



# **Parents' Perceptions of the Sexuality of their Young Adults with Intellectual Disabilities: Experiences from The Netherlands**

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## **List of Acronyms**

ID	Intellectual Disability
WHO	World Health Organisation
UNCRPD	United Nations Convention on the Rights of People with Disabilities

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## **Abstract**

This study explores perceptions and experiences of parents in negotiating around the sexuality issues of their young adults with disabilities. Focusing on parents of those with intellectual disabilities, the study aimed to establish the views of parents and their parental practices regarding the sexuality of their adult children. Fieldwork mainly consisted of qualitative methods, including interviews with eight parents, from a range of different cultural and family backgrounds. Alongside interviews, one focus group discussion with three parents helped to encourage parents to identify shared and distinctive experiences. A key informant who provides psycho-social support for parents of young adults with disabilities, in a professional capacity, was also interviewed. The main findings of the study were the variations in parents' experiences and what disability means to them in terms of the sexuality of their adult children. Some parents expressed the belief that their children did not have the capacity to engage in sexual relations in a meaningful way. Mothers took the main responsibility for caring, for discussion and for parental guidance. Of eight informants, seven were women. For a few parents, discussion of sexuality posed no problems, and they accepted their adult children as beings able to have sexual partnerships. However, for some parents it was clear that these issues had rarely been discussed with anyone else, including with their disabled adult children. For some of these parents, cultural and religious obstacles seemed to be a challenge. The study identified a need for more informed support for parents in negotiating their young adults' sexuality, in the case of intellectual disabilities. Parenting intellectually challenges young adults is a unique process for each parent. They have varied situations and experiences that present enduring dilemmas.

## **Relevance to Development Studies**

Disability and sexuality are issues that concerns the wellbeing of persons with impairments who are disabled by the society. In many cases the disabled people were not given attention in the development discourse and that their rights were less respected and promoted. This made disabled people to be a group of people who experienced discrimination, oppression and little recognition in most societies. As development studies try to address social issues, this study will provide insight on the experiences of parents in their endeavours in facilitating the sexual wellbeing of young adults with intellectual disabilities

## **Keywords**

Sexuality, disability, parents, perceptions, adult children, Netherlands.

# Chapter 1

## Introduction and Overview

“Certainly, I never in my wildest dreams had planned for any of the experiences that we have had since having a child with a disability...It has changed absolutely every waking moment of our lives” (Parent of disabled child) (King et al 2006:358).

### 1.1 Introduction

Disability is an inevitable part of life that straddles all aspects of human existence with different meanings to parents and families in every society. Persons with disabilities are found in every age group, gender, class, colour in both developing and developed countries. There is a growing body of knowledge on disability and literature that tends to concentrate on caregiving, parenting, supporting and teaching children with disabilities (Carroll 2013). However, little has been published on the experiences of parents with disabilities in negotiating the sexuality of their young adult children with disabilities.

The World Health Organisation (2009) stressed that person with disabilities have the same sexual and reproductive needs as anyone in the society. The right of persons with disabilities to intimacy, have families, explore and enjoy their sexuality, and the breeding of children is at the heart of the United Nations Convention on the Rights of People with Disabilities, Article 23. It emphasises the need for these rights to be acknowledged and respected in both public and private spheres. Sexual rights are entitlements of all human beings whether disabled or not. Some studies argue that:

“Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. It 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” (Stoffelen et al 2017:9).

Some feminist theorists claim that while some perspectives on human rights considers individuals as self-regulating, intellectually disabled persons mostly rely on parents and family members (Silvers 2004). Thus, the lives of persons with intellectual disabilities rely on their family members, parents or guardians and care givers. Consequently, various studies proposed that parents are the primary source of sexuality education and viewed it normal and positive in promoting the sexual wellbeing of the young adults (Steutel 2009; Lamb 2010; Bay-Cheng 2013). Against this backdrop, it is the purpose of this study to explore the perceptions and experiences of parents on the sexuality of young adults with intellectual disabilities in their care.

## 1.2 Background

The World Health Organisation (2009) reported that 10% of the population of the world are people with disabilities and 30% of the world families lived with a member with a disability. The World Health Survey (2011) reported that 15.3 % of the world population are disabled people. This indicates an increase of 6% the population for the 2009 to 2011. From time immemorial, people with disabilities have been denied information about sexual and reproductive health and the right to explore their sexuality and form relationships and families. Some of young adults with intellectual disabilities experienced forced sterilisations, forced abortions, forced marriages, sexual violence and denial to sex (WHO 2009). Thus, people with intellectual disabilities are vulnerable to deprivation of their sexual rights in the hands of their parents and care givers as well as professionals. Many of such practices were the result of medical models of disability that viewed disability as a medical condition that require medical treatment less recognition as full citizens of the society with choices and rights like others.

Disability drew attention of development discourses globally, regionally and nationally that resulted in the adoption of the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) in 2008. The convention was founded in the human rights principles of dignity, equality, inclusion and participation of person with disability. Skarstad expresses that literature on the UNCRPD reveal that the convention is grounded in the idea that persons with disabilities are not passive human being, but they are “active agents rather than medical objects or objects of pity” (Skarstad 2018:25). Critical studies on disabilities suggests that the formulation of the UNCRPD was a result of the low visibility of persons with disabilities and the continued marginalisation of such group of people in both private and public spheres in the face of the Universal Declaration of Human Rights (UDHR). Article 23 of the convention stresses that persons with disabilities have sexual and reproductive health rights like anyone else in the society. The UNCRPD conceptualises disability as a result of perceptions and attitudes of both the society and state to persons with various impairments (Rioux et al., 2011) Thus, the challenges faced by people with disabilities are not a result of their disabilities, but the creation of the society.

The UNCRPD stresses that all the rights of persons with disabilities should be respected, promoted and implemented in all states. Article 23 of the Convention spells out the set of sexual reproductive health rights that persons with disabilities are entitled to. However, the Convention does not specify how these rights can be realised by all persons with disabilities considering the heterogeneity of disabilities, severity of the disabilities and varying ability to make decisions on the part of disabled people themselves.

## 1.3 Context of the Study

The population of children with disabilities in Netherlands for this study is based on the 2012 statistics. “In 2012, the Netherlands was home to between 109,000 and 129,000 children with a motor, perceptual or mental disability. This amounts to approximately 3.5 percent of all children in the country”

(Dutch NGO Coalition for Child Rights 2014:36). These statistics reflect that many thousands of families are faced with the realities of bringing up a disabled teenager and having to facilitate their sexual wellbeing.

The Netherlands is among the leading countries that has increasingly operationalised almost all the human rights instruments. The country ratified the United Nation Convention on the Rights of Persons with Disabilities UNCRPD in 2016. It is widely regarded as the country of law and rights. In addition to that, it is a host of many international human rights institutions and organisation. The country has made deliberate efforts to put in place necessary laws and policies that are meant to promote and protect the rights of the citizens and all vulnerable groups. However, this does not make the country immune to cases of violations of persons with disabilities. It is reported that,

“A total of 4,259 discrimination complaints were received last year. A massive 35 percent of them involved pregnancy discrimination. There were also 416 complaints of discrimination based on race, age, religion or sexual orientation. The Institute ruled on 161 of these complaints and found discrimination in 48 percent of these cases” (nltimes.nl 2018/04/16).

The report indicates statistics of incidences that were reported only, what more of those unreported cases. This shows that ratification of the convention and the formulation of supportive policies would translate to practice. Skarstad (2018) propounds that human rights provide some guidelines on how we should relate to each other and reducing chances of causing harm to each other in our day do day interactions. Although human rights and policies inform on how to do things, it does not mean the society has been transformed. It is the means to the end, and not the end.

World-wide, the Netherlands has long been regarded as relatively progressive on sexuality education and sexual reproductive health. It is mostly suggested that sexuality, issues are discussed openly in schools, families, public spaces and health care centres (Krebbekx et al 2017). This gives an impression that parents and children in the Netherlands can freely discuss sexuality issues that are commonly regarded as taboos in many societies in the world. As a matter of policy and practice, The Netherlands has implemented sex education as a compulsory curriculum for both primary and secondary schools. Thus, sexual and reproductive health rights and sexual diversity knowledge are imparted to children from a tender age. Rutgers (2018) claims that the Dutch sex education is grounded in the notion that young people are curious about sexuality and it is their right to have correct and full information on sexual and reproductive health rights to enable them to make informed decisions. As a result of this approach, students at secondary school levels are expected to be knowledgeable of their sexuality, proper use of condoms and contraception methods, pleasurable consensual sex, sexually transmitted diseases, social skills and relationships.

The Dutch community cannot be treated as a homogenous group with respect to perceptions and practices related to intellectual disabilities and sexuality rights. It is as multicultural country with diverse and conflicting philosophies and practices based on ethnic backgrounds of the citizens. The cross pollination of cultures may can create opportunities and dilemmas in

parenting and how sexuality matters are discussed between parents and adolescents with disabilities. The ethnic and cultural differences in the Netherlands are viewed to be conservatives that are retrogressive in the sexual and reproductive health (Krebbekx et al 2017). These cultural diversities in the society provides the framings on how disability and sexuality can be defined in the Netherlands. Choruma (2006) asserts that misconceptions about the occurrence of disability are based on traditional myths, taboos systems, superstitions, and religious beliefs. Some of the traditional misconceptions about disability are that having a child with disability is a curse to the family or punishment from angry gods. This has a bearing on how parents view sexuality of intellectually disabled young adults. Therefore, understanding the perceptions of parents on sexuality requires to explore what intellectual disability mean to them.

## 1.4 The Research Problem

Dominant conception about people with intellectual and other disabilities have been continually ramified in our minds every day consciously and unconsciously through the print and electronic media and all forms of communication that we interact with. The media is full of images that portray sex as privileged to “perfect bodies” (non-disabled) and these images socialise the society to a culture of “normal and abnormal” acceptable and unacceptable sexuality (Regnerus 2007; Shapiro 2010; Wilkins 2008). Thus, how sexuality is portrayed in the media is disability blind, it does not acknowledge the existence of people with intellectual disabilities and it perpetuate the negative attitudes of the society regarding sexuality and disabilities. In addition to the media, there are multiply, complex and multidimensional facets that accounts for how individuals and the society at large views disability and sexuality.

Sexuality is an essential part of every human being in forming the biological, psychological and social wellbeing and of every individual whether disabled or not. It includes sex, gender identities, sexual orientation, eroticism, pleasure, intimacy and reproduction (World Health Organisation 2002; Christensen et al 2017). However,

“various studies established that people with intellectual disabilities have low levels of sexual knowledge than other people in the society due to repressive care givers, attitudes towards sexual education, lack of appropriate education and training, societal predispositions, misperceptions, lack of privacy, independence upon care givers and meanings of persons with disabilities as asexual or hypersexual” (Kramers-Olen 2017:368).

Some studies claim that, “Parents are the primary source of sexual education and socialisation” (Christensen et al 2017:712). In this respect, parenting is central to the sexuality of young adults with intellectual disabilities. This suggest that, parents undergo diverse parenting experiences in relation to the sexuality of young adults with intellectual disabilities in their care (either biological children, adopted or foster children. In this regard, the research is concerned with exploring the perceptions and experiences of

parents regarding the sexuality of the young adults with intellectual disabilities in their care.

## 1.5 Questions and Working Hypothesis

The key objectives of the research are to explore the parents' perceptions and experiences in relation to the sexuality of their young adults with intellectual disabilities. More so, to understand and to fill the knowledge gaps in the studies of parenting young adults with disability regarding sexuality rights.

- To explore the meanings given to disabled young adults' sexuality by their parents and guardians.
- To understand how issues of their children's sexuality are handled by parents of young adults with disabilities.

The main question of the research is: **How do parents perceive the sexuality of young adults with intellectual disability?**

The sub-questions are as follows:

1. What dilemmas or difficulties do parents identify in relation to negotiating the sexuality of their young adults with intellectual disabilities?
2. What ways do they suggest of resolving difficulties or dilemmas?

