strangers before love and friendship.

Mikael Lindfelt (2010) stresses that the notion of being strangers can work as an important reminder of how the other cannot be controlled in a mutual encounter. He emphasizes that estrangement is not primarily a description of the other, but that it hints at the impossibility of holding a hegemonic attitude towards the other, whether this attitude is built on a presumed objectivity. The emphasis on estrangement also points at the very subject itself, in the sense that every person is variously constituted by the complex and manifold relationships one is in, and by the fact that it is not always clear who a person is. Sometimes I do not understand why I myself react the way I do, and this confusion must also be placed in relation to others. By encountering others it becomes clearer who I am, and perhaps who I want to become. Estrangement can furthermore be a reminder of that every genuine encounter is about the paradoxes in the openness for changing and being changed without any clear goals in mind on the one hand, and the constant movement between being close and distant on the other.[218]

From these deliberations the concept of friendship emerges as an ethically motivated ideal, and the category of friendship becomes a mutual part of the existential structure of human personal existence.

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[217] Kronqvist 2008, 136-137, 157-163.

[218] Lindfelt 2010, 201.

The movement from stranger to friendship is thus from a relational perspective a movement towards the creative opportunities of life. The moral demand that is placed upon human beings in friendship and love no longer appears as a problem. Quite the opposite, seeing someone as an obligation might already be an expression of love. The recognition of something as an obligation exposes a commitment to the other, which can be seen as a natural form of communication involving a dialectic tension between differentiation and fellowship. Hence, coming to know someone is not done on my own.[219]

While friendship from an Aristotelian point of view is an activity of freedom, the counter-narrative of friendship that I propose is a different form of activity, namely a "dynamic activity within which we seek to live virtuous lives worthy of being called truly human".[220] Friendship is thus not something we can choose or do alone, but a skill that is learned through encountering the stranger – the one we do not know. And as friendship is not based on likeness the meaning of friendship becomes truly contextual.[221] Although the Christian concept of friendship has been formed through a variety of dilemmas, not least in the early Christian monasteries where it was largely debated whether nuns and monks could enter into friendship, or whether friendship was possible between people in different hierarchical positions, or whether people within the monasteries could befriend people in the outside world,[222] I maintain that the Christian narrative frames friendship in a way that makes sense of encountering the one's least like us.

While many in liberal societies are not ascribing themselves to a Christian value system, it can be argued that friendship framed in the Christian narrative entails recognizing one another in constructive and health-bringing ways that has the power to resist bad social practices.[223] As Swinton (2000) asserts, Christian friendship is both *centripetal* and *centrifugal*, which means that it reaches inward to contribute to creating a loving an inclusive community, and outward to embrace and stand with the outcasts.[224] Now, it can be argued that this is indeed a very

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[219] Lindfelt 2010, 202-203; Kronqvist 2008, 137, 290.

[220] Swinton 2000, 50.

[221] Swinton 2000, 50-51; 2007, 219.

[222] Österberg 2007, 56.

[223] Swinton 2007, 219.

[224] Swinton 2000, 51.

radical *choice*, and that this model of friendship is radically dependent on liberal values such as freedom and choice. But as we shall see, it is quite the opposite. In this thesis I use the community model of L'Arche to show how befriending people with disabilities can widen both a narrow conception of morality and what it means to be human. While I in article 3 make my case for the practical implications of such friendship, I will here tend more specifically to what friendship looks like in the L'Arche communities and how such friendship is connected to the idea of divine providence.

3.4.4 Friendship in L'Arche

When Jean Vanier, the founder of L'Arche, in 1964 asked two men from an institution for men with intellectual disabilities,[225] to come and live with him, he had no agenda other than to answer to what he considered a call. As he visited the institution, and they time and time again asked him if he would come back, if he considered himself their *friend*, he experienced them to cry out for relationship with him. He saw a beauty in these men that he thought was destroyed in this large and violent institution. This beauty he regarded as God's presence. The fact that these abused and wounded people had the ability to be open for friendship and community was to Vanier a sign of God's presence. The fact that these people, despite their obvious physical and intellectual limitations, were so gifted with regards to building relationships, was to him nothing less than a witness of what is really at the core of human being in the Christian narrative of creation – friendship and being in relation. And this basic philosophy, which still is an elementary view in the L'Arche communities, demonstrates that community life is not about doing morally good deeds for people with disabilities, but simply to respond to the presence of God in other people. And this is how the notion of providence is connected to friendship; by revealing himself in the needs of others, God invites people to respond and act. In this view every human being that we encounter is a providential gift to us.[226]

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[225] There was actually initially three men invited, but after only one night together one of them went back to the institution. See Reinders 2015, 353.

[226] Reinders 2015, 353-358; Swinton 2007, 237; See also *The Miracle, the Message, the Story* by Kathryn Spink (2006) which is the biography of Jean Vanier and L'Arche.

