**Supporting people with intellectual and developmental disabilities in their adult strive for sexual relationships and parenthood**

**Abstract**

**Introduction**: In order to enable adults with intellectual and developmental disabilities (IDD) to live a full and meaningful life, there has been a growing emphasis on people with IDD’s right to equal opportunities, including experiencing sexual relationships and parenthood. Despite this emphasis, many people with IDD do not get the opportunity to fulfill their desires in these domains. Parents and service providers are key sources of support for adults with IDD; as such, the current study examined their attitudes and perceptions of their roles in regard to the domains of sexuality and parenthood of adults with IDD. The aim of the current article was to suggest a framework through which to provide optimal support in these areas of life. **Methods**: The study was based on a qualitative analysis of interviews with 30 parents of adults with IDD and 40 service providers. **Results**: The findings demonstrated that parents and service providers provided partial support in regard to the sexuality of adults with IDD, and similarly expressed reservations and concerns about the topic. Service providers focused on the goal of teaching skills related to the sexual domain and protecting against potential harm. Correspondingly, the parents wanted to transfer the responsibility of approaching this issue to the staff. In regard to parenting, service providers and parents held negative attitudes. **Conclusions**: **Policy Implications**: The current study proposes that adults with IDD should be provided with holistic support, in which sexuality and parenthood are included as part of the components that are pertinent to leading a meaningful life in adulthood.

*Keywords*: sexuality, parenthood, direct support staff, parents, intellectual and development disabilities; holistic support

**Introduction**

For many years, adulthood was viewed as a transition period between childhood and old age, and not as a significant developmental stage in its own right. Nowadays, the period of adulthood is perceived to be a time characterized by both changes and upheavals and, accordingly, also a time of significant opportunities for personal development and growth. Without the opportunity to confront the challenges and stages posed by adulthood, there is a risk of deterioration and loneliness (Sneed, Whitbourne, Schwartz, & Huang, 2012). The capacity for people with IDD to experience a developmental process that will allow them to construct, among other things, a separate identity during their adult lives depends on the support and opportunities provided to them by their parents and service providers.

 In recent years, as part of the larger support system provided to adults with IDD, there has been a growing emphasis on providing them with opportunities to live a full and meaningful life, which includes having experiences with sexual relationships and even parenthood. The recognition of the rights of people with IDD for establishing intimate relationships and their own families began to take root in the early 1990s, when the first steps were taken for them to be able to exercise their right to express their needs and desires. These strides highlighted the transition from focusing on the disability to focusing the barriers that exist for people with disabilities which prevent them from achieving self-actualization (Fraley, Mona & Theodore, 2007; Shuttleworth, 2007). The primary milestone in this respect was the Convention on the Rights of Persons with Disabilities, which was adopted by the United Nations General Assembly on December 13, 2006. Article 23 of the Convention, which addresses respect for home and the family, reads:

States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that: (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized; (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided; (c) Persons with disabilities, including children, retain their fertility on an equal basis with others (United Nations, 2006).

The principles of the Convention, as they are phrased, unequivocally define the rights of persons with disabilities to maintain intimate relationships and to establish a family of their own. However, the question arises: To what extent does this recognition affect their lives in reality, and to what extent are the rights of the treaty incorporated into the lives of adults with IDD and to what extent are they attainable to them?

 Previous findings have shown that, despite declarations made about the rights of people with IDD, and despite the protests that take place against the discriminatory social attitudes toward them, the reality of their lives, in regard to the possibility of having sexual and family ties, is not adequately addressed or supported. Many staff members still advocate for an approach that controls and regulates the sexuality of people with IDD (Brown & Pirtle, 2008). In addition, in at least some cases, parents exhibit an even more conservative stance (Cuskelly & Bryde, 2004; Evans, McGuire, Healy, & Carley, 2009). Many people with IDD continue to report that they feel lonely and dissatisfied with their interpersonal lives (Drew & Hardman, 2004; Kelly, Crowley, & Hamilton, 2009; Lafferty, McConkey, & Taggart, 2013; Neuman & Reiter, 2017; Rushbrooke, Murray, & Townsend, 2014). Similarly, even in regard to parenthood, the attitudes of both close others and the larger society are often negative, and in practice, there continue to be measures in place to prevent pregnancy and childbirth (Esmail, Darry, Walter, & Knupp, 2010; Schaaf, 2011; Shildrick, 2007). Many women with IDD report that, as they were growing up, they were told that they would never be mothers, and that since their lives were already complex enough, there was no reason to add any additional difficulties (Prilleltensky, 2004). The assumption is that people with IDD do not have the abilities to be good enough parents (Booth, 2000; Booth & Booth, 2004).