This study assumes that parents attached meanings to intellectual disabilities that consequently determine their views and repossesses to sexuality issues of their young adults with intellectual disabilities. Reactions of parents to intellectual disability, therefore affects the possibilities and limitations of young adults with disabilities in enjoying their sexuality as full citizens in the society. It further assumes that parents experience some dilemmas in their parenting process and they have some ways of going around the sexuality concerns of their young adults with disabilities.

## 1.6 Justification and Relevance

Parenting of young adults with intellectual disabilities is an interesting subject that has been researched by various social scientists. In as much as there is an increase of literature of disability and sexuality, there is lack of or limited information on how parents perceive and negotiate around sexuality issues of young adults with intellectual disabilities. While the focus of this paper is on the Netherlands context, the issues discussed are equally relevant to the families and organisations in other parts of the world concerned with enhancing sexual wellbeing of young adults with intellectual disabilities. In this view, the research will establish the gaps in the parental decisions, experiences and the perceptions of parents in relation to sexuality of young adults with disabilities. More so, it will contribute to the intervention measures that can be adopted by development organisations in their sexual and reproductive health programmes. Lastly, the research will contribute scholarly insights that may lead to further studies on the subject under study.

## 1.7 Theoretical and Analytical Concepts

For the purpose of this study, the key terms sexuality, impairment, attitude and disability will be understood in the manner defined herein as defined in the following sub-section.

### 1.7.1 Definition of Terms

The World Health Organisation (WHO 2015) defines **sexuality** as the state of well-being physically, emotionally, mentally and socially in relation to sexuality. SIECUS (2011) defines sexuality as a multidimensional concept that encapsulate the biological, social, physiological, spiritual, ethical and cultural aspects of sexuality.

“it encompasses not only the certain aspects of reproductive health – such as being able to control one’s fertility through access to contraception and abortion and being free from sexually transmitted infections (STIs), sexual dysfunction and sequelae sexual violence or female genital mutilation – but also the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence” (WHO 2015:1).

Impairment is defined as the lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body (Oliver 2009). The term ‘attitude’ is understood here to mean a relatively enduring set of beliefs, ideas, feelings and behavioural tendencies towards something socially significant (Hogg and Vaughan 2005). Disability is the limitations or restrictions of activity caused by a contemporary social situation which takes no or little account of impairments. (Oliver 2009). In other words, it is a socially constructed barriers imposed on people with impairments by the society. The World Health Organisation (2009) define disability as long-term physical, mental, intellectual or sensory impairments which in their interaction with the society, they are faced with limitations. Intellectual disability (ID) can be understood as mental retardation (Einfeld and Emerson, 2008). This refers to cognitive and developmental functional deficits that appears during childhood. (WHO, 1992).

### 1.7.2 A Constructivist Approach

The research is grounded in the social constructivist theoretical frameworks that help to understand the production of meanings and practices in the society. Social constructionism is the approach that the world is constructed through the interaction of human beings and their interpretation of their circumstances (O’Leary 2014). This implies that disability and sexuality are socially constructed and that we can only understand the views of parents of such young adults through seeking the truths from them. Previous studies established that “Sexuality is shaped by the cultural beliefs, values and social norms that are conveyed by the family of origin, communities, education systems, religion, the media and social policy” (Sexuality Information and Education Council of the United States (SIECUS) 2004) cited in (Christensen et al 2017:711). The use of social constructivist theories provided a broad knowledge on the discourses and debates on dynamic facets on disability. Thus, understanding disability is the key to unlock how parents perceive

sexuality of young adults with intellectual disabilities. Explanation of the theories employed in the study is the core of the chapter two that is on literature review.

## **1.8 Ethical and Methodological Choices**

This study started with a qualitative design and ended up adopting a phenomenological methodology, discussed further in Chapter 3. Qualitative interviews and focus group discussion were used to generate data required to answer the research questions, from interviews with 7 parents (3 individual interviews and a focus group of 5), as well as an interview with one professional who also took part in the focus group discussion. Whilst the sample is small, this proved enough to have a range of responses and people with very varied backgrounds. Of the eight, seven were women however, which is discussed further in Chapter 3. The researcher used volunteer sampling, through a snowball method of making contacts, in recruiting participants for the study. The process of data making was guided by all research ethics that are required to be observed in social research. This included, voluntary participation, confidentiality, informed consent and the rights of the interviewee to withdraw from participation just to mention a few. Personal identity (name and country origin) were kept private. Interviewees were at liberty to use their real name, or to remain anonymous. Since all 8 respondents preferred anonymity, pseudonyms were created (see Table 1 in Chapter 3). The researcher did not provide any incentives to the research participants. A research report produced was used for academic purpose.

## **1.9 Chapter summary**

This chapter has provided overview of the study that includes, the background, context, statement of the problem, working hypothesis, research objectives, research questions, justification of the study, theoretical and analytical concepts, ethical and methodological choices and definition of key term. The following chapters will be concerned with theorising disability (Chapter 2), with methodological choices (Chapter 3), and with parents' perceptions (Chapter 4), beyond fears and towards solutions (Chapter 5) and conclusion (Chapter 6).

# **Chapter 2 Literature Review and Concepts**

## **2.1 Introduction**

This chapter is concerned with reviewing various studies and literature relevant to disability, parenting, sexuality and theories that can help to articulate the problem under study. The research reviewed previous studies on disability from various disciplines and engage theories and concepts that can unpack disability in intersectional and critical way. By understanding disability from a constructivist theoretical position can help to answer the second theme of the study that is sexuality.

## **2.2 Theorising Disability: Intersectional and Critical Approaches**

Disability is a cross cutting social issue that cannot be understood from one angle, however its complexity can be conceptualised by using different theories. Theorising disability from the intersectional and critical approaches formed the bases of arguments and discussion in the whole study. The theoretical frameworks used are some of the dominant social constructivist theories that seek to explain how meanings are produced and the practices that buttress the meanings. These are, intersectionality, feminist disability theory, critical disability theory and the social model theory. Instead of using a single theory, the research used an eclectic approach with attempts to cover the most crucial social constructions of disability. Such constructions, to a greater extend influence how parents understand disability and their perceptions on the sexuality of the young adults with disabilities as they are part of the social system that create and reproduce meanings in the social world.

The term disability often refers to the functional limitations of the body in certain situations, environments and circumstances due to some impairments that are long term in nature. These may be physically observable or invisible impairments that can be identified in action and expression. Maxey and Beckert (2017) propound that disability is a broad term that expresses bodily constraints in functioning due to impairments in the process of interaction between the body and the environment including the cultural implications associated with disabilities. Thus, disability cannot be conceptualised as bodily impairments in isolation of its interaction with the sociocultural elements that shapes the society. “Disabled people are those people with impairments who are disabled by society” (Morris 2001:2). In this regard impairments are features of an individual and disabilities are limitations presented by the society. Oliver (1990) cited in Watson (2012) argues that disability as a product of how the society is organised and that social relations forms the plays a pivotal role in the construction disabilities and the experiences of disabled persons.

The social model of disabilities dismisses the conception that people with disabilities are the problem because of their impairments in the society, but

rather the society is the problem (Giddens and Griffiths 2006). “As a result of the social model, disabled people were able to understand that they were not at fault: society was” (Watson 2012:195). Thus, the model shifts self-blame from the disabled people to the systems in the society that disables the impaired. It gives the sense of citizenship to people with disabilities and opportunities to experience life like anyone in the society. In addition to that it stresses the need to have disability friendly environments and coexistence among people without discrimination.

Feminist disability theory provides an in-depth understanding of intersections of various ways in which the society creates and reproduce the identities of disability. Feminist approaches expose that the very concept of disabilities is gendered and highlight different experiences among disabled women and between disabled women and men, in a patriarchal society that propels inequalities among all groups and social classes (Casper and Talley 2016). A feminist interdisciplinary approach seeks to understand how social relations and bodies are gendered and sexed, relating these social understandings to more technical policy and medical debates and practices to construct the impaired bodies as disabled (Thomson, 2002, cited in Caspers and Talley 2016). Feminist disability studies stress that disability like gender is a universal concept constructed by and embedded in all aspects of culture, including institution, identities, practices, politics and communities. Thus, feminist disability theory broadens the conceptualisation of disability as an intersection of various systems that create the identities and meanings of disabilities that are sustaining the practices and treatment of such people in the society. From this perspective, disability itself is socially constructed.

Intersectionality is the concept that individuals have different identities, social complex positions that result from the intersecting axis of oppression and privileges that are inherently interconnected and cannot be disentangled, and that it creates unique forms of disadvantages in the society as well as various interpretations of the world view (de Beco 2017). It views disabled people as a heterogeneous group that experiences disadvantages based on the various situations and social identities like gender, race and social class that perpetually and systematically disadvantage them in both private and public spheres.

Experiences of persons with disabilities, family experiences and conceptions about disability cannot be oversimplified, it can mislead because there are multiple personal factors embedded in the differences based on gender, age, socioeconomic status, sexuality, ethnicity, or cultural heritages that underlie the oppression of persons with disabilities in the society. “Disability is the outcome of an oppressive relationship between people with impairments and the rest of society” (Burchardt 2004:736). It furthers that, women are more disadvantaged than men due to the double deprivation because of gender and disability. Additionally, people with intellectual impairments appear to be more disadvantaged than those with other forms of disabilities. In view of the above, studying disability issues from an intersectionality position can help to understand the dynamics of disability in the different contexts and identities and establish how people with disabilities are viewed and treated in different settings and the systematic oppression to persons with disabilities (WHO 2011; Hussain et al 2002; Emerson 2003).

The critical disability theory emphasizes the certainty of difference, it challenges the assumptions of sameness and assimilation (Treacy 2016). That is, it demands the reorganization of our society's basic social institutions. The theory shifts focus from the individual pathology of disability that is premised in defining disability as biological impairments to conceptualise disability from a human rights approach. Hosking (2008) argues that,

“the critical disability theory adopts a version of the social model based on the principles that (1) disability is a social construct, not the inevitable consequence of impairment, (2) disability is best characterised as a complex interrelationship between impairment, individual response to impairment, and the social environment, and (3) the social disadvantage experienced by disabled people is caused by the physical, institutional and attitudinal (together, the ‘social’) environment which fails to meet the needs of people who do not match the social expectation of ‘normalcy’ (Hosking 2008: 6).

In addition to that, it emphasises on the asymmetric power relations between the able bodied and those with impairments that often perpetuate the objectification of the latter and construction of disability. In view of this theory, the sexuality of young adults with ID is affected by their family environment, perceptions and attitudes of parents/care givers and attitudes towards the young adults with ID that illuminate their impairment as inability to explore their sexuality and make their own choices.

The social model defines disability as a social construct. It is the society that disables persons with impairments in their interaction with the building blocks of the society that are determined by the same society (Morris 2001). Disability are the constraints experienced by persons with impairments to perform competently with others as a result of social barriers and environment.

The social model of disability is premised on the elimination of disabling systems in the society. The model is identified with the work of Michel Oliver in his encounter with the Fundamental Principles document (UPIAS 1976) and his own his experiences of impairment and disability (Oliver 2009). The concept is of the position that disability is “socially created rather than the result of ‘biological deficiency’ and the defining (production) of disabled people as an oppressed group” Beckett and (Campbell 2015: 279). It makes a clear difference between impairments and disability. The concept unpacks the challenges experienced by persons with impairments because of social, cultural, economic and environmental barriers to participation in society and self-determination as full citizens with equal entitlements like those without impairments (Burchardt 2004). In other words, it's not the biological and physical being of an individual that makes one to be disabled like being partially blind, hearing and speech impairments or lacking a limb. These are features of individuals that do not translate to disability. Capri et al (2018) argue that the social model provides an understanding that the way people respond to impairments is what makes them disabled. In other words, disability is not an intrinsic attribute of a person, but that interaction of the individual with the social, physical, political, and economic environments limits the competences of individuals with disabilities. This framework shifts focus from the pathologizing impairments.

