

Sexuality of Individuals with Intellectual Disabilities from Siblings' Perspective: A Phenomenological Study

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Abstract

The aim of this study is to reveal the perspectives of non-disabled siblings regarding the sexuality of individuals with intellectual disabilities. The research was designed as phenomenology, one of the qualitative research models. Siblings of individuals between the ages of 18-33 and those with intellectual disabilities participated in the study. While collecting the data, a demographic information form and a semi-structured interview form created by the researchers were used. Content analysis steps were followed in the analysis of the data. According to the results obtained from the research, three main themes have been identified: the sexuality and sexual development of individuals with intellectual disabilities through the eyes of their non-disabled siblings, the views of non-disabled siblings on the sexual life of individuals with intellectual disabilities, and the reflections of the sexuality of individuals with intellectual disabilities on their non-disabled siblings' sexuality and social participation. In light of the results obtained, studies on the sexuality of individuals with intellectual disabilities were discussed and parallel results were reached; however, it was seen that more research is needed due to the limited number of studies that included evaluations from the eyes of siblings without disabilities.

Keywords: Sexually explicit behaviour, sexuality, individual with intellectual disability, sibling.

About the Article

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Introduction

The situation experienced by individuals with intellectual disabilities can be explained as a significant lag in general mental functions caused by one or a series of reasons before, during or after birth, and various difficulties may be experienced due to this development lagging behind (Aydın, 2016). Difficulties in cognitive functions such as memory, speaking, reasoning, decision making, focusing, and being aware of one's own characteristics affect the individual's life both with himself and with others (Aydın, 2016; Varol, 2006). Considering that cognitive development also affects sexual development and related situations, the experience of sexuality by individuals with intellectual disabilities often have incomplete, contradictory, and uncertain information about sexuality (Brkić-Jovanović et al., 2021). This situation makes it difficult to determine the knowledge and attitudes of individuals with intellectual disabilities towards sexuality (Kijak, 2013).

Sexual development emerges as such aspects of human development as emotional, social, and cognitive development. According to the definition of Acun and Erten (1992), sexual development means that the individual changes and grows sexually, has a healthy attitude towards this change and growth, and solves the problems s/he experiences in the sexual field and is sufficient. As can be deduced from the definition, sexual development is not only related to biological development, but to social, emotional and cognitive development, as well (Tuzcuoğlu & Tuzcuoğlu, 2004). Understanding sexual development also requires knowing some basic concepts. In this study, sexuality will be the focus of attention, and other related concepts will be mentioned from time to time.

Sexuality is a process of interaction between two sexes with cognitive, emotional and operational aspects, which provides interest, intimacy, contact, love, desire, pleasure and reproduction (Cumurcu Elbozan et al., 2012). When we consider interpersonal sexuality, it should be noted that sexuality does not only consist of sexual intercourse but that it is an important human right regardless of age, gender, or developmental level. Within this context, it is one of the most basic rights of individuals with intellectual disabilities to experience sexuality, which is also the subject of this study.

Individuals with intellectual disabilities, too, have similar sexual desires and needs to other individuals (Borawska-Charko et al., 2016). However, due to the false beliefs and myths about the sexuality of individuals with intellectual disabilities, this fact can be neglected. As Foucault, stated, sexuality is a concept that cannot be considered separately in a social context (cited in Berktay, 2009). Most of the time, prejudices about the sexuality of individuals with intellectual disabilities come into play (Sınanmış & Kolburan, 2019). The thoughts of parents and society regarding the sexual development and sexuality of individuals with intellectual disabilities should also be taken into consideration (Çelik, 2017b). Because the social attitude towards individuals with intellectual disabilities makes it difficult for individuals with intellectual disabilities to adapt to the changes in adolescence (Çelik & İpçi, 2020). In general, it is a widespread idea that sexual maturation processes cannot occur in individuals with intellectual



disabilities and therefore they cannot enter puberty and will always remain children (Bilge & Baykal, 2008; Menghini, 2012). In addition, it is thought, by a large portion of the individuals who make up society, that individuals with intellectual disabilities need support, protection, or control. In addition, individuals with intellectual disabilities are seen as asexual beings who cannot make appropriate decisions about their own sexuality (Murphy & Young 2005; Swango-Wilson, 2009).

Most of the time, the perception that there is a problem in the sexuality of an individual with intellectual disabilities lies in his inability to control his sexual behaviours when he is with other people and not knowing what to do where and when (Demir & Aysoy, 2002). What is meant by sexual behaviours are the behaviours that fulfil and do not fulfil sexual intercourse (the latter being kissing and touching the breasts and genital area). It can be said that the forms of intercourse that occur before sexual intercourse are included in the behaviours that do not fulfil intercourse (Smith & Udry, 1985). Such features that individuals adopt as culture, ethnicity, and education affect sexual behaviour.

In individuals who need special education, sexual behaviours also differ according to the degree of intellectual disabilities and the level of being trainable (Bilge & Baykal, 2008; Vrijmoeth et al., 2012). It has been observed that individuals with intellectual disabilities exhibit, during adolescence, such behaviours as rubbing on another object, playing with their genitals, touching or reaching out to touch the breasts or genitals of individuals of the opposite sex, kissing their lips, undressing anywhere and uncontrolled masturbation (Bilge et al., 2013; Konuk Er et al., 2016). The main reason for this is thought to be the limitations of individuals with intellectual disabilities in cognitive and social skills (Chave-Cox, 2014). In addition, individuals with intellectual disabilities seem to have difficulties understanding the complexity of sexuality and controlling their sexual behaviour (Lindsay, 2002).

The inadequacy of social awareness about the problems related to sexuality and the lack of research on the subject were also effective in the emergence of the problems (Kijak, 2013). Studies reveal that the level of knowledge of adults with intellectual disabilities is low (Isler et al., 2009; Siebelink et al., 2006), which may lead to negative attitudes towards sexuality (Bernert & Ogletree 2013) and higher rates of sexual abuse (Schaafsma et al., 2013; Liou, 2014) Accordingly, researchers emphasize that any inappropriate or challenging sexual behaviour, such as masturbating in public or interfering with another person's personal space, should be attributed to a lack of knowledge about sexuality, not to the degree of cognitive capacity (Franco et al., 2012). Besides, having no sexual feelings or desire is a condition that can be seen in individuals with intellectual disabilities (Bosch, 2006; Treiber, 2011). This situation changes according to the individual's level of intellectual disability and, therefore, their level of being trainable (Vrijmoeth, et al., 2012). Therefore, individuals with intellectual disabilities need the support of their parents to meet their age-appropriate physical, psychological, and sexual needs (Barnett et al., 2003).



When the literature is examined, it is seen that most of the studies are based on the results obtained from the parents—especially the mothers—of individuals who need special education and have intellectual disabilities. The fact that most of the care responsibilities of individuals with mental retardation rest with the mother can be seen as one of the reasons for this. In addition, it is difficult to collect direct information, especially from people with advanced mental disabilities, in the needs analysis regarding sexual education to be conducted for the mentally handicapped, and the collected information may be insufficient. For this reason, healthier information can be collected from individuals with mild intellectual disability. To eliminate this limitation, information can be collected from both individuals with mild intellectual disability, teachers, and parents (Anderson, 2015; Dallos & Draper, 2012; Finlay et al., 2015; Kök, 2010; Schaafsma et al., 2015; Wilkinson et al., 2015).