 In summary, it appears that alongside the struggle for gaining rights, many people with IDD do not receive adequate support that would allow them to realize their desires when it comes to sexual and parenthood experiences (Neuman & Reiter, 2017). The disconnect between the desired (the declared) and the reality (life itself) may be due to several factors. First, social attitudes toward people with IDD continue to be influenced by stereotypical and conservative perceptions, which rest on the assumption that people with IDD lack understanding and maturity, and are unable to maintain sexual relationships, intimate relationships, and a family life (Kramers-Olen, 2016; Lafferty et al., 2013; Reiter & Bryen, 2012; Rogers, 2010; Young, Gore, & McCarthy, 2012). Moreover, public discourse surrounding these issues often evokes feelings of discomfort, rejection, and apprehension (Esmail et al., 2010; Schaaf, 2011; Shildrick, 2007). At the same time, the sexuality of people with IDD has raised concerns regarding their vulnerability to experience sexual violence on the one hand (Schaaf, 2011; Shildrick, 2007), and the possibility that they may harm another on the other hand (which is based on the stereotypical perception that people with IDD are unable to control their impulses) (Lyden, 2007; Shildrick, 2007). In this regard, it is important to consider that service providers and parents, by virtue of their role in the lives of individuals with IDD, are sometimes forced to make decisions regarding safety and health issues, and these decisions are often inconsistent with the declarations of the rights of people with IDD (Hawkins, Redley, & Holland, 2011). In practice, people with IDD do not receive adequate support and services that would allow them to exercise their right to sexuality and parenthood (McBrien & Power, 2002). An open question remains as to how to provide people with IDD with a suitable support system that would allow them to enjoy a full and meaningful life, which includes sexual relationships and the experience of parenthood.

 Despite the changes that have occurred surrounding attitudes and perceptions toward people with IDD, the support they receive largely continues to focus on learning life skills designed to help them overcome difficulties arising from their disabilities, as well as to function independently and integrate as best as possible into the normative lifestyle of the community and society as a whole (Abbott & McConkey, 2006). The emphasis remains on imparting skills that promote functional independence. These skills make it possible to expand people with IDD’s participation within the normative societal lifestyle; however, if this type of participation does not correspond with an individual’s preferences and expectations, the contribution to their quality of life may be negligible (Lafferty et al., 2013; Schalock, Bonham, & Verdugo, 2008; Shogren, Thompson, Shaw, Grandfield, & Hagiwara, 2018). However, despite the growing emphasis on the social and political changes that are necessary for enabling people with IDD to enjoy equal opportunities (macro-level factors), there remains a lack of knowledge and guidelines in place for providing individual guidance and support to individuals with IDD (micro-level factors) (Bigby et al., 2017; Bigby, Whiteside, & Douglas, 2019). Accordingly, the question of how to support people with IDD in such a way that would allow them to realize their rights to a life in which intimacy, sexuality, and parenthood are included, remains unanswered (Kazukauskas & Lam, 2010; Hamilton, 2009; Natasha & Miriam, 2017).

**The Current Research**

The current research was based on a large-scale study conducted with parents of adults with IDD and service providers who assist them. The present article focused on analyzing the findings (thematic content analysis) which emerged in conversations conducted with parents and service providers of adults with IDD. These conversations surrounded the sexuality and idea of parenthood of individuals with IDD, as well as parents’ and service providers’ perceptions of their roles in the context of these topics and their attitudes about the topics. The aim of the article was to examine how these perceptions and attitudes can contribute to the creation of guidelines for providing optimal support to individuals with IDD.

The research questions were as follows:

(1) What are service providers’ attitudes regarding the sexuality and parenthood of people with IDD (both in general, and in regard to their service recipients), and how are these attitudes reflected in their view about their role in regard to these areas?

(2) What are the parents’ attitudes regarding the sexuality and parenthood of people with IDD (including their own sons and daughter), and how are these attitudes reflected in their view about their role in regard to these areas?

**Methods**

The current study employed qualitative methods, including semi-structured interviews and thematic content analysis. We applied a hermeneutic-phenomenological approach, which is used to unravel the meanings participants attribute to the phenomenon under study (Jorgensen, 1989; Willis, 1991).

**Participants**

The study was based on a non-probability voluntary sample. The sample included two groups: a parent group and a service provider group. The first group included 30 biological parents of adults with mild to moderate IDD (14 fathers and 16 mothers). Thirteenparents hadhadfour parentsThe adults with IDD lived in a variety of types of residences, ranging from semi-sheltered housing to open residences. Parents’ mean age was 61 (range: 49-91), and the mean age of the children with IDD was 30 (range: 22-53). Eleven parents had children who were involved in an intimate relationship at the time of the interview. The second group was composed of 40 direct support staff who worked with adults with IDD. There were 14 male support providers and 24 were female support providers. The mean age of the support providers was 47 (range: 30-68) and 13 of them were relatives of a person with disability. The mean number of years that the support providers worked with adults with IDD was 12 (range: 1-35).

**Instrument**

The study employed semi-structured individual interviews. On the basis of the research questions, the interview protocol included questions in the areas of sexuality and parenthood, specifically in relation to adults with IDD. the interview included a number of supplemental questions for the purpose of encouraging discussion. Examples of such questions, by topic, are outlined below.

In regard to attitudes toward the desires of people with IDD (in terms of sexuality/parenthood):

* When you think about the topic, what associations come to mind?
* What is your stance on these topics?
* In your opinion, what is the message that should be conveyed about these topics?
* Have you dealt directly with these topics in the past (and if so, explain in detail)?
* How do you think you would react to matters related to these topics?