The critical disability theory and the social model approach are both grounded in the notion that the society disables people with impairments (Goodley 2014). Therefore, the sexual wellbeing of persons with disabilities cannot be understood in isolation of the societal attitudes and practices that defines sexuality in every society. In addition to that, they both demand the elimination of all forms of barriers that are faced by persons with impairments in the society. In the same vein, the availability and unavailability of the sexual and reproductive health need of persons with ID are socially determined. Thus, means the ability of the young adults with ID to explore and enjoy their sexuality rest on the society's perception on their sexuality.

## **2.3 Sexuality and Intellectual Disability, Rights Dilemmas**

Sexual education is one of the fundamental needs in the development process of every person whether disabled or not. However, there seem to be considerable challenges in providing such education to persons with intellectual disabilities characterised by reluctance and dilemmas as they are viewed to as not capable of making decision regarding their sexuality (McDaniels and Fleming 2016). In addition to that, their study established that, young adults with disabilities lack skills and knowledge required to form health relationships, establish appropriate sexual boundaries and are often vulnerable to sexual exploitation. Preceding reports to the above study established that, sexual and reproductive health needs of people with disabilities change throughout their life cycle like everyone else and differs according to gender and age as the face different challenges in at each level of their life (WHO 2009). In this regard, age appropriate education is necessary in for them to have the potential to enjoy their sexual and reproductive health rights.

Sexuality and disability are both clouded with taboos and myths in all societies. Discussion on these issues are mostly avoided in families. This is attributed by the family beliefs, values, ethnicity and practices. In some societies, sexuality issues are discussed and learn at communal levels during ceremonies, rites of passage and rituals where boys are initiated from boyhood to adult and girlhood to womanhood and that forms part of cultural practices. Kins and Beyers (2010) argue that rites of passage that mark transition from childhood to adulthood is still exhibited in traditional cultures and the post-industrial societies shifted to individualism. However not all societies still have such practices due to globalisation, cultural erosion and cross pollination of cultures. The roles and responsibilities that were taken by community head to educate young adults about sexuality have been left to educational institutions and individual families and parents.

Wehmeyer (2007) cited in Brown et al (2009) propound that for people with ID to make effective choices, knowledge and experience are the key. In this regard, there is need for the young adults with ID to have information, exposure and practical skills in their sexuality. Thus, parents have a fundamental responsibility to impart the necessary knowledge in a way that that can be comprehended by their young adults with intellectual disabilities.

However, in many cases there are limited opportunities for young adults with disabilities to make their sexual choices. According to Brown et al (2009) numerous studies have put forward the argument that there are few prospects for young adults with ID to have comprehensive sexuality education and skills.

Some studies of young adults with ID and those without ID shows that the latter have a higher chance of making independent choices as compared to the former. This entails the need for diligent approaches that can avail the potentials of adolescents with ID to make informed decision. Brown et al (2009) assert that risk in some families and service providers is that is that the young adults' choices are not valued and think they know the choices of the adolescent with ID. This means parents must acknowledged that people with ID are rational beings, entitled to make their own determinations about their own life choices.

In societies where disability and sexuality are considered sacrosanct, parents are in dilemma to balance the reality and the societal values. Carroll (2013) established that the society presents certain attitudes towards both persons with disabilities and their parents which often makes them tired and frustrated by their situation. This frustration influences how they will view the disabilities of their young adult and their parental practise in respect of sexuality of the young adult.

## **2.4 Chapter summary**

The chapter reviewed various literature on theories of disability that formed the bedrock of the arguments in the study. It critically discussed the complementarities and divergences of intersectional and critical theories in explaining the dynamics of disability, and how the society produce and reproduce perceptions and attitudes towards disability and sexuality of intellectually disabled young adults. The following chapter will focus on the methodological choices used in the study to collect primary data that shall be presented and analysed in chapter 4 and 3. The discussions in the chapters 4 and 5 return to the conceptual frameworks discussed in this chapter and use them to analyse the data generated during fieldwork.

## **Chapter 3**

### **Methodological Choices**

#### **3.1 Introduction**

Thus, from the critical and social model perspectives of disability, the parents and families would ‘enable the young adults with disabilities sexually, rather than further disabling them’. This chapter presents a description of the methodology that was used in this research. The chapter will have three major constituent parts namely (i) methodology, (ii) making data, and (iii) reflections on fieldwork experiences

#### **3.2 Methodology Adopted: Phenomenology**

The study was qualitative in nature. Qualitative research is the means through which the researcher can establish people’s own understanding of their lives in their own words and social contexts that makes their social world (Richards 2015). As the research was concerned with establishing the perceptions and experiences of parents regarding the sexuality of young adults with intellectual disabilities, it considered phenomenology as the best methodology. Thus, the research was conceived and conducted from a perspective that, there is no single truth about the experiences of the parents of young adults with disabilities, but rather a multiple truth. Phenomenological studies acknowledge the lived experiences of participants in a study as the best source of truth in qualitative research and the means through which the researcher can understand the relationship between the individual and the phenomena (in this case parenting and sexuality of young adults with disabilities) which determines their worldview (Smith et al 2009; van Manen 2014). The objective of the phenomenological study is to produce rich descriptions on lived experiences of respondents in relation to a particular phenomenon, expressing how they feel, what they think, as well as reflecting on their thoughts and actions (O’Leary 2017). Thus, the researcher delves into the realities of the researched in their natural settings and derive meaning from the data made from the interaction.

The study used the interpretative phenomenological analysis in synthesizing the multiple and complex narratives from interviews. The findings were presented in themes that emerged from the interviews as shown in chapter 4 and 5 in attempts to answer the research question of the study. In as much as the findings may not be generalised over a large population, the strength of the study is in the richness of the synthesised findings that illuminate perceptions and experiences on disability and sexuality in the eyes of parents from social constructivist perspectives. In addition to that, it adds value in highlighting gapes for further studies and initiating strategies of supporting parents in enhancing the sexuality of young adults with intellectual disabilities.

### **3.3 ‘Making Data’**

The researcher preferred to use the term ‘making’ data rather than the common term data ‘collection’. Richards (2015) posited that qualitative data is a product of collaborative process between the researcher and the researched through conversations that enable the respondent to give detailed accounts for the researcher to make meaning out of it. In this study, the researcher used unstructured and semi structured open-ended questions in face-to face interviews with individual parents and focus groups discussion. Some researchers commented that qualitative interviews are essential to establish detailed knowledge about families of young adults with intellectual disabilities and to engage the parents and family members to express their experiences (Maxwell and Barr, 2003). Disability and sexuality are both sensitive topics that requires a careful approach to engage the participants in interviews.

The researcher recorded the interviews and transcribed them later. It helped the interviewer to concentrate on asking and listening. More so, the researcher was able to probe further for more information and make follow ups to get a whole some understanding of the narratives of the parents. The interviewing process gave the researcher opportunities to verify the information provided by the parents by asking the same question in a different way. In addition to that, enabled the researcher to actively listen to the parents, observing the verbal language and the body expressions. In addition to that, it helped to determine the extent to which to take the interviews. For instance, some interviews were longer than the others. The researcher would choose to start with the more critical questions to maximise the time and opportunity for interviewing. However, the length of the interview was not much of substance to the researcher, but the quality of the data obtained.

#### ***3.3.1 Focus group discussion***

In addition to one on one interviews the researcher conducted a focus group discussion. The researcher hired a room at Holendrecht Community Centre in Amsterdam for the purpose of having the focus group discussions. The place was convenient to all the participants regarding accessibility and that it was in the neighbourhood of some participants. The researcher considered that the parents had other commitments and that there is need to meet them at the place they are used to. Grace (not real name), professional who work in supporting parents of children with disabilities assisted in the recruitment Stoneman (2007) propounds that it is difficult for researchers to access families of persons with disabilities and they mainly depend on gate keepers who mostly select participants they consider “good” to complete the study. This can result in biases on the information established by the researcher. In this case, since the researcher had no prior meetings with the participants, Grace’s presence was important as it enabled the participants to feel more comfortable with the researcher during the interview process. The researcher was also aware of the power dynamics involved in gender, class and cultural

differences, which could either influence parents to open or could close down discussion. The researcher observed that the parents were mostly at ease during the interviews, and during informal discussion before and after the interview itself. Some parents expressed their excitement and anticipation of having the opportunity to discuss something they had never discussed in this way in their lives before. Most of the participants commented that it was a relief to hear from other parents with similar experiences and to learn from them about how they dealt with the issues around sexuality in relation to their adult children with intellectual disabilities.

Despite differences in languages, where necessary the researcher used fellow participants in the focus group discussion to interpret for their colleagues who were not well conversant with English. If the one translating missed some important points, fellow participants would highlight such gaps in translation. Thus, instead of the translation being the role of a single individual in the group, some group members would ask if the translation matched the intended message, checking repeatedly as the focus group continued, that the meanings were being understood. Therefore, to a greater extent, data that was obtained from the interviews and the focus group discussion was translated in a way that seemed to represent quite closely the original and intended message from the interviewees and participants.

### ***3.3.2 Identification of possible participants***

Researching disability and sexuality involves some important methodological choices, due to the sensitive nature of the topic. Some noteworthy problems include how to identify and contact families for the study. The researcher started by joining social media disability family support groups and creating rapport with members of these groups. This approach yielded contacts with eight parents interested in taking part in the study. However, five of them were not able to take part in the study since their children with intellectual disabilities who were below the age of 18. The researcher then asked to meet the interested parents for a cup of coffee and an informal discussion and this next step enabled us to build trust, so that participants and the researcher came to talk in a more relaxed and informal manner once interviews started. The result overall was that most participants felt relatively open to discuss the highly sensitive topics of the study, without seeming to feel intimidated or overly cautious. The researcher was very aware that trust forms the solid foundation upon which truth, honesty and openness are built, as has been noted by O'Leary (2014). Any cultural or gender barriers that might have existed between the researcher and the parents who participated in the one-to-one interviews, seemed less significant an obstacle once rapport had been built, before the formal interview engagements began.

### ***3.3.3 Volunteer sampling and snowball sampling methods***

The study used two sampling methods in recruiting participants for the study. The first was volunteer sampling and the second snowball sampling. Volunteer sampling is a process through which participants for a study are selected by requesting interested individuals willing to volunteer (O'Leary 2017). The researcher advertised for interested research participants on a

Facebook group that got overwhelming responses of eight parents. Five of the parents did not have children with 18 years and above. The eligible number was three parents. The researcher used the sampling strategy because the topic disability and sexuality are always regarded to be sensitive. It requires people who are free to discuss the issues without being compelled by any means as this is in keeping with the research ethics.

On the second stage the researcher used the snowball sampling approach in selecting parents and service providers in Amsterdam. The snowball sampling is the way of getting participants for the research through referrals from other participants (Laws et al 2003). The method is regarded as the best when working with populations that are not easy to identify and accessed. The researcher argues that the approach was the most ideal for the study since the research did not have prior knowledge of parents of young adults with disabilities. Five (5) parents were identified through referrals. The researcher started with the ambassador for the parents of intellectually challenged children and later referred to other parents and a professional working with parents of disabled children.

### ***3.3.4 The study sample***

Table 1 below shows some details of the research participants. Because of the qualitative design used, the study interviewed a small sample of 8 parents. The thrust of the research was not on quantity of the respondents, but quality of the narratives generated from in-depth interviews with parents on their perceptions and lived parental experiences on sexuality of young adults with disabilities.

**Table 1: Interviewees (using pseudonyms)**

NAME	Male/ Female	NUMBER OF DISABLED YOUNG ADULTS	PLACE & DATE
Daisy	F	1 (26 years, Male)	Amsterdam 11.07.18
Sandra	F	1 (23 years, Male)	The Hague 14.07.18
Robin	M	1 (23 years, Male)	The Hague 16.07.18
Caro	F	1 (25 years, Female)	Amsterdam 20.08.18
Maria	F	2 (24 years, Female) (20 years, Male)	Amsterdam 20.08.18
Playo	F	2 (22 years, Male) (18 years, Male)	Amsterdam 20.08.18
Mary	F	1 (26 years, Male)	Amsterdam 20.08.18
Grace	F	Professional	Amsterdam 20.08.18

O'Leary (2017) stressed that the goal of qualitative research is not to seek the representativeness of the sample used in the study but the richness of data

from the few rather than views of many. The selection of the sample was based on one being a parent/ care giver of a young adult with intellectual disabilities. The young adults were supposed to be from the age of 18 years to 26 years. And, professionals who work with parents of young adults of the similar age. The standards set for participant qualifications were to enable the researcher to keep focus on the experiences of parents of young adults with similar characteristics. In addition to decisions on sample sizes, the researcher considered time a valuable asset given the limited period the study was to be done. Thus, working with a small manageable sample and generation of rich data was paramount to the researcher.

### **3.4 Managing the data and making sense out of it**

During interviews the researcher recorded the discussions after getting consent from the respondent to do so. The recorded audios were later transcribed into text. The texts produced were the direct words said by the respondents. All scripts were scrutinised to identify common themes and diverging themes from the data made. The two major themes of the emerged from the study are: (a) Coming to terms with disability and sexuality (b) Beyond fears towards solutions. These themes formed the foundations of the discussions in chapter 4 and chapter 5 respectively. The sub thematic areas in the respective chapters are the fabric that made the major theme. The establishment of the themes were done through data coding. Data coding refers to categorization of related data or data retention for the purpose of understanding the patterns and explanations in a precise way of gaining insight from the data (Richards 2015). The process of coding enabled the researcher to analyse the data, derive meaning out of it and discuss it in relation to previous studies without distorting the intended meanings from the researched. Extracts of direct statements from the respondents were used to substantiate the claims made by the study.

### **3.5 Reflecting on Fieldwork Experience**

It has been a challenging experience for the researcher to identify the participants for the study. Due to passion of the researcher in intellectual disabilities, he devised different approaches to access the interested parents for the study. He joined the Facebook disability support groups for professionals and parents. The groups were composed of Dutch and Non-Dutch parent of children of various disabilities.

The researcher had to use knowledge and experience gain in working with persons with intellectual challenges for the past seven years. The researcher was aware that engaging parents to discuss disability of their young adults was not an easy task and more difficult to bring in sexuality as a subject of focus in the discussions. In addition to that, the nationality, colour and sex of the researcher was also a challenge on its own. Seven of the nine participants were women. More so, being a black person researching in a white community was a mammoth task on its own considering the racial issues that influences how the target participants would perceive “blackness”. The skill of building a rapport with participants was the key to unlock the doors. The

relationship and trust that was built between the researcher and the participant opens windows for the discussions. The researcher had informal meetings over drinks and coffee with the participants as a way of getting to know each other before requesting for formal interviews with them.

The researcher declared his professional experience and passion in working with people with disabilities. It is during this period that the researcher shared his successes in advocating for the rights of persons with intellectual disabilities and coordination a group of youth with disabilities in claiming their social, economic, political and legal spaces in his country of origin. Disclosure of the researcher's professional background gave an identity of being a family member in the disability community. In other words, the researcher was regarded as an insider rather than an outsider. This worked positively to initiate discussion on sexuality with female participants.

The researcher observed that the participants were very relaxed during the formal interviews and the sensitiveness of the subject was neutralised by the trust and confidence that was between the researcher and the participants. Almost all the participants disclosed that they had never had a discussion of that nature in their entire parenting experience. They showed signs of relief after the interviews and as the matter was like a thorn in the flesh with no one to share the matter with. At the end of the interviews most parents echoed that they feel some relief. Such remarks were so touching to the researcher. The researcher encouraged the parents to share some of the issues with other parents of disabled young adults and learn how they are going about the sexuality issues.

Challenges of using the interviews in this study included language. Some of the respondents were more fluent in their native languages than English, in this case Dutch and Twi (Ghanaian dominant language). Working with respondents of a different language presents a risk of losing the real and intended meanings that are said in the original language. O'Leary (2014) expressed that the use of English in a research reduces the richness of the data because "language is metaphorical, mythical, poetic, and full of hidden meanings, riddles and assumptions and that during the process of interpretation and translation such treasure in language can be lost." (O'Leary 2014:53). Due to limitations of time, the study did not adopt a PAR approach, which could have been suitable for a longer-term approach. This is because PAR requires more time than was available. In addition to that, the study could have more than eight participants but due to limited time it was impossible to have large numbers of respondents. This also resulted in the failure of the study to include the voice of the young adults in the study. The researcher used interpreters to translate some statements that were said in the Twi language.

### **3.5 Conclusion**

This chapter focused on the processes involved in the identification of parents for the study and the selection criteria used by the researcher. It provided brief profiles of the participants, and described the instruments used to establish the information needed to answer the research questions. These instruments

were justified, showing why they were preferred as the most suitable for this study. The chapter also discussed how the methodology facilitated establishing findings that could be presented in the following chapters, four and five respectively.

# **Chapter 4**

## **Parents' perceptions and experiences**

### **4.1 Introduction**

The narratives of parents which we consider in this chapter indicate that they have different opinions on the question of how disability influences sexuality. This reflects the heterogeneity of the parents themselves. Their contexts and experiences are very diverse and are complicated by intersectionalities of race, age, class and gender. Thus, the multiple and complex determinants of their perspectives include their background, family support systems, societal treatment of parents of intellectually disabled young adults, understandings of what disability is, their positions in the society, gender, ethnic background, religious beliefs, and their own experiences with their young adults. To give this substance, this chapter presents the data derived from interviews, and analyses it as the data is presented. The parents' views are presented verbatim, following the logical order of the sub-question of the study, and reflecting on other themes that emerged as the research and analysis was conducted. Throughout, the findings are discussed with reference to relevant literature.

### **4.2 Coming to terms with disability and sexuality**

The study established that the meanings attached to disabilities are not static, they evolve and change over time. The parents' experiences in the family and society have a strong bearing on how they perceive disability and their parental practices. These findings are in consistence with previous researches on how people make meanings of their social world and how these meanings continue to change over time. "We all live in a social world, influenced by and influencing others around us, one-person changes, the surrounding individuals necessarily respond in some way" (Carroll 2013:10). One of the parents said that:

"Disability does not mean inability, but if I were to be asked what disability mean to me in the past 10 years, I would give a different answer. My understanding of disability from childhood has changed because of what I have seen and learnt from here in Europe". I came to Europe when I was young so I don't share the same mentality with people who are 15 years older than me, because I don't care, I have spent a lot of time with Nigerians and I understand that people will treat you differently just because you have a disabled child, I even continually educate my family about my children and it's not an easy task" (Interview with Playo, mother of 2 sons, 22 and 18 years old with ID, Amsterdam, 20.08.18)

This follows that, the way in which some parents now view disability changed through socialisation in a society that has a different approach to disability. Thus, change of environment due to migration or displacement can contribute in the changes of perceiving disability. Rieser and Mason (1990) cited in Beckett and Buckner (2012) established that attitudes toward disability and how people conceptualise disability is not an inborn propensity

of human beings, rather it is acquired through socialisation. In other words, coming to terms with disabilities in a family is a life-long experience characterised by everchanging perceptions of the child's disability and how it impacts on the family structure (Skinner and Weisner 2007) One of the participants said that:

"I would say that my son has got limitations, but I can't give a definitive answer because the dictionary doesn't give a clear definition, so there isn't a definite answer, every other person can give their own answer depending with your own situation" (Interview with Playo, mother of 2 sons, 22 and 18 years old with ID, Amsterdam, 20.08.18)

The study found that, parents of disabled young adults are not immune to the influence of the negative attitudes towards disabled people in the society. These negative attitudes stigmatise disability and creates challenges to both the child and the parents in coming to terms with everyday living. This confirms (Carroll 2013) that parents' experiences include the way in which the society perceive having a disability and being a parent of such a child. Some of the perceptions are based on the religious beliefs of the individuals and the society at large. Thus, religious frameworks of explaining disability contribute to how the parents view disability in a society where religion is the basis of explaining social phenomenon. The views of the parent echoed the notion of Karma, a theologian perspective that the present lives of individuals are linked to their past and that the present life could be a positive or negative reward of the past deeds. In the same vein, having a child with a disability is viewed as a punishment from God (John et al 2017). In an interview, one mother narrated that:

"Following the birth of my first child with disabilities, my family disintegrated. My husband divorced me, and some family members do not want to associate with me. In my culture it is a sign of punishment from the gods if you have a disabled child" (Interview with Maria, mother of a 24 years old daughter and 20 years old son with ID, Amsterdam, 20.08.18).

Some parents are of the position that a child with a disability is a gift from God because they are capable to care for their child. Such are in sync with the previous studies that sociocultural disposition of the family may evoke positive attributions such as the child with intellectual disabilities is a gift from God or a divine blessing other than a curse or punishment from God (O'Hara and Bouras 2007). These interpretations have impact in the circumstances in which the child will be brought up. A mother of two disabled sons said that:

"My dad would always say you know what, there is a reason why God gave you that child because you can handle it, because sometimes certain topics come up and you will see that everybody is not comfortable talking about it." (Interview with Playo, mother of 2 sons, 22 and 18 years old with ID, Amsterdam, 20.08.18)

Research suggests the reality for many parents and families is a mixture of joy and sorrow in terms of experience, when they give birth and bring up a child with intellectual disability (Kearney and Griffin, 2001; Little and Clark, 2006; Trute et al., 2007 cited in Doody et al., 2013). Discovering that one is giving birth to a child with disabilities can subject parents and families

to mixed reactions even before the birth, manifested in feelings of anger, grief, confusion and emotional distress (Einfeld and Emerson, 2008). Other studies have indicated that different families react very differently to demands placed upon them by having someone with ID in the family (Hewitt-Taylor, 2005). As one study reported:

“The birth of a child with a disability confronts parents with a demanding reality, contrasting with their expectations of having a healthy new born. The confrontation is followed by the onset of an adaptation process in which parents typically experience a range of emotions, including grief, rage, disappointment, anxiety, protectiveness, guilt, and depression” (Leemreis et al 2013:1).

The same researchers established that perceptions of parents were also the result of societal attitudes, which influenced how individual parents viewed themselves and were able or not to accept disability in the family. In the interviews conducted for this study, how parents reacted to the intellectual disability of their child was demonstrated in different ways, with some variations among parents. Some of these varying opinions are now explored.

### **4.3 “Their sexual feelings would be still there”**

In this study it was established that parents acknowledge that young adults with disabilities are sexual like anyone in the without disabilities. Their concern is on the ability of their children to have relationships in which sexual activities are expected. Similarly, to other studies it was noted that parents perceive their young adults as sexually innocent. Young adults with intellectual disabilities are regarded as sexually innocent and parents are much concerned with striking the balance between the perceived innocence and manifestation of sexual behaviour as well as struggle in appropriateness of discussing sexual matters with them (Byers et al. 2008; Ballard and Gross 2009; Wilson et al. 2010; Stone et al. 2013). The following statements were said by participants.