When the family is considered to be a system, the presence of an individual with intellectual disabilities and special needs in the family will affect all the individuals in this system. The other sibling or siblings will also have their share of positive or negative effects. From this point of view, it is possible for siblings of individuals with special needs to experience many emotional and behavioural problems (Naylor & Prescott, 2004; Walton & Ingersoll, 2015). For example, Sarı (2004) enumerates the reactions of individuals with normal development towards their siblings with special needs as resentment, enmity, jealousy, fear, guilt, rejection, shame, boredom, and sadness.

When the relevant literature is examined, it is seen that there are very few studies on the sexuality and sexual development of adults with intellectual disabilities, and the absence of a study addressing how siblings are affected by this process, what they experience, and their perspectives on their siblings with intellectual disabilities increases the importance of the present research. It is thought that the data to be obtained from this study will be beneficial to the experts who will conduct research in terms of the sexuality of individuals with intellectual disabilities and the mental health of their non-disabled siblings, the families of individuals with intellectual disabilities and the whole society. In this context, the research aims to reveal the sexuality of individuals with intellectual disabilities siblings'. The research sought answers to the following questions:

- 1) What is the sibling's view of the sexuality of the mentally retarded individual?
- 2) What are the sibling's reactions towards the sexual acts of the mentally retarded individual?
- 3) How did the sexuality of the mentally retarded individual reflect on his/her sibling's sexuality?

Method

Within the scope of the research, how individuals with intellectual disabilities experience sexuality and how this process reflects on the sibling with normal development have been tried to be discussed from the perspective of their siblings. For this purpose, the qualitative research method was preferred. Allowing for the search and understanding of events, facts and situations in their natural environments, qualitative research helps to make the subject matter visible by creating various themes and sub-themes (Neuman, 2006; Punch, 2011; Yıldırım & Şimşek, 2006).

The research was designed as phenomenology, one of the qualitative research models. How a phenomenon is experienced by people, what it means to them, and how it affects them are among the fields of phenomenology (Creswell, 2017). Within the scope of the research, it was decided that, with the phenomenology model, it would be more appropriate to look at the perspectives and reactions of siblings regarding the sexuality of individuals with intellectual disabilities and what reflections this situation has.

Participants

The study group consisted of 10 siblings, 5 female and 5 male, aged between 19-32, showing normal development. Individuals with intellectual disabilities (1 female and 9 male), on the other hand, have the characteristics of mild-moderate or severe intellectual disability in the 18-33 age range. While determining the study group, snowball sampling, one of the purposive sampling methods used in qualitative research, was used. Due to the sensitivity of the subject and the difficulty in reaching the study group the individuals in the study, group were reached through the guidance of individuals who knew each other.

Demographic information about the individuals who make up the study group is presented in Table 1:

 Table 1.

 Demographic Information of the Study Group

Participants	Age	Education	Gender	Marital status	Disability level	Disabled sibling's age	Disabled sibling's gender
P1	29	University	Female	Single	Mild	29	Male
P2	29	University	Male	Single	Mild	30	Male
P3	29	University	Male	Married	Moderate	23	Male
P4	21	University	Female	Single	Moderate	18	Female
P5	22	University	Female	Single	Moderate	20	Male
P6	32	University	Female	Married	Severe	24	Male



P7	24	Master	Male	Single	Moderate	23	Male
P8	24	University	Female	Married	Severe	23	Male
P9	32	High school	Male	Married	Severe	33	Male
P10	19	University	Male	Single	Moderate	26	Male

Materials

Demographic Information Form: This is the form prepared by the researchers in which information about the age, gender, education level and degree of intellectual disability of the participants and their siblings is collected.

Semi-Structured Interview Form: A semi-structured interview form was prepared to reach the views of siblings with normal development regarding the sexuality of individuals with intellectual disabilities. The questions in the form, which aimed to gather the participants' perspectives on the sexuality of their siblings with intellectual disabilities, their reactions, and reflections on sexually explicit behaviours, were carefully crafted. In preparing the questions, care was taken to ensure that they were easy to understand, multidimensional, and did not guide the respondents.

Data Analysis

First of all, Ethics Committee Permission was obtained from Istanbul Okan University for the study (meeting date: 10.11.2021 and number of meetings: 144). Then, a semi-structured interview form was prepared. Although the questions were prepared as a draft in advance, care was taken to arrange the topics that may be meaningful for the research during the interview in a way that allows them to be discussed and that the questions and the way they are asked are not guided. In the first part of the interview, an interview form consisting of personal information was filled out by the participant. After the preliminary briefing explaining the research subject, data collection purposes, voluntariness, and ethical commitments to the protection of personal data, interviews were started. In the personal information section of the interview forms, demographic information about the participant, his/her siblings and parents was collected. The interviews lasted approximately 30 minutes.

After the transcription of the audio recordings of the interviews, the transcriptions were combined with the notes of the interviewer; and content analysis was carried out on the themes determined according to the answers given for research purposes. In the analysis process, multiple readings and note-taking were carried out, then the main themes and sub-themes were determined, and the data were organized and interpreted by including the expressions stated by the participants. Participants in the study group (Participant 1 = P1) were coded and these codings were used in the analysis of the data.



The Participatory Role of Researchers

After one of the researchers completed his undergraduate and graduate education in the field of special education, he worked with students from different age groups and their families in the field of special education for a long time and carried out his academic studies within this scope. He has studied on the sexuality, sexual development and sexual health of individuals who need special education. In addition, he has been responsible for the training of special education teacher candidates for a long time. The other researcher was trained in the field of guidance and psychological counselling and worked with children with autism and their families for a while. She also has studies on parent-child relationships.

Persugsiveness

Many methods are used to increase credibility in qualitative research, the diversification method being one of them. This method means using more than one method: the researcher and the data collection method (Lincoln & Guba, 1985). In this study, attention was paid to the fact that the participants, who were the data source, had different characteristics (gender, siblings' intellectual disability levels, etc.) and contributed from different perspectives. In addition, in order to increase credibility, the researchers returned to the data sources repeatedly and analyzed the emerging themes and sub-themes in a comparative way. In addition, the researchers received support in the process by seeking expert opinions on the design and conclusion of the research.

Transferability

Transferability is when research to be conducted in the context of the same topic with different participants yields similar results (Lincoln & Guba, 1985). In order to ensure transferability, the demographic information of the participants is given in detail. One of the methods used in the research to increase transferability is direct citation. In the results of this research, the narratives of the participants were directly quoted, allowing them to reflect their thoughts and feelings with their own expressions.

Consistency

In order to ensure consistency in qualitative research, it is necessary to conduct a consistency analysis (Lincoln & Guba, 1985). In this study, consistency analysis was conducted by an assistant professor from Istanbul Okan University Special Education Teaching Department. In the research, the consistency in the data collection and coding processes, the conceptual consistency and the relationship between the data and the results were supervised by the expert and his support was taken to ensure the reliability of the research.