In regard to attitudes toward the current rights and declarations (in terms of sexuality/parenthood):

* What rights should people with IDD have in regard to these topics?
* What are the important and fundamental conditions that need to be in place to enable people with IDD to exercise these rights?
* Given the current movement (declarations and legislation), do you have concerns about these topics?
* What do you think the circumstances surrounding these topics will be like 20 years from now?

In regard to their roles as parents/support providers, and their perceptions about the role of others (in terms of sexuality/parenthood):

* When it comes to instruction and intervention, what do you think the emphasis should be on?
* In your opinion, who do you think that people with IDD should turn to when they need help with these topics?
* Do you currently have a role when it comes to these topics?
* Are you currently, or have you previously been, involved in preparing an individual with IDD for life with regard to these topics?
* Is there any additional information that you need in order to guide him/her?
* In your opinion, what will your role be in the future?

Procedure

The study was conducted with the approval of, and in collaboration with, the Ministry of Social Affairs and Social Services in Israel and all study procedures were approved by the Ethics Committee. Thirty parents and 40 support staff agreed to participate in the study and signed declarations of informed consent. Interviews were held individually. Two research assistants, who have had previous experience with working and interviewing adults with IDD, conducted the interviews.

All participants were ensured about confidentiality and anonymity. They were also told that they had the right to not answer any question and to stop the interview at any time. All participants provided consent to having the interview recorded and transcribed. Only the interviewer and interviewee were present during each interview. In several cases, when the interview could not be completed within a single session, a second meeting was held. Each interview lasted between one and two hours in total. The parent interviews were held in the participants’ homes, and the support staff interviews were conducted in the participants’ workplace.

**Data Analysis**

Two researchers independently coded and analyzed the interviews using thematic content analysis (TCA). Initially, each of the researchers conducted the analysis independently, focusing on the ways in which the interviewees’ narratives reflected their feelings, beliefs, and ideas in relation to the study’s research questions. The researchers then shared the results of the content analysis with one another and discussed them until mutual agreement was achieved. Trustworthiness and credibility were achieved through peer debriefing, whereby an expert colleague reviewed the analysis and provided critical feedback (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). The external reviewer confirmed the themes extracted by the researchers.

**Results**

 This section describes the main themes that arose in response to the two research questions: (1) What are service providers’ attitudes toward the sexuality and parenthood of people with IDD (including their service recipients), and how are these attitudes reflected in their view about their role in relation to these topics? (2) What are parents’ attitudes toward the sexuality and parenthood of people with IDD (including their sons and daughters), and how are these attitudes reflected in their view of their role in regard to these topics?

**Service Providers**

**Sexuality**. In regard to the sexuality of people with IDD, service providers described four main themes. The themes presented two opposing viewpoints regarding their perceptions about this topic and, consequently, two opposing viewpoints regarding their perceptions of their role. On the one hand, a positive stance is described, as indicated by the theme, *recognition of need*. Responses that corresponded with this theme emphasized that sexuality is a natural, basic, and human need, which is applicable to all human beings. Excerpts of some of the responses which portray this theme include:

* It’s the most human thing that there is. I also do it, so why not them? How are they different?
* At first, I had a hard time thinking about it. Over time, I changed my mind. The way it is treated should be just like any other typical person.
* They have the right to have fun just like any other person on earth. Just because there is a problem in the head, doesn’t mean that there is a problem with sex. But I’m not against it. It is an integral part of a relationship and it’s natural.

Some of the interviewees emphasized that this type of recognition depends on the abilities and the adults with IDD:

* I think it’s okay. It is completely natural. If they are capable, then why not?
* I think that sexuality is a very very important part of a human being’s life and if both people want to satisfy the need that exists, and if they fulfill it in a way that is respectful to oneself and to the other person, then I am happy for them.

In accordance with this positive attitude, another theme arose in which service providers described their role as being focused on, *teaching physiological and technical aspects*:

* They must be taught to understand the human body. Where does physical desire come from and why, and what do I do with myself and what do I do with the other person? To understand what is pleasurable and what is not.
* To expose them to a certain level of knowledge. To explore, to teach, and to present them with more practical things.
* It is her right to know that she can pleasure herself. It is her right to have sex without love. To know about protection and to receive all the explanations and guidance.
* They must be taught, just like regular people, how to have sexual relations, to see how it all works. If lubricants or contraceptives are needed. Gentleness and foreplay beforehand, stimulation.

Along with this positive attitude, service providers expressed reservations in regard to the sexual domain. In this context, the theme – *concern of abuse and harm* –arose. In some of the descriptions, difficulty with understanding and interpreting the idea of reciprocity in regard to sex was mentioned:

* What’s important is that there will be mutual consent. That one person won’t abuse the other.
* That there will not be a situation in which the woman does not want to, and the man wants to, and he continues. Or that the man satisfies his sexual desire and does things that she does not want.

In some of the descriptions, there was a concern about extreme circumstances of coercion and violence:

* Confirm that there is no violence or lack of knowledge that could cause harm or injury, or a violent act towards the woman.
* When an urge is aroused, they may harm others.
* I am afraid of violence, of behavioral consequences. If there is a lack of peace or satisfaction. It is important that no one will be harmed.

