Disabled Desires?

About Individuals with Severe Mental Impairments and the Human Right to Sexuality

The Scream – Edvard Munch

Master Thesis Applied Ethics

Utrecht University, 2012

Student: Ada Aust (3862852)

Supervisor: Dr. Ineke Bolt

Second Supervisor: Caroline Harnacke

For my brother.

Table of Content

Abstract

This thesis seeks to argue for a policy concerning the sexuality of individuals with severe mental impairments living in a home[1]. The general situation concerning the sexuality of individuals with severe mental impairments will be illustrated as well as shown that in homes the matter of sexuality still causes unease and vagueness of how it should be handled. By referring to the human rights framework, a human right to sexuality is stipulated and justified. Additionally, this thesis tries to show that there is a responsibility of homes towards the right to sexuality in the context of the severely mentally impaired. The issue of the extent of the home's policy will be shortly addressed. It will be concluded that an interdisciplinary study is needed in order to achieve appropriate guidelines which take the wishes and vulnerability of the severely mentally impaired as well as their carers and parents into account.

Introduction

My brother, David, turned 21 few months ago. Not only does he have a severe mental impairment, but also a severe physical one. This is due to a dysfunction of the myelin part of the brain. The actual reasons for that are unknown. It is likely that it is rooted in a metabolism disease which might be traced back to a genetic heredity transmission. His mental abilities can be compared to an infant of 8-10 months. His physical impairments are highly visible as well and include, among others, the inability to walk and the necessity of using a wheelchair.

[1] In this thesis, the expression 'home' refers to 'residential home', where individuals with severe mental impairments live. Residential homes are facilities with internal day structuring. Day structuring encompasses, for instance, arrangements to advance life skills in context of the client's personal sphere and social contacts as well as arrangements to prepare, form and conduct leisure activities (*my translation,* 'Erster Bericht über die Situation der Heime und die Betreuung der Bewohnerinnen und Bewohner', 1)

His life is highly dependent on my parents, me and the carers in the home he lives in. When he is hungry, someone has to feed him. When his diapers need to be changed, someone needs to change them for him. When he wants to play, someone needs to realise this as well. His interests and what he likes is a life long learning process for my parents and me. It starts with small things: He cannot, and hence does not, tell us whether he likes the sausages that way or rather in another or not at all. He does not tell us whether he likes the trousers he is wearing, or not, or would rather have them in black.

We had and still have to figure these things out – through a different way of communication (i.e. through his mimic and emotional expressions preferences can be identified). We learned through different forms of communication that he likes swimming, horse riding, going for walks, that he loves sausages in any way and that he doesn't care about his trousers as long he looks pretty. Some of the things we know for sure, others we assume. With that comes a certain responsibility to form a life according to his own wishes, interests and needs. We have to tell the carers what he likes. We have to make sure that he gets what he needs to have a life based on presumptions what he would like to do in certain moments of life (which other individuals would just do). On the other hand, we are also dependent on the carers to let us know what they figured out. There is my brother who depends on us to give him the best opportunity to develop and with that we need to hand him over to carers, who are professionals in this area, and to give him the opportunity to be with his friends and in an environment where his skills are improved.

In the past years, I have been seeing my brother occasionally rapping his diapers in the area of his genitals. He further likes to touch breasts. Is this an indication that he has a need for the exploration of his sexuality? Or is it rather a biological process which just happens? Are we responsible, because of his high dependence on us, to give him a sexual education or a sort of therapy to help him to live his sexuality to the fullest? And how do we know, that he wants a sexual education or a sort of therapy, *or* is rather satisfied with the way it is? Above that, can we assume that the home, he is living in, has a responsibility, too?

The example of my brother is only one example among many others. The following thesis is concerned with the sexuality of individuals with severe mental impairments.

I will mainly concentrate on individuals with severe mental impairments. This is because of two reasons. Firstly, and obviously, because of personal interest and necessity to explore this matter to be able to handle a very intimate situation as best as possible. And, secondly, because of the experience, that in homes those situations are handled in diverse ways. Due to the diversity of how the situations are handled, the individuals with severe mental impairments have different access to their sexuality (some of them not even at all). On the other side, the carers have to handle intimate situations which leaves them at unease, because of the uncertainty how to handle those situations. In many of these situations a moral conflict occurs as I will exemplify in the cases I am going to illustrate in chapter one. The matter of sexuality in the context of individuals with severe mental impairments lacks discussion and practical guidelines for the carers and the homes.
Further, I believe, that there is a moral difference between individuals with only physical impairments, individuals with light mental impairments and individuals with severe mental impairments. I grant this difference in the fact that the severely mentally impaired are unable to act upon (and sometimes even to realise) their needs and wishes due to their mental inability. Certainly, they intuitively act according to their instincts and do what they need and wish for, however, their cognitive abilities do fail them to rationally identify them, whereas people with physical impairments and light mental impairments are able to identify their wishes and needs and are able to act according to their wishes and needs. This results in a relationship where one party, the individuals with severe mental impairments, is highly dependent on the other, the carers, in regard of the fulfilment of basic needs and wishes. Thus, the question is raised regarding the moral responsibility of homes towards the sexuality of their clients.

The exploring and living of sexuality can include the matter of reproduction as well. I will leave this aspect out, because of two reasons. Firstly, reproduction is not of primary issue in most cases where individuals with severe mental impairments are living in a home due to the lack of living and exploring their sexuality in the first place. Therefore I argue, that in the first instance the issue of how to handle the existence of sexuality of

the individuals with severe mental impairments living in homes should be solved. Secondly, reproduction, as the cases will illustrate, does not play a role at all. Many of the clients with severe mental impairments would neither mentally nor physically be able to have coitus and to reproduce. Certainly, there are cases where the matter of reproduction plays a role, however, as important this aspect is to discuss, I rather would like to concentrate on other aspects of sexuality.

Sexuality does involve many other things than only having sexual intercourse. The *World Health Organisation* (WHO) defines sexuality as follows:

> "Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors."

Hence, I will concentrate on a concept of sexuality that involves primarily eroticism, intimacy and sexual pleasures, because in many cases the severely mentally impaired are unlikely (due to body functions and mental abilities) to reproduce. This should not mean that I am not aware of the fact, that there are cases where this aspect has to be discussed. Nevertheless, because severely mentally impaired living in homes already lack the experience of eroticism, intimacy and sexual pleasure, it is of primary importance to discuss this matter first, and leave the aspect of reproduction, and with that the aspect of coitus, out - for *now*.

The central question is whether a home should implement a policy regarding the matter of sexuality, and if there is a moral obligation, of what nature shall this policy be?
In chapter one, I will present four cases of individuals living in a home with different physical and mental abilities as well as an example how a carer is dealing with the situation. I hope to demonstrate with these examples that there is not only a diversity within the cases regarding the matter of sexuality, but also general an uneasiness as to how to handle those situations. Further I will try to give an overview of the situation concerning sexuality and individuals with severe mental impairments living in a home. My aim is to illustrate that there are indeed situations where interests conflict, where

moral questions arise and above all, and most important, that the matter of sexuality in the context of individuals with severe mental impairments living in a home needs to be seriously discussed.

Chapter two is concerned with the question whether the right to sexuality can be identified as a human right. First, a human right to sexuality will be derived from the *UN Universal Declaration of Human Rights* (UDHR) and the *UN Convention on the Rights of Persons with Disabilities* (CRPD). Afterwards, the dispute about the human rights framework will be shortly outlined. It will be argued, with the help of Martha Nussbaum's Capabilities Approach, that there are indeed human rights. The chapter concludes by claiming that a life worthy in dignity also encompasses a human right to sexuality.

Chapter three evaluates whether the right to sexuality entails responsibilities of the homes where individuals with severe mental impairments are living. I will argue, that the conception of negative and positive rights is vague, because some rights can be considered, depending on phrasing and situation, as either positive or negative. Hence, I claim that the right to sexuality should not be defined in terms whether it is a positive or a negative right, but rather whether it entails responsibilities of others; and if yes, from whom and of what kind, depending on the occurring situations. I strive to demonstrate that in the situation of the severely mentally impaired living in a home there is indeed a responsibility to implement a policy.

Chapter four addresses the issues of the home's policy. Thereby, analogues to the cases presented in chapter one, the moral challenges will be identified. By virtue of the complexity of these challenges, the chapter concentrates only on the question of sexual assistance. In this regard, the chapter aspires to discuss who is competent to decide whether sexual assistance is an option with the help of the risk-related standard of competence. I do not intend to give an explicit answer, or give a complete overlook of the moral challenges involved; I rather aim to highlight, that an interdisciplinary discussion is necessary based on the complexity and difficulty the issue of the sexuality of individuals with severe mental impairments involves.

I. The Sexual Needs of Individuals with Severe Mental Impairments

1.1 Five Cases

Many individuals with severe mental impairments are living in homes. They are dependent on their carers for everyday actions – ensuring a humanely standard of hygiene and fulfilling the clients basic needs. They are further dependent on the carers that they organise around them a life according to the wishes and needs of the individuals with severe mental impairments. This can involve many things: their favourite food, therapies, the opportunity to listen to their favourite music, going for walks, making sure that their clothes are fresh and taking care of their health state.
In consequence, the carers in the home have to adapt to very different situations and individuals. Furthermore they are responsible for their clients to make sure that their basic needs are fulfilled, and, sometimes even more, to give them the possibility to enjoy their preferences in regard of what they like to do, to eat etc, in order to fulfil what they wish for.

Being severely mentally impaired, can mean many things. The WHO defines disability as follows:

> "Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives."

Mental disabilities are defined in terms of a certain lower level of intelligence with the resulting effects on language, motor and social abilities. There is a broad variety of cognitive disabilities. In general cognitive disabilities are arranged in a serial order from light to heavy depending on the level of intelligence. In individuals with a severe mental impairment, or profound mental retardation, the IQ is under 20 in adults, which corresponds to a mental age below three years. This results in severe limitation in self-

care, continence, communication and mobility, and includes profound mental subnormal.[2]

Accordingly, individuals with impairments differ in their needs and abilities. Physical impairments, as well as mental ones, do play an important part. Additionally, every individual is different and requires a different caring and has different needs to fulfil. This has also an effect on their sexuality and involves a complexity of aspects, corresponding to their abilities, which need to be considered.

In preparation for this thesis, I visited a home in Germany where individuals with severe mental impairments live. The individuals living there are all very different from each other. All of them have mental impairments. Some of them are more severely mentally impaired, others less. Some of them are able to feed themselves, others have to be fed. Some of them are able to walk, others are sitting in wheelchairs. Some of them are able to talk, random words, some can even (more or less) have proper conversations. Others again never will speak a single word, but rather make sounds. Some cannot move their legs, others have bodily deformation and yet others cannot see or hear. Some of them do express their sexuality very obviously, others not that obvious, and, then again, others not at all.

