Sexuality and intellectual disability

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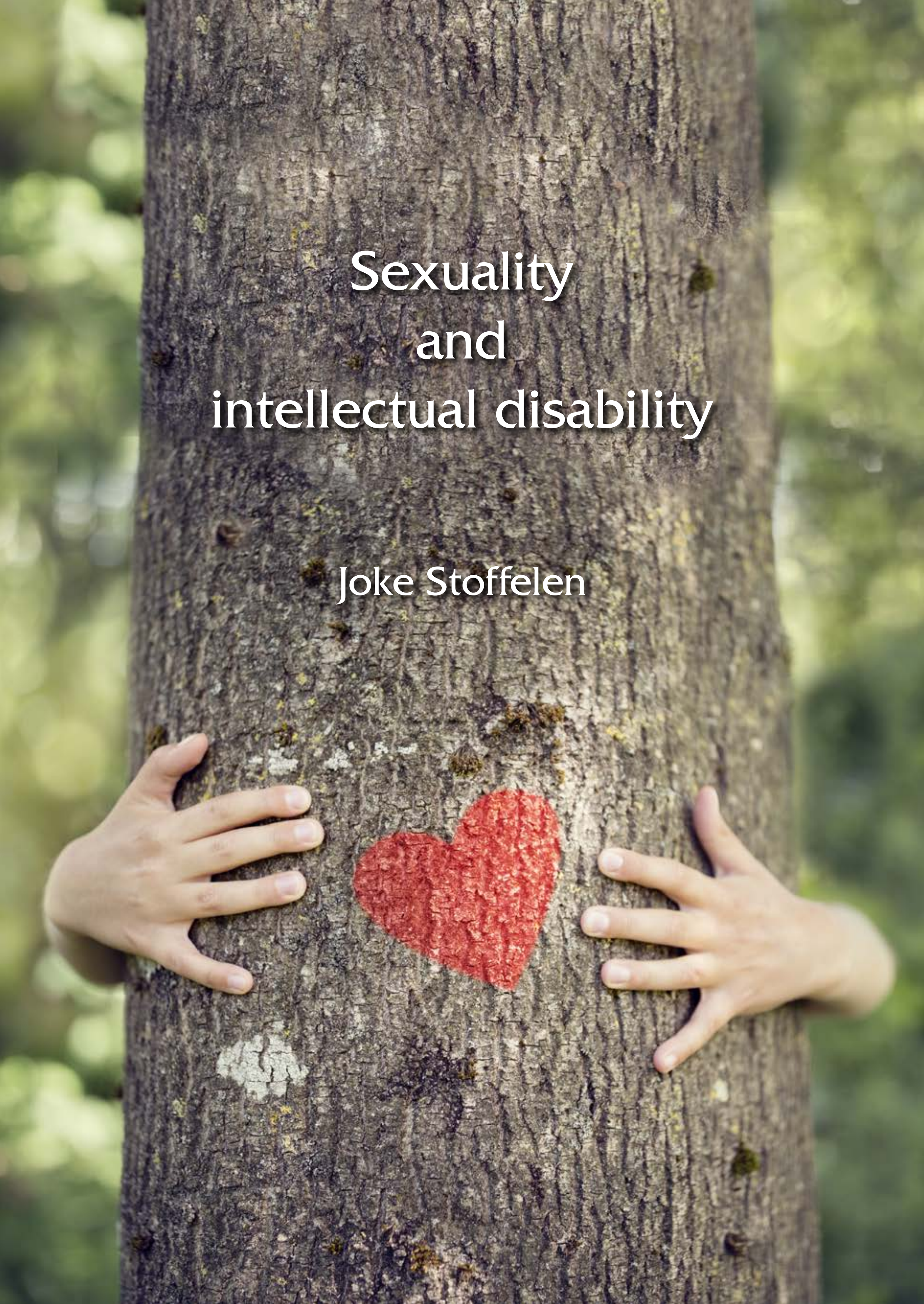

Sexuality
and
intellectual disability

Joke Stoffelen

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Sexuality
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Contents

Chapter 1

Introduction

1.1 Introduction

People with an intellectual disability (ID) have sexual needs, wishes and desires. They often find and experience sexuality to be a complicated matter. In this thesis, we want to explore the topic of sexuality among people with ID. First of all, definitions are clarified (1.2). Next, an outline is given of the barriers that people with ID encounter in realizing their sexual rights (1.3). This leads to the research questions of the thesis, described in 1.4. A framework has been added from which the research was carried out. The various studies are explained in paragraphs 1.5 to 1.8 and conclude with a conclusion (1.9).

1.2 Definitions

Sex, sexuality, sexual health, sexual rights, are terms that have a connection and resemble with each other. The World Association for Sexual Health (WAS, n.d.) states that sexual health is influenced by a multitude of factors such as societal factors, sexual behaviour, attitudes, biological factors and genetic disorders. Sexual health is also more than reproductive health (WAS, n.d.). The WAS has, after consultation with the WHO, formulated the following definitions on the terms “sex”, “sexuality”, “sexual health” and “sexual rights”:

> Sex
> Sex refers to the biological characteristics which define humans as female or male. [These sets of biological characteristics are not mutually exclusive as there are individuals who possess both, but these characteristics tend to differentiate humans as males and females. In general use in many languages, the term sex is often used to mean "sexual activity", but for technical purposes in the context of sexuality and sexual health discussions, the above definition is preferred.]
>
> Sexuality
> Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.
>
> Sexual health
> Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual

> health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.
>
> Sexual rights
> Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus documents. These include the right of all persons, free of coercion, discrimination and violence, to:
> - the highest attainable standard of health in relation to sexuality, including access to sexual and reproductive health care services;
> - seek, receive and impart information in relation to sexuality;
> - sexuality education;
> - respect for bodily integrity;
> - choice of partner;
> - decide to be sexually active or not;
> - consensual sexual relations;
> - consensual marriage;
> - decide whether or not, and when to have children;
> - and pursue a satisfying, safe and pleasurable sexual life. (WAS, n.d.)

The definition of “intellectual disability” is formulated as follows by The American Association on Intellectual and Developmental Disabilities (AAIDD):

> Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18 (AAIDD, n.d.).

1.3 Sexuality and intellectual disability

In 2008, the AAIDD (2008) states that it is important to pay attention to the sexual rights of people with ID. These rights are not self-evident. People with ID experience barriers in realizing their sexual rights in practice. The most important ones: people with ID are extra vulnerable to sexual abuse; they have a lack of knowledge and skills; they are dependent on others; and they have limited information.

Sexual abuse

For people with an ID, sexual abuse remains an essential problem (Abbott & Howarth, 2005; Eastgate, Van Driel, Lennox & Scheermeyer, 2011; Hickson, Khemka, Golden, Chatzistyli, 2008; Reiter, Bryen, & Shachar, 2007; Van Berlo et al., 2011). Overprotection, segregation and a lack of skills, makes them especially vulnerable to sexual abuse (Hollomotz, 2011).

A lack of knowledge and skills

A lack of knowledge about sexuality and sexual rights makes people with an ID especially vulnerable (Murphy & O'Callaghan, 2004; O'Callaghan & Murphy, 2007). People with an ID receive less education about sexuality. Through this, they have less knowledge and skills about sexual health topics than their peers without an ID (Healy, McGuire, Evans & Carley, 2009; Kelly, Crowley & Hamilton 2009; Lesseliers, 1999; Leutar & Mihoković, 2007; McCabe, 1999; McCarthy, 2009; Murphy & O'Callaghan, 2004).

Dependence on others

The dependence on others for care and support, is of influence. Individuals with ID come into contact with many professional carers. *"Many of the youth live in a protected world with a high level of oversight"* (Löfgren-Mårtenson, 2004, p. 204). This support relationship is characterized not only by dependence, but also by a difference in power. This kind of support relationship makes a person with an ID even more vulnerable, especially if someone in their environment has malicious intentions. Bernert (2011) and McGuire and Bayley (2011) found that people with an ID experience resistance from their immediate surroundings when exercising their sexual rights. Family members and caregivers apply different norms to people with an ID then they do to themselves or to people without a disability (Evans, McGuire, Healy, & Carley, 2009; Christian, Stinson, & Dotson, 2002; Swango-Wilson, 2008; Yool, Langdon, & Garner, 2003).

Limited information

People with an ID also have little access to information about their rights due to the inaccessible language used in the human rights documents. Training and support can help people with ID, family members, and carers talk about the sensitive topic of sexuality (Abbott & Howarth, 2005; Evans et al., 2009).

1.4 Research questions

The outlined obstacles make it difficult for people with IDs to realize their sexual rights and to develop themselves sexually. This dissertation is meant to further explore the subject of sexuality and ID.
Our research questions are as follows:

- What can scientific literature tell us about sexuality in relation to ID?

- In what way is support provided to people with IDs concerning the themes of sexual health and sexual rights?
- What do people with IDs themselves find important with regard to their sexual rights?
- How is sexuality experienced by specific groups such as lesbians, homosexuals, bisexuals and transgender people with IDs?

The primary aim of this dissertation is to assemble scientific knowledge of sexuality and ID. Additionally, we wish to promote understanding of the complexity and the significance of sexuality for people with IDs, and to call for increased attention to this subject.

Framework

The studies will be conducted in the Netherlands and this can influence the outcomes. Possible influences are the tolerant attitude of the Dutch society in general towards sexuality and sexual diversity, the fact that people with a mild ID often live and work in society (sometimes independently, sometimes in group homes), the involvement of family and parents in the lives of people with an ID and the well-educated support staff.

1.5 Overview of scientific literature

An overview of the scientific literature in the field of sexuality and gender in people with IDs is contained in Chapter 2. This chapter also serves to introduce the subject of this dissertation: sexuality and ID. The research questions of this study are as follows: can specific themes be distinguished within the literature? Have particular themes been neglected? What is the influence of gender?

1.6 Support for people with intellectual disabilities

The care support plans in the Netherlands play a crucial part in the support of people with IDs. The agreements for health-care insurance according to the Exceptional Medical Expenses Act (Algemene wet bijzondere zorg) came into effect in 2009 (Algemene Maatregel van Bestuur, 2009). These oblige health-care providers to specify the goals of their care and support in a plan and to discuss this with clients. In this way, people can have a say in the care and support that they receive and can make their personal wishes known. Because of the significant consequences a plan has for care and support, we initiated a study of these plans in relation to sexuality (Chapter 3). The final research question is this: in what way does the plan for care and support provide assistance regarding sexual health and sexual rights to people with IDs? To this end, the texts of support plans for clients of health-care and support institutions in the Netherlands were inspected for terms that are related to sexuality and sexual health, and the content of the plans was examined.

1.7 Listening to the people themselves

Research on sexuality in people with IDs often involves the questioning of so-called “proxies”: family members, caregivers and health-care providers. These outcomes should be assessed with a certain degree of caution. After all, it can be questioned to what extent such proxies can articulate the ideas of people with IDs, and what degree of bias is present (Schalock & Felce, 2004). People with IDs are well able to communicate and discuss their ideas and experiences concerning sensitive topics (Goodley, 2005; Schoeters et al., 2005; Tuffrey-Wijne, 2012; Tuffrey & Davies, 2006; Tuffrey-Wijne, Bernal, Butler, Hollins & Curfs, 2007). We initiated a study where we engaged in dialogue with people with IDs and listened to their ideas and needs. For this purpose, we used the nominal group technique (NGT). The NGT method is a structured and specific form of focus research. It is a single-question technique that combines qualitative and quantitative methods of data collection and is suitable for use in relatively small groups. The NGT-question was put to the group members by using a story line in graphic form. In this way, we hoped to answer the research question, “What do people with an ID themselves find important with regard to their sexual rights?” This process was aided by members of the self-advocacy group Landelijke Federatie Belangenbehartiging (LFB). They participated actively in various portions of the study.

1.8 Specific groups

Scientific research on sexual diversity in people with IDs is scarce (Fraley, Mona & Theodore, 2007). Table 1 in the Appendix presents a recent summary of a Pub Med search for “sex” and “ID” and states the number of articles containing the various search terms. The number of articles on sexual diversity is strikingly low. We aim to learn more about this specific group of people with IDs. Chapter 5 describes the study of people with IDs who are homosexual, lesbian or bisexual. We inquired after their daily life experiences. What positive and negative experiences do they encounter? What are their needs and desires? What sort of support do they want to receive?

The perspectives of lesbian or bisexual women are missing from virtually all studies: these people seem to be invisible (Burns and Davies, 2011; Duke, 2011; McCarthy, 2001). To gain insight into the perspectives of lesbian and bisexual women with mild IDs, a study was initiated that specifically targeted these women (Chapter 6). We inquired about their daily life experiences and their wishes and support needs.

1.9 Conclusion

Chapter 7 contains a summary of the various studies and a discussion of the results. We discuss the contribution that we have made to the scientific debate on sexuality in people with IDs. In addition, we offer a statement of value that explains the significance of the study for everyday practical situations. We also give recommendations for future research. To conclude, we present a summary of all the articles in an easy-to-read style. In this way, we hope to make the outcomes accessible for persons with less developed reading skills, such as those with IDs.

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Algemene Maatregel van Bestuur (2009), KB, Stb. 2009, 131.

Appendix

Table 1. PubMed search

(sex*) AND (intellectual disability) AND …	Results Period: 1 January 2010 – 7 July 2017	Results on 7 July 2017
Child	1004	3320
Behavi*	532	1304
Health*	724	1091
Risk*	532	906
Pregnan*	223	808
Social	321	744
Relation*	335	741
Education	301	657
Parent*	238	564
Problem*	253	517
Woman	263	482
Women	252	435
Man	149	319
Prevention	162	296
Information	173	290
Experien*	172	271
Abuse	121	260
Men	130	242
Skill*	110	223
Knowledge	139	223
Attitude	88	204
Needs	145	197
Sexuolog	49	166
Contracept*	26	101
Rights	28	61
Preferen*	34	59
HIV	17	28
Friendship	13	23
Stigma*	9	20
Lesbian	10	19
Empower*	10	12
LGBT	4	4
Social media	3	4
Homo*	0	1

Chapter 2

Sexual health of people with an intellectual disability

Stoffelen, J.M.T., Schaafsma, D., Kok, G., & Curfs, L.M.G. (2017). Chapter Seven - Sexual Health of People with an Intellectual Disability. *International Review of Research in Developmental Disabilities, 52,* 201-237. https://doi.org/10.1016/bs.irrdd.2017.07.004

Abstract

People have sexual needs, expressions, drives, and desires. Sexuality should be a positive part of the human experience and human life. People with an intellectual disability, like everyone else, have sexual feelings, needs, and desires. However, some aspects can be essentially different for them. This warrants special attention.

2.1 Introduction

All people have sexual needs, expressions, drives, and desires. According to Aristoteles (the Greek philosopher who lived in ancient times), we are "social animals, not made to live alone". In essence, people want to contact other human beings for friendship, support, recognition, acceptance, and sex. These forms of contact empower people "to live more effectively, more healthily, and for longer" (Pahl, 2000, p. 149).

Nussbaum (2014, p. 57) describes sexuality as an essential human capability: "Having the opportunity for sexual satisfaction and choices about reproduction." Further, the World Association for Sexual Health (WAS) promotes sexual health by developing sexual rights for all. The WAS (2014) has specified a number of sexual health rights, including the right to privacy, the right to sexual health, the right to marriage and to start a family, the right to decide on the number of children, the right to information and education, the right to freedom of opinion and expression, and the right to protection of these rights. Unfortunately, many different religious traditions have created different laws, doctrines, and traditions regarding (un)acceptable sexual behaviors (Westheimer, 2005) that might not be in concordance with these rights.

Sexuality should be a positive part of the human experience and human life. As such, these rights are afforded to all people, including those with a disability. People with an intellectual disability (ID), like everyone else, have sexual feelings, needs, and desires. However, some aspects can be fundamentally different for them. These differences warrant special attention.

According to recent estimates, 1.04% of the global population has an ID (Maulik, Mascarenhas, Mathers, Dua & Saxena, 2011). Just as the population of people with an ID is very diverse (Chiurazzi & Pirozzi, 2016), so too are they diverse in terms of sexual experiences, sexual desires and needs, and sexual knowledge (Schaafsma, Kok, Stoffelen & Curfs, 2017). Sexuality surrounds us every day and we encounter "concerns", "issues" and "questions". People with ID also have specific problems with sexuality and their own concerns, issues and questions. These specific themes are discussed in the next section.

The objective of this chapter is to provide an overview of issues concerning sexuality and gender in people with an ID. We describe what can be different for them (compared to the general population) and why, and what the important items are concerning sexuality. To begin, we focus briefly on the concept of ID and on the heterogeneity of the group of people with an ID. We explain various syndromes that are linked with ID and their experiences with sexuality and gender. In the third section, we address the sexual rights of people with an ID and how sexual rights are a starting point and an important basis for providing high-quality care and support. In Section 4 we discuss a number of focus points, including people with severe and profound IDs, relationships, identifying sexual abuse, and enjoyable, safe sex and sexual empowerment. In Section 5 we address the gender differences in people with an ID in relation to sexuality, and in Section 6 we focus on sexual diversity, a rather neglected topic for people with ID. In Section 7 we discuss the research that has been conducted in the Netherlands to provide support to people with ID who have experienced sexual problems and who identify as homosexual. Finally, Section 8 contains some concluding remarks.

2.2 Characteristics of intellectual disability

ID, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association, 2013), is characterized by a substantial impairment in both cognitive functioning (an IQ of below 70) and adaptive behavior, originating in the developmental period (before age 18). Impairments can impact a range of skills, including conceptual skills (such as reading and writing, understanding money, time, and numbers), social skills (such as interpersonal relationships, self-confidence, obeying rules and laws, avoiding victimization) and practical adaptive skills (including activities of daily living, dealing with money, healthcare, and safety).

The definitions of ID are not unequivocal. The conceptual framework is also subject to change (Schalock et al., 2010, 2012). For a description of the concept of ID and an explanation of the context of the definitions used, see De Bruijn, Buntinx and Twint (2014). Traditionally, intellectual functioning is subdivided into various levels (World Health Organization, 2016), including

- Mild ID: IQ 50/55-70;
- Moderate ID: IQ 35/40-50/55;
- Severe ID: IQ 20/25-35/40;
- Profound ID: IQ below 20/25.

2.2.3 Specific syndromes, sexuality and gender

Genetic factors can increase the risk of ID (Veltman & Brunner, 2012), and play an important role in the development of developmental disorders. This often occurs not only to people with severe or profound ID, even to people with mild ID (de Ligt et al., 2012). Just as individuals with different genetic syndromes display distinct behavior profiles (Dykens & Hodapp, 1999), individuals with various genetic syndromes (e.g., Prader-Willi syndrome or Down syndrome) may differentially experience aberrant, sexual development or sexual health. In many genetic syndromes, the sexual development or sexual health is so aberrant and sometimes gender-specific that it can have consequences for providing effective care and support to people with both an ID and a specific syndrome. Here, we describe the five most well-known syndromes in people with intellectual disability in relation to sexuality: Down syndrome, Prader-Willi syndrome, Williams syndrome, Fragile X syndrome, and Fetal Alcohol syndrome (FAS). Table 1 provides an overview of 19 additional syndromes, with related characteristics concerning some aspect of sexuality. Please note, not all of the syndromes are always genetic (e.g., FAS) or linked with ID (e.g., Turner syndrome and Klinefelter syndrome). Further, the descriptions only provide an image of people with a particular syndrome. In several syndromes, the behavioral phenotypes can change with age. And furthermore, there can be a within-group variation (Hodapp & Dykens, 2004).

2.2.3.1 Down Syndrome

Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all (Rex & Preus, 1982; Kraijer & Plas, 2007). There are several characteristics concerning sexuality related to individuals with Down syndrome. First, the pubertal development is often incomplete in people with Down syndrome. Second, males are often infertile and have a higher risk of testicular cancer. Finally, females have a lower risk of breast cancer and the menopause begins earlier (Beumer & Bevers, 2014).

2.2.3.2 Prader-Willi Syndrome

Prader-Willi syndrome is the most common known genetic cause of life-threatening obesity in children. Although the cause is complex, it results from an abnormality on the 15th chromosome. It occurs in males and females equally and in all races (Holm et al., 1993; Kraijer & Plas, 2007). There are several characteristics concerning sexuality for individuals with Prader-Willi syndrome. First, there is a difference in sexual development between boys and girls. Specifically, there is a reduced level of sex hormones in boys after the age of 9, resulting in no deepening of the voice and little male hair growth (however, pubic hair appears earlier than in their peers). The fertility is reduced. In girls, the breast development is indistinguishable from fat accumulation, menstruation is rare, menstrual cycle disturbances occur after puberty, and fertility is reduced (Hendrikx & Mulder, 2016).

2.2.3.3 Williams Syndrome

Williams syndrome is a genetic condition that is present at birth and can affect males and females and all races equally. It is characterized by medical problems, including cardiovascular disease, developmental delays, and learning challenges. These often occur side by side with striking verbal abilities, highly social personalities, and an affinity for music (Kraijer & Plas, 2007). In regard to sexuality (Bankras, van Loon, & Reijenga, 2011), young people with Williams syndrome have an early onset of puberty and a growth spurt. Because of their tendency to be overly friendly with strangers, their lack of social judgment skills, and a limited social network, individuals with Williams syndrome are vulnerable to sexual abuse. Young girls and women are often unable to deal effectively with menstruation and experience an early menopause (Bankras et al., 2011).

2.2.3.4 Fragile X Syndrome

Persons with Fragile X syndrome have often ID (most mild to moderate). Usually, males are more severely affected by this disorder than females. One-third of individuals with Fragile X syndrome also have an autism spectrum disorder. There may be an elongated head, big ears, a high forehead, a big chin, dental crowding, hyperlaxity, flat feet and often a soft velvety skin (Kraijer & Plas, 2007). Characteristics concerning sexuality include boys with Fragile X syndrome have large testes and girls experience early puberty, premenstrual syndrome and experience an early menopauze. Boys and girls are normally fertile (Peters & Safi, 2012).

2.2.3.5 Fetal Alcohol Syndrome

Fetal Alcohol Spectrum Disorder (FAS and FASD) is a set of congenital abnormalities due to alcohol use in pregnancy. Effects of alcohol on the child consist of physical, mental, behavioral and / or learning problems that have consequences throughout life. Individuals with FAS or FASD are prone to be sexually deviant behavior (Demirdas, Ganzevoort & Fischer, 2016). In their research, Streissguth et al. (2004) reported inappropriate sexual behaviour, such as making inappropriate sexual advances or inappropriate sexual touching, compulsive sexual behavior, and masturbating in public.

2.3 Sexual rights

People with ID have human rights (Stainton & Clare, 2012), including sexual rights. According to the American Association on Intellectual and Developmental Disabilities (AAIDD), “These sexual rights and needs must be affirmed, defended, and respected” (in “Position Statement Sexuality” AAIDD, 2008). The World Health Organization (2015) also cited specific rights for people with ID: they have the right to sexual and reproductive health services, the right to decide about their own fertility, the right to information and education about sexual health, and people with a disability must not be compelled to undergo involuntary procedures such as sterilization.

2.3.1 Rights cannot be taken for granted

Having sexual rights and exercising these rights in daily life cannot be taken for granted by people with an ID (Ignagni, Fudge Schormans, Liddiard & Runswick-Cole, 2016; Watson, Venema, Molloy & Reich, 2002). Unfortunately, many individuals with ID are not given the respect and support that is required to realize these sexual rights. Watson et al. (2002) indicate examples as “a lack of privacy, inability to find a partner, and restrictive institutional policies or rules” as barrier to exercising their sexual rights. For people with an ID who live in an institution, the right to privacy is poorly acknowledged (Hollomotz, 2008). Further, because of overprotection, segregation and a lack of social skills, people with an ID are especially vulnerable to sexual abuse (Hollomotz, 2011). Hollomotz (2011) interviewed 29 people with a mild ID (12 men and 17 women) to explore the social causes for the risk of sexual violence and reported,

> ...He brought a games console, cause he knew I likes games and he brought a games console in to specifically...I think the phrase 'give me a hand' while I was playing on the games console...I won't go down how it escalated from that. It did...and then you elbow them in the face to get them off you and they go and tell on you because they raped you. They say you raped them. (in Hollomotz, 2011, p. 71)

2.3.2 The right to protection

Sexual abuse has been a serious problem for people with ID for many years. The figures for sexual abuse range, indicating that from 25% to 82% of individuals with ID experience sexual abuse (Abbott & Howarth, 2005; Eastgate, Van Driel, Lennox & Scheermeyer, 2011; Hickson, Khemka, Golden & Chatzistyli, 2008; McCarthy, 2001; Reiter, Bryen & Shachar, 2007; Stoffelen, Kok, Hospers & Curfs, 2013; van Berlo et al., 2011). Others have reported that the risk of sexual abuse for people with an ID is estimated to be three times higher than for people without ID (Rapport commissie Samson, 2012; Reiter, 2007; van Berlo et al, 2011). Even studies examining the sexuality of people with an ID, not specifically focusing on abuse, have reported incidents of sexual abuse in this group (Schaafsma, Stoffelen, Kok, & Curfs, 2013; Stoffelen et al., 2013). Reiter et al. (2007) found that young people with an ID are more often abused than young people without a disability and they are more likely to be forced to do things they do not want to do. Approximately 40% of the respondents with ID had been subjected to sexual abuse (Reiter et al., 2007).

People with an ID are especially vulnerable to sexual abuse, in part, because of a lack of knowledge (Fyson & Kitson, 2010). People with an ID receive less education about sexuality. As a result, they usually have less knowledge about topics such as masturbation, pregnancy, safe sex, reproduction, and sexual diversity than their peers without an ID (Healy, McGuire, Evans, & Carley, 2009; Kelly, Crowley, & Hamilton, 2009; Lesseliers, 1999; Leutar & Mihoković, 2007; McCabe, 1999; McCarthy, 2009; Murphy & O'Callaghan, 2004; Schaafsma et al., 2017). In one study by McCarthy (2009), 14 out of 23 women did not know how their conception worked, 11 lacked knowledge about reproduction, 6 were not familiar with menopause, and 1 did not understand the connection between sex and pregnancy. McCarthy (2014) further reported one women's passivity regarding taking contraception "I don't ask, I just go and have it (contraception), I don't ask".

Moreover, social skills, communication skills, and decision skills are often inadequate for individuals with ID (Egemo-Helm et al., 2007; Hayahsi, Arakida & Ohashi, 2011; Khemka, Hickson & Reynolds, 2005; McCarthy, 2014; Miltenberger et al., 1999). Lack of knowledge and skills concerning sexuality can result in someone being less capable of recognizing risky situations, which in turn increases the risk of sexual abuse (Schaafsma, 2013). Another important factor is the dependence on others for care and support. In their daily lives, individuals with ID come into contact with many professional carers (Löfgren-Mårtenson, 2004; Stoffelen, Schaafsma, Kok, & Curfs, 2018). This support relationship is characterized not only by dependence, but also by a difference in power. This kind of support relationship makes a person with an ID even more vulnerable, especially if someone in his or her environment has malicious intentions. The dependency is related to a lack of empowerment. For many people with an ID, it is difficult to take action if they experience something unpleasant, which is partly because they are not always taken seriously, but also because they do not know how they should act in such situations (Scharlo, Ebbers, & Spijker, 2014, p.19).

Finally, sexual abuse has a major impact on the lives of victims. Experiences with sexual abuse can lead to severe mental problems such as depression and anxiety (Sequeira, Howlin and Hollins, 2003). Hickson et al. (2008) concluded that women with ID with a history of sexual abuse struggle more with decision making than women with ID who had not been subjected to sexual abuse. They also experience more stress, have more comorbidity with other conditions, and more frequently need to receive therapeutic support. Sequeira et al. (2003) reported similar findings, as they found that individuals with ID who were victims of sexual abuse often have more psychiatric and behavioral problems.

2.3.3 The right to information and education

A lack of knowledge about sexuality and sexual rights makes people with an ID especially vulnerable (Murphy & O'Callaghan, 2004; O'Callaghan & Murphy, 2007). In O’Callaghan and Murphy’s (2007) study, approximately half of the participants thought they were not allowed to have sex. In their opinion, it was illegal. Alternatively, participants were unsure as to whether or not they were legally allowed to have sex. In the same study, half of the adults with an ID did not know that there are laws that protect them from having to engage in sexual activities with guardians or caretakers.

When it comes to exercising their sexual rights, people with ID encounter resistance in their immediate surroundings (Bernert, 2011; McGuire & Bayley, 2011). For example, family members and staff carers often have different standards for people with an ID than they do for themselves, and they are often resistant to allowing education about sexuality and sexual rights (Christian, Stinson & Dotson, 2001; Evans, McGuire, Healy, & Carley, 2009; Swango-Wilson, 2008; Yool, Langdon, & Garner, 2003). A questionnaire among family (n = 155) and care staff (n = 153) indicated significant differences in opinions between family and care staff (Evans et al., 2009). Care staff was more likely to support people with ID in (sexual) relationships, whereas family carers accepted only platonic friendships and non-intimate relationships. Eighty percent of the family carers did not support sexual relationships of people with ID. Young, Gore and McCarthy (2012) found in semi-structured interviews with 10 staff members attitudes that correlate with negative, traditional and gender stereotypes. Men with an ID were perceived as sexually motivated and women with an ID as sexually innocent.

People with an ID also have little access to information about their rights due to the inaccessible language used in the human rights documents. Stories and personal biographies in understandable language can enable people with an ID to understand these rights and exercise them in their daily lives (Abbott, 2013). Training and support can help people with ID, family members, and carers talk about the sensitive topic of sexuality (Abbott & Howarth, 2005; Evans et al., 2009; Stoffelen et al., 2013). A study conducted among 39 participants with an ID showed that they are fully capable of indicating what they think is important: a respectful relationship, sex and sex related subjects as sex education, and feeling safe and comfortable (Stoffelen et al., submitted). Unfortunately, Evans et al. (2009) found low levels of staff training (12%) and low levels of family carer training regarding sexual education (8%), indicating a need for further training and support.

2.3.4 The right to have children

Of all sexual rights, the right for individuals with ID to have children is one of the most controversial in society (Hendriks & Legemaate, 2009). In the Netherlands, a disincentive policy regarding sexual expressions for people with ID is in force (VWS, 2004, 2006), despite the opposing views of the Health Council of the Netherlands, associations of parents of children with disabilities, the Royal Dutch Society for the Promotion of Medicine, and legal frameworks such as the European Convention on Human Rights and the Medical Treatment Agreement Act (Kalthoff, 2015).