“There are many disabled people who have never been in a relationship, but their sexual feelings would still be there. So, they will have to find some kind of outlet for it. You know I can envisage a situation where you are using a sex worker who is coming in to help but then the understanding of the disabled person is that they want a formal of relationship with that person”. (Interview with Robin, father of a 23 years old son with ID, The Hague, 16.07.18)

“For my child I can’t say there is anything wrong with his sexuality because he is very active, and he is now 22years, sometimes I can see that his penis is very hard and sometimes I can see he plays with it and he doesn’t understand it but. I am lucky in a way I can say sometimes he gets erected and plays with it and sperms come out and you can see he has relaxed. So as long as he is able to do it by himself its fine..... I let him play with it”. (Interview with Daisy, mother of a 22 years old son with ID, Amsterdam, 11.07.18)

In a group discussion it came out that the parents have different views regarding the sexuality of young adults with disabilities and these diverse

perspectives are determined by their understanding of disability. One parent said: "I think it would be too much for someone with a disability to be having a sexual partner". (Interview with Sandra, mother of a 23 years old son with ID, The Hague, 14.07.18) Others disagreed, suggesting that each parent not only has a unique situation but also a unique way to define the sexuality of their disabled child or children. These different narratives are returned to in Chapter 5. As one professional mentioned:

"I can't say people think alike about sexuality of disabled children. They are of different opinions. It only depends on how much they know about disability..." (Interview with Grace, Female Professional, Amsterdam, 20.08.18)

#### **4.4 Negotiating Parental responsibilities**

Parents acknowledge that they have a responsibility to orient their young children on sexual matters. Parents instil their children with knowledge about sexual matters and socially acceptable sexual contact that conforms to a given environment and setting. (DiIorioetal 2003; Guo and Nathanson 2011; Levin et al. 2012). From the narratives of parents there is a common appreciation that parents have critical role in mediating sexuality matters. The parents also articulated that as much as it is ideal for them to discuss and teach their children about sexuality it is difficult for them to do so, citing the cultural issues that are shrouded around sexuality. In addition to that parents were of the view that arranged marriages could be appropriate for young adults with disabilities.

"In an ideal world it would be the parents, okay, but we all know even where there is no disability it's one thing that parents are rarely ready to talk to their children about. So, it would either be their peer group known in their school with their disability, so they first learn about these types of thing or if that's not possible then it has to be umm the institution which there is if there is no one else who can do it". (Interview with Caro, mother of a 25 years old daughter with ID, Amsterdam, 20.08.18)

Parents in the study indicated that under normal circumstances, their young adults with disabilities should learn about sexuality from their peer young adults. More so, parents cited need for professional support from the institutions that assist them in the caring of their children. This indicates that the subject of sexuality should be part of the caring professionals who are working with families of young adults with disabilities. The lack of professional support makes parents clueless on how to handle issues of sexuality.

"Parents must be supported...by the care institutions I mean the social care network which they have. Probably the parents know the best way of doing it on approaching of the subject because they probably know the child best in terms of their disability". (Interview with Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18).

Some of the parents are of the view that there are some changes with regards to discussions about sexuality in the Netherland. The fact that there is a fairly sexuality diversity tolerance in the Dutch society, it is also possible to

discuss sexuality issues. There has been a shift in the way sexuality was viewed in the last decade and how it is today. In this regard, there are opportunities for parents to engage in sexuality discussions.

“I think I would say we have a fairly free and an open approach to it. The discussion of sexual matters is less tippled than it used to be. You know the whole last twenty years, the whole question of gay rights and people living through what would have been termed “alternative lifestyle” you know. Those people have been setting their rights and there have been, it has been coping a cultural turn around. I would say here it’s quite an open discussion that could happen and that could be heard”. (Interview with Sandra, mother of a 23 years old son with ID, The Hague, 14.07.18).

It was observed that the notion of openness of sexuality discussions in the Dutch communities was not universal to all families, it was still a sensitive issue that people usually avoid and leave the responsibility to the school. This leaves a young people with intellectual disabilities with limited information about sexuality as the main curriculum used is not tailor made to accommodate those with developmental disabilities. The skill levels of people with intellectual disabilities to make and communicate choices differ widely because of the individual nature of intellectual development and the complex combination of personal and environmental characteristics (Brown et al 2009). A professional working with parents said that:

“In some parts of Holland, we don't talk about sex.....parents don't talk about it at home, but at schools they talk about it. A lot of people are asking me about this, a lot of people forget about people in homes have different backgrounds and in Holland everyone talks differently about sex and so people tend to forget that you can't discuss sex with people unless you have good connections with the parents”. (Interview with Grace, Female Professional, Amsterdam, 20.08.18).

#### **4.4.1 No topic is a taboo to me**

The study found that there was a shift from the dominant traditional perspectives that view sexuality and disability as taboo to a more liberal view that is sexuality should be an open subject. In some cultures, discussions about sexuality between mothers and sons are regarded as awkward. Addlakha et al (2017) propound that in as much as one may agree that sexuality is a basic human right, there is need to appreciate that how the knowledge is shared with persons with disabilities is shaped by contextual sociocultural, religious ideas and practices. However, some parents highlighted the need to change how they were socialised to open opportunities to discuss sexuality matters in the family. In buttressing the need for a change in cultural beliefs that views sexuality and disabilities to be taboos, another parent said that she will take a leading role in the family despite how the subject could be viewed awkward. In her experience, it showed that the family was appreciating her sexuality discussions with her disabled two sons. In this case the mother is free to discuss such issue with her sons as she said that:

“What I have come to realise from this discussion with other ladies is that apart from the fact that we all have children with disabilities ,the other thing

is that we are all Africans and you have to change that African mentality that all things are a taboo like here now we are all seated and talking about sexual reproductive issues and having your period which is totally a no go ,but even me ex-husband can't get me so is my family because for me I have no boundary and no topic is a taboo to me, I talk about anything and with my son of he brings up anything we talk about it. If I bring certain boundaries into my life, then I can't help my children...I don't mind talking about it no matter how embarrassing it is, and I have come to realise that my family is slow on catching up somehow, they seem to understand. I have come to learn that I just have to change the way I was raised if I'm going to help my child because these things, we're talking about are real". (Interview with Playo, mother of 2 sons, 22 and 18 years old with ID, Amsterdam, 20.08.18).

The study established that there are no unified efforts from both mothers and fathers in facilitating sexuality knowledge to their children. The parenting of a young adults with disabilities is a gendered role. It was observed that, mainly mothers are the ones who spearhead the discussions on sexuality. Thus, the caring and socialisation of a young adult with disabilities are gendered roles among the families that participated in the study. The contribution of fathers in the sexual education of the young adults was not profiled in the discussions.

#### **4.5 Is my daughter going to get married some day?**

From both the interviews and group discussion it was established that parents have mixed feelings regarding their young adults being in relationships and getting married. The fears are that their young adults are not able to handle relationships and marriages. Secondly that who will consider marrying a person with disabilities. Thirdly their young adults will be more vulnerable to abuse in the marriages and that it is better for the man who asks marriage to a disabled lady to stay in the same house with the mother of the lady. In addition to that parents fear that if their children get married to someone with disabilities, they may have a disabled baby.

"If someone comes and says they have an interest in my daughter I still has some reservations because she's still vulnerable,...the person has to come and live in my house that is where I feel my daughter is safe and for that person to get to know her ,because at the end of the day she's still vulnerable so it's not cut and dry like any normal child so they are always looking after your children sometimes it may seem extreme but people don't understand". (Interview with Maria, mother of a 24 years old daughter and 20 years old son with ID, Amsterdam, 20.08.18)

It was established that parents also worry about the possibilities of their young adults to be in relationships and get married someday. To some extent, their worries are based on the facts that they never witnessed a marriage of intellectually disabled couples. This is because of the dominant view that marriage is impossible for persons with intellectual disabilities WHO (2009). Thus, relationships and marriages among young adults with disabilities was not common. This indicates the dominant societal view that person with intellectual disabilities are incapable of having relationships. Some parents expressed their worries that:

“I was having that conversation with another parent that how will life be for our kids what are the choices they are going to make because he's going to get married at some point how is that going to end up ...so that makes disabilities very difficult”. (Interview with Caro, mother of a 25 years old daughter with ID, Amsterdam, 20.08.18)

The study also established that there is low awareness and publicity in the media regarding the sexuality of young adults with disabilities. Some parents indicated that they never heard about marriage of couples with intellectual disabilities.

“I haven't seen an autistic child married before so sometimes I get worried thinking that is my daughter going to get married someday... So sometimes I think how she is going to get married if a person is like this there was a time I asked if there is a dating site”. (Interview with Maria, mother of a 24 years old daughter and 20 years old son with ID, Amsterdam, 20.08.18).

What the media portrays is how the society is organised, and this influences how society perceive their young adults with disabilities with disabilities as well (Beckett and Buckner 2012)

## 4.6 A sensitive issue

Findings from this study shows that parents experience challenges imparting sexuality education and skills to young adults with intellectual disabilities as compared to non-disabled children. A host of studies agree that young adults learn about sex and sexuality intentionally or unintentionally in their daily lives through different mediums like movies, music, books and relationships (Best 2000; Brown and Strasburger 2007; Clay 2003; Luttrell 2003; Martin 1996; Pascoe 2007). However, their findings seem to view young adults as a homogeneous group with the same capacity of articulating and deducing meaning from sexuality material that can be at their disposal. Contrary to their notion, the study established that how youth learn about sexuality is not a one size fits all approach. Youth with intellectual disabilities may find it difficult to make sense out of the informal approaches to sexuality education like non-disabled children and hence the need for the parents to brace up to ensure their young adults are sexually educated.

“In an ideal situation where there is no disability the young adults learn about sex in at school, television, friends, magazines, the internet and experimenting but disabled children cannot do that, they don't understand. You must teach him and it's difficult. At times I wonder how I can teach my son all that sexuality issues and being the mother makes it more difficult. Talking about sex with your son I can't imagine, at the same time, if I don't no one will do it for him”. (Interview with Mary, mother of 26 years old son with ID, Amsterdam, 20.08.18)

The study established that some parents avoid discussing sexuality issues with their young adults due to lack of appropriate skills and information that can be comprehended by their children. The findings agree with related studies on sexuality of young adults without disabilities in that parents experience challenges in discussing sexuality with their young adults (Pluhar and Kuriloff 2004; Romo et al. 2010; Crichton et al. 2012). In the case of

parents of young adults with intellectual disabilities as established in this study, the parents have a perception that the severity of the disability can make further constraints to facilitate the sexuality education. The parent laments that:

“...talking about sexuality he does not even understand what it is, he just gets erected and don't know what it is. I know maybe hormones are doing something within him and then he finds a way to masturbate and feels that he is relaxed again”. (Interview with Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18)

“To talk about it, it depends on the kind of disability the child has for example if the child has mental disability, they have problems understanding and you need a professional someone. I have an autistic daughter it is very difficult for her to understand many things even simple things later on sexual things, it will be difficult for her to understand”. (Interview with Caro, mother of a 25 years old daughter with ID, Amsterdam, 20.08.18)

## 4.7 Who will care for the baby?

The study established that parents have many fears about the reactions of their young adults with disabilities after they give birth. They are of the view that the young adults would not be able to understand the meaning of having a baby and how to take care. They are of the position that they will be responsible of taking care of their grandchildren. However, the problem would be complicated when the parents are no longer able to provide the care due to sickness or death. The parents eloquently expressed that:

“... I am 55 years now, who is going to be with him if I am no longer around because he is not able to be in a relationship with someone. So, if he gets someone pregnant, who is going to have the burden of taking care of the baby and mother? My attention should be 100% focused on my son, loving him all his life until God takes me then I am no more there. But bringing someone to have a baby with him and then put another burden on that child. Most parents don't agree with me on this especially the African parents, they want their children to have babies and I don't go for that”. (Interview with Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18)

## 4.8 Conclusion

Coming to terms with intellectual disability and sexuality is a lifelong process that demands parent to be flexible to adjust to the ever-changing sexuality of their young adults with disabilities. The identity of 'parent of an intellectually disabled young adult' and 'young adult with intellectual disabilities' are laden with stigma and socially predetermined conceptions of what such parents and their children deserve and should be in society, including Dutch society. This accounts for the danger of systematic oppression and violation of sexual rights of young adults with intellectual disabilities. How intellectual disability is viewed by parents can either create barriers or opportunities for young adults to explore and experience their sexual life in a fulfilling way. The

parents are aware that the young adults with disabilities are sexual, but what to do with their sexuality is a challenge to many parents they assume a responsibility to enable the young adults to be sexually skilled. Some parents were of the position that going against the dominant societal perceptions of regarding disability and sexuality as sensitive and taboo issues is the only way through which families and parents can promote and protect the sexuality rights of intellectually disabled young adults. Though there might be some resistance from significant members of the family, their strength in overcoming the negative forces is in the value they place in the lives of the intellectually disabled young adults to live and enjoy sexual rights like anyone in the society. In addition to their appreciation of the sexual rights of their young adults with intellectual disabilities they wonder and worry about their chances to have fulfilling relationships and marriages like other young adults. Further to that, worry about the ability of their young adults to care for children if they are given an opportunity to have babies. In a nutshell, the varied perceptions of parents are grounded in their parental experiences punctuated by multiples challenges that comes with being parents of intellectually disabled young adult and dilemmas faced in respect to their sexuality. However, some parents don't only think 'out of the box' in attempts to provide solutions to their challenges, they think 'as if there is no box'. They suggested a host of practical strategies to overcome their dilemmas, what the study refers to as "beyond fears towards solutions" in Chapter 5.

# **Chapter 5**

## **Beyond Fears towards Solutions**

### **5.1 Introduction**

The last chapter established that there are several kinds of narratives surrounding the sexuality and sexual education of persons with intellectual disabilities, based on the parents' own understandings. Their conceptions – and perhaps also their misconceptions about the sexuality of persons with disabilities are expressed in the form of stories about their young adults and others they know of. This chapter presents the views of parents regarding strategies and practices they perceive could help to remedy some of their dilemmas, dilemmas which were established in the preceding chapter themed 'coming to terms with disability and sexuality'. This profiles various practices that were suggested to be the way forward amid the challenges experienced.

The study established that despite the existence of disabilities from time immemorial, it is still difficult for parents to come to terms with intellectual disability in the family. The differences between the chronological age and the intellectual development of the young adult with disabilities create numerous challenges for parents who are trying to negotiate the sexuality of their young adult children, as this study has shown. The biological development of young adults with disabilities and their responses to the sexual hormones creates dilemmas for their parents regarding how to facilitate the sexual wellbeing of their adult children. The study asked parents to suggest various strategies that could be devised to resolve some of these dilemmas. In some of the interviews, obstacles to resolving sexuality dilemmas were encountered. In other cases, perhaps the more liberal parents reflected on joint decision-making with their adult children with intellectual disabilities. Some of these approaches they thought can be mastered by their children; others depend on improved awareness and provision by others. Through various initiatives some parents try to go beyond the dominant views that sexuality issues are sensitive and awkward. Overall, I found that narratives that parents express reflect their attitudes.

In the rest of this chapter, I present what parents interviewed presented as some of the strategic means available to them, in order to enable their young adults with intellectual disabilities to explore and enjoy their own sexuality (or not). Societal perceptions on disabilities may not always appreciate the biological developments and hormonal changes taking place within the bodies of young adults with disabilities, however the biological facts are only part of the story. The findings in this chapter largely confirm the view that a wide range of attitudes exists in any society about the navigating or mediating role of parents towards the sexuality and relationships of their adult children with ID (Sinclair et al 2015).

## 5.2 Key Finding: Parental Responses Vary

Some parents highlighted that their young adults are vulnerable due to the nature of their disabilities because they are not independent. The study argues that, the vulnerability referred to by parents is a clear manifestation of limited sexuality knowledge and skills among young adults with intellectual disabilities. This also prolongs dependency of young adults with disabilities on family members and parents and viewing intellectual disabilities as inherent incapacity to articulated sexuality matters. Hollomotz (2011) established that sexual vulnerability is a result of practices that focus on risk other than capabilities of intellectually disabled young adults. Parents narrated that the young adults with intellectual disabilities have challenges in expressing themselves and lack sexual negotiation skills. At times their communication is misunderstood. If they have been abused, if they try to report such issues, they are not believed. In this regard, some “cruel” people in the society take advantage of these incompetence and abuse the intellectually disabled. A parent said:

“it's very complicated especially if it's a daughter because they may not be able to tell what happened to them when they have been sexually abused and it's very worrisome because people may not believe them”. (Interview with Caro, mother of a 25 years old daughter with ID, Amsterdam, 20.08.18).

Other studies pointed out that in most cases the dependence of young adults with intellectual disabilities on family is longer than that of non-disabled adolescents (Dura-Vila et al 2010). Therefore, sexual wellbeing of young adults with disabilities are at prone to manipulation and abuse by parents, families, care givers and service providers. In view of the above, the sexuality rights of the young adults with intellectual disabilities are less obvious than their parents' concerns to be involved.

### 5.2.1 *No to sex in my house*

It was found that parents acknowledge that their young adults with disabilities are sexual and sexually functional as they reported that they have noted the erected penis of their young adults. They stressed that they were comfortable with their sons masturbating as a way of gratifying their sexual desires. They cited that they would not allow their sons to have girlfriend or professional sex-workers to have sex with their sons. Summing this position, some parents said that:

“He has the best way, when he feels erected, I allow him to masturbate and when his penis is erected, he can masturbate so why should I allow him to have someone coming to the house to have sex with him when he is able to do it himself and relax. Here in Netherlands there are professional sex-workers to provide sex to people with disabilities. For him I haven't tried because I can't imagine someone coming to my house to have sex with my son”. (Interview with Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18).

This follows that masturbation is viewed as the acceptable way for sexual gratification for the young adults with intellectual disabilities. This suggest the notion that parents were over protecting their young adults with

intellectual challenges and depriving them with the opportunities to experience sexual encounters with mates of opposite sex or having sexual partners of either sex.

### ***5.2.2 ‘Sexual pleasure but no babies please’***

The study found that some parents acknowledge the need for their young adults with intellectual disabilities to have sexual pleasure as their right. However, they expressed concern over the possibilities of their young adults to fall pregnant and their capacity to take care of the children. They stressed that child bearing was a difficult process that cannot be comprehended by young adults with disabilities. This indicates that young adults with intellectual disabilities lack caring skills that are required for a child to grow in a child friendly manner. In other words, parents can make deliberate efforts to ensure that no procreation would take place if their young adults have sexual partners.

“The main worry with parents is that their child will have a baby and not be able to keep him or if they have sex what happens, …yah so you have to put each case individually but I think parents are always going to be around to help, but there should be a supportive way that two people should be allowed to be together as long as there is no one person dominating another person” (Interview with Sandra, mother of a 23 years old son with ID, The Hague, 14.07.18)

In addition to lack of caring skills among the intellectually disabled young adults, some parents subscribe to the position that the form of disability and its severity determines the possibilities of the young adult to bear a child. These sentiments were raised citing the health complications related to pregnancy and child bearing.

“We have some that are capable of doing that, it all depends on how severe the disability is. We have some that can do that, and they can be supported to have kids and there are some that are not capable. So, it comes through at the kind of disability” (Interview with Mary, mother of 26 years old son with ID, Amsterdam, 20.08.18)

In some interviews it was established that there is fear in parents that their young adults may bear offspring with disabilities. This thinking is grounded in the thinking that intellectually disability is always genetically inherited. However, some studies show that intellectual disability is as result of brain damage during the prenatal, perinatal and postnatal stages of a child. Thus, lack of clear understanding of the causes of ID contributes to the fears and uncertainties of the parents. As a result, they prefer that the young adults to enjoy sexual pleasure and not bear children. This accounts for the sterilization that is done on some persons with intellectual disabilities. WHO (2009) reported that persons with disabilities experience violations of their sexual rights that included forced sterilizations, forced abortions, or forced marriages. Such practices are contrary to the rights of persons with disabilities to form families and reproduce as provided in the UNCRPD. More so, some parents have a view that if a young adult with disabilities give birth, the born baby would be a burden to the society. Parents cited that birth of a child comes

with different responsibilities and that would be difficult for young adults with disabilities to meet such responsibilities.

“Unless they are already sure that the child being born is not going to be a burden to the society. They even try to prevent those who can walk and talk and are also sexually active from getting pregnancy. They allow you to have sexual pleasure but not to go and have babies but if it happens accidentally yeah, but they don’t encourage you to do that”. (Interview with Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18)

It was established that some parents prefer abortion when the young adult with intellectual disabilities falls pregnant. However, these abortions are not performed with consent of the child. Parent decide without considering the views of the young adults. However, decisions to have abortion are as well based on the individual beliefs. This also reflect the ongoing debates on the right to abortion and its morality and the sanctity of life.

“Yes, if someone became pregnant as a parent, I would be sad that, pregnancy was ended because I don’t believe in abortion, but I realise other people do and at the same time the damage to someone whose pregnant with disabilities may course more problem. If I find out such a situation, I would think that life is precious, I would do my best to enable that child to live, I appreciate other people’s thinking because they just end life when it’s convenient for them”. (Interview with Sandra, mother of a 23 years old son with ID, The Hague, 14.07.18)

### ***5.2.3 ‘Striking a balance’***

Parents expressed that they have challenges in balancing their interests and those of the child. They felt that their young adults with intellectual disabilities are not able to make sound choices and decisions in their lives.

“So much you know, I think would come down to what is the level of disability and what is their understanding of what’s going on? I think, if the level of disability is low and the level of understanding is high then they have as much right to their own privacies as anyone else”. (Interview with Robin, father of a 23 years old son with ID, The Hague, 16.07.18)

At times what might seem to be good for the child may be consider not the best alternative from the eyes of the parents.

“Yes that’s what I was saying about looking for a dating site and if I find somebody, then I have to decide for her because even if I show her she won’t know whether the person is good for her or not”.(Interview with Maria, mother of a 24 years old daughter and 20 years old son with ID, Amsterdam, 20.08.18)

In addition to that, they think the level of disability matters in the consideration of their choices. Where some decisions conflict, the parents would ask for professional support to override the interests of the child. However, these findings are in keeping with previous studies on how intellectual disability is viewed in general. One of the parents stated that:

“So, I think were possible yeah you have to engage the child. Umm but if that isn’t possible then certainly the parents or legal guardians have to be involved and there has to be a cooperation also and the, what do you say,

care system or the care authorities I think they will also have some kind of input". (Interview with Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18)

Intellectual disability is commonly regarded as one of the disabilities that requires family support and care in the whole life of the disabled member with often limited self-determination (Chadwick et al., 2013; Taggart et al., 2012). However, such perspectives undermine the choices of young adults with disabilities as well exploring their potential.