Findings

In this section, the views of the participants about the sexuality of their siblings with intellectual disabilities are discussed. After the research data from semi-structured interviews were converted into texts, they were analyzed by applying content analysis. The findings obtained as the result of the analysis of the data in line with the purposes of the research were gathered under three main themes. These themes, sub-themes, and samples from participant views on related themes are given below.

Theme 1 Sexuality and sexual development of individuals with intellectual disabilities in their siblings' view

Table 2.Sexuality and Sexual Development of Individuals with Intellectual Disabilities in Their Siblings' View

Main theme	Sub-themes	Codes	Participants
	sexual development	development unlike a normal individual	P7,
		lack of sexual urges	P7, P10, P1, P4
		siblings as all-time babies	P9, P5,
C		view of siblings as little brothers and sisters	P4,
Sexuality and sexual development		having sexual development like a normal individual	P10,
of individuals		beginning to notice the opposite sex	P4,
with intellectual		having erections	P7,
disabilities in their siblings' view sexually explicit behaviours		rubbing	P1, P2, P8,
	masturbation	P2, P3, P10,	
		touching and want to touch	P2, P3, P1, P4,
			P6,
		no sexual behaviour	P5, P9,
	places of sexually	in her/his room	P1, P8
	explicit behaviour	in society	P2, P1,
		where she/he is alone	P10, P2,
	Emotions related to	getting excited	P3,
	the sexuality of	getting angry	P10,
	siblings with intellectual disabilities	not knowing what affects them	P9, P1,

As seen in Table 2, when the views of the siblings who constitute the study group regarding the sexuality and sexual development of their siblings with intellectual disabilities were taken into consideration, four sub-themes emerged. The four sub-themes that make up the content of this theme were sexual development (did not develop like a normal individual, sexual impulses do not develop, siblings are always babies, siblings are always seen as little siblings, sexual development like a normal individual, starting to notice the opposite sex, having an erection), sexually explicit behaviours



(rubbing, masturbation, touching and wanting to touch, no sexual behaviour), places where sexual behaviour is done (in his own room, in the community, where he is alone), and the feelings related to sexuality (excitement, anger, not knowing what is affected). Some examples of the answers of the siblings regarding these sub-themes are given below:

Opinions of siblings on sexual development

Upon considering the findings obtained as the result of the evaluation of the research data, it was seen that the siblings emphasized that the sexual development of individuals with intellectual disabilities was different from that of normal individuals. This situation can be seen in the speech of P7, one of the siblings, regarding the sexual development of his brother with mental retardation: "Now I can say that it does not develop like a normal individual. These are the things we definitely observe in his family environment. Nothing much to do with the sexual development of a normal adolescent or a normal individual... And, I don't think his urges have developed... The age of puberty and so on weren't the same as mine." (P7). One of the siblings, P9, said that she always saw her brother with intellectual disabilities as a baby: "My elder brother was like an adult baby living by us.". On the other hand, some siblings say that the sexual development of their mentally retarded sibling is not different from normal individuals. (P10) expressed this as "My brother's sexual development is normal, I guess. Of course, it is a bit different from that of a normal man, but it's nothing extraordinary." P4, one of the siblings, stated the sexual development of her sibling with intellectual disabilities as "You know, they don't have such sexual drives in sexual development." (P4).

When the views of the siblings participating in the research were evaluated, it was seen that the sexual development of siblings with mental retardation is different from that of normal individuals and that their siblings will always remain like babies even if they grow up. Some of the siblings also stated that the sexual impulses of their siblings with intellectual disabilities did not develop.

Opinions on sexually explicit behaviours

When the "sexual behaviours" sub-theme obtained as the result of the analysis of the data was evaluated, it was stated that the sexual behaviours of siblings with mental retardation were generally behaviours such as rubbing, masturbation, touching and touching other people. Regarding his brother's rubbing behaviour, P8 said: "When he had a sexual need, he would go to a different room and take a pillow-like item under him and crawl on the floor. He wouldn't want us to enter the room," while P1 also stated, "There is rubbing behaviour; he is rubbing while lying face down on a hard floor" in support of this. Regarding masturbation, one of the brothers, P1 said, "He used to masturbate too. At first, he didn't know what to do. You know, he was touching himself, but he couldn't quite do it. But later he slowly figured it out himself. He started to do it, of course, we tried to teach him that not everyone should do this— he should go to a place alone when he needs such a thing. We have had some success with that. He



doesn't do it anymore. He can isolate himself and satisfy these needs," while P3 said that his brother with mental retardation masturbates. "Let me tell you about his masturbation behaviour at some point every day, he did not do it every day, but he had contact with himself. Every day at certain points now. Since we couldn't get into his head, I don't know what he would be affected by" (P3).

On the other hand, one of the participants explains the behaviour of his brother with intellectual disabilities as touching his genitals, unlike masturbation, as follows: "At that time, I saw that she was putting his hand into his pajamas, but she was not doing anything, I mean, she was just putting it in, not like masturbation. At that time, for example, we were warned. ... For example, something happened. She did a lot for a while and then gave it up. For example, she did this at night, and at night she put her hand inside. But you know, for a very short time, you know, not like a masturbation period." (P4). While the behaviour of touching someone else may be directed towards someone both within the family and outside the family, the siblings P1 and P2 shared their observations and experiences in this regard: "He tried to touch my breasts when I was 11-12 years old during my developmental period. But now he's not doing it. He wanted so much to touch me. For example, as I was walking in the corridor, I was passing by him, and he was throwing his hand like that. Probably he wondered why it was not flat there because first, he was looking at himself, then he stretched out his hand there. He did this a lot on the street. For example, as we were walking, a woman came in front of us and put her hand there directly. He wanted to touch every woman he saw on the street." (P1) and "For example, when he saw a woman at work, he had things like going and touching her, he could do it to anyone in the middle of the street. He was making these touches on everyone, he was touching my mother, my cousins, everyone. We experienced them." (P2). One of the brothers, P4, also said along these lines, "My brother was doing it to people. Dad's sisters, mom's sisters, and the like. You know, that's not nice." (P4), while P6 expressed the sexually explicit behaviour of his brother with mental retardation as "He tends to reach out and hug people. He wants to hug and touch... that's a constant problem between us."

When the answers given by the siblings are evaluated, it is seen that the sexual behaviours of the siblings with intellectual disabilities are generally revealed as masturbation, rubbing and touching someone of the opposite sex. In addition, it is seen that some siblings touch the mother and sisters in the family with no apparent awareness of family relations or social environment.