In accordance with the concern over someone being harmed, service providers described their role through the theme, *teaching the boundaries of what is allowed and what is forbidden*:

* We must teach them when to do it (for example, not to do it while at work).
* That they shouldn’t switch partners each week… to work on understanding the idea that, I have a partner so I will only have sex with him and vice versa. We need to teach them to maintain respect and intimacy. Not to scream all the time.

**Parenthood.** Service providers’ attitudes about parenthood for people with IDD were unequivocally negative. They refrained from describing having any role in this context. The theme, *incapability/immaturity*, arose from participants’ responses. It referred to the difficulty that people with IDD would have in dealing with the challenges of parenthood since they themselves are treated as children who are unable to function independently, and therefore, they would not be able to care for a child:

* I don’t think that it’s appropriate, they themselves are children. They aren’t ready to be a parent… How will a girl with an intellectual disability be pregnant? She is a girl, not a woman.
* Coping with parenthood is difficult, irrespective of having an IDD. There is a concern that they are children and are not aware of the difficulties that await them.
* The right exists, but there are limitations and so long as they are not entirely independent, I do not think they can care for someone.

Along with doubts about their maturity level, emerged another theme – *concern for the well-being of the child who will be born*. This concern is described in the context of the suffering that will be inflicted on the child due to the parents not being able to care for him:

* A child cannot grow up in their surroundings. It will impair his development. He will end up being just like them. Therefore, it’s important to also care for the child, and not just for the parents. They won’t be able to raise children. They won’t be able to contribute to a child’s life. I think those kids are miserable.
* I have always been against it and I still am. Bringing a child into the world is not such a big deal, rather taking care of him is. To raise him, to provide him with an education and a parental figure. I cannot bare to see children suffer [interviewee started crying] because I have worked with children like these and it’s awful. There is nothing worse than it. If they are born healthy, then they are ashamed of their father and mother who are not able to behave, and who cannot help them with their homework.

Another concern that arose regarded the worry that there will end up being a role reversal when the son or daughter grows up and finds themselves caring for their parents:

* It’s hard to say it, but it will not do them nor the baby any good. It happens based on the whim of the couple, but it is not fair to the child. It will cause damage and afterwards there will be a reversal of roles, the child will end up becoming the parent.
* A situation in which children need to take care of their parents is not a normal situation. That’s not how it should be.

Additional reluctance on the part of the service providers were represented by the theme, *the burden falls on society and people*. Service providers indicated their concern that the responsibility will fall on society and the parents (of those with IDD):

* Why burden society? The money, and energy of society.
* Their parents already have one person to take care of. And what now? They will have twice as much hard work taking care of others. The family, the parents will now have to deal with it.
* It will fall on the grandparents and they will only be in the child’s life for a limited time.

A fourth theme concerned the hesitations surrounding the genetic aspect of IDD. Service providers raised concerns about the increase in the number of people with IDD in the general population and argued that action should be taken to *reduce the number of people with disabilities in the world*:

* Because if there were more special needs people in the world, what would the world be like?
* Preliminary tests should be conducted so that the child won’t be disabled as well. Many times it’s hereditary so it’s not right to allow this to happen.
* Very very problematic. Genetically, often already in the screening tests you can see that defects have passed on to the children and then it is advisable to have an abortion.

**Parents**

**Sexuality**.Four central themes represented parents’ attitudes toward the topic of sexuality. In relation to their perceptions of their roles, two main themes emerged. In regard to parents’ attitudes toward sexuality, they expressed mixed messages. On the one hand, one of the themes portrayed a positive attitude that referred to sexuality as a *response to a natural need*:

* I think that they deserve to experience their sexuality just like any other person. They deserve it too. To experience this basic need.
* I think that they are allowed to lead a full sexual life.
* Completely natural. It makes sense. They are flesh and blood, just like us. It’s most natural. Not much different than any other person’s needs. It’s like breathing and running.
* It calms them and provides them with an acceptable release, and it has a positive effect on their sense of well-being.

On the other hand, reservations were described in response to people with IDD’s sexuality, which were captured by three central themes. In the theme – *concern of harm or sexual abuse* – concerns that the person with the disability will be a victim of abuse or, alternatively, be the abuser, were described:

* Yes, I am concerned about who the partner will be that she will have sex with, how it will happen. If it will be right for her. Maybe if she connects with someone more experienced than her, then it will be easier. I’m worried that she will fall in love with a man and will want it very much and will force him to do things that she doesn’t necessary want.
* I think that there is a certain chance that she will hurt someone. My concern is actually in this direction. Maybe she will not know how to behave.
* It may be that he will touch too much, that he won’t know when to stop. There might be an incident in which a complaint of rape will be alleged. Because of a lack of maturity, because of impulsivity, obsession. I don’t know…it may be that he will be the one who will cross the line.

Other reservations were described through the theme, *immaturity*, which primarily referred to parents’ descriptions of their sons/daughters as being childish and therefore unable to notice, understand, and consider others:

* He is self-centered. He doesn’t notice others yet and maybe he never will. He needs to know how to be considerate of others. He really doesn’t know how to do that at the moment.
* I hope he understands as much as possible, at his level. That is in regard to point A. In regard to point H. I will say it again, I am troubled by his childishness. As much as we have tried to help in this matter, I don’t feel that we have succeeded. He doesn’t understand.

Finally, an additional theme is described in the context of society as a whole, and the way in which society treats the sexuality of people with IDD. The theme – *lack of acceptance from society* – represents this stereotypical position:

* Society doesn’t accept it. It’s hard to digest…they continue to look at people with special needs as if they are children and have no ability to make decisions on their own, to understand, to feel. And in the sexual domain, they ignore it and don’t engage with it, rather only pay attention to the harm and abuse.

In regard to the perception of their role within the context of sexuality, parents responded in ways that reflected two different themes. In line the first theme, *a need to provide education and guidance to people with IDD,* parents described their recognition that help is necessary:

* They deserve sex education. If, for a couple without special needs, things progress naturally, and they have knowledge about it and a sense of understanding which comes from the home or from friends, then they are equipped with knowledge.
* They deserve guidance, I’m very much in favor of it. It’s good that he will be aware, that he won’t be afraid of physical touch. It’s ok to touch, if she wants to of course, but only with support and explanations.

In regard to the question about who should provide the help, parents emphasized that they do not want to engage with this issue at this stage of their lives. Through the theme – *transfer the responsibility to the staff* – parents described their expectation that the service providers will take on this responsibility:

* I really don’t know, to this day, if she is having sex. When I used to hear that she was walking around the village at two in the morning, and even when they found her in someone’s room naked, I was in shock. I don’t want to be involved, I leave it up to the staff.
* It doesn’t come up at home because he didn’t seem to show any need until he went to the village. His current relationship really surprised us. He wasn’t interested at all and then, all of a sudden, he was in a relationship. I would have taken initiative if I knew what needs to be done. I should have a role, but I’m not sure if every other week on the weekends is effective. It should be the responsibility of the staff.

**Parenthood**. Similar to service providers, parents’ attitudes regarding parenthood were unequivocally negative. Additionally, they did not perceive that they had any role in this matter. As reflected by three central themes, parents described their negative attitudes. Parents described the inability of people with IDD, including their own sons and daughters, to be parents. The theme, *an inability to cope with the challenges of parenthood*, characterized the negative perceptions that parents of adults with IDD held about the emotional, functional and economic ability of adults with IDD to be parents.

* I do not see such a possibility arising. With his disabilities, it seems a bit delusional to me. I don’t think that he will be able to cope. He really likes to play with small children, he is empathetic, but he will not be able to take care of everyday needs. To change his diapers, to bathe him and to take him to school. The most basic things.
* Everything that’s related to emotions, and financially, how will they get by? In adolescence, what then? All aspects relating to raising children, the emotional aspect, the economic aspect. To take care of someone other than yourself.
* I think she is capable of being a mother in terms of her insights and her approach to children, but it’s not right for her to be a mother because of the need to know how to take care of a newborn and that requires much beyond being nice to him. We talked with her and it’s clear to her that she will not be a mother.
* I have an unequivocal opinion. I do not intend to raise the next generation of abnormal children. I see no possibility of this. If abnormalities are found in pregnancy, I am in favor of abortion. The experience is difficult.

In the next theme – *concern that the burden will fall on them* – parents addressed their needs and their unwillingness to take on the worry, care, and responsibility of raising another child in their current stage of life.

* It’s been enough for me – I raised one child like this, and that’s all. If you agree to it as a parent, you are sacrificing yourself. Everything falls on the parents.
* I had enough of raising children…I don’t feel that if my son has a need to be a parent, that I then have to raise the child. I don’t feel that I should have to take care of the child, nor should my family. It’s not simple and, for us as parents, how much longer will we be here [in this stage]? How much longer will we be healthy? It’s not simple.
* Do not burden the parents. I wouldn’t want a second round of needing to guide a child. I want to have the time to accomplish the things I want to do in my life. To have fun and relax.

Finally, parents expressed another reservation related to the societal domain. In the theme – *an additional burden on society* – parents described the additional burden placed on the community and its institutions:

* No children. There is nothing to talk about. There is no reason for such people to have children. People who are already supported by the state, to bring children into the world… they are children themselves.
* The community, it has so many problems of its own. It’s difficult for the community to participate in such a project…
* In my opinion, society is against it. They feel as if it creates additional burdens and responsibilities.

**Discussion**

The overarching goal of the current study was to create a framework that would provide optimal support for adults with intellectual and developmental disabilities (IDD). The study focused on the domains of sexual relationships and parenthood, areas that often raise reservations and questions regarding the appropriate support systems. Given that parents and service providers are major sources of support in the lives of many people with IDD, their attitudes and perceptions of their roles in regard to everything related to these areas of life is important. In a series of previous studies, it was found that adults with IDD attach great importance to intimate relationships in their lives, but that they do not see their parents or service providers as people to turn to for help, support, and guidance in these areas, and actually are concerned about their over-involvement (Neuman, 2019; Neuman, 2020; Neuman & Reiter, 2017). In other words, parents and service providers are not only *not* perceived as sources of support, but rather are perceived as a threat. Therefore, the present article focused on a qualitative analysis of attitudes and role perceptions of parents and service providers, in everything related to the areas of sexuality and parenthood of people with IDD. The findings indicated a complex picture of conflicting and disorganized attitudes, both on the part of the parents and the service providers. It appears that, along with the recognition of rights, there are also concerns, reservations, and even objections.