This list goes on and on. It clarifies that, when talking about impairments, the diversity of cases seems endless, each differs from the other. To the different needs and abilities, physical and mental functions, are added the different characters and personal needs which differ in each of the individuals who are living in the home. For the carers this means to adapt and to identify certain needs of the clients – every person individually. When talking about sexuality the diversity of physical and mental impairments makes the matter of sexuality in cases of the severely mentally impaired even more complex. This is based on the fact, that every individual not only develops their sexuality in a unique way and experiences it, but also in these cases other aspects, such as their physical and mental abilities as well as their health status, have to be considered (as the four following examples will illustrate).

[2] See World Health Organisation Homepage for further information about the classification of disabilities and resulting effects on physical and mental abilities.

Person A needs a high level of assistance. This implies for instance feeding, changing of diapers and washing. He is unable to talk, but able to make sounds to signalise what he wants and needs. Those sounds are easy to interpret for the carers, and, thus, his likes and dislikes can be identified. It is obvious that he has a need for sexuality. Despite his heavy physical impairments, he is able to touch himself. He further is able to masturbate. It needs time until he reaches his genitals since he is wearing diapers. Due to his epileptic attacks, someone always needs to be close to him. On the weekends, he has the possibility to be naked and to enjoy himself. Nevertheless his carer has to be in the room while he is enjoying himself, because of the chance of an epileptic attack. When it happens that he is touching himself in a common room, then his carer stops him from doing it. He is only allowed to enjoy himself when space and time is organised for him and it depends, again, on the carer whether he can be naked at the same time.

Case two contains another aspect – the aspects of assumed beliefs and wishes. Due to the fact that the parents of Person B are strict believers and the matter of sexuality only is of importance in context of reproduction within marriage, the topic of sexuality has never been addressed. Moreover, carers are unsure whether to address the issue or not, because of the unease towards certain believes of the parents and the assumption that this person might follow the same beliefs. In addition to that, Person B is unable to touch himself, because of his physical restrictions. It is questionable whether his sexual impulse does exist or not since he is unable to move and lacks verbal communication skills. Sexuality, therefore, does not play a role in his everyday life.

Another person, Person C, also severely mentally impaired, does not feel anything in her legs and therefore has also no feeling around her genitals; however, she is slightly able to articulate. She expresses intimacy through the need of physical closeness to other people. She hugs, kisses and touches other people. The carers let her go on with it; nevertheless, whether she wishes for experiences of other aspects of sexuality, such as pleasure and eroticism, or not, is left open. The possible problem can occur when she shares intimacy with individuals who do not want to be hugged or kissed. When she hugs someone, it may happen, that she holds on to the hugged person and does not want to loosen the hug. It is problematic for the carers to identify where to draw the line in regard to who she is allowed to hug, to kiss and to touch. She further developed her own strategy to get physical closeness.

Person D is severely mentally disabled. His mental abilities correspond to the age of an infant between 8-10 months. His body features developed more or less ‘normal’. He is unable to talk, or to walk, and sits in a wheelchair. Through sounds he is able to communicate with others, yet, in many situations it is hard to identify what exactly he wants. It happens that he fingers himself in the area of his genitals, but this leaves rather the impression of the sexuality of a small child. He further likes to explore his body when he is, for example, taking a bath. Physical contact to others is of high importance to him. This can be identified by the smile he gives the other person, when he is hugged or kissed on the cheeks.

Those cases intend to demonstrate that sexuality may be expressed differently, dependent on the individual. One can list many more examples which all would differ. I believe these examples do demonstrate a point. It is obvious that sexuality among individuals with severe mental impairments is as different and individualistic as their characters and impairments are as well.

Angela Moll concludes from her research, that people with a severe mental impairments experience their sexuality in an unique way – as every other human being does. The experience of sexuality varies from every individual, because, as the definition of the WHO illustrated in the introduction, through thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships sexuality is expressed and experienced. Those aspects vary dependent on the individual who experiences it. Individuals with severe mental impairments might not have relationships or the direct need for the sexual act, however, this is not necessary for having a sexual need. As the definition of WHO points out sexuality does not necessarily involve all aspects. As the examples show eroticism, pleasures and intimacy are expressed through different ways of behaviour and practices. In other words, masturbation can be identified as a pleasure to enjoy and hugging and kissing as need for intimacy. Intimacy and pleasure are also involved in many other aspects of our sexuality such as being naked and enjoying one’s own body. In the cases of individuals with severe mental impairments those aspects are of much greater importance, and are part of their sexuality, because the physical development of the sexuality of severely mentally disabled persons takes place in most cases in the same way as people without disabilities develop their sexuality.

Nevertheless, due to the discrepancy of their sexual-age and their intelligence-age, problems can arise which are mainly rooted in their social environment and have an high impact on the psychosexual development of the severely mentally disabled (*my translation,* Moll 39).[3]

Above that, as the examples might show, there is no prototype of an individual with mental impairments. They all differ from each other and so do their expression and experiences of sexuality differ. *Pro Familia*[4] claims, that

> "from the research which took place over the last years, one thing became clear: The development of sexuality is as important to every individual with mental impairment as for any other individual without impairments. Many specialists in this area agree on that individuals which are mentally impaired do not have a 'special' sexuality. They have the same basic needs as every other human being has" (*my translation,* Pro Familia).

Sexuality cannot be defined in one particular way. As three of the examples showed, individuals with severe mental impairments satisfy their need for sexuality, and their sexuality itself, differently in their subjectively unique way. One of them expresses it through masturbation, the others through the need of body contact. Sexuality is therefore in this paper not reduced to genital sexuality, but rather to the intimate interaction between individuals and the enjoyment of one's own body. Bodily closeness like hugging and kissing belongs to this as well as the matter of masturbation and nakedness.

Sexuality and disability encompasses another problem. As Tom Shakespeare points out, the disabled are often seen as asexual (9). There is indeed a certain ideology about people with impairments when it comes to sexuality. Michel Desjardins explores in his article *The Sexualized Body of the Child* the picture of the intellectually disabled as an eternal child who is asexual (70). The picture of "the eternal child" can be applied to the severely mentally disabled, too. Another aspect is bodily norms (features) that are implied when talking about sexuality, which the disabled apparently are unable to satisfy. Abby L. Wilkerson introduces the concept of "Normate Sex", a social constructed ideology about sexuality. "Normate Sex" has the characteristics of being

[3] See Moll, especially Chapter IV, for an insightful overlook on the resulting problems.

"Heterosexual, Married, Monogamous, Procreative, Non-Commercial, In Pairs, In A Relationship, Same Generation, No Pornography, Body's Only" (Wilkerson 186).

People with severe mental impairments seem not to fit into the socially created ideology about sexuality and have, thereby, often been claimed as asexual. This ideology is created on the ground of many reasons: in the past the sexuality of the disabled, and especially of the severe mentally disabled, were suppressed and was seen as non-existing. This attitude changed whereas the state and the handling of educational institutions still create a certain ideology towards the sexuality of severely mentally disabled - an ideology, which is not equal to the ideology of the sexuality of people without disabilities. This ideology is, for instance, by reasons of avoidance in media, in politics and in education. When talking about sexuality, the subject often only includes people with 'norm' body and mind features.

Returning to the above mentioned cases, the side of the carer is also of crucial importance in homes, because the possibility of expressing the sexuality is highly dependent on the carer and how he/ she is handling the situation and their own view on sexuality.

Person E is a carer in a home. She tries to give space and time for intimacy, but her clients are not allowed to touch themselves in the common rooms. She is very scared of the aspect of misuse and, thus, is very sceptical towards sexual therapies and assistance for individuals with severe mental impairments.

In the home there are also individuals who never expressed a need for sexuality, who never touched themselves or demonstrated their sexuality in any other way. This has to be differentiated again between those who are able to do it, and those who are unable due to body functioning. It is not always the case that there is a need and the cases have to be considered on an individual basis.

[4] Pro Familia is a German non-profit organisation that offer guidance with questions concerning sexuality and relationships, pregnancy and the planning of families.

Person E: “Our clients are not often naked or have the possibility of lying in bed with a nice blanket to experience their body. Body contacts are uncommon as well. (...) You also happen to find yourself in extreme situations, when, for example, you’re pampering someone and then this person gets an erection.” (*my translation*).

Since there is a close interaction between carers and clients in homes, not only the positions of individuals with severe mental impairments is of relevance, but also the position of carers. Carers happen to find themselves in situations where the intimate needs of their clients become obvious. This causes among carers not only unease, but also insecurity how to handle these situations.

1.2 The Concept of Sexual Assistance as an Option in Exploring Sexuality

An option for exploring sexuality introduces the concept of sexual assistance. Sexual assistance can be seen as one option for an educational process in exploring one’s sexuality in the cases of severe mentally disabled. Sexual assistance can be defined in two ways: active and passive sexual assistance (Stinkes).

According to Stinkes, passive assistance means to create concrete requirements for the realisation of a self-determined sexuality. This can happen, for instance, through sexual pedagogy or sexual advisory, through information about methods, through the acquisition of materials and adjutants, through the acquisition of videos and also through the organisation of prostitutes or appointment with other services. Active assistance describes all forms of assistance, which imply that the assistant perform sexual interactions with the client. This can be part of an erotic massage, the support for masturbation or the actual sexual act (*my translation*, Stinkes 5).

Lothar Standfort differentiates between sexual assistance and sexual companionship. The former implies that the disabled person tells the assistant what he needs and the assistant fulfils the request which the disabled person is unable to carry out. A sexual companion offers a surrogate relationship. For a certain amount of time the sexual companion is in an emotional relationship. During this time different experiences can be made, sexual ones, too (*my translation*, Standfort 28). Consequently when it comes to active assistance one has to differentiate between sexual assistance and sexual companionship.

Some of the passive and active sexual assistance described above are not applicable to every individual with a severe mental impairment; even when it comes to sexual assistance certain problems do occur in the sense that the client tells the assistant what to do. Both authors mention that sexual assistance has not been practised on individuals with severe mental impairments yet. However, through physical therapies individuals with severe mental impairments could be instructed how to handle their physical sexual needs, how they can fulfil those needs and to give them the opportunity to develop their sexuality according to their own needs; and, beyond that, how to express it to their family and carers to let them know that they have a sexual need. Additionally, sexual companionship can take place in order to experience their sexuality on a psychosexual level.

When I am talking about sexual assistance in context of the severely mentally disabled in the following, I refer to the active and passive concept. My conception differentiates between Stanford and Stinkes conception, because, both of their conceptions rather apply to individuals with physical and/or light mental impairments. In the context of severely mentally impaired, the passive concept is be understood in the sense of pedagogical educational process in terms of giving space and time, educating the mentally disabled through learning therapy how to handle their physical needs and how to advance those to be able to fully live and understand their sexuality. The active is to be seen in a way of a sexual companion, who interacts with severely mentally disabled on a physical and emotional level.