Opinions on the places where sexually explicit behaviours are made

The sub-theme of "Places where sexually explicit behaviours are made", which emerged as the result of the analysis of the research data, was created within the framework of three codes: in his own room, in public and in the places where he is alone. When the concepts that make up this sub-theme are examined, some of the opinions of the siblings can be given as follows: "It causes too much rubbing. But it's usually like this. My parents taught him, so when such a situation happens, he closes the door of his room and we



do not see him." (P1). One of the siblings, P3, said that his mentally retarded brother went to a place where he could be alone while masturbating. "He can isolate himself and meet this need." P10 also said on these lines that his mentally retarded brother chose places where he could feel comfortable while masturbating. One of the siblings, P1, described another sexually explicit behaviour of "touching someone" in public as follows: "For example, we were going to visit a relative. There were girls there. He wanted to touch them, or he wanted to touch me, or he wanted to touch my mother." P2's mentally retarded brother did the act of touching another person everywhere: "He was directly touching women in his adolescence. I was afraid to go out with my brother."

While some participants' statements show that their intellectually disabled siblings would prefer to perform sexual behaviours in places where they feel comfortable and in their own rooms, others show that they did it in public.

Opinions of siblings regarding sexually related emotions of individuals with intellectual disabilities

Another sub-theme, which emerged as a result of the evaluation of the answers given by the siblings during the interview, is the opinions of siblings regarding the sexually related emotions of individuals with intellectual disabilities. The codes that make up this theme are excitement, anger, and not knowing what affects them.

In the sexuality of individuals with intellectual disabilities, the emotions observed by their siblings were often extreme excitement and anger when they could not perform the sexual behaviour. One of the siblings, P3 said, "It doesn't matter whether it's a lady or a girl relative or whoever it is, his behaviour changes and he gets extremely excited... of course, he gets angry when he can't express his feelings." Another sibling, P10, expressed that his mentally retarded sibling was not able to experience sexuality and that he was angry as "...sometimes he gets angrier, maybe because he did not experience sexuality".

As the last thing in this theme, there are opinions of the participants who say that they have not seen any sexual behaviour, impulse, etc. in their siblings: "I don't think I know much about it, frankly, it's that advanced. It's because I don't see it. I don't see any sexual behaviour, so no. I never noticed." (P5). P8, one of the siblings who participated in the research, stated that she did not observe anything about the sexual behaviour of her sibling with intellectual disabilities and that it was difficult for her to talk about it as follows: "My brother did not have such a thing about sexual development. It is difficult for me to talk about these issues."

When we look at the statements of the siblings, it is seen that the siblings with mental retardation show their feelings about sexuality with extreme excitement and they get angry because they cannot express them.



Theme 2 Opinions of siblings about the sexual life of individuals with intellectual disabilities

 Table 3.

 Reactions of Siblings Towards the Sexual Life of Individuals with Intellectual Disabilities

Main theme	Sub-themes	Codes	Participants
Siblings' reactions	Emotional	surprise	P4,
to the sexual lives	reactions	sadness	P2,
of individuals with		embarrassment	P1, P2,
intellectual		anxiety	P7, P4,
disability		happiness	P4, P10,
		anger	P1, P6,
		unresponsiveness	P3, P7,
	Cognitive	like a child	P9,
	reactions	mustn't get married	P7, P1, P4, P6, P10
		can get married	P2,
		I wish she/he would have sex	P3,
		can't have sex with someone	P1,

As can be seen in Table 3, where the reactions of siblings without intellectual disabilities regarding the sexual lives of individuals with intellectual disabilities are given, these views were toned down under two sub-themes. These sub-themes are in the form of emotional reactions (surprise, sadness, embarrassment, anxiety, happiness, anger, not reacting), and cognitive reactions (he should not marry like a child, he can get married, if only he had sex, he could not have a sexual relationship with someone). Some of the statements of the siblings regarding these sub-themes are given below.

Emotional reactions

As a result of the analysis of the data in the research, the first sub-theme of the main theme of "Siblings' reactions to the sexual lives of individuals with intellectual disabilities" was emotional reactions.

The emotional response sub-theme consisted of seven codes: surprise, sadness, embarrassment, anxiety, anger, happiness and unresponsiveness. Some of the statements of the siblings regarding these sub-themes are given below.

One of the siblings, P4, said that they were surprised when they saw the sexually explicit behaviour of their brother with mental retardation: "I was very surprised. For example, I was very surprised that he touched our breasts, but we didn't show it, we didn't react anyway, we just thought, where does it come from." Another brother said that he felt sorry for the sexual behaviour of his mentally retarded sibling: "When I see him like that, his breathing changes in distress, I see his face reddening, I know he can't do it, and of course, what can you feel? He wants to do the natural thing, but he can't, he's in trouble." P1 and P2, on the other hand, expressed their embarrassment due to the behaviour of touching and groping another person exhibited by their mentally handicapped siblings



as follows: "I used to feel very embarrassed when women touched their breasts - especially if it was someone we didn't know outside- and I wished I hadn't been out with her." (P1), "I was just ashamed. In other words, I was thinking about how we would explain it when a girl who was around our age or just in the developmental stage, for example, a twenty-year-old girl, went to the street and he touched her breast" (P2).

P7, one of the siblings who participated in the research, expressed that he was worried about the sexual behaviour of his brother with mental retardation as follows: "Now I worry about my brother like this, if what he is doing is misunderstood by people, if the other party reacts to it because we see such news in Turkey, maybe you must know something about the violence against people with disabilities. We are afraid, of course, whether there is such a thing as a disabled person who does not make him conscious, whether he stays in the institution or if his place of residence is safe. So, after all, we don't know what the caregivers are thinking there.". P6, one of the siblings, expressed that he got anary when he saw the sexual behaviour of his sibling with mental retardation as follows: "He tends to reach out and hug people. Wants to hug, wants to touch. What's my reaction? I'm yelling, look, didn't I tell you!" P4 and P10, on the other hand, expressed that they were happy when their mentally retarded siblings exhibited sexual behaviour in this way: "It shows all the features of young girls. I am being so happy," said P4. And "But when I saw it for the first time, it was not surprising to me that it was seen as instinctive, that is, it was the first time that I saw him instinctively using his instincts and trying to relax in this way. But I was still pleased, just because such a thing happened, I was glad that after all, he was listening to his instincts and doing such a thing." said P10. P3 and P8 also expressed that they did not have any reaction when they saw the sexual behaviour of their siblings with mental retardation as follows: "I did not give an extreme reaction when I saw the sexual behaviour of my brother." (P3) and "We did not have a reaction, we allowed him to do this. He already had a private space, as he wanted, and no one bothered him during that time." (P8).

When the codes constituting this sub-theme were examined, it was seen that their emotional reactions to the sexual behaviours of their siblings with intellectual disabilities were basically a surprise, because it was an unexpected situation when they first encountered these behaviours. They were sad because their siblings with intellectual disabilities did not exhibit these behaviours when they were alone, and they were embarrassed because their siblings exhibited their sexual behaviours against everyone in society. At the same time, the participants are worried because they do not know where their brothers and sisters learned some sexual behaviours—they could be taught by someone. They are happy because their siblings' sexual behaviours are a part of development, and they show natural development. They are angry at their siblings' sexual behaviours because it will create misunderstandings and discomfort in the environment. And the participants did not respond to the sexual behaviour of their siblings with mental retardation, as it was normal.