Parents with an ID are a very heterogeneous group. There are parents with or without an institutional history and parents without the “label” of ID. Regardless, they all experience barriers while fulfilling their role as parents, such as social pressure not to have children or to have an abortion, and the fear and pressure that their children will be taken away from them after they are born. In addition, these parents often have to deal with stress, depression and poor mental health, and they tend to have a smaller social network. In response to these pressures, a position paper from the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) project group recommended that the label “ID” should not be directly equivalent to “incompetent” parenthood. Rather, they recommended giving more attention and support to vulnerable families (Llewellyn, Traustadóttir, McConnell & Sigurjónsdóttir, 2010). It should be noted that the project group is not culturally diverse, the members come from Western countries.

Children of parents with an ID do grow up in an environment with a multiplicity of problems: they are more likely to live in an unsafe situation, they are often stigmatized, and their parents often have financial problems (Kalthoff, 2015). Research into the perspective of children is scarce. A systematic literature review (Gilhuber,2017) to eight studies on the perspective of the child, learned that children with ID parents have an ambivalent relationship towards their parents. The children have positive and negative experiences, and their needs are not always recognized by their patents. Research shows, that parents with ID who have lower scores of social adaptability benefit from video training (Hodes, 2017). The Video feedback Intervention for Positive Parenting with the focus on Sensitive Discipline (VIPP-SD) showed parents videos of educational situations and reviewed them with the parents with ID. As a result, parents learned to see the child's perspective and they developed more empathy, which makes them more sensitive to their child’s needs. Finally, Llewellyn et al. (2010) pointed out that the term “parents with an ID” usually concerns the mothers. In the scientific literature, and in research and in healthcare, little attention is paid to the fathers and their perspective. Llewellyn et al. (2010) advocate to include fathers and to compare parents with ID with parents without ID to gain more knowledge on how the intellectual disability of parents influences their parenting skills.

2.4 Points of interest

As stated previously, people with an ID experience a variety of problems in the area of sexuality. These problems are not only due to the characteristics of an ID, but also due to environmental factors that may impact the individual with ID. People with an ID often require support throughout their lives to function as normally as possible in society, and this need for support also extends to the area of sexuality.

2.4.1 People with severe and profound intellectual disability

In research into sexuality, virtually no attention is paid to people with a severe ID (Duke, 2011; Hubert, 2009; Kok, Maassen, Maaskant & Curfs, 2009). Hubert (2009) used ethnographic methods for research with people with severe ID and found that individuals with severe ID are extremely dependent on others. They had no control over their sexual expression and intimate relationships. Further, their sexual experiences appeared to be primarily physical in nature. Kok et al. (2009) interviewed 12 staff members, all with more than five years of work experience. Carers indicated that it is difficult to assess the sexual needs or preferences of people with severe ID due to their intellectual and communicative limitations and behavioral problems. Overall, individuals with severe and very severe IDs experience the care and support in the area of sexuality (Kok et al., 2009).

> I think that it would be good if we knew more about the sexuality of our clients. During my training, sexuality was discussed only theoretically and was not applied to clients. And all the courses that I have taken are about people with mild ID. We don't know nearly enough about the sexual development of our clients.

> Female who works with people with severe ID, 8 years of experience, in Kok et al. (2009, p. 203)

2.4.2 Relationships

People with an ID report various problems regarding finding, entering into, and maintaining friendships and sexual relationships (Abbot & Burns, 2007; Abbot & Howarth, 2007). These problems are reflected, for example, in the size of their social networks; these are smaller relative to the networks of people without an ID (Hollomotz, 2011). Loneliness is also a major problem for people with an ID. There are indications that half of the individuals with an ID are lonely, while 15%-30% of the people without ID are lonely (Gilmore & Cuskelly, 2014). A theoretical model of vulnerability comprises three important domains: social attitudes and expectations; opportunities and experiences; and skills. Deficits or problems in these domains may result in loneliness. Gilmore and Cuskelly (2014) highlight the need to apply the model of vulnerability to understand the experiences of loneliness of people with ID.

A number of conditions contribute to problems with forming personal relationships, starting with the ID itself. As stated previously (De Bruijn et al., 2014; Gilmore & Cuskelly, 2014; Schalock et al., 2010, 2012; WHO, 2016), an ID is characterized by limitations in cognitive functioning and adaptive behavior, including limitations in social and communicative skills, which are essential to personal relationships.

The environment also contributes to problems with personal (and sexual) relationships (Gilmore & Cuskelly, 2014). People with an ID are often dependent on others (i.e. their parents or professional carers) for care and support. This dependence on others means that they are also dependent on them for information and sex education (Schaafsma, Kok, Stoffelen, van Doorn & Curfs, 2014). Research has shown that people with an ID receive little or no education about sexuality (Levy & Packman, 2004; McCabe, Cummins & Deeks, 1999; Murphy & O'Callaghan, 2004; Schaafsma, 2013; Schaafsma et al., 2013). Murphy and O'Callaghan (2004) assessed the sexual knowledge and vulnerability for sexual abuse among 60 young adults with ID and 60 young adults without ID. Adults with ID were significantly less well-informed on almost all aspects of sex. Further, if individuals with ID do receive sex education, then they often have difficulty remembering the information (Löfgren-Mårtenson, 2012).

Why are people with an ID given so little suitable education, despite all the problems surrounding sexuality and the obvious fact that they have difficulty understanding and remembering information? Despite the increasingly positive attitudes with respect to the sexuality of people with an ID (Christian et al, 2001; Cuskelly & Bryde, 2004; Lafferty, McConkey, & Simpson, 2012; Rohleder, Braathen, Swartz & Eide, 2009), research indicates that sexuality is still seen as a taboo topic (Bernert & Ogletree, 2013; Löfgren-Mårtenson, 2004; McCabe et al., 1999; Rohleder, 2010). In others words, you should not talk about sex or sexuality with individuals with ID. This lack of talking about sexuality could explain why family members and professional carers do not address the topic of sexuality sufficiently (Abbott & Burns, 2007; Abbott & Howarth, 2007; Kok et al., 2009). For example, one individual with ID stated, “I tried to talk to my mum about it but she just blew up, and she said, if you go on and on about it, I’ll take you out of the center” (female in Abbott & Burns, 2007).

As a result, individuals with ID often do not understand how they should deal with questions related to sexuality (Howard-Barr, Rienzo, Pigg & James, 2005) and consequently act inappropriately (Evans et al., 2009). They are also sometimes given inconsistent information. For example, a carer could approve of someone being in a relationship, while there is no room for sexual experiences.

The perceptions and attitudes on sex of care staff influence people with ID. After all, why would you provide sex education to someone if you do not acknowledge that they have sexual needs or you do not recognize those needs? Although many people with an ID indicate that they want to have sexual relationships, the environment discourages these kind of relationships (Healy et al., 2009; Kelly et al., 2009; Löfgren-Mårtenson, 2004). On the one hand, these reactions by care staff and family members are a result from fear of pregnancy or sexual abuse. On the other hand, it is due to the stigmatization of people with an ID being “eternal children” (Wilkinson, Theodore & Raczka, 2015) and/or that they exist in a state of permanent adolescence (Hollomotz, 2011). Sexual activities are incompatible with these stigmatized images. In cases where sex education is provided in an organization, then, it is often in response to questions or problems, instead of proactive, preventative education (Abbott & Burns, 2007; Abbott & Howarth, 2007; Schaafsma et al., 2014).

Moreover, there is often no room for sexual experimentation. Löfgren-Mårtenson (2004, p. 205) notes a difference between male and female staff members:

> ...female staff members are more restrictive concerning sexual expression among the young adults. In contrast, their male counterparts tend to allow increased sexual expression and are more open to letting it ‘go further’ than the female staff members. Since so few men work in the field, the consequence is a female world with a restrictive set of rules. The female staff members focus primarily on the male’s sexual behaviour in order to protect the young women.

In short, many gains can still be made in the area of personal relationships. Enlarging the social networks of individuals with ID and improving their qualities is an important initial step. In addition, attention should also be paid to increasing the knowledge, skills, and attitudes of individuals working with individuals with ID concerning personal relationships. Professional carers and family members play an important role in this process (Abbott & Burns, 2007; Healy et al., 2009; Kelly et al., 2009; Löfgren-Mårtenson, 2004; Schaafsma et al., 2014).

2.4.3 Signs of sexual abuse

Often individuals with ID might not be aware that abuse has occurred or understand that sexual abuse has happened, making it important for others to know and recognize signs of abuse (Scharlo et al., 2014; Stoffelen et al., 2013). For example, sex could take place voluntarily, but involving an undesirable difference in power, such as between a client and his/her carer. For example, one individual stated, “It happened at night. Then they come to you. Then they wake you up” (male, aged 53, in Stoffelen et al., 2013, p. 260).

Sexual abuse can be detected in various ways (Heestermans, van den Boogaard & Embregts, 2015). Of course, the clearest signal is when a third party sees the actual abuse taking place. Detection can also result from a disclosure -perhaps spontaneous- by the victim, when they tell someone else about the abuse, deliberately or otherwise.

Direct signals can also indicate abuse, such as a minor with a sexually transmittable disease or a mentally incompetent woman with a severe ID who is found to be pregnant. A vague (possibly spontaneous) disclosure can also be a sign of sexual abuse (Heestermans et al., 2015). For example, a client may report that he/she no longer wants to play with a neighbor because the activities are too painful.

Finally, indirect signals may also indicate abuse. These can, not only, be physical signals, such as mysterious wounds around the genitals and/or rectum, but also behavioral signals such as various types of pain, anxiety, or problem behavior. It is important to consider that the injuries may also have other causes that are unrelated to abuse and to conduct a full assessment before jumping to conclusions (Heestermans et al., 2015).

2.4.4 Sexual Empowerment

Although individual and environmental factors can increase the vulnerability to sexual abuse of someone with an ID, such factors can also reduce vulnerability. At the individual level, more attention should be paid to increasing skills, such as decision-making skills (Khemka et al., 2005) and knowledge related to empowerment. Professional carers and family members have an important responsibility in this regard (Heestermans et al., 2015). They could, for example, provide proper training to individuals with ID.

2.5 Sexuality and gender

In very general terms, two types of sex can be distinguished: solo sex and sex with a partner. Safe sex is defined as having sex without the risk of sexually transmitted diseases (STDs) and unplanned pregnancy. Enjoyable or pleasurable sex is defined as having sexual experiences that are free of coercion and take place without pain or negative feelings. Unfortunately, positive sexual experiences are rare in people with ID in comparison to their peers without ID (Leutar & Mihoković, 2007; McCabe, 1999; Siebelink, de Jong, Taal & Roelvink, 2006). In part, this lack of positive feelings has to do with the above-mentioned aspects, such as lack of knowledge, skills, support, or the possibility to engage in experimentation. Moreover, the sexual experiences of males and females with an ID also differ. In this next section, we explore the differences between men and women with ID.

In the scientific literature on sexuality and people with an ID, a distinction is not always made regarding gender. Porter, Christian & Poling (2003) screened eight scientific journals regarding the gender of the participants and reported that 65% of the articles referred to participants, of which 26% did not report any gender. In cases where gender was distinguished, 6% of the articles referred to female participants, 8% referred to male participants and 60% referred to both female and male participants. Based on these results, the authors concluded that the gender effect was unclear in many studies. Wilson (2009) is a proponent of specifying gender in research (more about Wilson's work in the Section "men"). This specification is necessary to gain insight into gender-specific factors to obtain a better understanding of sexuality in people with an ID. In our research into sexuality and sexual health, we have made efforts to specify gender differences.

2.5.1 Women with intellectual disability

Noonan-Walsh and Heller (2002) concluded that gender has a specific influence on the health of people during their lives. A literature review (Ouellette-Kuntz, 2005) into the health of people with ID showed that some attention is paid to the gynecological health of women, such as examinations for menopause, menstruation, Pap smears, mammography and uterine tumors. Due to the lack of focus on women with an ID in research on other aspects of health and socioeconomic status, Noonan-Walsh and Heller focused on a number of topics beyond health that are important for females with an ID in their book. For example, in relation to sexuality, they examined sterilization, birth control, sexuality, parenthood, and risk and vulnerability. McCarthy (2001, 2002, 2009) has argued in favor of specific attention for research into the sexuality of females with an ID (McCarthy, Hunt & Milne-Skillman, 2017). Support and assistance for females with ID are emphatically required because women are faced more frequently with sexual violence and abuse, their self-image is often poor, and they have little enjoyment from sex.

In general, women with an ID have a negative view of their own sexuality. These results were shown in a study involving 17 women with an ID (McCarthy, 2001). Most of these women did not see themselves as a sexual person, even though they were sexually active. For example, one individual (MC) told the interviewer (MM):

> MC: I have no sexual feelings whatsoever.
> MM: But you do have sex, so is it something you want or is it something that just happens to you?
> MC: A rather lot of it is forced on me. (in McCarthy, 2001, pp. 199)

According to McCarthy (2001), there are four important factors that contribute to the generally negative experiences with sex reported by women with an ID: (1) a lack of sexual autonomy, (2) the nature of the sexual activities that took place, (3) the fact that the activities are primarily experienced on a physical level, and (4) many experiences with sexual abuse.

Sexual autonomy means that you can decide for yourself what you want to do with whom, where, when, and how (WHO, 2015). To make these decisions, however, you must have certain knowledge and skills. For example, you must know what you like and do not like in terms of sex. Masturbation is one way to discover your own body and to determine what you like and do not like. Fewer women with an ID report having experience with masturbation than their peers without ID (McCarthy, 2001, 2009). For example, one participant (EY), told the interviewer (MM).

> MM: Is it (masturbation) wrong for men and women?
> EY: For women because they can injure themselves. If they put their hand up the front and keep rubbing themselves, they might injure their vagina or something like that…. (in McCarthy, 2011, pp. 129)
>
> Another participant (MC) responded,
>
> MM: Do you think women get sexual urges?
> MC: No.
> MM: Why not?
> MC: The only sexual urges a woman can have is if a fella takes her to have sex. Otherwise they haven’t got any. (in McCarthy, 2001, p. 130)

Masturbation is an important, but neglected topic in sexual health for women with ID. The topic is mainly approached from a negative point of view. In the study of Bernert and Ogletree (2013) none of the 14 women reported to have experience with masturbation. Further, McCarthy (2001, p. 128) found that masturbation was a sensitive topic, stating, “Two women (of the 17 women) avoided the question completely… None of the women readily or confidently reported that they masturbated, despite.” Masturbation by men is judged more positively by women with ID. For example, one woman stated, “...men do it a lot if they feel sexually inclined towards a woman and they can’t get one, but for women it’s not a good idea, even if they’re in bed, because it doesn’t prove anything and it’s wrong to do it” (McCarthy, 2001, p. 129). McCarthy (2002) concludes that there is no reason to ascertain that women with ID really masturbate less than other women. She points out that women with ID find it uncomfortable to talk about this subject. It is essential that positive attention is given to masturbation, as for individuals who are not capable of having sex with others, masturbation offers an outlet and a way to experience sexuality.

In addition, knowledge and skills in terms of setting limits are important. The empowerment of people with ID is generally lower than people without disabilities, and women are even more vulnerable in this respect. Bernert (2011) interviewed 14 women with ID and reported that women had a strong sense of autonomy: "It's my life, not [theirs]." The women felt they were adult women. However, this sexual autonomy was often thwarted by their male sexual partners, by professional carers, or by family members. Bernert (2011, p. 134) reported: "In many ways, the women were not able to act autonomously without services or assistance from outsiders, and thus, assistance from outsiders was essential to the women's autonomy. This inverted relationship between autonomy and dependence held true for all of the women."

The sexual activities of women with an ID appear to be primarily focused on giving pleasure to men (McCarthy, 2001). Penetration (vaginal and anal sex) is at the top of the list, followed by the woman touching the penis or giving fellatio. At the bottom of the list is cunnilingus given by the man. Besides the usual focus on giving pleasure to the male sex partner, many women experience pain during sex, resulting in a frequently negative association with sex. Anal sex and oral sex (fellatio) were reported as the least favorite activities. One-third of the women indicated that they preferred to kiss and hug (McCarthy, 2001). As a result, the study by Bernert & Ogletree (2013), interviewing 14 women with ID, showed that abstinence is used as a strategy to avoid negative experiences such as pregnancy, STDs, coercion, and abuse. One participant stated, "I'm scared of it. It might hurt." She also wanted to avoid pregnancy and HIV, another reason she's said to "don't have sex" (in Bernert & Ogleetree, 2013, p. 245). Another participant stated, "Well, I mean if you're not, if you're not very careful, you get trouble doin' things you're not suppose to do. Things like (sex)" (in Bernert & Ogleetree, 2013, p. 245).

The knowledge and experiences of this group of women with ID was primarily focused on the physical level of sexuality. It appears that women primarily learn factual aspects (how to do something), and that no attention is paid to feelings such as pleasure, desire, and excitement. It also appears that men pay little attention to the woman's feelings during sex. Fitzgerald and Withers (2011) interviewed 10 women with ID about their sexuality and sexual identity. The women stated that they did not see themselves as sexual beings, but as passive with respect to sexuality. They felt that sexual activity should primarily focus on giving pleasure to the man and that it was not their task to participate actively in sexual activities. They did not experience any pleasure from these activities. The women considered themselves to be of little value. Fitzgerald and Withers (2011, p. 10) concluded:

> The implicit messages given by the women throughout the interviews were that men were somehow better and more valuable than women, although paradoxically a number of women said that they worked harder than men. The women seemed to view men as being privileged in society without merit. They felt

> powerless in relation to men, and this was reflected in their accounts of sexual and financial exploitation.

A literature review by McCarthy (2014) showed that the situation has not changed substantially during the past 10 years for women with an ID. As one staff member questioned, "When have they had an opportunity to have a positive experience? I mean, they're not educated about it. They don't have the right place to do it. So how are they going to see sex as positive?" (Bernert & Ogletree, 2013, p. 246). More recently, authors have urged a greater focus on the pleasurable aspects of sexuality: "...professionals providing services and education should emphasise sex positive messages that contribute to sexual self-efficacy, self-determination, and self-advocacy among women" (Bernert & Ogletree, 2013, p. 247). The sexual script that these women learn must include sexual expression, pleasure, and mutual exchange.

2.5.2 Men with intellectual disability

Research into the sexuality of males with an ID is frequently limited to two aspects: (1) the high risk of HIV, or (2) being a perpetrator of sexual abuse/engaging in undesirable or problematic behavior. Wilson (2009) denounced the lack of attention for the specific sexual health problems of males.

In a review of four international journals (Journal of Intellectual Disability Research, Journal of Applied Research in Intellectual Disabilities, American Journal on Mental Retardation, and Journal of Intellectual and Developmental Disability) focusing specifically on research involving people with an ID, Wilson (2009) studied the titles of articles published since 2000 that focused on males and females with ID. For males (search terms: "male, man, boy, or men") he found the following: 3 articles about "mental health"; 9 articles about "sexual matters" in which male sexuality was primarily presented in a problematic context; 9 articles about "health and well-being"; 10 articles about "crime/antisocial behavior", of which 6 were related to sexuality ("sexual abuse, sex offenders, sexually abusive behavior"); 8 articles about "language", and 6 articles on other topics. For purposes of comparison, the same study was conducted for females (search terms: "female, woman, girl or women"). He found 21 articles about "health and well-being"; 1 article about sexuality, in which women were victims of sexual abuse; 3 articles about "crime/antisocial behavior" and 12 articles about "other" topics. The differences in focus for males and females are striking. Furthermore, the negative approach to male sexuality is striking.

Another literature review (Ouellette-Kuntz (2005) found that while there is attention paid to a part of the sexual health problems of females with an ID, no attention is paid to the specific sexual health problems of males, such as prostate screening and examination of testes. Hogg and Tuffrey-Wijne (2008) conducted a literature review on the incidence and prevalence of cancer in people with an ID. In the literature review, they reported significantly more cases of testicular cancer in males with a severe or very severe ID and in males with Down syndrome. Thus, they argued in favor of screening for gender-specific forms of cancer, both in males and females with an ID.

The problems experienced by men with an ID with respect to pleasurable and safe sex concern masturbation, among other aspects. The problems included a lack of understanding about how to masturbate, being unable to have an orgasm, masturbating inappropriately, or using objects for masturbation that are harmful (Cambridge, Beadle-Brown, Milne, Mansell, & Whelton, 2011; van Doorn, Van den Bogaard & Embregts, 2014). For males with an ID, many of these problems can be traced back to a lack of knowledge, skills, and support.

In summary, it can be stated that education and support should focus on preventing problems such as unplanned pregnancies, sexual abuse, or STDs. However, it is also important to pay attention to the pleasurable and enjoyable aspects of sexuality. Masturbation, or solo sex, is a theme that deserves explicit attention for individuals with an ID. It is a way to explore one's own body and sexuality. In the case of women in particular, this exploration is not always taken for granted.

Finally, people with an ID often have little space to experiment sexually. This lack of experimentation is because the protective environment exerts control, resulting in little privacy. To develop sexually, however, room for experimentation is essential. A balance must be struck between protecting someone with an ID and offering them the possibility to develop sexually. In addition, more research is needed into the gender-specific health problems and needs of males and females with an ID.

2.6 Sexual diversity

Sexual diversity refers to “the full range of sexuality which includes all aspects of sexual attraction, behavior, identity, expression, orientation, relationships and response. It refers to all aspects of humans as sexual beings” according to the International Planned Parenthood Federation (2008, p. 66). Sexual diversity also occurs in people with ID. However, very little is known about the extent to which the sexual diversity differs relative to the general population. For the time being, there is no reason to assume that there is a substantial difference between these groups. People with ID experience additional prejudices and discrimination from other people with ID as well as from people without ID. Further, lesbian, gay, bisexual, or transgender (LGBT) individuals with ID have few opportunities to make social acquaintances (Abbott, 2013; Abbott & Burns, 2007; Abbott & Howarth, 2005, 2007; Fraley, Mona & Theodore, 2007; McCann, Lee & Brown, 2016; Stoffelen et al., 2013, 2018).

2.6.1 Prevalence

Estimating the number of LGBT people with an ID is not a simple task. To estimate the number of homosexual or bisexual people without intellectual disability, a “self-identified” criterion is used (Bakker & Wijsen, 2013). Savin-Williams and Cohen (2007) distinguish seven stages in the sexual development of LGBT youths: (1) feeling different; (2) attraction to same sex; (3) doubting own heterosexuality; (4) sex with someone of the same gender; (5) self-identification; (6) coming-out; and (7) acceptance. A certain level of cognitive ability is needed for this self-identification process (Vanwesenbeeck, 2006). However, for many people with an ID, especially if the disability is moderate, severe, or very severe, self-identification may not be possible (Kok et al., 2009). The lack of research into the prevalence of sexual diversity among people with an ID is therefore not particularly surprising (Löfgren-Mårtenson, 2009; Noonan & Taylor Gomez, 2011). Precisely because of their disability, many people with an ID do not identify themselves as LGBT and/or they experience sexuality in a completely different way (Kok et al., 2009; Stoffelen et al., 2013). McCann et al. (2016, p. 50) conclude in their review of the literature concerning ID and LGBT: “...some are LGBT and some men with ID have sex with other men.”

2.6.2 Scarce research

Research into sexual diversity among people with ID is scarce (Fraley et al., 2007). Almost no research is available concerning experiences with same-sex relationships for people with an ID (Abbott, 2013). Of the research that has been performed, it is primarily from the male perspective, leading to great underrepresentation of women with an ID (Abbott, 2013; Abbott & Howarth, 2005, 2007; Cambridge, 1997; Cambridge & Mellan, 2000; Stoffelen et al., 2013). The perspective of lesbian, bisexual or transgender women is absent in virtually all research; these women appear to be invisible (Bernert & Ogletree, 2013; Burns & Davies, 2011; Duke, 2011; McCann et al., 2016; McCarthy, 2001). In a study conducted by Abbott and Howarth (2005), the authors attempted to better understand the experiences of gay, lesbian and bisexual men and women, through interviews with 71 staff members, 9 women, and 11 men with ID. They concluded, “It was relatively easy to find men to interview but we struggled to find nine lesbian and bisexual women with ID”.

2.6.3 Prejudice and stigmatization

The few studies that have been conducted into individuals with an ID who are LGBT have noted the prejudice and stigmatization experienced by this group. Individuals with an ID who are homosexual experience prejudice and intimidation from the outside world. Because they have an ID and are homosexual, they are doubly stigmatized; this double stigma is referred to as a “layered” stigma (Crocker 2005; Duke, 2011; Goffman, 1963; Löfgren-Mårtenson, 2009; Meyer, 2003). Prejudice and discrimination limit the possibilities to participate in society and the opportunities to develop friendships (Hall, 2010). For example, individuals with an ID who are LGBT experience bullying, exclusion, or discrimination by others (Abbott, 2013; Burns & Davies, 2011; Duke, 2011; Leutar & Mihoković, 2007; Löfgren-Martenson, 2004, 2009; Stoffelen et al., 2013). These individuals are often bullied at work or when they go to cafés or nightclubs (Duke, 2011; Stoffelen et al., 2013). They are also stigmatized by homosexuals without intellectual disability (Stoffelen et al., 2013). In the "homosexual world" people with an ID find themselves at the bottom of the "gay pecking order" due to their lack of social contacts and money (Thompson, Bryson & De Castell, 2001).

Further, people with and without IDs often have prejudices and are negative about homosexuality. As such, young people with an ID sometimes internalize the homophobic and heterosexual attitude of their carers, teachers, parents, and co-workers (Duke, 2011). As a further result of this stigmatization, individuals with an ID who are LGBT are often reluctant to tell others that they are homosexual (Stoffelen et al., 2013). For example, one individual stated, "I'm afraid how they will react. At my work . . . when I say I like girls . . . they don't want to sit next to me..." (Female, aged 29, in Stoffelen et al., 2013, p. 261).

In response to prejudice and stigma, individuals with an ID are afraid to be themselves in public. They often find it difficult to be assertive about their sexuality (Abbott & Howarth, 2005, 2007; Cambridge & Mellan, 2000; Duke, 2011; Stoffelen et al. 2013). For example, one individual stated, "If I get new work, I will definitely keep my mouth shut…" (Male, aged 51, in Stoffelen et al., 2013, p. 261). And another individual said,

> They hollered at me and called me a homo. That wasn't nice. They were disciplined by the boss. Homos are people too. They are just normal people… (Male, aged 53, in Stoffelen et al., 2013, p. 261)

2.6.4 Social contacts

Many people meet their future partners at work, through friends, or during other social contacts. For individuals with an ID who are LGBT, it is more difficult to meet others and their social networks are often very limited. The chance that they will make contact with another individual who is LGBT is small (Abbott & Howarth, 2005; Fraley et al., 2007; Stoffelen et al., 2013). In the Netherlands, occasional meetups for individuals with an ID who are LGBT (COC-cafes) are held, but the required travel is a problem for many people, especially those who live outside the big cities (Stoffelen et al., 2013). Unfortunately, transportation is always a problem if you have an ID (Shakespeare, 2006). This transportation problem is unfortunate because it is crucial to meet others, for example, to experiment with relationships, gain experience, develop a positive self-image, and become empowered (Duke, 2011). To overcome the issues with transportation, Fraley et al. (2007) referred to the possibilities offered by the internet, although the experiences are not always positive (Stoffelen et al., 2013; 2018), as one participant noted:

> I'm now looking on dating sites. I've registered for several: Badoo, Tinder. I'm not really looking, because looking doesn't help… but I did have contact with someone for years. And now I want more. It was a faker, it was a man. On Facebook, it looked like a pretty woman…. I felt awful about this for a long time. It kept me awake. It was miserable. (Female, aged 23, in Stoffelen et al., 2018)

Another individual stated,

> Of course, I would like to have a relationship sometime, but I'm not looking specifically. If you force yourself to look, then you find the weirdest types. You have to wait for someone you really like. I don't know many people, hardly any women… I'm the only woman in my group of friends. (Female, aged 25, in Stoffelen et al., 2018)

And finally,

> I have my eye on a girl. She lives a few streets away. But she also has problems with anxiety, so neither of us dares to make contact. It could take a long time. (Female, aged 25, in Stoffelen et al., 2018)

2.6.5 Support

Although research into the specific health problems of LGBT people with an ID is scarce (Fraley et al., 2007), some research indicates that LGBT individuals with an ID have an increased risk of depression, anxiety, drug use, loneliness, sexual problems and sexual violence (Bakker & Wijsen, 2013; Clarke, Ellis, Peel & Riggs, 2010; de Graaf, Bakker & Wijsen, 2014; Duke, 2011;). Thus, when it comes to sexual diversity and supporting people with an ID three aspects are vitally important: (1) providing information, education and training; (2) providing positive support; and (3) providing accessible information.

Information, education, and training about sexuality are crucial; not only for people with an ID, but also for their carers, family members; and others who represent their interests. The informational material should focus especially on sexual diversity and themes such as prevention of HIV/AIDS, attention to homophobia, and gaining access to the LGBT community (Duke, 2011; Fraley et al., 2007; Löfgren-Mårtenson, 2009; Noonan & Taylor Gomez, 2011; Stoffelen et al. 2013; Thompson, 2007). Finally, providing support and role models is important for the development of a positive identity (Abbott, 2013; Abbott & Howarth, 2005; Duke, 2011; Löfgren-Mårtenson, 2009; Noonan & Taylor Gomez, 2011; Stoffelen et al., 2013). "It's probably also pretty hard for them to understand it themselves, because one knows how difficult it is for other homosexuals to be accepted and so you know it must be even more difficult for mentally challenged people to understand and accept themselves…" (staff member in Löfgren-Mårtenson, 2009, p. 23-24).

Accessible information about LGBT sexuality by means of good, easy-to-read books, and websites is needed for people with an ID (Duke, 2011; Löfgren-Mårtenson, 2009; Stoffelen et al., 2013). Löfgren-Mårtenson (2009) interviewed people with ID, parents, and staff members to identify and describe the variety of sexual expression, such as homosexuality and bisexuality. She describes in her article the situation in Sweden, "Easy-to-read literature designed for people with ID in Sweden consists of a single book about homosexuality, and it is about male homosexuality. Books about same-sex sexuality among women do not exist at all, even if they form part of the plot of at least one recent easy-to-read book" (Löfgren-Mårtenson, 2009, pp. 25-26).

In summary, it can be stated that attention for sexual diversity among people with an ID is still a neglected aspect. These individuals are faced with the double stigma of having both an ID and a different sexual preference. This group has a great need for specific support. In research, women are greatly underrepresented.