1.3 Ethical Challenges

Tom Shakespeare concludes from his research about the sexual politics of disability, which focuses on individuals with either physical and/or light mental impairments, that "disabled people's rights to sexual expression, on the one hand, and the freedom from sexual abuse on the other hand, are not assured in the majority of residential settings" (36). Shakespeare highlights very important aspects. There is the right to sexual expression, but also the fear of misuse. Person E, the carer, in my example, does personify this dilemma of the contradicting elements of 'inflicting harm on someone' and 'giving the opportunity that a need is fulfilled'. She wants to give the clients the

freedom to sexually express themselves, but at the same time the fear of misuse always plays an important role in the question what should be offered to the individuals who express a certain sexual need. Another issue is the matter of normalisation of sexuality in the cases of individuals with severe mental impairments. Again Person E demonstrates that she tries to adhere to socially common agreed norms when she stops them from touching themselves in the common room. Additionally the opportunity of sexual expression is in practise highly dependent on the carer's own view on sexuality and therefore, the question arises, how to evaluate the cases where subjective values are imposed on the individuals. The example of Person B shows this, too. The parents who are highly religious and never addressed the issue of sexuality. Because, according to them, it just does not exist.
Consequently, the question is raised whether a home has a responsibility to adapt a policy/ guidelines concerning the matter to secure for their clients a free development of the sexuality?

If there should be a home's policy what aspects should be discussed in these guiding principles? One aspect is certainly the matter of sexual assistance: If there is a responsibility, when should passive or active assistance take place? There are certain risks involved when it comes to the question of sexual assistance which have to be considered in this context. The lack of experience of active sexual assistance of individuals with severe mental impairments can cause emotional disturbance and misunderstanding of the relationship towards the companion. Furthermore, there can be cases imagined, where the wish for this assistance is only attributed. Therefore the problem of abuse comes in, when the question is posed whether there is really a wish for assistance, or not.

Hence, the question is posed, whether homes should secure the opportunity for the living of sexuality for individuals with severe mental impairments. Part of this question includes the problem that individuals with severe mental impairments require assistance in every day life situation. In regard to their sexuality they require assistance, too. The question, whether a third party has a responsibility to ensure the opportunity for living their sexuality or not, needs to be addressed.

I will try to answer these questions in the next chapter with the help of the human rights framework. The human rights framework entitles rights to all human beings, and, thereby, includes also individuals with severe mental impairments. Above that, the UN introduced in 2006, a *Convention on the Rights of Persons with Disabilities*. Further the conventions refer, directly and indirectly, to sexuality.

II. A Sexual Right as a Human Right?

In this chapter I will shortly illustrate that a right to sexuality can indeed be derived from the *UN Universal Declaration of Human Rights* (UDHR) as well as the *UN Convention on the Rights for Persons with Disabilities* (CRPD). Human Rights represent universal moral claims for all individuals living in this world and, thereby, do face some criticism (which will be outlined in the following).
Hence, I will claim, despite the criticism, that there are indeed human rights which are universal and every human being should be entitled to. This claim can be supported by Martha Nussbaum's capabilities approach. Additionally, whether the sexual right can be morally justified as a human right will be discussed.

2.1 Human Rights Conventions about Sexuality

In this paragraph I will explore the status of international rights on the basis of human rights by the United Nations in context of sexuality. First I will identify aspects of the *UN Universal Declaration of Human Rights* and the *UN Convention on the Rights of Persons with Disabilities* in a not direct context with sexuality, but which can be interpreted in that way. Second, I will show that the matter of sexuality is explicitly mentioned in the *UN Convention on the Rights of Persons with Disabilities*.

The UDHR does express at certain points, not explicitly, a right to sexuality as a human right. I will not go through the conventions in detail; however, exemplify that a right to sexuality is recognised as a human right.
The UDHR claims in Article 3 that "Everyone has the right to life, liberty and security of person." This article obviously does not state anything about sexuality, but about the right to life and liberty of a person. It can be interpreted in a way, that life and liberty of

a person entails also a right to development as a human being. Sexuality, as it was defined at the start of this thesis, is one of the central aspects of being a human. Article 3 of the UDHR can be interpreted in a way that sexuality is part of being a human and would grant a right to this part of life and liberty of a person, too. The same argumentation can be applied to Article 10 of the CRPD. Article 10 states that "States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others".

The central part of these two articles is the right to life and being a person. As sexuality is part of being a human, and the UN Conventions declare a right to life and the development of a person in liberty, a right to sexuality can be implied. In regard to the stated definition of sexuality, sexuality does encompass many things and therefore the full expression is not necessarily part of being a human, but when one has a sexuality and a wish for exploring this sexuality, a right can be derived.
Article 14 of the CRPD, again has the same central aspect: "(1) States Parties shall ensure that persons with disabilities, on an equal basis with others: (a) Enjoy the right to liberty and security of person". Of course, these are very vague interpretations. The articles themselves are rather concerned with the liberty and security of a person in a sense of being able to express one's opinion, live a life according to one's wishes, not having the fear of danger, being not political controlled etc. Nevertheless, when one takes for granted that sexuality is part of being a human, and its development is part of our development of personality, as Sigmund Freud claimed, it is also part (amongst other things like the development of opinions, interests, political views and so on) of our integrity as a person which should not be limited as proclaimed by the UN Conventions. Certainly not having a need to sexuality, i.e. being asexual, does not mean not being a human. The definition of the WHO does include those cases, too, when it is stated: "sexuality can include all of these dimensions, not all of them are always experienced or expressed".

More directly is the issue of sexuality addressed in Article 17 of the CRPD:

> "Protecting the integrity of the person" that states shall "(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area

> of sexual and reproductive health and population-based public health programmes".

But what is meant by sexual health? Sexual health can be defined as follows:

> "Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." (WHO)

According to the interpretation of the WHO the Article 17 (a) of the CRPD can be displayed in a way that disabled have a right to a respectful and positive development of sexuality and sexual relationships as part of their sexual health. Thus, as the WHO states, for sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. Hence, when disabled have a right to sexual health, a right to sexuality can indirectly be derived from it.

The claim that a right to sexuality can be implied from the UDHR is supported by Ruth Dixon-Mueller et al. She also claims in her article *Towards a Sexual Ethics of Rights and Responsibilities* that sexual rights can be derived from UN Declarations of Human Rights. According to her, for example, from the UDHR; where a right for self-determination, freedom of association and expression, liberty and security of the person, non-discrimination and equal treatment under the law, the enjoyment of the highest attainable standard of physical and mental health, and protection from cruel, inhuman or degrading treatment is included.

Additionally, Dixon Mueller states:

> "sexual rights also derive from principles of gender equality as affirmed in the 1979 Convention on the Elimination of All Forms of Discrimination Against Women and other documents, and from principles of non-discrimination based on sexual orientation and gender identity as proposed in the 2007 Yogyakarta Principles, among other sources" (Dixon-Mueller 111).

It is obvious that the articles of the UN Conventions do address aspects of sexuality. Nevertheless a clear statement what sexual rights as human rights entail is vague. An example, how a definition of sexual rights as human right might look like, illustrates the attempt of the WHO.

> "Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to the highest attainable standard of sexual health, including access to sexual and reproductive health care services; seek, receive and impart information related to sexuality; sexuality education; respect for bodily integrity; choose their partner, decide to be sexually active or not; consensual sexual relations; consensual marriage; decide whether or not, and when, to have children; and pursue a satisfying, safe and pleasurable sexual life." (WHO)

The issue of the vagueness addresses the *International Council for Human Rights* in their discussion paper on sexuality and human rights in 2009. This shows that a right to sexuality is recognised as a human right by the declarations, however, the problem is identified as follows: "The issue today is no longer whether human rights will engage with sexuality, but rather involves very particular practical questions: on what terms, for whom, for what purposes, about which aspects of sexuality, and with what limits."

Another problem of the human right to sexuality mentions Dixon-Mueller. She states in her article, that the concept of sexual responsibilities, i.e. the individual's responsibilities towards their fellow human beings, still differs according to the commentators. One of the problems listed I would like to illustrate here in context of sexual responsibilities in correspondence with individuals with severe mental impairments and their right to sexuality. Dixon-Mueller addresses the issue of abuse and the dilemma of not being able to exercise the right to sexuality: "Some argue that powerless persons may not be able to exercise their rights or meet their responsibilities without jeopardizing their personal safety, and that their inability to do so can result in 'blaming the victim'" (116).

In context of individuals with severe mental impairments, this issue highlights their vulnerability and the risk of abuse; and whether this would outweigh their right to sexuality. Another issue, which is not directly revealed in the UN Conventions, is the matter of responsibility of a third party, i.e. homes, carers and guardians, to the right to sexuality towards the individuals with severe mental impairments.

Before discussing the responsibilities of third parties towards individuals with severe mental impairments by evaluating whether a negative or positive right to sexuality can be derived by the UN Conventions, the human rights framework needs to be defended

in regard why human rights should be respected. In this context the question of whether a right to sexuality can be vindicated as a human right on moral ground, or not, arises.

2.2 In Defence of the Human Rights Framework

As the above demonstrated, a right to sexuality as a human right can be derived from the declaration of human rights by the United Nations. Human rights "aim at identifying the fundamental prerequisites for each human being leading a minimally good life" (Fagan, IEP). Thus, the right to sexuality can be characterised as being part of a minimal good life. The human rights framework faces challenges in regard of the justification of human rights in general and undergoes some criticism. In the following the central challenges will be shortly outlined.
I do not aim to give a solid and complete defence of the human rights framework since this is not central topic of my thesis; I rather seek to reason why I am of the opinion that there are indeed human rights and, thereby, why the human rights framework is a good approach for solving the problem of this thesis.

The *UN Universal Declaration of Human Rights* is founded on the grounds of the concept of human dignity, which gives reason why we must grant rights to all human beings (Düwell 1). In the modern conception, those rights have all human being just because they are human beings (Düwell 3). In the documents of the Universal Declaration of Human Rights " 'human dignity' refers to the inherent worth of each individual, who is consequently endowed with inalienable rights" (Düwell 3). Accordingly, human dignity is to be understood in the way that it has absolute value and cannot be balanced or outweighed. Further, analogue to the modern conception of human dignity, every human being has dignity, due to its inherent worth, and, thus, every human being has the status of a rights-holder (Düwell 3, *see also* Düwell 2010, 225).