Cognitive reactions

One of the sub-themes that emerged as a result of the analysis of the research data is "cognitive reactions"; which is composed of seven codes: a child, should not get married, can get married, if only they would have sexual intercourse, cannot have sexual intercourse with someone, should receive sexual education, and cannot receive sexual education. Some of the opinions that make up these codes are given below.

From some cognitive point of view, the participants see their mentally retarded siblings as children. P9 said, "I did not think that my brother would experience sexuality because he is a disabled person, who is closed to communication and does not speak. My brother was like a grown baby living with us. So, what can you say to a one-year-old? Whatever you can say to an infant about marriage, you can only say to my brother." Another participant, P7, stated that it would "not be ethical" for his brother to get married: "I don't think it's ethical for my brother to get married. Think of it this way: you are an individual, but your parents are not self-sufficient people, they do not meet their own life needs, I am talking about basic life needs. So, I think that would be a very devastating thing for a child." P1 said that the marriage of his mentally handicapped brother would create chaos: "He is not able to live a life with someone. After all, it is a sexual need. They also have these needs, and they must satisfy them somehow. That's why he's exhibiting sexual behaviour. But, as I said, getting him to marry someone and letting him have a relationship with someone, I think, will drag us into great chaos." P4, P6 and P10 also made statements along similar lines: "My sister is not one to get married. What kind of person she will marry—you know, these are a lot of question marks. Because he may not be able to live in the same house with a person," (P4). "How would that be if such individuals got married or how would their sexual life be, I thought about that at that moment. So, in the end, it seemed like something very bad was going to happen. For example, let's say they had sexual intercourse and a pregnancy took place. Their children would be mentally handicapped, sort of like this" (P6). "My brother's sexuality does not scare me, but if it comes to marriage or something, I don't know what the consequences will be, so it may have slightly different results. well," (P10).

One of the participants, P1, said that a long-lasting marriage could be good for his brother, "He can have a relationship to get married, but I don't want it to happen if it's not going to be permanent. For once, I don't want him to live, so it's better not to live at all. He'll have a relationship for once, and instead of getting attached to him he'll suffer from it for years, and my brother should not suffer at all." One of the participants, P3, stated that her brother should experience sexuality: "I wish my brother could experience sexuality. You know, such an environment, such an education. I wish he had a place to live. After all, people have needs too. I don't know how far this can go. I myself didn't experience a thing like that, because I had a girlfriend at a very young age and got married at an early age. I got married as soon as I finished college. I can only imagine what kind of troubles not being able to experience these things can cause." P9, another participant, said that he could not feel the sexual feelings of his brother with intellectual disabilities: "I did not observe anything in terms of sexuality in my childhood and



adulthood. I don't think you will feel these feelings. You know, he cannot experience anything emotionally."

P1, P2 and P6 stated that it would be beneficial for their siblings with intellectual disabilities to receive sexual education in order to control their own sexual behaviours as follows: "I think that sexual education is an important issue for individuals with special needs, and they should receive training when necessary. I think this affects their behaviour both towards us and towards others," (P1). "My brother can get sexual education. Why would it be so good? What's the use? He will learn to control it. For example, it would be very good. It could be of use for so many things. Maybe it will give him daily relaxation. Maybe it would be better if he received sexual education, could masturbate more comfortably, and could do it on his own regularly, on his own will," (P2). "I think a good sex education will be beneficial for him and myself. I do not know what to do. Look, you asked me, does my brother ejaculate, or masturbate? I don't know anything about them. I'm just guessing" (P7).

When we evaluate the discourses of the siblings who participated in the research, it is seen that the siblings are worried about the sexuality and marriage of their siblings with mental retardation, they do not find it "ethical" for their siblings with intellectual disabilities to get married, and some siblings do not know what kind of result this situation will create. It was also observed that some of the siblings stated that it is necessary to receive sexual education in order for their mentally retarded siblings to better exhibit their sexual behaviours and to have a healthier sexual life.

Theme 3 Reflections on the sexuality of individuals with intellectual disabilities on their non-disabled siblings' sexuality and social participation

Table 4.

Opinions of Individuals with Intellectual Disabilities on the Reflection of Their Sexuality on Their Non-Disabled Siblings' Sexuality and Social Participation

Main theme	Sub-themes	Participants
Opinions of	Imitation	P1, P2,
individuals with	inability to share sexual topics	P2,
intellectual	disgust with sexuality	P8,
disabilities on the	had no effect	P3, P4, P7, P10
reflection of their	siblings' sexual behaviour affects social participation	P3, P1,
sexuality on their non-disabled siblings' sexuality and social participation	siblings' sexual behaviour does not affect social participation	P2, P4, P7, P8, P10

As seen in Table 4, the opinions of individuals with intellectual disabilities regarding the reflections of their sexuality on their non-disabled siblings' sexuality and social participation consist of six sub-themes. These sub-themes are imitation, inability to share



sexual issues, disgust with sexuality, no effect, and siblings' sexual behaviours affect participation in society, siblings' sexual behaviours do not affect participation in society.

The last theme that emerged as the result of the analysis of the data is the effect of the sexuality of individuals with intellectual disabilities on their siblings' sexuality. The subthemes that make up this theme are imitation, isolation, aversion to sexuality and no effect. One of the participants, P1, said that he imitated the sexual behaviour of his mentally retarded brother: "As my mother said, I saw my elder brother rubbing when I was 4-5 and tried to imitate him. This happened a few times but then didn't happen again." Another participant expressed how he was affected by his sibling's sexual orientation as follows: "But now that you asked, something came to my mind. I have nothing to learn from my elder brother. This is what came to my mind. My brother was obsessed with boobs. When I first thought of sexual things in adolescence, the first thing that caught my attention was breasts, that is, on a woman's body. Then my elder brother turned to leas, and leas attracted my attention after breasts. I wonder if my elder brother and I are going the same way. For example, if my brother were normal, his sexual development would be ahead and I could share something with him," (P2). From a different point of view, P8 stated how she was disgusted with sexuality because of the sexual behaviours of her brother as follows: "When he had a sexual need, he would go to a different room and take a pillow-like thing under him and crawl on the floor. He didn't want us to enter the room. For me, the concept of sexuality was a sickening thing back then. So, I was ashamed and disgusted. I am just trying to get over it," (P8). Among the participants, P3, P4, P7 and P10 stated the reasons why their siblings' sexual development and behaviours did not reflect on their own sexuality as follows: "I know my brother's sexual development periods and their transition to puberty. My brother's sexual behaviour seems like his sexual orientation was revealed a little late, like masturbation, so it did not affect my sexual development much," (P10). "My brother's sexual behaviour has no effect on my sexual life. We live completely independently. I am conscious of that. So, I don't think so," (P7). "My brother's sexual behaviour did not affect my sexual life," (P3). "My sister's sexual life is of course very different from mine. I have a brother right now. Here's what I can say, I can experience feelings such as touching, getting pleasure, kissing, and hugging him whenever I want. Here's the other way I get my period, I can masturbate when I want. But I am aware of this, and I am aware of where it can be done and where it cannot be done, do I want it now and is the environment suitable, but how does my sister say whether she wants it or not, how does she realize it?" (P4).