In Christian literature people with disabilities are frequently used as means to making the so called normal people morally better, and sometimes this is precisely what the L'Arche communities are criticized for. But such critique only reveals the misconceptions of what L'Arche is really about – which is being-in-relationship – and this critique highlights the difficulties in seeing beyond an Aristotelian concept of friendship. Instead, Hans S. Reinders suggest, friendship has to be evaluated against the idea of an ultimate end, which I discuss in article 2 in relation the concept of health. In a theological perspective moral life is always about responding to God's offer of friendship, which means that friendship *precedes* human actions. In this view human actions are a response to how we imagine God responding to the other. A key point here is that this kind of friendship follows a three-way-logic, rather than a two-way-logic and that means that even though befriending a person with a disability – which seems irrational in a two-way-logic – might appear as if the person with a disability is used as a means when he/she is not.[227]

The question is, then, how to figure out how to receive the other so that the presence of people with disabilities will appear as a gift that enables us to learn what our unshaken belief in our abilities usually prevents us from seeing. People tend to believe that goodness in a person merely is revealed to us by examples of greatness and perfection, while doing so means that small gestures are overlooked. And yet usually it is the small things that reveal the greatest wonders of love.[228] Kronqvist writes:

> It is easy to feel awe and amazement in front of astounding beauty or goodness when nothing is demanded of us, but much more difficult to respond to the demands love makes on us in the grittier cases.[229]

What Kronqvist suggests is that the difficulty to love the "grittier cases" might not be the issue at all, but instead one's own ability to love appears as the issue. While I do not suggest that disabilities make up a *better* reason for loving, they can, however, more clearly reveal the

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[227] Reinders 2008, 316-320.

[228] Kronqvist 2008, 284.

[229] Kronqvist 2008, 284.

demands that love makes on us. In the face of disability the reality of relationship and the responsibility that is in such relationship is undeniable. The love that demands, needs, and takes effort might easily be forgotten in the life of independent people who appear to be without needs. The willingness to accept an image of perfection as a reason for love reveals in itself a temptation in love. The assumption that one could not possibly love a person with a disability reveals, perhaps, more about common assumptions of perfection than it does about love. To make judgements about desirable objects of love says more about ourselves wanting to be judges over love, rather than to be judged by it.[230] In L'Arche, friendship is not dependent on skills, abilities or personal achievements but upon receiving. In everyday life relationships are built with people with disabilities in the little things. Jean Vanier writes:

> Our lives in l'Arche are disarmingly simple. We often say that half the day is taken up with dirtying things and the other half with cleaning up! That is not entirely true because we also have work, celebrations, meals and prayer. But that does say something about the littleness and ordinariness of our lives. This is particularly evident when we are with people who have severe handicaps. They need a lot of presence and caring in all the vital acts of the body: bathing, toilet, clothing, feeding and so on. Many of them cannot be left alone during the day, even for short periods; their anguish is too great. Much of our life is situated around touch: holding them, bathing them, playing with them. Of course there is no place for interesting conversation. Play and laughter is the only communication possible. We experience communion with them around all the very little things-to-do of each day.[231]

Often Vanier says that we are all called to do, not extraordinary things, but ordinary things with extraordinary love. And his description of the everyday life of L'Arche bears witness of precisely that. When Vanier in 2015 won the Templeton Prize for his work in L'Arche he emphasized in his speech

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[230] Kronqvist 2008, 285.

[231] Vanier 2007, 297-298.

> To be with is to live side by side, it is to enter into mutual relationships of friendship and concern. It is to laugh and to cry together, it is to mutually transform each other. Each person becomes a gift for the other, revealing to each other that we are all part of a huge and wonderful family, the family of God. We are all profoundly the same as human beings, but also profoundly different, we all have our special gifts and unique mission in our lives. This wonderful family, from its earliest origins and since then with all those who have been spread over this planet from generation to generation, is composed of people of different cultures and abilities, each of whom have their strength and their weakness, and each of whom is precious.[232]

People with disabilities do perhaps not have intellectual gifts, but they have a unique gift of the heart. They do not aspire to be successful in their achievements, but they long for personal relationships of love that can give them life and meaning. The friendship in L'Arche reveals what a so called "loving gaze" is really about, namely allowing the other to be other and not attempt to change him or her according to one's own preferences. The friendship in L'Arche reveals that seeing someone as beautiful demands all senses. Kronqvist (2008) suggests that one comes to recognize someone's individuality not only through spending time observing the person, but by touching and feeling someone's movement, by feeling someone's hands, by listening to the tone of their voice, and so on, all of which are at the core of friendship in L'Arche. This is the dialogical character of a relationship, previously described.[233]

The friendship in L'Arche is not true because it is mirroring the sameness of persons, but because the people who have chosen to become friends of people with disabilities have been transformed through befriending the rejected.[234] This is the vision of friendship that I will argue can serve as a foundation for resisting the indignity of people with (profound intellectual) disabilities.

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[232] Jean Vanier's prepared speech: http://www.templetonprize.org/pdfs/2015/20150518-Vanier-Templeton-Prize-ceremony-talk.pdf. Downloaded 15.5.2016.

[233] Kronqvist 2008, 290.

[234] Reinders 2015, 360-361.

3.4.5 Discussion

In this final chapter before my concluding discussion I have discussed the concept of friendship and being-in-relationship as the basic concept for constructing a counter-narrative of morality and human being. In article 3 I contrast the narrow moral framework of morality and human being with the stories about friendships in the communities of L'Arche. The L'Arche communities are brought forth as an example of how befriending people with disabilities can challenge mainstream ethical narratives and widen the narrow view of morality and what it means to be human. In L'Arche people with and without disabilities share their lives in a family like setting, and those who have lived in L'Arche reveal that befriending people with disabilities has been a catalyst for moral transformation and a route towards a view of human being that allows people with intellectual disabilities to touch and open hearts.

The argument for drawing on the stories of L'Arche is that I maintain that by keeping the discussion within a narrow medical framework, people with disabilities will always be underdogs because of their chromosomal deviations or medical "defects". Their quality of life can never make sense in that context. The friendship account becomes important because while the Disability-rights movement and the greater disability community has fought hard for the rights of people with disabilities, the strict focus on empowerment, self-awareness and self-advocacy continues to exclude people with profound intellectual disabilities. They can never represent themselves, make autonomous choices or express their dreams and wishes. This means that if we want to have a truly inclusive society, where all individuals are of equal worth, we need to widen our conceptions and look for further perspectives on how to perceive life as a human being. This is where the culture of L'Arche can be helpful.

The most important goal of L'Arche is to build community. Community in the L'Arche context means groupings of people who have chosen to leave their own environment to live with others, to work from a new vision of human beings and their relationships with each other and God. The L'Arche communities are also clearly defined by acknowledging the brokenness of human beings. Many people go to live in a L'Arche community to do a good sacrificial thing living with people with disabilities, but usually discover that living in community is not about doing things for others, but to learn how to receive and be with. This way of thinking certainly requires an acceptance that we are all people in need – we are all dependent on other people. L'Arche is not primarily an example of an ideal way of living realized by morally superior people, but rather an example of learning a deeper truth about oneself, God and others.

Hence, bringing forth the concept of friendship, and the example of L'Arche, resonate well with the theological view on life that I propose in article 2 in which the idea of proximate ends and an ultimate end is included. The ultimate end is here articulated to be communion with God, and all other life goals are to be evaluated against this end. While communion with God does involve the relationship between human beings and God, it is most evidently expressed in the inter-human relationships that are so intimately connected that they in a theological view are analogous to the Triune relationship. The disability perspective sheds light on troublesome aspects of life usually perceived as lack of health or failure to flourish as human beings, mistakenly attributed to individual and medical causes, rather than social, political, and economical ones. The disability perspective demonstrates that human well-being and flourishing entail a wide range of different experiences, which challenges accounts of diversity wrongly identified as pathology.

I argue that theology has resources that can transform the way the absence of health is commonly experienced and explained, and a particular theological concept of health presents possibilities to be the kind of communities that offer people a safety-net for bodies and identities that are at risk of marginalization, and the resources to bear what otherwise would be unbearable. Through this view, I suggest, a space is created where it is possible to see the value of even the most broken body, which presses people to act differently and take a different stance. And this is ultimately what a liberating account of health can provide – more tenderness, more love, and no "I" without a "we".

In article 3 I argue that L'Arche can be viewed as an alternative cultural setting in which widened perspectives on disability and human life can grow, and I propose that attention to changing attitudes could be a legitimate complement to legislation and rights and that the presence of people with disabilities in our societies could make a positive contribution, and possibly even change how practices like prenatal testing are implemented. I suggest that if people with disabilities would be welcomed to actually participate in peoples' lives, though friendships, the moral culture could possibly be changed in a way that regulations would no longer matter in the same way. Jean Vanier and L'Arche show that the vision and realization of values are not always a result of planning, strategy or theoretical ideas, but a result of *life lived*. This means that the insights drawn from L'Arche about what it means to be human and human fulfilment do not spring from great thoughts or moral principles, but from encountering people with a wide range of abilities and gifts.

4 Concluding Discussion

In this thesis I have demonstrated that far too much of our physical, social and cultural spheres are designed in ways that propagate patterns of harmful exclusion for people with disabilities. The persistent assumption that people with disabilities are the undesirable "other" in society is argued to be a consequence of such patterns. Since reproduction concerns most people, in one way or another, the practice of prenatal testing is argued to be a major source of expressed notions about what it means to be human and to have a human body. For this reason I have used prenatal testing as a kind of case-study, or simply as an example of how certain moral truths and knowledge are produced in this particular context. By implementing a feminist disability perspective, drawn mainly from disability studies literature encompassing feminist approaches and disability theology, as well as experience-based narratives of disability, I have identified some key features in these patterns of exclusion. While there are certainly other spheres of life in which such patterns occur, I have focused on how they can be identified in the cultural narratives of *normalcy, parenthood, dignity*, and *friendship,* and therefore the subtasks and the themes of the articles have been chosen accordingly. Cultural narratives are here understood as stories we generally live by, stories that help us make sense of ourselves in the world, stories that inform our lives, but also limits our actions and ways of responding to other people and to the challenges life throws at us. Because these narratives are argued to give us a sense of security, I have called them comforting narratives as well. These narratives are thus argued to have immense moral significance in our lives.

The problematic notions that most evidently occur in the narratives can be gathered together in the following six claims: (1) *disability is equal to catastrophe and suffering*, and thus incompatible with happiness and good quality of life; (2) *people with disabilities are defined, named and judged on the basis of their genetic condition*, and thus always viewed as disabled first and people second; (3) *people with intellectual disabilities are not persons or fully human,* because they presumably lack in capacity to reason; (4) *the elimination of (people with) disabilities lead to social improvement*, since neither parents nor society would be economically or socially burdened by them, and since increased health is a sign of societal advancement; (5) *disability is the ultimate threat against the liberal value system* in which autonomy, individual freedom and choice, rights, utility, productivity, efficiency and success are important ideals; and last, but perhaps most problematic, (6) *the idea of inclusive human dignity is granted only people who fit into the normalcy paradigm*, hence people with disabilities are of less worth than the so called normal people.

By discussing various historical and contemporary notions of embodiment, health, reproduction, and dignity I have exemplified ways in which a narrow view of both humanity and morality manifests itself, and I have pointed at the need for an ethical framework that helps us think critically about the social implications of difference, and about the ways certain people are often seen as more valuable than others. In the reminder of this chapter I will present some of the main features of the constructive responses I have proposed to these claims.

In society there is a strong underlying assumption that disability is equal to suffering. Ideas of suffering have a long history in religion, ethics, and health care, particularly in discourses about the good life. The alleviation, prevention and elimination of suffering have thus come to be important goals of health care and biomedical science. Because health care professionals are the dominant gatekeepers of health, the medical understanding of disability and the normalcy narrative enforce the presumption that disability is a catastrophe to be avoided at all cost. While various emancipatory groups, such as the women's movement, have tried to occupy the gatekeeping role, these have tended to simply focus on moving the power from one place to another without thoroughly questioning the oppressive elements of power in the first place. Therefore I argue that the gatekeeping role of health need to be moved to another place, tentatively to that of theology, but also that this project need to consistently be self-reflexive and self-critical of its own relationship to power.

In something called the *Biocultures Manifesto*, Lennard J. Davis and David B. Morris (2007) write that biology, which at times is used as a metaphor for science, is as intrinsic to the embodied state of the readers and writers as history and culture are intrinsic to the professional bodies of knowledge known as science and biology. They suggest that to think of science without including a historical a cultural analysis would be like thinking of the literary text without the surrounding and embedding weave of discursive knowledges, active or dormant at particular moments. The biological without the cultural, or the cultural without the biological is doomed to be reductionist at best and inaccurate at worst. Social constructionism is self-limited and inaccurate if it implies that social facts may be entirely dissociated from biological facts. Therefore the biological must work in a dialectical relation with the cultural.[235] While I do argue that disability in large is a social, historical and cultural construction, I also want to underline that biology does play an important part in the discourse about disability, since disability is indeed an embodied experience as well. The main problem about medicine being in a dominant gatekeeping role of health, and by effect of disability, is the meaning that usually is ascribed to the biological.

For this reason a crucial route towards reimagining disability, and there through the widening of the medical understanding of human being, is the implementation of experience-based narratives of disability. I argue that bodies that are radically different from the norm can work to produce new knowledge about human existence. Nevertheless, many of the narratives brought forth in this thesis do now allow us to look away from the fact that there are many disabilities that cause some serious pain and suffering, but these narratives *also* reveal that pain and suffering do not constitute the entire human existence. Those who live with chronic pain witness that they have had to learn how to live *with* pain, and therefore I argue that to think seriously and constructively about suffering, one has to deprive it of meaning. While there is an evident risk involved, however, in doing so, which is the risk of trivializing another person's very real experience of pain as a tragic and horrible aspect of life, I argue that there is a much greater risk in *not* doing so, which is the risk of ascribing meaning to pain and suffering. And since I argue that the latter is one of the main reasons to why people with disabilities have been, and are, victims of harmful exclusion, I believe that the former is one worth taking. But here the methodological move to listen to the stories of people in pain, and taking them seriously, become crucial because it only through them we can begin to better understand what it means to accept suffering and pain as inescapable aspects of human being. In the project

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[235] Davis & Morris 2007, 411-418.

of rethinking the relations between bodies and selves, subjects and society, these narratives can teach consciousness a certain kind of freedom from the sufferings and limitations of the body. Because, after all, we are all at risk of becoming disabled at one point or another in our lives.

Now, in addition to the narrative account of disability I have proposed a theological account of human being and health that places the inter-corporeal and relational aspect of human existence at the centre. This perspective allows for a view that sees interpersonal relationships as both *necessary* and *determent* of human well-being, and it allows a view of health that does not equate disability with the whole of human existence. The theological account of human beings as *creatures* further underlines in what ways limitation, dependency and relationality are inherent in the human condition, which calls for a certain mindset and attitude towards the other. A body in pain needs the care of others. Therefore the suffering of another person calls us to act in solidarity and love, because that is the moral demand of being-in-relationship. When we recognize the humanness and personhood in the other, in the disabled, the moral demand is to ease the conditions for the other, and help make the other's life livable. This calls us to sit with the one who suffers, and bear what otherwise would be unbearable. I maintain that people with disabilities bears witness of *tough* human beings, rather than some extraordinary fragility. The people who are constantly exposed by their vulnerability and need of help reveal to those who are desperately trying to hide their own vulnerability that life can be good *as it is*. Therefore disabilities witness the beauty of interdependence rather than horrific isolation. From this perspective living life with a disability does not prevent bright future prospects; it does not exclude happiness or quality of life, which brings us to the question of dignity.

I argue that theology can transform the way the absence of health is commonly experienced and explained, and consequently a door is opened for a view of an inclusive concept of human dignity as well. I argue that increased relevance in the principle of human dignity relies ultimately upon the social and political networks people live in, how they are viewed and treated, and whether the conditions for people living a decent life are improved. An inclusive concept of human dignity is therefore in the hands of the other, because all human life is.

Argumentatively I therefore defend the principle of human dignity as a value commitment that is embodied in institutions and practices, and in small gestures that express: "it is good that you exist." This mindset is in the context of this thesis explained through the concept of friendship or simply being-in-relationship. The true nature of friendship, I suggest, will not be found in human activities that are centered on self-justification or "being-in-competition-with."[236] Instead, it is found in the view of human being as inter-dependent, and in a view of love as vulnerable. Such love places my own happiness in the hands of the other, which opens up the possibility that I may lose the ground beneath my feet in losing you. By not trying to determine what something should be like, or who someone ought to be in order to be valued, love and friendship can be said to open up life itself,[237] and as it were, friendship can be seen as a route towards challenging mainstream ethical narratives and positions a catalyst for moral transformation.

Despite claims about how characteristics and capabilities are not criteria for possessing dignity, it is evident that there is a strong tendency in culture, especially within health care, to presume that people with disabilities are of less (moral, economic, human) worth than those who fit into the normalcy paradigm. I argue that if we take serious that human dignity and human rights are core values in society, then we must make sure that *all* forms of human existence are governed by these values. If we claim to ensure the protection of all human beings, then we simply cannot uphold practices that compromise and question the worth of certain people. Instead we need to recognize and embrace all human beings in the way human embodied existence is actually lived, and shape the society accordingly, and not the other way around so that human beings have to desperately try to fit into a normative image of human being. The history cannot be changed, but just as the history has shaped the present, so do present actions shape the future. The practice of prenatal testing and selective abortion as they are implemented and explained to date is not creating a future in which the diversity of human beings is celebrated. Rather, the eugenic logic that underpins such practices is creating a future in which some

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[236] Cf. Comensoli 2011, 119.

[237] Cf. Kronqvist 2008, 316-330.

people are worthy and dignified and some are not. Rather than creating a world according to our preconceived notion of what could be beautiful in it, we should be discovering the beauty of the world, by accepting the unpredictability in whatever forms and shapes it may take.

Inclusive communities are places of welcome. A society that welcomes people with disabilities values their presence and misses them if they are absent. Inclusion is thus not merely about accepting someone once they are already here, but about saying that the world is a more beautiful place because of their presence. Since this is what most people want for themselves – to be recognized and valued – inclusion is not about any single individual, or any specific minority group, but it involves *everyone*. Inclusion is thus not primarily a political program but a mindset and an attitude. It is a way of thinking, and a way of treating others. Therefore there is a moral significance in the different ways of relating to each other. Hence, the idea of inclusion entails the premise that *everyone is of value, and everyone has a right to belong*.

4.1 Endnote and prospects for future research

One scholar who has influenced my thinking greatly is Rosemarie Garland-Thomson who is commonly regarded the pioneer for combining a disability perspective with feminist theory. In fact, she is the one who has coined the very term feminist disability studies. In a postscript to her widely read and reprinted article "Integrating Disability, Transforming Feminist Theory" (2011), she describes how she for the first time used the expression feminist disability theory as if it was an existent critical discourse that she was addressing rather than something she was working out for herself. Her aim was to show that disability theory was everywhere in feminist studies if one would just know how to look for it. Her hope was to establish an academic specialization that scholars would put on their CVs, that departments at universities would list it as a job description, that colleagues would use as a professional self-description. I guess Garland-Thomson has inspired me to dream of something similar in the process of writing this thesis. In the *Introduction* I write that I have found no better description for my work than feminist disability theology. Presently there is no established academic specialization termed feminist disability theology, other than by brief mentioning, although there are a few feminist theologians who elaborate on the issue of disability.[238] Hence, in the spirit of Garland-Thomson I will "send out [the] words into the world as an act of faith that they will do the cultural work [I] intend them to do."[239]

Just as there has been immense *harmful* power in naming people with disabilities as deviant, deficient and undesirable, I believe there can be *liberating* power in explicitly naming one's research feminist disability theology. Many established disability theologians are men who do not pay much attention to the specific concerns that the issue of disability raises for women, nor do they regard the important emancipatory approaches that feminists have developed over the years of struggle for equality. For this reason an explicit feminist disability theology is much needed. While this thesis serves to fill a tiny part of that void, there are many important issues that I have not been able to include. In the remaining part of this thesis I will propose a few subjects that are of interest in future research.

One such subject of interest would be intimate relationships between people with disabilities, especially in relation to theological accounts of love and marriage. The implementation of the emerging accounts of queer theology would here be of value since there are many important connections between heteronormativity and the normalcy narrative in culture. Connected to this question would also be the issue of the sexuality of girls and women with disabilities, which is a highly overlooked matter in much disability research. Against recent reports on the increased violence against people with disabilities in care homes and institutions, as well as reports suggesting that women with disabilities are in a 2-4 time greater danger than able-bodied women of being subjected to sexual violence, it would be interesting to follow in Vappu Viemerö's, associate professor in psychology, footsteps and study various aspects of violence and disability, but from an ethical

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[238] Nancy Eiesland, Sharon Betcher and Deborah Beth Creamer are the ones I have found to use the description feminist disability theology in their research. See Schumm 2010; also *Disability Theology*.