2.7 Support for sexuological problems

Greenwood and Wilkinson (2013) conducted a literature review related to aspects of sexual health of women with ID, including sexual health care. They noticed a lack of "primary care-focused research and practice guidelines for the sexual health care of adult women with ID" (Greenwood & Wilkinson, 2013, p. 1).

From research into the sexual problems of women with an ID, the following aspects have emerged: lack of knowledge and skills, negative experiences, no understanding of one's own sexual desires, pain during intercourse, and dissatisfaction with their sex partner, the absence of a partner, and no access to help (Greenwood & Wilkinson, 2013; van Doorn et al., 2014). Research involving men has also shown inadequate knowledge and skills, dissatisfaction with a partner (or the lack of partner) for sexual contact or a sexual relationship, excessive or inappropriate masturbation, inappropriate touching and/or approaching others, and erection problems (van Doorn et al., 2014).

For problems with sexuality, people with an ID can contact sexologists. In the Netherlands, sexologists can be employed in residential settings for people with an ID. Most of the referrals to the sexologists have something to do with the embarrassment of the carers when faced with the sexual health needs of residents (Manders, Stoffelen, Kedde, van Zelst, Kok & Curfs, 2010). These sexologists collaborate within the national sexology platform working with people with mild ID (Landelijk Platform Netwerk Seksuologie en LVB). The platform endeavors to disseminate knowledge on diagnostics, research, and organization. Using the national sexology platform, Van Zenderen and Hehenkamp (2015) investigated the reasons for referral of 154 clients (67% male, 23% female; 15.5% with moderate ID, 54.5% with mild ID, and 14% with borderline ID). The main reasons for referral were sexual abuse and/or violence, sexual dissatisfaction, and inappropriate sexual behavior. More sexuological support is required for people with ID. In addition, we need research beyond just the Netherlands.

2.8 Conclusion

Just as those without ID, individuals with ID have sexual needs, expressions, drives, and desires. Individuals with an ID may also differ from the general population of people without an ID in certain aspects. These aspects, therefore, require extra attention.

Those who provide support to people with ID should have insight into the differences in sexual development experienced by individuals with ID and they must be knowledgeable as to which aspects are unusual. As in the general population, asexuality is present but it is not the norm. Rather, people with a mild ID want to have relationships and sexual experiences. Although very little research has been conducted into the sexuality of people with a severe ID, it is believed that all individuals want to experience relationships.

To address the diverse nature of individuals with an ID, it is important to take account of their learning difficulties and limitations in adaptive skills when providing sex education to this population. Such difficulties and limitations may make it more difficult for individuals with an ID to understand and remember information. It is therefore important to adapt the sex education curriculum accordingly. For example, repeating information and practicing skills a number of times are essential activities for this group.

Research into the development of sex education material has shown that too much emphasis is still placed on talking about individuals with an ID instead of talking *with* the individuals with an ID. Engaging in dialogue with the individuals with an ID is essential when approaching the “loaded” topic of sex. It is essential to determine the individual’s perspective on sexuality, while trying to think and act outside one's own normative framework.

The positive aspects of sexuality should also be given attention. At the same time, the associated hazards should also be taken into account, such as sexual abuse, unplanned pregnancy, and STDs. Entering into and maintaining relationships is a problematic area for people with an ID, especially where sexual relationships are concerned. Education on these aspects must begin early and be attuned to the possibilities of the target group.

Masturbation, or solo sex, should also be addressed in the informative material. Especially among females, there is often a lack of experience with masturbation and orgasm. Males, in contrast, may engage in masturbation in an unhealthy or inappropriate way. Specific attention for pleasurable and healthy masturbation is therefore required.

Many women with an ID do not experience enjoyable sex with a partner. Rather, during sexual activity the focus is primarily on giving pleasure to the male sex partner. Attention to the satisfaction of the woman and how she can have an orgasm is therefore important. Further, more research into gender-specific sexual health in women and men with ID is needed to better understand their specific needs and the factors that play a role in this process. Research is also needed to change the often prevailing gender stereotypes about ID and sexuality.

Finally, sexual diversity is also present in people with an ID. Consequently, they are faced with a double stigma: they not only have an ID but also a different sexual preference. More attention for this group and providing specific support to them is important to improve their quality of life and sexual health.

As stated previously, this chapter is primarily about the sexual health of individuals with a mild ID. Little research has been conducted into the sexuality of people with a severe or very severe ID. Almost no data on the sexuality of these groups are available. When using a term “intellectual disability” or “learning disability” and descriptions of the degree of ID it is important to keep in mind the important statement preceding these definitions that people with ID are “people first”. Supporting or rejecting the sexual needs and wishes of people with ID reflects the attitudes, values, and beliefs of our society and deeply affects their lives.

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Appendix

Table 1. Overview of specific syndromes and corresponding issues concerning sexuality and gender

Syndrome	Characteristics
Down syndrome	o Pubertal development is often incomplete o Males are often infertile o Males have a higher risk of testicular cancer o Females have a lower risk of breast cancer o In females menopause begins earlier
Prader-Willi syndrome	o Reduced levels of sex hormones in boys after the age of 9: No deepening of the voice, little male hair growth (however, pubic hair appears earlier than in their peers) o In girls: Breast development is indistinguishable from fat accumulation, menstruation is rare, menstrual cycle disturbances occur after puberty, and fertility is reduced o People with PWS also have sexual feelings and sexual needs. Sex education should be provided, with a focus on preventing sexual abuse
Williams syndrome	o Early onset of puberty; growth spurt in puberty o Vulnerability to sexual abuse due to the tendency to be overly friendly with strangers, a lack of social judgment skills, and a limited social network o Inability to deal effectively with menstruation o Early menopause
Fragile X syndrome	o Boys have large testes o Girls experience early puberty and premenstrual syndrome
Cornelia de Lange syndrome	o Boys have a high likelihood of undescended testes o Growth spurt in puberty
Smith-Magenis syndrome	o Carriers of a specific mutation may have polyembolokoilamania (the tendency to insert objects into body openings) o Early onset of puberty o Premature menopause o Children tend to engage in 'self-hugging' when excited o In girls there is a relationship between increased behavioural problems and the menstrual cycle
Congenital infections: Rubella, herpes infection, toxoplasmosis	o Sexual development can be disrupted o Menstrual problems: Irregular menstruation and premenstrual syndrome o Early menopause
Klinefelter syndrome	Occurs only in boys o Small penis and small testes, breast growth, reduced muscle mass and feminine distribution of body fat o Delayed or incomplete puberty: Little body hair o In males: Decreased libido, reduced muscle mass and reduced bone mass, infertility (99%-100%), increased risk of breast cancer
Turner syndrome	Occurs only in girls o No breast development o Spontaneous puberty, but late stagnation occurs in 10%-20% o Infertility (95%-98%)
Sotos syndrome	o Early onset of puberty o In girls: Irregular menstruation o Emotional vulnerability and low self-confidence
Neurofibromatosis	o During puberty: delayed growth or excessively rapid development o Women under the age of 50 have a 50-fold increased risk of breast cancer

Syndrome	Characteristics
Charge syndrome	o Delayed or absent puberty, resulting in aberrant growth o In boys: Low testosterone levels o In girls: Ovulation dysfunction
Fetal Alcohol Syndrome	Prone to sexually deviant behaviour
Rubinstein Taybi syndrome	o In boys: Incomplete or delayed descent of testes (78%-100%) o Genital abnormalities: Hypospadias in 11% of the boys: The urethra is too short and the urinary opening is not at the head of the penis; occasionally a minor to severe downward bending of the penis when erect; o In girls: Heavy menstruation and metrorrhagia (bleeding from the uterus outside the menstrual period)
1p36 Deletion syndrome	o Puberty can begin earlier or later than normal o Genital abnormalities: Hypospadias in boys and hypoplasia (incomplete development) in boys and girls
Congenital defects in glycosylation	o In girls: Absence of puberty; no pregnancies are known o In boys: Normal puberty, testes are often shrunken
Wolf-Hirschhorn syndrome	o All people known to have this syndrome have been infertile o Genital abnormalities: In boys hypospadias and cryptorchidism (undescended testes); in girls aplasia/hypoplasia of the clitoris (excessive or inadequate development), congenital abnormalities of the uterus or vagina and streak gonads (empty fibrous tissue instead of gonads)
Phelan-McDermid or 22q13.3 Deletion syndrome	o Pubertal development and menstruation proceed normally o Nothing is known about fertility
Lesch-Nyhan syndrome	o Puberty is often delayed o Testes are sometimes underdeveloped

Chapter 3

Sexuality and Individual Support Plans for People with Intellectual Disabilities

Stoffelen, J.M.T., Herps, M.A., Buntinx, W.H.E., Schaafsma, D., Kok, G., & Curfs, L.M.G.
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Abstract

Background Sexual rights and sexuality are important aspects of Quality of Life, also for people with intellectual disabilities (ID). However, providing support in this area to people with ID poses some challenges. In this study, the content of individual support plan (ISP) documents was analysed to determine the extent to which sexuality and sexual rights are addressed in part of the ISP documents.

Method Content analysis was carried out on a sample of 187 ISP documents from seven different service provider organisations in the Netherlands. First, we conducted a lexical search using terms related to sexuality and sexual health. The retrieved segments were then analysed.

Results A total of 159 ISP documents (85%) of 60 men and 99 women contained some reference to aspects of sexuality. However, these references were mostly descriptive and offered little guidance in terms of providing support. Moreover, these notations mostly described negative or problematic aspects of sexuality. References to sexual education, treatment, intervention programmes or support strategies were rarely found in the ISP documents.

Conclusions Although sexuality is addressed in most ISP documents, there is little information available about the provision of professional support in this area, that would give people the opportunity to exert sexual rights. As sexuality and exerting sexual rights is important for people with ID as well as for other people, it is recommended that issues surrounding proactive sex education, shared decision making and the implementation of sexual health care plans are addressed in the ISP.

3.1 Introduction

3.1.1 Individual support planning

Individual support planning (ISP) has become a key aspect of support for people with intellectual disabilities (ID) in many countries around the world (Robertson et al., 2007; Schwartz, Holburn, &]acobson, 2000), and is regarded as a key aspect of person-centered support (Robertson et al., 2007). It refers to the process of developing, implementing and evaluating individual goals and objectives in terms of personal outcomes. The ISP document is the written or digital document that describes these goals and objectives (Thompson et al., 2009; Herps, Buntinx, & Curfs, 2013), and thus should reflect the current support that is provided to enhance personal outcomes (Thompson et al., 2009). The content of the ISP document should be based on an ongoing dialogue between staff and the person regarding the individual's wishes and preferences, but research has shown that people with ID are not always meaningfully involved in this process (Williams & Robinson, 2000, Herps et al., 2013; Herps, Buntinx & Curfs, 2016).

Balancing different perspectives and developing an ISP document that incorporates the provision of professional support can be difficult when conflicting interests arise, or when sensitive subjects are addressed (Tuffrey-Wijne, Bernal, Butler, Hollins, & Curfs, 2007; Wagemans, van Schrojenstein Lantman-de-Valk, Tuffrey-Wijne, Widdershoven, & Curfs, 2010). For the purpose of this study, we chose the topic of "sexuality" as an example of a sensitive and perhaps difficult subject in terms of providing support for people with ID, and studied the extent to which this topic is addressed in ISP documents. We are aware of only one other study that has researched the topic of sexuality in ISP documents. Stancliffe, Hayden, & Lakin (1999) studied the content of 126 ISP documents and found no individual goals on sexuality.

3.1.2 Sexuality and sexual rights of persons with ID

People with ID have human rights (Stainton & Clare, 2012), including sexual rights. The World Association for Sexual Health (2014) has specified the number of sexual health rights, including the right to privacy, the right to sexual health, the right to marriage and to start a family, the right to decide on the number of children, the right to information and education, the right to freedom of opinion and expression, and the right to protection of these rights. According to the American Association on Intellectual and Developmental Disabilities (AAIDD), "These sexual rights and needs must be affirmed, defended, and respected" (in 'Position Statement Sexuality' AAIDD; 2008).

3.1.2.1 Definitions of sexual rights

Three authoritative organisations have defined sexual rights from the perspective of human rights: the WHO (2015), The World Association for Sexual Health (WAS, 2014) and The International Planned Parenthood Federation (IPPF, 2003). Though not specifically written for people with ID, people with ID also have sexual needs, wishes and questions, as well as sexual rights that need to be addressed (AAIDD, 2008; UNCRPD, 2006, article 25), and sexuality and sexual health are as such important and constitute a part of the concept of Quality of Life (Schalock, Keith, Verdugo & Gomez, 2010). Nussbaum (2014, pp. 57) describes sexuality as an essential human capability: “Having the opportunity for sexual satisfaction and choices about reproduction”, and states that it is important to protect this.

3.1.2.2 Sexual rights and people with ID

However, understanding sexual rights and exercising these rights in daily life is not always straightforward for people with ID. Richards, Miodrag, Watson, Feldman, Aunos, Cox-Lindenbaum & Griffiths (2009, p. 211) conclude that *“*sexuality is a complex and unresolved issue due to the imposition of a social construct and the continued pathologizing of the disability itself.” People with an ID experience a variety of problems in the area of sexuality. They do not always get the respect and support that is needed (Watson, Venema, Molloy & Reich, 2002; Ignagni, Schormans, Liddiard & Runswick-Cole, 2016). Issues such as overprotection - along with a lack of skills and knowledge - can make people with ID vulnerable to sexual abuse (O'Callaghan & Murphy, 2007; Murphy, O'Callaghan & Clare, 2007; Hollomotz, 2011). Individuals with ID are more likely than the general population to have had negative sexual experiences, or to have been sexually abused (Abbott & Howarth, 2005; Reiter, Bryen & Shachar, 2007; Hickson, Khemka, Golden & Chatzistyli, 2008; Van Berlo et al., 2011; Eastgate, Van Driel, Lennox & Scheermeyer, 2011; Stoffelen, Kok, Hospers & Curfs, 2013). People with ID often face resistance in their direct surroundings when it comes to exerting their sexual rights (Bernert, 2011; McGuire & Bayley, 2011) and the need for privacy in residential settings is often badly recognised (Hollomotz, 2008). Family members and other support providers set different norms for themselves (or other people without disabilities) than for people with ID (Christian, Stinson & Dotson, 2002; Yool, Langdon & Garner, 2003; Swango-Wilson, 2008). Information about sexual rights is often not easy to understand by people with ID (Abbott, 2013), and they receive less sexual education than people without disabilities (Schaafsma, Kok, Stoffelen & Curfs 2013). Furthermore, some people with ID have difficulties memorising the information that is presented during sexual education (Löfgren-Mårtenson, 2012). Having had less sexual education or not having had tailor made sex education, can result in people with ID having less knowledge about topics such as masturbation, pregnancy, safe sex, reproduction and sexual diversity, as compared to peers without an ID (Leutar & Mihokovic, 2007; Healy, McGuire, Evans & Carley et al, 2009; Kelly, Crowley & Hamilton, 2009; McCarthy, 2009; Schaafsma, Kok, Stoffelen & Curfs, 2017). Moreover, the social, communicative and decision-making competences of some individuals with ID are limited (Hayahsi, Arakida & Ohashi, 2011). Finally, although sexual education materials for people with ID have been developed, people with ID and their caregivers are rarely or not involved in the development of such materials (Schaafsma, Kok, Stoffelen & Curfs, 2015).

This is in spite of research which shows that active involvement of the target population is one of the conditions for the development of effective health promotion or education programmes (Bartholomew Eldredge, Markham, Ruiter, Fernandez, Kok & Parcel, 2016). An example of research involving people with an intellectual disability is the study of Frawley and Bigby (2014).

3.1.2.3 Aim and research questions

The complexities surrounding sexuality and sex education, alongside issues regarding sexual rights, suggest that sexuality is an important issue for people with ID, and should, as such be addressed in ISP documents. Furthermore, Dutch policy requires sexuality to be addressed in ISP documents (Herps, Buntinx & Curfs, 2016).

In line with this, the aim of the present study is to understand to what extent sexuality, sexual health and sexual rights are mentioned in such documents. The study has an exploratory and descriptive design. The research questions are outlined below:

1. To what extent are “sexual health” and “sexual rights” mentioned in the ISP documents of people with ID?
2. When references are made to sexuality in ISP documents, what subjects or issues are covered?
3. How is support provided to people with ID with regard to aspects related to sexual health and sexual rights described in terms of individual support goals?

3.2 Methods

3.2.1 Procedure

For the purpose of this study, we used data that were collected by Herps et al. (2016). From the original sample of eight organisations, data of one organisation could not be used because the authors could not consult the full ISP document but rather only an excerpt of individual goals and resources as described in those excerpts. This resulted in a sample of 187 ISP documents of people with ID from seven service providers in the Netherlands. These organisations all provide residential support to people with intellectual disabilities and are located in the north (n=2), the middle (n=1) and south (n=4) of the Netherlands. Two organisations provide residential support to more than 2.000 people with ID, four provide between 1.000 and 2.000 people with ID support and one organization provides less than 1.000 people support.

The ISP documents constituted a total of 3,444 pages with individual ISP documents ranging between 4 and 76 pages; *M* = 18.42; *SD* = 9.88). The ISP documents belonged to 95 men with ID and 92 women with ID, aged between 20 and 83 years (*M* = 43.14; *SD* = 13.97). Table 1 shows the demographic characteristics of the present sample. Information regarding the degree of the disabilities was either found in the ISP document or, when the information was not found in the ISP document, was provided by the organization.

3.2.2 Analysis

Content analysis was completed on all 187 ISP documents. The definitions of sexual rights were used to develop search terms (see Appendix A). The search terms were developed through content analysis by two researchers to ensure inter-coder reliability. A lexical search using these search terms was carried out on all ISP documents using the qualitative data software programme MaxQDA. The lexical search identified paragraphs in which at least one of the search terms was present.

Table 1 Level of ID and age of people in the ISP sample

Level ID Age	Mild (%)	Moderate (%)	Severe (%)	Profound ID	Unknown (%)	Total%
20-34	25 (13.4)	13 (7,0)	12 (6.4)	3 (1,6)	2 (1.1)	55 (29.4)
35-49	16 (8.6)	25 (13,4)	18 (9.6)	9 (4,8)	3 (1.6)	71 (38.0)
50+	11 (5.9)	20 (10,7)	18 (9.6)	8 (4,3)	4 (2.1)	61 (32.6)
Total	*52 (27.8)*	*58 (31,0)*	*48 (25.7)*	20 (10,7)	*9 (4.8)*	*187 (100)*

The lexical search resulted in 6,185 segments being identified, of which 270 segments were found to be relevant in the context of the research questions. Selection of relevance was assessed by carefully reading the segment, determining if it was related to the research questions, and then coding it using a codebook. For example, 3,979 segments were found in the lexical search for “relations”. Many segments in which this term was found were, however, not related to sexual relations, but rather referred to interpersonal relationships with, for example, family or friends. Search terms that included “education”, “privacy” and “rights” led to segments being identified that were unrelated to the topic of this study. These segments were not relevant in the context of our research questions and therefore not included in the analysis.

We identified eight themes on which segments were coded. These themes were: sexuality; sexual health; information and sexual education; developing and maintaining relationships; physical contact; parenting or the desire to be a parent; privacy; and joining an advocacy group related to sexuality. The relevant segments were then independently coded on these themes by two researchers with an agreement rate of 99%. The researchers discussed any differences until consensus was reached. By using a structured coding system, all paragraphs were coded. our analyses are shown in Table 2.

Finally, any goals that were found in ISP documents (Herps, Buntinx, Schalock, Breukelen, & Curfs, 2016) were read and coded as to whether they were related to the topic of the present study or not.

3.3 Results

3.3.1 Relevant segments in ISP documents

Relevant segments were found in 85.0% (N = 159) of the ISP documents. In 77 ISP documents, segments related to one topic/domain/search term were found; in 54 ISP documents we found segments on two search topics; in 27 ISP documents we found segments related to three different search topics; and in 15 ISP documents we found segments related to four different search topics.

Table 2 Quantitative results of the original lexical search

	Results 187 ISP documents		Relevant segments	
Themes	ISP documents (%)	Hits (*n*)	ISP documents (%)	*n*
Sexuality	92 (49.19)	236	56 (29.95)	87
Sexual health	116 (63.04)	761	31 (16.58)	53
Information and sexual education	15 (8.02)	17	4 (2.14)	4
Developing and maintaining relationships	184 (98.39)	3,979	20 (10.70)	64
Physical contact	111 (59.36)	404	18 (9.63)	23
Parenting/ desire to be a parent	115 (61.49)	321	27 (14.44)	36
Privacy	55 (29.41)	86	3 (1.60)	3
Joining advocacy groups	101 (54.01)	381	0	0
Total	*789 (422.91)*	*6,185*	*159 (84.61)*	*270*

3.3.2 Content and nature of references to sexuality in ISP documents

Table 3 presents the eight themes that we found, relating to demographic information of the people with ID whose files contained information related to these themes (age, gender and level of ID). The most striking findings regarding the eight themes are described below.

Table 3 Information of the people with ID and the domains

		Gender		Age		Level of intellectual functioning				
Themes	*n*	Male	Female	*M*	*SD*	Mild	Moderate	Severe	Profound	Unknown
Sexuality	56	29	27	42.39	12.80	11	21	18	3	3
Sexual health	31	2	29	39.87	13.24	11	12	3	5	0
Information/Education	4	3	1	39.50	12.42	1	2	0	0	1
Developing and maintaining relationships	20	7	13	43.40	13.90	12	8	0	0	0
Physical contact	18	10	8	42.38	14.10	2	0	7	9	0
Parenting/ desire to be a parent	27	8	19	43.74	15.19	11	10	4	2	0
Privacy	3	1	2	49.69	12.04	0	2	1	0	0
Joining advocacy groups	0	0	0	0	0	0	0	0	0	0

3.3.3 Sexuality

We describe the following aspects regarding sexuality: (non)sexual behaviour (a description of behaviour of the individual with ID that may look sexual, but is interpreted as non-sexual behaviour); sexual preferences. We also describe findings that indicate that the individual has been sexually abused. We found these results in 56 ISP documents.

(Non)sexual behaviour

Eight ISP documents described how the individual expresses his or her sexual needs (in some documents we found information about more than one expression); masturbation was found in six (3.21%) ISP documents; the use of specialised sexual service provision in one ISP document (0.53%); and the use of porn and chat rooms in three ISP documents (1.60%). One ISP document described that the person had used an alternative dating service but that this has not been followed-up as his parents and group home could not agree upon it. It did not state how the person is expressing his sexual needs instead.

Furthermore, several findings relate to a description of behaviour of the individual with ID that may look sexual, but is interpreted as non-sexual behaviour. See for example these two quotes:

> The individual is aware of her body. She is not sexually active. She does like to be touched and tickled, but this carries no sexual meaning for her. (Woman, 45 years old, profound ID)
>
> He has a girlfriend in his group home. This is expressed in holding hands and often sitting together. He likes to cuddle; this is not something sexual for him but rather has to do with attention and attachment. (Man, 52 years old, moderate ID)

In 13 ISP documents (6.95%), reference was found to the individual showing inappropriate or inhibited sexual behaviour. In three cases, this behaviour was linked to the individual having been sexually abused. Yet none of these ISP documents contained information about treatment or support regarding these issues, nor was there any reference to other (professional) treatment plans.

Sexual preferences

With regard to sexual diversity, two ISP documents (1.06%) noted that the individual concerned has interest in a partner of the same sex.

Sexual abuse

In 12 ISP documents (6.24%), reference was made to sexual abuse of the individual. Four ISP documents disclosed that sexual abuse of the individual had led to trauma. In two ISP documents, treatment of this trauma was mentioned.

> Individual has had Psychomotor Therapy in 2006 and 2007. The reason for this was a posttraumatic stress disorder stemming from alleged sexual abuse. She shows signs of impulse control disorder. (Woman, 46 years, level of ID unknown)

3.3.4 Sexual health

Sexual health refers to the (access to and use of) contraceptives. Table 3 shows that results were mostly found in ISP documents of women. In most instances, contraceptives were used as a remedy for premenstrual syndrome or problem behaviour during menstruation. In one ISP document it was made explicit that contraceptives were used to prevent pregnancy. In six ISP documents it was reported that the person had been sterilised.

> She occasionally fainted (see: Medical). She has had abdominal pains for a longer period of time. She has been examined, but no clear answers emerged. She kept complaining about abdominal pains, leading to adjustments in her medication and for quite a long time she used Provera. When she kept complaining about abdominal pains, she got some extra Naproxen. Finally, the gynecologist decided with her parents to operate and remove her uterus. This has been successful, she no longer menstruates and so does not suffer from abdominal pains. (Woman, 34 years old, moderate ID)

3.3.5 Information and sexual education

A reference to sexual education or information was found in four ISP documents (2.14%). These were mostly statements of whether or not the person had been educated sexually, but most of these ISP documents (three) did not explain how this is relevant in current support provision or how follow-up is provided. For example:

> He has had sexual education at school. He is interested in the other sex, age accordingly. (Man, 20 years old, level of ID unknown)

3.3.6 Developing and maintaining relationships

Table 3 shows that we found segments of developing and maintaining relationships in 20 ISP documents. This could be that the person with ID has expressed that he or she wants to have a boy- or girlfriend or that the person has a boy- or girlfriend. Two ISP documents reported that a legal commitment had been made. In four ISP documents it wasn’t clear whether the boy- or girlfriend was a regular friend or a sexual partner. The ISP documents did not state how people with ID are supported in their relationship: they describe that the person is in a relationship and how it is expressed (e.g. by holding hands or seeing each other weekly), and only in 5 ISP documents we found minimal information about the support that is given.

> She has been in a relationship since 2003. This is a friendly relationship and sometimes they kiss. Her boyfriend is often at her flat, he often cleans it for her. (Woman, 63 years old, mild ID)

The lack of a description of support is also found in ISP documents in which the person with ID is described to be "vulnerable" in social contacts or when he or she is in a relationship but is experiencing difficulties in this area. Most ISP documents describe this risk or problem, but do not provide an account of how support is then being provided.

> He is regarded as vulnerable and easily influenced. He easily feels pressured by others and has the need to prove himself. There is a risk that he is overburdened by his environment. (Man, 26 years old, mild ID)
>
> …when they see each other and sleep together but also when they take time to do things for themselves. He finds it difficult to give his girlfriend space if she - for example - wants to go out with a friend or family member. (Man, 36 years old, level of ID unknown)

This description of the risk or problem is also found with respect to the wishes of individuals, with the exception of four ISP documents, in which a support goal was described in the area of finding a girlfriend.

3.3.7 Physical contact

Table 3 shows that information regarding physical contact is mostly found in ISP documents of people with severe or profound ID. It then often relates to how the individual responds to physical contact such as cuddling or during physical care. The reaction to physical contact can be interpreted as a means of making contact with others, as this citation illustrates: "Person likes to cuddle with staff" (Woman, 47 years old, severe ID), but it can also be an expression of affection and sexual feelings.

> He sometimes likes to have contact with other residents. He can laugh at what is happening around him, but he also seeks physical contact (with his hand) with other residents. Residents respond in different ways, depending on the moment and the person. Some people like it, and keep the physical contact, other people pull their hand back. (Man, 21 years old, severe ID)
>
> He doesn't like it when you touch him a lot, for example when getting dressed and shaved. He lets you know by whining and grabbing you. (Man, 47 years old, severe ID)

3.3.8 Parenting or the desire to be a parent

As is shown in table 3, in 27 ISP documents we found information related to “children”, mostly of women with mild to moderate ID. In two cases (1.07%), it was reported that the person with ID has or had children. In one case the ISP only reported that there were two children and one child died. The only information given about this child is that it lives “abroad”. In the other case the ISP reported that the person with ID is mother of seven children. She sees them every two weeks. All her children have an intellectual disability and live with a foster family or in an institution.

Often, it is stated in more general terms that the person is aware of his or her disability and how this influences his or her life.

> He thinks about it sometimes, what if he didn’t have this disability. How would his life be? Would he be married and have children? (Man, 46 years old, mild ID)

One ISP document stated explicitly that the person with ID wants to be a parent and is frustrated that she is not.

> She likes her brother’s children, but at the same time experiences the frustrations of not being able to raise children herself. (Woman, 36 years old, mild ID)

In one ISP document (0.53%) it was made clear that the individual *does not* want to get married or have children:

> She has a boyfriend. They give each other kisses, but there is no sexual relationship. If her boyfriend talks about marriage or children, she says she does not want that. (Woman, 63 years old, mild ID)

3.3.9 Privacy

Three ISP documents (1.60%) provided information on privacy in relation to sexuality.

> She does not talk about sexual feelings, she finds this private. She does however talk and giggle about cuddling and kissing with X. (Woman, 64 years old, moderate ID)

> He needs guidance in order to respect the privacy of others. It has happened that the privacy of other group members was violated. This was caused by his disability and/or sexual needs. (Man, 42 years old, severe ID)

3.3.10 Joining an advocacy group regarding sexual rights

No segments were found regarding the wish to meet up or join an interest or advocacy group regarding sexual rights. In 30 ISP documents (16.04%), all from one service provider organisation, a standard reference was made: “She/he can not stand for her/his own rights and interests”.

3.3.11 Provision of professional support

As is described throughout the results, little information about the attitude of staff and the use of sexual education, treatment or other support strategies was found in the ISP documents. In only eight ISP documents (4.28%), was the attitude of staff with regard to sexuality described. Reference to the use of interventions or programmes regarding sexuality was not found in any of the ISP documents.

> She can "test" new people to see how they react. For example, taking her shirt off in a public area. This rarely happens now. She does say things like: "I wet my pants" or "I don't feel so good" (when this is not true). Respond casually on this, change the subject or ignore it. That is the best way to deal with it. If you stick to this for a few weeks, this behaviour will fade away. (Woman, 27 years old, mild ID)

> In working with her you need to take into account that she has had bad experiences with men. It is therefore inappropriate for a male to provide support in this area. In supporting her, you should also take her vulnerability into account. Support staff should listen to her talking about her relationship and the feelings she has about this. Support staff need to help her in realizing her dream of living together with someone. It is important to keep the relationship with her father and family a subject of conversation. (Woman, 43 years old, mild ID)

Support goals describe the areas in which and the way in which support is provided. A total of 475 goals were found in the 187 ISP documents. Four of these goals (0.84%) concerned sexuality or (intimate) relationships, see for example this goal:

> I want to build my relationship with S. I want to explore the possibilities of getting married or living together. I need support to stand up for myself and make my own choices (in my relationship). (Man, 56 years old, mild ID)

3.4 Discussion

In this study, we examined ISP documents of people with ID using residential support services in the Netherlands. We were interested in the extent to which "sexual health" and "sexual rights" were mentioned in ISP documents; what subjects or issues regarding sexuality were covered; and how support is being provided to people with ID regarding aspects related to sexual health and sexual rights. To our knowledge, no such study has been carried out before.

With respect to the extent to which sexual health and sexual rights were found in ISP documents, we found that 85% of the ISP documents provided information in this area. This high number may be the result from Dutch policy requiring that sexuality is addressed in ISP documents (Herps, Buntinx & Curfs, 2016).

Most often, information in the ISP documents regarding sexuality-related topics were sexuality (sexual or non-sexual behaviour, sexual abuse, sexual preferences), sexual health, and parenting / desire to be a parent. This concerns a limited number of parts of the overall concept of sexuality.

In ISP documents, there should be congruence between the individual’s support needs and the support agreements and goals that are set (Thompson et al., 2009). The third research question concerned how support is being provided on sexual health and sexual rights. The results of the present study show that there is a large discrepancy between the amount of information that describes aspects of sexuality of individuals with ID, and the amount of support strategies, agreements or goals in this area. We found little references to counselling, or indications for support provision in instances of negative sexual experience or abuse (Abbott & Howarth, 2005; Hollomotz, 2008). Furthermore, little reference was made to the use of sex education programmes or other interventions related to sexuality and relationships (Löfgren-Mårtenson, 2012; Schaafsma et al., 2013, 2015).

There are several possible explanations for the lack of support goals or strategies regarding sexuality being found in the ISP documents. First, it is possible that the individual with ID or their relatives do not want this to be written in the ISP document. Herps et al. (2013) reported that people with ID prefer negative life experiences not to be included in the ISP document. However, this does not fully explain the high number of ISP documents that did describe aspects related to sexuality but did not include an account of support in this area. Another possibility is that more information can be found in individual treatment plans or medical files, for example when sexual abuse has led to trauma, or with regard to the motivation for using contraceptives or performing sterilisation. Though we did not find reference to such files, this does not mean that they do not exist. Third, previous research has shown that support staff can feel inhibited in talking about this subject (Abbott & Howarth, 2007; Richards et al. 2009) and that family members and other support providers set different norms for themselves (or other people without disabilities) than for people with ID (Christian, Stinson & Dotson, 2002; Yool, Langdon & Garner, 2003; Swango-Wilson, 2008). The results of our study show that sexuality is being talked about, but it may well be that staff feels inhibited in making agreements about supporting the individual in this area or that differences in opinions and attitudes is reflected in the absence of specific support agreements (Christian, Stinson & Dotson, 2002; Yool, Langdon, & Garner, 2003; Swango-Wilson, 2008; Schaafsma et al., 2013, 2014, 2015). A lack of support agreements in the area of sexuality may result in people with ID not being able to exercise their sexual rights, to satisfy their needs or for them to feel less able to talk about it.

It is important to note, when interpreting the results of this study, that a lack of information regarding sexuality in the ISP documents does not necessarily reflect a lack of support with respect to sexuality in daily practice. Paper plans do not necessarily reflect the individual’s life in the fullest, and previous studies indicate that developing ISP documents can be a rather bureaucratic exercise, which is done simply because it is required (Mansell & Beadle-Brown, 2004; Osgood, 2005; Herps et al., 2016).

3.4.1 Implications for providing professional support

The results of our study have at least three important implications for providing professional support to people with ID in relation to sexuality. First, sexuality, sexual health and sexual rights are important subjects to talk about with people with ID. It should be part of the support needs assessment that addresses the individual's needs and wishes (Thompson et al., 2009; Schaafsma et al., 2017). Second, talking about sexuality, specifically with people with ID, is not easy for many people (Abbott & Howarth, 2007; Stoffelen et al., 2013; Schaafsma et al., 2017; Richards et al., 2009). Not only the individual support staff should be provided with support to talk about sexuality and other sensitive topics with people with ID, their relatives and their colleagues. The whole system (government, schools, agencies, advocacy groups, families) should be set up to create respect and recognition of rights for the sexuality of people with an intellectual disability (Richards et al., 2009). Third, sexuality is a subject that needs more attention. Individuals with ID, their relatives, and staff need to be given guidance on how to address this subject in a respectful manner: by talking about it in a way that takes into account the vulnerability and sensitivity of the individuals involved, by increasing knowledge about the topic, and by increasing the support available in this area. Furthermore, the wishes of people with ID should determine the strategy of support. The search for the cause and meaning of behaviour, must be leading for professional support providers. And assuming that every human being is a sexual being, professional support providers need to be more sensitive about behaviour, whether or not it is sexual. An open mind is required instead of acting from their own standards and values.

Finally, we endorse the view of Richards et al. (2009). They advocate a holistic approach "in which all systems and supports work cohesively, simultaneously, seamlessly, and in harmony to ensure that persons with developmental disability achieve equality in sexual rights" (Richards et al, 2009, p. 210).

3.4.2 Strengths and limitations of the present study

When interpreting the results, the following strengths and limitations should be considered. A relative strength of the present study is the number of ISP documents we analysed and the fact that these were sourced from different service provider organisations. In the Netherlands, every service provider organisation develops and implements their own ISP procedures and forms. When the protocol of the ISP document does not mention the topic "sexuality", the chances are that it gets forgotten or ignored. By including different organisations in this study, we incorporated different kinds of forms, and, in doing so, reduced the chance of potential biases influencing the data.

There are also several limitations in this study. First, we used only one source in this study: ISP documents. The results raise different questions which could have been answered if other sources were used, e.g. interviews with people with ID, their family and staff. The use of other sources such as medical documents can also provide more information. This would be interesting for further research.

This is the first article that looked into how sexuality is described in ISP documents. The study was exploratory and as such, did not focus on finding differences between groups within this set of data. However, further research could be done to explore the results in more depth by examining differences in gender, age and level of ID.

As described above, future research that involves multiple sources and analysis of differences between groups could be done to get a better understanding of sexuality in ISP documents. Furthermore, international comparison is recommended. It contributes to a better understanding of sexuality of people with ID and their quality of live, to compare how sexual health and sexual rights are addressed in ISP in other countries. And finally, it would be interesting to investigate the whole system of government, schools, agencies, advocacy groups, families, and their vision, role and opportunities on sexuality of people with an intellectual disability.

3.4.3 Recommendations

The ISP document should be a document that can be used as a practical guide to put into practice the wishes and preferences of individuals with ID, also in relation to sexual health. It's important to talk to people with ID and taking their views seriously to find out what place and value sexuality has in their lives, what specific support they need and wish for, and to practice the concept of shared decision-making. As such, we recommend the use of clear language and the setting out of realistic and achievable goals, alongside a description of the type of support needed and how this should be achieved. Because the ISP is person-centered, the person with ID and people important to him or her, should be involved in decision making. The whole ISP document should reflect that serious consideration has been given to sexuality –including different aspects of sexual rights, the need for proactive sex education, and how goals related to this can be implemented.

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Appendix A. Search terms based on three definitions of sexual rights (table 1)

Common subjects in the three documents on sexual rights (table 1)	Search terms related to*	Search terms*
The right to life	Safety	seks*, sex*
The right to equality, be free of discrimination	Sexual freedom, homosexuality, sexual diversity	seks*, sex*
The right to sexual health care	sexual health; treatment; contraceptives.	voorbehoed*, pil, condoom*, sterilisatie, spiraal* *(contraceptive, contraceptive pill, condom, sterilization, contraceptive coil)*
The right to information and education	Sexual information; education; training	voorlichting, educatie (*information, education)*
The right to bodily integrity	Touching; stroking; setting boundaries	lichaam*, aanraken (*body, contact*)
The right to choose their partner, to choose whether or not to marry (based on equality and consensual)	Partner; boyfriend/girlfriend; dating; relationship; marriage; friend.	vriend*, partner, man, vrouw, verkering, relatie, trouwen *(friend, partner, man, woman, engagement, relation, marriage)*
The right to privacy	Privacy	priv*
The right to be sexually active or not	Sexually active	seks*, sex*
The right to decide whether or not, and when, to have children	Children	kind* (*child*)
The right to pursue a satisfying, safe and pleasurable sexual life	Sexual satisfied, safe sex and sexual pleasure,	seks*, sex*
The right to the freedom of thoughts, opinions, and expression	Sexual fantasies, sexual desires, sexual expression	seks*, sex*
The right to enjoy the benefits of scientific progress and its application	Sexual research	seks*, sex*
The right to be free from torture, violence and coercion	Sexual abuse, sexual violence, sexual coercion	seks*, sex*
The right to freedom of assembly and political participation	Advocacy group	belangen* (*interests)*
The right to access to justice, remedies and redress	Sexual abuse, declaration	seks*, sex*

*The terms that were used were the Dutch words and synonyms.

Chapter 4

Views on sex

Using the Nominal Group Technique to study the conceptions on sexuality and sexual rights of people with mild intellectual disabilities. An example of an inclusive research design.

Stoffelen, J.M.T., Schaafsma, D., Kok, G., & Curfs, L.M.G. (submitted).
Views on sex. Using the Nominal Group Technique to study the conceptions on sexuality and sexual rights of people with mild intellectual disabilities.
An example of an inclusive research design.

Abstract

Aim In the area of sexuality, people with intellectual disabilities have an important contribution to make; the importance of listening to their stories cannot be underestimated. This study describes the ideas and experiences regarding sexuality of people with intellectual disabilities and their sexual rights, using the Nominal Group Technique (NGT).

Methods The NGT was used to explore the views of people with mild intellectual disabilities on sexual needs and issues. NGT is a structured and specific form of focus group research. It is a “single-question” technique that combines quantitative and qualitative methods of data collection for relatively small groups. NGT involves four steps: silent generation of ideas, round robin recording of ideas, clarification of ideas and ranking of ideas. It was an inclusive research project: people with an intellectual disability were involved in the design, planning, performance, and analysis of the study.

Findings In total 39 people with mild intellectual disabilities were able to explore their experiences and ideas on sexuality. They were able to answer questions like: What are their needs? What are their problems? They were capable of expressing their views, needs and barriers on sexuality and sexual rights. The most important items for them were the relationship between two people (47%), sex and sex related subjects as sex education (23%), and feeling safe and comfortable (10%).

Conclusion People with mild intellectual disabilities are capable of expressing their views on sexuality and sexual rights. The participants stated that they need support in achieving these rights. The NGT appears to be an appropriate methodology on sensitive issues as sexuality and sexual rights.

4.1 Introduction

4.1.1 Human rights

People with intellectual disabilities (IDs) have human rights (Stainton & Clare, 2012), they also have sexual rights. According to the American Association on Intellectual and Developmental Disabilities, *"*These sexual rights and needs must be affirmed, defended, and respected" (in '*Position Statement Sexuality'* AAIDD, 2008). People with mild intellectual disabilities have the right to make independent decisions about with whom, how and when they want to have sex. In this respect, they have the right to dignity, respect, privacy, confidentiality and freedom. People have the right to education, information and protection, and the right to have children and to make decisions about contraception. But how do they experience these rights in their daily lives? Are they capable of realizing these rights?

4.1.2 Sexual rights in practice

The World Association for Sexual Health (WAS) designed *The Millennium Development Goals* (2008). Promoting sexual health is a key role because "Individuals and communities who experience sexual wellbeing are better positioned to contribute to be eradication of individual and societal poverty"*.* The WAS declared sexual rights from the point of view that *"*sexuality is an integral part of the personality of every human being.*"* Watson, Venema, Molloy and Reich (2002) analysed sexual rights in relation to people with an ID. Based on a literature review, they came to the conclusion that these rights have not been fully acknowledged or confirmed. People with an ID do not receive the respect or the support they require. Hollomotz (2008) studied the right to privacy for people with an ID in a residential setting, and concluded that this right is poorly acknowledged. Overprotection, segregation and a lack of skills among the residents themselves make these people especially vulnerable to sexual abuse (Hollomotz, 2011). For people with an ID, sexual abuse remains a serious problem (Abbott & Howarth, 2005; Eastgate, Van Driel, Lennox & Scheermeyer, 2011; Hickson, Khemka, Golden, Chatzistyli, 2008; Reiter, Bryen, & Shachar, 2007; Stoffelen, Kok, Hospers, & Curfs, 2013; Van Berlo et al., 2011). A lack of knowledge about sexuality and sexual rights makes people with an ID especially vulnerable (Murphy & O'Callaghan, 2007; O'Callaghan & Murphy, 2007). Bernert (2011) and McGuire and Bayley (2011) found that people with an ID experience resistance from their immediate surroundings when exercising their sexual rights. Family members and caregivers apply different norms to people with an ID then they do to themselves or to people without a disability (Christian, Stinson, & Dotson, 2002; Swango-Wilson, 2008; Yool, Langdon, & Garner, 2003). Training and support can enable family members and caregivers to talk about the sexuality of people with an ID and to discuss this topic with them (Abbott & Howarth, 2005; Evans, McGuire, Healy, & Carley, 2009; Stoffelen et al., 2013).

People with an ID have indicated the barriers they experience with their sexuality: being unable to talk openly with their parents or caregivers about their sexual relationships, a lack of privacy, overly strict institutional regulations, not having any examples to follow and experiencing inadequate support, no sex education that matches their level, questions and needs (Abbott & Howarth, 2005; Borawska-Charko, Rohleder, & Finlay, 2016; Friedman, Arnold, Owen, & Sandman, 2014; Healy, McGuire, Evans, & Carley, 2009; Schaafsma, Kok, Stoffelen & Curfs, 2017; Stoffelen et al., 2013).

4.1.3 Talking with the people themselves

When studying the sexuality of people with an ID, proxies are often queried instead of the actual subjects. These proxies are often family members, staff from support institutions and caregivers. However, this should be done cautiously. It is difficult to predict the extent to which the responses of the proxies would match the responses of the subjects if they were questioned themselves (Schalock & Felce, 2004). People with an ID are in fact fully capable of discussing their views and experiences on “difficult” topics (Goodley, 2005; Schoeters et al., 2005; Tuffrey-Wijne, 2007, 2012; Tuffrey & Davies, 2006; Tuffrey-Wijne, Bernal, Butler, Hollins, & Curfs, 2007). They are also capable of discussing the research itself with the researchers (McDonald & Kidney, 2012; Walmsley & Johnson, 2003). More research about sexuality is needed in which people with an ID are questioned directly, not through their proxies. To support these people effectively, knowledge about their needs and wishes regarding sexuality is essential (Galea, Butler, Iancono, & Leigthon, 2004; McCarthy, 2001).

4.1.4 Inclusive research

Participative research with people with an ID, is a new step to achieve empowerment of people with intellectual disabilities. Walmsley and Johnson (2003) refer to the history in which people with intellectual disabilities were seen as people who “had nothing to say that was of value to researchers” and were “passive beneficiaries”. They refer to Atkinson and Williams (1990) and their publication which represent the voices of people with intellectual disabilities. More than 200 people with an ID talked about their experiences and their stories through drawings, poems, and other contributions. This caused a “paradigm shift”. Since then, people with intellectual disabilities are involved in scientific research. Unfortunately, inclusive research on sex is scarce. They examined with people with an ID the societal barriers that lead to safer sexual lives.

4.1.5 A method: The Nominal Group Technique

One method that can be used to study the opinions of people with an ID is the Nominal Group Technique (NGT). Previous research (Friedman et al., 2014; Tuffrey-Wijne et al., 2007; Roeden, Maaskant & Curfs, 2011) has shown that NGT is an effective and acceptable method for determining and collecting the ideas and standpoints of people with an ID. NGT is a structured and specific form of focus group research; it was first used at the end of the 1960s and was developed further by Van de Ven and Delbecq in 1972. These authors advocate this method when researchers want to determine the views of "users" themselves in their own language, where the influence of the researcher is minimised. The method is also suitable to use in determining the consensus in groups where the members are not of equal standing or have a relationship of authority, and in groups where participants find it difficult to express their individual views or are incapable of doing so (Porter, 2012, 2013; Stewart, Shamdasani & Rook, 2007). The method is widely used in health-care studies; see Harvey and Holmes (2012) for a review of the relevant literature. NGT is a "single-question" technique that combines quantitative and qualitative methods of data collection for relatively small groups (Moore, 1987) and has a number of basic steps: (1) Generating individual ideas; (2) Collecting the ideas; (3) Presenting and clarifying the ideas; and (4) Selecting and ranking the ideas.

4.1.6 Aim

In this study, a structured method (NGT) was used to hold discussions with people with an ID. Our aim was to acquire insight into what people in the target group believe is important with respect to sexuality and their sexual rights. We addressed the following research question: What do people with a mild ID believe is important with respect to their sexual rights? We wanted to know how they experience their sexual rights in their daily lives. What are their wishes? What are their constraints? What kind of support do they need?

4.2 Method

The study design describes the research set-up, the membership of the advisory group, the components of the study with which the advisory members were involved, how the participants were recruited and how they were informed about the study. In addition, attention is paid to the methodology, ethics and the analysis.

4.2.1 Advisory group

An advisory group was established for this study. This group consisted of four participants from LFB Zuidoost (a Self-Advocacy Group in the Netherlands) and their coaches. Their involvement in the study included a number of elements and tasks: involved and providing advice on the research design, the story line, the drawings; supporting group meetings; collaborating on the "interim step" of the NGT method; devising a follow-up and the analysis. The collaboration on the "interim step" of the NGT method consisted of selecting ideas from each group and preparing a voting form. The co-researchers were guarding the principles of inclusive research: the issue must matter to people with an ID; the research must represent their views and experiences; people were treated with respect by the researchers (Walmsley & Jonhnson, 2003).

4.2.2 Participants

In total, 39 people participated in the study, which included 14 women and 25 men. The average age was 44 years (with a range from 23 to 70 years). Researchers did not inquire after the level of social, emotional of intellectual function, nor the ethnicity of the participants. The participants in the research project were recruited from the Onderling Sterk groups in the Netherlands. Onderling Sterk groups are self-advocacy groups. There are no criteria for participation in these groups. The majority of people who join the Onderling Sterk groups function at the level of mild ID.

The participants were divided into six groups, all of whom signed a statement of consent. The NGT method consists two group meetings. Some participants attended the first group meeting, but not the second one, and vice versa. In total, 35 participants attended the first meeting and 39 participants attended the second meeting. The meetings were facilitated by coaches and members of the advisory group. Between the two meetings, the researchers and members of the advisory group met six times, see “4.2.5.2 Between the meetings”.

4.2.3 Informed consent

The staff of LFB Zuidoost had contact with the groups beforehand; the participants were informed about the study verbally. In addition, they received an informational folder about the study in advance. The dates for the two meetings were coordinated in mutual consultation. As a result, people who were not interested in the study were given the opportunity to indicate this and were not present on the planned dates. At the beginning of each meeting, the participants were informed about the aim, the rules and procedures with the aid of a PowerPoint presentation. In this way, the participants were informed multiple times about the study. The informed consent procedure was based on a procedure developed by Thomas and Kroes (2005), see also Schaafsma et al. (2017). Topics in this procedure were: goal of the meetings, confidentially, voluntariness, support. All participants signed a statement of consent. Following the two meetings, all participants received a certificate of participation and a report on the method and the outcomes of the meetings in which they had participated.

4.2.4 Ethics

The study was presented to and received the approval of the Ethics Review Committee of the Faculty of Psychology and Neuroscience, Maastricht University. To support the participants, a qualified and experienced confidential counsellor was available. However, none of the participants made use of this option.

4.2.5 Nominal group technique

To introduce the topic and the research question to the participants, an illustrated storyline was used. As a result, the research question was placed in a context and should be better understandable by the participants (Van Veen, 2011). The storyline was devised together with the advisory group, and an artist was commissioned to make the necessary drawings. The storyline consisted of eight drawings which told the story of Sanne and Tom, occasionally supported with a few words such as “in love”, “together”, and “dreams”. With the final drawing, the research question was presented to the participants: “What do Sanne and Tom need?”

4.2.5.1 First meeting

Step 0: Introduction

At the beginning of every meeting, the participants were welcomed and informed about the aim of the research and the method used. After this, the storyline was shown and the research question was presented.

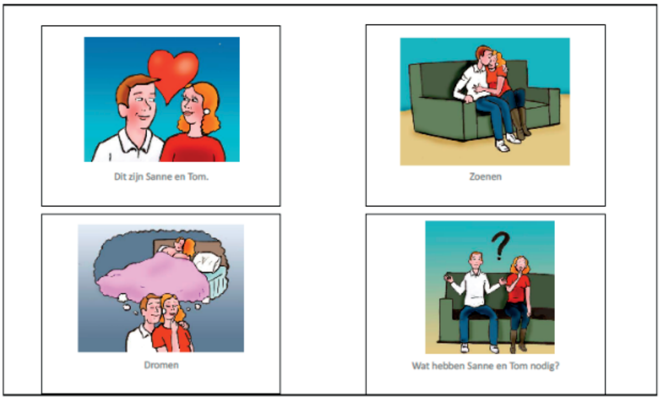

Figure 1 Examples of drawings of the storyline

Step 1: Generating individual ideas

The participants were invited to write down their individual ideas and experiences in silence. It was emphasised that all ideas and experiences are good and no limitation was placed on the number of ideas. A few participants were unable to write or could only write with difficulty and were aided in noting down their ideas by the coaches or members of the advisory group. The facilitators could encourage the participants, but could not make any suggestions. As a result, bias due to the influence of third parties was reduced as much as possible.

Step 2: Collecting the ideas

All ideas were collected and compiled on a flip chart. The participants, or one of the facilitators, read the ideas aloud. There was room for the addition of new ideas, and these were also collected. No opportunity to discuss the ideas was provided at this time; the aim was just to collect as many ideas and experiences as possible.

Step 3: Presenting the ideas

The participants read their ideas on the flip chart out loud. The other participants could ask for clarification. The purpose of this step was to make sure the idea was clear to everyone. For example, one of the participants had written “talk about it”. Following clarification, it became clear that idea was to “talk about what's on your mind with a caregiver”. Another participant wrote: “don't sleep with each other right away”. After discussing this idea, it turned out that the idea was to: “not sleep with each other right away, but date each other for a while first and get to know each other”.

4.2.5.2 Between the meetings

Between the two meetings, the researchers and members of the advisory group met. The flip charts with all the ideas and additions were compiled into a single list. Difficult words were converted into easily understandable language. This resulted in a group list of ideas of each group.

4.2.5.3 Second meeting

Step 4: Selecting and ranking the ideas

At the beginning of the second meeting, all participants were again informed about the aim and method used, and about the storyline of Sanne and Tom and the “single question”: “What do Sanne and Tom need?” Participants received the group list of ideas on a large sheet of paper, which was then discussed by the entire group. The participants received a pen and a pair of scissors and were asked to cut out the five ideas which they thought were the most important. During the first two group meetings, the participants received all group ideas on separate cards (see Roeden et al., 2011, and Truffrey et al., 2007). However, the participants were overwhelmed by the amount of cards, so this aspect of the method was changed. Providing a single sheet of ideas which they could cross out or cut out enabled them to have a better overview.

The participants were invited to evaluate these five most important ideas by rating them from 1 to 5. Five points for the most valuable idea, and one point for the least important idea. For this purpose, five voting boxes were made in declining sizes, where the largest voting box displayed the numeral 5, and the smallest displayed the numeral 1. ”This is just like Eurovision Song Contest”′ said one of the participants. After the voting, the voting boxes were opened, the votes were counted and written on the flip chart. It became clear to all participants which ideas they found important and valued most highly as a group. This was discussed by the entire group.

4.2.6 Analysis

All the participants' ideas were collected per group and compiled into a single summary list; the group list. The participants ranked the five best ideas by assigning a ranking of 1 to 5 for each idea. This resulted in a group idea score which had received the highest ranking. All the ideas from the group lists and the highest ranked ideas from the individual groups were entered separately and analysed with NVivo8 and discussed with the co-researchers with an ID. In order to compare the value of the ideas of the six groups we calculated the factor of each group. Just because not all groups had an equal number of participants. The outcomes were corrected with this factor. In this way we could calculate the percentages of each idea.

4.3 Results

First, we pay attention to the results of working with the NGT-methodology. Then we pay attention to the content. The 39 participants in the study were capable of expressing their views and answering the question "What do Sanne and Tom need?". Seven participants (of the 39 participants) were aided in noting down their ideas by facilitators. In total 198 ideas were submitted by the participants during session 1. And 140 ideas left to be valued in session 2. A total of 867 points were given to all 140 ideas. The participants were divided into six groups. Each individual listed 3 to 5 ideas on average. When compiling a group list, similar ideas were combined. The six group lists consisted of 15 to 58 ideas each. The outcomes are displayed beside the description of the meeting process.

4.3.1 Working with NGT

The participants used various strategies to answer the question about the needs of Sanne and Tom. Some of them got to work immediately, went off by themselves and wrote down many ideas. Others found it more difficult to write something down; they made contact with others to find out what was meant to be done or to come up with ideas. They were supported by the facilitators who went through the question with them again and encouraged them to formulate their ideas.

The atmosphere was pleasant in all the meetings. During the introduction of the study, there was initially some shyness and joking. When the story of Sanne and Tom was shown, however, many people responded seriously and began to talk spontaneously about their own experiences,

> That also happened to me. I also went for a walk in the park with my girlfriend. (Man, 29 years)

Most participants got to work in a very focused and serious fashion. Some of them also had a need to immediately say aloud what they had written down. Because working in silence was advantageous, they were asked to wait before they told their story. This did not cause any problems. With only a few exceptions, the participants enjoyed presenting their ideas to each other.

They also thought it was exciting to talk in a group about such a sensitive topic.

> This is the first time I have told you about this. My brother knows about it. My caregiver knows about it. And now you know about it too. (Man, 48 years)

Most of the participants responded respectfully to each other's stories and ideas and encouraged each other to describe them clearly, “That's right!”, ”I think you mean…” or ”I always call that …”.

While selecting the five most important ideas, the participants were generally somewhat noisier. They indicated the difficulty in making a choice and the need for time to do so. They thought very seriously about what was really important to them.

> This is hard, but I decided against my “red car of love” after all, even though I really liked it. No... that’s too bad, but that's the way it goes! (Man, 29 years)

The evaluation showed that the participants appreciated the meetings: ”Is it really done? Are you going to come back?” They stated that, at the meetings, they were rather tense initially, “This is something you don't talk easily about”. When the meeting ended, they indicated their satisfaction: “It was fun!” Participants indicated that they appreciated being able to talk seriously about sexuality.

4.3.2 Results NGT meetings

The 39 participants had ideas about what Sanne and Tom needed and discussed these ideas with each other in six groups.

Relationship

The participants gave the highest ranking (47%) to the relationship between two people, for example: “it must come from both sides”, “being happy together”, “accepting each other”, “being together”, “accepting each other as you are”. This high rating means that the participants considered the relationship between two people of great value. Participants told about their experiences with relationships.

> I have been married. But it did not go well anymore. My wife did nothing at all and I had to do everything. After work I had to do all the cooking and cleaning. I got a depression...We divorced... after many years, and after trying everything. (Man, 59 years)

A participant talked about his relationship and the involvement of everyone with this relationship:

> She listens to her family-members. And they don’t like me. We argue about that. I ask her: with whom are you dating? With your family or with me? I have a disability and her family find that difficult. But I am who I am. (Man, 36 years)

Some participants felt sad because of the missed opportunities in their lives.

> I was dating a girl from the laundry. And then my father found out. He said: “She is not the right girl for you.” So, I broke with her. Yes, I did. Otherwise I would have been married now. And perhaps had a couple of children. Sometimes I think back and then I regret. (Man, 56 years).

Sex and sex related issues

In addition, participants indicated that sex and issues related to sex as sex education and lovemaking were important (23%). For example, “kissing”, “sex education”, “embarrassed to talk about it”, “fear of pregnancy”, and “safe sex”.

> I never dared to do anything. I was so afraid to get children. My family has scared me. It's now too late to get children. If I was young, I would not listen anymore to my family. (Woman, 64 years)

> Why aint there a booklet about what's normal and what not?... I didn’t know that sex with my bother wasn’t normal. Later I heard that is not normal. That you don’t do that with your brother. But how could I know?... How it's supposed to be? And how it doesn’t belong. I would like to have that. Then I read about it. And then I know how it should be. How you get children. And all about sex. And what's up with sex. And what you should do and don’t... I would like to know that. And accept your own body. I think that is very important. I'm having trouble with that. I find it difficult. (Woman, 39 years)

Feeling safe and comfortable

A ranking of 10% was given by the participants to feeling safe and comfortable. The ideas they had given were, for example: “having your own room that can be locked”, “not being ashamed of your body”, “indicate boundaries”. Many participants live together with other people with a disability in a group home. Despite the fact that each has its own room, each ones’ privacy is not always respected. Monitoring your privacy becomes even more difficult when it comes to sensitive subjects as relationships, sexuality or using contraceptives. Not all conversations with care staff take place at one's room or at the group office. Group members hear or sometimes know what's going on.

> I talk with care staff at my room. Nowhere else …. (Woman, 36 years)

In their daily lives people with intellectual disabilities are dependent on others, no matter how independent they live.

> We have a bathroom in the hallway. If you go there, go on your bathrobe. A roommate always walks naked through the hallway. And he never locks up the door. I do not like that. (Woman, 41 years)

Participants talked about negative experiences. One participant told about his experience with stalking:

> … My brother has taken action and I never had any more contact with my friend. I was so relieved. I could breathe again. I was so glad I have told my brother. My brother is my best friend. He helps me when I need him! (Man, 48 years)
>
> I think back of the unpleasant things that happened. I had a friend and he wanted me to do things I did not want. I do not really want to remember this. (Women, 34 years)

The participant talked with her coach about it in a separated room. After a while she decided to write her ideas on paper during the first meeting.

Other ideas got a low ranking: ideas about children 5%, family and friends 4%, choosing with whom you live 4%, income and money 4%, and support 3%.

4.4 Discussion

People with an ID are capable of stating what they think is important when it comes to sexuality and their sexual rights. Important aspects for them include the relationship between two people, sex related items as sex education and lovemaking, and feeling safe and comfortable. This corresponds to a number of the sexual rights that have been defined (WHO, 2015), such as the right to a voluntary sexual relationship, the right to bodily integrity, the right to pursue a satisfying, a safe and a pleasurable sex life, the right to choose your own partner, the right to education, information and protection. The outcomes indicate that more values and aspects are important for people with intellectual disabilities: quality of life; empowerment; communication and social skills, a good home. The key issues are not only about the physical aspects of sexuality but also the emotional and psychological aspects and capabilities. It is in line with the plea of Schaafsma et al. (2017) for sex education which includes the improvement of sexually-related skills as well.

The present study confirms that people with an ID are fully capable of discussing their views and experiences on sensitive topics (Goodley, 2005; Schoeters et al., 2005; Tuffrey-Wijne, 2007, 2012; Tuffrey & Davies, 2006, Tuffrey-Wijne et al., 2007). They are also capable of discussing the study itself with the researchers (McDonald & Kidney, 2012; Walmsley & Johnson, 2003). The outcomes of the study conducted by Watson et al.

(2002) – that the sexual rights of people with an ID are not fully acknowledged and confirmed, and that they need support – are consistent with the outcomes of the present study, in which people frequently used terms such as “respect”, “acceptance” and “being honest”. The fact that the realisation of these rights is not naturally and that people experience constraints and concerns is shown through the responses in which terms such as “fear” and “shame” were used. With one of the groups, a follow-up meeting was held during which the participants indicated that they wished to have support from their caregiver or family. Other studies have also shown that people with an ID indicate that they need support when it comes to sexuality (Abbott & Howarth, 2005; Hollomotz, 2011; Schaafsma et al., 2017; Stoffelen et al., 2013). This calls for a support plan that pays attention to sexuality and sexual health (Stoffelen, Herps, Buntinx, Schaafsma, Kok, & Curfs, 2017).

The presentation of the results include data that are not strictly NGT findings (see “Working with NGT”). It provides notion how working with the NGT methodology affects people. The atmosphere, the active method, and telling stories to each other, works inviting for people with intellectual disabilities.

In the present study, the topic of sexual abuse was also addressed. For example, three participants indicated that they had experiences with sexual abuse. Relative to a total of 39 participants, this appears to be a substantially lower rate of sexual abuse than generally indicated by research on this topic (Abbott & Howarth, 2005; Eastgate et al., 2011; Hickson, Khemka, Golden, Chatzistyli, 2008; Reiter et al., 2007; Stoffelen et al., 2013; Van Berlo et al., 2011). A possible reason is that the design of the present study did not focus on sexual abuse. Consequently, these meetings did not lend themselves very well to discussing the specific experiences.

4.4.1 Limitations

The participants were recruited from “self-advocacy groups. These groups were heterogeneous: more men than women; difference in age; difference in verbal abilities. Hollomotz (2011) concluded that these groups contribute to the development of a positive identity and to improving people's self-confidence and assertiveness. The outcomes therefore cannot simply be attributed to the “target group” of all people with an ID. This is not only because this group is extremely heterogeneous, but also because the people who are active in self-advocacy groups are not representative of the general population. People with an impaired functional level who live in an intramural setting are rarely active in such groups.

To determine a valid group consensus and group ideas, a minimum group size is desirable. Stewart et al. (2007) referred to a group size of 8 to 12 individuals in focus groups. Van de Ven and Delbecq (1972) concluded that a group size of 5 to 8 individuals is acceptable with the nominal groups. In the present study, the group size ranged from 3 to

14 individuals. Further research into the ideal size for the specific target group of people with an ID is needed.

Interaction between the participants themselves and with the facilitators in focus groups can have undesirable effects on the outcomes (Stewart et al., 2007). This is why one of the rules of the present study was working in silence. During the first part of the meetings, this aspect was emphasised and the participants worked quietly; during the second part of the meetings, it was sometimes substantially noisier. The participants found it difficult to choose, and apparently needed to make this known to each other and to seek support for their choices. It helped them to talk to each other about these choices.

And finally, there was a difference in literacy skills among the participants. Facilitators helped seven participants (of the 39 participants) to write down their ideas. Despite the instruction to the facilitators to influence people as little as possible, there will be bias.

4.4.2 Conclusion

It is of great importance to understand the views of people with an ID on sexuality and sexual rights. Therefore, it is essential to ask these people directly about their ideas and opinions. All service providers should seek proactively the views of their service users. Only when supporters listen carefully to the wishes and needs of people, they are capable to provide good care. Not just about sexuality but about all sorts of items. Talking seriously with people with intellectual disabilities about life issues, shows engagement.

The present study has shown that they are capable of expressing their views about such a sensitive topic. The nominal group technique appears to be a suitable method for this purpose. People indicate that they need support to realize these rights. More attention should be paid to this aspect in the institutional support plan and the daily support activities. The NGT is suitable for inclusive research with people with an ID.

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Appendix

Table 1 Results of the six groups

Top 3 of the most highly rated ideas from each group (with total score)
Group 1 (4 participants)
1. Living circumstances (11 points)
2. Accept your body (10 points)
3. Living together (9 points)
Group 2 (first meeting, 11 participants; second meeting, 14 participants)
1. Mutual trust (25 points)
2. Respect (23 points)
3. Setting limits (14 points)
Sex (14 points)
Accepting each other as you are (14 points)
Group 3 (first meeting, 4 participants; second meeting, 6 participants)
1. Income (20 points)
2. Mutual trust (13 points)
Being happy together (13 points)
Feelings must come from both sides. Both of you have to want it (13 points)
3. A private home (11 points)
Group 4 (3 participants)
1. No family interference (9 points)
2. Fear of pregnancy (8 points)
3. Your own room that can be locked (5 points)
Embarrassed to talk about it (5 points)
Sex is a big taboo if you are disabled (5 points)
Money and work (5 points)
Group 5 (first meeting, 6 participants; second meeting, 5 participants)
1. Being there for each other in sickness and health (10 points)
2. Loving each other (10 points)
3. Having a good connection with each other (5 points)
Keeping their friends (5 points)
Being honest with each other (5 points)
Understanding each other (5 points)
Contraceptives (5 points)
Time to get to know each other and see if they are compatible (5 points)
Setting limits (5 points)
It has to come from both sides (5 points)
It's about what's inside, not how you look on the outside (5 points)
Being faithful to each other (5 points)
Group 6 (7 participants)
1. It has to come from both sides (20 points)
2. Living together (15 points)
3. Being together (13 points)

Chapter 5

Homosexuality among people with a mild intellectual disability: an explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability

Stoffelen J., Kok G., Hospers H., & Curfs L.M.G. (2013). Homosexuality among people with a mild intellectual disability: an explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability. *Journal of Intellectual Disability Research, 57,* 257-267. doi: 10.1111/j.1365-2788.2011.01532.x

Abstract

Background

Empirical research on homosexuality among people with an intellectual disability (ID) is limited and, to date, very little is known regarding the personal experiences of gay and lesbian people with an ID. This study set out to answer the question: What are the lived experiences of a specific cohort of homosexual people with an intellectual disability living in the Netherlands?

Method To answer this question, a qualitative study was performed in which 21 people with a mild ID were interviewed via semi-structured interviews. In this study, 19 participants were men and two were women (average age = 40.5 years).

Results Participants reported positive and negative experiences, and talked about their gay or lesbian identity. Almost half of the participants (n = 10) reported that they had experienced sexual abuse including partner violence (n = 6). Additionally, they indicated that there was a lack of support for homosexual people with an ID.

Conclusion Specific problems impact the lives of homosexual people with ID, namely the high prevalence of negative sexual experiences, the lack of support, training and sex education, and their search for a suitable partner.

5.1 Introduction

Homosexuality among people with an intellectual disability (ID) is an underexposed topic. Furthermore, most studies among this group are about men and only a few are about lesbians (McCarthy 1996, 2001; Abbott & Burns 2007; Abbott & Howarth 2007; Burns & Davies 2011). Research on sexuality regarding the general population usually suffers from a similar gender bias (Vincke & Woertman 2006). Homosexual people with an ID can be seen as a minority within a minority. Pioneering studies on same-sex relationships of people with ID were conducted by Abbott & Howarth (2005, 2007), Abbott & Burns (2007) and Cambridge (1996).

People with an ID are subjected to stigmatisation (Dijker & Koomen 1996, 2007; Dijker et al. 2000; Finlay & Lyons 1998). As Shakespeare (2006) points out, “Many disabled people are in the community, but are not a part of the community”. A theoretical concept like normalisation is inadequate (Oliver 2009; van Alphen 2011; van Alphen et al. 2011). Oliver (2009) advocates an inclusive society where disabling barriers are eradicated. Sexuality is an important form of intimacy, but friendship and acceptance can be more fundamental than sex for people with disabilities (Shakespeare 2006).

Gay and lesbian people with an ID are often subjected to what is termed “layered stigma”. They are stigmatised not only because they have an ID but also because they are gay or lesbian (Goffman 1963; Meyer 2003; Crocker 2005). Prejudice and discrimination limit their social inclusion and their opportunity for developing friendships (Hall 2010). This is especially true for people who have a severe ID (Hubert 2009). Crocker (2005) distinguishes between visible and concealable stigmas and delineates a number of coping strategies employed by stigmatised individuals such as concealing the stigmatised condition, being vigilant and aware of prejudices, and withdrawing from stigmatising situations.

Meyer (2003), in his “minority stress” model, postulates that a higher prevalence of psychological distress among gay, lesbian and bisexual people is, at least in part, attributable to the fact that they experience “social stressors” related to stigma and prejudice. On the whole, gay, lesbian and bisexual people experience more violence, verbal abuse and discrimination than heterosexual people (Sandfort 2005; van Wijk et al. 2005; Kuyper & Bakker 2006).

Thompson et al. (2001) claim that the current prevailing conceptions of “intellectual disability” and “homosexuality” offer an inadequate framework for understanding gay and lesbian people with an ID. There are theories about the development of a homosexual identity and what is important for a person’s psychosocial well-being (Vincke & Woertman 2006). Withers et al. (2001) show that people with an ID do not always refer to themselves as being “gay” or “bisexual”, and can feel uncomfortable with this label. In the “world of gays”, people with an ID are at the bottom of “the gay pecking order” because they lack social and financial power (Ridge et al., as cited in Thompson et al. 2001). In lesbian communities, the social environment is slightly more inclusive but full acceptance is still lacking, according to Appleby (1994). People with an ID experience even more oppression as a result of their dependence on others who often hold negative attitudes towards gay and lesbian people. Additionally, negative attitudes towards homosexuality are frequently held by other people with ID (Konstantareas & Lunsky 1997; Murphy & O'Callaghan 2004; Leutar & Mihokovic´ 2007; Löfgren-Martenson 2009). Gay men with an ID are frequently inclined to conceal and deny their sexual identity. They often find it difficult to be open about their homosexuality (Cambridge & Mellan, 2000; Abbott & Howarth 2005, 2007).

5.1.1 Aim

Considering sexuality, people with ID have an important contribution to make; the importance to listen to their stories cannot be underestimated. This exploratory study sets out to gain insight into the lives of a specific cohort of people with an ID who are homosexually active or who identify themselves as gay or lesbian and are living in the Netherlands. Through in-depth interviews, the following topics were addressed: How do people with an intellectual disability, who are gay or lesbian, experience their daily lives? Answers to the following sub-questions were sought: What positive or negative experiences do they encounter? What are their needs and what problems do they experience? What are their support needs? What is their lifestyle like?

5.2 Method

5.2.1 Participants

Participants were gay and lesbian people with an ID. In total, 24 people with a mild ID were invited to participate in the study, of which three opted not to participate. Of the remaining 21, 19 were men and two were women. Nineteen participants were recruited through the Dutch Gay, Lesbian, Bisexual, and Transgender Organisation (COC) meeting places. These meeting places are run by volunteers and are usually open once a month. Researchers visited these places and explained the purpose of the research. Three participants were recruited through intermediaries of associations that seek to support people living with a disability. The intermediaries and the researchers explained the research. Participants were asked to contact the researchers themselves if they wanted to participate in the research. All participants were adults, aged 20 years or older. The mean age was 40.5 years with a range of 20 to 62 years.

5.2.2 Informed consent

Approval of the Ethics Committee at Maastricht University was obtained before the start of the study.

Several guidelines for conducting research with people with an ID have been developed (e.g. Dalton & McVilley 2004; Perry 2004; Schuurman et al. 2004; Thomas & Kroese 2005). In this study, the “informed consent procedure” for participants with an ID developed by Thomas & Kroese (2005) was employed. In this procedure, participants are not only informed about the research but they also have to answer a few questions in order to indicate that they have understood the information received. Information about confidentiality, anonymity and working with recording equipment was included. Attention was drawn to the participant’s right to withdraw at any stage of the data collection. All participants were able to understand this information, decided to participate in the study and signed the consent forms. Participants were told that if they felt that they wanted support after the interview, they could meet with an independent qualified counsellor (psychiatrist with specific expertise in people with ID).

5.2.3 The interview

Participants were asked about their sexuality in a semi-structured interview, with a topic list of interview questions (see Appendix 1). The list was developed using input from professionals in the field of ID and in conjunction with members of the target population. Two pilot interviews were conducted.

5.2.4 Analysis

The interviews were audio-taped, recorded interviews were typed out verbatim and the transcripts were analysed using NVivo version 8.

5.3 Results

In total, 17 interviews were conducted with 21 people with an ID. Two participants were interviewed together with their gay partner (2 x 2 participants); three participants preferred one interview together (1 x 3 participants); and 14 participants preferred an individual interview (14 x 1 participant). The following topics were analysed and are presented in following sections: sexual experiences, gay or lesbian identity, support, the relationship with family and the relationship with one’s partner.

5.3.1 Sexual experiences

All participants talked about their sexual experiences. These experiences could be categorised as heterosexual or homosexual experiences, and as positive or negative experiences. Of the 21 participants, nine participants had had experience of heterosexual sex. A few spoke of a long-term relationship. The remainder mentioned an occasional kiss, a brief sexual contact or a short-term relationship. With the exception of one, these participants indicated seeking homosexual contact afterwards.

> For a while I acted as if I was heterosexual . . . I had several girlfriends but not much happened. I never really had a need for sex with them. (Man, 20 years old)
>
> My father said that I had to try it . . . Well, I tried it with a girl. She liked it but I didn't. (Man, 29 years old)

Of the 21 participants included in the study, nine men indicated having had a homosexual experience at a young age. Many mentioned being 12 years of age or younger. All nine indicated that they had been institutionalised at a young age (elementary school age) and that they had slept in dormitories in the institution. The forests around the institution were used as a place for sexual intercourse during the day; the dormitories at night. Most participants had difficulty reporting the age at which these experiences occurred. They often were unsure as to how old they were.

> At night it happened. They would come to you. Then they would make you wake up. (Man, 53 years old)
>
> Always sneaking into the woods . . . sometimes in the bushes . . . Sometimes you were forced. (Man, 40 years old)

Of the 21 participants, 18 men talked about homosexual experiences. Negative experiences marked by violence against homosexuals, sexual abuse and intimidation were reported by 10 participants (all men). When asked about sexual abuse, 10 male participants reported having been the victim of sexual abuse, usually in their youth. Four experienced this at home with the perpetrator being the father or stepfather, one was abused in the context of leisure activities and five were subjected to sexual abuse in the institution they lived in when they were young. In institutions, the perpetrator was usually a fellow resident and/or a caretaker.

Additionally, five men reported knowing someone else who had been sexually abused.

> Yes, in bed, I had to touch my penis . . . I also had to masturbate. My father was interested in that. Well, not very nice actually. (Man, 53 years old)
>
> When I was 12 years old. An unknown man. He raped me. That happened at the swimming pool. Later I thought: that's why I'm gay. (Man, 29 years old)

> Usually, I don't talk about it . . . Father P . . . who did things, long ago . . . that was wrong. They threatened us . . . They said that he would kill us when we would say anything ... I was very young. Fortunately, that is all over. (Man, 40 years old)

Positive experiences were reported by nine participants (all men). They are satisfied with their relationship, former homosexual contacts or their current independent way of life.

> My friend will sleep here once a month. It is written down on the calendar. That is also described in my support plan. (Man, 53 years old)
>
> We are happy with each other. These are our rings. Look, with the date and our names. (Man, 48 years old)
>
> I'm proud that I can do what I want to do. (Man, 46 years old)

A large number of participants (12) said that they had to hide their sexual relations and sexual experiences. Most participants stated that this hidden sexual contact happened in the past when they were living either in an institution or a group home where little or no privacy was offered and sex was forbidden by the institution or by the caretakers. Although the living situations of most participants at the time of the interviews (eight recently moved) allow for more privacy, three reported still being inhibited by the close proximity of housemates and caretakers.

> They usually have an eye on that here. (Man, 26 years old)
>
> Yes, it's very difficult. It's difficult to take a friend upstairs and say 'I'm in my room now. (Man, 26 years old)

The participants were asked if and how they prevent sexually transmitted infections and HIV.

Of the 18 men, five men reported always using condoms, three men were using condoms sometimes, six men stated that they get an HIV test once a year and were using condoms sometimes, two men were unclear what preventative measures they took and two sexually active men reported not taking any preventive measures. Having an HIV test every year is seen as a way of prevention.

Of the 18 men, four men reported that they have sex with more than one partner and one man reported that he has penetrative anal sex with his partner. None of the condom users have anal sex. In this study, three participants (two women and one man) reported that they have no sexual experiences.

> I learned on a course how to use a condom. They have told me to always use them. (Man, 26 years old)

It is not clear if the participants report past behaviour or the intention for future behaviour.

> When do you use a condom? Always. Why? You should do. (Man, 52 years old)

5.3.2 Gay or lesbian identity

Of the 21 participants, 18 (16 men and two women) stated that they found it easier to be openly gay or lesbian now than in the past.

> I am proud to be gay . . . Well, of the way I live . . . How I live . . . Well, I open the door. I like the air outside and if I see a good-looking man walk by, then my day is perfect. (Man, 29 years old)

> In those days, they didn't talk about this. I thought I was sick. (Man, 40 years old)

However, not all of the participants were open about their sexual identity in all settings. Of the 21 participants, six men said that they have had positive reactions from colleagues at work or from fellow participants in their day programme. At the same time, 15 (13 men and two women) reported having experienced discrimination as a result of their sexual orientation when going out, on the street, and from friends. They mentioned being subjected to verbal and physical abuse in the form of name-calling, hitting and bullying.

Negative reactions to sexual orientation appeared to be most prevalent at work and in day programmes. For six participants (five men and one woman), the situation at work had improved by the time they were interviewed. For an additional five (men), negative reactions to their gay or lesbian identity were ongoing at the time of the interview.

> They hollered at me and called me a homo. That wasn't nice. They were disciplined by the boss. Homos are people too. They are just normal people. (Man, 53 years old)

> If I get new work, I will definitely keep my mouth shut… (Man, 51 years old)

> I'm afraid how they will react. At my work… when I say I like girls… they don't want to sit next to me. (Woman, 29 years old)

5.3.3 Support

The degree to which participants felt supported by healthcare institutions varied. Of the 21 participants, eight (six men and two women) said that they were satisfied with the support they receive from professional caretakers. Participants were especially positive about the support they receive from lesbian or gay caretakers, as this made it easier for them to discuss taboo issues relating to homosexuality. At the same time, four men reported being dissatisfied with the support they receive from their institution because caretakers decline to talk about sexuality even when the participants have questions.

> No . . . they just want to hear all the details… No, I don't feel the need to share that because I know that it's all just talk and when it comes down to it . . . they won't do anything about it… (Man, 49 years old)

> They only talk about sex in a teasing fashion: 'Do you have a dildo?' . . . Teasing, as if all I never talk about is sex. (Man, 40 years old)

Of the 21 participants, five men had received coaching from a sexologist and were very happy with the coaching. It helped them in their relationship with their partner. Three participants (two men and one woman) enthusiastically discussed a course on sexuality and empowerment that they were following. One participant (man) told about the sex education he had received from his father.

> We have recently had a course . . . I think it is important that you know . . . and you do it safely. We talked about various things . . . loverboys. Pregnancy or a serious illness, I'm not really waiting for it, no. (Woman, 29 years old)

> … at school… it was on a DVD… they explained all . . . and you didn't have to answer. (Man, 20 years old)

> My father gave me condoms and all those things. (Man, 29 years old)

5.3.4 Family

A number of participants discussed, without prompting, experiences with their family. In fact, 19 (17 men and two women) mentioned that they had told one or more family members that they are gay or lesbian. For eight (seven men and one woman) of these 19, the reactions to their coming out were positive. Generally, siblings reacted positively but parents tended not to want to discuss homosexuality.

> My father accepts it under certain conditions… that I don't do anything crazy… and my mother, well, she cannot deal with it. No, she would rather not know. We never talk about it. (Man, 49 years old)

Two participants (men) reported having no contact with their parents. One of these two men believes this is because he is gay.

> … They don't want any contact with me… no one wants to have contact with me. Otherwise, they would have called but they don't. (Man, 48 years old)

5.3.5 Partner

In the interviews, two of the 21 participants (men) reported living with their partner, and seven men reported being in a long-term relationship but not living with their partner.

Most participants also indicated being quite satisfied with the contact they have with their partner. Moreover, six men indicated that they had been, in some way or another, poorly treated or abused by their previous partner.

> I've also had a friend . . . for 10 years . . . I had to give my money . . . it lasted many years. Then he beat me. Then I thought: it's enough. (Man, 51 years old)

> He forced me with everything, including sexually… In my house, he even threw out all my plants… he threw out everything. Terrible! (Man, 29 years old)

Additionally, nine participants (seven men and two women) indicated that they are currently looking for a partner and that this is important to them.

> A long-term boyfriend you can talk to. I'm looking but it's hard to find. (Man, 48 years old)

Many participants (seven men and two women) indicated that they hope to find a partner at the meeting places offered by the COC. They also reported that their caretakers often do not know how to best support them in looking for a partner.

> …so, when you are looking for a new boyfriend, they don't know where you can place an ad and they just don't know . . . they have no idea where to begin. (Man, 49 years old).

Participants themselves also often do not know how to find a new partner.

> I don't know a lot of people with an intellectual disability who are also gay outside of my own group of friends and the people from the COC. (Man, 28 years old)

> I don't think a lot live here. Yeah, then that makes it difficult… (Man, 26 years old)

Having feelings of loneliness and not feeling a part of society were reported by six participants (men).

5.4 Discussion

This study investigated the experiences of people with an ID who reported that they are homosexually active, or who identify themselves as gay or lesbian, by conducting in-depth interviews. Sexual experiences and specific problems relating to sexual orientation as well as support needs were explored in a semi-structured interview setting.

Participants reported positive and negative sexual experiences. Additionally, a number of participants reported finding it difficult to be open about their homosexual identity. The findings also show that homosexual people with an ID would like to receive additional support, particularly in seeking a new partner. Furthermore, participants in this study reported that despite having disclosed their sexual orientation to family members, some – particularly parents – shy away from talking about this.

The findings of this study point to specific problems that impact the lives of homosexual people with an ID, namely the high prevalence of negative sexual experiences, their need for support, being open about their sexual identity in all settings and their search for a suitable partner.

5.4.1 Sexual experiences

Many participants reported negative sexual experiences and sexual abuse, mostly in the far past. This is in line with previous research demonstrating rates of sexual abuse of people with an ID between 25% and 83% (van Berlo 1995; McCarthy 2001; Levy & Packman 2004; O'Callaghan & Murphy 2007; Cambridge et al. 2011). Regarding the location where sexual abuse took place, there appear to be differences between gay and lesbian people with and without an ID. In our study, the participants indicated that this usually occurred in their living environment. According to the 2009 Rutgers Nisso Groep (2009) study, sexual abuse of gay and lesbian people without an ID usually occurs in public places (32%). In addition to sexual abuse, the participants in our study reported other negative sexual experiences including having been in a relationship marked by violence and/or intimidation, or being scared of getting caught during sexual intercourse.

The participants were asked if and how they prevent sexually transmitted infections and HIV. It is not clear if the participants report past behaviour or the intention for future behaviour. People with ID often seek approval for the answers they give or for a choice they have made (Williams 2011). Homosexual people with ID belong to a "hidden" population and are not used to participate in research. Clarke et al. (2010) notes: "They [homosexual people] may be concerned about how their experiences will be represented and how the research findings will be used." Therefore, it is likely that participants give socially desirable answers. The identified power imbalances in sexual relationships can also have an impact on the ability to have safer sex.

Furthermore, the participants experience a lack of privacy. Participants indicated that this is often attributable to their living environment, as privacy in their living environment is frequently lacking, despite the recently improved living conditions. These findings correspond with previous research showing that the creation and preservation of privacy in the living environments of people with an ID requires attention (Kempton & Kahn 1991; Abbott & Howarth 2005).

Although the participants reported many negative experiences, they also refer to positive experiences. Furthermore, three participants reported that they have had no sexual experiences. Allen (2007) notes that although people may identify with being homosexual, it does not necessarily mean that he or she has acted on those desires. When participants talked about their heterosexual experiences, it seems they arose through social pressure. Some participants tell how proud they are with their current relationship, their way of living and meeting others. It helps them to be positive in life.

5.4.2 Support

The participants in this study were relatively satisfied with the support they receive from supporters and caretakers. Nonetheless, a number of participants reported that the support they receive from care institutions could be improved. Caretakers appear to be shy when it comes to providing guidance to people with an ID on matters pertaining to sexuality (Richards et al. 2009) and, in particular, homosexuality (Thompson et al. 2001; Abbott & Howarth 2005, 2007). Abbott & Burns (2007) conclude that it is necessary to support homosexual people with ID, Löfgren-Martenson (2009) confirms this. It is important to listen carefully to them. Support workers must be conscious of the imbalance of power between them and a person with ID (Williams 2011). The example of writing on the calendar when a friend will stay overnight shows how people may get forced by their environment and can not manage certain intimate aspects of their own lives.

Specific support needs for homosexual people with an ID include the provision of training programmes, the creation of safe working and living environments, and the identification of meeting places.

5.4.3 Training programmes

People with an ID often lack training in which behaviours are socially acceptable (Shakespeare 2006), especially when it comes to sexuality (McCarthy 2001). Specific training programmes are therefore necessary. Specific training programmes on sexuality could support and help people with an ID to identify and prevent socially (un)acceptable situations (Kempton & Kahn 1991; Cambridge 1997; Cambridge & Mellan 2000; Thompson et al. 2001; Gust et al. 2003; Löfgren-Martenson 2009; Richards et al. 2009). It is also good to explain when and how people should protect themselves against sexually transmitted diseases. Burns & Davies (2011) underline the importance of education programmes focussing on gender roles and with the emphasis on developing more positive attitudes towards homosexuality.

In this study, six participants mentioned feelings of loneliness. They do not feel part of society and face problems with friendship. People with ID often have problems with friendships and are often isolated in subgroups. Therefore, it is necessary that they get training and support in helping build connections with other people in an inclusive society (Shakespeare 2006; Oliver 2009).

Additionally, guardians, caretakers, professionals and families could be trained and supported (Kempton & Kahn 1991; Cambridge 1997; Thompson et al. 2001; Hingsburger & Tough 2002; Löfgren-Martenson 2004, 2009; Abbott & Howarth 2007; Richards et al. 2009) in order to overcome shyness when discussing sexuality. Such training programmes would likely indirectly function to support people with an ID and make it easier for them to disclose their sexual identity.

5.4.4 A safe environment

Additionally, and in line with the findings of other studies (Gust et al. 2003; Abbott & Howarth 2005), our study has shown that homosexual people with an ID need to live and work in places that feel safe and that offer adequate privacy. Of the 21 participants in our study, 15 reported having experienced negative reactions to their sexual identity. In the study of Abbott & Howarth (2005), these numbers are even higher (i.e. 19 of 20 participants talked about being bullied or harassed). The reduction and prevention of discrimination in the working and living environments of people with an ID needs to be prioritised.

5.4.5 Meeting places

Lastly, the participants in our study indicated that they would like to have more meeting places in order to find a partner. This is in line with previous research (Thompson et al. 2001; Abbott & Howarth 2005). The COC meeting places do offer gay and lesbian people with ID opportunities to meet potential partners. In our study, almost all participants indicated being familiar with this service and felt supported by the volunteers working in these cafés.

In England, such special meeting places are now also available. In the past, the LGB (lesbian, gay and bisexual) community has been less than welcoming to people with ID (Abbott & Burns 2007). Abbott & Howarth (2005) found a strong need for such similar meeting places. Both in the Netherlands and in England, people with ID do not feel comfortable and are excluded on the “scene”. Increasing awareness of these meeting places among not only gay and lesbian people with an ID but also their guardians, caretakers and families could serve to improve access to such services. Additionally, alternative meeting places could be created.

5.4.6 Limitations

There are several reasons to be cautious when interpreting the results of this study. First, people with ID have a strong tendency to seek approval and a tendency towards acquiescence in interviews (Finlay & Lyons 2001; Perry 2004; Rapley 2004; Williams 2011). Second, sexuality is a sensitive topic. Research on sexuality is more susceptible to response bias than other study subjects. Participants can provide a misrepresentation of their sexual lives (van Lankveld & Laan 2004). Interpreting the recall of negative sexual experiences is complex and requires careful evaluation (Merckelbach et al. 2001; van Oosten & Höing 2006; Giesbrecht et al. 2010). Sexual abuse is a complex issue and there are differences between judicial and psychological definitions in what exactly is understood by the terms sexual abuse or sexual violence (Oosten & Höing). In this study, participants were asked about their experiences, and it is possible that some events were omitted. It is also possible that a participant was a perpetrator of sexual abuse him or herself but decided not to tell. It is also possible that they reported experiences of sexual abuse or sexual violence that never took place.

This study's findings should be interpreted in the light of a few limitations. Only two of the respondents were women, meaning that the experiences of lesbians are underrepresented in this study. McCarthy (1996) found very few women (3%) who had had sex with another woman and concluded that there is a big difference in sexual experiences between women and men with ID, even if adjustments for underreporting for women are made.

Participants were interviewed only once and for a limited amount of time. Longer, longitudinal interviews with the participants would have provided richer and more reliable data about the participants' experiences, for instance, issues such as the use of contraceptives, the types of sex people were having and what sort of sex education they have received. Most participants were essentially recruited from the COC meeting places, so it is difficult to generalise with regard to other people with ID who do not use these services.

Lastly, the chosen method for collecting data, namely an interview, resulted in the fact that predominantly people with a mild ID were recruited. This research methodology is not suitable for people with severe ID.

Attention to and awareness of sexuality among people with an ID is increasing. However, when people with an ID express a gay or lesbian identity, this is often thought to be "going too far". In order to attain and maintain sexual rights among gay and lesbian people with an ID, effort on the part of all involved is imperative.

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Appendix Interview schedule/topic list

Coming Out
When is somebody gay/lesbian?
How can you see if somebody is gay/lesbian?
Are you gay/lesbian?
How did you find out?
Do you talk about it with others? With whom?

Setting/environment
How does your family respond?
How do the people at your work respond?
How do facilitators respond?
Have you experienced unpleasant incidents? Discrimination? Pointing? Abuse?

Sexuality
What was your first experience? How old were you then?
Do you have a regular partner? Do you have multiple partners?
Do you have sex with people without intellectual disabilities?
Do you get gifts or money for sex?
Have you ever had sex with a woman/man?
Where do you have sex? And when?
What is masturbation? Do you ever masturbate? Where? Is it allowed?
Can you have sex freely? Without interference from supervisors? In your own room? Can you lock the door?
Do you have sex only when you want it? Or do you have sex against your will?
What is STD?
What is AIDS/HIV?
What can you do about it?
Do you use condoms? Always?
If you use medicine, what sort of medicine? Does this influence your sex drive? How do you know this?

Lifestyle
Do you know other gay men/lesbians?
Do you have contact with other gay men/lesbians?
Do you visit gay bars? Which? Why?
Are there gay meeting places in the region (parks, parking places, pubs, nightclubs)?
Can anyone see/notice that you're gay/lesbian? How?
Do you have a role model? Who is your idol?
Is there anything you would like to change in your life? What?

Where are you proud of?

Evaluation interview

How was the interview?
Which questions did you like?
Which questions were difficult?
Where there questions I shouldn't ask?
Are there any questions I forgot?

Chapter 6

Women Who Love
An Explorative Study on Experiences of Lesbian and Bisexual Women with a Mild Intellectual Disability in the Netherlands

Stoffelen, J.M.T., Schaafsma, D., Kok, G., & Curfs, L.M.G. (2018). Women Who Love
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Abstract

Aim Empirical research that addresses sexual orientation in people with an intellectual disability (ID) is limited, and very little is known regarding the personal experiences of lesbian and bisexual women with ID. This study set out to answer the question: *What are the experiences of lesbian and bisexual women with a mild intellectual disability in the Netherlands?*

Methods Ten lesbian and bisexual women (average age of 33 years) with a mild intellectual disability took part in our study comprising of semi-structured interviews.

Results Participants reported that they had found it hard to talk to others about sensitive subjects such as their sexuality, and had been left to figure out information regarding their sexual orientation without support or guidance. Our results point to a lack of information, sexual education and role models when it comes to lesbian sex and women with an intellectual disability. Social contact was often limited, and participants experienced difficulties finding a partner. Furthermore, participants often had to cope with mental health problems and had struggled with loneliness, depression and addiction. Last but not least, our participants reported that they had been discriminated against.

Conclusion Coming out (revealing your sexual orientation) is not easy when you have an intellectual disability. To enable women with ID who have lesbian or bisexual feelings to understand and secure their sexual rights in their daily lives is important. Therefore, it is necessary to provide support in the following domains: sexual education and training, social contact and assertiveness.

6 Introduction

6.1 Sexual rights

People with an intellectual disability (ID) have the same human rights as everyone else (Stainton & Clare, 2012), and therefore also the same sexual rights. A working definition of sexual rights has been formulated and established by the World Health Organization (WHO, 2016). These rights - for example to choose a partner, to equality, to liberty, to non-discrimination, to privacy, to the freedom of thoughts, opinions and expression - are guiding principles. In 2006, the United Nations adopted The Convention on the Rights of Persons with Disabilities (UN, 2006), which recognized the equal and inalienable rights of people with a disability. Article 25 includes "the area of sexual and reproductive health" and "require(s) health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons…". The American Association on Intellectual and Developmental Disabilities (AAIDD, 2008) has also acknowledged the sexual rights of people with an ID: "These rights and needs must be affirmed, defended, and respected". Sexual orientation is one of the rights mentioned in the Position Statement of the AAIDD. Unfortunately, these rights are not always self-evident for people with ID (Ignagni, Schormans, Liddwiard, & Runswick-Cole, 2016; Watson, Venema, Molloy, & Reich, 2002). Often, individuals with an ID do not get the respect, or the necessary support, to achieve their sexual rights.

6.1.1 Women with ID

Studies on sexuality in general among women with ID are also limited, and the results often describe negative perceptions, negative experiences, and failures in sex education: "disempowerment is woven into every strand of the lives of many women with intellectual disability" (McCarthy, 2014). Research from the perspective of women with ID who have sexual feelings for other women is very underrepresented in scientific studies (Abbott, 2013; Abbott and Howarth, 2005, 2007; Bernert and Ogletree, 2013; Burns and Davies, 2011; Duke, 2011; McCann, Lee and Brown, 2016; Stoffelen, Kok, Hospers, & Curfs, 2013).

6.1.2 LGBT with ID

Lesbian women, gay men, bisexual individuals and transgender individuals (LGBT) without an ID experience an increased risk for health problems such as depression, anxiety disorders, drug and alcohol abuse, loneliness, sexual problems, and an increased risk of sexual violence (Clarke, Ellis, Peel and Riggs, 2010). Research into the specific health problems among LGBT people with intellectual disabilities is scarce (Duke, 2011; Fraley, Mona and Theodore, 2007; McCann et al., 2016). In a review of the literature, McCann et al. (2016) included 14 papers that addressed the views, issues, concerns of people with ID who identified as LGBT. More awareness of the interests of LGBT individuals with ID is needed. Reducing stigma and discrimination can improve the health and well-being of LGBT individuals (McCann et al., 2016). In the existing literature, we found that three important themes emerged in relation to LGBT individuals with ID: stigma, social contact and support.

Stigma

Gay, lesbian, and bisexual individuals with an ID experience prejudice and harassment from the outside world. They often have to deal with the double stigma associated with their intellectual disability and their sexual orientation. This has also been referred to as “layered” stigma (Duke, 2011; Goffman, 1963; Meyer, 2003). Experiencing prejudice and discrimination can limit an individual’s opportunities to participate in society, and limit opportunities to develop friendships (Hall, 2010). LGBT individuals with intellectual disabilities often lack social and financial power (Thompson, Bryson and De Castell, 2001). Moreover, they are more likely to experience exclusion, discrimination and harassment (Abbott, 2013; Burns and Davies, 2011; Duke, 2011; Leutar and Mihokovic, 2007; Löfgren Mårtenson, 2004, 2009; Stoffelen et al., 2013). Peers with ID often have prejudices and negative attitudes towards homosexuality. Young people with ID sometimes internalise the homophobic and heterosexual attitudes of nurses, teachers and parents (Duke, 2011). Gay men, lesbian and bisexual individuals with ID find it difficult to be open about their sexual orientation (Abbott and Howarth, 2005, 2007; Cambridge and Mellan, 2000; Duke, 2011; Stoffelen et al, 2013).

Social contact

Many people meet their partners at work, whilst pursuing leisure-activities, or via their social network. Gay men, lesbian and bisexual individuals with ID experience difficulties when it comes to finding sexual partners. Their social network is often limited, and they are often stigmatized; this reduces the chance of finding a partner (Abbott and Howard, 2005; Fraley et al., 2007; Stoffelen et al., 2013). A literature search carried out by McCarthy (2014) confirms this, and shows that there are yet more obstacles for women with ID, including low self-esteem, a lack of assertiveness needed to set sexual boundaries, and a lack of sex education to emphasise the enjoyable side of sex and to provide information about dealing with risky situations. In the Netherlands, LGBT individuals with ID find it hard to meet up with friends due to their limited mobility (Stoffelen et al., 2013). Lack of mobility is a big problem for people with a disability (Shakespeare, 2006), and one that can prevent them from leading an independent life. To meet others is important. For example, in order to experience relationships, to develop a positive self-image, and become more assertive. The internet can offer an alternative to meeting people in person (Fraley et al., 2007), although the experiences of people with ID using the internet are not always positive (Stoffelen et al., 2013).

Support

Some issues deserve special attention when it comes to supporting LGBT individuals with ID, namely sex education and training, and the provision of positive support, role models, and accessible information. Sex education and training is not only necessary for individuals with ID but also for the individual's support network and family. Sexual diversity must be included in the programme (Duke, 2011; Löfgren Mårtenson, 2009; Noonan and Taylor Gomez, 2011; Schaafsma, Stoffelen, Kok and Curfs, 2013; Stoffelen et al., 2013) along with a number of items and issues such as prevention of HIV/AIDS, homophobia, sexual orientation, and having access to the LGBT community (Fraley et al., 2007; Noonan and Taylor Gomez, 2011; Stoffelen et al., 2013; Thompson 2007). The provision of positive support and role models is important in terms of the development of a positive identity (Abbott, 2013; Abbott and Howarth, 2005; Duke, 2011; Löfgren Mårtenson, 2009; Noonan and Taylor Gomez, 2011; Stoffelen et al., 2013). It is essential to provide accessible information about LGBT sexuality, for example via good "easy to read" books, websites, and photo-stories (Abbott, 2013; Duke, 2011).

6.1.3 Aim and research questions

To date, the sexual experiences of women with ID have received scant attention in research, and little is known of the personal experiences of lesbian and bisexual women with ID. The additional (sexual) vulnerability of women with ID in general underlines the need for a study among this specific group. In this exploratory study, our aim is to gain insight into the lives of a specific cohort of women with ID who have sexual feelings for other women, or who identify themselves as lesbian or bisexual, and are living in the Netherlands. Through in-depth interviews, the following topics were addressed: What are the experiences of lesbian and bisexual women with a mild intellectual disability in the Netherlands? Furthermore, we asked the following sub-questions: What positive or negative experiences do these women encounter? What are the (support) needs of these individuals, and what problems do they experience?

6.2 Methods

Participants

Participants were lesbian or bisexual women with mild ID. Thirteen women were invited to participate in the study, and of these, three decided not to participate. The participants were recruited through intermediaries of associations that support people who are diagnosed with an ID and sexologists who work with people with ID. These intermediaries, sexologists and the researchers explained the research to potential participants. All participants received a leaflet containing information about the research: our research goals, the questions addressed in our research, as well as information about confidentiality and support. Participants were asked to contact the researchers themselves if they wanted to participate in the research. All participants were adults. The mean age was 33 years with an age range of 25 to 47 years (Table 1). The women lived in various provinces all over the Netherlands. The process of finding participants was intensive. Women with an ID who are lesbian or bisexual seem to be invisible, in that they are often not recognised or noticed, even by their own support workers.

Informed consent

Approval of the Ethical Review Committee Psychology and Neurosciences at Maastricht University was obtained before the start of the study. Several guidelines for conducting research with people with an ID have been developed [e.g. Dalton and McVilley, 2004; Perry, 2004; Thomas and Kroese, 2005). In this study, we used the “informed consent procedure” for participants with an ID developed by Thomas and Kroese (2005). In following this procedure, participants are not only informed about the research but they also have to answer a few questions in order to indicate that they have understood the information received. Information about confidentiality, reporting sexual abuse, anonymity, and working with recording equipment was included (Schaafsma, Kok, Stoffelen and Curfs, 2017). Attention was drawn to the participant’s right to withdraw at any stage of the data collection. All participants were able to understand this information, decided to participate in the study, and signed the consent forms. Participants were told that if they felt that they wanted additional support after the interview, they could meet with an independent qualified counsellor (a psychiatrist with specific expertise in people with ID).

Table 1 Summary of Selected Demographic Information of Participants

Demographic variable	Description	N=10
Age	20-29	4
	30-39	4
	40-49	2
Ethnicity	Native Dutch	10
Residential placement	Living independently with support	3
	Own apartment in a care complex	6
	Living in a care complex	1
Marital status	Single	6
	In a relationship	2
	Married	2

The interview

Participants were asked about their sexuality in an explorative semi-structured interview, using a topic list of interview questions (see Appendix 1). The list was developed using input from professionals in the field of ID and in conjunction with members of the target population. Two pilot interviews were conducted. These interviews are included in this study. The interviews lasted approximately one hour, depending on participants’ ability to concentrate.

Analysis

The interviews were audio-taped. Recorded interviews were typed out verbatim, and the transcripts were analysed using NVivo version 10. For analysis, a three-step approach was applied. In step 1, paragraphs of individual transcriptions were given codes, which were basically short descriptions of the contents of those paragraphs. In step two, categories were identified from the list of codes. Codes that were similar were merged. Step 3 consisted of identifying subcategories within the major categories. Analyses were conducted by the first author.

6.3 Results

In total, eight interviews were conducted with 10 women with an ID. Two participants were interviewed together with their partner (2 x 2 participants); six participants preferred an individual interview. The following topics were identified and are presented in the following sections: support, coming out, sexual experiences, mental health, social contact, and discrimination.

6.3.1 Support

Eight participants talked about the support they had received. This support came from several sources and was related to different life domains: finance and administration, mental wellbeing, physical health, and household matters. The participants had to interact with all sorts of support workers, including supervisors, trainees, personal coaches, and work assistants. Often, these people provided support once a week for a short period of time. As a result, some participants found it difficult to build a relationship of trust with these support workers, and to talk to them about sensitive subjects like sex. They must often seek information without any support or input from others.

> No, I don't talk to them about it (sexuality). It's none of their business… They don't stop talking about it… There are almost no men, only women. When I go to my doctor I don't talk about it either. And he doesn't ask me about it. (34 years)
>
> Well, I have my own coach. I never discussed it (sexuality). We never talk about sex…. They are curious. That's what they are. They don't have time. They have half an hour…One is always in a hurry. Then I just think: go away… I want my one support worker, not an intern. (47 years)

However, six participants reported that they were content with the professional support workers, who helped them find their way in the LGBT community, and made them feel safe and accepted.

> My mentor, he is the best. I picked him myself. He is also gay. That makes you feel safe…. (40 years)
>
> Who is a good support worker? Someone who helps me find my way. So, I do not have to figure out everything alone. (26 years)

6.3.2 Coming out

Six out of ten participants talked about their coming out experiences; the age at which they came out ranged from 13 years to adulthood. Some women had been supported in the process of coming out; others had been left to deal with it alone. All women felt insecure about themselves, had to deal with being verbally unskilled, and were not used to standing up for themselves.

> I knew it from my 15th and kept it secret. My uncle was killed because he was gay. Also nowadays, I keep it secret, sometimes. It's just hard, sometimes…. Many women are anxious when it comes to telling the outside world who you are. I did it because I want to support people who are still afraid. I want to be a role model for them. (40 years)
>
> From childhood… How shall I say it…? I knew it but it was not allowed. I met my husband and had children… Then I saw her and I thought: now I am sure! All those years I hadn't thought about it… (47 years)
>
> A homosexual friend said: You have to learn to speak up for yourself. I know you are homosexual. You are ready for it! (38 years)
>
> I knew it since I was a child…during my teenage years. I had butterflies in my stomach when I saw women. (36 years)
>
> I found it very difficult to tell my father that I am a lesbian. I thought he would become angry. (25 years)

Nine participants talked about how their friends had responded to their coming out. One woman reported that this news had elicited negative reactions, one woman had experienced a combination of negative and positive reactions, and seven women had experienced only positive reactions. For all of them, it was nerve-racking to tell friends about their sexual orientation. Most women didn't know other lesbian or bisexual women.

> We know few other women like us. (47 years)
>
> Among my friends, I'm the only one who is gay. (25 years)

In contrast with the other participants, one couple appeared not to be an exception in their network of friends and family:

> All our friends…almost everyone is gay… oh, no, one is bisexual. (38 years)

Finding a partner was an issue for six women. Two participants indicated that they hoped to find a friend online, and two women thought that they might find a partner at meeting places offered by the COC[1]. Two women reported that they did not know how to find a partner.

> Where can I find them? (26 years)

> If you search in a forced way, you get weird people. You have to wait till you find someone you really like. (25 years)

6.3.3 Sexual experiences

All participants spoke openly about their sexual experiences: eight women had sexual experience - all with both men and women - and two women had not had any sexual encounters. These eight women reported that they'd had to find out almost everything by themselves when it came to having sex with another woman.

> The first time, everything was very strange. It's very different with women. We don't have videos that show how to do it. I never had solo sex. My girlfriend knew how to do this. I found it very strange. I had to learn it. (25 years)

> I don't have experience with sex. I have kissed with a boy. And I didn't like it. In terms of sex, I have no experience. (25 years)

> Sex with a woman is different. It is no longer an obligation every evening…. now it's fine and a pleasure. It is more enjoyable (than with men). (47 years)

> I didn't know how to reach sexual climax. I was curious…. And it was fine. (40 years)

> Someone who was in love with me, stalked me. That made me very anxious. I didn't dare to pick up the telephone anymore. It was hard to talk about it with others. Fortunately, it happened a long time ago. I have never had sex with women. Nor with men. Regularly, I fall in love. I dream a lot of being in love. (35 years)

Experiences with sexual abuse were reported by three participants. These experiences included sexual assault, rape, sexual abuse and online sexual betrayal. In all of these

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[1] COC is a LGBT organisation in the Netherlands; COC stands for 'Cultuur en Ontspannings Centrum' (Culture and Recreation Center); which is a name from the time that homosexuality was not as accepted as it is today.

cases, the perpetrator was a man. These experiences had a great impact on the lives of the women. Two participants had multiple experiences with sexual abuse. These traumatic episodes and experiences still influence their daily lives. They struggle with fear, negative feelings and depression.

> …assaults at work…touching my breasts…. The ex of my mother didn't keep his hands to himself…. Therefore, I can't express my feelings with a man. I became sick. (40 years)
>
> For many years, I had online contact - on Facebook - with a beautiful woman. But it turned out to be fake. It was a man. I felt very bad about it. I couldn't sleep for a long time. What a misery! I was heartbroken. I had a very bad time. Then I told my mom about it. We didn't report this to the police. There was too little evidence. (25 years)
>
> I have had many nasty experiences with sex…Yes, I was raped. I have flashbacks…. I want sex, but I don't dare… the fear is stronger…. (38 years)

6.3.4 Mental health

Six out of ten participants had experienced mental health problems and have struggled with extreme loneliness, depression, alcohol addiction, anxiety, and being bullied. These six women talked openly about the difficulties in their lives, how they had tried to deal with them, and the mental health problems that can arise.

> For a long period, I had a bad time. I wasn't well, mentally. I have autism, got depressed, I stayed in bed for a year. Then I received psychological treatment and moved to another group home. There, the owner of the particular group home stole my money, approached me aggressively…. So, I moved on again… I went to live with my mother. That was not easy at all. (25 years)
>
> I lived on my own and had my own apartment… and I was very lonely… I recently suffered from a serious depression…and can't stop thinking… I have appointments with a psychiatrist. (25 years)
>
> Positive thinking is the best… Otherwise I start brooding… I can worry a lot… then I go to my doctor… he just talks to me and we laugh a lot… (25 years)
>
> I have a lot of grief…In my life many unpleasant things have happened… I drank a lot… Now not anymore… (38 years)

The participants received support to cope with these problems from family members and professionals such as paid care staff, psychiatrists, or general practitioners.

6.3.5 Social contact

Family members are important when it comes to social contact. Six participants talked about contacts with siblings: four participants described good contact with their family members; two participants talked about negative experiences and no longer have contact with their siblings.

> My sister was the first who knew (lesbian feelings). I asked her to tell my parents. And she did. They responded well. (35 years)
>
> My sister…no contact…She annoys me. My brother-in-law too. (34 years)

Alongside siblings, others family members were referred to: parents, children, aunts, a niece and grandparents. The reaction of one grandmother was:

> If you are gay, you are no longer my little baby. (38 years)

The parents of eight participants reacted in a positive way:

> …she (mother) always said it was good when I fall in love with a girl. (29 years)

Two participants were unsure about the reaction of their parents:

> I never mentioned it to my father. He always said: 'Gay people are dirty'. (25 years)

Nine participants reported having a good relationship with friends. They talked about a circle of friends and social activities. How large and stable the circle of friends was, was not always clear.

> Due to my autism, it is hard to make contact… I can be very lonely... Now I have two very good friends... I have to force myself to get (socially) involved. (25 years)
>
> …I occasionally get comments…Sometimes I do get sad…Someone with whom I get along well…I do not feel happy. (25 years)

Seven participants lived in a care complex at the time of data collection: one lived in a group home and six lived in a private apartment in a care complex. Many have therefore had to deal with roommates or neighbours who live in the same care complex. Four participants talked about the reactions of their housemates, and the social contact they have with them. This contact was usually restricted to moments when they had a cup of coffee together.

> I have mentioned it… but I don't know if they understand it. They don't ask. I have the feeling that they do not understand me…. I keep it to myself. (35 years)
>
> …It is none of their business. (36 years)

And, as previously mentioned, nine participants mentioned how their friends responded to their coming out.

6.3.6 Discrimination

Of the ten participants, seven women talked about their - mostly negative - experiences with being openly lesbian. In the first instance, they reported that they experienced no discrimination: *"*Nowadays, everything is very different...we can do whatever we like…" (40 years). Thereafter, they gave examples that in fact demonstrate the opposite:

> Quite often, foreign people don't accept us…We don't feel at ease…I don't find it important if people know who we are… (38 years)
>
> In society it's normal… a man with a woman, or a woman with a man. People act weird. They avoid me… I feel it. (35 years)
>
> They say: within ten years you will have a man… They don't take me seriously…Sometimes, it makes me sad. (25 years)

Two women talked about how they hide their sexuality.

> You cannot see that I am bisexual. (36 years)
>
> We walk side by side…never hand in hand. (38 years)

Despite the difficulties these women encountered, six out of ten women were open about their sexuality at work and in day programs.

> She was bullied at work... they shouted: 'lesbian, lesbian, lesbian!' And they threw wads of paper at her. If it was up to me… I would beat them. (38 years)
>
> They can say whatever they want… (34 years)

6.4 Discussion

This study used in-depth interviews to investigate the experiences of ten women with an ID who reported that they are lesbian or bisexual. We were interested in the lived experiences of lesbian and bisexual women with a mild ID in the Netherlands. To our knowledge, no such a study of this kind has been carried out before. Sexual experiences - and specific problems relating to sexual orientation as well as support needs - were explored in a semi-structured interview setting. Six general themes emerged in our data: support, coming out, sexual experiences, mental health, social contact, and discrimination.

Women with an ID need to interact with professionals providing support in relation to various life domains. When it comes to sexuality, it has been shown that relatives and support workers have different standards for themselves than for people with ID (Christian, Stinson and Dotson, 2001; Dinwoodie, Greenhill and Cookson, 2016; Swango-Wilson, 2008; Yool, Langdon and Garner, 2003). As a result, it is difficult for participants to talk to others about sensitive subjects such as their sexuality. They must often seek information without any support or input from others. Some of the participants we interviewed received support and guidance from the LGBT community. Coming out (revealing your sexual orientation) is not easy when you have an ID. All participants in our study were not used to standing up for themselves, often felt insecure, and had low verbal skills. Generally, with regard to having sex with another woman, most women had to figure out everything by themselves. This corresponds with the findings of Dinwoodie et al. (2016). This lack of support, feelings of insecurity, the lack of empowerment, and the limited verbal skills, hinders them to be self-conscious and find a partner. Six out of ten participants reported that they had experienced difficulties in finding a partner. Although the positive reactions of friends encouraged them in their “coming out” process, they lacked a role model. This had affected their sexual experiences. Eight women reported that they had to find out almost everything by themselves. Three participants reported having been sexually abused by a male perpetrator. Social contact tended to be limited to relatives and friends. Other social networks such as those provided by work, leisure clubs and neighbourhoods were hardly mentioned.

The experiences of our participants are consistent with those previously reported in the literature (mainly in reference to gay men with an ID) and include negative perceptions, negative experiences, failures in sex education, exclusion, discrimination, and harassment (Abbott, 2013; Burns and Davies, 2011; Dinwoodie et al., 2016; Löfgren Mårtsenson, 2004, 2009; McCarthy, 2014; Stoffelen et al., 2013). Additionally, participants in our study reported various mental health problems, including feelings of depression, and anxiety. This corresponds with the outcome of research by Clarke et al. (2010), who reported that LGBT individuals without an ID are also at increased risk for mental health problems.

6.4.1 Supporting women with ID

Providing support to lesbian or bisexual women with an ID is an essential part of securing their sexual rights. To do this, it is necessary to provide support in the following three domains: 1. sex education and training, 2. social contact, and 3. assertiveness. Naturally, in order to provide proper and adequate support, it is important to listen carefully to the wishes and needs of each individual, and to pay attention to individual circumstances and constraints.

Sex education and training

When it comes to providing sex education for people with intellectual disabilities, it is important to take into account particular learning disabilities, and any limitations in adaptive skills, which may make it harder to understand and remember information. In other words, sex education should be tailored to the particular needs of individuals. To proactively pay attention to the positive aspects of sex (Schaafsma, Kok, Stoffelen and Curfs, 2014), rather than providing sex education only when there are problems, or in relation to potential problems, is also of value. There is hardly any information available for women with an ID who are lesbian or bisexual that provides answers to their specific questions or focuses on the pleasurable aspects of sex with another woman (Duke, 2011; Löfgren Mårtenson, 2009; Noonan and Taylor Gomez, 2011; Stoffelen et al., 2103).

Social contact

Social contact is important in terms of experimenting with relationships, gaining experiences, developing a positive self-image, and avoiding loneliness. In this study, we found that participants' social contact was mainly limited to relatives and friends. To meet a (sexual) partner, it is necessary for LGBT women meet other LGBT women. Therefore, it would be helpful to provide support that focuses on developing social skills, enabling access to transport, increasing opportunities to meet others, and developing the financial ability to undertake social activities (Fulford and Cobigo, 2016). This would contribute directly to quality of life. To provide support to individuals navigating their way in the LGBT community, is also important. Facilitating peer support can mean that support is provided in an accessible and approachable manner, and it can reduce feelings of isolation (Dinwoodie et al., 2016). Commitment is required from the LGBT community - by connecting the specific needs of these women -, from caregivers and family members. Releasing everyone's own normative framework is essential to match optimally to the wishes and needs of these women.

Assertiveness

Loshek and Terrell (2015) point to the positive link between sexual assertiveness and positive physical and mental health outcomes for women. They distinguish three dimensions of sexual assertiveness in their sexual assertiveness questionnaire: the ability to initiate and communicate about desired sex, the ability to refuse unwanted sex, and the ability to communicate about sexual history and risk. For women with ID who are lesbian or bisexual, it is important to expand sexual assertiveness and to become resilient towards homophobic peers, caregivers, teachers and parents. Unfortunately, people with ID are often stigmatized (Ali, Hassiotis, Strydom and King, 2012; Ali, King, Strydom and Hassiotis, 2016; Paterson, McKenzie and Lindsay, 2012) and those who are lesbian, gay or bisexual have to face a double stigma (Dinwoodie et al., 2016; Duke, 2011; Löfgren Mårtenson, 2009; Meyer, 2003). Therefore, it is important that precisely these women (women with ID who are lesbian or bisexual) are supported so that they can become more sexually assertive and learn to cope with this double stigma. Only in this way, can these women practice their sexual rights as provided defined in the UN convention (2006).

6.4.2 Social awareness

Women with ID are part of our society and organizational systems. Richards et al. (2009) state that organizational systems, families, support staff, agencies, schools, and governments have a social assignment to establish a climate of openness and attention to the sexuality of people with ID. Richards et al. (2009) advocate a holistic approach:

> …in which all systems and supports work cohesively, simultaneously, seamlessly, and in harmony to ensure that persons with developmental disability achieve equality in sexual rights…working together to support the individual with ID and takes a positive approach to ensuring that their sexual rights and needs are met. (Richards et al., 2009, p. 210)

An inviting attitude of all is necessary for this vulnerable group: women with ID who are lesbian or bi-sexual. Only then, they can develop themselves and claim a full-fledged place in our society.

Limitations

There are several reasons to be cautious when interpreting the results of this study. First, the number of participants is limited. To recruit enough participants for this study, was a difficult assignment. Support providers judged that some women with ID were too vulnerable to be interviewed. Some women decided not to participate. They did not want to talk to a researcher about such a sensitive subject. Or intermediaries did not know any women with ID who are lesbian or bi sexual. Second, participants were interviewed only once, about a sensitive topic and in a short amount of time. The results would have been richer if there had been more interviews with every participant. In this way, our participants would have become accustomed to the researcher, perhaps resulting in more intimate conversations and more reliable data. Because people with ID have a strong tendency to seek approval, and a tendency towards acquiescence in interviews, there is a strong likelihood that the data will be distorted (Finlay and Lyons, 2001; Williams, 2011). As to the methodology, the reliability of this study would have increased when the analyses were conducted by two authors. Lastly, in this study, we interviewed a specific cohort of women with ID. Namely, women with a mild ID who were willing and able to talk about a sensitive topic with an unknown researcher. This sample is not representative of all lesbian and bisexual women with ID in the Netherlands.

Recommendations

The population of people with ID is very heterogeneous; sexual diversity also exists within this group. In order to affirm, defend and respect the sexual rights of these individuals, we would like to make some recommendations.

First, sexuality is an important life domain. More effort should be made to increase awareness about sexual diversity in people with intellectual disabilities. Efforts to raise awareness should focus particularly on those who support individuals with an ID (such as staff, counsellors and teachers). The aim is for LGBT women with ID to become more self-aware and less vulnerable, and to able to use all possible resources and methods made available to them. Intellectual disability services and the LGBT community should implement policies to actively include and support LGBT people with ID. In addition, those developing and providing sex education should ensure that sexual education and training programmes are developed in a systematic way and in line with the latest scientific research (Schaafsma et al., 2013, 2014). Intellectual disability services and (special education) schools should monitor the quality of these sex education programmes. And finally, additional research is needed to learn more about sexuality and people with ID, in particular LGBT women with ID. Research institutions and funding bodies must prioritise research that focuses on this minority group in order for their fundamental human and sexual rights to be met. Research can contribute to a better and more fulfilling life for lesbian and bisexual women with ID.

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Appendix Interview schedule/topic list

Coming Out

What makes somebody lesbian?
Are you lesbian/someone who loves women?
How did you find out?
Do you talk about it with others? With whom?

Setting/environment

How does your family respond?
How do the people at your work respond?
How do facilitators respond?
Have you experienced unpleasant incidents?
Discrimination? Pointing? Abuse?

Sexuality

What was your first experience? How old were you then?
Do you have a partner?
Do you have sex with people without intellectual disabilities?
Do you get gifts or money for sex?
Have you ever had sex with a man?
Where do you have sex? And when?
What is masturbation? Do you ever masturbate?
Where? Is it allowed?
Can you have sex freely? Without interference from supervisors? In your own room? Can you lock the door?
Do you have sex only when you want it? Or do you have sex against your will?
What is an STD?
What can you do about it?

Lifestyle

Do you know other lesbians?
Do you have contact with other lesbians?
Do you visit bars for lesbians? Which? Why?
Can anyone see/notice that you’re lesbian? How?
Is there anything you would like to change in your life? What?
Where are you proud of?

Evaluation interview

How was the interview?
Which questions did you like?

Which questions were difficult?
Were there questions I shouldn’t have asked?
Are there any questions I forgot?

Chapter 7

General discussion

7.1 Introduction

"Like anyone else, individuals with developmental disabilities are sexual beings. They have sexual feelings, attitudes, and engage in sexual behaviour. Similarly, they are entitled to the same rights for basic and fundamental sexual health" (Coleman, 2002, p. 5). Coleman trenchantly articulates the view that was the guiding principle for our dissertation, and served as the starting point for our exploration of the theme of "sexuality and intellectual disability".

The subject of sexuality and people with intellectual disabilities (IDs) touches on many areas. The basic aim of the study was to obtain a better understanding of this complex material. Four research questions were formulated for this purpose. After an explanation of the research questions (Section 7.2) and the results (Section 7.3), we reflect on the methodological shortcomings of this type of studies (Section 7.4). The conclusion and recommendations (Section 7.5) present wide perspectives on the significance of the results for people with IDs, their families, their direct caregivers and the organisations responsible for care and support. We conclude with a number of reflections (Section 7.6).

7.2 The research questions

The four research questions formulated on the subject of sexuality and people with IDs are as follows.

> Research Question 1: *What is already known from scientific literature on sexuality in relation to IDs?*

Can specific themes be distinguished within the literature? Have particular themes been neglected? What is the influence of gender? Chapter 2 discusses and summarises the scientific literature that treats this first research question.

> Research Question 2: *In what way is support provided to people with IDs concerning the themes of sexual health and sexual rights?*

Many people with IDs rely on care and support systems. To support people with IDs in the Netherlands, the Individual Support Plan (ISP) document for care and support is of great importance. Use of the plan is a requirement for organisations that offer assistance under the provisions of the Long-term Care Act (Wet langdurige zorg, formerly known as the Algemene wet bijzondere zorg). In 2012, approximately 189,000 people in the Netherlands with IDs received care, support or both (Ministry of Health, Welfare and Sport, 2012). In view of the crucial role that the individual support plan occupies in the assistance sector, a study of these documents in relation to sexuality was initiated (Chapter 3).

> Research Question 3: *What do people with IDs themselves find important with regard to their sexual rights?*

People with IDs are rarely the object of scientific research. There is little or no attention to their ideas, desires, needs and experiences concerning sexuality (Winges-Yanez, 2014). Consequently, our third research question was aimed at ascertaining the ideas and opinions of people with IDs themselves. These findings are given in Chapter 4.

> Research Question 4: *How is sexuality experienced by specific groups such as lesbians, homosexuals, bisexuals and transgender (LHBT) people with IDs?*

Scientific literature on sexual diversity in people with IDs has always been scarce, and still is. We wanted to learn more about this specific under-represented group of people with IDs and discover their perspectives. This fourth and last research question produced two articles (Chapters 5 and 6): the perspective of a predominantly male group of people with IDs (19 men and 2 women) and the perspective of an exclusively female group with IDs (10 women).

7.3 Results of the studies

The primary results and conclusions concerning the research questions are given below.

7.3.1 Knowledge from scientific literature (Chapter 2)

In the article summarising the scientific literature in the area of people with IDs, we asked what the principal themes were. Our guiding principle was Nussbaum's capability approach (2014), which views sexuality as an essential human capability. We also referred to sexual rights as formulated by the World Association for Sexual Health (WAS, 2014). We obtained results related to issues such as obstacles to the attainment of sexual rights, gender and sexual diversity. The lack of literature devoted to people with severe IDs was striking.

Sexual rights

Sexual rights contribute to sexual health and to quality of life (Schalock, Keith, Verdugo and Gomez, 2010). However, achieving these rights is not a matter of course for people with IDs. People are "innately hampered" by their IDs because they have reduced cognitive and adaptive skills (De Bruijn, Buntinx and Twint, 2014; Gilmore and Cuskelly, 2014; Schalock et al., 2010b; Schalock et al., 2012). This results in a lack of sexual knowledge and of social, communicative and decision-making skills, as well as dependence on third parties and a lack of resilience. In addition, genetic factors can exert an influence on sexual development and behaviour. As a result of the influence of the IDs and genetic factors, people with IDs find themselves more vulnerable to sexual abuse than the general population (Abbott and Howarth, 2005; Eastgate, Van Driel, Lennox and Scheermeyer, 2011; Hickson, Khemka, Golden and Chatzistyli, 2008; McCarthy, 2001; Reiter, Bryen and Shachar, 2007; Stoffelen, Kok, Hospers and Curfs, 2013; Van Berlo et al., 2011). Similarly, people with IDs encounter problems in finding and maintaining sexual relationships (Abbot and Burns, 2007; Abbot and Howarth, 2007). There has been some societal controversy in the Netherlands about whether the wish of people with IDs to have children should be encouraged.

Gender

Scientific literature does not always differentiate according to gender (Porter, Christian and Poling, 2003; Wilson, 2009). This specification is needed to gain better insight, considering the numerous areas in which men and women differ. Attention is devoted to the gynaecological health of women, but this is less true of their sexual autonomy, skills and activities. With men, attention is particularly focussed on the risk of HIV infection, the perpetration of sexual abuse and problematic sexual behaviour. Less attention is paid to specific sexual health problems such as screening for prostate or testicular cancer.

Sexual diversity

Sexual diversity is also found in people with IDs. LGBT populations with IDs such as lesbians, homosexuals, bisexuals and transgender people are confronted with prejudices, stigma, problems with social relationships and lack of adequate support. Scientific research on sexual diversity in people with IDs is still scarce (Fraley, Mona and Theodore, 2007; Abbott, 2013).

7.3.2 Support for people with IDs (Chapter 3)

The support plans for 187 clients of seven Dutch institutions were subjected to a lexical search for terms related to sexuality and sexual health. The fragments thus discovered were then analysed. In the 187 ISP documents, a total of 475 goals were set out, but only 4 of these involved sexuality or intimate relationships. References to aspects of sexuality were found in 159 ISP documents (85%). Sixty of these ISP documents belonged to men, the other 99 to women. The references were primarily descriptive in nature. We found mostly descriptions of negative or problematic aspects of sexuality. References to sex education, treatment or intervention programmes were virtually absent. There was a considerable discrepancy between the quantity of information describing aspects of sexuality in people with IDs and the number of support strategies, arrangements or goals in this area. Only 8 ISP plans (4.28%) contained information on the attitude of caregivers with regard to sexuality. These were mostly descriptions of how to react to clients in certain situations. We discovered few references that led to counselling or indications of support in the event of negative sexual experiences or abuse. Twelve documents reported sexual abuse, and of these, 4 documents reported that this abuse led to a trauma, while only 2 mentioned treatment for the trauma.

7.3.3 People’s stories (Chapter 4)

Science has paid hardly any attention to the stories and experiences of people with IDs. To uncover the ideas, needs and desires of these people, we engaged in a dialogue with them. As a basis for the study, we used the nominal group technique (NGT). The NGT method is a structured and specific form of focus research. People with IDs were involved in the design, planning, and execution of this study, as well as the analysis of the results. For example, a story line was developed in collaboration with members of a self-advocacy group. This resulted in the story of Sanne and Tom, two fictitious characters who fall in love. The story consisted of eight drawings telling the story of Sanne and Tom, occasionally supplemented with a few words such as “in love”, “together” or “dreams”. We asked the participants the following question: *“What do Sanne and Tom need?”* A total of 39 people with IDs took part in the discussions, divided into six groups. In total, 140 ideas were offered. While working according to the NGT method, people stated ideas, worked in a serious and concentrated manner, shared their experiences with one another, interacted respectfully with one another and encouraged one another to express their ideas clearly. They indicated that they found this manner of working rewarding.

Over all group outcomes, the most often valued items were the relationship between two people (47%), sex-related topics such as sex education (23%) and feeling safe and comfortable (10%). The study revealed that attainment of sexual rights is not a matter of course, and that people encounter obstacles. The participants stated that they require support in order to attain these rights.

7.3.4 Sexual diversity (Chapters 5 and 6)

In an exploratory study, we investigated the theme of sexual diversity in people with IDs. The first diversity study, described in Chapter 5, focussed on the experiences of 19 men and 2 women with mild IDs. The issues that they raised were the need for support, the desire to openly declare their identity in all sorts of settings, and the search for a partner. According to the participants, they particularly needed expert assistance in finding a partner. Here, there were differences between their valuation of the support received from a live-in caregiver (often negative) and from a sex therapist (often positive). We were struck by the high prevalence of negative sexual experiences and the number of reports of partner abuse.

In the first study of sexual diversity, women were greatly in the minority. We knew of no study of sexual diversity that questioned only women. To devote attention to this specific perspective, we initiated a follow-up study that recorded the experiences of 10 women. The women found it difficult to talk about such a sensitive topic as their sexuality. The results were indicative of a lack of information, sex education and role models. The women encountered little support in their search for information. Their social contact with others was often limited, and they found it difficult to find a partner. In addition, six participants suffered from mental health problems such as loneliness, depression and addiction. Seven participants also reported having experienced discrimination.

7.4 Methodological review

All the studies had methodological shortcomings, meaning that the results must be interpreted with caution. Each of the previous chapters whose subject is an individual study devotes extensive attention to the methodological shortcomings of that study. This section focusses once more on the research groups, recruitment, reliability, perspectives, framework and research methods.

Research groups

People with moderate to severe IDs were under-represented in these studies. They appear only in Chapters 2 and 3, and briefly at that. Chapters 4, 5 and 6 describe the perspectives of people with mild IDs. This can be attributed to the research design. We performed a qualitative study in which people with IDs were questioned on their ideas and experiences. A method of this type lends itself to working with people with mild IDs, but excludes those with moderate to severe IDs.

Recruitment of participants

The recruitment of participants for the study as described in Chapters 4, 5 and 6 had the effect that a specific group of individuals took part in the studies: they were primarily persons who were active members of a self-advocacy group or visited cafés sponsored by the COC, the Dutch organisation for the emancipation of homosexuals. They are thus not generally representative of the entire population with IDs. Furthermore, men were over-represented, and the number of participants for study 6 was limited. All outcomes must therefore be interpreted with a degree of caution.

Reliability

Research on sexuality is a sensitive subject. Like most people, people with IDs are not accustomed to talking about sexuality, so the performance ofthe people with ID and the way the researchers interpret them can yield a distorted view of reality. Additionally, participants in the LGBT studies were interviewed only once. Multiple interviews over a longer period, allowing a bond of trust to be built up between participants and researchers, would have led to richer and more reliable results. Finally, people with IDs tend to give socially acceptable answers (Finlay and Lyons, 2001; Paterson, McKenzie, and Lindsay, 2012). All these factors contribute to the conclusion that the participants' statements must be interpreted with a degree of caution.

Perspective

The various studies place strong emphasis on the perspective of people with IDs. When discussing sexuality in people with IDs, a number of stakeholders can be identified. Examples are family members, caregivers, doctors and support organisations. They all play a role in the lives of people with IDs and thus have an influence on the attainment of their sexual rights. The perspective of the stakeholders is covered only to a small extent in these studies. More attention to these perspectives would have led to better and more detailed insights. After all, these people are actively involved in the process and have an influence on the lives of people with IDs.

Framework

The studies were conducted in the Netherlands and this can influence the outcomes. Possible influences are the tolerant attitude of the Dutch society in general towards sexuality and sexual diversity, the fact that people with a mild ID often live and work in society (sometimes independently, sometimes in group homes), the involvement of family and parents in the lives of people with an ID and the well-educated support staff.

Research methods

The studies described in Chapters 3 to 6 could be supplemented with longitudinal research. This would also generate richer and more reliable data and lead to better insight into sexuality, sexual rights, the needs and desires in this area of people with IDs, and the support they wish for. In the various studies, concepts such as “sex”, “relationships” and “friendship” were not defined in advance. As a result, the studies are probably subject to some bias, as participants and authors of the ISP plans regularly use different definitions of such concepts. A study that focusses on the way in which this terminology is applied is therefore essential.

7.5 Conclusions and recommendations

The conclusion and recommendations are arranged in groups of people with IDs, support providers and health-care and support organisations.

7.5.1 People with IDs

Sexuality is an important subject for people with IDs. People with mild IDs are well able to communicate their ideas, wishes and needs concerning sexuality. They value not only the physical aspects, but the emotional and psychological aspects as well. Providing good sexual care and support demands more knowledge of how to develop the concept of shared decision-making (Ouwens, Van der Burg, Faber and Van der Weijden, 2012). The concept proceeds from mutual decisions about interventions and treatment aims on the part of the client, in cooperation with the assistance provider. This requires that a client is self-empowered enough to acquire sufficient knowledge and information for making such decisions. There is a distinct need for research on the use of this concept for people with IDs in connection with a sensitive subject like sexuality.

Gender and genetics have an influence on the sexual development and experience of people with IDs. The sexual behaviour of men is different from that of women, as are the sexual problems they encounter. Research into gender and genetically-specific sexuality will be needed to obtain better insight into the separate needs of men and women, and the exact role of genetic factors.

People with IDs are sexually vulnerable and are not adept at self-defence. Sex education must therefore not only be tailored to people's wishes and focussed on sexuality and opportunities for experiencing it. Attention must also be devoted to social relationships and skills, sexual rights, sexual health, recognition of signs of abuse, power imbalances, and the reporting of undesired situations. We also advocate a highly inclusive concept of sex education. This education should be based on scientific knowledge, and must answer the needs of people with IDs. Besides communicating knowledge, it should also address skills training, and provide support and training for the direct network of people with IDs: partners, family members and caregivers. Schaafsma (2013) advocates a number of improvements in sex education programmes: the use of an intervention-directed framework, the recruitment of relevant participants, the identification of effective methods and the evaluation of programmes.

Sexual diversity occurs in people with IDs. LGBT people with IDs encounter specific problems that affect their quality of life. They require assistance in the form of a safe life and work environment, in protection against venereal disease, in initiating and maintaining relationships, in protecting their privacy, in meeting others and in developing a positive self-image. Scientific literature on LGBT people with IDs has always been scarce, and still is. More qualitative and quantitative research is needed to obtain a thorough understanding of this specific target group, especially women who are lesbian, bisexual or transgender. It is not only the perspectives of these women themselves that should be further investigated; the same applies to closely involved figures such as family, friends and direct caregivers. The outlook and policies of support organisations should also be studied. These insights should lead to instruments for practice and policy that will contribute to the quality of life of LGBT people with IDs. Besides this, the "world" of transgender people with IDs has barely been scientifically explored to date.

In scientific research on sexuality, people with severe IDs constitute a minority. Very often, sexuality is not the main theme of studies involving this specific group (see De Geus-Neelen, Van Oorsouw, Hendriks and Embregts, 2017). Insight into the characteristic desires, needs and experiences of people with severe IDs will enhance the life quality of this group, whose sexuality has been seriously neglected by science.

7.5.2 Support providers

Support providers are important to the lives of people with IDs. These are often professionals, but can frequently also be family members, friends or volunteers.

Professional support providers must know about and take into account the ID as such, as well as the influence of biological factors. Additionally, we recommend that they should consult with the people themselves and find out what their stories are. What do they dream about? What questions do they have? What support needs do they have? One must have an open attitude to genuinely listen to people with attention for the positive aspects of sexuality. Tuffrey-Wijne (2013) gives examples of how to engage in conversation with people about sensitive subjects (see also Tuffrey-Wijne and Davies, 2006; Tuffrey-Wijne, Bernal, Butler, Hollins, and Curfs, 2007).

Sex education is often given by professional support providers. Here, they must also address the positive aspects of sexuality, without neglecting other aspects such as sexual abuse, unplanned pregnancy, "healthy" masturbation (particularly for women) and venereal disease.

The support plan is used as a tool for recording the arrangements made for professional support. When establishing the need for support, it is good to investigate why people display a particular sexual behaviour, what that behaviour truly indicates and what the person hopes to communicate by it. Research by Herps (2017) shows that support plans still leave room for improvement. Professional support providers are advised to expand their competencies. With reference to the findings of this study, we advise the improvement of the competencies related to sexuality, specifically knowledge, insight, skills and attitude. The support plan must display coherent links between the person's wishes and support needs, the goals, the arrangements and the evaluation for support.

In addition to professional support providers, there are also family members, friends and volunteers. Training and support of this group of people will help them to overcome their shame and embarrassment about having to deal with sexuality. This will indirectly benefit the support for people with IDs.

7.5.3 Organisations

Outside the circle of people with their families, volunteers and professional support givers, care and support organisations also play a part in dealing with the sexuality of people with IDs.

When the policies of an organisation supporting people with IDs are sensitive to sexuality, this gives evidence of respect for and recognition of the sexual rights of people with such disabilities. This means that sexual policy should not only be aimed at the elimination of risks; it should strive to create a frame of reference for the people themselves, their families and support providers. In this way, sexual rights for these people can be attained. This involves supporting the people and their families, but also offering the organisation's employees support and active training for engaging in dialogue, recognising support needs and providing opportunities for people to obtain their rights in a safe and positive way. Organisations must ensure that sex education and training programmes conform to quality standards.

In view of current developments in care and support for people with IDs, it is also important to work with partners in the area of sexuality. After all, it is increasingly the case that people live extramurally or independently for longer periods of time. This makes it necessary to achieve cooperation and coordination between education, welfare and care organisations, primary and secondary care, and government when dealing with the area of sexuality. People with IDs are increasingly being required to deal with a variety of care and support organisations. Besides, factors such as high abuse rates, lack of adequate support, and health risks and problems attest to the need to attend to sexuality and the chain of cooperation described above.

7.6 Conclusion

We have several final reflections in connection with the subject of this study. First, the topic of sexuality in people with IDs merits more attention in both science and in practice. The theme of sexuality should be viewed in the broader context of sexual rights and especially demands consideration in relation to the quality of life of people with IDs. Consequently, it is vital not to neglect the people in question and to listen to their ideas, needs and desires; first, because their stories matter, but also because the telling of these stories has an empowering effect. The stories of people with severe IDs also deserve study. Indeed, how can we “understand” these people without knowledge and consideration of an essential component of their humanity? Finally, there should be more attention for the position of professional support providers, particularly for situations in which they feel hesitant to take action. Demands are made of them even though they do not command sufficient skills, knowledge and instruments to be able to meet those demands. The complexity surrounding the divergent opinions within different cultures and world views will have to be addressed on a future occasion.

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Summary

The subject of this dissertation is sexuality and people with intellectual disabilities (IDs). Like the rest of us, people with IDs have sexual feelings, needs and desires. Sexuality often proves complicated for them. This dissertation is meant to explore this theme and gain a better understanding.

Chapter 1

The introductory chapter gives a concise introduction to the research questions and the lines of investigation. The first question is focused on what is known in the scientific literature on the topic of sexuality in relation to ID. The second research question concerns the way in which care is given in support of people with IDs related to the themes of sexual health and sexual rights. The third question is about what people with IDs themselves consider important about their sexual rights. To this end, we engage in dialogue with people themselves. The last research question has sexual diversity as its subject. People with IDs also have different forms of sexual orientation. The experiences of these specific groups have been explored.

Chapter 2

Chapter 2 summarises the scientific literature on the subject of people with IDs. This chapter also serves as an extensive introduction to the topic. A number of important themes are elaborated.

First of all, attention is paid to the concept of ID and the gradations in disability. People with IDs have a substantial deficit both in cognitive function (an IQ of under 70) and in adaptive behaviour which presented before the age of 18. Based on four examples (Down syndrome, Prader-Willi syndrome, Fragile-X syndrome and Fetal Alcohol Syndrome), biological factors are illustrated that influence details in relation to sexuality.

Sexual rights for people with IDs make up the next theme. These rights do not come as a matter of course. People face obstacles in the area of privacy and overprotection, but also suffer from lack of knowledge and skills. Three rights are explicitly stated. First, there is a right to protection. People with IDs are vulnerable and have a considerable risk of being sexually abused. This vulnerability can be attributed to a lack of sexual knowledge and social skills. Next comes the right to information and education. People encounter resistance in this area from their immediate environment. In other words, family members and caregivers apply standards of acceptable behaviour to people with IDs that are different to the norms they apply to themselves. Additionally, people with IDs have scarcely any access to ready information on their sexual rights. The third right is a controversial and sensitive topic: the right to have children. Parents with IDs encounter barriers when fulfilling their duties as parents. Children of parents with IDs grow up in an environment with numerous problems.

People with IDs find that they have problems concerning sexuality, which is a theme of fundamental importance. These problems are related not only to IDs, but to environmental factors as well. Scientific research devotes hardly any attention to the group of people with severe IDs. They are extremely dependent on others, and their caregivers often find it difficult to figure out their desires and needs. People with mild IDs find it difficult to initiate and maintain social relationships. This makes them vulnerable to situations such as loneliness and sexual abuse. Signs of sexual abuse are discussed in detail. Teaching people with IDs to become resilient offers them protection against this vulnerability.

The issue of gender also deserves attention. Scientific research on sexuality in people with IDs does not always differentiate according to gender. This specification is needed to gain better insight, considering the differences between men and women. The physical health of women is taken into consideration, but there is less attention to their sexual autonomy, skills and activities. Many women with IDs do not experience pleasurable sex with a partner. It is therefore important to pay attention to the woman's satisfaction and to find ways to help her achieve orgasm. In men, attention is particularly focussed on the risk of HIV infection, the perpetration of sexual abuse and problematic sexual behaviour. There is less attention for specific problems of sexual health such as screening for prostate or testicular cancer.

The theme of sexual diversity is also treated in this literature exploration. Sexual diversity is present in people with IDs. LGBT groups with IDs such as lesbians, homosexuals, bisexuals and transgender people are confronted with prejudices, stigma, problems with social relationships and lack of adequate support. Scientific literature on sexual diversity in people with IDs is still scarce.

Finally, many problems are found in both women and men with IDs. These include such problems as a lack of knowledge and skills, and dissatisfaction with a partner. Additionally, women and men experience separate problems, which are also discussed. The literature exploration is concluded with a number of concluding remarks. The importance of knowing the sexual desires, needs and problems of people with IDs is pointed out.

Chapter 3

Chapter 3 describes the study of the contents of the support plans for people with IDs. Sexuality is a component of the plans. These plans play a highly important role in the Netherlands. The agreements for health-care insurance according to the Exceptional Medical Expenses Act (AWBZ) came into effect in 2009. These oblige health-care providers to specify the goals of their care and support in a plan and to discuss this with clients. In this way, people can have a say in the care and support that they receive and can make their personal wishes known. The purpose of this statutory regulation is to promote person-oriented support and to improve the quality of life of the people covered by this regulation.

A lexical search was performed in selected support plans with keywords related to definitions of sexual rights. Subsequently, the fragments found were encoded and analyzed. Reference to the theme of sexuality was found in 159 of the 187 plans (85%). However, these references consisted primarily of descriptions of negative or problematic aspects of sexuality. References to sex education, treatment or intervention programmes were virtually absent. Only eight plans contained information on the attitude of caregivers, and only four stated goals regarding sexuality. Although we found few references to sexuality in the plans, this is not to say that the subject plays no role in the daily supervision of people with IDs. Sexuality is a sensitive subject and there are various reasons why it may not find its way into the support plan. For example, a person with an ID or their family members may have been unwilling to share information concerning sexuality.

Chapter 4

Chapter 4 discusses research in which we conversed with the people themselves about sexuality. The goal was to explore the views on sexuality of people with a mild ID. To this end, we used the nominal group technique (NGT). The NGT method is a structured and specific form of focus group research. It is a single-question technique that combines qualitative and quantitative methods of data collection in relatively small groups. People with IDs took part in the design, planning, and execution of the study, as well as the analysis of the research.

A total of 39 people with IDs, divided into 6 groups, were questioned about their ideas, desires and needs. They named as most important items the relationship between two people (47%) and related topics such as sex education (23%) and feeling safe and comfortable (10%). The participants stated that they required support in order to attain these rights. The results of the research show that for people with IDs, values such as quality of life, empowerment, communication and social skills and a good place to live, are important. The most important issues concern not only the physical aspects of sexuality, but the emotional and psychological aspects and skills as well. Furthermore, the study confirms that people with IDs are capable of discussing sensitive subjects. The NGT proved to be a suitable method for this purpose. The method also showed itself to be usable for participative research on people with IDs.

Chapter 5

Chapter 5 describes the results of an exploratory study on sexual diversity in people with IDs. It examines in detail the experiences of 19 men and 2 women with mild IDs. The issues that they raised were the need for support, the desire to openly declare their identity in all sorts of settings, and the search for a partner. According to the participants, they particularly needed expert assistance in finding a partner. Here, there were differences in their valuation of the support received from a caregiver (often negative) and a sex therapist. Notable was the high prevalence of negative sexual experiences and the number of reports of partner abuse.

The interviews reveal issues that are important for supporting this specific group of people with IDs. It concerns things like training programmes for recognising and avoiding undesirable situations, prevention of venereal disease and the development of a positive self-image. Additionally, creating a safe living and working environment is of great value, as this serves to lower the risk of discrimination and bullying, or even prevent it. Finally, having safe meeting places is important.

Chapter 6

In chapter 6 we describe the outcomes of a study on sexual diversity in women with IDs. The experiences of sexuality of 10 women were questioned. The women found it difficult to talk about such a sensitive topic as sexuality. The results were indicative of a lack of information, sex education and role models. The women encountered little support in their search for information. Their social contact with others was often limited, and it was difficult for them to find a partner. In addition, six participants suffered from mental health problems such as loneliness, depression and addiction. Seven participants also reported having experienced discrimination.

Adequate support for lesbian or bisexual women with IDs calls for support in three areas. The first of these is sex education and training that take the ID into account. There is also a need for support during social contact so that these women can experience how to initiate and experiment with relationships, develop a positive self-image and escape feelings of loneliness. It is also essential to promote sexual assertiveness and resilience against stigma. Women with IDs are an element of society. They need an open and embracing attitude on the part of family, friends, support organisations, schools and government in order to develop themselves and claim their position in society.

Chapter 7

The starting point for this thesis was to obtain a better understanding of the topic of sexuality in relation to ID. Four research questions were formulated for this purpose, resulting in five studies. The most important results and conclusions with regard to the research questions are described in this chapter. Likewise, methodological notes are placed with the investigations. A closer look will be taken at the shortcomings of the studies. In particular, the underrepresentation of people with a moderate to very severe ID among the research groups, the method of recruitment of participants for the research, the reliability of findings and possible biases by making an emphatic emphasis on the perspective of people with an ID itself and less on other people involved. The conclusion and recommendations are arranged in groups of people with IDs, caregivers and health-care and support providers.

Sexuality is a subject of importance for people with IDs. People with mild IDs are well able to communicate their ideas, wishes and needs concerning sexuality. They value not only the physical aspects, but the emotional and psychological aspects as well. In daily life, they experience problems to realize their sexual rights. They are dealing with overprotection, segregation, stigmatization and lack of privacy. People with IDs are vulnerable and not very resistant, not only in the area of sexuality. Sexual diversity can be found in people with IDs, which again poses specific problems. The experiences, needs and desires of people with severe IDs have received hardly any scientific study. We advocate more attention for this group.

Both professionals and individuals such as family, friends and volunteers provide support to people with IDs. It is important that they are aware of the ID as such, as well as the influence of biological factors on sexuality. Sex education must be not only about skills, but should discuss the positive aspects of sexuality. The support plan can be a useful tool. Attention to the position of parents and professional supporters around the complex theme of sexuality is justified. After all, requirements are imposed on them without having sufficient skills and knowledge to meet these requirements. Shame and divergent views within different cultures and philosophies do not make things any easier.

Care and support organisations play an important role in dealing with the sexuality of people with IDs. We advocate public policies that are sensitive to sexuality. Additionally, collaboration and agreement with possible partners in the field is advised. Consultation with the people themselves and their direct stakeholders is essential.

We conclude with a single consideration on the basis of the scientific exploration. The subject of sexuality among people with an ID deserves more attention from both science and practice. The group of people with IDs is heterogeneous. There must be sufficient attention for the diversity between people. Consideration of the theme in a broader context of sexual rights is desirable with explicit attention to the relation to quality of life. Finally, attention is requested for the position of relatives of family members and professional supporters.

Samenvatting

Het onderwerp van deze dissertatie is seksualiteit en mensen met een verstandelijke beperking (VB). Ook mensen met een VB hebben seksuele gevoelens, wensen en verlangens. In deze dissertatie wordt het thema seksualiteit en VB nader verkend. Het doel is beter zicht te krijgen op dit veel omvattend en complex onderwerp.

Hoofdstuk 1

Het inleidend hoofdstuk bevat een toelichting op de vier, voor een nadere verkenning van het onderwerp, geformuleerde onderzoeksvragen. De eerste vraag is gericht op wat in de wetenschappelijke literatuur bekend is over het onderwerp seksualiteit in relatie tot VB. Op welke wijze in de zorg invulling gegeven wordt aan ondersteuning van mensen met een VB rond de thema’s van seksuele gezondheid en seksuele rechten, betreft de tweede onderzoeksvraag. De derde vraag gaat over wat mensen met een VB zelf belangrijk vinden omtrent hun seksuele rechten. Hiertoe wordt met de mensen zelf in gesprek gegaan. De laatste onderzoeksvraag heeft als onderwerp seksuele diversiteit. Ook bij mensen met een VB is sprake van verschillende vormen van seksuele geaardheid. De ervaringen van deze specifieke groepen zijn exploratief verkend.

Hoofdstuk 2

In hoofdstuk 2 wordt als een eerste verkenning een samenvatting gegeven van de wetenschappelijke literatuur op het gebied van seksualiteit bij mensen met een VB.

Allereerst wordt aandacht besteed aan het begrip VB en de gradaties in beperking. Mensen met een VB hebben een substantiële beperking in zowel cognitief functioneren (een IQ van minder dan 70) als adaptief gedrag, en het is ontstaan vóór de leeftijd van 18 jaar. Aan de hand van een viertal voorbeelden (Downsyndroom, Prader-Willi syndroom, Fragile-X syndroom en Fetal Alcohol Syndroom) worden biologische factoren geïllustreerd die van invloed zijn op bijzonderheden in relatie tot seksualiteit.