When we evaluate the answers given by the participants, it is seen that some participants are not affected by the sexuality and sexually explicit behaviours of their siblings with mental retardation. In addition, a participant was disgusted with sexuality for a long time because of his sibling's sexual behaviours.

Among the siblings participating in the study, P1 and P3 stated how their social participation was affected by the sexual behaviour of their siblings with intellectual disabilities as follows: "For example, we were going to visit a relative. There were girls



there. He wanted to touch them. Or he wanted to touch me, or he wanted to touch my mother. If I had cousins, he would want to touch them. He wanted to touch everyone he saw. When my brother was only 15-16 years old, we would all be nervous when we were outside," (P1). "My brother's sexual behaviour and disability naturally affect participation in the social environment. For example, my brother is even attracted to my wife. When we sit together, he gets very excited, of course, when he cannot express his feelings, he gets angry. For example, he swears a lot. My brother started swearing or something. He has a habit of biting his hand when he gets angry. He starts biting his hand and gets very excited. He is also extremely interested in my sister-in-law. Likewise, when he sees her," (P3). On the contrary, some participants, P2, P4, P7, P8 and P10 stated how their siblings' sexual behaviours did not have any effect on their participation in society as follows: "He was directly touching women at puberty. At that time, I was afraid to go out with my elder brother, but it did not affect me much to enter my social circle. Anyway, we didn't have anything to hold my brother and let's go out together," (P2). "My sister's sexual behaviour did not affect my social participation, no," (P4). "There was no change in my social environment because of my brother's sexual behaviours. I may have been in isolation just because my brother is disabled. Another thing I would like to add about my brother's sexuality is that society is not conscious of it," (P7). "There was no obstacle related to this issue," (P8). "It did not create any problems regarding my social participation. No. I did not see any sexual orientation in my brother or any behaviour that would cause distress in society," (P10).

When the participants' discourses are analysed, it is seen that some of the participants' social participation is affected due to their siblings' sexual behaviour; but, on the other hand, some participants state that they are not affected by this situation.

Results and Discussion

Talking about sexual development and discussing perspectives on sexuality are very difficult topics in many societies today. There are very limited studies on the sexuality of individuals with intellectual disabilities (Boyacıoğlu et al., Gümüş & Altınsoy, 2015; Yıldız, 2020). When the literature is examined, in some studies on the subject, opinions about the sexuality of individuals with intellectual disabilities were obtained from their parents (mostly their mothers), teachers and field experts (Çelik, 2017a; Çelik, 2017b; Günlü, 2015; Gürbüz, 2018; Palas Karaca et al., 2016). In this study, it is aimed to examine in depth the perspectives of non-disabled siblings regarding the sexuality of individuals with intellectual disabilities, unlike the aforementioned study groups. Since the studies on the sexuality of individuals with intellectual disabilities from the viewpoint of their non-disabled siblings are quite limited, it is difficult to make comparisons across the relevant literature.

The first results reached in our study in line with the related purpose are that the sexual behaviour of individuals with mental retardation is mostly in the form of rubbing and masturbation, that these behaviours are at home and outside the home, and that



emotions such as excitement and embarrassment are accompanied during the behaviours. As stated at the beginning, these observations belong to the siblings of individuals with intellectual disabilities. Masturbation and rubbing behaviours may be useful for relaxation, falling asleep faster, balancing the effects of negative life experiences, etc. (Morales et al., 2018). If these behaviours develop feelings such as embarrassment and excessive excitement in the individual with intellectual disabilities, if there is a problem in performing other activities in daily life due to excessive sexual behaviour, if the family overly emphasizes such behaviours attracting attention and constantly warning, sexual behaviours may become harmful and occur in inappropriate places and times (Kavaklı, 1992). Research has shown that families, especially their children with intellectual disabilities, engage in sexual behavior in front of others or outside, causing them fear, and that they want to keep this situation under control (Gürol et al., 2014; Kök & Akyüz, 2015). Kijak's (2013) study with 133 individuals with intellectual disabilities revealed that men masturbate approximately twice as often as women. Considering that the individuals with intellectual disabilities in our study were males, except for one person, it can be said that the findings of the present research are compatible with this finding.

Another result reached in our study is that some of the participants stated that their siblings with intellectual disabilities did not have any sexual impulses. This situation is in parallel with the information in the literature that individuals with intellectual disabilities often cannot make appropriate decisions about their own sexuality due to the need for support, protection, and control, and they are affirmed as asexual (Murphy & Young 2005; Swango-Wilson, 2009).

It was observed that some of the participants emphasized that their siblings with mental retardation were "like children" and that they did not actually encounter any sexual behaviour. Similarly, in studies in which parents' opinions are sought regarding the sexuality of individuals who need special education and have intellectual disabilities, it has been found that parents continue to see their children as young children who do not display any sexual behaviour (Bilge & Baykal, 2008; Çelik, 2017a; Çiftçi Tekinarslan & Eratay, 2013; Menghini, 2012; Moll & Moll 2010). Families can sometimes use doing nothing as a method against the sexual behavior of individuals with mental disabilities (Kürtüncü & Kurt, 2020). However, when an individual completes childhood and becomes an adolescent, his or her changing sexual behavior may be ignored and described as "child-like".

Another result obtained from the research is that the reactions of the participants regarding the sexuality of individuals with intellectual disabilities are quite different. The results show that siblings react emotionally in a wide rangeof ways, from happiness to anxiety and anger. Some of them stated that they did not have any emotional reactions. The possibility that they may have had difficulty in describing or expressing their feelings, especially on such an issue, was also taken into consideration. The mentally retarded sibling's taking a step into adult sexuality during adolescence makes some siblings happy. Again, it was observed that the possibility of sexual abuse of the mentally



retarded individual and not knowing how to support their mentally retarded siblings in the process worried the siblings. Unlike siblings, Çelik's (2017a) study similarly focuses on the intense emotional reactions experienced by mothers around fear and anxiety. Since being the sibling of an individual with intellectual disabilities is defined as "being like his mother" according to the statements of a few of the participants, it is not an unexpected result that siblings also experience similar feelings (Moll & Moll 2010).

In the data of the study, regarding cognitive reactions apart from emotional reactions, it is seen that a significant part of the participants has the idea that their siblings should not get married regarding the future lives of their siblings with mental retardation. Based on this thought, there are some views that s/he cannot establish a long-term relationship because s/he has a mental deficiency, that the person s/he will marry will not want to deal with her/him for life, and that if s/he has a child, this may have negative effects on the child. Although the majority have a similar opinion, there are also some brothers and sisters who think otherwise. In addition, it has been determined that the participants of the research have requested to receive sexual education on issues related to sexuality and the sexual development of their siblings with mental retardation. When some studies are examined, individuals with intellectual disabilities have low knowledge levels (Isler et al., 2009; Siebelink et al., 2006), negative attitudes towards sexuality (Bernert & Ogletree 2013) and higher rates of sexual abuse (Schaafsma et al., 2015). According to siblings, it would be beneficial to give sexual health education to both parents and themselves and to individuals with intellectual disabilities (Lambrick & Glaser, 2004). Considering that information about sexuality is mostly learned from family and the immediate environment, it is thought that it would be more effective to include other members of the family along with individuals with intellectual disabilities in sexual health education.