Service providers’ descriptions of their attitudes toward the topic of sexuality were conflicting. On the one hand, they expressed a positive attitudes and desire to enable, support, and encourage sexual relations among adults with IDD and, on the other hand, they raised concerns about abuse and harm, primarily due to the inadequate functioning of adults with IDD. Accordingly, in describing their roles, two central goals were identified. The first goal focused on assisting those with IDD to learn the physiological aspects and skills relevant to sexual relations, and the second goal focused on teaching the appropriate boundaries concerning what is allowed and what is not allowed, as well as preventing dangerous situations. Service providers did not address the participation of “service recipients” in the dilemmas that accompany issues of sexuality and parenthood during their interviews. Their mission was focused on functioning (by transferring information and skills) and protection, rather than guidance in the complex matters of life that constitute fulfillment (as much as is possible) in adulthood.

Service providers expressed unequivocal opposition to the possibility of parenthood. Their opposition was based on their assessments in regard to the inabilities and immaturity of adults with IDD, their concern for the well-being of the child to be born, the additional burden that would be placed on society and their parents, and the need to reduce the number of people with disabilities in the world. Compared to the amount of detail provided regarding their role as service providers in the context of sexuality, in the matter of parenthood, service providers did not address their role. A possible explanation for this finding may be rooted in the gap that exists between the currently accepted declarations regarding the rights of people with IDD, and service providers’ assessments of the complex implications of parenthood for adults with IDD.

Parents expressed two different positions in regard to sexuality (similarly to service providers). On the one hand, they recognized the rights of adults with IDD to experience sexual motivation. Sexuality in this regard is a natural and normative expression among adults. Adults with IDD are also entitled to explorations and experiences in this area during their lives. On the other hand, parents also described their concerns of abuse and harm. In all things related to parenthood, parents of adults with IDD, similarly to service providers, expressed clear and unequivocal opposition. They noted a fear of harm and abuse, concern that the burden would fall on them, and concern over the additional burden that would be placed on the community and society. It is apparent that they “pity” society and its institutions while, at the same time, assume that dealing with it would be primarily their responsibility, functionally and financially. Some parents expressed a reluctance to raising children again and some were concerned that they too were getting older and would not always be there to provide guidance and help.

In terms of their perception of their role in the sexual domain, parents sought to transfer the responsibility of guiding their children to the service providers, and they did not want to engage with it themselves. In terms of parenthood, in accordance with their unequivocally negative attitudes, they did not see themselves as holding any role nor did they express an expectation that the service providers would either. In this regard, similar to service providers, it is possible that there remains a conflict between accepted declarations about rights and parents’ personal concerns, which creates a barrier to holding an open discourse about their role in this domain.

During the interviews, parents appeared to focus quite a bit on their needs and the possible impact on themselves. Similar to service providers, they did not refer to the possibility of having a dialogue with the adults with IDD, of treating them as partners in making decisions about their own lives. Based on these findings, and in considering the central position that parents have in the lives of their children, the question arises as to whether parents’ desire not to take part in guiding and intervening in these matters, counteracts their influence on their children.

The current study demonstrated that, along with efforts to support the rights of people with IDD, parents and service providers fail to address the needs of the individual that they support and continue to treat adults with IDD primarily in terms of their concerns. In order to try and change this reality and enable people with IDD to enjoy a good quality of life, one must try to consider how to help build a mutual and supportive relationship between support providers and support recipients. Support in matters related to sexuality and parenthood are complex and are interconnected with one’s values, cultural norms and personal experiences. An open and reciprocal discourse is necessary for enabling parents, service providers, and service recipients to express their worldviews and perspectives within a shared discourse. The purpose of this discourse would be to try and clarify complex issues. The discourse will not necessarily lead to mutual agreement, but it will allow for parents to express their perceptions and expectations; for service providers to take a more holistic perspective on their guiding role in the areas of sexuality and parenthood; and for adults with IDD to express their opinions, desires, and aspirations (regardless of challenges, difficulties, and complex questions that accompany the matters of sexuality and parenthood). The overarching goal of support is not merely to achieve self-actualization in sexual and familial realms, but to treat these areas of life as possible components of the path towards achieving personal fulfillment and meaning in life during adulthood.

The stage of adulthood provides an opportunity to engage on a unique developmental journey on the path towards finding one’s identity, finding meaning in life, and achieving separation. This journey is often not simple, but it allows the individual to re-design his path and try to build – at each stage of adulthood – the necessary foundations for enjoying a high quality of life and experiencing a sense of self-fulfillment (Gambhir & Chadha, 2013). Dealing with challenges, while supporting and guiding adults with IDD to enhance their self-determination is part of the journey for achieving individuation and a meaningful life. In this regard, it is possible to adopt the proposed principles of the holistic support model (Neuman, 2020). According to this model, support is based on a broad vision for autonomy of the service recipient. Engaging in discussion on the issues of sexuality and parenthood will help adults with IDD get to know themselves and their environments, and formulate a clear set of priorities, with which they could make informed decisions. In order to help support providers learn about the worlds of their support recipients – including their abilities, difficulties, needs, and cultural backgrounds – the model suggests conducting a holistic and dynamic evaluation. This assessment includes an observation of the dynamic interaction between the person with IDD and his social, family, and interpersonal environment. The relationship between the person with the disability and his support providers is thus based on holistic support of mutual interchange, and not on unilateral decisions made by parents and service providers regarding the ways in which of adults with IDD should respond and behave. This approach will allow service recipients to be true partners in making decisions about their own lives.

**Implications for Practice**

In light of the study’s findings, it appears that the challenge facing parents and service providers is to try to convey to the individual with the disability, that his desires, attitudes, and needs are integral parts of him and that they are desirable and valued, without stipulating certain conditions about their feasibility. Parents’ and staff members’ claim that people with IDD have the right to enjoy their sexuality were not in line with the reservations they simultaneously expressed. In order to deal with the mixed messages conveyed to adults with IDD by their parents and service providers, one must try and separate the concerns and dilemmas from the importance of encouraging individuals with IDD to express their aspirations and dreams. It is important to note that sexuality and parenthood are not standalone areas of life, but rather are integral parts of one’s broader adult life. During service providers’ training processes, and while guiding parents of people with IDD, it is important to aim for a holistic approach that addresses the psychological, physiological, emotional, and social aspects of sexuality and parenthood, within the context of interpersonal relationships more generally.

 At the same time, we must take into account that sexuality and parenthood are significant experiences which offer opportunities for growth and development in adulthood. Most of us do not become autonomous adults in the blink of an eye; rather, we must go through a process that allows for growth and development. Significant interpersonal relationships, besides being first and foremost an expression of a basic human need, are a medium for engaging in interactions and gaining experiences while going through a developmental process. In this regard, adults with IDD should be encouraged to take an active role in the discussion and decision-making about issues on these topics, to be active in coping with issues that arise in these domains. Along with changing attitudes and perceptions, it is important to consider that, in order to provide people with IDD with equal opportunities in regard to the sexual and familial domains, one must confront the lack of accessibility within society. Social declarations are insufficient and are sometimes even perceived by parents and service providers as “righteous.” Without a supportive infrastructure and sufficient allocation of resources that will provide protection, instruction, guidance and more, declarations on their own will not allow for adults with IDD to exercise their rights. Involvement in an intimate partnership requires a new approach and accessibility in regard to a variety of different aspects (physical, cognitive, etc.), as well as necessitates setting boundaries and safety and protection measures to prevent harm and abuse.

Limitations of the Study and Recommendations for Further Research

It is important to note that the author’s professional experience served as an underlying impetus for this study’s focus and research questions. This experience played an important role in defining the research questions, developing the research tools, and gaining access to the research population. This experience may also have served to bias the positions, values and perceptions guiding the study. The current study focused on parents’ and service providers’ perspectives regarding their role as supporters of people with IDD in the areas of sexuality and parenthood. In future research, it will be important to examine how people with IDD view the role of parents and service providers in these domains, both in terms of the existing support and the absence of support. In other words, it is important that their full partnership be recognized when engaging in discussions on these topics. In addition, it will be important to examine whether there is a gender difference in the needs and desires of men and women with IDD in relation to sexuality and parenthood. Finally, the current study reported on the concerns expressed that adults with IDD becoming parents could lead to the birth of more people with IDD. In this regard, the reservations were not only about the challenges of raising a child with a disability, but also about the social and public implications of an increase in the number of people with disabilities. Future studies should examine such attitudes in greater depth.

**Declarations**

**References**

Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, *10*(3), 275-287.

Bigby, C., Douglas, J., Carney, T., Then, S.-N., Wiesel, I., & Smith, E. (2017). Delivering decision-making support to people with cognitive disability – What has been learned from pilot programs in Australia from 2010 to 2015. *Australian Journal of Social Issues*, *52*(3), 222-240.

Bigby, C., Whiteside, M., & Douglas, J. (2019). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual & Developmental Disability*, *44*(4), 396-409.

Booth, T. (2000). Parents with learning difficulties, child protection and the courts. *Representing Children, 13*(3), 175-188.

Booth, T. & Booth, W. (2004). Findings from a court study of care proceedings involving parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 1*(3-4), 179-181.

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*, 195-207.

Brown, R. D., & Pirtle, T. (2008). Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: Examining beliefs using a Q-methodology approach. *Sex Education, 8,* 59–75.

Cuskelly, M. & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample. *Journal of Intellectual and Developmental Disability, 29*(3), 255-264.

Drew, C. J., & Hardman, M. L. (2004). *Mental retardation: A lifespan approach to people with intellectual disabilities.* New Jersey: Merrill Prentice Hall.

Esmail, S., Darry, K., Walter, A., & Knupp, H. (2010). [Attitudes and perceptions towards disability and sexuality](http://www.tandfonline.com/doi/abs/10.3109/09638280903419277). *Disability and Rehabilitation, 32*(14), 1148-1155.

Evans, D. S., McGuire, B. E., Healy, E. & Carley, S. N. (2009), Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family carer perspectives. *Journal of Intellectual Disability Research, 53*, 913–921.