De seksuele rechten voor mensen met een VB is een volgend thema in deze literatuurverkenning. Deze rechten zijn geen vanzelfsprekendheid. Mensen hebben te maken met overbescherming en belemmeringen op het gebied van privacy, maar ook met een gebrek aan kennis en vaardigheden. Een drietal rechten worden geëxpliciteerd. Zo is er het recht op bescherming. Mensen met een VB zijn kwetsbaar en hebben een grote kans op seksueel misbruik. Deze kwetsbaarheid kan worden verklaard vanuit een gebrek aan seksuele kennis en een gebrek aan (sociale) vaardigheden. Verder is er het recht op informatie en educatie. Daarbij stuiten mensen op weerstand vanuit hun directe omgeving. Zo hanteren familieleden en ondersteuners andere normen voor wat gebruikelijk is voor mensen met een VB, dan voor henzelf. Daarnaast hebben mensen met een VB nauwelijks de beschikking over toegankelijke informatie over hun seksuele rechten. Als derde recht wordt het recht op kinderen toegelicht. Een controversieel en gevoelig thema. Ouders met een VB ervaren barrières bij het vervullen van hun taak als ouder. Kinderen met ouders met een VB groeien op in een omgeving met een veelheid aan problemen.

Mensen met een VB ervaren problemen rondom seksualiteit, een wezenlijk thema. Deze problemen hebben niet alleen te maken met de VB maar ook met omgevingsfactoren. In wetenschappelijk onderzoek is nauwelijks aandacht voor de groep van mensen met een (zeer) ernstige VB. Zij zijn zeer afhankelijk van anderen. Begeleiders vinden het moeilijk om hun wensen en behoeften te achterhalen. Mensen met een lichte VB ervaren problemen in het aangaan en onderhouden van sociale relaties. Dat maakt hen kwetsbaar voor bijvoorbeeld eenzaamheid en seksueel misbruik. Signalen van seksueel misbruik worden nader toegelicht. Het weerbaar maken van mensen met een VB, biedt hen bescherming tegen deze kwetsbaarheid.

Gender is een ook een issue dat aandacht verdiend. In wetenschappelijk onderzoek naar seksualiteit bij mensen met een VB wordt niet altijd onderscheid gemaakt naar gender. Deze specificatie is nodig voor een beter inzicht gezien de verschillen tussen mannen en vrouwen op tal van gebieden. Bij vrouwen is er wel aandacht voor de lichamelijke gezondheid, maar minder aandacht voor hun seksuele autonomie, vaardigheden en activiteiten. Veel vrouwen met een VB ervaren geen plezierige seks met een partner. Aandacht voor de tevredenheid van de vrouw en hoe ze bijvoorbeeld een orgasme kan hebben, is daarom belangrijk. Bij mannen is er met name aandacht voor het risico op hiv, als pleger van seksueel misbruik en voor problematisch seksueel gedrag. Er is minder aandacht voor specifieke seksuele gezondheidsproblemen als screening op prostaat- of testikelkanker.

Het thema seksuele diversiteit is eveneens opgenomen in de literatuurverkenning. Seksuele diversiteit komt voor bij mensen met een VB. Lesbiennes, homoseksuelen, biseksuelen en transgenders (LHBT-ers) met een VB worden geconfronteerd met vooroordelen, stigma, problemen rondom sociale relaties en een gebrek aan adequate ondersteuning. Wetenschappelijk onderzoek naar seksuele diversiteit bij mensen met een VB is nog steeds schaars.

Veel problemen komen zowel bij vrouwen als mannen met een VB voor. Het gaat dan over een gebrek aan kennis en vaardigheden over seksualiteit en aan seksualiteit gerelateerde onderwerpen of over ontevredenheid met de partner. Daarnaast kennen vrouwen andere problemen dan mannen, deze worden toegelicht. De literatuurverkenning wordt afgesloten met enkele concluderende opmerkingen. Gewezen wordt op het belang van het weet hebben van de seksuele wensen, behoeften en problemen van mensen met een VB.

Hoofdstuk 3

In hoofdstuk 3 wordt een studie beschreven naar de wijze waarop en de mate waarin het onderwerp seksualiteit in ondersteuningsplannen voor mensen met een VB aan bod komt. Het werken met ondersteuningsplannen is vanaf 2009 verplicht door het van kracht worden van het Besluit zorgplanbespreking AWBZ. Zorgverleners moeten de doelen van de zorg- en ondersteuning in een plan vastleggen en met hun cliënten bespreken. Mensen krijgen op deze wijze inspraak over de zorg en ondersteuning en ze kunnen hun persoonlijke wensen kenbaar maken. Doel van deze wettelijke regeling is om persoonsgerichte ondersteuning te bevorderen en de kwaliteit van bestaan van de mensen, vallend onder deze regeling, te verbeteren.

Een lexicale search werd uitgevoerd in geselecteerde ondersteuningsplannen met zoekwoorden gerelateerd aan definities over seksuele rechten. Vervolgens werden de gevonden fragmenten gecodeerd en geanalyseerd. Verwijzing naar het thema seksualiteit werd in 159 van de 187 plannen (85%) gevonden. Echter, de verwijzingen bestonden met name uit beschrijvingen van negatieve of problematische aspecten van seksualiteit. Verwijzingen naar seksuele educatie, behandeling, of interventieprogramma's werden nauwelijks vastgesteld. In slechts 8 plannen vonden we informatie over de houding van begeleiders en in slechts 4 plannen doelen rondom seksualiteit. Ondanks de schaarse verwijzingen naar ondersteuning op het vlak van seksualiteit in de plannen, hoeft dit niet te betekenen dat het onderwerp geen rol speelt bij de dagelijkse begeleiding van mensen met een VB. Seksualiteit is een sensitief onderwerp en om verschillende redenen kan het mogelijk zijn dat het niet in het ondersteuningsplan aan bod komt. Bijvoorbeeld omdat de persoon met de VB zelf dit niet wil of omdat zijn naasten geen informatie over seksualiteit in het ondersteuningsplan willen laten opnemen.

Hoofdstuk 4

In hoofdstuk 4 wordt het onderzoek beschreven waarbij met mensen zelf in gesprek is gegaan over het thema seksualiteit. Hier was het doel het verkennen van de opvattingen over seksualiteit van mensen met een lichte VB. Gebruik werd daarbij gemaakt van de 'Nominal Group Technique' (NGT). NGT is een gestructureerde en specifieke vorm van focusgroep onderzoek. Het is een 'single-question'-techniek die kwantitatieve en kwalitatieve methoden voor gegevensverzameling combineert voor relatief kleine groepen. Mensen met een VB waren betrokken bij het ontwerp, de planning, de uitvoering en de analyse van het onderzoek.

Verdeeld over 6 groepen werden in totaal 39 mensen met een VB gevraagd naar hun ideeën, wensen en behoeften. De belangrijkste items waren voor hen de relatie tussen twee personen (47%), seks en gerelateerde onderwerpen als seksuele voorlichting (23%) en een veilig en comfortabel gevoel (10%). De deelnemers verklaarden dat ze ondersteuning nodig hebben bij het verwezenlijken van deze rechten. De uitkomsten van het onderzoek laten zien dat voor mensen met een VB waarden als kwaliteit van leven, empowerment, communicatie en sociale vaardigheden en een goede plek om te wonen, belangrijk zijn. Inzake seksualiteit gaat het niet alleen over de fysieke aspecten van seksualiteit, maar ook over de emotionele en psychologische aspecten, evenals vaardigheden. Deze worden door de deelnemers eveneens als belangrijk beschouwd. Uit het onderzoek blijkt dat mensen met een VB in staat zijn om over sensitieve onderwerpen zoals seksualiteit en verwante onderwerpen te praten. De NGT is hiervoor een geschikte methodiek.

Hoofdstuk 5

In hoofdstuk 5 worden de resultaten beschreven van een exploratief onderzoek naar seksuele diversiteit bij mensen met een VB. De ervaringen van 19 mannen en 2 vrouwen met een lichte VB zijn nader onderzocht. De issues die bij hen speelden waren: de behoefte aan ondersteuning, de wens om openlijk te kunnen uitkomen voor hun identiteit in allerlei settings, en de zoektocht naar een partner. Met name bij het zoeken naar een partner gaven deelnemers aan deskundige ondersteuning nodig te hebben. Daarbij werd verschil gemaakt in waardering van de ondersteuning door een woonbegeleider (veelal negatief) en een seksuoloog (overwegend positief). Opvallend was de hoge prevalentie van negatieve (seksuele) ervaringen en het aantal meldingen van mishandeling door een partner.

Uit de interviews komen zaken naar voren die van belang zijn voor het ondersteunen van deze specifieke groep mensen met een VB. Het gaat daarbij om zaken als trainingsprogramma’s voor het herkennen en voorkomen van sociaal onwenselijke situaties, het voorkomen van seksueel overdraagbare aandoeningen (Soa’s), en het bijdragen aan de ontwikkeling van een positieve identiteit. Daarnaast is het creëren van een veilige woon- en werkomgeving van belang zodat de kans op ervaringen met discriminatie en pesten worden verkleind en voorkomen. Tot slot zijn ontmoetingsplaatsen van betekenis.

Hoofdstuk 6

In hoofdstuk 6 geven we de uitkomsten weer van onderzoek naar seksuele diversiteit bij vrouwen met een VB. De ervaringen rond seksualiteit van 10 vrouwen zijn nader bevraagd. De vrouwen vonden het moeilijk om te praten over een sensitief onderwerp als seksualiteit. De resultaten wezen op een gebrek aan informatie over seksualiteit en aan seksualiteit gerelateerde zaken; seksuele educatie werd als een gemis ervaren; en rolmodellen waren niet beschikbaar. De vrouwen ervoeren weinig steun bij hun zoektocht naar informatie over het onderwerp seksualiteit. Het sociale contact met anderen was vaak beperkt. Ze gaven aan moeite te hebben met het vinden van een partner. Bovendien kampten zes deelnemers met psychische gezondheidsproblemen als eenzaamheid, depressie en verslaving. Ook meldden zeven deelnemers nadelige gevolgen van discriminatie.

Om vrouwen met een VB die lesbisch of biseksueel zijn adequaat te ondersteunen, is support nodig op drie onderdelen. Allereerst op het gebied van seksuele educatie en training waarbij rekening wordt gehouden met de VB. Daarnaast is ondersteuning bij sociaal contact nodig zodat deze vrouwen ervaringen opdoen in het aangaan en experimenteren met relaties, het ontwikkelen van een positief zelfbeeld en het voorkomen van eenzaamheid. Ook is het bevorderen van (seksuele) assertiviteit en het weerbaar maken tegen stigma onontbeerlijk. Vrouwen met een VB maken deel uit van de samenleving. Een open en uitnodigende houding van familie, vrienden, ondersteuningsorganisaties, school en overheid, is nodig zodat zij zichzelf kunnen ontwikkelen en hun plek in de samenleving kunnen claimen.

Hoofdstuk 7

Uitgangspunt bij dit proefschrift was het verkrijgen van een beter inzicht in het onderwerp seksualiteit in relatie tot de VB. Voor deze verkenning werd een viertal onderzoeksvragen geformuleerd. Deze vragen resulteerden in een vijftal studies. De belangrijkste resultaten en conclusies met betrekking tot de onderzoeksvragen worden in dit hoofdstuk beschreven. Eveneens worden methodologische kanttekeningen bij de onderzoeken geplaatst. Er wordt nader ingezoomd op de tekortkomingen van de studies. Met name de ondervertegenwoordiging van mensen met een matige tot zeer ernstige VB bij de onderzoeksgroepen, de wijze van werving van deelnemers voor het onderzoek, de betrouwbaarheid van bevindingen en mogelijke vertekeningen door het leggen van een nadrukkelijk accent op het perspectief van mensen met een VB zelf en minder op andere betrokkenen. De conclusies en aanbevelingen zijn gegroepeerd naar mensen met een VB, ondersteuners en zorg- en ondersteuningsorganisaties.

Seksualiteit is een onderwerp dat van betekenis is voor mensen met een VB. Mensen met een lichte VB zijn goed in staat om hun ideeën, behoeften en verlangens rondom seksualiteit kenbaar te maken. Zij hechten niet alleen waarde aan de fysieke aspecten van seksualiteit maar ook aan psychologische en emotionele aspecten. In het dagelijkse leven ervaren zij problemen om hun seksuele rechten te realiseren. Zij hebben te maken met overbescherming, segregatie, stigmatisering en gebrek aan privacy. Mensen met een VB zijn kwetsbaar en weinig weerbaar, niet alleen op het gebied van seksualiteit. Seksuele diversiteit komt voor bij mensen met een VB, hetgeen weer specifieke problemen met zich meebrengt. De ervaringen, wensen en behoeften van mensen met een (zeer) ernstige VB zijn nauwelijks wetenschappelijk bestudeerd. We pleiten dan ook voor aandacht voor deze groep.

Professionals, maar ook familie, vrienden en vrijwilligers, ondersteunen mensen met een VB. Belangrijk is dat zij zich bewust zijn van de VB ‘an sich’ en biologische factoren die van invloed zijn op de seksualiteit. Bij seksuele educatie moet er, naast aandacht voor vaardigheden, ook aandacht zijn voor de positieve aspecten van seksualiteit. Het ondersteuningsplan kan hierbij een nuttig hulpmiddel zijn. Aandacht voor de positie en veelal handelingsverlegenheid van ouders en professionele ondersteuners rond het complexe thema van seksualiteit is gerechtvaardigd. Immers aan hen worden eisen gesteld zonder dat zij over voldoende vaardigheden en kennis beschikken om aan deze eisen te voldoen. Schaamte en uiteenlopende opvattingen binnen verschillende culturen en levensbeschouwingen maken het geheel niet eenvoudiger.

Zorg- en ondersteuningsorganisaties spelen een rol bij seksualiteit van mensen met een VB. We pleiten voor een seksualiteit sensitief beleid. Daarnaast is samenwerking en afstemming met samenwerkingspartners in het veld geboden. Overleg met de mensen zelf en hun directbetrokkenen is daarbij essentieel.

Afgesloten wordt met een enkele overweging naar aanleiding van de uitgevoerde verkenning. Het onderwerp seksualiteit bij mensen met een VB verdient meer aandacht van zowel wetenschap als praktijk. De groep van mensen met een VB is heterogeen. Voldoende oog moet er zijn voor de diversiteit tussen de mensen onderling. Beschouwing van het thema in een bredere context van seksuele rechten is gewenst met nadrukkelijk aandacht voor de relatie tot het thema kwaliteit van leven. Tot slot wordt aandacht gevraagd voor de positie en veelal de handelingsverlegenheid van naasten en professionele ondersteuners.

Samenvatting in begrijpelijke taal

Dit boekje gaat over onderzoek naar seks. En over mensen met een verstandelijke beperking.

In hoofdstuk 1 staan 4 vragen. Hiermee zijn we gestart.
Dit waren de vragen:
1. Wat weten we over seks en mensen met een verstandelijke beperking?
2. Wat staat er in de ondersteuningsplannen over seks?
3. Wat vinden mensen zelf belangrijk?
4. Sommige mensen zijn lesbisch, homo, bi of transgender. Wat zijn hun ervaringen?

We hebben veel gelezen. Over seks en mensen met een verstandelijke beperking. Een samenvatting staat in hoofdstuk 2. Wat hebben we hiervan geleerd?
- Soms hebben mensen een verstandelijke beperking. Dan hebben ze moeite met begrijpen en toepassen.
- Door wat ze meekrijgen bij hun geboorte, kunnen mensen anders zijn. Zo begint bij vrouwen met het Downsyndroom de overgang eerder. En ze hebben een kleinere kans op borstkanker.
- We weten weinig over seks bij mensen met een (zeer) ernstige verstandelijke beperking.
- Alle mensen hebben seksuele rechten. Ook mensen met een verstandelijke beperking. Maar zij hebben moeite om deze rechten uit te voeren.
- Bij onderzoek naar seks wordt niet altijd rekening gehouden of je vrouw of man bent.
- Sommige mensen zijn lesbisch, homo, bi of transgender. Ook mensen met een verstandelijke beperking.

In hoofdstuk 3 hebben we gekeken naar ondersteuningsplannen. Seks moet een onderdeel zijn van het plan. In 184 plannen hebben we gekeken wat erin staat. Er staat niet veel in over seks. In 159 plannen staat ‘iets’. Het gaat vaak over problemen. Weinig over voorlichting of behandeling. In 8 plannen staat iets over ondersteuning. En in 4 plannen iets over doelen. Waarom staat er zo weinig in over seks? We denken dat mensen het niet altijd fijn vinden. Misschien willen mensen niks over seks in het plan opschrijven. Omdat het gevoelig ligt. Het gaat over een privé onderwerp.

We hebben met 39 mensen gepraat over seks. In hoofdstuk 4 hebben we dat opgeschreven. We hebben ze gevraagd wat ze belangrijk vinden. Daarvoor mochten ze punten geven. De meeste punten kregen:
1. De relatie tussen twee mensen
2. Seks en voorlichting
3. Veiligheid

We weten nu dat mensen gevoel, gedrag en bescherming, belangrijk vinden.

Sommige mensen zijn lesbisch, homo, bi of transgender. We hebben gepraat met ze. Dat staat in hoofdstuk 5.

We hebben gepraat met 19 mannen en 2 vrouwen. Mensen vertelden dat ze:
- behoefte hebben aan ondersteuning
- zichzelf willen zijn in hun huis, op hun werk en op straat
- een vriend(in) zoeken.

Een aantal zaken vielen op:
- de hulp van woonbegeleiders beviel soms niet
- de seksuoloog geeft wel goede hulp en advies
- veel mensen hebben seksueel misbruik meegemaakt
- mensen maken vaak ruzie met hun vriend en slaan elkaar dan.

We wilden meer weten over vrouwen die lesbisch of bi zijn. We hebben met 10 vrouwen gepraat. Dat staat in hoofdstuk 6.

De vrouwen vertelden dat ze:
- weinig informatie over seks hebben, weinig scholing en geen voorbeelden
- bijna geen andere vrouwen kennen die lesbisch of bi zijn
- het moeilijk vinden om een vriendin te vinden
- last hebben van eenzaamheid, depressies of verslaving
- en gediscrimineerd worden.

In hoofdstuk 7 staat wat we geleerd hebben. En we hebben een aantal tips.

Mensen met een verstandelijke beperking:
- kunnen goed vertellen over seks: hun dromen, gevoelens en ervaringen
- vinden gevoelens, gedrag en bescherming belangrijk
- zijn kwetsbaar en komen niet goed voor zichzelf op
- die lesbisch, homo, bi of transgender zijn, hebben andere problemen.

Ondersteuners (begeleiders, familie of vrienden):
- moeten rekening houden met de beperking van mensen
- horen aandacht te hebben voor het leren van vaardigheden bij voorlichting: hoe doe je iets?
- mogen ook aandacht hebben voor de positieve kanten van seks
- kunnen in het ondersteuningsplan schrijven over seks
- hoeven niet bang te zijn om te praten over seks
- en kunnen met mensen praten over seks.

Organisaties:
- horen beleid te maken over seks, ook over de mooie kanten van seks
- moeten beter samenwerken met anderen.

Wat hebben wij geleerd van alle onderzoeken?

- Seks verdient aandacht van onderzoekers
- Seks is belangrijk in het leven van mensen met een verstandelijke beperking
- Van de verhalen van mensen zelf kun je leren
- Er moet ook aandacht zijn voor de ondersteuners.

Valorisatie addendum

1. Inleiding

Het doel van dit proefschrift is om door onderzoek een beter inzicht te verwerven in het onderwerp seksualiteit in relatie tot verstandelijke beperking (VB). Met dit valorisatie-addendum wordt de opgedane kennis benut om de 'praktijk' van aanbevelingen te voorzien en onderscheiden naar: maatschappelijke relevantie (2), doelgroepen (3), appel op doelgroepen (4), activiteiten (5) en innovatie (6).

2. Maatschappelijke relevantie

De maatschappelijke relevantie van het onderzoek naar seksualiteit bij mensen met een VB is wezenlijk. Het onderwerp seksualiteit is in de 'wereld' van zorg voor mensen met een VB niet nieuw. Er is aandacht voor seksualiteit en steeds meer instellingen hebben seksuologen in dienst. Maar het accent ligt nog te vaak op probleemgedrag van mensen met een VB, de risico's van seksueel gedrag zoals ongewenste zwangerschappen, de loverboyproblematiek die met name bij meisjes met een lichte VB speelt, en seksueel misbruik.

Enkele aspecten die in deze thesis aandacht krijgen zijn relatief nieuw: het perspectief van mensen zelf; de positieve dimensies van seksualiteit, de seksuele rechten van mensen, seksuele diversiteit en gender.

3. Voor wie?

In de discussie van de thesis worden aanbevelingen gedaan voor mensen met een VB zelf, hun ondersteuners, de zorg- en ondersteuningsorganisaties. Vanzelfsprekend zijn de uitkomsten van dit onderzoek van belang voor meer 'stakeholders' als het gaat om de zorg en ondersteuning van mensen met een VB. Hieronder volgt een aantal van deze betrokkenen.

Dichtbij mensen

Mensen met een VB wonen steeds vaker in een gewone wijk, en maken ook daarbij gebruik van algemene voorzieningen en verenigingen als welzijnsvoorzieningen, vrijetijdsvoorzieningen en sportverenigingen. Daarnaast zijn tal van vrijwilligers actief bij verenigingen en organisaties. Al deze mensen staan in direct contact met en vaak dichtbij mensen met een VB. Zij krijgen te maken met vragen, wensen en gedrag, ook rondom seksualiteit.

Door het wonen in de wijk zijn mensen met een VB aangewezen op het gebruik van algemene gezondheidsdiensten, zoals huisarts, apotheek, GGD, etc. Deze gezondheidsdiensten beschikken niet altijd over de kennis die nodig is om mensen met een VB te ondersteunen. Voor hen kunnen de uitkomsten van dit onderzoek van betekenis zijn om betere zorg te geven en signalen rondom seksualiteit eerder op te pikken en deze adequaat te beantwoorden.

Belangenorganisaties

In Nederland zijn belangenorganisaties voor mensen zelf en hun ouders en naasten actief. De belangenorganisaties voor mensen met een VB zelf zijn beperkt tot de landelijke Vereniging LFB met lokale of regionale Onderling Sterk groepen. Er zijn daarnaast tal van ouderorganisaties voor ouders en naasten van mensen met een VB actief. Dit kunnen algemene organisaties zijn zoals KansPlus, op christelijke waarden georganiseerde organisaties als Dit Koningskind, of syndroomspecifieke organisaties als de Stichting Downsyndroom. De zorg- en ondersteunersorganisaties zijn verenigd in de Vereniging Gehandicaptenzorg Nederland (VGN). Deze landelijke vereniging ondersteunt gehandicaptenorganisaties, mengt zich in maatschappelijke discussies, en ondersteunt en stimuleert innovaties. Voor deze belangenorganisaties zijn de uitkomsten van dit onderzoek interessant. Ze kunnen er op verschillende manieren aandacht aan besteden. Door het organiseren van themabijeenkomsten of door artikelen in hun tijdschriften kunnen zij een bijdrage leveren aan de bewustwording van het belang van seksualiteit voor de kwaliteit van leven van mensen met een VB.

Opleidingsinstituten

Ander stakeholders zijn de opleidingsinstituten die de professionals van de toekomst opleiden en of de huidige professionals bijscholen. In Nederland zijn dat MBO-, HBO- en universitaire opleidingen. Veel professionals geven aan handelingsverlegen te zijn doordat er tijdens hun opleiding te weinig of nauwelijks aandacht was voor de positieve aspecten van seksualiteit en de andere dimensies die hiermee verbonden zijn zoals seksuele rechten en het perspectief van de mensen om wie het gaat en hun naasten.

Financiers

Zorgverzekeraars en gemeenten zijn ook belanghebbende want zij financieren de zorg voor mensen met een VB, sluiten contracten met aanbieders en stellen kwaliteitseisen. Aandacht voor seksualiteit als bijdrage aan kwaliteit van leven krijgt hierbij nauwelijks aandacht. Het is een onderwerp dat wordt genegeerd.

4. Appel

Uit de thesis blijkt dat seksualiteit een onderwerp is dat van betekenis is voor mensen met een VB. Maar seksualiteit en het realiseren van seksuele rechten is voor mensen met een VB geen vanzelfsprekendheid. Mensen met een VB zijn in deze kwetsbaar. Ze lopen een groter risico op seksueel misbruik, en ondervinden meer weerstand vanuit hun directe omgeving als het om seksualiteit gaat. Bij vragen en ondersteuning hebben zij te maken met handelingsverlegenheid, en onvoldoende vaardigheden en kennis bij naasten, vrijwilligers en professionals mede vanwege de complexiteit van het thema. Schaamte en uiteenlopende opvattingen binnen verschillende culturen en levensbeschouwingen maken het geheel niet eenvoudiger. Bij een thema als seksualiteit zijn vele stakeholders te onderscheiden, zie paragraaf 3. Sommigen staan in direct contact met mensen met een VB, anderen staan verder weg als belangenorganisatie, opleidingsinstituut of financier.

Seksualiteit is een wezenlijk thema dat bijdraagt aan de kwaliteit van leven. Mensen met een VB hebben op dit gebied ondersteuning nodig. Van elkaar en van anderen. Elke stakeholder kan vanuit zijn of haar mogelijkheden een positieve bijdrage leveren aan dit specifieke onderdeel van kwaliteit van leven. De uitkomsten van de verschillende onderzoeken laten zien dat verbeteringen wenselijk zijn. Deze zijn van directe invloed zijn op de kwaliteit van leven van mensen met een VB. Daarom doe ik een appel op elke stakeholder om de verantwoordelijkheid op te pakken en vanuit zijn of haar positie zich in te zetten voor kwaliteit van leven en voor het realiseren van mensenrechten, ook voor mensen met een VB.

5. Activiteiten

Gedurende het promotietraject zijn verschillende activiteiten ondernomen om het onderwerp onder de aandacht te brengen van diverse partijen.

Presentaties

Tal van presentaties zijn gegeven voor verschillende doelgroepen over de door ons gerealiseerde onderzoeken Bijvoorbeeld voor seksuologen tijdens symposia van de Nederlandse Wetenschappelijke Vereniging voor Seksuologie (NVVS); voor wetenschappers tijdens nationale congressen van de Wetenschappelijke Vereniging voor Seksuele Disfuncties (WVSD), The Institute for the Study of Education and Human Development of Focus op Onderzoek en tijdens internationale congressen van The International Association for the Scientific Study of Intellectual and Developmental (IASSIDD); voor werkers in de zorg en ondersteuning tijdens symposia van het Kennisplein Gehandicaptensector, het Euregionaal Congresbureau, referaatbijeenkomsten voor organisaties in de zorg; voor ouderverenigingen; cliëntenraden van organisaties, organisaties van mensen met een VB; en voor de overheid.

Onderwijs

In het onderwijs heeft het onderdeel Seksualiteit en mensen met een VB inmiddels een plek gekregen bij de opleiding van GZ-psychologen van het RINO in Eindhoven. Hier worden de mensen opgeleid dit niet alleen mensen met een VB ondersteunen maar ook de teams van medewerkers in het veld.

Publicaties

Naast publicaties in internationale wetenschappelijke tijdschriften, zijn artikelen en congresverslagen geschreven voor de werkers in 'het veld': het Nederlands tijdschrift voor zorg aan mensen met verstandelijke beperkingen (NTZ), het Tijdschrift voor seksuologie, het Nederlands Tijdschrift voor Evidence Based Pratice, en is het hoofdstuk *'Seksuele gezondheid van mensen met een verstandelijke beperking'* geschreven voor het Nederlandstalige handboek Seksuologie (uitgave medio 2018). Meegewerkt is aan interviews voor het blad Klik Verstandelijk Gehandicaptenzorg gericht op werkers in de directe zorg en het blad Markant van de VGN.

Activiteiten

Om aandacht voor onderzoek met mensen met een VB te genereren is in 2013 door het Gouverneur Kremers Centrum een landelijke studiedag georganiseerd voor onderzoekers, (beleids)medewerkers, en naasten van mensen met een VB onder de noemer *'Niet zonder ons, participatie van mensen met een verstandelijke beperking in zorg, onderzoek en beleid.'* Seksualiteit was een van de onderwerpen. Verder is geparticipeerd in een onderzoeksadviescommissie van Rutgers WPF en Movisie. Het verslag van dit onderzoek is in 2011 uitgebracht onder de titel: *'Beperkt weerbaar. Onderzoek naar seksueel geweld bij mensen met een lichamelijke, zintuiglijke of verstandelijke beperking'.*

Elke twee jaar worden in Nederland de Special Olympics georganiseerd, de grootste sportorganisatie voor mensen met een VB. Naast het sporten en de wedstrijden is er een nevenprogramma Healthy Athletes. Dit is een programma dat al sinds 2006 onderdeel is van deze Nationale Spelen. Health Promotion is een van de onderdelen van dit nevenprogramma en richt zich op gezondheidspromotie voor mensen met een VB. Binnen dit onderdeel is er sinds enkele jaren aandacht voor gezonde seksuele ontwikkeling.

6. Innovatie

Om (wetenschappelijke) kennis te implementeren in de dagelijkse praktijk van zorg en ondersteuning voor mensen met een VB, wordt een nieuw project opgestart onder de voorlopige werktitel 'Praten over seks'. Het doel is dat toekomstige werkers in de zorg mét mensen met een VB in gesprek gaan over handelingsverlegenheid zoals bij seksualiteit.

Het doel is om meer te weten te komen over de handelingsverlegenheid van werkers in de zorg, en ook van mensen zelf. Daarmee willen we een positieve bijdrage leveren aan de kwaliteit van leven van mensen met een VB. Een voorstel voor dit project is in voorbereiding en wordt ingediend bij financiers.

Dankwoord

Het onderzoek naar seksualiteit bij mensen met een verstandelijke was een lange ‘reis’. Veel mensen wil ik bedanken voor hun ondersteuning, positieve feedback, bemoedigende woorden en reisleiding. Een aantal mensen wil ik in het bijzonder bedanken.

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Curriculum Vitae

Joke Stoffelen was born in Groesbeek, the Netherlands on the 13e of January 1962. After completing her secondary school education, she started working (and studying) in the field of care for people with intellectual disabilities (the Groesbeekse Tehuizen/Pluryn). She has been working at Zorgbelang Gelderland |Utrecht, since 2001. The focus here is on advice and process support for organizations in the field of care, social work, education and governments. She studied Health Sciences at Maastricht University and graduated at 2007. The title of the thesis was 'Palliative care for people with intellectual disability'. She started her PhD project under the guidance of Prof. dr. Leopold Curfs and Prof. dr. Gerjo Kok. For more than ten years she was also involved in Onderling Sterk, an advocacy group for people with an intellectual disability. The Dutch Healthy Athletes programme, a part of the Special Olympics, has her attention and interest.