Considering the effects of the sexuality of siblings with intellectual disabilities on their own sexuality and their participation in social life; most of the participants stated that they did not have any positive or negative effects on their inclusion in social life due to the sexual behaviour of their siblings with mental retardation. A few of the participants stated that they engaged in some sexual behaviour by imitation, especially in the early stages, or that they were disgusted with sexuality for a long time and were just trying to overcome this situation. Being exposed to sexual stimuli too much, especially in the early stages, can negatively affect the sexual development of individuals with or without intellectual disabilities. However, the lack of or less social awareness of the sexuality of individuals with intellectual disabilities or the limited number of studies on the subject make it difficult to determine the knowledge and attitudes of individuals with intellectual disabilities towards sexuality (Kijak, 2013) and the knowledge of siblings about their own sexuality, influencing their attitudes. In addition, it should be taken into account that it may be difficult for some individuals with intellectual disabilities to receive feedback directly from themselves, to talk about and learn about sexual development, sexual behaviors or sexual health, due to limitations in the speech field (Yılmaz, 2020).



Although it has been observed that various results have been revealed in studies conducted with siblings of individuals with intellectual disabilities, siblings with typical development in the relevant families may be affected by the stress experienced by the parents, problem-solving skills in the family, communication style, etc. It was concluded that it was affected by these factors (Giallo & Gavidia-Payne, 2006). It is thought that it is appropriate to make evaluations from a holistic perspective, taking into account all elements in the family in the process and without neglecting anyone.

Recommendations

Considering the results obtained from the research, the sexuality of individuals with intellectual disabilities is a subject that should be discussed both in a psychological and sociological context. Although living with an individual with intellectual disabilities is mostly handled from the perspective of mothers, the relationship that the individual has with his/her sibling, who shares the same room, goes out together, sexual behaviours, their reflections, etc. are very important issues. However, the fact that this issue has not been mentioned much until now suggests that siblings of individuals with intellectual disabilities are a group that can be ignored. More work on this topic is essential.

It can be said that it is important to provide sexual health education to individuals with mental disabilities, and that this education should be designed and implemented to include the whole family. It may be recommended to conduct family education programs and cognitive level education, as well as practical and skill development-oriented studies that include interaction between parent-child and siblings.

Another suggestion is to support individuals with mental disabilities and their families socially and emotionally. For this purpose, group psychological counseling, group guidance or psycho-educational studies can be designed especially for typically developing siblings with common experiences.

It is thought that the study will make an important contribution to new research with several results and an original topic. However, there are certainly some limitations to this study. The data obtained in the study are limited to the views shared by 10 adult participants living in Istanbul and their answers to the questions in the interview form. Considering that sexuality is affected by intercultural differences, this issue can be studied with different cultures and age groups in Turkey.



References

- Acun, S., & Erten, G.B. (1999). Çocuk gelişimi. İstanbul: Esin.
- Anderson, S. (2015). Sex education programs focused on "Protection" and "Prevention" with little attention given to supporting people to develop healthy, positive sexual relationships. Research and Practice in Intellectual and Developmental Disabilities, 2(1), 98-100.
- Aydın, Ş. (2016). Fiziksel ve/veya zihinsel engelli çocuk annelerinin depresyon düzeylerinin incelenmesi (Yayımlanmamış yüksek lisans tezi). Üsküdar Üniversitesi, İstanbul.
- Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: Supporting parents' adaptation to their child with special needs. *Infants and Young Children*, 16(3), 184–200.
- Berktay, F. (2009). Feminist teorinin önemli bir alanı: Cinsellik. Cogito, 58, 58-72.
- Bernert, D. J., & Ogletree, R. J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research*, 57(3), 240-249.
- Bilge, A., & Baykal, Z. (2008). Zihinsel engelli bireyler ve cinsellik. http://www.onceokuloncesi.com/makale-arastirma-ve-bilimsel-yazilar/zihinsel-engellibireyler-ve-cinsellik-25674.html. 01-16-2010
- Bilge, A., Ceber E., Demireloz, M., & Baykal Akmese, Z. (2013). Zihinsel engellilerin ebeveynlerine verilen cinsel sağlık & üreme sağlığı eğitiminin zihinsel engelliler için etkinliğinin belirlenmesi. *Türkiye Klinikleri, 33*(3), 648-655. https://doi.org/10.5336/medsci.2012-30037
- Borawska-Charko, M., Rohleder, P., & Finlay, W. M. (2017). The sexual health knowledge of people with intellectual disabilities: A review. Sexuality Research and Social Policy, 14(4), 393-409.
- Bosch, E. (2006). Sexualität und beziehungen bei menschen mit einer geistigen behinderung. (Ein Handund Arbeitsbuch. 2. Auflage). Tübingen: dgvt- Verlag.
- Boyacığlu, N.E., Karaçam, Z. D., & Keser Özcan, N. (2018). Engellere rağmen cinsellik: zihinsel yetersizliğe sahip çocuklarda cinsellik. Sağlık Bilimleri ve Meslekleri Dergisi, 5(2), 275-280. https://doi.org/10.17681/hsp.291360
- Brkić-Jovanović, N., Runjo, V., Tamaš, D., Slavković, S., & Milankov, V. (2021). Persons with intellectual disability: Sexual behaviour, knowledge and assertiveness. *Zdravstveno Varstvo, 60* (2), 82–89. https://doi.org/10.2478/sjph-2021-0013
- Chave-Cox, R.S. (2014). Forensic examination of the mentally disabled sexual abuse complainant. Journal of Forensic and Legal Medicine, 25, 71-75.
- Creswell, J. W. (2017). Eğitim araştırmaları nicel ve nitel araştırmanın planlanması, yürütülmesi ve değerlendirilmesi. (H. Ekşi, Ed.). İstanbul: EDAM.
- Cumurcu Elbozan, B., Karlıdağ, R., & Almış Han, B. (2012). Fiziksel engellilerde cinsellik. *Psikiyatride Güncel Yaklaşımlar, 4*(1), 84-98.
- Çelik, Ö. (2017a). Zihinsel yetersizliği olan bireylerin cinselliği ile ilgili çalışmalar yapan uzman görüşleri. *Turkish Studies, 12*(17), 113-132.