[239] Garland-Thomson 2011, 43.

point of view. As the issues of guilt and shame have been central in the discourse about rape and sexual violence, a theological perspective would be interesting to incorporate as well. In this thesis I have pointed out that theologies of wholesomeness are highly problematic in relation to disability, and in this matter it would be interesting to look further into both the Christian tradition and contemporary theological accounts. Eschatological perspectives on "human becoming" or perceptions about disability in life after this could be fruitful.

In the recent book *Childhood and Disability in the Nordic Countries. Being, Becoming, Belonging* (2015) the authors express that while the living conditions and life quality for children with disabilities and their families are quite good in the Nordic countries, compared to many other places in the world, there are still problematic issues to resolve. There seems to be a gap between the formal system and the practical reality. There is poor access to information and fragmentation in services. In the future there will also likely be widened social inequalities and increasing ethnic diversity, and these issues are therefore important in future research as well.

As for biomedical technologies, such as prenatal testing, there is still work to be done. The methods for testing are constantly developed into more sophisticated forms, and the legislation appears to be far behind these new developments in many countries. An ongoing discussion about the goals end purposes of these practices ought to be encouraged in a variety of research fields and experience-based narratives of families that have a member with disabilities should be properly included. I strongly believe that more and better knowledge will emerge once the biomedical sciences and the humanities align themselves in research. As Davis & Morris (2007) contend in their *Bioculture Manifesto*, the strict divide between "soft" and "hard" sciences needs to be abandoned in present day research on questions concerning human life. The presumption that the humanities are the realm of values and the sciences are the realm of facts is simply not true. None of these can be fully understood without knowing the historical, social, cultural, discursive fields surrounding the data.

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Svensk sammanfattning

Den här avhandlingen åskådliggör att en stor del av våra fysiska, sociala och kulturella sfärer är utformade på ett sätt som möjliggör marginalisering av människor med funktionsnedsättningar. Ett viktigt syfte med avhandlingen är därför att visa att den till synes orubbliga föreställningen att människor med funktionsnedsättningar är oönskade i samhället är en konsekvens av sådana marginaliserande tanke- och handlingsmönster. Eftersom familjebildning och reproduktion är en central aspekt av många människors liv kan fosterdiagnostikpraxisen sägas vara ett relevant exempel för att fånga in grundläggande föreställningar om vad det innebär att vara människa och att ha en mänsklig kropp. Därför diskuteras i avhandlingen fosterdiagnostiken som ett slags ”case-study”, eller som ett exempel på hur kunskap och vissa moraliska sanningar produceras i denna specifika kontext. Genom att implementera en så kallad ”feministisk funktionsnedsättningsteologi” tillsammans med erfarenhetsbaserade narrativ om funktionshinder identifierar jag några kärnpunkter i givna marginaliseringsmönster. Trots att sådana mönster framträder i en mängd olika livssfärer, lyfter jag specifikt fram kulturella narrativ om *normalitet*, *föräldraskap*, *människovärde* (dignity) och *vänskap*. Med kulturella narrativ avser jag berättelser som människor generellt lever i enlighet med och som informerar människors liv, men också som berättelser som begränsar människors handlingar och sätt att reagera på andra människor. Jag visar att narrativ är moraliskt viktiga eftersom de ger människor trygghet och säkerhet, och därför kallar jag dem parallellt med kulturella narrativ för ”tröstande narrativ” (comforting narratives).

I avhandlingen ingår fyra separata artiklar som publicerats, eller som är godkända för publikation, i akademiska journaler. På olika sätt aktualiserar dessa fyra studier de kulturella narrativ som jag menar möjliggör en marginalisering av människor med funktionsnedsättningar. I narrativen framträder några problematiska aspekter särskilt tydligt, och dessa kan sammanfattas i sex påståenden: (1) *funktionsnedsättningar är detsamma som katastrof och lidande*, och därför oförenliga med lycka och god livskvalité; (2) *människor med funktionsnedsättning är definierade, kallade och bedömda utifrån deras* *genetiska uppsättning*, och därför sedda som funktionsnedsatta i första hand, och människor i andra hand; (3) *människor med kognitiva funktionsnedsättningar är inte personer eller fullvärdiga människor*, eftersom de antas sakna förmåga att tänka rationellt; (4) *eliminering av (människor med) funktionsnedsättningar leder till social förbättring*, eftersom föräldrar och samhället inte blir ekonomiskt eller socialt belastade av dem, och eftersom ökad hälsa är ett tecken på samhällelig utveckling; (5) *funktionsnedsättningar är det ultimata hotet mot ett liberalt värdesystem* i vilket autonomi, individuell frihet och val, nytta, produktivitet, effektivitet och framgång är viktiga ideal; och sist, men kanske mest problematiskt, (6) *idén om ett inklusivt människovärde förunnas endast människor som passar in i ett normalitetsparadigm*, och därför är människor med funktionsnedsättningar mindre värda än så kallade normala människor.

I avhandlingen diskuteras en rad historiska och samtida föreställningar om kroppslighet, hälsa, reproduktion, och människovärde. Därigenom exemplifierar jag olika sätt på vilka en begränsad syn på både det mänskliga och på moral manifesteras. Utifrån dessa pekar denna avhandling på behovet av ett etiskt ramverk som öppnar upp för att tänka kritiskt kring sociala implikationer av olikhet och annorlundaskap, och kring sätt på vilka vissa människor ses som mindre värda än andra. Förutom en kritisk diskussion innefattar avhandlingen också en konstruktiv ansats att bemöta de problematiska aspekter som framträder i de kulturella narrativen. I det följande presenteras några särdrag i dessa.

I samhället finns en stark föreställning om att funktionsnedsättningar är lika med lidande. Historiskt sett har lidande varit en central fråga i religiösa och etiska diskurser, inte minst i anslutning till frågan om det goda livet. Lindrande, förhindrande och eliminering av lidande har blivit viktiga mål inom hälso- och sjukvård, liksom i biomedicinsk vetenskap. För att medicinska experter och sjukvårdspersonal fungerar som de primära ”portvakterna” för förståelsen av hälsa har den medicinska synen på funktionsnedsättningar tillsammans med normalitetsnarrativet stärkt föreställningen att funktionsnedsättningar är en katastrof som måste undvikas till varje pris. Trots att olika frihetsrörelser – så som kvinnorörelsen och handikapprörelsen – gjort anspråk på rollen som portvaktare för hälsa, har dessa tenderat att fokusera primärt på att förskjuta makten från en aktör till en annan, utan att grundligt ifrågasätta de förtryckande element som finns i inbyggda i själva makten. Därför för jag i den här avhandlingen fram argumentet att tolkningsföreträdet vad gäller hälsa bör utmanas och flyttas – förslagsvis till teologin – men också att detta projekt behöver ha en genomgående självreflexiv och självkritisk relation till den makt som tolkningen medför.

Ett centralt argument, och samtidigt metodiskt grepp, i avhandlingen är att erfarenhetsberättelser om funktionsnedsättningar, tillsammans med sociala, historiska och kulturella förklaringsmodeller, kan vidga den tongivande medicinsk-biologiska synen på det mänskliga och på hälsa. Jag menar alltså att kroppar som skiljer sig radikalt från den förmodade normen kan producera ny kunskap om mänskligt varande, samtidigt som det också bör understrykas att många av de berättelser som lyfts fram i avhandlingen vittnar om att många funktionsnedsättningar innebär reell smärta och lidande. Den springande punkten i många berättelser är dock att smärta och lidande inte behöver definiera den totala mänskliga existensen. Många som lever med kronisk smärta bär vittne om att det går att lära sig leva med smärta. Därför är ett viktigt steg i att tänka annorlunda om funktionsnedsättningar att aldrig tillskriva smärta mening. Trots att det föreligger en uppenbar risk i att på detta sätt trivialisera en annan människas upplevelse av smärta som en tragisk verklighet, menar jag att det motsatta är ännu mera problematiskt. I denna avhandling lyfts just detta, att funktionsnedsättningar tillskrivs mening, upp som en central orsak till att människor med funktionsnedsättningar blivit offer för marginalisering. Genom att lyssna till, och ta på allvar, berättelser om och av människor i smärta, menar jag att vi bättre kan förstå vad det innebär att acceptera smärta och lidande som oundvikliga element av det mänskliga livet och varandet. Genom dessa berättelser kan relationen mellan kroppen och självet, mellan enskilda subjekt och samhället, visa på en viss frihet från de kroppsliga begränsningar varje människa står inför.

Utöver detta narrativa perspektiv diskuterar jag i avhandlingen en specifik teologisk syn på mänskligt varande och hälsa. Denna teologiska syn baserar sig särskilt på en så kallad kroppsöverskridande och relationell föreställning av den mänskliga existensen. Jag argumenterar för att ett sådant perspektiv öppnar upp för ett synsätt som ger utrymmer för tanken att personliga relationer är både nödvändiga och avgörande för mänskligt välbefinnande. Därtill öppnar det upp för en syn på hälsa som inte jämställer funktionsnedsättningar med helheten av mänskligt varande. En teologisk förståelse av människor som *skapade* varelser aktualiserar på vilka sätt begränsningar, beroende och relationalitet är inbyggda i det mänskliga, vilket jag menar frammana ett specifikt förhållningssätt till andra människor. En kropp i smärta behöver en annan människas vård och omsorg. Därför kräver lidande hos den andra att vi bemöter den andra med solidaritet och kärlek. Detta är det moraliska kravet som finns i relationellt mänskligt varande. När mänskligheten och personskapet erkänns i den andre, i den med funktionsnedsättningar, är det moraliska kravet att underlätta livsomständigheterna för den andra – att göra den andras liv uthärdligt. Detta förhållningssätt manar var och en att sitta med den som lider, och tillsammans bära det som verkar vara olidligt. Människor som konstant blottas av sin sårbarhet och sitt behov av andras hjälp kan lära de som desperat försöker dölja sin egen sårbarhet att livet kan vara gott *så som det är*. Därför framhåller jag att människor med funktionsnedsättningar bär vittne om skönheten i ömsesidigt beroende, snarare än om en fruktansvärd isolation. Ur detta perspektiv behöver inte funktionsnedsättningar utesluta goda framtidsutsikter eller en god livskvalité.

Jag argumenterar för att ett teologiskt perspektiv kan förändra sättet på vilket hälsa vanligen upplevs och förklaras, och därmed kan tanken om ett inklusivt männoskovärdesbegrepp rimliggöras. Frågan om hur principen om alla människors lika värde kan göras relevant, beror sist och slutligen på de sociala och politiska nätverk som människor finns i, hur människor blir betraktade och behandlade, och huruvida livsomständigheterna för människor underlättas. Ett inklusivt människovärdesbegrepp är således i händerna på den andre, eftersom allt mänskligt liv är det. Därför försvarar jag i den här avhandlingen människovärdesprincipen som ett värdeåtagande som förkroppsligas i institutioner och praktiker, och i små gester som uttrycker ”det är gott att du finns”. Detta förhållningssätt är i kontexten för denna avhandling förklarat genom idén om vänskap eller nära relationer. Den syn på vänskap som jag diskuterar handlar i grunden om ömsesidigt beroende, och om en syn på kärlek som sårbar. En sådan kärlek placerar den egna lyckan i händerna på den andre. Genom att inte bestämma hur eller vem den andre borde vara för att ses som värdefull, kan vänskap och kärlek fungera som redskap för att bredda på själva livssynen. På detta sätt kan vänskap också förstås som en motberättelse till tongivande etiska narrativ, och som en katalysator for moralisk transformation.

Trots att det ofta sägs att egenskaper och kapaciteter inte är kriterium för innehavandet av människovärde finns det en stark tendens i kulturen, speciellt inom hälso- och sjukvården, att anta att människor med funktionsnedsättningar är mindre värda – moraliskt, ekonomiskt, och mänskligt – än människor som kan sägas passa in i normalitetsparadigmet. Jag menar att om en tar på allvar att människovärde och mänskliga rättigheter är centrala värderingar i samhället, måste vi garantera att alla former av mänskligt liv skyddas av dessa värderingar. I ett sådant samhälle kan inte praktiker existera som ifrågasätter värdet hos vissa människor. Istället för att människor ska anpassas efter ett färdigformat samhälle, bör alla människor – så som mänskligt liv faktiskt levs och upplevs – först erkännas, och utifrån den mångfald av mänsklig erfarenhet som finns bör samhället formas.

Historien kan inte ändras, men precis som historien formar nuet kan handlingar och förhållningssätt idag forma framtiden. Så som fosterdiagnostikpraxisen och praxisen kring selektiv abort ser ut idag bidrar den inte till en framtid i vilken diversitet bland människor uppmärksammas och ses som värdefull. Istället skapar den eugeniska logik som finns inbyggd i sådana praktiker ett samhälle i vilket vissa människor är värdefulla och värdiga, medan andra inte är det. Istället för att skapa en värld utifrån redan bestämda idéer om vem som gör världen vacker, kunde den sanna skönheten i världen upptäckas genom acceptans av den oförutsägbarhet mänskligt liv innebär – i vilken form den än tar.

Inklusiva samhällen är välkomnande samhällen. Ett samhälle som välkomnar människor med funktionsnedsättningar värdesätter deras närvaro och saknar dem om de inte är där. Inklusion handlar därför inte bara om att acceptera någon som redan är här, men om att säga att världen faktiskt är en vackrare plats tack vare denna någons närvaro. Alla människor vill bli erkända och värdesatta, och därför handlar inklusion inte enbart om någon enskild individ eller minoritetsgrupp, men om alla människor. Inklusion är inte primärt ett politiskt program, men ett förhållningssätt och en attityd. Det är ett sätt att tänka, och ett sätt att behandla andra. Därför finns det moralisk signifikans i hur människor relaterar till varandra. Inklusion handlar alltså om att alla människor är värdefulla, och om att alla människor har rätt att höra till.

Carolin Ahlvik-Harju

RESISTING INDIGNITY

A Feminist Disability Theology

This critical constructive work sets out to show that much of our physical, social and cultural spheres are designed in ways that propagate patterns of harmful exclusion for people with disabilities. The persistent assumption that people with disabilities are the undesirable “other” in society is argued to be a consequence of such patterns. Since reproduction and founding a family are important aspects of most people’s lives, the author discusses the practice of prenatal testing and selective abortion as a relevant case for highlighting common notions of what it means to be human and to have a human body.

By discussing various historical and contemporary notions of embodiment, health, reproduction, and dignity, the author exemplifies ways in which a narrow view of both humanity and morality manifests itself, and points at the need for an ethical framework that enables us to think critically about the social implications of difference, and about the ways certain people are often seen as more valuable than others.

By implementing a feminist disability perspective, drawn mainly from disability studies literature encompassing feminist approaches and disability theology, as well as experience-based narratives of disability, the author identifies and analyzes problematic aspects of, and gives constructive responses to, patterns of exclusion that occur in the cultural narratives of normalcy, parenthood, dignity, and friendship.

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