Fraley, S., Mona, L., & Theodore, P. (2007). The sexual lives of lesbian, gay, and bisexual people with disabilities: Psychological perspectives. *Sexuality Research and Social Policy: Journal of NSRC, 4(*1), 15–26.

Gambhir, V., & Chadha, N. K. (2013). Psychological experiences of midlife. *Indian* *Journal of Positive Psychology, 4*(1), 26-31.

Hamilton, C. (2009). ‘Now I’d like to sleep with Rachael’ – Researching sexuality support in a service agency group home. *Disability & Society, 24*, 303-315.

Hawkins, R., Redley, M., & Holland, A. J. (2011). Duty of care and autonomy: How support workers managed the tension between protecting service users from risk and promoting their independence in a specialist group home. *Journal of Intellectual Disability Research, 55*(9), 873-884.

Jorgensen, D. L. (1989). *Participant observation: A methodology for human studies.* London: Sage Publications.

Kazukauskas, K. A. & Lam, C. S. (2010). Disability and sexuality: Knowledge, attitudes, and level of comfort among certified rehabilitation. *Rehabilitation Counseling Bulletin, 54*, 15-25.

Kelly, G., Crowley, H., & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: ‘It’d be kind of nice to be trusted’. *British Journal of Learning Disabilities, 37*, 308-315.

Kramers-Olen, A. (2016). Sexuality, intellectual disability, and human rights legislation. *South African Journal of Psychology, 46*(4), 504-516

[Lafferty](http://www.tandfonline.com/author/Lafferty%2C%2BAttracta), A., [McConkey](http://www.tandfonline.com/author/McConkey%2C%2BRoy), R., & [Taggart](http://www.tandfonline.com/author/Taggart%2C%2BLaurence), L. (2013). Beyond friendship: The nature and meaning of close personal relationships as perceived by adults with learning disabilities. [*Disability & Society, 28*(8), 1074-1088.](http://www.tandfonline.com/toc/cdso20/current)

Lyden, M. (2007). Assessment of sexual consent capacity. *Sexuality and Disability, 25*(1), 3-20.

McBrien, J. & Power, M. (2002). Professional attitudes to supporting parents with learning disabilities. *Tizard Learning Disability Review, 7*(3), 16-22.

Natasha, A. & Miriam, T. G. (2017). Pleasure, sex, prohibition, intellectual disability, and dangerous ideas. *An International Journal on Sexual and Reproductive Health and Rights*, *25*, 114-120.

a

, 1-

16

Neuman, R. (2020b). Parents' perceptions regarding couple relationships of their adult children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 33*(2), 310-320.

Neuman, R., & Reiter, S. (2017). Couple relationships as perceived by adults with intellectual disability: Implications for quality of life and self-concept. International *Journal of Developmental Disabilities, 63*(3), 138-147.

Prilleltensky, O. (2004). *Motherhood and disability – Children and choices*. Palgrave Macmillam.

Reiter S., & Bryen. N. D. (2012). Attitudinal barriers to rehabilitation. In J. H. Stone & M. Blouin (Eds.), *International encyclopedia of rehabilitation*. Buffalo, NY: Center for International and Exchange (CIRRIE).

Rogers, C. (2010). But it’s not all about the sex: Mothering, normalization and young learning disabled people*. Disability and Society, 25*(1), 63-74.

Rushbrooke, E., Murray, C., & Townsend, S. (2014). The experiences of intimate relationships by adults with intellectual disabilities: A qualitative study. *Journal of Applied Research in Intellectual Disabilities, 27*(6), 531-541.

Schaaf, N. (2011). Negotiating sexuality in the convention on the rights of persons with disabilities. *International Journal on Human Rights, 8*(14), 113- 131.

Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning, 31*(2), 181-190.

Shildrick, M. (2007). Contested pleasures: The sociopolitical economy of disability and sexuality. *Sexuality Research and Social Policy, 4*(1), 53-66.

Shogren, K. A., Thompson, J. R., Shaw, L. A., Grandfield, E. M., & Hagiwara, M. (2018). Detecting changes in support needs over time. *American Journal on Intellectual and Developmental Disabilities, 123*(4), 315-328.

Shuttleworth, R. (2007). Critical research and policy debates in disability and sexuality studies. *Sexuality Research and Social Policy, 4*(1), 1-14.

Sneed, J. R., Whitbourne, S. K., Schwartz, S. J., & Huang, S. (2012). The relationship between identity, intimacy, and midlife well-being: Findings from the Rochester Adult Longitudinal Study. *Psychology and Aging, 27*(2), 318-323.

United Nations. (2006). Convention on the rights of persons with disabilities (CRPD): Article 23 – Respect for home and the family. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-23-respect-for-home-and-the-family.html

Willis, G. (1991). Phenomenological inquiry: Life world perception. In E. C. Short (Ed.), *Forms of curriculum inquiry* (pp. 173–186). Albany, NY: State University of New York.

Young, R., Gore, N., & McCarthy, M. (2012) Staff attitudes towards sexuality in relation to gender of people with intellectual disability: A qualitative study. *Journal of Intellectual & Developmental Disability, 37*(4), 343-347.