- Çelik, Ö. (2017b). Zihinsel yetersizliği olan çocukların cinselliği hakkında annelerinin görüşleri. *Turkish Studies*, 12(18), 211-234.
- Çelik, Ö., & İpçi, K. (2020). Zihinsel yetersizliği olan bireylere yönelik cinsel istismar: Ulusal haber ajanslarına yansıyan olgular üzerinden bir inceleme. Eğitimde Nitel Araştırmalar Dergisi Journal of Qualitative Research in Education, 8(2), 737-753. doi: 10.14689/issn.2148-624.1.8c.2s.14m
- Çiftçi Tekinaslan, İ., & Eratay, E. (2013). Zihinsel yetersizliği olan bireylerin ergenlik dönemine uyum sürecinde ebeveyn davranışlarının incelenmesi. NWSA-Education Sciences, 8(3), 363-374.
- Dallos, R., & Draper, R. (2012). Aile terapisine giriş: Sistemik teori ve uygulama. (Ş. Kesici ve C. Kiper, Translators). Ankara: Nobel.
- Demir, Ö., & Aysoy, M. (2002). State institute of statistics Prime Ministry Republice of Turkey and Turkish prime ministry presidency of Administration on disabled people. Basic characteristics of disabled population. Türkiye Özürlüler Araştırması, Ankara Devlet İstatistik Enstitüsü Matbaası, 29(13), 5-20.
- Konuk Er, R., Girgin Büyükbayraktar, B., & Kesici, Ş. (2016). Özel eğitime ihtiyacı olan öğrencilere yönelik cinsel eğitim programının geliştirilmesi. *Turkish Journal of Education*, 5(4), 224-234.
- Finlay, W. M. L., Rohleder, P., Taylor, N., & Culfear, H. (2015). Understanding as a practical issue in sexual health education for people with intellectual disabilities: A study using two qualitative methods. *Health Psychology*, 34(4), 328-338. https://doi.org/10.1037/hea0000128
- Franco, D. G., Cardoso, J., & Neto, I. (2012). Attitudes towards affectivity and sexuality of people with intellectual disability. Sexuality and Disability, 30(3), 261-287.
- Giallo, R. & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research*, 50(12), 937-948. https://doi.org/10.1111/j.1365-2788.2006.00928.x
- Gümüş, S. S., & Altınsoy, M. (2015). Hatay okullarında engellilerin cinsel eğitimi durum değerlendirmesi. Adnan Menderes Üniversitesi Eğitim Fakültesi Eğitim Bilimleri Dergisi, 6(2), 63-72.
- Günlü, Y. (2015). Ergenlik döneminde zihinsel yetersizliğe sahip çocuğu olan ebeveynlerin çocuklarinin cinselliği ile ilgili görüşlerinin belirlenmesi (Yayımlanmamış yüksek lisans tezi). Ankara Üniversitesi, Ankara.
- Gürbüz, S. (2018). Ergenlik dönemindeki zihin yetersizliği olan bireylerin cinsel gelişim özelliklerinin ebeveyn görüşleri ile değerlendirilmesi: Bir ölçek geliştirme çalışması (Yayımlanmamış yüksek lisans tezi). Bolu Abant İzzet Baysal Üniversitesi, Bolu.
- Isler, A., Beytut, D., Tas, F., & Conk, Z. (2009). A study on sexuality with the parents of adolescents with intellectual disability. Sexuality and Disability, 27(4), 229-237.
- Kavaklı, A. (1992). Çocukluk yaşlarında büyüme ve gelişme. İstanbul: Hilal Matbaacılık.
- Kijak, R. (2013). The sexuality of adults with intellectual disability in Poland. Sexuality and Disability, 31(2), 109–123.
- Kök, G. (2010). Zihinsel engelli çocuğun cinsel sağlığına yönelik ebeveynlere verilen sağlık eğitiminin etkinliğinin incelenmesi (Yayımlanmamış doktora tezi). T.C. Genelkurmay Başkanlığı Gülhane Askeri Tıp Akademisi Komutanlığı Sağlık Bilimleri Enstitüsü, Ankara.



- Kürtüncü, M. & Kurt, A. (2020). Sexual education and development in children with intellectual disability: Mothers' opinions. Sexuality and Disability, 38, 455-468. https://doi.org/10.1007/s11195-020-09638-z
- Lambrick, F., & Glaser, W. (2004). Sex offenders with an intellectual disability. Sexual Abuse, 16(4), 381-392.
- Lincoln, Y. S., & Guba, E. G., (1985). Naturalistic inquiry. Newbury Park, Calif.: Sage.
- Lindsay, W. R. (2002). Research and literature on sex offenders with intellectual and developmental disabilities. *Journal of Intellectual Disability of Research*, 46(1), 74-85.
- Liou, WY. (2014). An illustrated scale measuring the sexual-abuse prevention knowledge of female high school students with intellectual disabilities in Taiwan. Sexuality and Disability, 32(2), 135-151.
- Menghini, A. (2012). Sexualität von Frauen und Männern mit Lernschwierigkeiten in vollbetreuten Wohneinrichtungen.http://bidok.uibk.ac.at/library/menghini-sexualitaetdipl.html#idp10353888 Stand: 19.05.2015
- Moll, A., & Moll, B. (2010). Sexualität geistig Behinderter: behinderte Sexualitä; über die Wichtigkeit von Sexualität fürs Menschsein. German: CreateSpace.
- Morales, E., Gauthier, V., Edwards, G., Courtois, F., Lamontagne, A., & Guérette, A. (2018). Codesigning sex toys for adults with motor disabilities. *Sexuality and Disability*, 36(1), 47-68.
- Murphy, G. C., & Young, A. E. (2005). Employment participation following spinal cord injury: Relation to selected participant demographic, injury and psychological characteristics. *Disability and Rehabilitation*, 27(21), 1297-1306. https://doi.org/10.1080/09638280500164644
- Naylor, A., & Prescott, P. (2004). Invisible children? The need for support groups for siblings of disabled children. British Journal of Special Education, 31(4), 199–206. https://doi.org/10.1111/j.0952-3383.2004.00355.x
- Neuman, W. L. (2006). Toplumsal araştırma yöntemleri: Nitel ve nicel yaklaşımlar. (S. Özge, Translator). İstanbul: Yayın Odası.
- Palas Karaca, P., Başgöl, Ş., Cangöl, E., Aslan, E., & Cangöl, S. (2016). Özel eğitim ve rehabilitasyon merkezi çalışanlarının engelli bireylerin cinsel eğitimi konusundaki görüşleri. *Balıkesir Sağlık Bilimleri Dergisi*, 5(1), 13-17.
- Punch, K. F. (2011). Sosyal araştırmalara giriş: Nicel ve nitel yaklaşımlar. (D. Bayrak, H. B. Arslan, Z. Akyüz Translators). Ankara: Siyasal.
- Sarı, H. (2004). Engelli çocukların ailelerinde oluşan dinamikler ve aile bireyleri üzerinde etkisi. Çoluk Çocuk Dergisi, 35, 13-17.
- Schaafsma, D., Stoffelen, J. M. T., Kok, G., & Curfs, L. M. G. (2013). Exploring the development of existing sex education programmes for people with intellectual disabilities: An intervention mapping approach. *Journal of Applied Research in Intellectual Disabilies*, 26(2), 157-166.
- Schaafsma, D., Kok, G., Stoffelen, J. M. T. & Curfs, L. M. G. (2015). Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review. *The Journal of Sex Research*, 52(4), 412-432. https://doi.org/10.1080/00224499.2014.91937



- Siebelink, EM., de Jong, M. D., Taal, E., & Roelvink, L. (2006). