

When Will I be Loved?

Regulated Sexualities amongst Intellectually
Disabled People.

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Assiduus usus uni rei deditus et ingenium et artem saepe vincit
(Cicero, in "For Cornelius Balbus")

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This study required full devotion. Cicero's line¹ inspired me through the difficult path that goes by the name of graduating. The piece not only demanded a whole heap, but faith in the topic was truly important as the actuality of the matter made it more fragile than ever. Therefore, it could be said that I was not able to finish the study if I would not have had the constant help of others. Those who supported me through the termination of my love affair, the stressing days at my internship and above all, guided me during the physical and mental breakdowns whilst researching and writing this study. My own defined deviancy and cessations made this study extremely personal.

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¹ English translation: Constant practice devoted to one subject often prevails over both intelligence and skill.

Table of Contents

1	Coming to Terms with a Deviant Past.	
	1.1 Exploring otherness: Questions of interest and its relevance	7
	1.2 Constraining deviant bodies : Purposes and utilisation of theories	9
	1.3 “We are not interested to cooperate with this study”: Methodology and perils	10
	1.4 Backbone: Where to go from here?	12
2	A Comparative Analysis of Previous Research on Managing the Sexual, Intellectually Disabled Body.	
	2.1 <i>Unsilencing</i> silenced bodies	14
	2.2 A Mandatory Message: “Study how those <i>others</i> are regulated. Right now!”	15
	2.3 “Histoire de l’imbécile”	18
	2.4 Taking stock of academic writings	21
	2.5 Victimising them or feeling uncomfortable?	24
3	Presenting a Caregivers’ Dialogue: Sexuality amongst the Care-Needy.	
	3.1 A little trip to the Mytylschool	25
	3.2 Meet the caregivers: a dialogue	26
	3.3 Chairman, can you put sexuality back on the agenda, please?	29
	3.4 Paid sex as an upshot?	31
	3.5 I think we must not let these young people <i>do it</i>	33
	3.6 Should we ignore or pay for these sexualities?	34
4	Presenting a Parental Dialogue: Sexuality of the Anomalous Kid.	
	4.1 My mother would be ok with it, but we still got his mother	36
	4.2 Where can I learn something about my son’s sexuality?	37
	4.3 Intellectually disabled youngsters in puberty	39
	4.4 Paid sex as an upshot?	41
	4.5 I do not see the point of connecting the dots	42
	4.6 Parent’s mutual understanding in disliking the practices of caregivers	43
	4.7 I feel pretty gloomy because of this documenting	45

5	“I am Different. No, I am Normal, but I am Special”. Regulated Sexualities in the Lives of Intellectually Disabled People.	
	5.1 Building meaning without physicality	47
	5.2 I was actually never allowed to date	48
	5.3 I just want to sit naked at a bar	51
	5.4 They documented in my personal folder: “Do not argue with Anton”	54
	5.5 Intellectually disabled, but unable to love?	55
6	Modifying Collective Sexual Consiousness	
	6.1 Are you a presumable upholder?	57
	6.2 A handbook: how can one ensure sexual regulation?	58
	6.3 Amare et sapere vix deo conceditur	60
	References	61

Abstract

Lately, a lot of attention has been paid to several cases of sexual abuse amongst people with intellectual disabilities in The Netherlands. However this does not improve societal prejudices about the sexualities of people with intellectual disabilities, nor does it create nutritious soil for them to explore their sexuality. Nevertheless, sexuality should hold a favourable position in everyone's life, whether one is disabled or not. But most people with intellectual disabilities are at one point in their lives institutionalized in service group agency homes or under the reign of representatives, caregivers and parents. By implementing a discourse analysis, this thesis examines these institutionalization principles, in order to determine which position sexuality holds in the lives of people with intellectual disabilities. Following Foucault, the thesis portrays how the disciplinary practices, forthcoming from institutionalization, regulate the sexuality of the intellectually disabled individual. As it is argued that people with intellectual disabilities represent a "deviation" amongst *men*, this thesis discusses that their sexualities are (1) subjugated to "institutional administration" and (2) controlled by "institutional management". A "double control" of the intellectually disabled sexual body is thereby ensured, which in turn, enforces the desexualisation of this social minority group.

1 Coming to Terms with a Deviant Past.

1.1 Exploring otherness: Questions of interest and its relevance

I still remember it vividly; I was about six years old and for some reason all my peers thought that I was a rather anomalous kid. They defined me as different because of my high body weight, my swishing and the fact that my mouth was always open. This was also the reason that my classmates bullied me with names such as Mongol or fat moron. It was therefore highly likely that I would consort with my own sort of girls and boys. My kind of person would thus be a hodgepodge of Roald Dahl's *Matilda*, J.K. Rowling's *Harry Potter* and *What's Eating Gilbert Grape's* intellectually disabled protagonist Arnie Grape - hence all deviant youngsters. At that time, my sister helped me find these "others".

A long time ago, I sat at the corner of a swimming pool during a holiday with my family. As young sisters can be very hateful towards each other, at this specific moment down at the pool, my sister and I got into a fight. Instead of calling each other names, my sister avenged in an original way: she ran to a group of guys. Of course, I was totally shocked, not only because of the fact that she just walked to that group, but mainly because these guys were not able-bodied; the group consisted of twelve disabled guys all suffering Down syndrome.² In a split second, these guys started running at me. For a long time, this was the scariest thing I ever experienced. Obviously, a ten-year-old girl will be very impressed and scared if twelve guys start running at her; but my fear was caused by an inner feeling of sadness and rebellion. I was sad because I saw twelve persons with Down syndrome, while realising that they were completely different compared to my able bodied self. Secondly, I felt rebellious, since I wondered why other people identified me with them.

As the story goes, I never did anything with this experience or these feelings, until now. My fascination with people with intellectual disabilities was triggered a while ago by the movie *Yo, también* (Pastor & Naharro, 2009). This controversial movie screens a post-modern love story, wherein protagonist Daniel - a man in his thirties with Down syndrome - has love feelings for an able-bodied woman at work, named Laura. Eventually, they become friends and at one night Laura invites Daniel into the bedroom, offering her body as a sexual charity to Daniel. But as the crucial sexual moment hits in, the screen turns black. This meant that I had to adjust my feelings towards this movie, because I was surprised that *Yo, también* did not show the protagonist' sex or intimate behavior. Several questions came to mind: did the screen turn black because the sexual construction consisted

² "Disabled" refers to a person "having a physical or mental condition that limits their movements, senses, or activities". Able-bodied means that a person is "fit and healthy" and "not physically disabled". However, this definition does not take into account that able-bodied likewise implies that a person is "not mentally disabled". Definitions are available from URL: <http://oxforddictionaries.com/definition/english/>.

out of a disabled and an able-bodied body? Thereon building, is there a possibility for people with intellectual disabilities to figure out their sexuality in contemporary Western society? Hopefully, the tone is set, so let me refine the study.

With this study I pursue to reflect on the sexuality of people with intellectual disabilities in The Netherlands. I will try to answer my main research question: *how are the sexualities of people with intellectual disabilities regulated by the disciplinary practices of caregivers and parents?* This query instantly refers to the theoretical paradigm of French philosopher Michel Foucault. I will explore with Foucault that the sexualities of people with intellectual disabilities are regulated, amongst others, by the effectiveness of institutionalised “techniques of power” (Foucault 1978: 141). Nonetheless, the query is in want of a solid definition of sexuality. Therefore I will regard sexuality as a tripartite phenomenon consisting of sexual identities, bodies *and* pleasures.³

I aim to describe how the regulation of sexualities is inter alia an effect of institutionalisation. For that reason, I will keep in mind that contemporary Western society inevitably is comprised out of diverse institutions, such as the state, language, schools and the like. However Foucault’s paradigm describes how these institutions essentially enact the disciplining of every individual citizen. This disciplining then contains different levels and techniques, an idea which Foucault described in his remarkable book *Discipline and Punish* (1975). In order to argue that the regulation of sexualities is enforced by institutionalisation, I would like to base my research on Foucault’s theoretical paradigm. Yet, it is merely important to note that everyone is one way or another, confronted with the disciplining and drilling functions of institutions. But my starting point will be somewhat different since I research the sexualities of people who are seen as deviant, so I will be investigate if this deviancy amongst *men* requires institutionalised techniques of power that ensure a “double control”.

It is desirable to examine this, since there is little known about institutions’ disciplining function upon the sexuality of the intellectually disabled individual or how this sexual body is possibly sexually restricted. Research has been done in the name of the institute exploring their offered courses on sexuality or studying the explanations on how caregivers are supposed to deal with the sexuality of their residents (Lacombe 1999, McCann 2003; Quinn & Browne 2009; Volman & Landeen 2007, in Quinn 2011: 21). Recent studies have also shown that in Western society a lot of people with disabilities, specifically those with intellectual disabilities, are the survivors of sexual abuse (Rutgers WPF & Movisie 2011; WHO 2011).

Contemporary Western society, Dutch state and even particular health care organisations are not clearly denying the sexualities of people with intellectual disabilities. Nevertheless, it does seem as they are only indicating residents’ negative understandings to sexual practices. However I am not arguing that these investigations are unjust, since it is extremely important that they will be conducted to reduce the starting principles of sexual abuse, but I will reason that these organisations regulate an

³ The utilisation of this concept is borrowed from Abby Wilkerson as seen in her article ‘Disability, Sex Radicalism and Political Agency’ (2002: 40).

animalistic and righteous need for another human being, solely because one is lesser cognitive developed. In the meantime, what can the reader expect from the academic?

1.2 Constraining deviant bodies: Purposes and utilisation of theories

One could perceive the upcoming study as a rich disputation or just as a somewhat different research standpoint, as my lead is inspired on “Disability and the Myth of the Independent Researcher” by English sociologist Colin Barnes. In this article Barnes argues that “disability research is about researching oppression”, this means that I should also join my disabled informants in “their struggles to confront and overcome this oppression” and not be independent researcher (1996: 110). This academic positioning needs a better argumentation and I will do so by elaborating on “Situated Knowledges” of American philosopher and biologist Donna Haraway in the methodological section, but for now it is important to note that I pursue to follow Barnes’ description, since I try to voice the sexual identities, bodies and pleasures of people with intellectual disabilities. This study advocates the oppressed, intellectually disabled people.

Able-bodied people are not constantly subjected towards the power of those who take care of them, such as caregivers or parents. Being care-needy indirectly implies rooted obedience. One of the purposes of this study then is to align how the intellectual disabled body is subsumed to a double charged disciplining, hence “double control” (Foucault 1978, 1980; Tremain 2005; Friedner 2010). In order to meet my aspiration of developing an argumentation on how people with intellectual disabilities are oppressed by institutionalisation, I need to carefully distinguish its political arena. I will firstly come to terms with Foucault’s conceptions of “institutions of power” and “techniques of power” (1978: 141). These theories will serve as an opening to highlight leading themes within the field of institutionalisation, namely “bio-politics” and “bio-power” (Foucault 1978, 1980; Friedner 2010). Mostly by means of bio-power, the human body becomes a standardised body; a conceptualisation which the intellectually disabled body cannot meet. The utility of the bipartite power phenomenon lies in its acknowledgement and description of institutions’ disciplining practices. Therefore I will perceive both bio-power and bio-politics as techniques of power, ensuring an “administration of bodies” and a “calculated management of life” (Foucault 1978: 138-140), which will have severe consequences for the intellectually disabled body.

Nevertheless, to fulfil the promise of a nuanced debate on the matter, I need to acknowledge Foucault’s claim that power is not merely repressive as it is also productive (1980: 98). Power at that stage, originates resistance; a thought, which will function as, a central thread in this study, or as seen in the article “How to Talk About the Body?” of French philosopher Bruno Latour: “Biopower should have a bio-counterpower. Without it, ‘body talk’ will never be any more effective than the songs of slaves longing for freedom (2004: 227)”. Latour argues that bio-politics and bio-power, as techniques of power, are interwoven in our daily lives, therefore these functions also meet times of struggle and resistance. I will portray by means of discourse analysis how the intellectually disabled body can

deploy resistance. However, it is argued that these resistance-like practices are still modified to the norm: onward sexuality will most likely be no outcome, as sexual identities, bodies and pleasures are arranged according to the requirements of heteronormativity (Butler 1993).

Moreover, I will apply another concept of American philosopher Judith Butler, namely performativity, as she claims that an overall, subjective body is actually based upon a reiteration of norms that rule within a certain discourse (1993: 270). But this will give me firm ground to carefully address the origin of the difference between being disabled or able-bodied. By doing so the concepts of normality and normativity need to be further described, since they impose certain values and norms on an individual (Link, in Tremain 2005: 194). All human beings are under society's spell, but people with intellectual disabilities will never meet the normative requirements, as they are abnormal from the start. I will further eliminate this generalisation by using the book *Stigma* (1963) of Canadian sociologist Erving Goffman. I will investigate if people with intellectual disabilities are sexually restricted by means of this assigned stigma. Previous literature for example studied how people with intellectual disabilities are mainly identified as asexual and innocent (McRuer 2010; Gomez 2012). These stigmatisations on asexuality and innocence may provide footing to perceive intellectually disabled persons as an infant, since they are from the start not able-bodied enough to formalize their own lives. This decrease of the intellectually disabled' capabilities and treating one as being less capable can provoke a reduction of the sexual, intellectually disabled body to an infantile state or condition. I will further describe this claim in the entrant chapters, but let me first explain how my hunt for empirical data stagnated the study in the initial stages.

1.3 *"We are not interested to cooperate with this study": Methodology and perils*

Realizing that this study deals with a great taboo, namely the sexuality of people with intellectual disabilities in the Netherlands, I knew from the start that it would be hard to access the reasonably sheltered worlds of people with intellectual disabilities. Therefore I decided that I wanted to voice two research groups. The first research group consisted out of Dutch citizens with intellectual disabilities who were in a particular way acquainted with the practices of health care organizations, residential health care organisations, group home agencies or family replacements homes. My second research group then, consisted out of Dutch people who provided care to the intellectually disabled individuals from the first group, hence professional institutionalized caregivers and parents.

But during my search for informants I found out more and more that it is highly necessary to discuss this topic, since it was extremely difficult to gather information on the matter; one should for example take into account that residents and caregivers have certain privacy rights. And on a second note, one should reckon that caregivers are required to get approval from their working institute to cooperate with external investigations. Third, in order to interview people with intellectual disabilities I needed permission from their guardians, either caregivers or parents. To formalize this study then, essential methodological choices were made. In order to get in contact with Dutch citizens with

intellectual disabilities and their caregivers or parents, I used personal contacts. Since I also wanted to participate in the daily lives of people with intellectual disabilities I found it necessary to observe e.g. classes, workshops, and theatre rehearsals. Therefore I decided to contact diverse health care organisations through the consignment of a standard contact letter. Most of the times I received emails back saying that they were not interested to cooperate with this study. Eventually I got *in*, since some of the informants came to an arrangement with health care organisations.

Consequently, I profited by using two methodological instruments, namely semi-structured interviews and participant observations. The semi-structured interviews were of great use when talking to the resident's caregivers, parents and volunteers working for a particular health care organisation or providing help during the resident's day-care programme. Throughout the research I figured that I should also voice the bodies of people with intellectual disabilities, by inserting real life experiences. Therefore I decided to do an interview with two intellectually disabled people for which I used unstructured interviews. Both respondents had a rather high cognitive level; they were able to listen and speak for a long time.⁴ Finally, participant observation came into play when I shadowed during the day-care programmes for people with intellectual disabilities, such as theatre rehearsals, working in a restaurant and observations of classes wherein that specific health care organisation provided courses on sexuality and intimacy to their residents.

All data was collected during a period of four months, namely January 2012 to April 2012. The query of this study was based on twelve interviews and anonymity was constantly pursued; the given names in the study are thus fictitious. Moreover, it has to be mentioned that I studied the topic of sexuality and intellectual disabilities for my undergraduate thesis.⁵ During this process I got familiar with the scarcity of useable literature on the matter; the query is thus verified on behalf of the foregoing ethnography. One could pose that this indicates a potential weakness of the study, as some important statements in my query are depending on the gathering and outcomes of data. With this knowledge then the study is delineated to The Netherlands, as a language barrier would not be too helpful. The second limitation concerns the number of health care organisations that were investigated.

One could wonder how generalisations are made on the base of twelve interviews; for answering this righteous question I devote myself to the academic positioning of Haraway in "Situated Knowledges": "All knowledge is a condensed node in an agonistic power field [and] science is a contestable text and a power field; the content is the form. Period (1988: 577)". Haraway's idea that knowledge is created throughout power and that content is merely intrinsic to a specific claim made me realise how truth claims in science are actually based on a radical historical specificity, and therefore those claims can be contested (578). Her writing inspired me throughout this

⁴ This does not mean that other people with intellectual disabilities cannot, I am merely arguing that the people I spoke were able to do so.

⁵ *The Good, the Bad and the Disabled: an Investigation in Desexualisation as an Effect of Institutionalization* (2010). Undergraduate thesis: University of Amsterdam.

investigation as it is very true that every truth claim itself is situated and thereby becomes *that* truth at the moment wherein it is situated - with this study then I am “building meaning and bodies that have a chance for life” at a particular moment (580). To voice those people that are unheard, one cannot be an “independent researcher” (Barnes 1996: 108).

In the upcoming thesis I will explore the breaking of the boundaries between science and politics, as “any epistemology is a political epistemology (Latour 2004: 221)”. Advocating the sexual rights of people with intellectual disabilities break this boundary, as sex is always political (Rubin 1984: 171). This inevitably means that some conventional positions were broken during this investigation; since an academic is also required to give unheard and oppressed individuals a voice and to show how they are sometimes more able at doing what they *may* do. Thereby, a lot of attention has been paid lately to the claim that institutional housing groups seem to cope with many forms of sexual abuse (*Volkskrant*, November 14th 2011). Nevertheless, few academics have discussed the sexual feelings amongst people with intellectual disabilities (Gomez 2012), neither questioned how their sexual identities, bodies *and* pleasures are restricted by means of institutionalised techniques of power, but I will do just so.

1.4 *Backbone: Where to go from here?*

With this study I will give answer to the following question: *how are the sexualities of people with intellectual disabilities regulated by the disciplinary practices of caregivers and parents?* The emergence of this question and its possible answers need a firm structure. Therefore, in the second chapter I will present a theoretically comparative analysis wherein I will situate the prior and recent academic polemic on the sexuality of people with intellectual disabilities. This will give me firm footing to answer the question: *how are the sexualities of people with intellectual disabilities represented in previous research?* Some studies might actuated an even more negative stigma for people with intellectual disabilities, so these studies may not improve societal prejudices about the sexuality of people with intellectual disabilities. However, I wonder if the latter actually arises the likelihood of interrupting the discovery of one’s sexuality.

The third chapter offers a dialogue, I will analyse the gathered data on the basis of a discourse analysis. The usefulness of this methodology lies in the fact that it can portray how sexuality has become political (Rubin 1984: 171). I will give answer to the ensuing question: *how are the sexualities of people with intellectual disabilities professionally regulated and managed by caregivers?* More specifically, I wonder how institutionalised, professional caregivers nurture the sexuality of people with intellectual disabilities. The fourth chapter will have the same set up as the third one, only then I will wonder: *how are the sexualities of people with intellectual disabilities regulated by the practices of parents and its forthcoming familial relationships?* During my fieldwork I noticed that it is necessary to do so, as every parent and family yield a different position to ‘talking and thinking’ about their child’s sexuality.

In the subsequent fifth chapter I will give voice to the sexual stories of people with intellectual disabilities. But this part shall merely envision the techniques of my two intellectually disabled informants for possibly providing resistance to the disciplinary practices of caregivers and parents. These results shall give answer to the following query: *how do people with intellectual disabilities cope with their regulated sexualities? And how do they resist?* A conclusion will be presented in the sixth section, wherein I will explore how people with intellectual disabilities represent “biological danger” (Foucault 1978: 138). They are therefore dually controlled subjugated to the societal techniques of power. In the end, this not only enforces sexual regulation amongst this social minority group, but it also puts desexualisation into effect. All that has to be said then, is that what is studied - the disciplining principles of institutions upon the sexuality of people with intellectual disabilities - is my truth, and “subjectivity is multidimensional; so, therefore, is vision (Haraway 1988: 586)”.

2 A Comparative Analysis of Previous Research on Managing the Sexual, Intellectually Disabled Body.

2.1 Unsilencing silenced bodies

Imagine Annette, a 30 year-old woman with curly red hair and a charming silk dress. She has a well-proportioned body and loves to wear high heels. If you would see her walking down the street you would seriously think about approaching. While you collect all your thoughts and jokes to impress her, you discover something whilst she walks into your direction. It seems the red-head's face is paralysed, as her tongue hangs out her mouth so easily. She also stumbles; her left hip seems in a fight with her right hip. Indeed, Annette has a hip dysplasia and she also stutters and pronounces sentences in an unconventional way. Maybe Annette is gloomy, but she is most of all misunderstood and silenced; could her intellectual disability be the reason? She has kissed a guy before and remembers how that last kiss made her feel heatedly. The one thing Annette longs for is occasional sexual activity. Her caregivers will not help her, since they do not like the fact that Annette likes to have occasional sex. Annette is physically capable to have sex, but to do so, she is required to be in a relationship. Secondly, Annette cannot hire or visit a sex worker; she has not got enough money, since her intellectual disability makes her depending on a payment. Annette's body then is hushed ever since she cannot develop herself sexually. I wonder then, how Annette can fulfil her desire. How is it possible that someone else can reprove a 30 year-old woman that she is better off having sex in a relationship? Or more specifically, how can a person with an intellectual disability - who has reached the minimum legal age for consensual sex - actually *do* her sexuality?

A while ago I got more familiar and fascinated with the idea that discussing, or even acknowledging silenced sexualities, is still a big taboo in Western society.⁶ Theorists, institutions and popular media seem to publish a rather normative reasoning on why those sexualities are silenced. If for example a news magazine would discuss Annette's desires, then her silenced body will be presumably harmfully represented. Perhaps this news magazine would discuss the possible pleasures Annette is about to discover, but the reader is most likely informed about the amount of risks that sexual experience could entail as 'Annette might get pregnant', or 'maybe Annette does not even like to perform these sexual acts', since she is mentally incompetent. This means then that Annette's right to discover her own sexuality is taken from her by an argumentation that is solely based on what others perceive to be her intellectual disability. Intellectual disablement implies that a person has a lower cognitive level, but it somehow also signifies a lack of self-reliance and accountability in

⁶ With silenced sexualities I mean e.g. a man who is in his transition of becoming a woman or an eighteen year-old adolescent with Down syndrome who desires both men and women.

comparison to people not diagnosed with intellectual disablement. This makes me wonder if these are legitimate reasons to deprive a person from her/his own desires in relation to sexuality.

I will elaborate this more in the following chapters, but for now I would like to portray the rather oversimplified reasoning why the intellectually disabled body should or should not gradually evolve into the performance of sex, pleasures and subsequently identity and subjectivity. Previous research seems to be focused mostly on victimisation of the people involved the victimhood by concluding that: “people with intellectual disabilities are more often sexually abused than people without a disability (Rutgers WPF & Movisie 2011: 179)”. In this chapter I will explore the following question: *how are the sexualities of people with intellectual disabilities represented in previous research?* Therefore I will conduct a comparative analysis wherein all sorts of positioning’s towards the sexuality of intellectually disabled people will be explained. I also wonder if these studies actuated an even more negative stigma for people with intellectual disabilities. Could it be that these results let normative thoughts emerge where some people in society may even identify intellectually disabled individuals as piteous and lonesome? This does not eliminate societal prejudices and maybe it even sharpens the judgement that disabled people should not discover their sexuality. This dominant discourse is based on diverse experiences, investigations and the like.

The upcoming paragraphs are divided into three sections. In the first section, I will insert my query on how caregivers and parents regulate the sexuality of intellectual disabilities, and why it is necessary to examine these disciplinary practices when trying to liberate the sexuality of intellectually disabled individuals. In addition, I will recommend a theoretical paradigm that exposes the disciplinary practices of caregivers and the like. The second section portrays the history of institutionalizing people with intellectual disabilities from 1850 until the current situation. I will also discuss the phenomenon of intellectual disabilities and what requirements, or rather defects, should be met when defining an intellectually disabled person. Finally, I will portray and unravel a few studies on the sexuality of people with intellectual disabilities where I will pay specific attention to negative publications and reasoning of that specific sexuality. Donna Haraway would say that I will portray how people with intellectual disabilities become “the embodied other” (1988: 575), and are thereby sexually restricted.

2.2 *A Mandatory Message: “Study how those others are regulated. Right now!”*

In this section I will elaborate my theoretical framework, which will be my lens for studying the regulated sexuality of intellectually disabled persons. Sexuality in this study is perceived as a tripartite phenomenon consisting of sexual identities, bodies *and* pleasures (Wilkerson 2002: 40). As I illustrated with Annette’s story, it seems difficult for intellectually disabled persons to discover and to develop their sexuality. With this study I question whether their need for institutionalised, professional care, and therefore their dependence on others, interrupts their sexual development. Caregivers have the power to decide for an intellectually disabled individual what (s)he can or cannot

do. This statement is inherent to the question if the disciplinary practices of institutions and their caregivers and parents influence the sexuality of those who are intellectually disabled. Let me take a look at these practices.

Foucault devoted a big part of his academic career to the historical analysis of the ‘mad’ and ‘the insane’, such as *Folie et Déraison* (1961) and *Naissance de Clinique* (1963). If one wants to study the phenomenon of disciplinary practices; Foucault offers an interesting paradigm to study the sexuality of people with intellectual disabilities. First of all, it has to be extremely clear that people with intellectual disabilities are perceived as different from the norm, hence as disabled. This binary between disable-bodiedness and able-bodiedness has its roots in the normalisation and medicalisation of society. Foucault describes in his second *Power/Knowledge* lecture (1980) how this normalisation is enabled and how it thereby affected the body of the ‘mad’, as (s)he was identified as unproductive and disabled. The insight derived from Foucault’s paradigm on exclusion and repression explains how abnormal people were excluded and banned from active participation in society (1980: 100), since they “represented a biological danger to others (1978: 138)”. People diagnosed with intellectual disabilities were thus institutionalised in distant residences.

In addition, the above-mentioned quotes actually portray the concept of bio-politics. I will quickly explain this concept as it is extremely usable when further researching the sexuality of intellectually disabled people. According to Foucault, bio-politics and thus bio-power came into play after *The Renaissance*. The population and economics of the modern Western state were growing extensively. Therefore society needed a new type of government, or as Foucault calls them: “institutions of power” (Foucault 1978: 141). From this time onward, the human population needed to be regulated, as life had to be fully optimised (Friedner 2010: 340). The body then becomes political as principles of optimisation are fought over this human landscape (Latour 2004: 227) and it is exactly at this point that social norms come into play: “Bio-politics is exercised over members of a national body by imposing certain norms of human conduct, thereby objectifying and shaping people for political regulation and economic exploitation (Prieue 2004: 399)”.

The above-mentioned means that every living soul in society is subjected to bio-politics. However, I believe that bio-power (a concept which is inherent to bio-politics) likewise makes the intellectually disabled body dually subjugated to the societal “institutions of power”. This has to do with the fact that bio-politics operates at the societal level, whereas bio-power disciplines the individual body (Foucault 1978: 139). Bio-power affirms the on-going distribution of normality and normativity of the hegemonic group in a society by certain “techniques of power”. Normativity will be utilised in this study as “the power of social and legal norms that are put upon people” (Link, cited in Waldschmidt 2005: 193), whereas normality counts in this study as “comparing people with each other in light of a standard (ibid: 194)”. The confluence of these two techniques of power thus causes the distinction between able-bodiedness and disable-bodiedness. As the third section will portray, most argumentation on why people with intellectual disabilities might better not discover their sexuality are

based on the presumption that people with intellectual disabilities are likely to be mentally incompetent because they are diagnosed as different. I reason however that having an intellectual disability does not make you less of a human and therefore less needy.⁷

Nonetheless, bio-politics and bio-power, as techniques of power, are therefore the actual producers of normalised social constructs and bodies. As a result, this “standardized body” (Link 2004: 15) becomes the dominant discourse on intellectual disablement. But both bio-politics and bio-power also ensure the subjugation to an “administration of bodies” and control by a “calculated management of life” (Foucault 1978: 138-140). With the analysis I will portray how these are transacted upon by caregivers and parents, since they e.g. document the entirety of things and guard the actions of the intellectually disabled twenty-four hours a day. Parents and caregivers thus regulate the sexualities of intellectually disabled people, since they do not “lend themselves to the constitution of the productive forms (Foucault 1980: 100)”. As it is believed that people with intellectual disabilities do not meet the normative standards of able-bodiedness, they are stigmatised with as abnormal, disable-bodied and disable-minded. I believe that due to this stigmatisation the sexuality of those “others” are regulated and therefore repressed.

This concept of stigmatisation allows me to highlight how intellectually disabled persons are identified when ‘talking and thinking’ sexuality amongst this social minority group. In his book *Stigma* (1963) Goffman explains that stigma originally referred to the “bodily signs to expose something unusual and bad about the moral status of the signifier (ibid: 1)”. Nowadays one could rather explain stigma as something that reduces the human body to a “tainted, discounted one” (ibid: 3). The author stresses that this reduction is made visible through the minds of those who do not encounter that stigma, hence the normal or the norm (ibid: 5). Thus, the minute able-bodied people discuss the possibility of people with intellectual disabilities practicing sex; the overall stigma of intellectual disablement seems to be central point of discussion, instead of the individual character and capacities of that body. Due this stigmatisation able-bodied people believe that they meet all the abilities and requirements to decide and manage the sexuality of disabled people. Goffman explains that: “the person with a shameful differentness can break with what is called reality, and obstinately attempt to employ an unconventional interpretation of the character of his social identity (ibid: 10)”. As a result, stigma can be utilised for insurgency purposes, thereby opening a door to inferior advantages. The idea of resistance will be thoroughly discussed in my analysis, since power is not merely repressive as it is also productive (Foucault 1980: 98). Or as Bruno Latour would say: “bio-power should have a bio-counterpower” (2004: 227) which means that if a person with an intellectual disability wants to discover his or her sexuality, a technique or a possibility for resistance can be found.

⁷ Understandably, I am merely arguing that being different does not make you less human. This then, does not mean that people who are depending on others should just ‘go about and have sex’. I am just advocating their sexual rights.

In the interim, I will conclude my thoughts with the claim that the sexuality of people with intellectual disabilities, and how it is regulated by able-bodied people's operations of power, should be studied more carefully, as "the category of sex is, from the start, normative (Butler 1993: 1)". Sexualities of people with intellectual disabilities are thus managed and verified by customary levels of sanity and mental competence. But in order to do so I first need to ask myself how it is possible that someone's life is managed and monitored by someone else. In The Netherlands this has its roots in institutionalizing people with intellectual disabilities. In the next paragraph, I will examine the emergence of this institutionalised history

2.3 "Histoire de l'imbécile"

This paragraph will give answer to the question: what entails intellectual disablement and which different categories can be defined? I will do so by introducing a short historical overview on how intellectual disablement is perceived in The Netherlands from 1850 until now. Eventually, this historical overview will give me firm ground to discuss the notion "quality of life", as discussed by Hans Kröber in his dissertation (2008).

The revised fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV 2010) thoroughly explains intellectual disablement.⁸ The publication does not employ the term intellectual disablement, but instead uses the term "mental retardation", which is a rather contested concept. Nevertheless, this international classification system defines mental retardation on the basis of three criteria: (1) intellectual functioning is clearly sub average, meaning that the IQ is below or around 70, (2) due to the sub average IQ adaptive functioning is limited in either one of the following: "communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety" and (3) all the above must be visible and diagnosed before the age of eighteen years.

Nowadays intellectual disablement is not solely defined on the basis of IQ tests, it is rather based on the amount of care one needs in everyday life. However, there are still slight discrepancies within the category of intellectual disablement. For now, I will not explain these differences, but I would like to address that these DSM criteria are also used for personal diagnosis in The Netherlands. In spite of the fact the term 'disability' is still subjected to many changes, but I will use the definition of 'disability' as provided by the World Health Organization in their report on disability:

Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factor (environmental and personal factors (2011: 4).

⁸ American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders* - Chapter 1. Disorder Usually First Diagnosed in Infancy, Childhood, or Adolescence. Available from URL: <http://dsm.psychiatryonline.org/content.aspx?bookid=22§ionid=1888402>.

Intellectually disabled persons still face discrimination and certain prejudices in contemporary Western society (Hannigan 1999; Morris 2001; Shakespeare & Watson 2002; WHO 2001, 2011). Even the informants described how some institutions and individuals still perceive people with intellectual disabilities as deviant. This otherness has a lot to do with different events throughout history, think about the earlier announced occurrence of normality as introduced by the medical field (Foucault 1976, in Lambrechts 1982: 257). But how did these opinions about intellectually disabled people emerge in The Netherlands?

Until 1850 there was no specific social attention for intellectually disabled people, or so-called ‘imbeciles’, as a social minority group. They were viewed as human beings who were extremely dangerous for society and thus inhumane (Foucault 1972: 161, in Lambrechts 1982: 53). They actually just walked about in society. It was around 1850 that housing facilities for ‘imbeciles’ were built. Mostly nuns and others, who followed the light of Christianity, took care of these residents.⁹ Dutch sociologist Evelien Tonkens notes that around this era no attention was paid to personal diagnosis or mental support; the only criterion for admission was destitution and thereby the constant need for care (2003: 1). From the 1850s onward, the intellectually disabled individual was regarded a psychiatric patient. Nevertheless, more housing institutions were build, and they mostly served as a hideaway from society, where the ‘imbeciles’ inhumanly lived until their last breath as care mostly consisted out of surveillance, control and physical care (SCP 2005: 12).

After 1900 new ways of thinking about intellectually disabled people emerged in the medical establishment. Doctors and caregivers believed that there was a need to differentiate between the levels of disability. This trend could be perceived as the first step in the direction of personal diagnosis and mental care. Around World War II the demand for institutional housing residences grew. Also a division between strong and weak citizens emerged. Consequently, the intellectually disabled individual could not keep up with all the requirements of hegemonic society. Therefore these housing institutions were perceived as a sub society in which all ‘imbeciles’ could live happily. In the same vein, it was around this time that the consent of sexuality was highly visible. The sexuality of people with intellectual disabilities needed to be controlled, and therefore female and male residents were strictly separated from each other in housing institutions (Tonkens 2003: 2).

After World War II a new level of medical expertise emerged in the understanding of the condition of intellectual disablement; not only doctors diagnosed intellectual disablement, but also behavioral scientist and other professionals became experts in this specific field. It seems that this trend eventually caused a more positive understanding towards people with intellectual disabilities. This new knowledge is particularly reflected on around the 1960s when the care for those “others” became more and more based on the “normalisation paradigm”. This paradigm entails that people with a disability have the right to a normal life. This entails that new-borns with a disability are not

⁹ <http://www.watze.info/voor.1850.htm>.

immediately locked up and institutionalised. Therefore, the implementation of this new perspective entailed that first-hand facilities were built, such as institutional housing groups and day-care organisations. All these new developments had to ensure that people with a disability could reintegrate in society as much as possible (SCP 2005: 12).

Consequently, this new “normalisation paradigm” enacted a shift that led to the disappearance of the traditional, medical model that had been used in The Netherlands for many decades. After the normalisation model, different models made their entrance, such as the humanistic model, which was introduced around the 1970s. This model included the vision that people, who were diagnosed as having an intellectual disability, should be able to *be* themselves; as everyone somehow voices the occurrence of disablement (Tonkens 2003: 3) - an ontology which quietly lives on nowadays (Shakespeare & Watson 2002: 27). Eventually during 1980s the idea arose that intellectually disabled people should gain the possibility of self-determination. Different from the humanistic perspective, this new focus entailed gaining individual rights, individual possibilities and the capability of making one’s own choices - thus becoming an intelligible subject (Tonkens 2003: 4).

Overall, it could be said that the former developments caused a shift from the dominant medical discourse surrounding disability to a new social way of looking at disability. This entailed that disability was merely a biological variation amongst people, which should be approached in a humanistic way. However, studies emerged that found this social model biased (Morris 2001: 2; WHO 2011: 4). Nevertheless, The Netherlands has a long history of institutionalizing people with intellectual disabilities. The Dutch social care model still tries to find its balance. On the one hand, care should consist out of supporting people with all the things that they want to do, on the other hand, realising that good care comes with its limitations by not being too invasive to people’s bodies and wellbeing.¹⁰ It is however argued that contemporary Dutch care service system pays most attention to the disability, meaning that a body is reduced to its proposed “deviation” (Kröber & Van Dongen 2003, in Kröber 2008: 20). This trend is criticised as it diminishes certain basic principles of the “quality of life”, or as Dutch director of Pamijer, a health care organisation which specializes in support for (mild) intellectual disability, Hans Kröber explains: “People with intellectual disabilities are hindered in their participation in society and preconditions are lacking to participate as an equivalent civilian (Schalock & Verdugo 2002). One of the domains of the quality of life - inclusion - is thereby compromised (Schalock & Verdugo 2002, in Kröber 2008: 50)”.¹¹

With his study, Kröber tries to improve the quality of life for people with an intellectual disability on the individual level. The concept “quality of life” was originally designed by Schalock and Verdugo (2002) in which the quality of one’s existence is constantly depending on the overall personal wellbeing and the interaction a person has with his or her environment (2008: 37). Kröber argues that people with intellectual disabilities cope with a lower level of quality in their lives, as they

¹⁰ A claim which I will further address in the upcoming writing.

¹¹ Translated from Dutch, KV.

are not that well included in Dutch society, unlike able-bodied persons (ibid: 38). I would reason that, a favourable quality of life form would also entail the discovery, development and performance of one's sexuality. It however seems that lesser attention is paid to the development and actual fulfilment of sexuality amongst people with intellectual disabilities. Bodily pleasures seem to be excluded. With the analysis of different academic studies I can discover the position of sexuality in the lives of people with intellectual disabilities. Sexuality is related to becoming intelligible subjects. Denying people their sexuality is denying them their sense of self, excluding them from the possibility of subjectivity. The upcoming paragraphs will show how previous research dealt with the possibly loss of sexual subjectivity amongst people with intellectual disabilities.

2.4 *Taking stock of academic writings*

The topic of sexuality in the lives of intellectually disabled people covers a grand academic polemic, but previous studies all seem to yield different positions. I have analysed these different positions and by using Foucault's concept of bio-power as a basis, I can reflect on the ways in which sexuality of intellectually disabled people is regulated; insinuating that it does not improve the quality of life. In the introduction I already noted that a lot of investigation is devoted to the possible negative effects and risks of engaging in sexual acts with people with intellectual disabilities, such as sexual violence and intimidation. However, I wonder what enjoyable principles the intellectually disabled body can experience. The article 'Sexuality and People with Intellectual Disabilities' (Siebelink et al. 2006) is one of the few studies I found that perceives the sexual bodies of intellectually disabled individuals as possibly sexual. Siebelink et al. try to offer a righteous critique of our perception on people with intellectual disabilities, who we usually perceive as "asexual and [having] no need for loving or fulfilling relationships with others (ibid: 283)". The study discovered that their respondents had a great need for "conventional sexual needs, such as kissing, intercourse, and masturbation and even more relational needs (ibid: 290)". As even intercourse seems to count as a noticeable activity in the lives of the intellectually disabled informants, maybe they are ready and steady for maintaining their own sexual citizenship, or as Siebelink et al. describe: "Our respondents appeared to already have considerable experience with many facets of romantic relationships and sexuality, and they also appeared to have many needs for relationships and sexual activities (ibid: 292)".

This quote struck me, because it raised several fundamental questions in my mind. Firstly, if certain institutions within society have access to these numbers, why are people with intellectual disabilities not offered the possibilities to discover their sexuality? Secondly, as one of the informants mentioned, how come that this social minority group is represented in medical studies as rather innocent and maybe even asexual? As the former results show; many of their respondents have had a sexual experience. The problem rather seems to be that this sexual experience is highly exceptional. Therefore those bodies are retained and repressed in their sexual development and their sexual identity.

Perhaps this has something to do with current research results and beliefs on the sexuality of intellectually disabled people. Let me refine this statement.

In 2011 the World Health Care Organization, a worldwide leading institute, which specializes in global health, published the report “World Report on Disability” (WRD 2011). WHO spend around 350 pages to claim that people with disabilities, whether they have an intellectual or physical disability, face a lot of discrimination (ibid: 6) and mostly live their lives in rather poor economic circumstances (ibid: 10). This report then tries to uncover the several personal and environmental issues people with disabilities seem to face throughout the whole world (ibid: 17).

This is a positive outcome, as WHO is a prominent institution; WHO is thus able to convey several recommendations to improve further developments. However, I did encounter some serious problems when reading this study. The first being the limited amount of attention paid to describe the sexual needs of people with intellectual disabilities. Being a healthy and good functioning person, also involves the ability of expressing oneself sexually.¹² Secondly, when discussing the areas of sexuality, WHO mainly focusses on the possible risks such as the amount of violence and sexual abuse people with disabilities seem to encounter: “The prevalence of sexual abuse against people with disabilities has been shown to be higher, especially for institutionalised men and women with intellectual disabilities, intimate partners and adolescents (2011: 59)”. Obviously, these research results will immediately encourage policymakers, caregivers and parents to possibly reduce and restrict the possibilities for people with intellectual disabilities to discover their own sexual identities, bodies and pleasures. Nevertheless, WHO also recognizes the worldwide existing prejudice that people with disabilities “are asexual or else that they should have their sexuality and fertility controlled”. WHO likewise reports that in some countries forced sterilisation is still practised - a practice that is highly gendered as well, seeing that the victims are mostly women (ibid: 78).

Unfortunately, the report does not offer solutions on how people with disabilities - specifically those with an intellectual disability - can express their selves sexually. The “World Report on Disability” only seems to address the practical difficulties when ‘talking and thinking’ sexuality with this social minority group. This is not beneficial to Dutch people with an intellectually disabled body that in the same year Rutgers WPF published their research results in “Beperkt Weerbaar” (2011). This report from Rutgers WPF similarly argues that people with intellectual disabilities are more often the survivors of sexual violence, than people without a disability (179). As the title of the study notes, this apparently has something to do with the fact that people with intellectual disabilities are less capable of defending themselves, compared to able bodies. A conclusion that I draw from these studies is that on the individual level they do not improve the personal and environmental experiences when it comes down to sexuality for people with an intellectual disabilities as they actually cultivate a

¹² I see an apparent link to the previous phenomenon of “quality of life”.

victimizing discourse. Nevertheless, these studies are not the only determining factor that interrupts and influences the sexual wellbeing of people with an intellectual disability. The responsibility for this effect also lies with the direct, day to day professionals that interact with people with intellectual disabilities such as caregivers and parents of disabled people. They are partially responsible for this development as they use disciplinary practices when devolves upon exploring oneself sexually. This argumentation will be further highlighted in the upcoming chapters, but for now I will discuss some studies that also acknowledge my presumption.

When sexual rights are officially part of a human right (WHO 2001), how can one get access to these rights if society defines him or her as mentally incompetent? In a recent study, titled “Relationships, sexuality and decision-making capacity in people with an intellectual disability” (McGuire & Bayley 2011) Irish psychologists McGuire and Bayley argue that “caregivers and service providers face a difficult dilemma in promoting sexual autonomy among people with an intellectual disability (398)”. The authors state that this has a lot to do with the fact that our society is embedded in a culture of “conservatism and paternalism”, wherein silence remains the best outcome. Once again, this study confirms that it is partially the responsibility of caregivers to discuss the sexuality of people with intellectual disabilities. Furthermore, if sexuality is on the agenda, then it is highly subjected to the normative view uttered by others (ibid: 399).

Australian sociologist Chris Quinn and his team also address the problem of normativity in their article “Talkin’ or Avoiding” (Quinn et al. 2011). They note that the participants of their study - mental health nurses - acknowledged the fact that their consumers have several sexual concerns. Nevertheless, these concerns were still a low priority for the nurses, as there is a culture of silencing sexuality. It was difficult to talk with their patients about their sexual needs for a number of reasons, “such as feeling comfortable with one’s sexuality identity or the sexual identity of another, and their personal belief system surrounding sexuality and sexual practices (ibid: 25)”. The sexualities of the mental health patients were thus mixed up by personal reasonings, instead of professional ones (ibid: 26).

Therefore it could be said that it is difficult to talk about this topic in the field of mental health care providers and this has its negative effects on the lives of people with intellectual disabilities. Canadian sociologist Marie-Claude Lacombe writes that according to Dr. Bill Maurice, students in medical school never really studied the sexuality of patients, since it was only mentioned in passing (Lacombe 1999: 11). This culture of silencing sexuality even leaps through in school institutions, which is highly problematic. I wonder what is discussed in medical school or what education is provided for professionals on the sexuality of intellectually disabled people. For now, it appears that students or caregivers learn a lot about how to control their patient, resident or client. Sexuality then, becomes a restrictive experience, which has all to do with the fact that “the mere thought of friendships, intimacies, and sexuality creates *discomfort* and unease among most families, caregivers

and virtually all health professionals (Whetstone & Rich 1999: 4)”. Nonetheless, the performances of your sexuality is an important feature of life, or as the foregoing authors likewise note: “Without the joy and pleasures of warm friendships, caring intimacy, and sexual expression, the quality of life for anyone is less than what should be acceptable (ibid: 4)”.

Finally, I should recognize those studies and institutions that advocate the sexual rights of people with intellectual disabilities, as the American Association on Mental Retardation announced in a new policy that people with “mental retardation and related disabilities have the right to start and end relationships with others and to express themselves sexually (American Association on Mental Retardation 2002, in Siebelink et al. 2006: 283). Some studies also report that the personnel of service agency group homes are approaching the resident’s need for sexuality or sexuality supervision more positively (Murray & Minnes 1994; Lofgren-Martenson 2004, in Hamilton 2009: 304). However, personnel should be properly trained to also deal with sexual parts of care when interacting with people with an intellectual disability, as this is an integral part of their lives.

2.5 *Victimising them or feeling uncomfortable?*

With this chapter I conducted a comparative analysis of previous research studying sexuality amongst intellectually disabled people. The main question was based on my curiosity, wondering how a person with an intellectual disability - who has reached the minimum legal age for consensual sex - can practice her/his sexuality. Eventually, this caused me to answer how the sexualities of people with intellectual disabilities are represented in previous research. In order to do so I first explained how people with intellectual disabilities became institutionalised in The Netherland. Institutionalisation restricted people with intellectual disabilities to be included in society; they therefore do not profit from all “quality of life” basic principles (Kröber 2008: 38). I also reflected on other studies that previously researched the matter and I found that worldwide leading institute World Health Care Organization reflects on sexuality in the lives of intellectually disabled people in a victimizing way, as they do not focus on sexuality in an extensive way, but merely report on how sexual abuse manifests itself amongst institutionalised men and women with intellectual disabilities (2011: 59). Dutch sexuality centre Rutgers WPF likewise exposed a victimizing portrait of the intellectually disabled individual (2011: 179). Other studies noted that “caregivers and service providers face a difficult dilemma in promoting sexual autonomy among people with an intellectual disability” (McGuire & Bayley 2011: 398) and that sexuality is still low priority for caregivers, thereby promoting silenced sexualities (Quinn et al. 2011: 25). Hereby I specifically found that sexuality creates “*discomfort* and unease among most families, caregivers and virtually all health professionals (Whetstone & Rich 1999: 4)”. Nevertheless, this chapter led me to wonder how institutionalised, professional caregivers take care of the sexuality of their intellectually disabled residents and clients. In the entrant chapter I will *inter alia* use the analysis of this academic disability polemic to research this question.

3 Presenting a Caregivers' Dialogue: Sexuality amongst the Care-Needy.

3.1 *A little trip to the Mytyschool*

On a drizzling Tuesday I had a meeting with a teacher of Mytyschool 'De Regenboog'.¹³ This special school offers Dutch regular educational programs that can be adapted to the wishes, needs and capacities of the individual students up to twenty years of age. De Regenboog is located in a green and wealthy looking residential area in Haarlem. The school is far-off the normal land: I could not reach this school by public transport, since the nearest bus stop was a twenty-minute walk away. While I walked to the entrance of the school I noticed that I felt nervous; I was about to discover the ins and outs of the daily lives of youngsters with intellectual disabilities.

The concierge opened the guarded doors for me. The corridors were filled with bright and colourful drawings of the students. The midst of the corridors was reserved for highly developed wheelchairs, futuristic to say the least; the vehicles seem to be made for cyborg-esq individuals.¹⁴ And I, I was the odd one out, expecting to be rubbernecked. I felt numb walking into the classroom introducing myself to teacher Jolene, I saw a student *standing* in one of the futuristic vehicles with a spit cup located under his face. He made non-verbal sounds and quite interestingly, the teacher seemed to understand what he said. According to her Mark asked if I wanted to sit down next to him. As I sat next to Mark, a girl with Pippi Longstocking hair moved Mark and his vehicle away and sat next to me. She stared at me. Whilst the minutes went by and the first lesson of the day began, I felt her left hand touching my face, arms, shoulders and almost my breasts. I did not stop her, because I did not mind her longing for interaction or contact, but as I tried to resume my focus I heard Jolene say that she was not allowed to do that, because 'you cannot touch people involuntarily'.

One could start a discussion wondering if the interruption of 'you cannot touch people involuntarily' is necessary. Even though I believe that Jolene implemented a very true and understandable pedagogical lesson, I also wondered if Jolene or any of the other caregivers would sort out this event in a different manner than solely the reprimand. Would they deal with the possible details that this girl has a need for bodily contact or that she might be insecure about her own breasts and therefore touches other ones, simply to compare? And how did Jolene know what student Mark said when he was making those non-linguistic sounds?

It made me wonder how caregivers can take care of the sexuality of intellectually disabled people when they sometimes have limited access to one's needs, wishes and questions. And more importantly what discourses on sexual intimacy and - care do caregivers hold on to? It is important to

¹³ A Mytyschool is a school for toddlers, children and adolescents with a multiple disability. For more information visit: www.mytyschoolderegenboog.nl

¹⁴ A being with both biological (natural) and artificial (cultural) parts.

answer these wonderments as caregivers are not only the executors of Dutch' institutions of power, such as welfare policies, but they also embody their own social context. Therefore, in this chapter I will study the following question: *how are the sexualities of people with intellectual disabilities professionally regulated or managed by caregivers?* It is necessary to explore this question, as it will portray what caregivers face when it comes down to nurturing, monitoring or taking care of the sexuality of intellectually disabled individuals. Throughout this dialogue it will become clearer how these carers justify their caring based on policies whilst staying loyal to their own social context, and how this caring actually entails forms of discipline and regulation.

This chapter shall be divided into four sections. In the first one I will shortly portray which struggles Anton, Rick and Nicole faced during their professional counselling of people with intellectual disabilities. This first part situates the different discourses amongst caregivers and health care institutions. In the second part I will share the professional experiences of two sexual education teachers, which they face when they discuss the sexuality of people with intellectual disabilities. This will allow me to portray how caregivers on occasion determine what an intellectually disabled client can or cannot *do* regarding their sexuality. To put it differently, the social context of caregivers can be perceived as an intruder in the search and development of one's sexuality. Thirdly, I will wonder if health care organisations provide something supplementary other than sexual education to their intellectually disabled resident. Maybe some organisations or caregivers agree with their residents' wish of hiring a sex worker. The latter will give me a solid base to introduce the possible positive and negative effects of paid sex amongst this social minority group - which will be supported by the experiences of the director of FleksZorg.¹⁵ In the final part I will share some other experiences of a professional with regard to the sexuality of his intellectually disabled employees. As the foregoing shows, in this chapter I solely focus on the people that I encountered as having an institutionalised, professional relationship with intellectually disabled individuals, hence caregivers.

3.2 *Meet the caregivers: a dialogue*

As I wonder in this chapter how the sexualities of people with intellectual disabilities are professionally regulated and managed by caregivers, I need to unravel the construed discourses in the field. If professional caregivers possibly regulate the sexuality of their residents, than this regulation will be intertwined throughout daily life. This is the reason then, why intellectually disabled persons, most of the time, do not decide when they eat or what they buy when they go shopping; everything is monitored (Interview I, VII & VIII). In order to regulate one's sexuality, something that is intrinsic to one's being, all other living areas need to be disciplined. These regulation principles are partially emerged from national health care policies, but also from caregiver's experiences and the like. One should thus ask which layers of regulation can be discovered in the lives of those intellectually

¹⁵ A sexual service agency that delivers 'sex care' to people with disabilities in "whatever field and of whatever severity" (Interview XI).

disabled people. In this first part I will portray the struggles Anton, Rick and Nicole faced during their professional counselling of people with intellectual disabilities. This part then envisions how their own social context was not in accordance with the policies of the employing (health care) organisations.

Two of the first persons I met were Rick and Anton; a homosexual couple that experiences two ‘abnormalities’ within their relationship. First of all, Rick is twenty years older than Anton and secondly, Anton has a mild intellectual disability. In the fifth chapter I will tell more about their relational experiences, but in this chapter I will utilize their familiarities, as this couple has various professional experiences with intellectually disabled individuals and their sexuality.

Anton and Rick both work as a volunteer at COC Amsterdam.¹⁶ Since 2007 Anton has been the official ambassador for chronically ill and intellectually disabled people in the Netherlands. He is also co-founder of café Oké; a café for homosexuals with multiple disabilities. Rick used to be the coordinator of café Oké, but he lost his position a few years ago. According to Rick this had something to do with Rick’s and Anton’s social context, since their context represents a love affair between an able-bodied and disabled-bodied person. Apparently, this relationship was not acting in compliance with COC’s policy. It could be said that existing policies always fulfil a role of mastery. A mastery, which is the servant of, normalised society, since COC’s politics “isolates [the] individual life to the point that it ceases to be a human life (Vatter 2009: 8)”. Rick’s individual choice of having a relationship with a disabled person may not serve society’s goal of standardised, obedient bodies (Link 2004: 15). The policy of COC restricts both Rick and Anton of having this individual life in COC’s public space - thereby their sexuality is regulated within COC’s borders. According to Rick, COC inserted their policy as an excuse, which portrays the infinite power of organised structures. I therefore identify COC’s practice as a Foucauldian “institution of power”. But this example also made me realise that institutional policies enact societal obligingness to normativity and normality. And in turn, enforces sexual normativity and normality, thereby creating a collective sexual consciousness. Sexuality then becomes a product of normative, able-bodiedness punishing all those sexualities that are deviant. Gratefully, this incident did not stop Rick and Anton to love one another nor did it stop their activities for café Oké. Even though this café tries to liberate homosexual intellectually disabled individuals, it became apparent in another interview that café Oké is restricted by normalised politics.

For many years COC’s café Oké took place in the no longer existing but famous homosexual bar Sappho. For this research I had the chance to speak with ex-owner Nicole and she told me more about COC’s apparent intolerance towards people with an intellectual disability. According to Nicole, the first café meetings did not precede that smoothly as COC could not live with the thought that people with a lower IQ, perhaps being on medication, would be smoking and drinking beer at café

¹⁶ An organisation that strives for gay rights in the Netherlands.

Oké. Professional caregivers and the like, who in return need to obey to organisational and national policies, can have the power to patronize or restrict the intellectually disabled individual to be included in normal society; they thereby indirectly manage the sexual lives of those who are disabled. After this pronouncement I also asked Nicole how she felt about COC's positioning, as they are the foreman of an interest group that voices people who represent a double minority. Nicole explained that she felt frustrated at that time, as she realised that these actors "accidentally did not have any prejudices against homosexuality, but they *did* live up to the prejudices against intellectual disablement by means of their practices". I reason then that the previous patronizations and policies of COC might have had its effect on the sexual lives of those intellectually disabled that visited the café.

But the social context of a caregiver can also play an important origin when regulating the sexuality of people with intellectual disabilities, since it defines how a caregiver thinks, beliefs or feels about sexuality. These interests can be ascribed onto the intellectually disabled body. Two of my respondents told me that the life of an intellectually disabled person knows an extremely high passage on caregivers; in twenty years one warns four hundred caregivers. According to them, these numbers also interrupt the development and search for a sexuality (Interview I & IX). Maybe this passage interrupts the development of a long-term trust relationship, something which is highly necessary when discussing, discovering and developing the sexuality of an intellectually care-needy person, as they seemingly cannot 'think' for their selves. But if Dutch welfare state and organisations have access to these numbers how come that sexuality does not seem to be a "serious issue" amongst caregivers and health care organisations? At least, according to Nicole, that is what her parents seemed to notice when they wanted to know more about her brother's sexuality (Interview II)¹⁷:

You hope that they [caregivers] discuss this subject or that they meet it. I can imagine that everything does not work out immediately, but you have to figure it out by yourself. I found that very strange in my brother's health care organisation, since it was like: "No topic". It [sexuality] is still not a topic.

Maybe sexuality is not that grounded in the land of the carers, because they realise that sexuality is a 'complex' subject and cannot be captured in policies. Possibly, this is the reason why sexuality is far too often diminished as an unenforceable subject in the lives of intellectually disabled people. Nevertheless, one specific health care organisation I talked to seemed to adhere another sexual discourse, as they offer sexual educational programs to their caregivers and clients. In the upcoming paragraph I will extensively report on these attempts, but even though they implemented another discourse, it became apparent that the social context of a caregiver can indeed regulate and manage the sexuality of their disabled clients.

¹⁷ Nicole is not related to her brother. Nicole's parents 'adopted' him into their family; they are solely his visit family.

3.3 *Chairman, can you put sexuality back on the agenda, please?*

In the south of the Netherlands, there is one prevailing health care organisation, called Amarant. This large organisation is spread across the region Noord-Brabant and is divided into three different care departments, namely “normal people with autism, people with intellectual disabilities and youngsters with a mild intellectual disability” (Interview V). As a health care organisation, Amarant has its own policy, saying that every client has its own personal plan.¹⁸ This personal plan is divided into eight domains and these areas are based on the earlier addressed “quality of life” principle by Robert Schalock. Sexuality is solely part of the domain ‘health and wellbeing’.¹⁹ This means in Amarant’s case that taking care of a client is a constant reflection of that personal plan. Care is thus measured on the basis of opening a folder in which the personal plan is preserved; a plan which seemingly addresses every need. Could this personal plan be one of the first hazards to overcome when addressing a clients’ sexuality?

In March 2012 I learned more about the personal plan when I had the chance to speak with two employees of Amarant. Nicky and Sara both work at the Educational Centre, a centre that offers educational programs to caregivers and clients of Amarant. Nicky noted in our interview that there is an extremely high demand for sexual education nowadays. This is in her and Sara’s opinion a good and necessary development, since “[sexuality] has been untouched” within the personal plan domains (Interview V). If the clients’ sexuality is on the agenda these days, how would that work? “We invite a caregiver to the Educational Centre and we discuss what his/her client wants to know about sex, but we also talk over how the caregiver can manage this need”, Nicky explained enthusiastically. Even though Amarant liberatingly provides sexual education to their clients, I also wondered if this meant that caregivers determine whether the client can discover his or her sexuality. Nicky explained this as the following: “When the caregiver creates a personal plan together with the client, but rather feels that her/his client is not concerned with sexuality, then there is no other option for the client to discover sexuality. At that point, it is done”. Nicky hereby acknowledges that getting access to one’s sexuality is extremely difficult when a caregiver already decided for a client that (s)he is not interested in sexuality. After this pronouncement I asked Nicky if there is any role left for the Educational Centre when they see that a caregiver noted “not applicable” with regard to the clients’ sexuality:

The only thing Amarant can do is to show all caregivers that something as “not applicable” does not exist. The cluster manager or the manager of the residences can obviously control that, so they should watch and account people for that. There is a positive shift nowadays; there is at least recognition that sexuality and intimacy plays a role with all our clients.

¹⁸ In the course of this interview I heard my informants for the first time talking about ‘clients’. Any person who is registered with Amarant is called a client. Apparently, other health care organisations likewise employ this term to refer to their new care-needy persons.

¹⁹ Sexuality is hereby perceived as an aspect of health; sexuality is thus medicalised for those who are care-needy.

Also Sara seemed to be pretty sceptical about which position the professional health field yields with regards to sexuality. She acknowledges that a caregivers' social context plays a crucial role in what one can and cannot know about sex:

The norms and values of that specific caregiver are hegemonic in the way they talk about sexuality. So if you are a caregiver for whom homosexuality is not an option, then you will most likely talk to a client as if homosexuality does not exist. So you approach him in a way that you assume he falls for the other sex: "If you fall in love with a girl..." Consequently, you do not give the client the possibility to fall for men. By education we can make people aware of that.

Sara verifies the idea that caregivers easily regulate a client's sexuality, as they somehow preach their own sexual, social context through their taking care of an intellectually disabled person; the caregiver thereby obtains a deterministic role in the discovery, development and performance of their clients' sexuality. Following Butler it could be said that the sexuality of an intellectually disabled individual is a reiteration of the caregivers' norms. According to the voices of Nicky and Sara, Amarant tries to distinguish itself from the dominant health discourse; a discourse that is mainly preoccupied with victimizing trends instead of educating or showing intellectually disabled people how to *do* their sexuality (Rutgers PWF & Movisie 2011; WHO 2011).

But also Anton admitted that caregivers determine far too often what clients can or cannot learn, know or discover about sexualities. Caregivers are thereby determining the availability to and of the client's sexuality. At least, that is what Anton noticed during his professional search for new visitors for café Oké, since many organisations told him that sexuality and homosexuality "do not play a role" in their organisation. Later on in the interview Anton explained that by the determination of caregiver's social context, a great variety of contexts arise. This assemblage may awaken struggle between all parties and interrupt the search for sexuality amongst intellectually disabled people. Or as Anton clarifies by an example about a girl who wanted to visit café Oké:

Her caregiver wrote a letter to us asking how everything worked. Well, it lasted for six months: she did not come. All of a sudden we received a letter saying: "Could you please stop sending mail, because she is not interested". This letter came from another address than the first one. Apparently, there was some disagreement between the caregivers; one part had told her that she definitely should not go to the café and the other half thought it was good for her.

Anton expressed on the basis of this experience that institutionalised, professional care actually balances a thin line of deciding for those who are intellectually disabled, and in The Netherlands this decisive authority is called "the representative".²⁰ This means then that a caregiver can respond in the name of her or his dependent, whilst the dependent may not be notified. And since I spoke with Anton beforehand, I had an opportunity to verify Anton's words on the basis of the interview I had with

²⁰ More information can be found on the webpage of health insurance company CZ: <https://medicinfor.cz.nl/%7B9d807e1f-14db-4856-b8a2-6ab486f945cf%7D>

Nicky and Sara. Therefore, I asked Nicky if and how Amarant associates itself with sexual diversity, such as homosexuality or transsexualism:

At the moment, people do not talk openly about sexuality, but we have to ask ourselves if we should. Do you want the client to talk about sex all day? You do not want that, because clients also have a difficult time stopping - they miss that boundary - and you do not want everybody to talk all day about sex. You cannot.

Nicky firstly refers sexual diversity to “being open about sexuality”, but she also links this to “talking about sex all day”. According to Nicky, helping a client to discover, develop and perform their sexuality or even talking about different sexualities, can evoke a stormy discussion within the health care field. The disabled client could possibly get enslaved to the sexual talks, as (s)he misses “that boundary” to distinguish what is normal and what is not. Even though I do understand Nicky’s arguments, I reason that the above-mentioned quote encourages a stigmatisation of people with intellectual disabilities as being hypersexual; a labelling that instead effectuates regulation rather than improving one’s sexuality.

I found in this paragraph that Amarant yields a modern position towards the sexuality of intellectually disabled people, since they offer sexual education. But according to Nicky, Sara and Anton, the general health field is characterized by caregivers’ social contexts, which play a deterministic role in the discovery, development and performance of the clients’ sexuality. Sexual tolerance seems to form a hurdle and as the informants argued, maybe this has something to do with the fact that policymakers, caregivers and the like mostly seem to worry about the sexuality of their client. These worries may be produced by the results of research on the apparent sexual abuse amongst intellectually disabled people. Even though sexuality is “integral to being human” (WHO 1975, in Gomez 2012: 243), the above-mentioned effects do not always verify this assumption. At present, I would like to lighten the sky by introducing one of the ‘solutions’ with which an intellectually disabled individual can discover one’s sexual identity, body and pleasure, namely paid sex.

3.4 Paid sex as an upshot?

After I spoke with Nicky and Sara about the personal plan, I asked whether Amarant’s sexual care program solely consisted out of sexual education or if Amarant also utilizes the services of sex workers. “Yes, that is possible, there are a lot of possibilities and someone can also use the services of SAR”, Nicky answered vividly.²¹ At that point I wondered if people with intellectual disabilities are financially able to hire a sex worker, as Nicky previously told me that most people with intellectual disabilities are depending on a payment. If so, how would this experience fit in the budgeted plan?

²¹ SAR stands for ‘Stichting Alternatieve Relatie Bemiddeling’. The foundation SAR assists people with a physical or intellectual disability during their search for a sexual alternative - this alternative actually refers to their database of sex workers.

“The clients have to see it as a little trip, where to money has to be reserved”, Nicky explained. But according to Sara paid sex may not be the idealistic solution for every intellectually disabled person to perform his or her sexuality, since clients also have their own preferences:

A colleague told me the other day that someone hired a man, she called someone from SAR, and the client said: “Well that man is really ugly, forget it”. It seems as if hiring a sex worker would be the solution and that the client just accepts everything.

The above-mentioned interchange made me wonder how I would perform my sexuality if (1) my desires would be part of a budgeted plan and (2) my needs are met by a person selected, by someone else, from a database of people. Sexuality then becomes a respite, an abstraction, shaped into a moralised process in which all pros and cons are confronted. The founder of FleksZorg likewise stated in her interview that the possible solution of paid sex is all too often not that feasible: “Due to limited financial resources and a lack of payments, some clients only occasionally have an appointment, while the need or even the necessity to support their sexuality is much higher”. The sexualities of people with intellectual disabilities are thus indirectly regulated by Dutch national policies on payments, but this regulation is also visible amongst organisational policies, such as those of FleksZorg.

In April 2005 Lisa decided to establish FleksZorg. Nowadays this organisation has over thousand clients and only “a small part of these clients contact FleksZorg without guidance from organisation or family. The overwhelming majority are thus institutionalised in care facilities or receive outpatient counselling from a care facility” (Interview by mail). The occasional sexual times are thus mostly monitored by caregivers or parents: the performance of sexuality becomes an arrangement, since FleksZorg mostly discusses with a caregiver, and not with a client, how the “sex carer” can give substance to the sexual desire of the client. Nevertheless, Lisa ensured me that every disabled person can profit of FleksZorg’s care, since (s)he can find whatever she is sexually looking for.²² Or at least, almost everything:

If a sex carer receives a request that does not fit within the prevailing rules of ‘usual and women-friendly sex’ then that request can either be immediately *rejected* or the client will be referred back to me or my partner. Therefore FleksZorg uses inventory conversations, to prevent any negotiation ‘in or outside the bed’. During this conversation we explain the borders of usual and women-friendly sex to the client.

FleksZorg’s policy includes several restrictions towards their (intellectually) disabled clients. First off, the sexual need must conform to usual and women-friendly sex. If it fails to satisfy it can be refused. The organisational policy therefore regulates the performance of any sexuality that does not abide to women-friendly sex. Second, the client is not allowed to negotiate in or outside the bed. This means

²² Throughout my data collection I constantly heard that intellectually disabled women do not utilize the facilities of sexual service agencies. Amusingly, people with disabilities appear to be a reflection of normal, able-bodied society, since mentally competent women would never pay for sex.

that the organisational policy regulates the discovery and development of sexualities. Thirdly, I would like to portray how FleksZorg's sexual acts-policy is subjected to heteronormativity: it has to be women-friendly and the sex request needs to obey to the prevailing rules of usual sex. The sexual desire or need of the intellectually disabled individual needs to gratify to the idealistic construct of sex as we know it (Butler 1993: 1). Hence, the sexualities of FleksZorg's clients are forced to adhere to the socially constructed sexual gender roles (Butler 1990: 10).

Later on Lisa explained to me that her clients have to face another, earlier barrier of norms, namely those of families and health care organisations. If these parties do not agree with a preferred sexual desire then the request for a sex worker can be "forbidden by that health care organisation or family". Afterwards, the client is left alone and her/his request can only be entertained in an informative way as the client is "depending on those caregivers" (Interview XI). Institutional and familial sexual understandings have the power to restrict the intellectually disabled body to experience her/his personal need. According to Lisa, it could be said that the social contexts of caregivers and parents improve regulation of the sexualities of intellectually disabled people.

In short, in this section I discussed whether paid sex can be an upshot for the sexualities of intellectually disabled people. It is argued that this 'solution' is not that feasible, as people with intellectual disabilities are often depending on payments. Sexual needs and desires can be regulated by FleksZorg's organisational policies or by the social context of caregivers and parents. Nevertheless, Lisa, as well both Nicky and Sara, acknowledge the sexualities of their intellectually disabled clients. One of the informants though, who has a professional relation with regard to intellectually disabled people, seemed to negate the sexual needs of his employees.

3.5 *I think we must not let these young people do it*

Seeing that this chapter deals with the question how the sexualities of people with intellectual disabilities are professionally regulated or managed by caregivers, I also need to bear in mind that some caregivers or employers might believe that people with intellectual disabilities do not have a necessity for sexuality. Although FleksZorg and Amarant acknowledge the need of intellectually disabled people for sexuality, one specific informant brushed this need off. This dismissal came forward during an interview with the floor manager of café Doodies. This café provides daytime care for people with intellectual disabilities. They are aspired to offer these people a normal workplace, so this café is rather committed to a work ethos than a care ethos. Doodies likewise has an aspiration to treat every employee as completely human, but strangely enough, floor manager Alex did not acknowledge the sexuality of his employees: "I do not think that this subgroup is sexual, they do not have those feelings. Well I do not know if they have that, but at least they do not reflect it, they do not know what you can do with it". Alex hereby denied the sexual capabilities of his intellectually disabled employees. Nevertheless, I still wondered whether Alex' employees can be rather flirtatious

together. Alex said that sexual activities or flirts do not happen in café Doodies and that able-bodied people should not connect the sexual dots for this social minority group:

I do not know if they get it, maybe it sounds pretty harsh, but I think that we should not let these young people *do* it [sex]. What they do not know, will not kill them. And really, these guys, they are ok with everything.

Even though Alex explained later that some employees have a relationship, I understood more and more that I should not take that too seriously as they “only give kisses on the cheek”. Able-bodied people carry the key to the secret garden of sexual pleasures, but ‘we’ must not tell ‘them’. This imposed ignorance essentially thwarts the process of intellectual and emotional growth amongst people with intellectual disabilities. This thwarting is rather ambiguous, as policies of daytime care and health care organisation actually aim at the development of intellectual and emotional growth. This chapter made me realise that professional care offers a structural life to people with intellectual disabilities, instead of developing a more qualified life-form. I claim this has only one motivation; that is the “optimization of life”.

The “optimization of life” entails that all citizens of a certain “national body” are shaped into a normative being. The human conduct of a national body is thus verified on the basis of that prevailing normativity, “thereby objectifying and shaping people for political regulation and economic exploitation (Priewe 2004: 399)”. As people with intellectual disabilities seem to suffer from unpredictable behaviors and could not obey to the norms of normative conduct, they are thereby detracted from the authoritative group. This powerful group represents the able-bodied people in a society and this group does not cope with resistance; they thereby keep people with intellectual disabilities ignorant and withhold the access to certain basic and qualifying principles of life as that may cause confrontation. And confrontation will not happen soon, as the authoritative group “somehow pretends to know what is good for the others” (Interview II). This means then that people with intellectual disabilities are shaped into obedient citizens, since biddable individuals are more of use during this genesis of “optimization”.

3.6 Should we ignore or pay for these sexualities?

With this chapter I wondered how the sexualities of people with intellectual disabilities are professionally regulated or managed by caregivers. I namely focused on existing policies within health care organisations, how caregivers utter these policies and how caregivers utilize their own social context while taking care of their disabled client. Policies, whether they have immediate relation to sexuality or not, always fulfil a role of mastery, as it can turn all individuals into obedient citizens (Link 2004: 15). In this chapter I encountered different policies that delimited intellectually disabled people in their (sexual) lives. Policies then partially restrict the intellectually disabled body from discovering, developing and performing one’s sexuality.

Caregivers occasionally have a hard time recognizing and implementing policies, since they may be interfered by their own social context. This means then that these vast sexual discourses, which are turned into policies and rules, may not satisfy the wishes and needs of the intellectually disabled individual nor does it suit the sexual opinions and beliefs of caregivers. Therefore, the caregivers' social context obtains a deterministic role when taking care of the clients' sexuality. Thereby coming, many informants told me that sexuality is not perceived as a grounded or serious topic in the personal care plans for intellectually disabled people. Nevertheless, some health care organisations do provide sexual education or use the services of sex work agencies to meet with the clients' sexual needs. Other informants ignored the sexuality of their employees and clients. It is therefore hard to tell which sexual discourse caregivers hold on to when regulating and managing the sexuality of the intellectually disabled clients. Nonetheless, this chapter made me realise that parents play an important role in the sexual discovery, development and performance of their intellectually disabled child. Lisa's example on how sexual needs and wishes can be brushed away by families, led me to wonder how parents take care of the sexuality of their intellectually disabled child. I will further examine this query in the upcoming chapter.

4 Presenting a Parental Dialogue: Sexuality of the Anomalous Kid.

4.1 *My mother would be ok with it, but we still got his mother*

When I was having lunch with a theatre group for people with intellectual disabilities, I met an interesting girl. Her name was Amber and she had brown hair and cute puberty pimples. I immediately noticed her big eyes. Amber is 22 years old and her intellectual disability reads PDD-NOS: a non-specified form of autism. She immediately told me: “I am completely normal you know, everyone has something”. Although I wanted to know more about her disability, Amber suddenly started talking about her mother on how she never listens to her. I cannot even recall how this conversation started as it all happened so fast, I only knew that I did not want to be the one interrupting Amber.

“I got a boyfriend for four years, but I do not know if I want to live together. I wanted it before though”, Amber said unexpectedly. These sentences would obviously provide a chance for me to get access to her sexual life. Nonetheless, I remained loyal to her own topic of interest and asked if her mother would be ok with Amber’s consideration when she would decide to live together with her boyfriend: “Yes, my mother would be ok with it, but we still got his mother”. Apparently, before Amber can provide herself with the happiness she wants, both parental parties need to be ‘ok’ with a decision like this. Obviously, the parental role consists of patronizing moments and reprimands, but an able-bodied 22 year-old would at one point be capable to resist this power form and for example leave the house. I wondered if Amber had any say in this at all. Later on, Amber fulfilled my own presumption and declared that her mother never listens to Amber, only because Amber is different: “I got a disability of course”. Does this mean then that being autistic makes you less capable to decide on your own? Does this likewise mean that people with intellectual disabilities are constantly subjugated to several forms of restrictions?

Therefore, in this chapter I shall study the following question: *how are the sexualities of people with intellectual disabilities regulated by parents and its forthcoming familial relationships?* Discussing your sexuality with family members is already pretty spooky, but the fact that parents sometimes need to decide or fill up the sexuality for their child, due the child’s intellectual disability, must be hard for both parties. I will portray various experiences that two different families faced when they regulated, nurtured and patronised the sexuality of their intellectually disabled child. It is important to do so, as every parent adheres another upbringing formula, so this will have different outcomes on ‘talking and thinking’ sexuality with your children. Yet these two families seem to have a mutual understanding in disliking the practices of caregivers and health care organisations when ‘talking and thinking’ about the sexuality of their children.

This fourth chapter consists out of six parts. In the first one, I will introduce the family Vanderbilt and discuss how they are very involved with the sexuality of their son Jules; they wanted to prepare themselves, but Hester and Cees faced some difficult times finding information about the sexualities of people with intellectual disabilities. In the second part I will reflect on how Hester sexually educates and reprimands Jules, since he does things normal teenagers do not do. But I will also portray how Hester finds it difficult to see how Jules' caregiver reprimands and controls Jules. From then on, the Holland family will be introduced and I will discuss how both families reacted to my suggestion of hiring a prostitute for their disabled children. In the fourth part I will devote attention to the Holland family and discuss how mother Ruby believes that her son Jonathan is not ready for sexuality yet. In the subsequent paragraph I will portray how both families have a mutual understanding in disliking the practices of professional caregivers. The query of this chapter shall be answered in the sixth part.

4.2 *Where can I learn something about my son's sexuality?*

The earlier formulated "quality of life" domains are respectively social relations, social participation, personal development, physical wellbeing, self-determination, material wellbeing, emotional wellbeing and rights (Schalock & Verdugo 2002, in Kröber 2008: 37). First of all, even able-bodied people are not familiar with a truly positive development of the above categories.²³ Secondly, I learnt during my fieldwork that the intellectually disabled body does not have optimal access to these eight domains, as they are under the reign of representatives, caregivers and parents. Since sexuality should have its fair share in every domain, I wonder in this chapter how parents regulate the sexualities of their intellectually disabled child.

The Vanderbilt family home represented a perfect implementation of nineteenth-century architecture. Two things were different from the plain, average house: the Vanderbilt's had a separate room for Jules to play in and the front door had an extra stair to prevent accidents, while carrying Jules and his wheelchair into the house. Father Cees offered me tea in the garden and soon after mother Hester joined us. When Jules was born, neither the doctors nor Cees and Hester knew that he had an intellectual disability. After Jules first birthday the doctors stated that Jules had perinatal hypoxia during birth, which caused scar tissue on Jules' actually fully developed brain.²⁴ Nowadays Jules also has a physical disability and moves in a wheelchair. Jules' calendar age is eighteen, but he has a developmental age around four.

"I guess Jules was fifteen when we noticed that he got sexually interested", Cees said straightforwardly. Cees still remembers how this notification was raised by older brother Hendrik,

²³ One should think about times of war or high unemployment rates in several Western countries. According to a study of the *Vrije Universiteit Amsterdam*, even a third of the Dutch feel lonely. Article available from URL: <http://www.spectrum-gelderland.nl/smartsite.dws?id=55818&ch=CRP>

²⁴ Perinatal hypoxia means that the fetus is deprived of an adequate oxygen supply during labor.

since he advised Cees and Hester to fix Jules' room: "You should remove those silly children's posters and replace it by a more exciting one", Hester revived Hendrik's words. Even though both parents wanted to support Jules' sexual journey, they did not know what to do or where to go to, as sexuality did not seem to be an important topic at Jules' care institutions. Cees remembers: "Everywhere I went I got zero or I was told: "There is nothing". There is most definitely no larger framework or change of experience".

In the preceding chapter Nicole and Anton likewise argued that they felt as if the sexualities of people with intellectual disabilities did not seem to be an important issue amongst (health care) organisations. According to Cees, when institutions or health care organisations *do* discuss the sexualities of their clients, it is subject to negative arguments or apparent experiences. Cees encountered this negativity last year, when he joined an informative meeting on the sexuality of people with intellectual disabilities. The presenter of the meeting showed the audience some figures on sexual abuse amongst people with intellectual disabilities during transport, and the number was extremely high. Cees still remembers how he was surprised, wondering - that if these numbers were indeed this high - why the Dutch government has not taken any measures. Therefore, he asked the presenter to the source of the figures: "The woman did not know the exact numbers or the origin of the source: 'presumably foreign figures were attached'. So we are dealing here with desired imaging without empirical support".

Cees' story implicates that the existing negativity about the sexuality of intellectually disabled people may be based on "desired imaging without empirical support". The quote reflects how desired imaging can effectuate an even bigger victimizing stigmatisation around the sexuality of intellectually disabled people. This victimizing trend gives caregivers or family member's firm reason not to discuss the sexuality of their dependent, as it only opens up difficult practices where to the disabled body cannot meet anyway. Sexuality then is surely political as American cultural anthropologist Gayle Rubin already argued in her famous 'Thinking Sex' (1984). For people with intellectual disabilities, sexuality is something one can have access to unless one understands its difficulties, such as language and the like. Sexual activities, desires or identities may only be developed when an individual meets the harsh undefined requirement of having a standard cognitive level.²⁵

In this paragraph I discussed how Hester and Cees found out that Jules got sexually interested, while I reflected on their quest for information on the sexuality of their intellectually disabled son Jules. Cees argued that there is little; a statement which corresponds with the experiences of Anton and Nicole in chapter three. But Cees also argued that when he found information about these sexualities, it had a negative approach, which he referred to as "desired imaging without empirical support". I argued that this does not improve societal prejudices, seeing that it is believed that people

²⁵ This does not mean that if you have access to the divine ground of sexual bodies, pleasures and identities that you can do whatever you want. It is here merely argued that one has access to heteronormative sexuality: cross-generational sex, same-sex desires or SM - practices are probably still off limits.

with intellectual disabilities are more vulnerable for sexual abuses than able-bodied people. In the upcoming paragraph it will be portrayed how Hester narrates about Jules' sexual education.

4.3 *Intellectually disabled youngsters in puberty*

This paragraph explicates Cees' and Hester's modern position towards sexuality, since they believe that sexuality is just as essential as eating. But Hester finds it hard to sexually educate Jules. She portrayed one of these difficulties, saying that she sometimes needs to educate and nurture Jules in a different way than her other able-bodied children. Apparently, this also includes correcting or reprimanding his sexual excesses:

When I take Jules to the supermarket, he hangs in the cashiers' blouse and starts saying: "Oh, pretty, pretty". *Another* fifteen year old boy would not do that, because he knows that it is unacceptable and not something polite to do; it is taboo. It is hard, because you have to teach Jules not to do so.

Hester hereby explains that Jules' sexual excesses are different from normal guys, as "another fifteen-year-old boy", would discover his sexuality in secrecy. This argument can likewise be alleged when Hester explained that Jules watches "adolescent girls imitating K3 half-naked on YouTube". Other guys would do this in their bedroom, but Jules watches this in his special room, which is located behind the living room. Thereby his sexuality becomes public. These two examples awaken an ever longing discussion: private sexual activities are proper and non-tabooistic. But publicly executed sexual activities elicit shame and are socially forbidden. Jules did something 'wrong', as he discovered a part of his sexuality out in the open, without gene and awareness. Apparently, this impartiality is forthcoming from Jules' intellectual disability.

Another public sexual event occurred last year when the family went on a holiday. Hester explained that she rented an expensive house, so that Jules could have his own private swimming pool to swim in. Even though the mother adapted to Jules' situation, Jules himself did not want to swim in the private pool, but he did like to go to the public swimming pool. So, Hester asked: "Do you like it more there because you can play with all the children?" Upon which Jules said: "No, ladies bini [bikini] watching". Jules intentions are rather innocent, since he solely wants to look at women wearing bathing suits, but his actions can be interpreted as hypersexual and misogynistic. These interpretations can be perceived as such because Jules has to tell to truth constantly; he has to explain every little thing he is about to do, to his carers. His sexual desire of watching women in bikini's is thereby immediately out in the open and Jules' sexuality becomes a public affair. Does this means that being open about your sexuality actually makes you less (cognitively) developed and cultured? Nonetheless, these examples made me realise that Hester and Cees feel rather desperate sometimes, since they would like to help and nurture Jules in his sexuality, but according to them they just "do not know how".

Even though Cees and Hester feel distraught at times, they still remain involved in the sexuality of their son. The parental couple has discussed several sexual possibilities for Jules; for example buying Jules a *Playboy* magazine. Although they would “never do that”, Cees explained that Hester occasionally gives fashion magazines to Jules, wherein several women portray lingerie. Her reasoning for allowing Jules to watch these magazines are rather practical: “Sometimes there are moments when you want him to be quiet, for example when you are visiting someone and then you think like: ‘Well you know what, here you have a magazine’”.

The fact that Hester deploys Jules’ stigma, made me understand that Hester and Cees are aware of their disciplinary practices, but also feel guilty about it. This guilt is originated in frustration, they do not know how to explain to Jules that “some sexual activities need to take place inside his bedroom”, whilst remaining involved in the quest to Jules’ positive sexual development. This became apparent when Hester explained what she disliked about caregivers’ practices when ‘talking and thinking’ sexuality. Apparently, Jules’ main carer Anja has the tendency to discuss every sexual deviancy with Jules’ parents.

Every Thursday night Anja gives Jules a bath, but at one point Anja asked Hester: “Can I have a word with you?” While Jules was sitting in the bathtub, Anja and Hester were standing in the hallway and Anja said: “I just wanted to discuss something with you, well I do not know how you look at it, but when Jules sits in the bathtub he touches his *thing*”. Older brother Hendrik replied to Anja: “What *thing*?” By dint of Hendrik’s comment Hester became attentive to the fact that Anja and other caregivers can treat their intellectually disabled clients as little children, since Anja could not or did not pronounce an actual designation for the male sex. Hester explained that she replied to Anja wonderingly, saying that Jules’ activity was actually pretty standard, since every boy or child touches their *thing*. Anja responded as the following: “I just wanted to know what your policy was”, while Hester replied: “We do not have a policy for that, he just does it”. In the interview she expanded on Anja’s motives a little bit more: “You notice that Anja has an opinion about Jules’ actions and so she says: “Ok, so your policy is that you let him have his way?”, and then I just said: “Yes Anja, that is our policy””.

The above-mentioned example portrays how the social context of the caregiver plays an important role when discussing the sexuality of people with intellectual disabilities: it is Anja’s method to immediately pass this act to Hester. Subsequently, Anja decide to fall back onto policies, since Hester’s beliefs were immediately documented, or as Hester explained: “Well then it is documented somewhere, that is how it goes; everything is documented. So the next time caregivers come they can read that our policy implies that Jules can touch his penis while taking a bath”. Even though Hester understands these policies, seeing that the transfer between caregivers must go smoothly, she finds it difficult that any act of Jules is documented in his personal folder.

The fact that everything is documented into a notebook is crucial for portraying the disciplinary principles amongst caregivers. Caregivers and parents are required to document the

entirety of things, since “every aspect of an intellectually disabled’s life includes policy”. Hester showed me how she even documented Jules’ eating habits saying that “Jules enjoyed his three sandwiches today”. This documentation actually amplifies and ratifies regulation and monitoring, since it makes deviant behavior visible. This documenting then actually represents the subjugation to Foucault’s concept of “institutional administration” (Foucault 1978: 139).

With this paragraph I showed how Hester reprimands Jules when he executes his sexuality in public. Nevertheless, Hester finds it difficult to reprimand Jules for his sexual excesses, but it is necessary to do so, since normal youngsters would not do that. Yet Hester, as a mother, does not like it when professional caregivers patronize Jules or treat him as a young child. Just like caregivers, parents can regulate the sexualities of intellectually disabled people by means of documentation. Hester and Cees are however seriously involved in and concerned about Jules’ sexuality, as they try to invent various solutions for Jules’ sexual needs. In the next paragraph I will discuss one of these solutions, namely hiring a sex worker. I will discuss whether the Vanderbilt and Holland family would ever hire a sex worker in order to meet with the sexual needs of their disabled children.

4.4 Paid sex as an upshot?

In the previous chapter I already reflected on paid sex. The informants explained that paid sex is not necessarily a good solution, since people with intellectual disabilities are mostly depending on a payment and are likewise depending on the sexual preferences of their caring. The director of FleksZorg noted in our interview that parents have the power to reject the sexual request of their child. If so, it must be hard for parents or family members to consciously decided for their relative how they can or cannot have sex, or as Jules’ older brother Hendrik explained to me: “I would find it incredibly hard and strange to initiate (...) we should not be the ones arranging that”. Fortunately, I felt comfortable enough in the surrounding of the family Vanderbilt to ask them if they would ever hire a sex worker for Jules. Cees replied that he had “no objection in principle”, but that I overwhelmed him with this question, seeing that he “never really thought about it”, but at first glance he “would not have any objection, but he is not sure whether he would like it or not”.

Hester likewise said she would not necessarily like it, but she would arrange it for Jules, as it would be most favourable and enjoyable for him. Afterwards she explained to me that she felt a bit gloomy, since she realised that Jules will, most likely, never experience normal sexuality. Standard sexual activities, like going on dates, starting love affairs or embodying relational sex are never within reach for Jules. And if so, these activities have to be supervised and arranged by his caregivers or parents, since he propels in a wheelchair and cannot speak easily.

The second family, I interviewed, was the Holland family. This family consists of two people: that is mother Ruby and her 22 year-old son Jonathan. Before Jonathan was born, Ruby and her deceased spouse did not know that their child suffered from Down syndrome, but as Ruby says: “You

cannot send them back, they are your children”. Rapidly, we talked about her faced difficulty in nurturing Jonathan sexually and she shared her prior idea of taking Jonathan to a sex worker. Eventually, Ruby did not pursue the idea as she “did not want to wake up in the middle of the night, thinking who is this on top of me”, seeing that it is Jonathan. I asked her if this idea occurred recently:

No, I thought about it when he was about sixteen, but I just pushed it back in my head. He is not ready for that in some ways. There are different layers of their intelligence than we have it. It is totally different.

Ruby seems to be worried, since she does not want to wake up in the middle of the night, because Jonathan could be lying on her body. Jonathan is portrayed by Ruby as rather wild, because if he would go to a sex worker, his sexual desires will be awakened. After that, he will not be capable of seeing the difference between another woman and his mother, as they are both just women and therefore represent his sexual desire. This train of thought actually discharges Jonathan’s emotional and empathic capabilities as a grown 22 year-old. In spite of these facts, her main reason not to hire a sex worker is because she thinks that her son is not ready for any sexual activity yet. Let me refine this in the upcoming paragraph.

4.5 I do not see the point of connecting the dots

In the previous paragraph I reflected why Ruby decided not to hire a sex worker for Jonathan. This decision seems to be based on her believe that her son is not ready for any sexual activity yet. Since this chapter discusses how parents regulate the sexuality of their intellectually disabled children, it is important to reflect on Ruby’s opinion. Seeing that Jonathan is depending on Ruby, as a mother and carer, Ruby has the power to decide for Jonathan what is good and what is not.

After her statement on sex workers I asked her if she feels that it would be good for Jonathan to exert sexual intercourse. She replied that she mostly believes that Jonathan would not be smart enough to *do* so, or as she explains: “When he has a girlfriend I could see them kiss and stuff - and he masturbates and it feels good - but I have not let him connect the dots”. “Connecting the dots” means that Ruby could for example explain to Jonathan that a penis can go into a vagina whilst a pleasant feeling arises. But Ruby does not feel the need to clarify this, as she feels that “Jonathan is not smart enough to understand”. Even though Jonathan has the bodily and emotional capacities of a young man, his intellectual disability inhibits him. So, Ruby has the power to restrict Jonathan from discovering, developing and performing his sexuality.

Because of this I asked Ruby why she would not connect the dots for her mature son: “I do not know how he would react and I do not know if he would understand that he cannot go around, jump on a woman and have sex with her, I do not know if he would understand that”. Next to Ruby’s difficulty of facing her son’s discovery, development and performance of his sexuality, I also wondered if she would be able to teach him how to perform woman-friendly sex, since Ruby told me

in the beginning that you can teach intellectually disabled children *anything*: “Yes, I can teach him if it does happen. He would get it from me that it is not right, but it do not really see the point of opening up Pandora’s Box for him”. Ruby’s statements on “not connecting the dots” and “not opening Pandora’s box”, makes me reason that she as a parent can enforce the regulation of Jonathan sexuality, since she imposes a dual control upon the intellectually disabled body, as the (sexual) needs are constantly watched over. I argue that this represents a Foucauldian institutional management which is in service of the “calculated management of life” (Foucault 1978: 139).

Later on, Ruby vividly clarified that sexuality as just needs to be approached as “a natural thing”, seeing that even “Jonathan has been masturbating on his own since he is ten years old”. Therefore I asked Ruby if she talked to Jonathan about his need to masturbate or if she would explain him anything about his bodily, hormonal and sexual development:

I tease him when I catch him doing it, but I have not discussed it with him, because I just do not see the point. I think it will be a while, unless he meets somebody who he is interested in and then it should be handled with gloves. You have to teach them what is right and what is wrong, you have to teach them how to act and not to be an asshole.

“By the right time” Ruby will teach her son the ins and outs about heteronormative sexuality. In Jonathan’s world, sexuality is solely a serious issue when he is truly interested in someone else, since his mother carries “the gloves”. For now, Jonathan can perform his sexuality theoretically, while Ruby (with) holds the key to Jonathan’s sexuality. But more interestingly, I heard Ruby and the other able-bodied informants constantly say that one can teach intellectually disabled people *anything* you would like them to learn, so why not teach them how to express themselves sexually?

4.6 *Parents’ mutual understanding in disliking the practices of caregivers*

This sixth paragraph will describe how Cees, Hester and Ruby occasionally dislike the practices of their child’s caregivers. Strangely enough, these families both have a different upbringing formula, but share a mutual understanding in disliking the practices of caregivers. This specifically means that they have a different opinion about the interpretation of the (sexual) guidance of their disabled children than institutionalised professionals do. In this section then, I will portray some of the visible conflicts amid parents and institutionalised, professional caregivers. It is necessary to do so as these struggles may tear the care-needy individual between interests, which can interfere the discovery, development and performance of one’s sexuality.

In the course of my fieldwork I often heard that people with intellectual disabilities can be very aggressive. According to some of the informants this has its roots in the constant misinterpretations by able-bodied people of the intellectually disabled intentions, capabilities and desires. Ruby clarified this statement on the basis of an example: “Which child wants to be set down in a home? If my mother would put me out of the house I would be aggressive too; they do not feel

loved”. But she also reasoned that the specific institutional structure grounds aggressiveness amongst people with intellectual disabilities, since it does not give them the ability to do what they would like to do, or as Ruby referred to Jonathan’s situation: “He has his own room: he does not have to go to bed at eight o’clock, because there are no caregivers around. He reads till midnight if he wants too”. Ruby calls these structural practices of health care organisation “monitoring”. Caregivers do not necessarily take care: they monitor all activities as they are always present in the residential facilities. I asked her if she thinks that this means that people with intellectual disabilities are disciplined by these institutions, whereupon Ruby responded in the following manner: “It is not disciplined, they can always ask people if something is interesting or if they want to know stuff, but there are a lot of people that monitor and control their activities you know”. I claim that this example represents both the “administration of bodies” and the “calculated management of life” (Foucault 1978: 138-140), since the needs of people with intellectual disabilities are constantly watched over, while their activities and opinions are documented.

Ruby’s quote, saying that “a lot of people monitor and control the activities” of intellectually disabled people, intrigued me. Therefore, I proposed to Ruby if one could thus say that these structural, daily schedules ensure the overall and sexual regulation of the lives for people with intellectual disabilities. Ruby reacted as the following: “Yes, it is regulated but there must be some *children* that are doing it [having sex]. But I do not think that is the main focus”. Even though Ruby does not agree with the monitored activities in institutions, she still feels that it is quite improper of caregivers to learn intellectually disabled people more about their sexuality, or as she noted about Jonathan’s school:

He has had a little bit of sexual orientation at school, but I found it quite inappropriate. Unless they are capable of talking or are living in a situation with the opposite sex, I do not see it necessary.

I found this statement remarkable, because it made me understand that parents and caregivers are not often on equal footing when it comes down to the sexual upbringing of those who are care-needy. In the former example, Jonathan’s school holds a probable liberating position towards sexuality, as they offer a track on sexual orientation. Ruby on the other hand believes that a course in sexual orientation is not that necessary, since these disabled people cannot speak. Apparently, in order to discover your sexuality one needs a certain required access; one needs to understand the sexual discourse in which the sexual ballgame is played. Sexuality can qualify a body and determine your place in society, while the qualification of that body likewise defines your sexuality (Butler 1993: 2). Disable-bodiedness denies your access to sexuality, since it will never meet a normative or heteronormative performance. I wonder if this is merely another result of our society based on paternalistic structures.

Hester also indirectly criticised the structural living spheres in service agency group homes and the like. She especially had a hard time realising that her son Jules will never have the opportunity

to do something rather spontaneous, for example to buy liquorice and then eat it all at once, like Hester told me she sometimes does. The fact that Jules will never be able to do so is in her opinion “pretty confronting”. By this example Hester tried to represent how the regulated lives in day-care-centres, health care institutions and the like prevent spontaneous outbursts or friendly irregularities amid people with intellectual disabilities. The foregoing examples portray how outbursts or irregularities are hard to find in the land of the carers, even though these outbursts are highly necessary when discovering, developing or performing one’s sexuality, seeing that sexuality usually does not cultivate by planned operational settings. As seen before, most sexual activities in the lives people with intellectual disabilities are actually planned, even by others. This is again an example of the “administration of bodies” (Foucault 1978: 139).²⁶

Using this section I tried to describe how both families have a different opinion about the (sexual) guidance of their intellectually disabled child, than the professional caregivers. This became visible when Ruby declared that she believes that Dutch health care organisations are not “particularly that good”, since they monitor a lot of the residents’ activities. Ruby also explained that Jonathan’s activities are not monitored, since he lives at home. There seems to be a big difference then between living at home or in a residence with regards to regulation. Both Ruby and Hester acknowledged the fact that the regulated lives in day-care-centres, health care institutions and the like prevent spontaneous outbursts or friendly irregularities amid people with intellectual disabilities. With this knowledge then I will answer my query of this chapter in the upcoming section.

4.7 *I feel pretty gloomy because of this documenting*

With this chapter I showed that parents play an important role in the sexual upbringing of their intellectually disabled child. Therefore I wanted to figure what discourses families initiate when regulating, nurturing and educating the sexuality of their intellectually disabled relative or child. The analysis is in light of my query, wondering how the sexualities of people with intellectual disabilities are regulated by parents and its forthcoming familial relationships.

Specifically, family Vanderbilt had a hard time finding any information about the sexualities of intellectually disabled people. Ruby Holland had access to the sexuality of her son, but she found it unnecessary for her son to participate in a sexual education program. This chapter also portrayed how Cees, Hester and Ruby are very involved with the sexuality of their children. Nevertheless, both Jules and Jonathan seem to carry out their sexualities out in the open and this ensures a parental reprimand. Both mothers relied on normative arguments while reprimanding their son’s, as normal youngsters would never do such a thing and you cannot show your sexuality publicly.

Moreover, I also found a difference in sexual upbringing amongst the two families; Cees and Hester would hire a sex worker for Jules, even though they do not like it. Ruby, on the other hand,

²⁶ See Chapter 3 and 4, specifically paragraph: Paid sex as an upshot?

thought about this 'solution' before, but she believes that Jonathan is not ready for that yet. Ruby specifically said that does not see the point of connecting the sexual dots for her disabled son, whereas Hester and Cees feel pretty gloomy because they realise that Jules will, most likely, never go out on dates. It is therefore hard for family members to realise that their relative can never do something spontaneously, since everything is monitored and documented in various folders - a practice both caregivers and parents do.

Nevertheless, both families adhere to a different opinion about the (sexual) guidance of their intellectually disabled child, than the professional caregivers, since I found that Hester and Ruby believed that structural living spheres ensure the monitoring of the intellectually disabled body. But I also showed that Jules' and Jonathan's sexualities were regulated by means of constant monitoring, reprimanding and documentation implemented by their parents. I likewise found that the intentions of the families sometimes did not correspond with those of the caregivers. This chapter then let me to wonder how people with intellectual disabilities develop, discover and perform their sexualities while being under the reign of caregivers and parents. More interestingly, do people with intellectual disabilities have a chance to resist these power games? If so, how do they utter their struggle?

5

“I am different. No, I am Normal, but I am Special”:

Regulated Sexualities in the Lives of Intellectually Disabled People

5.1 *Building meaning without physicality*

In the course of my observations at schools and day-care centres I noticed that people with intellectual disabilities are very tactual; they mainly use body linguistics to utter their preferences and the like. The day I met Amber, and participated with the theatre group for intellectual disabilities, I was astounded by the mutual body contact amongst this group. Before, during and after the theatre performance I observed ecstatic players, hugging and kissing each other. One player specifically caught my eye, since she welcomed me in an enthusiastic and physical way. Her name was Melissa. However, without her knowing it, I was already linked to Melissa by theatre teacher Angelique as she believed that Melissa’s story would be of great value to my research. Even though Melissa welcomed me in such a pleasant bodily way, I wondered if people with intellectual disabilities mainly rely on their physical capabilities to interact with others. More interestingly, if so, are they permitted by health care’s organisational policies, caregivers and parents to express themselves as such?

Richard, one of the informants, explained to me that people with intellectual disabilities are tactual, and they are so for a reason. Nonetheless, it seems that this need cannot be met anymore, since new policy changed the physical atmosphere in health care organisations. Richard has worked with intellectually disabled people for over thirty years. During our interview he explained that the health care organisations were much more emancipated and liberated in precedent years, but their atmospheres have changed over time due to a number of sexual abuse cases:

Formerly, we interacted with each other more easily. But then there were a few of those abuses, so nowadays people pay much more attention. When they [intellectually disabled individuals] saw you, they kissed and hugged you, but you cannot do that anymore. It used to be normal though.

First of all, Richard portrays how physical contact is made in connection with (negative) sexual excesses. Does this mean that a ban on physical contact must prevent the deployment of sexualities? Second, following Foucault, this quote portrays how people with intellectual disabilities are dually subjugated to the disciplinary practices of their carers, since they need to live their life according to a personal plan that is based on policies. But it also explicates how people with intellectual disabilities are, in comparison to able-bodied people, dually controlled by the disciplinary practices of their carers, since their needs and interactions are constantly watched over (Foucault 1978: 139). This realisation caused me to wonder if Richard, after having thirty years of personal and professional experience, accepted these rules saying that he cannot hug or kiss his dependents anymore. Richard explained that

he “obviously, does not do [kissing, hugging] that anymore”, but he believes that this new policy is pretty ambiguous as intellectually disabled people mainly interact by bodily contact: “They are very tactual for a reason”. Many of the informants likewise described this as an important and distinctive characteristic amongst people with intellectual disabilities. This is a logical outcome as people with intellectual disabilities cannot easily connect with able-bodied people cognitively. They therefore need to rely on - and thus have a need for - emotional and bodily contact as they “receive information through touch and spheres”. This policy then deducted an opportunity for these intellectually disabled individuals to interact with Richard. This let me to wonder how people with intellectual disabilities live their lives, as even their physical releases seem to be surrounded by rules, policies and preferences. In my opinion, physicality can be easily linked to sexuality, since it can be an important tool of choice when discovering, developing and performing your sexuality. So how do people with intellectual disabilities *do* their sexuality?

This last analytical chapter will test my hypothesis, by giving answer to the following question: *how do people with intellectual disabilities cope with their regulated sexualities? And how do they resist?* Therefore, with this section I will merely give voice to those intellectually disabled individuals that embody their sexual otherness (Haraway 1988: 575). In order to do so, this chapter covers two parts. In the first one, I will give voice to Melissa’s sexuality and love life. The second part has a similar construction, since I will discuss the sexuality and love life of Anton.²⁷ These two stories portray all the beautiful loving moments, but it is merely my aim to demonstrate how their sexualities are subjected to the disciplinary practices of caregivers and parents, which ensures the regulation of Anton’s and Melissa’s sexuality.

5.2 *I was actually never allowed to date*

In this section I will explore Melissa’s love and sexual life. First of all, I will portray how her mother worked together with her caregivers as they managed Melissa’s love-life. Second, using Goffman, I will analyse how Melissa agrees with her assigned disabled otherness. Finally, I will discuss whether Melissa has found ways to resists the disciplinary practices of her parents and caregivers.

Melissa is a 26 year-old woman, but her cognitive age is fairly lower, or as Melissa explained: “Inside me, I am sixteen or eighteen”. Melissa has long brown hair, bright eyes and a full mouth, but Melissa explained that she is a “special person”. Melissa is diagnosed with the same disorder as Amber, namely a non-specified form of autism called PDD-NOS. But she rather identifies herself as a person with a double handicap; she has her intellectual disability on the one hand and the invisibility of that disability on the other. Melissa left her parental home in Hilversum a few years ago. Ever since

²⁷ In Chapter 3 Anton’s experiences were briefly covered (“Meet the caregivers”: a dialogue).

Melissa moved to Huizen, her parents moved with her.²⁸ Nonetheless, Melissa lives ‘independently’ nowadays.²⁹ After our introductory talk Melissa pronounced the efflux of her love life.

Approximately four months ago, boyfriend Peter broke up with Melissa; they were a couple for thirteen months. Broken hearts and ex-lovers effectuated sad stories, but I was shocked when Melissa voiced her story on the termination of her relationship. Apparently, Peter broke up with Melissa on January 15th this year. However, Melissa was not notified on January 15th, but on January 16th. Before Melissa even knew that Peter broke up with her, Melissa’s mother already knew the story, or as Melissa clarifies: “Well, his caregiver phoned my mom to tell her that he wanted to break up with me”. Eventually, Melissa’s mother expressed Peter’s decision on ending the relationship with Melissa. Yet Peter never told Melissa face-to-face that he broke up with her. After our interview I wondered why the 26 year-old Melissa did not actualize this break-up conversation herself, as even able-bodied sixteen-year-old youngsters have these conversations. Or more importantly, why were those caregivers interfering in her love-affair? Perhaps the caregivers interfered as a precaution, taking into account possible cognitive stagnations or spasms, but this precaution restricted Melissa and Peter from even trying to discover their capability of handling a similar conversation.

Shortly after, Melissa described how she eventually talked to Peter about the break-up. But again, a caregiver managed this talk. Not Peter, but the caregiver explained to Melissa that “the break-up was not her fault”. According to Melissa the managed intervention was successful: “I liked it that the caregiver joined us in the conversation”. Melissa did not clarify this feeling any further, but she did explain that her head is still filled with confusion and several questions; therefore her caregiver organised another conversation for both parties. In any case, it must be hard for Melissa to cope with her heartbreak, but by the end of our interview Melissa told me that it was probably best for them to part, as her ex-boyfriend was pretty strange after all: “He did not like to touch other people and Melissa loves to touch”. Melissa has a desire and need to touch other people, but how can Melissa’s nurturing environment meet this need? This led me to wonder whether Melissa’s parents were happy for their daughter of having a boyfriend, since a relationship usually means that a part of your needs and desires can be met. Melissa reacted to this question in the following manner: “My parents liked it. In the beginning mom thought: “Oh my god”. She thought... Well, you see, I was actually never allowed to date”. I asked Melissa if she knew why she was not allowed to date with guys:

Well, I get it. They thought that I could not handle it, but when Peter came into my life I was allowed to do so, because he had the exact thing [disability] as I have. I thought that was pretty funny, that it was ok then.

The parental reasoning for this decision can be solely apolitical, believing that Melissa’s love and intimacy capacities are better embraced by someone who understands her differentness. Goffman

²⁸ The distance between Hilversum and Huizen is approximately 11,5 kilometres, so Melissa and her parents could be united within fifteen minutes.

²⁹ This residential facility still offers twenty-four hour supervision to all their residents.

explains in *Stigma* (1963) that people who share a stigma are preserved by the stigmatised person as the “sympathetic other”, providing “a circle of lament to which he can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as the person who really is like any other normal person (20)”. Also Melissa seems to understand and accept why she is only allowed to date with intellectually disabled guys. I argue that her acceptance of this parental decision makes Melissa impersonate her own stigma and disability, thereby agreeing with her assigned “otherness”.³⁰ Therefore it can feel for both Melissa and her parents, that a disabled, “sympathetic other” partner better knows what Melissa needs or goes through than an able-bodied partner.

In Melissa’s world then, “otherness” solely becomes normal by societal processes of sharing and comparing. I argue that this normalisation process on otherness, and thus on disable-bodiedness, creates footing for Melissa to understand and agree the parental pronouncement that it would be best ‘to date your own kind of people’. Goffman explains further on in his book how these processes are put into motion:

Interestingly, the more the child is “handicapped” the more likely he is to be sent to a special school for persons of his kind, and the more abruptly he will have to face the view which the public at large takes of him. He will be told that he will have an easier time of it among “his own”, and thus learn that the town he thought he possessed was the wrong one, and that his lesser own is really his (1963: 33).

The realisation that “his lesser own is really his” occurs when the stigmatised other starts, for example, “dating or job-getting” (ibid: 33). In these pure, autonomous moments “the moment of truth” arises. These moments can be crucial for Melissa, as they create a chance to break free from her assigned differentness and thereby imply resistance against the “limits” (Pickett 1996: 447). But one should wonder how autonomous Melissa’s love life and sexuality are, since the caregivers arranged and managed the concerning break-up conversation. This made me reflect on the ‘string-anecdote’ theatre teacher Angelique informed me about. Therefore, I said to Melissa that I depicted her to feel stuck between the worlds and interests of caregivers and parents, and she replied to this imagination in the following manner:

Yes! I refer to them as strings. I am standing here in the middle [Melissa stands up] and I have two red strings on my body; on the one side are my parents and on the other side are the caregivers, I always felt that. When I lived with my mom and dad I only had one, but nowadays I also got the caregivers.

The above-mentioned quote portrays how Melissa feels herself to be in the middle of two sides, namely parents versus caregivers. However, I wondered if this means that she is torn and pulled from string to string. Melissa explicated in her answer that she is not pulled from interest to interest, but she

³⁰ In this sense “otherness” refers “to that which is defined by the normalized subject as otherness, as deviating from or falling below or failing to live up to the standards of [normalized] subjectivity”, as seen in the article Taylor, Foucault, and Otherness by William Connolly (1985: 371).

is tied to them, or as she explained on the basis of the subjectivity difference between herself (disable-bodied) and me (able-bodied):

Look, you are normal, you can stand wherever you want - Melissa cannot, I cannot do that. I am free, but I got a certain freedom. You do not have that, you can stand wherever you want, but Melissa cannot. This is what I mean with those strings. The strings are there because they want to protect you from stuff, so you are tied to people; I guess that is good.

Melissa further on explained that the imaginary strings are nice, but that she “sometimes does not like them”. This perception is triggered by her desire of not having a disability, because if she would not embody disablement she “could do whatever she would like to do”. Yet Melissa immediately protected her parents and caregivers by saying that “the strings are much looser than before, because [she] feels much more free nowadays”. But this scene also revealed how Melissa only enjoys a certain kind of freedom. The concept of freedom is subjected to many incentives, but Melissa claimed that she only has access to a limited, predefined form of freedom, as she is figuratively tied to the interests, beliefs, attitudes of caregivers and parents. If one feels tied to others, then it must be harder to discover, develop and perform your sexuality. Melissa’s intimacy is subjected to a dual control in comparison to able-bodied people, since parents and caregivers based their decisions about her relational qualities on her twenty-four hour deviancy while her needs and interactions were watched over. These disciplinary practices of caregivers and parents thereby ensure the “calculated management of [Melissa’s] life” (Foucault 1978: 139).

With this first section I portrayed some examples of Melissa’s regulated intimacy and love life. The section specifically described how Melissa’s caregiver and mother worked together, as they monitored and managed an important phase in Melissa’s live, namely the termination of her love affair. Thereon building, I showed that Melissa was not allowed to date before, but ever since she met someone with a similar disability she was allowed to do so. Melissa explained that she understands this parental decision and I showed that Melissa thereby embodies her otherness, but this means in this case that she cannot resist the indirectly, imposed limit. The second intellectually disabled informant indicated himself that he has felt sexually restricted in the past, since he was ceased by his institutionalised, professional caregivers. I will describe these perceptions in the upcoming second part.

5.3 *I just want to sit naked at a bar*

The fascinating position of Anton’s life was already a bit expounded in the third chapter. In brief, Arnold is diagnosed with a mild intellectual disability, but he is also homosexual and has a relationship with the 68 year-old Rick. Hence, their age difference comes down to twenty years. Just as Melissa, Anton referred to his disability as “having a double handicap”, since his intellectual disability is quite invisible. In this final paragraph I will not dwell more on Anton’s and Rick’s

professional experience with intellectual disabled people, but I will firstly concentrate on their love relationship and secondly on Anton's homosexual breakthrough in the 1980s whilst being an inhabitant of an institutional residential facility.

Anton and Rick met each other thirteen years ago. At that time Rick was a volunteer at COC and he assisted Anton in taking computer lessons. It was only some years ago that Rick and Anton liked each other a bit more. These feelings emerged when they went on a holiday together, but before doing so, Anton needed to bespeak these intentions with his caregivers. Seeing that Anton is disabled he depends on the services of his caregivers; they for example guarded his finances and decided whether this trip can be part of his planned budget. Eventually, Anton was able to do so and the holiday strengthened the feelings both men had for each other. Rick and Anton are still together nowadays, but I noticed during our interview that they do not refer to each other as lovers, but as "good friends". Yet I wondered if this definition is popular amongst homosexual partners or that Rick and Anton still need to be careful with their relational coming out. This made me want to know more about their relational perils and needs.

Rick and Anton acknowledge that a lot of people have some cumber with their shared intimacy. Even though Anton is diagnosed with an intellectual disability, they both attach great value to mutual equivalence. Anton explained that Rick "is not allowed to supervise Anton, since there is no difference between them". They share their love affair and that does not cover a professional caring relationship; they are equal with respect to each other. Rick even told me that "Anton is actually a better sexual partner than all the able-bodied partners he had". I proposed to Rick, since he has a rich experience with people with intellectual disabilities, if he believed that people with intellectual disabilities should be kept free with regard to the discovery and prosecution of their sexuality. He rejoined that the regulation of generalities for this social minority group is necessary, "but that caregivers must be careful not to patronize this group". Rick's statement made me realise that guidance should be a serious requirement during the complicated but great, sexual processes. In the upcoming paragraph I will explicate how caregivers guided Anton through the search, development and performance of his sexuality.

Back in the day, when Anton was a 23 year-old man, he denounced his homosexuality for the first time in his institutional family home.³¹ Anton has lived in this family home for over fourteen years and he has fought at this place many times for his sexual autonomy. In the late 1980s Anton told his caregivers that he had a different clothing style than the other residents - "I did not like those tent bags, but rather liked thongs as underwear". According to Anton, his thong-liking induced a contradicted atmosphere in the family home. At first view, this breakthrough seems to have little to do with sexuality, but Anton's choice to rather wear thongs actually refers to Anton's autonomy and

³¹ In this family home, supervision was obligatory twenty-four hours a day.

human right of making your own decisions; two instruments that are necessary to cultivate when discovering, developing and performing your sexuality.

Whilst Anton lived in his family home, newly hatched for his homosexuality, Anton had the need to discover the gay capital of the Netherlands. He presented his interest in Amsterdam to the caregivers and they said: “What do you want to do there?” Anton described to them that he would like to sit naked at a bar. “You said what? You want to sit at a bar, naked? Well, we do not do that”, Anton revived the shocking reaction of his caregivers. Anton saw no harm in his idea, so he asked why he could not do that and his caregivers replied that “they could not sell that”. Even though the caregivers portrayed their grudge towards Anton’s idea, it did not stop Anton to persuade his own feelings. Therefore, he raised his desire over and over again. In the beginning the caregivers responded in a rather indifferent way: “You asked what? Which question do you mean? You ask so many questions in a week, we do not know anymore what your question was”. After Anton repeatedly denounced his desire, the caregivers told him that they will discuss it in the caregivers’ team meeting. Hence, his request became managed while it was also documented in his personal, daily plan, or as Anton remembers “every time I left the caregivers documented where I was going”. This practice of documenting refers to the dual subjugation to “institutional administration” amongst people with intellectual disabilities in comparison to able-bodied people (Foucault 1978: 139).

Nonetheless, it lasted *nine* team meetings, which is around six months, to decide whether Anton could go to a café between 12 pm and 5 am or not. Soon after, Anton had permission to go, but he needed to be back home before 5am; even in Amsterdam’s liberal gay-scene not much is happening before this hour. In the interview Anton construed the reaction of his caregivers, after he had told them that he had been to a gay-bar, drinking Coca-Cola *naked* at the bar:

They said: “This is what we were afraid for, that you would go about and trick extremities”. So I asked them: “Why did not you tell me? Why did it last six months to make a decision and now after I have been investigated it, you do not agree”. Then they said: “Well, Anton we also searched your room, we looked into the contacts you had been having”.

The questions Anton raised to his caregivers actually revealed their disciplinary tactics, since they did not want Anton to discover all “extremities” that are out there in Amsterdam’s gay scene. They had the power to decide whether Anton could go or not. It also reveals how Anton needed to cope with an invasion of his privacy; whilst he was away, thinking that he was free to do whatever he wanted to do, there were people in his private space searching for things that might be ambiguous. This case is an example of “institutional management” - Anton is dually controlled in comparison to able-bodied people, since his (sexual) needs and interactions are constantly watched over (Foucault 1978: 139). But this also leads me to conclude that the sexualities of people with intellectual disabilities are far too often a public matter, instead of a private one. This paragraph then gave voice to Anton’s personal and sexual breakthroughs in the 1980s, while being a resident of his institutional family home. I also showed that his actions were answered through disciplinary practices of institutional management and

administration. Nevertheless, Anton likewise described how he has resisted these practices. But as I will show in the final, analytical paragraph, this did not work properly.

5.4 *They documented in my personal folder: "Do no argue with Anton"*

Precisely because Anton's behavior was such an exception - provoking contradicting situations between him and his caregivers - he was administered with medication. According to Anton, the adjustment in medication was necessary because Anton gave too much resistance, so these medications needed to keep him tranquil. But at one point he got quite annoyed; Anton swallowed all sorts of pills without exactly knowing why he took them. Together with his third psychiatrist Anton ran through his medication cupboard. Eventually in 2001, his psychiatrist discovered something terrible, and said: "Anton, you have been taking medication for your homosexuality". Apparently, these medications were originally recommended to Anton to reduce his frustrations, feelings of misunderstanding and supposed unruly behavior. Neither his first, nor his second psychiatrist, told Anton that he had been taking heavy medication to suppress his homosexuality. But how did these medications suppress his homosexuality?

"These medications defeat your real inner-being and therefore you cannot develop yourself sexually anymore; I did not get an erection and I felt musty all the time", Anton said straightforwardly. This medical 'solution' is a typical example of Foucault's bio-power. Foucault argues that bio-power controls everyone's movement; thoughts and ideas are being in a society. In the case of Anton, both his homosexuality and conflictual behavior kept him from being obedient to the normal. He did not live up to the norms and rules that were present in his care environment, so he needed to be 'punished' by means of medication. Anton's body was made docile by "appropriate methods of correction and rehabilitation [...] in order to restore deviant bodies to the norm (Foucault, in Allen 2005: p. 29)". Bio-power then, must go against all those people who represent a "biological danger" (Foucault 1978: 138) and thereby has a license to kill. Anton's medication prescription figuratively killed him, seeing that he did not get an erection anymore. Bio-power 'kills' those aspects that can multiply the biological danger; hence the sexual reproductive organs.

Even though Anton already received medication for his unruly behavior, his caregivers also noted in his personal folder from the year 2000 till 2005: "Do not argue with Anton". In chapter four Hester Vanderbilt already described how everything is documented in the lives of people with intellectual disabilities. These documentations then become a certain hatch for other caregivers, without the intellectually disabled knowing what her/his carers are saying or demanding, thereby ensuring the "calculated management of life". However, Anton noted that:

Things got much better nowadays, but before this is accomplished, you have to break down walls, literally and figuratively. After you have broken everything down, it becomes a little bit quieter and then people realise 'maybe we should have done things in a different way'.

I am more than pleased to hear that Anton opened up barriers and that he likewise paved the way for the contemporary intellectually disabled homosexual: “I have made people more empowered in terms of their homosexuality”. Yet Anton also admitted that these empowering practices are not always successful. Anton earlier helped a young intellectually disabled homosexual during the ups and downs of his sexual discovery, development and performance. Anton found out afterwards that he was placed on the black list of the health care organisation where the young homosexual was a resident: Anton was not allowed to contact the boy for a while. According to Anton, this is merely because he made the boy sexually, and thereby mentally, competent.

This final, analytical part actually discussed how Anton’s quest to mental and sexual competence was curbed by his caregivers, and indirectly by medication. All these examples will form a solid base to write the last paragraph, wherein I will evaluate the analysis, in order to take stock of the research results. On the one hand I shall specify how some intellectually disabled individuals were sexually regulated, while on the other hand, I will demonstrate how these bodies offered resistance.

5.5 *Intellectually disabled, but unable to love?*

This thesis evaluated how people with intellectual disabilities are regulated by the disciplinary practices of their caregivers and parents. But before jumping to the conclusion, I would like to clarify a few things, namely *how* were some of these sexualities regulated and *how* did they counterattacked the regulatory practices?

I portrayed how floor manager Alex denied the sexuality of his intellectually disabled employees at Doodies, saying that they absolutely have no clue what they can do with their sexuality. However these employees indirectly battled Alex’ statements, since some of his employees were in a relationship. I also evaluated the phenomenon of paid sex amongst intellectually disabled people. Nevertheless, paid sex actually encouraged sexual regulation, since caregivers, most of the time, need to arrange these meetings. Yet Lisa, director of FleksZorg, clarified that she had over thousand clients. I identify this number as a resistance-like practice, seeing that people with intellectual disabilities still utilize this kind of facility. They thereby discover, develop and perform their sexuality.

Next, I explored how the sexualities of Jules and Jonathan were often uttered publicly. Jules was previously reprimanded by his mother Hester, since he performed his sexuality differently than able-bodied youngsters; he stared shamelessly in the blouses of cashiers. Nevertheless, Jules kept performing these sexual acts and thereby implemented resistance. The fact that Jules rather wanted to swim in the public pool, instead of the private one, shows his ability to confrontation. Yet Jules’ sexuality was also regulated, since caregiver Anja made a report about his sexual act of touching his penis in the bath tub. This portrayed how his sexual actions are documented by both his caregivers and parents. Jonathan on the other hand did not have complete access to his sexuality, since his mother Ruby is in charge of the sexual key, saying that she did not want to open Pandora’s Box nor

wanted to connect the dots. But Ruby acknowledged the fact that Jonathan masturbates. In so doing, he can discover, develop and perform his sexuality. This act made me reason that Jonathan can battle the disciplinary practices of his mother.

After that, I voiced the sexual stories of Melissa and Anton, and I specifically found that Melissa's love-life was regulated extensively. Her mother and caregiver arranged and managed the break-up conversation between Melissa and her ex-lover. Therewithal, Melissa was not allowed to date before, but when she felt in love with a disabled person she was allowed to do so. Due to the fact that Melissa accepted and understood this parental decision, made her also accept her assigned "otherness". This makes me argue that acceptance of one's stigma could be identified as a form of confrontation. Anton's story displayed the most resistance-like practices, but it led me to wonder if this had anything to do with the fact that he 'solely' has a mild intellectual disability, and not a severe one. Nevertheless, he portrayed a few examples of the disciplinary practices by caregivers and how they were the prevailing party in this power game; they pretended that Anton was stupid and kept him ignorant, since he repeatedly needed to present his sexual desire for over a period of six months. But most shockingly, Anton received medication for his unruly behavior, which was in Anton's opinion, actually a way to reduce his homosexual behavior. Yet Anton survived these practices, since he is in a relationship with Rick for over a year, experiencing a great sex life. And at that time, during his emancipatory crossing, his caregivers were at their wits' end because he faced the disciplinary practices with pride; he wore thongs and after he was allowed to go to that homosexual bar, he sat at the bar, naked.

Moreover, this study made me found that the sexualities of people with intellectual disabilities are regulated, but they also have relationships, stair into cashiers' blouses and masturbate at the age of ten. These findings lead me conclude that people with intellectual disabilities either perform or have a need to perform their sexuality. But, keeping these disciplining techniques in mind, how can their sexualities evolve? I am now more than ever obliged to answer the main question of this study, and I will do so in the coming, concluding chapter.

6 Modifying Collective Sexual Consciousness

6.1 *Are you a presumable upholder?*

Ever since I took interest in and studied the titillating mechanism of human sexuality, people around me said over and over again: “So, that means you talk about sex all day”, or even worse “You must be a professional in doing sex then”. Whether I am a professional should not make a difference nor should it matter if I have a need to talk about sex all day. What does matter is that this research made me attentive to the fact that sexuality is situated in our lives as something rather sacred, untouchable and godlike. Or inspired by a Durkheimian fashion I would even say that humans seem to be in service of sexuality. As argued in the third chapter, this human obligingness created a collective sexual consciousness, hence normalised sexuality. Thereby coming, sexuality seems to be a heavenly practice only accessible for those people who interface divinity themselves: in comparison to able-bodied people, intellectually disabled people are not that divine, so their access can be denied.³² Perhaps this is the reason why *Yo, también*’s intellectually disabled protagonist Daniel only had a sexual experience by Laura’s charity.

In December 2011 I decided to study the topic of sexuality amongst intellectually disabled people. Not knowing how to define my interest I talked with friends, colleagues and regular customers of the pub where I worked. Every person seemed to be intrigued by the idea, saying that it would be highly necessary to portray the sexualities of this social minority group. Oddly enough, these same people also wondered why I wanted to advocate their sexuality; was it my motive to plead how they should be able to *have sex* or was I a presumable upholder of disabled people having children? To say the least, all reactions or opinions about the sexuality of intellectually disabled people were oversimplified. One acquaintance even said: “People with disabilities are so sexual and sexually frustrated; *when they have sex* they must *come* within a split second”. Nonetheless, through all this chitchat and late-night discussions I discovered one trend: able-bodied people acknowledge the sexual needs of people with intellectual disabilities, but they do not like the fact that disabled people would *do* something with or about these needs, as they might get pregnant, like one colleague said: “Then you are even worse off”.

This final section will give answer to the main research question of the study, namely *how are the sexualities of people with intellectual disabilities regulated by the disciplinary practices of caregivers and parents?* In the end, I will reason why the sacred and normalised figuration of

³² Divinity in this sense is based on the normalization of the human subject as seen in William Connolly’s article Taylor, Foucault, and Otherness (1985).

sexuality should be demolished in order for intellectually disabled people to discover, develop and perform their sexuality more often. I would like to modify the perception of a collective sexual consciousness, proposing that sexuality is not collectively sacred, but merely a personal embodiment of biological and cultural factors.

6.2 *A handbook: how can one ensure sexual regulation?*

Ever since I first set my eyes on Foucault's paradigm I was stunned by his witty way of thinking. In the fifth part of *History of Sexuality*, Foucault writes the following: "One had the right to kill those who represented a kind of biological danger to others (1978: 138)". His societal elucidation persuaded me to follow my heart and study the subject of sexuality amongst intellectually disabled people, since I realised that people with intellectual disabilities are still perceived by able-bodied folks as weird and sexually dangerous. This "biological danger" came forward during my fieldwork; I heard people say that they were afraid that "these people might get children", seeing that they still have properly functioning reproductive organs. While I listened to these opinions, Foucault's phrase inspired me, because what can represent "biological danger" better than the reproductive organs of intellectually disabled citizens?

By using this study, I showed that people with intellectual disabilities are metaphorically and figuratively killed by able-bodied people, since they are often under the reign of institutionalised practices. The study portrayed how the (sexual) activities and opinions of people with intellectual disabilities are constantly guarded and documented by able-bodied caregivers. In the end, this monitoring must ensure that intellectually disabled people utter less "biological danger" towards able-bodied people. With this study then, I tried to portray how monitoring by able-bodied is actually represented by institutionalised "techniques of power". With the upcoming part I will refute these techniques one more time, to eventually state that Western collective sexual consciousness needs to be modified in order to make the intellectually disabled individual less dangerous. Possibly this new perception may offer future soil to the intellectually disabled individual to discover, develop and perform her/his sexuality more often.

This study shows that, in order to fully optimize life, the human population needs to be regulated (Friedner 2010: 340). Or as Foucault would say, life needs to be "fostered" (1978: 138). During my fieldwork I noticed the implementation of this concept. Therefore I mainly utilised Foucault's paradigm, since it made me aware of the fact that life can only be optimised by a "power of life". In order to comply this endeavour, the human body designed several institutions of power in the seventeenth and eighteenth century, as these institutions were able to utter techniques of power that would foster human existence (ibid: 141). Bio-power and bio-politics are the most authoritative power mechanisms forthcoming from these institutions, since they both ensure the "administration of bodies" and the "calculated management of life". In the end, this means that the human population is

subjugated to an institutional administration and *controlled* by institutional management (ibid: 138-140). But why are the very people, who are dually subjugated and controlled by these power mechanisms, people with intellectual disabilities?

With this study I explored by employing several theoretical and empirical examples that intellectually disabled individuals are treated as different in comparison to able-bodied people. They represent an deviation amongst *men*. This defined deviation actually emerged from the techniques of power, since bio-power and bio-politics affirm the ongoing distribution of normality of the hegemonic, able-bodied group in society. The normative standards that are set to a body by bio-power and bio-politics makes the same body disciplined, or rather develops a “docile body that can be subjected, used, transformed and improved (Lane 1992: 84, in Friedner 2010: 338)”. Hence, bio-power and bio-politics ensure the optimization of the able-bodied body, representing the human population as a herd of standardised bodies. This “quasi-industrial standardization” (Link 2004: 23) is imposed on *men* as a law of truth. Hereby bio-power and bio-politics generate an able-bodied truth. Ungratefully, a truth that intellectually disabled people can never meet. This normalised truth only reinforces a stigmatisation of the intellectually disabled individual as deviant. As a result, this stigmatisation will have serious consequences for the identities and future lives of people with intellectual disabilities, since they are the representatives of “precarious social identities”, resulting at times in “segregation, sterilization, disqualification of citizenship rights, and denial of full social acceptance (Goffman 1963 and Prince 2001b, in Prince 2004: 71)”. Oddly enough, this process of truth generating is circular, so deviant bodies will always be tracked down by the societal institutions of power in order to foster life; people with intellectual disabilities are thus under a “double control”.

In this study caregivers and parents represented the Foucauldian institutions of power. The uttered disciplinary practices signified the Foucauldian techniques of power, since these practices were able to regulate the sexual lives of intellectually disabled people. Regulation then is made possible by institutionalised techniques of power that dually subjugate and control people with intellectual disabilities. Let me recapitulate how the sexualities of people with intellectual disabilities are regulated by the disciplinary practices of caregivers and parents. I reason that the analysis of my fieldwork showed that the disciplinary practices were implemented by dual subjugation and dual control. In the end, both practices enforce sexual regulation amongst intellectual disabled people. First off, compared with able-bodied people, intellectually disabled individuals are sexually dually controlled as (1) they carry their deviancy twenty-four hours a day while (2) their sexual needs are constantly watched over. Secondly, compared with able-bodied people, intellectually disabled individuals are sexually dually subjugated since (1) all their sexual activities and opinions are documented and because (2) the intellectually disabled individual solely can live her/his sexual life according to an administered, policy-based personal plan. This leads me to conclude that the institutions and techniques of power ensure desexualisation amongst people with intellectual

disabilities, since it limits one's sexual agency and autonomy. With desexualisation I do not intend to say that Dutch society is denying the sexuality of people with intellectual disabilities, by this I am referring to the disciplinary practices of caregivers and parents that eventually restrict the intellectually disabled body to discover, develop and perform her/his sexuality.

6.3 *Amare et sapere vix deo conceditur*

Towards the end of my investigation I laid my eyes onto the *Sexual Behaviour in the Human Male* (1948) by biologist and sexologist Alfred Kinsey. One quote in particular caught my eye, saying that children are constantly warned and restricted by parents and teachers against contact with sex and adults (121). This made me understand that people with intellectual disabilities often seem to be treated as children; they may not discover, develop or perform their sexuality, as they do not experience mature manhood/womanhood due to their cognitive underdevelopment. Therefore, I reason that people with intellectual disabilities are infantilised by their caregivers and parents, ensuring that they are sexually restricted or stigmatised as asexual.³³ In order for people with intellectual disabilities to enjoy sexuality more often, able-bodied people need to demolish societal institutions of power and its techniques of power. I believe that this will pave the way to break with our obligingness of a collective sexual consciousness. Or maybe one should reconsider human embodiment. But one should also wonder how feasible my hope is. Nevertheless, I would like to recapitulate this study by using a Latin proverb, namely *Amare et sapere vix deo conceditur*. Hence, one cannot love and be wise at the same time, as this is scarcely granted even to a God. In my opinion, this also means that an intellectually disabled individual does not need to be wise in order to love. Seeing sexuality as something both *a priori* and *a posteriori* with respect to the love, one should wonder why intellectually disabled people are sometimes kept away from loving. Only life itself is the consequence of error. Hopefully able-bodied people will keep this in mind when the sexuality of intellectually disabled people is misjudged in future times.

³³ “Infantilisation” is derived from infantilise, which means to “treat (someone) as a child or in a way which denies their maturity in age or experience”. Definition is available from URL: <http://oxforddictionaries.com/definition/english/infantilise>.

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