#### **5.2.4 'Liberal' parents**

Parents in the study indicated that young adults with intellectual disabilities have limited opportunities of exposure to sexuality educational, and lack sexually related skills and that it is their responsibility to provide sexuality knowledge to their children. They also expressed concern over their challenges in devising disability adaptable sexuality education skills and practices. In attempts to impart sexual education, some parents use visual aids like pictures, movies and some pornographic material. However, this was viewed to be beneficial in education the young adults with disabilities as well as meeting their sexual pleasure. A father in this study detailed that:

"I think the use of pornography in teaching can work. The whole question of pornography is a debatable one. I think most people or most expects in here would say that in some cases these pornographies can be helpful; it becomes helpful for them to release sexual pressure and frustration. The risk though is where to draw the line between healthiness in pornography and unhealthiest in pornography is. And I could imagine people with intellectual disabilities that it could become a problem because that then becomes a fixation you know. And I think the type of pornography will also be quite crucial. You know if our marriages were consenting on pornography and this would be representing some kind of normal or healthy relationship, umm that I think would be a better use of it than something more extreme for pornography. So, the type of pornography to be used or they are encouraged to use I think would also be quite crucial. There are some, I mean some pornography can be extremely exploitative you know and portray people in certain ways that are not realistic and if there are videos to be used then that I think has to be taken into account." (Interview with Robin, father of a 23 years old son with ID, The Hague, 16.07.18)

It was further established that parents are of the views that persons with intellectual disabilities can master skills through seeing and practice. That makes it difficult for make parents to teach their young adults with intellectual disabilities. The main dilemma was on where and how they could practice these sexual activities such as intimacy and use photographs:

"You could do it as a mutual in the bedroom you know or umm could even make use of photographs, yeah that's the other way of doing it. Umm just so, umm you're tailoring the concept or adjusting the concept to the intellectual disabilities or the individual". (Interview with Robin, father of a 23 years old son with ID, The Hague, 16.07.18)

In a group discussion the common response on the approaches that can be employed by parents was that they are clueless on how to go about the

whole issue of sexuality education for their children. It is a challenge that they must keep thinking on how to manage it every day. They lack skills and methods to use that can be produce better results in the lives of their young adult children. “I don't have a clue because as it is you make things as they go, because as it is you don't know how things will go”. (Interview with Maria, mother of a 24 years old daughter and 20 years old son with ID, Amsterdam, 20.08.18)

In the study it came out that parents have difficulties in making their children understand them in their endeavours to educate their children. They fail to discern friendship and marriage, and the appropriate behaviour expected in each situation. Single parenting poses challenges to imparting sexuality education and skills to children with intellectual disabilities. A single mother of young adult of son narrated that:

“There are people who come visit and they will be like this my husband ,and he thinks it's true ,so this other time he took a phone and wanted to call the lady and I told him you can't call her she has a husband and he was like no it's not her husband it's her brother, a family friend got married and I was showing him the pictures and I said uncle George got married that's his wife and he was like ooh is that the sister, so he doesn't know the difference between a husband and a wife because my husband and I don't really have a good relationship so he hasn't seen any love between us to help him know that people can get married and love each other”. (Interview with Playo, mother of 2 sons, 22 and 18 years old with ID, Amsterdam, 20.08.18).

This parent also cited the importance of having role models of husband and wife (father and mother) in an intact marriage for the children to learn from observation. In other words, fragmented family setups deprive children with intellectual disabilities to learn expected behaviours in relationships and the meaning of a relationship and marriage.

### **5.3 Key Finding: Shared Responsibilities?**

It was established from the interview that some parents have a legal authority to make decisions for the young adult due to their incapacity to make sound decisional. This legal authority is invested in the parents when the child has been assessed and proved to be incompetent to make independent decisions. This will give the parents to have the legal authority to override the choices of the young adult and make decisions for them. Given this, the parent is supposed to make decisions in the best interest of the child. However, it was established that the best interests of the child are not given priority in the choices made by parents with regards to sexuality of the young adult.

“Here when the child turns 18 years the parents have to go to court and they assess you to see if you are able to make decisions that are good for your child. So, if the child is not able to make decisions you the parent will do it”. (Interview with Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18)

It was further established that, in as much as the parents might be granted legal authority in some cases, they still need to consult the child and establish his or his preferences. “The interest should not be from the parent that I want

the grandchild. It has to come through the child". (Interview with Robin, father of a 23 years old son with ID, The Hague, 16.07.18). Interestingly, not all parents have the same view. Some maintain that they should make decisions for their child with who to date. The child must like what the parent likes.

"In this country after 18 years the court gives you the right to make decisions for your child after assessing you and if you are not able to do so then the court will find someone from the outside to do that. However, professionals cannot make decisions on their own but together with you and find what's best for the child". (Interview with Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18)

Parents in the study reflected that they rely on professionals who would help them make informed decisions for their children. It emerged that parents hold different positions with regards to the extent to which the professionals should make decisions for their child on having contraception. Some parents were of the view that they have the final decision. On the other hand, some parents felt that it's not always the case, there are some instances where the professionals use their own discretion.

## **5.4. Conclusion: Parents' on-going Dilemmas**

This chapter concludes that the parents have varied ideas they think may work in facing the dilemmas they have encountered in negotiating the sexuality of their adult children with ID. However, some suggestions presented parents with further moral dilemmas around justice and fairness to their young adults with intellectual disabilities, and could come into conflict with the parents' personal, cultural and religious convictions. Parents' consciousness of the sexuality rights and needs of their young adults with intellectual disabilities were indispensable. Sometimes, their inability to handle the challenges – presented could create additional dilemmas and problems. The parents often expressed concerned with their young adults' relative incompetence in sexual communication and wondered how they would be able to negotiate consent to sex, enter relationships or sustain marriage and parenthood. Some parents explicitly did not want their young adults to have sex in their own house. However, the challenge would then be where their adult children with ID would have the sex if they did find a sexual partner. Some parents viewed professional sex workers as a possible solution, but most could not imagine having a sex worker in their house. Some parents suggested that masturbation could help relieve the sexual frustrations of their adult children, but the appropriateness of how and where this could be a parental concern is an issue that remains. Parents of female young adults generally wanted their daughters to enjoy their sexual rights, but the challenges were greater than with males, because of the fear their daughters could become pregnant. If their daughters became pregnant, some thought abortion would be the best solution, but it was not clear whose choices and interests this served. After all, forced abortion would be a violation of the rights of these young women. In avoiding pregnancy some suggested sterilization as the remedy, but the same question of rights arises, since this should be the choice of the young adult and not of the parent, in most cases. Forced sterilization is also a violation of the rights

of these young adults. Some parents had legal authority but expressed an awareness at times that what they wanted was not necessarily what the young adult in their care would want. Others were of the opinion that professionals should make these difficult decisions for their young adults, especially regarding their sexuality. One or two parents suggested using visual aids like pictures, movies and pornographic material, might be a means enhance the sexual knowledge and skills of young adults in a safe way. Still the dilemmas arise around the fears that the young adult could become addicted or fixated with pornography and that this could result in unwanted behaviour inside and outside the home. Some parents appeared quite clueless and expressed the view that each day presented its challenges, and the feeling that no concrete solutions were available that could help them negotiate the issue. Though there seemingly have ideas and suggestions, to a greater extent the parents had far more questions than answers regarding how best to face and deal with their dilemmas.

## **Chapter 6**

### **Conclusion “They have their own Stories”**

The study concluded that parents have varied narratives on their perceptions and experiences regarding the sexuality of young adults with disabilities in their care. The differences in their views are based on the intersectionality of dynamic and complex individual identities, coupled with gender, age, religion, class, race, ethnicity and culture. Together, these positions of each individual differentially show how parenting a disabled young adult is experienced in different ways in various social contexts. The social identities of being a parent of a child with intellectual disability plays a role in how people relate to such a parent. Ideas, including the idea of being ‘blessed’ or ‘cursed’, depend on the context of the parent. The same goes for how the society views young adults with disabilities. Thus, how intellectual disability is viewed in the families and in society is also context-specific. The attitudes of parents towards the sexuality of their young adults with disabilities are not static either, but ever-evolving through contact with different information sources, and vary with migration status, socialisation, and an individual’s ability to adjust and adapt to the reality of disability and maintain contact with their support networks. Thus, every parent has a unique experience with his or her disabled young adults and how they view the sexuality of their young adult with disability.

The study established that disability and sexuality are both sensitive issues despite changing generations and the shift from a conservative society to a more liberal, open society where disability and sexuality are claimed to be discussed freely. However, differences between chronological age and cognitive development characterises intellectual disability and this can create dilemmas for parents in their attempts to ensure that their young adults with ID are well-equipped with knowledge and skills around sexuality. It emerged from this study that parents had a significant role in negotiating – or mediating – the sexuality of their young adults with ID. Parents could either enable or further disable their adult children in exploring and enjoying their sexuality as a right, or not. In addition to that, in attempts to share ideas about sexuality education, some young adults may find it awkward for their mothers (or more rarely fathers) to have such discussions on sexuality. On the other hand, some parents have suggested ways to enhance the sexual wellbeing of their young adults.

The study further concludes that parents and families can be agencies for further disabling – or enabling – young adults with intellectual disabilities – either by depriving them of the conducive environment and skills to enjoy their sexuality rights, or by making their enjoyment of these rights more possible. In this sense, parent and families are the means through which sexuality rights and skills are either enhanced or reduced. Thus, it becomes clear that intellectual disability and sexuality are socially constructed in way that both undermine and enhance the sexuality capabilities of young adults with intellectual disabilities. Parenting a young adult with intellectual

disabilities is life-long journey full of dilemmas and sign-posted by more questions than answers.

## **6.1 Recommendations**

With reference to the experiences in this study, the researcher suggests that future studies on this topic may build on this study using the participatory action research method. This is since the study established some challenges experienced by parents and the need for practical solutions to such challenges. The PAR method would create a greater opportunity for parents to share their experiences, breaking the silence on sexuality matters of young adults with disabilities. Resultantly, this could transform parents' views that undermine the sexual rights of young adults with intellectual disabilities to parents who appreciate and promote such rights. Even so, it is hoped that findings from this study create opportunities for replicating a similar approach in future studies, perhaps bringing in other methods, and further adding to parents' choices, by building up a body of research and knowledge that could adding valuable information to what is already available.

## References

Addlakha, R., Price, J. and Heidari, S. (2017) 'Disability and Sexuality: Claiming Sexual and Reproductive Rights', *Reproductive health matters* 25(50): 4-9.

Ballard, S. M. and Gross, K. H. (2009) Exploring parental perspectives on parent-child sexual communication. *American Journal of Sexuality Education*, 4: 40 –57.

Bay-Cheng, L.Y. (2013) Ethical parenting of sexually active youth: ensuring safety while enabling development. *Sex Education*, 13, 133–145.

Beckett, A. E. and Buckner, L. (2012) Promoting positive attitudes towards disabled people: definition of, rationale and prospects for anti-disablist education, *British Journal of Sociology of Education*

Beckett, A., E. and Campbell, T. (2015) The social model of disability as an oppositional device, *Disability & Society*, 30(2): 270-283 DOI: 10.1080/09687599.2014.999912

Best, A. (2000). *Prom Night: Youth, Schools and Popular Culture*. New York: Routledge.

Brown, I. and Brown, R., I. (2009) 'Choice as an Aspect of Quality of Life for People with Intellectual Disabilities', *Journal of Policy and Practice in Intellectual Disabilities* 6(1): 11-18.

Brown, J., D. and Strasburger, V., C (2007). 'From Calvin Klein to Paris Hilton and My Space: Adolescents, Sex, and the Media.' *Adolescent Sexuality, Adolescent Medicine: State of the Art Reviews* 18(3): 484–507.

Burchardt, T. (2004) 'Capabilities and Disability: The Capabilities Framework and the Social Model of Disability', *Disability and Society* 19(7): 735-751.

Burchardt, T. (2010) Capabilities and disability: the capabilities framework and the social model of disability, *Disability and Society*, 19 (7): 735-751

Byers, E. S., Sears, H.A. and Weaver, A.D. (2008) Parents' reports of sexual communication with children in kindergarten to grade 8. *Journal of Marriage and Family*, 70: 86 –96

Capri, C. and Swartz, L. (2018) 'We are Actually, After all, just Children': Caring Societies and South African Infantilisation of Adults with Intellectual Disability', *Disability & Society* 33(2): 285-308.

Carroll, D. W. (2013) Families of children with developmental disabilities: understanding stress and opportunities for growth. Washington, D.C.: American Psychological Association.

Casper, M. J. and Talley, H. L. (2016) Feminist Disability Studies. In G. Ritzer (Ed.). The Blackwell Encyclopedia of Sociology, doi:10.1002/9781405165518.wbeosf041.pub2

Cassidy, C., Goldberg, L. and Aston, M. (2016) "The Application of a Feminist Post structural Framework in Nursing Practice for Addressing Young Women's Sexual Health," *Journal of Clinical Nursing*, 25(15-16): 2378–2386. doi: 10.1111/jocn.13354.

CCR (2014) Children's Rights in the Netherlands 4th NGO Report of the Dutch NGO Coalition for Children's Rights.

Chadwick, D. D., Mannan. H., Iriarte, E. G., McConkey, R., O'Brien. P., Finlay, F., (2013) Family voices: life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities* 26: 119–132

Choruma, T. (2006) 'The Forgotten Tribe', Progressio, London.

Christensen, M. C., Wright, R. and Dunn, J. (2017) "'it's Awkward Stuff': Conversations About Sexuality with Young Children," *Child & Family Social Work*, 22(2), pp. 711–720. doi: 10.1111/cfs.12287.

Clay, A. (2003). 'Keeping' It Real: Black Youth, Hip-Hop Culture, and Black Identity.' *American Behavioral Scientist* 46(1): 1346–58.

Crichton, J., Ibisomi, L. and Gymah, S.O. (2012) Mother Daughter communication about sexual maturation, abstinence and unintended pregnancy: Experiences from an informal settlement in Nairobi, Kenya. *Journal of Adolescence*, 35, 21-30.

de Beco, G. (2017) 'Protecting the Invisible: An Intersectional Approach to International Human Rights Law', *Human Rights Law Review* 17(4): 633-663.

DiIorio, C., Pluhar, E. and Belcher, L. (2003) Parent-child communication about sexuality: a review of the literature from 1980–2002. *Journal of HIV/AIDS Prevention & Education for Adolescents & Children*, 5: 7 –32.

Doody, O., O'Connell, T. and O'Halloran, M. (2013). Raising a child with disability and dealing with life events: A mother's journey. *Journal of Intellectual Disabilities*, 17(4): 376-386.

Durà-Vilà, G., Dein, S. and Hodes, M. (2010) 'Children with Intellectual Disability: A Gain Not a Loss: Parental Beliefs and Family Life', *Clinical Child Psychology Psychiatry* 15(2): 171-184.

Einfeld, S., and Emerson, E. (2008). Intellectual disability. In Rutter, M., Bishop, D.V.M., Pine, D. S., Scott, S., Stevenson, J., Taylor, E., and Thapar, A. (Eds.),

Rutter's child and adolescent psychiatry (5th ed., pp. 820–840). Oxford: Blackwell.

Emerson E. (2003) Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research* 47, 385–399.

Giddens, A. and Griffiths, S. (2006) Sociology. 5Th ed., fully rev. and updated edn. Cambridge: Polity

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability and Society*, 28(5), 631-644.

Guo, W. and Nathanson, A. I. (2011) The effects of parental mediation of sexual content on the sexual knowledge, attitudes, and behaviors of adolescents in the US. *Journal of Children and Media* 5: 358–378.

Hewitt-Taylor, J. (2005) Caring for children with complex and continuing needs. *Nursing Standard* 19: 41–47

Hogg, M. and Vaughan, G. (2005) Social Psychology. 4th ed. London: Prentice Hal.

Hollomotz, A. (2011) Learning Difficulties and Sexual Vulnerability: A Social Approach, London, Jessica Kingsley.

Hosking, D.L. (2008) 'Critical disability theory', A paper presented at the 4th Biennial Disability Studies Conference at Lancaster University, UK.

Hussain, Y., Atkin, K. and Ahmad, W. (2002) South Asian Young Disabled People and their Families. Joseph Rowntree Foundation.

John, A., Bailey. L., E. and Jones. J., L. (2017) Culture and context: exploring attributions and caregiving approaches of parents of children with an intellectual disability in urban India: Child and family social work, Texas Christian University.

King, G., L. Zwaigenbaum, S. King, D. Baxter, P. Rosenbaum and A. Bates (2006) 'A Qualitative Investigation of Changes in the Belief Systems of Families of Children with Autism Or Down Syndrome', *Child: care, health and development* 32(3): 353-369.

Kins, E. and Beyers, W. (2010) 'Failure to Launch, Failure to Achieve Criteria for Adulthood?', *Journal of Adolescent Research* 25(5): 743-777.

Kramers-Olen, A. (2017) 'Quantitative Assessment of Sexual Knowledge and Consent Capacity in People with Mild to Moderate Intellectual Disability', *South African Journal of Psychology* 47(3): 367-378

Krebbekx, W., Spronk, R. and M'charek, A. (2017) 'Ethnicizing Sexuality: An Analysis of Research Practices in the Netherlands', *Ethnic and Racial Studies* 40(4): 636-655.

Lamb, S. (2010) Towards a sexual ethics curriculum: bringing philosophy and society to bear on individual development. *Harvard Educational Review*, 80, 81 –105

Laws, S., Harper, C., Marcus, R. and Save the Children (2003) *Research for development: a practical guide*. London: Sage.

Leemreis, W.H., Okkerse, J.M., de Laat, P.C., Madern, G.C., van Adrichem, L.N., Verhulst, F. and Oranje, A. P. (2014) Educational paper: Parenting a child with a disfiguring condition—how (well) do

Levin, D. S., Ward, L.M. and Neilson, E., C. (2012) Formative sexual communications, sexual agency and coercion, and youth sexual health. *Social Service Review*, 86, 487 –516.

Luttrell, W. (2003) *Pregnant Bodies, Fertile Minds: Gender, Race, and the Schooling of Pregnant Teens*. New York: Routledge

Martin, K., A. (1996) *Puberty, Sexuality, and the Self: Boys and Girls at Adolescence*. New York: Routledge

Maxey, M. and T.E. Beckert, T.E. (2017) 'Adolescents with Disabilities', *Adolescent Research Review* 2(2): 59-75.

Maxwell, V. and Barr, O. (2003) With the benefit of hindsight: a mother's reflections on raising a child with down syndrome. *Journal of Learning Disabilities* 7: 51–64.

McDaniels, B. and Fleming, A. (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability*, 34: 215–225

Morris, J. (2001) 'Impairment and Disability: Constructing an Ethics of Care that Promotes Human Rights', *Hypatia* 16(4): 1-16.

Netherlands Times (16/04/2018) <https://nltimes.nl/2018/04/16/complaints-discrimination-people-disabilities-record-high>

O'Hara, J. and Bouras, N. (2007) 'Intellectual Disabilities Across Cultures', (ED) Bhugra D. and Bhui K. *Textbook of cultural psychiatry*: 461-470. Cambridge University Press.

O'Leary, Z. (2014) *The essential guide to doing your research project*. 2nd edn. London: SAGE.

O'Leary, Z. (2017) *The Essential Guide to Doing Your Research Project*. Sage. London.

Oliver, M. (2009) *Understanding disability: from theory to practice*. 2nd edn. Hounds Mills, Basingstoke, Hampshire England: Palgrave Macmillan.

Pascoe, C., J. (2007) *Dude, You're a Fag: Masculinity and Sexuality in High School*. Berkeley: University of California Press: California.

Pluhar, E. I. and Kuriloff, P. (2004) What really matters in family communication about sexuality? A qualitative analysis of affect and style among African American mothers and adolescent daughters. *Sex Education*, 4, 303 –321.

Regnerus, M., D. (2007) *Forbidden Fruit: Sex and Religion in the Lives of American Teenagers*. Oxford-New York: Oxford University Press.

Richards, L. (2015) *Handling qualitative data: a practical guide*. 2nd edn. London: SAGE.

Rioux, M. H. (ed.) (2011) *Critical perspectives on human rights and disability law*. Leiden: Martinus Nijhoff.

Rioux, M.H., L.A.B. Marks, L.A.B., Basser, L.A. and Jones, M. (2011) *Critical Perspectives on Human Rights and Disability Law*. Martinus Nijhoff Publishers: Leiden

Romo, L. F., Bravo, M., Cruz, M.E., Rios, R.M. and Kouyoumdjian, C. (2010) “El sexo no es malo”: Maternal values accompanying contraceptive use advice to young Latina adolescent daughters. *Sexuality Research and Social Policy*, 7: 118 –127

Rutgers (2018) <https://www.rutgers.international/>

Schalet, A. (2011) *Not Under My Roof. Parents, Teens and the Culture of Sex*. Chicago, IL: The University of Chicago Press.

Shapiro, E. (2010) *Gender Circuits: Bodies and Identities in a Technological Age*. New York: Routledge.

Silvers, A., Herr, S. S., Gostin, L. O. and Koh, H. H. (2004) “Rights Are Still Right: The Case for Disability Rights,” *The Hastings Center Report*, 34(6), pp. 39–39. doi: 10.2307/3528176.

Sinclair, J., Unruh, D., Lindstrom, L., and Scanlon, D. (2015). Barriers to Sexuality for Individuals with Intellectual and Developmental Disabilities: A Literature Review. *Education and Training in Autism and Developmental Disabilities*, 50(1), 3-16. Retrieved from <http://www.jstor.org/stable/24827497>

Skarstad, K. (2018) Human rights through the lens of disability: *Netherlands Quarterly of Human Rights* 2018, 36(1) 24–42

Skinner, D. and Weisner, T.S., (2007) Sociocultural studies of families of children with intellectual disabilities. *Developmental Disabilities Research Reviews*, 13(4): 302-312.

Smith, J., Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Steutel, J. (2009) 'Towards a Sexual Ethics for Adolescence', *Journal of Moral Education* 38(2): 185-198.

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>

Stone, N., Ingham, R. and Gibbins, K. (2013) "Where do babies come from?" Barriers to early sexuality communication between parents and young children. *Sex Education*, 13, 228 –240

Stoneman, Z. (2007) 'Examining the Down Syndrome Advantage: Mothers and Fathers of Young Children with Disabilities', *Journal of Intellectual Disability Research* 51(12): 1006-1017.

Taggart, L., Truesdale-Kennedy, M., Ryan, A. and McConkey, R. (2012) Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disability* 16: 217–234.

Treacy, A.C. (2016) *A Mixed Methods Study of Sexual Health Education for Students with Disabilities* (Doctoral dissertation).

UNCRPD (2006). *Convention on the Rights of Persons with Disabilities*. New York. <http://www.un.org/disabilities/convention/conventionfull.shtml>

van Manen, M. (2014) *Phenomenology of Practice: Meaning-Giving Methods in Phenomenological Research and Writing*. London: Routledge.

Watson, N. (2012) 'Theorising the Lives of Disabled Children: How can Disability Theory Help?', *Children & Society* 26(3): 192-202.

Wilkins, A., C. (2008). *Wannabes, Goths, and Christians: The Boundaries of Sex, Style, and Status*. Chicago: University of Chicago Press.

Wilson, E.K., Dalberth, B.T., Koo, H.P. and Gard, J.C. (2010) Parents' perspectives on talking to preteenage children about sex. *Perspectives on Sexual & Reproductive Health*, 42, 56 –63

World Health Organization (2009) *World report on disability on disability*

World Health Organization (WHO) (1992). *International classification of diseases – 10th revision (ICD-10)*. Geneva: WHO.

WORLD HEALTH ORGANIZATION and WORLD BANK (2011). World report on disability. Geneva, Switzerland.

World Health Organization. (2002) Defining sexual health: report of a technical consultation on sexual health 28–31 January 2002.

World Health Organization. World report on disability. Geneva: WHO; 2011.

## **List of Interviewees (pseudonyms)**

Daisy, mother of a 26 years old son with ID, Amsterdam, 11.07.18.

Sandra, mother of a 23 years old son with ID, The Hague, 14.07.18.

Robin, father of a 23 years old son with ID, The Hague, 16.07.18.

Caro, mother of a 25 years old daughter with ID, Amsterdam, 20.08.18)

Maria, mother of a 24 years old daughter and 20 years old son with ID, Amsterdam, 20.08.18.

Playo, mother of 2 sons, 22 and 18 years old with ID, Amsterdam, 20.08.18.

Mary, mother of 26 years old son with ID, Amsterdam, 20.08.18)

Grace, Female Professional, Amsterdam, 20.08.18)