The concept of human dignity, as such, is vague, undergoes major criticism, articulates different approaches and, as Marcus Düwell highlights, raises numerous questions, e.g. "Who has dignity?" and "What specific moral obligations follow from attribution of dignity?" (Düwell 1; *see also* Düwell 2010, 222). Moreover, it must be justified why the

concept of human dignity gives reasons to grant rights to all human beings, in the first place. In current discussion, as Düwell mentions, not only the subject of human dignity is at dispute, but also the normative consequences of a status of dignity (4; *see also* Düwell 2010, 216 f). These problems need to be taken seriously within the discussion about the justification of the concept of human dignity as the foundation of human rights. Simultaneously, the concept does undergo other challenges. Some participants in the discussion would refuse the concept of dignity and rather replace it by the concept of 'autonomy'; others again claim that the concept is ambiguous and vague (Düwell 4). The vagueness and dispute around the concept of human dignity also challenges the justification of the human rights framework, since it is based on the claim that human dignity grants human beings rights

Besides, there are different approaches taken towards the concept of human dignity. Some interpret human dignity "as the exclusion of complete instrumentalization, according to Kant's formula that we should never treat human beings as 'means only'" (Düwell 5). Others take the approach of a more formal concept of human dignity, and then again others understands the concept of human dignity in terms of human capabilities and agency in order to realise a life in dignity. The different conceptions of human dignity lead to a different derivation of normative content of the concept and, therefore, covers different rights within the human rights framework in the sense that it covers some fundamental rights or the whole set of the rights (*see also* Düwell 2010, 224).

The dispute around the foundation of human rights entails further challenges to the human rights framework. Jeremy Waldron claims the following:

> "The idea that there might be such things as human rights, valid for all peoples in all times and places has often seen implausible in the face of the wide variety of what we would call "oppressive" and "inhumane" practise that are taken for granted – even expected – in different parts of the world" (3).

Human Rights hold the claim to be valid for all humans in the world. They rest on the belief of the existence "of a truly universal moral community comprising all human beings" (Fagan, IEP).

This universality can cause problems, because of the claim to respect cultural and social pluralism. Andrew Fagan indicates that for moral relativists something like moral universality does not exist. For moral relativists, moral beliefs and principles are founded in social and historical background, and their validity is dependent only on those cultures and society where they exist in. And indeed, "it is not self-evident, that we are justified in assuming that human rights should be respected in the whole world and should trump all other practical considerations, especially as it is doubtful whether all worldviews are compatible with the framework" (Düwell 7). With the claim of moral universality, as Düwell identifies, comes along the assumptions of moral authority of the human rights. This is challenged, when we understand human rights only as the result of political negotiations. If we do so, the claim of moral authority is then implausible (Düwell 7). A third challenge the human rights framework faces is concerned with its development and applications as well as the new challenges the human rights framework encounters, e.g. climate change (Düwell 8). The question of the scope of the human rights framework adds to the list of challenges (*see also* Düwell 2010, 219 & 226f).

Despite the criticism around the foundation of human rights, I agree with the modern conception that all human beings have rights because they are human beings. This is founded in the idea that every human beings is a being of dignity due to the respect for the inherent worth of humans. Human beings have an inherent worth, because we are ends in ourselves. Kant acknowledges this in his humanity formula, when he states that the rational being, as by its nature, is an end and, thus, an end itself. Kant only refers to rational beings. Rationality is often referred to as a condition of being a dignified human being. This notion undergoes the risk, that some from the community of human beings are excluded from the community of human beings with dignity. Severely mentally impaired are mostly incapable of rationality, nevertheless, they are human beings.

By the simple fact of being human, we hold an inherent worth and are to be treated as an end in itself, because, despite mental abilities or physical appearances, we all have one thing in common – the fact that we are human beings. If one human being is claimed to have an inherent worth and is to be treated as an end in itself, then, I hold, all

human beings have an inherent worth – simply by the fact that we are human. Hence, every human being should be granted the same respect for its dignity.

Since we are beings of dignity, we are beings that are to be respected for our dignity. Human rights acknowledge this notion. Rights, which human beings should be entitled to, to ensure a life in dignity and the respect for our dignity. The fact that we are all human beings, and with that, are all of the same nature entails, indeed, needs, interests, and attributes we all share – independent of cultural, historical or social backgrounds. These basic characteristics all humans share, need to be respected based on the respect for our dignity and, this gives reason, that there are indeed human rights every human being is entitled to.

For example, the infliction of harm on a being with dignity would disrespect his inherent worth. Either physical or mental harm is done when someone is, for example, discriminated in any way, because of body features. It disrespects the human being as a being with dignity. Human beings are ought to be respected, because of their inherent worth of being a human and, therefore, the moral acceptance of the infliction of harm in circumstances grounded in historical and cultural backgrounds, I think, is unjustifiable.

However, Sigrid Graumann brings forward the argument, that the membership of a species *alone* does not imply normative conclusion (*my translation*, 75). And, indeed, Peter Singer, for instance, neglects the view that all human beings are of equal value and species membership is crucial to moral status. Thereby, he refers to an overlap of cognitive abilities from some human and non-human beings. He concludes, that "the view that all human beings, irrespective of their cognitive abilities, have equal moral status, and that this status is superior to the moral status of the most intelligent nonhuman animals" cannot be defended and this view should be dropped. (Singer 567, 574). Nonetheless, there are reasons, and as I think good reasons, to argue that the severely mentally impaired do have an equal value and are beings who are entitled to human rights. Grauman mentions, that there might be in the strict sense no rational stringent reasons to include human beings, who do not, not yet, no longer or limited fulfil the properties of persons, in the group of human rights holder, but there are plausible reasons to not exclude them either (*my translation*, 201). In this context

Graumann names three criteria, that every human being should be entitled to human rights: first, because certain attributes (such as confidence, reasonable self-determination, the ability to act and communicate) are always only developed to a certain degree and can be lost at any time. Thus, we should see potential personality as sufficient for a full moral status. Second, it is important to keep in mind, that the judgement of the development of characteristic of personality are uncertain. We should assume that every born, living being has personality potential. Third, we should be aware of the fact that all human beings are born as non-autonomous beings, and depend on the unconditional recognition of their parents and their social and familiar environment (*my translation*, Graumann 201 f).

Hence, I maintain, that these reason do strengthen the claim that every human being independent of cognitive abilities should be entitled to human rights. Further, the human rights framework offers a good approach for solving the problem of this thesis, because it acknowledges an equal value in all human beings. Individuals with severe mental impairments are to be granted the same rights, because they are human beings and have a potential to develop a personality and as a human being. Moreover, the respect for the human dignity, entitles us with rights to ensure a life in dignity for all human beings. Whether the human rights framework adequately presents the human rights in order to ensure every human being a life in dignity, is not matter of the discussion. It is rather asked whether sexuality can be claimed to be a human right, and, thus, whether a human right to sexuality is necessary to ensure a life in dignity (I will come to that in section 2.3.).

The human rights framework entails every human being with a set of rights that address basic human needs, interests and other attributes we all share as human beings. It represents, thereby, "an universal understanding about what humans can claim, what they can do and what they can be" (Bailey 736). Martha Nussbaum capabilities approach tries to identify basic human capabilities, which all human beings share and should be entitled to. These capabilities offer reasons for human rights.

2.2.1 Nussbaum's Capabilities Approach and its Criticism

Nussbaum's capabilities approach represents her idea of what people are able to do and to be, "in a way informed by an intuitive idea of a life that is worthy of the dignity of the human being" (70). For Nussbaum, the capabilities are presented "as the source of political principle for a pluralistic society", and, thereby, can become an "overlapping consensus among people who otherwise have very different comprehensive conceptions of the good" (70). Governments are responsible to respect the capabilities which are core to a life lived in dignity and these capabilities should be respected and implemented by the governments of all nations in order to secure a dignified life for every human being. According to Nussbaum's approach every person should be treated as an end for who those capabilities should be assured in a state as guiding principles for a liberal pluralistic society (70). The idea of a threshold level adds on to Nussbaum's idea. The threshold level of each capabilities represents a social goal of getting every citizen above the threshold level, because a life underneath the threshold level does not assure a truly human functioning, a human life with dignity, for the citizens (Nussbaum 71). A minimum level of social justice is gained when every threshold level of each capability is fulfilled. Nussbaum understands those capabilities, each of them on an equal basis, as of central relevance to social justice (75). When an appropriate threshold level of one of the capabilities is not guaranteed to all citizens, the society fails in its attempt of being a fully just society. The list of capabilities is open-ended, and therefore it is possible that it undergoes modification. The current list consists of the following ten capabilities (Nussbaum 76 f): Life; Bodily Health; Bodily Integrity; Senses, Imagination, and Thought; Emotions; Practical Reason; Affiliation; Other Species; Play; and Control over One's Environment.[5]

Nussbaum's capabilities demonstrate the idea that there are indeed certain human capabilities which are universal and should be of the entitlement of every human being. Nussbaum's approach supports the idea of the human rights framework. The idea that

[5] For further explanation of these capabilities see Martha Nussbaum „Frontiers of Justice – Disability, Nationality, Species Membership" page 76 and 77.

there are universal human rights independent where one lives and to what society or culture one belongs to, in order to ensure a life in dignity.

Nussbaum's capabilities, however, differ from the human rights framework. Capabilities correspond to the idea what people are actually able to do and to be. Whereas the human rights represent a slightly different idea, the idea of what humans can claim to do and to be. Nussbaum claims that "capabilities (...) have a very close relationship to human rights, as understood in contemporary international discussions. (...) And they play a similar role, providing the philosophical underpinning for basic constitutional principles." (2000, 97). Rights in Nussbaum's sense do present combined capabilities: "to secure rights to citizens in these areas is to put them in a position of combined capability to function in that area" (2000, 98). With combined capabilities, Nussbaum means, "internal capabilities combined with suitable external conditions". She describes the example of a woman who has been widowed as child and, due to political and social circumstances, is not allowed to make another marriage. This woman has the internal capability for sexual expression, but not the combined capability, because she is suppressed from the regime of the country she is living in, in regard to marry again (Nussbaum 2000, 85). Capabilities give a justification for saying that people have certain natural rights (Nussbaum 2000, 100). Human capabilities give reasons for rights and are represented in the human rights framework.

Nussbaum's capabilities approach undergoes some criticism. Alison Jagger, for example, criticises Nussbaum in her article *Reasoning about Well-being: Nussbaum's Methods of Justifying the Capabilities* on the grounds of Nussbaum's choice of those capabilities. One point of Jagger's criticism, which is of interests in the context of this paper, is about the capabilities on Nussbaum's list. Jagger writes: "I have found no place in her extensive writing where she questions her own authority to decide what should be included in the list and what excluded from it" (314). Jagger further points out that Nussbaum does not "provide convincing justification for her list of capabilities" (320). Indeed, Nussbaum's list of capabilities seems to be based on her intuitive idea what person are able to do and to be. Further this list seems arbitrary, especially when Nussbaum states that it is open for further modifications. It seems that capabilities can be added and dismissed from the list as Nussbaum's pleases to do so.

Additionally, Nussbaum states that "the capabilities approach is fully universal: the capabilities in question are important for each and every citizens, in each and every nation, and each is to be treated as an end" (2000, 6). This implies that everyone, independent of mental or physical abilities, are entitled to her capabilities.
Of course, one could argue that the universality of her approach is problematic. Especially, when her capabilities should be realised in each and every nation. Cultural and social backgrounds could entail different values and norm systems where certain capabilities are more important to be entitled to than others; and maybe some others are of crucial importance which even are not on the list. Again the argument of Nussbaum's subjective choice of capabilities comes into place. Moreover the realisation of these capabilities into principles for governments seem for some of the capabilities highly problematic, because of the vagueness of how to translate some capabilities into governmental principles. Taking for example the capability of 'emotions' and the, thereby, implied ability of having attachments to things and people outside ourselves. Here the question arises, how governmental principles can ensure this?

I would like to leave this aside for one reason; the reason why I believe Nussbaum capabilities approach is a good way of solving the problem of sexuality as a human right. As I stated above, Nussbaum's capabilities have as their central aim to realise for all people a life that is worthy in dignity. I do agree, that a concept of social justice should and does have the individuals as central items, because a just society can not only exist when social and economical goods are distributed in a just way, but also when the individuals can access freely personal goods to make their life more fulfilling. Above all, as I demonstrated in the last section, all human beings are beings of dignity, because of their inherent worth and, thereby, human beings are entitled to live a life worthy in dignity. The aspects which belong to a dignified life are to be ensured for all persons by a just society. Consequently, I argue, that no matter how critical one sees Nussbaum's choice of capabilities or her claim of those being universal, that there are indeed certain functions of a human being that can be identified to be necessary to live a life worthy in dignity.

Another point of criticism, in context of individuals with impairments, presents Carolyn Bailey. She points out that "each of the items on her [Nussbaum's] list of functioning and capabilities is deemed essential to the living of a human life or a good human life". Due to the impossibility of achieve some capabilities especially for individuals with severe mental impairments, this risks to be read as leaving people with impairments as quite not human (Bailey 733). This claim is supported by Tania Burchardt, when she states that "making it a condition of living a good human life that one is to be able to form a conception of the good and engage in critical reflection about the planning of one's life risks classifying some people with cognitive impairments as incapable of having a good life " (Burchardt 744). Nevertheless, I argue, that it is not what Nussbaum intended to do. Nussbaum rather points at capabilities a human being should be entitled to have. In cases where the human being is unable to live up to some capabilities, social responsibility comes in. Bailey highlights the same aspect: "Nussbaum's own account incorporates important elements that signal not a dismissive orientation towards impairment, but rather the affirmation of the need for social responsibility" (734).

Nussbaum's claim, that the fulfilment of all her ten capabilities are central to a good human life, can be interpreted in a way that individuals with impairments are excluded from a life worthy in dignity. Despite this risky notion, I argue, that her approach does not imply a claim, that people with impairment are necessarily excluded from a good human life. Nussbaum's approach rather identifies certain human capabilities, which human beings should be entitled to be able to do and to be. It does not necessarily mean, if a human being is unable to achieve one of them, a life of dignity cannot be assured anymore. Society rather should make sure that everyone is not hindered to achieve these capabilities.

Above that, Nussbaum's approach intended to demonstrate that there are certain central human functioning's and capabilities, all human beings should be entitled to in order to live a life worthy in dignity. This supports the idea of the human rights framework. Human rights have their foundation in the concept of human dignity, which every human beings has based on the inherent worth of humans. To ensure a dignified human life, human beings are entitled to some rights. Indeed, one has to look critical at the

choice of rights (or in Nussbaum's case, capabilities), however, I hold, that the human rights framework can be defended on the grounds that there are human rights implied by the idea of the human dignity of every human being. The interesting question in this context is then the justification of sexuality as a human right and whether sexuality can be identified as an aspect of ensuring a life worthy in dignity.

2.3 Why should Sexuality be a Human Right?

What is central in Nussbaum's choice of her capabilities is the individual, and the respect for its dignity, itself and its development. A theory of justice is further based on a claim that individuals are able to live in a just society. To this belongs, in general, not only the fulfilment of basic human needs, but also a free development of one's personality according to one's wishes, i.e. religious freedom, freedom of speech and so on. The same aim has the human rights framework. In its preamble of *the UN Universal Declaration of Human Rights* it is written "Whereas 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". Thereby, the human rights aim to develop a life for every human being worthy in dignity. Further it claims, as above already mentioned, in Article 3 that "Everyone has the right to life, liberty and security of person". It can be concluded that the development of a person as a human being with dignity is a central aim for the human rights framework.

Sexuality is claimed to be one of the central aspect of being human. Even though there are cases where human beings are asexual. This, however, is just another interpretation of sexuality, but still is central to their being – not having it. The human rights convention, as above shown, does include sexuality in their rights. Martha Nussbaum as well does include sexuality in her list of capabilities (Nussbaum 76f).

Three of Nussbaum's capabilities include the matter of sexuality. Her third capability is Bodily Integrity. It implies "being able to move freely from place to place, to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction".

Therefore, the living and development of one's sexuality is playing part in this capability since it states that bodily integrity imply opportunities for sexual satisfaction.
Her fifth capability is emotions, which implies "being able to have attachments to things and people outside ourselves; to love those who we love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justifies anger. Not having one's emotional development blighted by fear and anxiety." This capability does not necessarily entails sexuality, but an instance which is part of sexuality – emotional development.
Her seventh capability describes affiliation. One aspect of this seventh capability sates: "having the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of nondiscrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin." This capability encompasses also a certain part of one's sexuality – the free development of sexual orientation.
From Nussbaum's capabilities three aspects of the living of one's sexuality can be derived – the opportunity for its satisfaction, its emotional development and free development of one's sexual orientation independent on any cultural norms and values.

According to Nussbaum these capabilities give a minimum basis for social justice. As certain aspects of sexuality are implied by those capabilities, sexuality (or the living of one's sexuality) belongs to this concept of a minimum basis of social justice. Supplementary, according to Nussbaum, sexuality belongs also to a life worthy in dignity. Hence, when factors are central to the individual's living which go beyond the fulfilment of human basic needs and are part of leading a good human life, sexuality should not be excluded. It is a central aspect of human beings and, thus, part of our lives.

A concept which aims for social justice, where not only an just distribution of economic goods is essential, but also the freedom and liberty of the individuals, sexuality should not be excluded from it. The human rights framework does aim at such a concept to fulfil the aim to offer every human being a life worthy in dignity and with that set moral basic principles for a just society based on economic, social and political basics.

When the individuals good human life is the intention of a framework, this also does include his/hers sexuality, because sexuality is an integral part of our nature of being human. Therefore, I claim, that it is justifiable that a right to sexuality is included in a human rights framework on the grounds that sexuality belongs to a good human life, to live worthy in dignity.

A right to sexuality implies, as Nussbaum would suggest, the opportunity for its satisfaction, its emotional development and free development of one's sexual orientation independent of any cultural norms and values. This would not be supported by everyone. For example Immanuel Kant or the Catholic Church would limit that right to sexuality to the context of reproduction in marriage.
Immanuel Kant states that "Human love is good-will, affection promoting the happiness of others and finding joy in their happiness. (...) Sexual love makes of the loved person an Object of appetite; as soon as the appetite has been stilled, the person is case aside as one casts away a lemon which has been sucked dry" (Soble 200).
According to Kant, the sexual act sacrifices one's humanity. Therefore, humans should not offer themselves as objects of appetite. Coitus would offer the other person involved to be used as in instrument to satisfy sexual desires. Kant goes even further stating that a "man is not his own property and cannot do with his body what he will" (Soble 201). Sexuality makes "humanity an instrument for satisfaction of their lusts and inclinations, and dishonour it by placing it on a level with animal nature" and therefore "exposes mankind to the danger of equality with the beasts" (Soble 200). One can interpret that for Kant sexuality does not only entail coitus, but also lust and sexual impulse. According to Kant, sexuality and the sexual act is always immoral and a misuse of sexuality - except when it happens in marriage. In Marriage both persons have equal rights over the other person (Soble 203). The claim that coitus is only permissible within marriage would be also supported by the Catholic Church. They claim that sexual intercourse is only permitted within marriage for serving the purpose of reproduction.

Analogue to the perceptions of Kant and the Catholic Church, a human right to sexuality can only be justified on grounds of a free reproduction within a marital context as well as right to sexuality within marriage. Nevertheless, I argue, that this limitation of

a right to sexuality, only corresponds to the perceptions of some, and would only ensure a good human life for some – those who follow the belief that sexuality should only be practised in context of reproduction within marriage.
The UN Conventions, we explored at the beginning of the chapter, do not limit this right to sexuality to marriage, nor to any particular sex, nor to any other aspect than to the aspect of not causing harm on others. The same approach takes Martha Nussbaum in her capabilities. It can be assumed that the living of sexuality is neither limited to the status of being married nor the act of coitus. Further it is broadly agreed on that sexuality is part of being human, and the expression of it can happen on very different levels – even asexuality is a level of that. Besides the definition of WHO, Sigmund Freud, for example, claims that sexuality is far more than pure reproduction. In *Über 'wilde' Psychoanalyse* Freud points out that the psychological aspect of sexuality should not be underestimated and the recognition of endearing feelings is part of a sex life, too. Thus, sexuality is also part of everyone's personality and living it is part of the exploration of one's personality. That does not imply that people who are asexual are not human beings, but being asexual also implies a certain sexuality which is lived by being not lived and not acted upon on. Another contributor in this debate, Irving Singer, also points out that sexuality is ingrained in our nature of being human (Soble 254). Of course, even Kant does not deny that sexuality is part of being human when he states that it "is true that without it a man would be incomplete; (...) and this would make him imperfect as a human being" (Soble 200). Nevertheless for Kant it is still immoral to follow the sexual impulse when this does not happen within marriage.

These conceptions show that sexuality is part of human beings. Moreover, sexuality does encompasses many things – and not only the act of coitus. Therefore, taking the a good human life as an goal within a concept of aiming at social justice and ensuring shared human rights, a right to a free development of one's sexuality cannot be excluded from it. A right to a free and full development of sexuality would ensure a life worthy in dignity because sexuality is part of our nature as human beings.

III. The Human Right to Sexuality and its Responsibilities

In the previous chapter I sought to show that a human right to sexuality is justifiable, and should not only entail the level of free reproduction in marital context, but also other parts which belong to a free and full development of the human sexuality as long as no harm is inflicted on others. The question arises, whether this human right to sexuality entails some responsibilities. If it does, can a moral responsibility for the implication of a home's policy be implied from it?

For answering these questions I will first briefly go into the theory of rights. I will outline Wesley Hohfeld's distinction and differentiate between negative and positive rights. With the help of Henry Shue's criticism, the claim that the right to sexuality should rather be characterised in terms of responsibilities corresponding to the different occurring situations will be developed. I aim to demonstrate that there is a moral responsibility of homes to implement a policy in regard to sexuality of individuals with severe mental impairments.

In the context of rights, one needs to differentiate between moral and legal rights. Moral rights are claims which are justifiable because of moral reason, independent of their social and legal application, to be legitimate. Whereas the application of legal rights needs to be traced back to the ruling law (*my translation,* Graumann 18).

The human rights are best to be thought of as legal and moral rights. The human rights framework entails different kinds of rights. Stein differentiate between first generation and second generation rights in this context. First generation rights entail rights to life, movement, thought, expression, association, religion, and political participation. Whereas, in general, second generation rights are concerned with standards of living. First generation rights are understood "as promoting equal treatment among individuals, and include prohibitions against state interference" (Stein 77). Second generation rights are seen "as providing equal opportunity" (Stein 78).

The theory of rights encompasses many approaches. I will concentrate here only on Wesley Hohfeld's approach and the differentiation between positive and negative rights in order to evaluate whether there is responsibility for home's to implement a policy regarding sexuality.

Wesley Hohfeld differentiates between 'rights' and 'claims' on the one side, and 'privileges' on the other side. Hohfelds defines right as "one's affirmative claim against another, and a privilege is one's freedom from a right or claim" (60). A privilege is, therefore, according to Hohfeld, the negation of a duty (39). A claim is a legitimate entitlement, which we can make effective against others (Graumann 16).

According to Sigrid Graumann, Hohfeld's classification of 'claims' entails positive and negative rights. Negative Rights are to be understood in the sense of claims, which demand on someone else, the other to permit something. That means not to interfere with something the other is doing or to omit something. In contrast positive rights are claims, which demand to do something for someone (*my translation*, Graumann 16). First generation rights of the human rights framework are sometimes thought of as negative rights, second generation rights as positive rights (Stein 77, 78).

The differentiation between positive and negative rights faces some criticism. Henry Shue points out that the protection of negative rights, also require positive actions, and, thereby, place a demand on others, not only 'not to interfere' with the right. Shue illustrates this in the context of rights to physical security:

> "It may be possible to avoid violating someone's right to physical security yourself by merely refraining from actions in any of the ways that would constitute violations. But it is impossible to protect anyone's rights to physical security without taking, or making payments, toward the taking of, a wide range of positive actions" (Shue 37).

In this context, Shue names the examples of police forces, criminal courts etc.

This illustrates the situation around positive and negative rights quite well. Negative rights, additionally, place on others the demand 'not to interfere', which requires also positive action, when the right of one person is an danger. This right needs to be ensured, and, then, positive actions are required. Taking an another example: the right to life. On the one hand, it is claimed to be a negative right. One is not allow to interfere with someone else's life in a sense not to kill that other person. But in a situation where the right to life of Person X is in danger, because Person Y wants to kill Person X and Person Z sees this scenario. Person Z has the duty to help in order to safe Person X's life in an extent that Person Z brings himself not in danger. Above that, the duty of interference is a demand on someone and brings along responsibilities to give the other person the entitlement of a certain right in a way not to interfere with it.

Coming to the central question whether the human right to sexuality can be identified as a negative right or positive right. In the previous chapter we examined articles of the UDHR (Article 3) and of the CRPD (Article 10, 14 and 17). From these articles a right to sexuality was implied. I claim, according to the categorisation of a positive and negative right, this right would be identified as a negative right at first. I will show with the help of the right to sexuality that the distinction between positive and negative rights is not a clear one, depending on the situations and phrasing of the matter. Thereby, it is rather important to identify the responsibilities of others towards one's right to sexuality. In this context, I will outline arguments, why there is a moral responsibility to implement a home's policy in context of the sexuality of individuals with severe mental impairments.

The right to sexuality as being part of being a human, which has been implied as being part of the right to life and liberty, can be understood as a negative right. This is because one has to allow the individuals to live their sexuality, but it does not make a claim on others to support this process. Others only have a duty not to interact with that right as long as no harm is been done. Article 17 on the "protecting the integrity of the person" in the CRPD claims to provide health programmes which include sexual health as well. This can be seen as a positive right, because this right requires positive actions of others to provide something for the disabled. However, the implied right to sexuality is again only a negative right, because, even though health programmes should be provided, sexuality is only implied by the right for sexual health. The right to sexuality is again only a negative right, because article 17 of the CRPD does not claim anything on someone to interact with the sexuality of the disabled.
It can be assumed, hereby, that the right to sexuality is a negative right and encompasses the moral demand not to interfere with. But this demand also implies, that in a situation where harm is done positive actions are undertaken to interfere with the right to sexuality of one person, to prevent the infliction of harm on another person.

In general, however, there should be no direct moral responsibilities towards the living and experience of another's person sexuality. My reasons for this are, sexuality is a very intimate matter for us being human beings. It is in many cases part of our personality

and belongs to us in the same way as we grave other basic needs. The development of it is again something that has to be sorted out by every person themselves, because of this intimacy and being integral part of personality. Nobody should interfere with that right, because the free development of it (and even the non-development of it in some cases) is part of us being a human and has to be decided and lived by every individual themselves as long no harm is done to any other person. Therefore the right to sexuality should primarily only entail the responsibility of non-interference.

Nevertheless there are situations where responsibilities of others arise. The right to sexuality, primarily, entails a responsibility of others not to interfere. This already implies that someone is able to act upon this right, and is able to realise that he has a right to sexuality. In the case of individuals with severe mental impairments, as the four cases exemplified, the circumstance of fully acting on the right to sexuality and the ability to realise such a right is not given. The UN Conventions clearly illustrate that a right to sexuality can be implied and therefore every individual, independent of a person's abilities, has a right to develop and live his or her sexuality in their own way as long as it does not harm others. As the case study showed, in homes the situation around the sexuality of the clients is highly dependent on the carers, and leaving as such, does not make sure that it is not interfered with their right of living their sexuality in their own ways. Sexuality was identified as part of our human nature. Another aspect of our human nature is the need for other basic needs, such as food, for example. If we do not consume food, we die. In the cases of the severely mentally impaired, the carer has to assist the client to make sure that food is consumed. This entails the preparation of meals and, in many cases, the feeding of it. If the home, and with that the carers, do not undertake these actions, the clients will – naturally – die. Thereby, it would be interfered with their right to life. Since their mental abilities neglect them the chance to realise the action which need to be taken in order to fulfil their need to food, positive actions from carers are required to make sure that the basic need for food is fulfilled. This gives reason for a responsibility to make sure that not only a theoretical entitlement to a right exists, with what is not interfered with, but practically can be acted upon.

The introduction of a home's policy not only acknowledge the right to sexuality, but also ensures, in practise, the right to sexuality for individuals with severe mental

impairments living in a home. The home's policy portrays the instance that the human right to sexuality is ensured and practically can be acted upon – even by those who are unable to realise that they have a right to sexuality. This leads to the second reason why there is a responsibility of homes, where individuals with severe mental impairments live, towards the right to sexuality. Sigrid Graumann states that right to rights and the right to life are in a close relationship. Because infants – with or without a disability – but also children and adults with severe cognitive and mental impairment cannot realise their right to life by their own, it becomes a positive right for maintaining and promoting life (*my translation*, Graumann 202). As I argued before, sexuality is part of our life as a human being, because it is part of being a human, and therefore, because severely mentally disabled cannot realise the right to life and with that their right to sexuality, this right should be ensured by others for them. So that they not only entitled to that right, but also able to act upon that right.

This claim can be supported by Martha Nussbaum capabilities approach. To show this, I would like to proceed to illustrate how she applies her approach to the subject of individuals with disabilities in order to outline the implications concerning this matter of sexuality analogue to Nussbaum.

The ultimate goal should be to give people with severe mental impairments every capability, or at least as many as possible. This is claimed by Nussbaum, too: "Society should strive to give (...) as many of the capabilities directly, and where direct empowerment is not possible, society ought to give her the capabilities through suitable arrangement of guardianship" (193). Nussbaum's brings in a third party, the party of guardianship for the individual with severe mental impairments. This guardianship should make it possible for the person with disabilities to have a access to all central capabilities. In the case of severely mentally impaired the entitlement to these capabilities imply an assistance of a third party, who is responsible to help the individual with the impairment to be able to have all capabilities. Hence, when it comes to sexuality, analogue to Nussbaum, someone should assist the individual with severe mental impairments to realise this capability for him, when he is unable to do it by himself.

The guardianship concept of individuals with severe mental impairments living in a home is expressed differently. Either parents, carers or the home itself take over the role for the guardianship. In general, the home takes over the general position of a guardianship by providing individual carers who are responsible for a selection of clients in terms of every day decision making processes. Therefore, the home as an institution who is responsible for the fulfilment of the capabilities can be argued to be guardian.

Based on the need of assistance to fulfil the opportunity of sexual satisfaction for individuals with severe mental impairments, the home should, as a guardian, strive for the fulfilment of the corresponding capability. In those situations it is not only the one who is cared for, but also the carer who needs guidance to fulfil this goal. Therefore a home's policy in regard to sexuality should be in charge in order to strive for the fulfilment of the corresponding capability.

In a nutshell, a home's policy concerning sexuality should be introduced to ensure the living of sexuality for the individuals with severe mental impairments. Because a human right to sexuality can be justified, but its realisation in homes lacks, a home's policy would be of help to ensure this right. Additionally, severely mentally impaired are not aware of this right, and, thus, the guardian is responsible to make sure that these individuals are entitled to that right. A home does represent a guardian and, therefore, I hold that the home is responsible to make sure that every individual in this home is entitled to the human right to sexuality and is able to act upon it when one pleases to do so and is not interfered with as long as no harm is done.

IV. The Home's Policy

In the previous two chapters, I tried to display that there is a human right to sexuality. This human right to sexuality involves a responsibility for homes where individuals with severe mental impairments live. The implementations of a home's policy for sexuality acts in correspondence to the responsibility towards the human right to sexuality. As the cases in chapter one sought to illustrate, not only a discrepancy in the achievement of this right exists, but also morally relevant issues occur in situations where sexuality plays a role. Issues like sexual assistance as an option for living one's

sexuality, abuse, and, in many cases of the severely mentally disabled, the inability to express an explicit wish, the problem of determination over another human being, the issue of world views and values about sexuality imposed on the clients by their carers and families, and the matter of intimacy. These issues must be addressed in a home's policy to guarantee, one the one hand, the safety of the clients and their entitlement to the right to sexuality, and, on the other hand, to give the carers guidelines how to approach the issue.

Due to a lack of space, the focus lies in this chapter on the issue of sexual assistance as an option for the severely mentally impaired to experience their sexuality. Sexual assistance offers practical options how the living of the sexuality of the severely mentally impaired can be approached. I do not intend to give a solution, but rather want to demonstrate the complexity and difficulty the issue of sexuality of the severely mentally impaired living in homes entails. I believe, that only some of the issues and aspects, which are essential to consider, are addressed, and, therefore, I do not claim completeness. First, I seek to demonstrate, that there is a moral difference between the passive and active concept of sexual assistance. The moral difference rests in the risk of the infliction of harm. With the help of the concept of competence, it will be evaluated who is competent to make the decision whether passive or active assistance is an option.

4.1 The Matter of Sexual Assistance

In chapter one the concept of sexual assistance was introduced. It was differentiated between active and passive assistance. Whereas active assistance is to be seen in a way of a sexual companion, who interacts with the severely mentally disabled on a physical and emotional level. The passive is to be understood in the sense of pedagogical educational process in terms of giving space and time; educating the mentally disabled through learning therapy how to handle their physical needs and how advance those to be able to fully live and understand their sexuality.

This differentiation clearly raises the question, whether both concept can be morally permissible, and under which circumstances? It is obvious, that there is a moral difference between active and passive assistance, because of a different level of risk

involved regarding the infliction of harm on the individual with severe mental impairments. Passive assistance involves a smaller risk of abuse. The concept of passive assistance encompasses the aspect of giving space and time for the client to be naked and enjoy himself. This action does not necessarily inflict harm as long as a third party does not intervene with it. However, it could be imagined, that, for example, a client does not like to be naked. Then, again, the home (and with that the carers) are responsible to make sure that every client feels comfortable and is not interfered with his own intimacy. Especially cases, where the severely mentally impaired is not able to verbally communicate the wish for being naked and enjoying himself/herself, need to be carefully evaluated by the home. There is another component the concept of passive assistance entails: learning therapy. This therapy does not unavoidable inflict harm on the patient. It rather serves the purpose to develop an understanding of the severely mentally impaired of what is going on. Learning therapy does not naturally imply physical interaction, and, as long as it happens in responds to the individuals reaction to it, the risk of the infliction of harm is kept at a minimum level. Nevertheless, it comprises the responsibility of the home to make sure that all these actions are undertaken in an appropriate process and circumstances in order to avoid the risk of abuse and/or mental and physical harm.

By contrast, active assistance involves a much greater risk of the infliction of harm and abuse. A third person actively interacts with the severely mentally impaired on a physical and emotional level. In cases where the severely mentally impaired is unable to agree to certain actions a high risk of abuse exists. Even in cases where the severely mentally impaired is able to agree verbally to certain actions, the question occurs whether the client is able to understand what is happening. The risk that greater harm is done than the improvement of the clients happiness is at stake. Other factors have to be taken into account: the evaluation of the status of the health, and the effects of sexual assistance can have on the health of a client, the sexual orientation of the client, and, whether the client likes his/her assistant or not. Of course, just because a risk is involved does not automatically mean that active assistance should never be permissible in context of individuals with severe mental impairments; it rather involves a greater responsibility of the homes to find guidelines to ensure that the active assistance is not

of abuse character. What is of high importance, according to my opinion, is the avoidance of infliction of harm on the patients – mentally and physically.

Hence, the guidelines should make sure that abuse and the infliction of harm is avoided. This requires an individualistic consideration of the cases in regard to, among others, whether an explicit wish can be attributed, whether the health status is at risk, whether he/she understands what is going. The avoidance of the infliction of harm on physical and mental level is of importance due to two reasons: first, and most importantly, it can be assumed, that it is in the client's best interest not to be harmed; and second, adequate guideline with the aim of the avoidance of harm and abuse for the clients, would ensure the home (and the carers) an appropriate tool to act in line with the human right to sexuality and ensure for themselves, on legal and moral grounds, security towards the risk of abuse.

In this context, the question is posed who is competent to make the decision, whether passive and/or active sexual assistance is a suitable option? A concept of competence and the risk-related standard of competence is introduced in order to evaluate who is competent to make this decision.

Tom Beauchamp and James Childress point out that there is a lack of a single acceptable definition of competence and a single acceptable standard of competence, however, the core meaning is "the ability to perform a task" (70).
I am going to focus on Beauchamp and Childress definition of a competent patient, because it highlights different aspects which usually are referred to in a decision-making process. They define patients or subjects as competent when they "have the capacity to understand the material information, to make judgement about the information in light of their values, to intend a certain outcome, and to communicate freely their wishes to care givers or investigators" (Beauchamp and Childress, 71). Analogue to this definition, it can be argued that individuals with severe mental impairments are incompetent independent of the fact whether they are able to verbally communicate a preference for a certain action or not. Nonetheless, Ron Berghmans clarifies, the issue concerning the mental capacity, in order to be claimed as competent or not, becomes controversial in context, among others, of the severely mentally impaired (251). And,

indeed, it is questionable whether a severely mentally impaired who verbally can express a wish, should per se be claimed as incompetent in any situation of making a decision, just because they might not fulfil the capacities which are needed to make a certain decision? Broadly, it is assumed, that the competence to decide is relative to the particular decision to be made (Beauchamp and Childress, 70). The risk-related standard of competence offers an approach in evaluating whether one is competent to make that particular decision, or not. The greater the risk, the more demanding standard is applied in the case of the patient's decision (Berghmans, 253). Berghmans indicates that this approach is based "on the conviction that our concern for the patient's welfare require that a higher level of capacity should be demanded for decisions pertaining to life and death, than for decisions which may result in lesser harm" (253). This approach naturally faces criticism within the debate. First, it is criticised, because it supports an asymmetric view on capacity; the view that "an individual may at the same time have capacity to consent to treatment but lack capacity to refuse it" (Berghmans 254). This asymmetry is for some contributors counter-intuitive, because it rejects the idea of the "principle of symmetrical competence", because it can effect whether an individual is competent, or not, highly dependent on the risks involved (Berghmans 254). Second, the "risk-related approach conflates two issues: on the one hand, the question whether or not an individual has capacity, and on the other hand, whether or not his or her choices should be respected or might be overruled on paternalistic grounds" (Berghmans 254). But the risk-related standard takes the authority of the patient into account. I suggest, that in the cases where individuals with severe mental impairments can communicate a wish, they can be claimed, to a certain degree, competent to make a decision – relative to the risks involved, and whether they are able to understand the consequences. The reason for that lies in the fact, that they indeed have wishes they can express and, thereby, I do not see, why the expression of preferences should be claimed per se as an incompetent decision for one thing or the other.

Thus, the question occurs, whether homes must regard the choice for sexual assistant as a competent choice, when an individual with severe mental impairments has the ability to understand the information, and the capacity to make a choice?

Individuals with severe mental impairments, who are unable to communicate verbally, can be regarded as incompetent to make the decision whether they want sexual

assistance or not. But there are cases, where the severely mentally impaired can communicate their wishes and preferences. Whether their mental abilities can make judgement about the choice, is questionable. Nevertheless, they should not to be claimed immediately as being incompetent to make this decision.

As outlined in the previous paragraph, the risk involved differs between passive and active sexual assistance. In cases of passive assistance the welfare of the client is not at high risk. If a client can verbally express a wish for having space and time to enjoy himself/herself, the client can be referred to be a competent decision maker. When it comes to active assistance, the consequences to the clients welfare are more risky than in the case of passive assistance. It is questionable, whether the client can evaluate the risks involved and the difficulties this decision may encounter, or not. I do not propose that the client should be considered as incompetent to make this decision, but rather that the decision should not only be made on his/her account to make sure that the infliction of harm on physical and mental level is avoided.

In the cases where individuals with severe mental impairments do not have the capacity to verbally communicate, they can be identified as incompetent, and the question is raised, who is competent to make the decision for them, and, thereby, who should have decisional authority?
It can be reasoned that carers as well as parents in an ideal situation are competent to make the decision whether active or passive assistance is an option for the client, because in an idealistic scenario both parties have the experience and capacity to evaluate the decision in terms of the clients wishes, and needs, and are familiar with the risks this procedure may involve. Nevertheless, it is not always the case that parents are familiar with all the wishes and needs for their child. Additionally certain interests of carers and parents do play a role.

Hence, I propose, that both parties do have a certain level of competence, whereat, in face of the risks involved, not only one party should be granted decisional authority. The complexity of issues and facts involved, which need to be taken into account to make a decision that portrays the best-possible balancing act between the high vulnerability of the individual and his/her human right to sexuality, requires a shared-

decision making process, and should not grant decisional authority to either party. In the risk of effecting the client's health, it is also important to consider a physician, or other specialists, because in regard to some aspects, neither parents nor carers are competent to overlook some of the consequences. Based on the fact that the client does not have the abilities to verbally express him/herself the risk of the infliction of harm is high, especially when it comes to active sexual assistance. Not only health issues should be taken into account, but also other relevant considerations of parents and carers, who both are, assumedly, equally aware of different things - everyone in their own perspective. Thus, I believe, a competent decision can be made in the best-interest of the client when a shared-decision making model is applied.

Beyond that, a home's policy is required to consider the legal background since most of the decision have to be made 'officially' by the custodian. In Germany, the carers and the home have to consult the custodian in making decisions. In the most cases, parents act as custodian for the client. Therefore, it must be evaluated whether the custodian has the competence to make such a decision. According to the German Civil Code (BGB), section 1901 'The Scope of the Custodianship, Duties of the Custodian': "The custodian must attend to the affairs of the person under custodianship in a manner that is conducive to his welfare. The best interests of the person under custodianship also includes the possibility for him, within his capabilities, to shape his life according to his own wishes and ideas". Supplementary, if carers, the home, or other persons, realise that this is not the case, they are legally obliged to inform the corresponding court. Additionally, the custodian is asked to hand in a yearly report about his/her actions to the court.

Thus, I deduce, that the responsibilities of home's in context of the matter of sexual assistance is, primarily, to make sure that the infliction of harm and the matter of abuse is avoided since it is not only the interests of the clients, but also gives the home and its carer moral and legal security to act in line with the human right to sexuality. Additionally, the expression of a wish, or preference, of the severely mentally impaired should not per se be considered, in regard to sexual assistance, as an incompetent decision. The capacities of the individual should rather be evaluated analogue to the risks involved. Thereby, when a high risk is at stake, a competent decision needs to

considered by different parties – parents, carers, and physicians. The responsibility of the home to make sure that the human right to sexuality is exercised in responds to the client wishes adds the dimensions to ensure that the custodian acts in accordance to the wishes of the individual. If this is not the case, then, they are ought to interfere in line with their opportunities in doing so.

