



# Parental Perceptions of the Sexuality of Adolescents with Intellectual Disabilities

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## Abstract

The sexuality of people with disabilities is often conceptualized as asexual. Furthermore, public discourse regards people with disabilities as highly prone to sexual abuse. The few studies that contemplate on parents' of people with intellectual disability (ID) point of view uncover the parents' perceptions towards their offspring's sexuality. Therefore, the purpose of this study was to examine the sexuality of adolescents with ID from their parents perceptions. The study was conducted using a phenomenological approach and included 21 in-depth, semi-structured interviews with parents of adolescents with ID. The interviews were analyzed using thematic analysis. Parents' perceptions of their children's sexuality and their involvement concerning sexuality reveal dilemmas and tensions that remain unresolved. Although some parents did tend to treat their children's sexuality as non-normative and as a source of problems and thus ignored, prevented, and limited their children's sexual expressions, other parents presented different perspectives, acknowledging the sexuality of adolescents with ID and their right to express it. The findings also reveal a new and exciting insight related to the conceptual space of physical contact between parents and children, which moves between physical expressions of love and care and feelings of prohibited sexuality. Professionals working with people with ID and their families should be allowed to create a professional dialogue that would enable the discussion and clarification of the dilemmas and challenges related to the subject.

**Keywords** Parents · Sexuality · Adolescents · Intellectual disabilities · Israel

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## Introduction

The sexuality of people with disabilities is often *conceptualized as asexual*. Furthermore, public discourse regards people with disabilities as highly prone to sexual abuse. The few studies that contemplate on parents of people with intellectual disability (ID) point of view uncover the parents' perceptions towards their offspring's sexuality [2]. Therefore, is it of great importance to examine the parents' opinions on this subject. However, very few studies in the literature examine the attitudes of parents toward the sexuality of people with ID in general, and specifically toward the sexuality of their children. The existing research focuses on two main issues: how parents of people with ID perceive the different aspects of the sexuality of people with ID, and what factors influence these attitudes. On the first issue, studies have been conducted in various countries around the world. For example, in Ireland, parents of children with ID were found to have conservative attitudes toward sexuality, which may be related to the Catholic culture and its stance toward sex and sexuality [6]. The existing literature in the field shows that, at the ideological level, parents recognize the right of people with ID to sexual expression and sexual education [13]. However, this recognition came with control and monitor the sexuality of their children [11]. Other studies point to different attitudes regarding sexual relations among people with ID as an expression of their sexuality [2]. Few parents recognize the importance of providing privacy without supervision to people with ID about sexuality [6]. The issue of parenting people with ID and bringing children into the world has been addressed in several studies; in most studies, negative or varied attitudes are raised concerning this subject [13, 21].

A review article of studies conducted in the 1970s found that most parents supported the sterilization of their children with ID as a preventive measure [22]. A more recent study shows that most parents oppose sterilization as a precautionary measure [2]. While Morales et al. point to a link between parental attitudes on this subject and the use of birth control [14]. The degree/severity of the disability was found to be a factor influencing parents' attitudes toward people with ID engaging in sexual relations. Findings from different studies show: that parents think that people with mild ID should be able to maintain relationships with people with moderate or severe mental disabilities [6]. Additionally, it was found, that one of the most influential factors on the attitudes of all parents regarding the sexuality of people with ID, is the level of autonomy of the person with the disability [14].

Besides, some demographic factors have been found to influence parents' perceptions regarding sexuality: parents' education and age [11]. Older parents hold less tolerant attitudes toward the sexuality of people with ID [11], and so do parents with lower levels of education. At the same time, it is possible that parents' attitudes toward their children with ID sexuality are also influenced by other factors, such as their culture [6]. For example, Pownall et al. [15] have examined Scottish mothers; the study findings indicate that mothers have difficulty coping with the sexual needs of their children. Some of the mothers, did not even think about their children's sexuality, and even noted that they believed their children had no interest in sex at this stage in their lives. The mothers themselves found it emotionally difficult to think of their children as sexually active. Other mothers considered their children asexual [15]. A study conducted in Sweden revealed that the parents referred to their children's sexual expression as "abnormal" [12]. Another study conducted in England on parents of children with multiple ID found that the parents noted that their children had no sexual feelings or behaviors and that they believed: their child was unable and would never be able to have full sexual relations based on informed consent [20].

Another aspect that affects parents' perceptions of sexuality is the child's gender. Mothers of daughters were often forced to recognize, the developing sexuality of their daughters due to the appearance of sexual signs, and the interest that the girls expressed in their presence. An additional factor in this context is the perceived vulnerability of girls and the fear of pregnancy. Mothers of sons did not feel as obliged to deal with the issue of sexuality [15].

Other reasons that parents gave included; a lack of sufficient knowledge regarding the issues having to do with sexuality and the difficulty, they felt in talking about sexuality with their children, whether the children have disabilities or not [16].

The literature also shows that parents fear the possible sexual exploitation of their children when the child has a complex ID, especially in women. The children are so dependent on the people who care for and treat them, sometimes within an intimate and physical therapeutic framework. Parents fear that the children may not be unaware of their situation [20].

The findings of these studies reveal that parents' feelings, combined with the absence of any tools or knowledge of how to cope with reality, create pressure for the parents. As a result, they adopt a restrictive position and assume responsibility and control over the sexuality and intimacy in the lives of young people with ID, while also encouraging their children to develop friendships, but not intimate relationships [12]. This restrictive position makes parents, according to Löfgren-Mårtenson [12], into "new institutional walls," even when the old ones have been removed. Therefore, the purpose of the study, was to examine the perceptions of parents of children with ID regarding the sexuality of their children.

## Method

In examining the perceptions and beliefs of parents of adolescent children with ID in Israel regarding the sexuality of their children, this study used phenomenological research. This approach enables systematic learning of a complex and multidimensional phenomenon, one that is by nature difficult to measure, from the subjective point of view of the person experiencing it [4]. The phenomenological approach allows us to focus on the processes and meanings that the experience represents to the participants, and its place in their everyday lives [4].

### Research Tools: Interview

A semi structured phenomenological interview was used [4]. This kind of interview is suitable for use when the researcher is interested in how participants understand and how they assign meaning to experiences in their lives. Therefore, this is the most suitable tool to use in this study, which attempts to uncover the perceptions of parents of adolescents with ID. In the context of conducting a semi structured interview, the interviewee is an expert with valuable knowledge of the topic under investigation who shares it with the interviewer and helps him, or she to understand that topic [4]. In this study, the interviews were conducted face-to-face at a location of the interviewee's chose.

The interview was based on an interview guide (see interview guide at "Appendix 1") containing, a demographic background questionnaire; some guided questions, most of them open-ended and comprehensive; and more focused questions that probe more deeply

into the topics raised by the interviewees themselves, in addition to raising issues that were not introduced by them during the open-ended question phase.

## Research Process

Following the approval of the Ethics Committee of the Ministry of Education and the University of Haifa, special education schools for students with ID were applied to assist in the recruitment of study participants. The application to the schools included information about the purpose of the study, the steps involved in it, the promise of confidentiality, and how to contact the first author. Contact was made possible through a phone call for further details and consent to participate in the study. With those who agreed to participate in the survey, a date was set for a face-to-face interview at a location of their choice.

At the beginning of the meeting, the researcher explained the participation in the study and the participants were asked to sign an informed consent form and fill out a socio-demographic questionnaire, after which the interview took place. The interviews took between 30 and 90 min and were all recorded and transcribed for data processing. The interviews were conducted by the first author of this study who has many years of experience and familiarity with the research population.

## Data Analysis

A thematic analysis of the interviews was performed using the familiarization, highlights and memo-writing/note taking techniques [3]. This thematic analysis and thematic coding were applied using a multiple-stage procedure, with the first step involving the interpretation of individual interviews (see “Appendix 2”). The themes were developed based on this analysis and were then cross-checked and compared with other interviews, thereby enabling comparison between individual and collective understanding. Narralyzer software was used to manage the data and organize the transcripts of the interviews. In the process of generalizing the themes, the second author carefully followed coding practices [1], reflecting the central message of the data while maintaining the study participants’ original wording as much as possible. This coding system was then tested by the two authors to achieve reliability by conducting a double-blinded coding of the two interviews.

## Results

The research findings present the demographic background of the study participants, see Tables 1 and 2:

Table 1 shows that 81% (N=17) of the participants completed high school and 71% (N=15) and 29% (N=6) have an academic education. Most of them are employed, 91% (N=19), and most are married, 81% (N=17); the rest, 19%, are divorced or widowed.

Table 2 presents the demographic background of the adolescents with intellectual disabilities.

The research findings revealed five main themes emerging from the interviews with the parents, mainly explaining the tensions that arise from the way the parents perceive their children’s sexuality. The main items were the following:

**Table 1** Characteristics of the Participants of the Study

Interview number	Age/gender	Education	Source of income	Family status
1	35/M	High school	Welfare	Married
2	55/M	High school	Driver	Married
3	44/M	Higher education	Teacher	Married
4	52/M	High school	Secretary	Married
5	50/M	High school	Cashier	Married
6	49/F	High school	Secretary	Married
7	38/M	Higher education	Social work	Married
8	40/M	High school	Seller	Widower
9	43/M	High school	Cashier	Divorced
10	45/F	High school	Allowances	Married
11	39/F	High school	Seller	Married
12	55/M	Higher education	Nurse	Married
13	60/M	High school	Caregiver	Married
14	42/F	High school	Caregiver	Divorcee
15	40/M	High school	Factory	Married
16	55/M	Higher education	Lawyer	Married
17	57/M	High school	Secretary	Married
18	48/F	High school	Cashier	widow
19	38/F	Higher education	Teacher	Married
20	45/M	Higher education	Hey TIC	Married
21	44/F	High school	Secretary	Married

**Table 2** The demographic background of the adolescents with ID

Variable	Values	Children with ID in (%) (N = 21)
Age	15–18	52.4
	19–21	47.6
Gender	Male	66.6
	Female	33.4
Primary disability	Intellectual disability	76.2
	General and chromosomal disability	4.7
	Down syndrome	19.1
Education framework	Special education school	85.7
	Rehabilitation center	14.3

## Exposure to Children's Sexuality

The parents described in the interviews how they were exposed to various aspects of their children's sexuality; for example, erections, masturbation, menstruation, sex therapy, sexual attraction, and interpersonal sexual contact. According to the parents, this exposure occurred in several areas:

One area is while caring for them in the home, as the children require support in their day-to-day functioning; for example: “He has... the... that’s his sensitivity spots, it’s impossible, it’s an area that he just doesn’t, let anyone touch him there, the only one who is still able to touch it with the sponge. This requires a lot of energy from us so that he would somehow agree... to... clean there” (P, 3).

Also, parents were exposed to various aspects of their children’s sexuality through reports received from the school’s professional staff. For example, in the case of suspected sexual abuse, as one mother described:

“One day, a few months ago, she went and told the school principal that someone did this and that and the other, she didn’t know how to explain, did this and that, she got frightened and called us..” (P, 12).

An additional area of exposure to the children’s sexual expressions occurs as a result of the fact that the parents live together with their children in the same house, not necessarily because of the child’s special needs. For example, one mother stated, “I’m aware of the fact that he pleasures himself, I see him in his room, covering himself with the blanket”... (P, 17).

Another space, according to the parents, is the discussion of the topic of sexuality that they have with their children. For example, one mother.

### **Ambiguity in the Parents’ Perceptions of Their Children’s Sexuality**

The study reveals a dilemma that was addressed by all the parents: the question of the existence or nonexistence of sexuality in their children. Some of the parents noted the gap between their child’s chronological age and their mental and functional development. For example:

“You raise a child like that, as far as you are concerned he is 16 years old, he is... for me he’s two years old, and when people come to me and tell me, listen, he has sexual needs, it’s like hearing a ‘boom’; you say, wait a minute... It isn’t possible that... here he is developing, and there he isn’t growing...” (P, 9).

Some of the parents expressed their doubts about the existence of any sexual needs in their child:

“So, for fantasy, he looks at some magazine of... ah... naked girls or things like that, and it does seem to turn him on. But I don’t think he has any sexual need; it’s more like a habit with him. He isn’t into it.. He isn’t developed enough” (P, 7).

The dilemma that some of the parents expressed about their children’s need for an intimate relationship is another expression of the question of the existence or nonexistence of sexuality. For example;

“What does it mean, for him, to fall in love?... the desire for closeness more than for sexuality.” (P, 11).

Parents also referred to their children’s cognitive disability as a factor affecting their ability and their need to be in an intimate, interpersonal relationship;

“He does not understand that there is such a thing as sex, he doesn’t know what happens in... “ (P, 13).

An examination of how parents perceive the existence of sexuality among their children indicates that it is characterized by indecision.

### **Between Love and Care and Illicit Sexual Contacts**

The significant involvement of the parents in assisting in the daily functioning of their children, especially during adolescence, and their exposure to the different expressions of their sexuality, which is sometimes perceived as nonnormative according to the parents' understanding, create situations in which the question of the normativity of the relationship between parents and their children raises feelings of discomfort among the parents. The parents noted some ways of relating to this discontent.

Some of the parents described their children as being sexless, which is to say that they “cleansed” the element of sexuality from any sexual situations. For example,

“If I’m getting dressed and he walks into the room... then he will not look at my breasts because it’s something that he doesn’t know the meaning of...” (P, 7).

Other parents addressed the issue from taking care of their children, and the responses from their surroundings:

“I bathed my daughter for many years because she can’t take a shower by herself; they told me at the school that she is too big now, and because I am a man, it is not appropriate for me to continue helping her in the shower. My wife passed away, and there is no one else to do it. Do you understand? What are they thinking; I’m her father” (P, 9).

The interviews show that the perspectives of other people are a factor that influences the parents' perceptions of whether or not the care they give to their children is normative.

The parents' perceptions of the sexuality of their children, as revealed in the interviews, is complex. This complexity is expressed in the ambiguity of the parents' perceptions regarding their children's sexuality, the very existence of sexuality in them, and its boundaries, as well as the question of whether or not their children are sexual. Additionally, this complexity raises feelings of discomfort that are expressed in the question of the normativity of the parents' sexuality within the spaces of affection and care for their children because of their difficulties in functioning. These dilemmas were not resolved during the interviews.

### **Parents' Reactions to Their Child's Sexual Expressions**

In the interviews, two main types of parental responses to the sexual feelings of their children were uncovered: avoidance and interference. The two answers often coexisted in most parents.

Avoidance—The most common reaction that the parents brought up was avoiding any intervention, such as a reaction to or a conversation about their child's sexuality. This response, according to the parents, was usually accompanied by their deliberations about whether or not to take any action; for example,

“My husband and I debated... whether we should buy him a sex doll... I had a hard time with it because I didn’t know if we should do it,... we asked ourselves many questions...” (P, 6).

The parents noted three main reasons for the high frequency of avoidance: embarrassment insufficient knowledge, and the fear that their reactions would cause damage. For example, concerning embarrassment,

“... I treat everything as if it’s just a natural thing; because it embarrasses me, I can’t talk about it...” (P, 15).

Some of the parents noted that they avoided interfering because they thought that they did not have enough knowledge of how to help their children with this subject. One mother stated

“I think he wants to have sex... but I don’t know how to help him with that... How can I help him with that?” (P, 9).

Concerning the mothers’ fears regarding the subject of sexual vulnerability:

“My biggest fear is that she would be sexually exploited... think of how many people touch her...., she’s used to being touched everywhere on the body, which is also something that bothers me so much. She doesn’t mind it, so I don’t ask her about it, I don’t want to stir this up with her, any frustrations” (P, 12).

In the interviews, all the parents addressed the subject of their avoidance as a deliberation of whether or not to take action regarding the sexuality of their children.

### **Interference to Prevent the Expression of Sexual Behavior of the Children**

Another response most of the parents addressed was interference aimed at preventing the expression of their child’s sexual behavior; parents described how they act to prevent their children from expressing their sexuality in various ways; for example,

“She fell in love with a boy from her day center, he kissed her very very hard on the cheek, her whole face got blue, it was shocking; I took a picture of it, she had a hematoma on her cheek when she got home, we got so scared... We started talking with the staff at the day center and his parents and tried to explain; we got a lot of people involved, and we made it clear to her that they probably couldn’t, that they had to stay away from each other because it was not good.” (P, 14).

Some of the parents explained their Interference as a need to protect their children; for example,

“They say it’s allowed... If she wants to do something with someone else, it is allowed, and we have to teach her what is permitted; it’s just important that she is safe, but I don’t agree; I don’t need her to get pregnant, so I took her to the doctor, and he gave her oral contraceptives.” (P, 17).

Another reaction that the parents spoke about was that of limiting their child’s sexual expressions to a specific place or situation. For the most part, the limitations described by the parent’s stem from the fact that their children’s behavior is unacceptable to them; for example,

“I’ve told him many times: No, now we do not touch one another, it’s tough for him because... he is a child that hugs a lot and gets a lot of hugs. So, I’ve told him many times, like; you can have a whole hug at the beginning, you can have a whole hug at the end, but not all day long.” (P, 11).



The interviews with the parents show that the parents' lives with their children force them to confront situations in which they are required to make decisions despite their dilemmas regarding their children's sexuality.

## Discussion

The purpose of the study was to examine the perceptions of parents of children with ID regarding the sexuality of their children. The findings raise the tensions dilemmas and the complexity in the way in which parents perceive their children's sexuality and in the various responses of parental involvement in their children's sexual expressions.

The complexity in the way that the parents perceive the sexuality of their children is shown in the vagueness they express regarding the very existence of that sexuality. It seems that the parents' have difficulty in addressing the gap between the sexual expressions of their children and the other characteristics of their behavior, that they perceived as childish. Previous studies have pointed to the denial of the child's sexuality by some parents, even though they had witnessed explicit expressions of sexuality [15].

In the current study, a trend of denial of the existence of sexuality and the sexual needs of children was found, and there are also dilemmas regarding this trend, as well as a certain degree of recognition of the sexuality and needs of the children. These findings reinforce Pownall et al. [15] notes, that Cognitive impairments and a socially marginalized position increase dependence on their families to assist with sexual matters. Specifically, The topic of sexuality brought to the forefront mothers' fears about their offspring's ability to cope with the challenges of adulthood [15].

The result that people with ID are often perceived as sexless, or that their sexuality is defined in terms of deviation and perceived as abnormal, is also reinforced by earlier studies [19]. People with ID are regarded as being unable to provide informed consent to sexual relations, as highly vulnerable to sexual violence, or as children with adult sexual impulses that are uncontrollable [22]. Shildrick [19] offers an explanation of the dynamics of silencing the sexuality of people with ID. Shildrick describes how the construction of people with ID as nonsexual beings and the absence of any social intervention in this field, in fact, constitute a means of controlling their sexuality through a mechanism of denial or no recognition.

### The Complexity of Parents' Coping with Ambiguous and Silenced Spaces Relating to the Sexuality of Children with ID

The challenge posed by the sexuality of adolescents with ID to their parents is the result of issues related to perceptions about any physical contact between parents and children. This vague and threatening space, described in the findings as ranging between the physical expressions of care and love in the relationship between the parents and their children, has been termed "the story that has not been told" [5].

The physical and emotional needs of adolescent's place parents in situations that may be perceived as sexual, whether during the physical care of the children or as physical expressions of love between parents and their children. These situations are sometimes interpreted by professionals, sometimes by the children and sometimes by the parents themselves, as an illicit expression of sexuality. As far as we know, there is no literature dealing with the ethics or the experience of physical contact in the relationship between parents and their

adolescent children, with or without ID. We propose to challenge the dichotomous perception of physical contact in relationships, by allowing for the existence of a gray area, in which physical touch may be simultaneously beneficial on the one hand but also potentially harmful on the other, and therefore, each case should be examined individually.

Moreover, in light of the dichotomous and superficial conceptions of this space, the development and expansion of the social discourse about the intimate connections between parents and children; about the appropriate ways in which the adults in the family must respond to the physical, sensual and emotional needs of children; and about the essence of the emotional and sexual maturity of adults are necessary in order to shed light onto these spaces of doubt, such as the spaces of physical touch, which is sometimes intimate, between parents and children with ID. This spaces of physical touch remain undiscussed and therefore vague and lacking in any clear boundaries of permissible and illicit daily practices.

The parents in this study are the parents of adolescents. Their approaches range from a perception of their children as children, to an understanding of their children as adults. However, unlike children or adults, whose attitude toward sexuality is regulated and controlled by any means [8]. The prevailing social perception of adolescents with ID, which is reflected in the words of these parents, is that they are neither children nor adults, and at the same time, they are both children and adults. They are perceived as children because of their care needs but are mature according to their age. As a result, the classification of their sexuality as the adult or childish is vague and unclear, and in their attempt to describe it, the parents speak of sexual expressions that may be interpreted as an adult and other behaviors that express childish immature sexuality. Moreover, in the face of all this complexity, there is the reality in which the parents must cope with situations in which they are sometimes required to provide intimate physical care to their children and be involved in activities such as; dressing and bathing them and helping them use the bathroom. The ambiguity concerning the degree of maturity of the people with ID, leads to further uncertainty regarding the role of the parents in terms of situations involving intimate physical touch.

Second, unlike parents of young children, the sexuality of people with ID is often perceived by society as well as by parents, as being no normative and therefore as something that must be monitored and sometimes prevented. On the other hand, parents describe their desire to respond to their children's emotional needs and to offer them warmth and love. This complexity creates situations in which, the parents are torn between the need to set limits to the sexual expressions of their children, which are perceived as no normative, and at the same time to maintain their protective and caring parental role by addressing their children's emotional needs.

Also, the supervision of the parents, as well as their children by various professionals, also contributes to the complexity that exists in this space. Foucault described the society in which we live as one that is full of judges of normality who are everywhere: the doctor, the teacher, and the social worker; and the person, no matter where he finds himself, is one who subordinates his body, gestures, behavior, tendencies, and achievements to this rule [8].

The significant dependence of parents and their children on professional caregivers, expose both parents and children, and the relationships between them, to a greater degree of supervision on the part of these professionals relative to the existing guidance of parents of young children.

The practice of care and affection between parents and their children, may take on a meaning of illicit sexuality not only according to the parent's interpretation of the situation

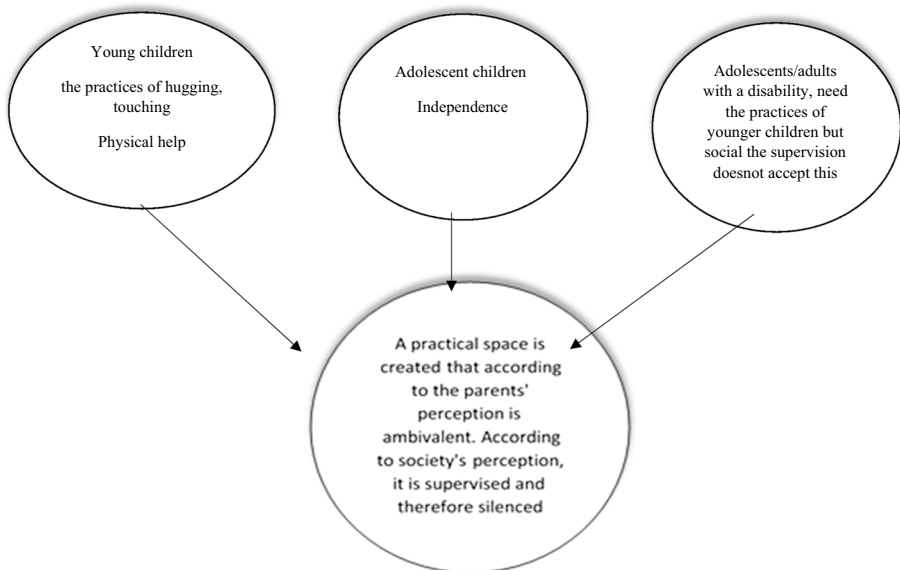
but also according to the definition of support and supervision professionals or the person with the disability; all this subordinates the parents not only to their judgment but also to the social understanding of the way their behaviors appear from the outside in situations that involve physical contact, adding to the complexity of dealing with these already complex situations. In this way, the parents of adolescents with ID are often in the space of physical contact with their children that represents a complex and vague reality in which touch can be beneficial but also harmful.

The findings of this study enable reflection about the complexity that characterizes parents' perceptions of their children's sexuality. The practices of parents' relationships with their children expose a space of intimate physical contact between them, whether as an expression of love or as a result of intimate physical care for the person with the disability. This space, which also exists in the relationships between parents and small children, is perceived in social discourse in a binary manner, as either benevolent or illicit, without reference to any gray area between these two extremes. The unique characteristics of parenting adolescents with ID make the parents' need to cope with these ambiguous and silenced spaces even more complicated; Fig. 1 illustrates this complexity.

The findings highlight the need for further studies to examine in depth the implications and effects that stem from the existence of such a space, concerning the gender of the parent and the child and to combinations of different genders.

### Limitations of the Study

This study examined a complex phenomenon whose most of her dimensions are unknown, making it difficult to assess. One limitation of the current study is that it did not explore the perspective of adolescents with ID. The study also failed to examine the perceptions of



**Fig. 1** The complexity of parents' perceptions of their children's sexuality

experts working with adolescents with ID about their perceptions of the sexuality of adolescents with ID to obtain a deeper understanding of the phenomenon.

Therefore, to deepen our understanding of the sexuality of people with ID, follow-up studies should be conducted that examine the sexuality of people with ID from their point of view as well as from the perspective of the professionals who care for them at school. Also, Frawley and Wilson [7] study reflect a need for more in-depth understanding of sexuality and sexual health to support “safe, informed, and pleasurable sexual relationships” (p. 482). Authors from both studies recommended expansion of sexual education for individuals with the literature is fraught with data concerning the exceedingly high rate of sexual abuse among individuals with ID as compared to their non-disabled peers [9, 10]. Many teachers recognized the need for appropriate sexual education but expressed concern that it could lead to harmful or inappropriate behavior [17]. Educator fears, lack of training, and confidence in teaching sexuality education need to be assuaged for reasonable progress to be made toward educating individuals with ID on issues relating to sexuality. Findings from several studies indicate neither training nor employer guidance on how to support individuals with ID in sexuality issues [18]. Most effective methods to provide sexuality and sexual health information to individuals with ID, as discussed previously, is an area with limited empirical support, in light of this challenges, we believe additional research to provide further insight into possible solutions is warranted.

Practical recommendations can be that professionals who work with people with ID and their families should be allowed to examine the complexities of the parents’ perceptions of their children’s sexuality and their attitudes toward these dilemmas. Also professional can create discourse that will enable discussion about and clarification of the difficulties and challenges of this topic. Specifically, such a professional dialogue could critically examine the meanings of physical touch between parents and their children and clarify what kinds of contact are beneficial and what types are harmful; what, if any, is the boundary between the two; and what are the tools that professionals can use in order to determine the nature of this physical touch.

## Compliance with Ethical Standards

**Conflict of interest** Author Iris Manor-Binyamini and Michal Schreiber-Divon declares that they have no conflict of interest.

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the Haifa University’s Ethics Committee (reference number 284/17).

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

## Appendices

### Appendix 1: Interview guide

Demographic background of the parents: age, gender, education, source of income,

Demographic background of the adolescents with ID: age, gender, primary disability, education framework

1. Tell me about you and your child.
2. Tell me about your history and experiences with your child around the subject of sexuality.
3. Tell me about signs and: physical expressions of sexuality, emotional expressions of sexuality, behavioral expressions of sexuality.
4. Did you or do you have any concerns about your child's sexuality.
5. Tell me about the way that you have been dealing with the subject of your child's sexuality.
6. Did your child receive sex education (at school, in another framework)?

## Appendix 2: An example of the data analysis procedure

Tell me about signs or physical expressions of sexuality, from your experience, with your child, things that you've seen, that you've experienced.

M, 17: "From the age of about 17... It started... all kinds of little behaviors of him, changed... Slowly I realized..."

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I'm aware of that fact that he pleasures himself,	masturbation
He goes into his room more and more, sometimes he shuts the door and sometimes he forgets I see him in his room covering himself	takes place at home
With a blanket"	embarrassment?

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