The above sought to highlight the issues involved, which need to be discussed in context how the human right to sexuality should be applied into practise. It is primarily intended to highlight questions which are of importance in a home's policy rather than giving solutions. The implementation of a home's policy needs to address those morally relevant questions to ensure an environment where the individual with severe mental impairments can act upon the right to sexuality without the fear of abuse and the matter of sexuality is adequately addressed. Further, it intended to show that an interdisciplinary discussion between medicine, pedagogy and ethics is necessary to be able to develop an environment for the severely mentally impaired living in a home, where the human right to sexuality is recognised and adequately realised for them.

Conclusion

This thesis portrayed that in home's where individuals with severe mental impairments are living, the developing and exploring of the client's sexuality lack. A right to sexuality was characterised as a human right, and, thereby, every human being is entitled to the right to sexuality. It was claimed, that in the case of individuals with severe mental impairments, this right entails the responsibility of homes to implement a policy in regard to sexuality. This home's policy needs to address morally relevant issues like the matter of sexual assistance and who, in this context, is competent to make a decision for a client. It is certain that vulnerable individuals should be protected from unwanted contact. Whatsoever, "because these individuals are vulnerable does not mean that all contact should be assumed to be unwanted" (Appel 153).

Above that, I sought to demonstrate, that the issues involving the right to sexuality in context of individuals with severe mental impairments, needs to undergo serious discussion; not only in the field of ethics, but also in other academic fields in order to

entitle individuals with severe mental impairments to - not only a theoretical - human right to sexuality. Of course, the issues involved in this topic are complex and difficult to address. Furthermore, the topic of sexuality of severely mentally impaired creates unease by those who are confronted with it. Thus I conclude, that an interdisciplinary discussion between medicine, pedagogy and ethics is needed to be able to create an environment for severely mentally impaired in which they are able to live adequately their sexuality.

My brother *has* a sexuality, maybe rather a childish one, which is primarily concerned with the exploring of his body than with anything else, however, this is part of the human sexuality, too. Most of us had, and have, the chance to explore themselves, why shouldn't he? Maybe the unease is rooted in the fact, that my parents and myself (and his carers) see that he is enjoying himself, while he is enjoying himself; we, then, are able to recognise the smile of enjoyment on his face. An aspect of our human life, which we hide from our family, friends and fellow humans and only show in intimate situations, my brother demonstrates publicly. Neglecting him the chance to be naked and enjoy himself, because of (sometimes an immense) unease of his carers, my parents and myself, (even we find ourselves in situation where we neglect him the chance) is – I believe – *wrong*.

Bibliography

- Appel, Jacob M. *Sex rights for the disabled?* Journal of Medical Ethics, 2010 (152-154).
- Baylies, Carolyn. *Disability and the Notion of Human Development: questions of rights and capabilities.* Disability and Society, (17:7) 2002 (725 — 739).
- Beauchcamp, Tom; Childress, James. *Principles of Biomedical Ethics*. Oxford: Oxford University Press, 2001. Google E-Book. 11th June, 2012.
- Berghmans, Ron; Dickenson, Donna and Ruud Ter Meulen. *Mental Capacity: In Research of Alternative Perspectives.* Health Care Analysis, Volume 12, Number 4, 2014 (251-263).
- Bundesministerium für Familie, Senioren, Frauen und Jugend. *Erster Bericht über die Situation der Heime und die Betreuung der Bewohnerinnen und Bewohner.* 2006.
- Burchardt, Tania. *Capabilities and Disability: the Capabilities Framework and the Social Model of Disability.* Disability and Society, (19:7) 2004 (735 – 751).
- Desjardins, Michel. "The Sexualized Body of the Child: Parents and the Politics of 'Voluntary' Sterilization of People Labeled Intellectually Disable". In *Sex and Disability.* By McRuer, Robert and Mollow, Anna. Ed. Durham and London: Duke University Press, 2012. Print.
- "Disabilities". *WHO.* World Health Organisation. 2012. Web. 6th June 2012.
- Dixon-Mueller, Ruth et al. *Towards a Sexual Ethics of Rights and Responsibilities.* Reproductive Health Matters (17: 33), 2009 (111-119).
- Düwell, Marcus. Innovational Research Incentives Scheme. *Human Dignity as the Foundation of Human Rights?* Utrecht University, 2010. PDF. <http://www.uu.nl/faculty/humanities/NL/Actueel/nieuws/Pages/20110713-32-583-563-human-dignity.aspx> 8thJune, 2012.
- Düwell, Marcus. "Human Dignity and Human Rights" In *Humiliation, Degradation, Dehumanization: Human Dignity Violated.* Kaufmann, Paulus ed. Springer: 2010. Google E-Book.
- Fagan, Andrew. "Human Rights". *IEP.* Internet Encyclopedia of Philosophy. 2005. Web. 6th June, 2012.

- Freud, Sigmund. *Über 'wilde' Psychoanalyse.* Web. 6th June, 2012. < http://www.textlog.de/freud-psychoanalyse-wilde-psychoanalyse.html>
- German Civil Code - BGB. *Section 1901, Scope of the Custodianship, duties of the custodian.*
- Graumann, Sigrid. *Assistierte Freiheit.* Utrecht: Utrecht University, 2009.
- Hohfeld, Wesley. Fundamental Legal Conceptions as Applied in Judical Reasoning. New Haven: Yale University Press, 1920. Internet Archive. PDF.
- Jagger, Alison. *Reasoning About Well-Being: Nussbaum's Methods of Justifying the Capabilities.* The Journal of Political Philosophy: Volume 14, Number 3, 2006 (301-322).
- "Mental Retardation". *WHO*. World Health Organisation. In "International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) Version for 2010". Web. 6th June 2012.
- Moll, Angela. *Sexualität geistig Behinderter – behinderte Sexualität*. 2010. Print.
- Nussbaum, Martha. *Frontiers of Justice – Disability, Nationality, Species Membership.* Cambridge: The Belknap Press of Harvard University Press, 2007. Print.
- Nussbaum, Martha. *Women and Human Development – The Capabilities Approach.** Cambridge: Cambridge University Press, 2000. Print.
- Shue, Henry. *Basic Rights: Subsistence, Affluence, and U.S. Foreign Policy.* Princeton: Princeton University Press, 1996. Google E-Book.
- "Sexual and Reproductive Health". *WHO.* World Health Organisation. 2012. Web. 6th June 2012.
- "Sexualität und geistige Behinderung". *Pro Familia*. Web. 6th June 2012.
- "Sexuality and Human Right – Discussion Paper". *ICHRP.* International Council for Human Rights. 2009. Web. 6th June, 2012.
- Singer, Peter. *Speciesism and Moral Status.* Metaphilosophy, Volume 40, Number 3-4, 2009 (567-581).
- Shakespeare, Tom; Gillespie-Sells, Kath; and Davies, Dominic. *The Sexual Politics of Disability: Untold Desires.* Cassell: 1996.
- Soble, Alan. *The Philosophy of Sex.* Maryland: Rowman & Littlefield Publishers, 2002. Print.

- Standfort, Luther. "Sexualassistenz und Sexualbegleitung – Empowerment und Konfliktprävention". In *Sexualität bei Menschen mit geistiger Behinderung.* Deutsche Gesellschaft für seelische Gesundheit bei Menschen mit geistiger Behinderung. Band 23. 2010. Web.6th June 2012.
- Stinkes, Ursula. "Sexualität und Behinderung – kein Tabuthema mehr?!" Lecture. 2006. Web. 6th June 2012. <http://www.sfk.s.bw.schule.de/pdfs/vortrag_stinkes.pdf>
- UN Convention on the Rights for Persons with Disabilities. *UN.* 2006. Web. 6th June, 2012.
- UN Universal Declaration of Human Rights. *UN.* Web. 6th June, 2012.
- Waldron, Jeremy. "Introduction". In *Theories of Rights*. Oxford: Oxford University Press, 1984. Print.
- Wilkerson, Abbey L. "Normate Sex and Its Discontents". In *Sex and Disability.* By McRuer, Robert and Mollow, Anna. Ed. Durham and London: Duke University Press, 2012. Print.

Background Readings

- Buller, Tom. *Competence and Risk-Relativity.* Bioethics, Volume 15, Number 2, 2001 (93-109).
- Mollow, Anna. "Is Sex Disability? Queer Theory and the Disability Drive." *In Sex and Disability.* McRuer, Robert; Mollow, Anna ed. Duke University Press, 2002 (285-312).
- O'Neill, O. *Some Limits of Informed Consent*. Journal of Medical Ethics (29), 2003 (4-7).
- Scully, Jackie Leach. *Drawing Line, Crossing Lines: Ethics and The Challenge of Disabled Embodiment.* Feminists Theology 2003 (265-280).
- Scully, Jackie Leach. *Moral Imagination, Disability and Embodiment*. Journal of Applied Philosophy, Vol. 24, No 4, 2007 (335-351).
- Shakespeare, Tom. *Disabled Sexuality: Toward Rights and Recognition.* Sexuality and Disability. Vol.18, No.3, 2000 (159-166).
- Shakespeare, Tom; Corker, Mairian ed. *Disability/Postmodernity*. Continuum, 2006.

- Shuttleworth, Russel. “Bridging Theory and Experience: A Critical-Interpretive Ethnography of Sexuality and Disability”. In *Sex and Disability*. McRuer, Robert; Mollow, Anna ed. Duke University Press, 2002 (54 –68).
- Sieber, Tobin. “A Sexual Culture for Disabled People”. In *Sex and Disability*. McRuer, Robert; Mollow, Anna ed. Duke University Press, 2002 (37-53).
- Walter, Joachim. “Selbstbestimmte Sexualität als Menschenrecht – eine Selbverständlichkeit auch für Menschen mit Beinträchtigungen!” *Sexualität und Behinderung* (BzgA: Sexualaufklärung und Familienplanung) 2001 (34-38).

Acknowledgement

"Against criticism a man can neither protest nor defend himself; he must act in spite of it, and it will gradually yield to him" (Johann Wolfgang von Goethe)

For all criticism I had to encounter in the past months and years, I am deeply grateful. Without it, I know now, I would not be able to write this master thesis, and without some of the criticism, I probably never would have. I highly value the knowledge and inspiration not only this programme offered me, but also I received from great teachers who accompanied me along my way.

Especially, I would like to thank my parents for their constant belief in me that I am able to be and to do whatever I truly want; and my fellow students and friends for their encouragement while writing this thesis and during the past year. Further I highly appreciate the caring participation of the home I visited.

Above all, the person I am most grateful to is my brother for the way he is, for what I was praised to learn from him, and from whom I neither want nor am able to depart. Without him, I would never have taken this enlightening opportunity to think and write about the sexuality of individuals with severe mental impairments, - a thesis I wrote *for* him, *because* of him and, in my heart, *with* him.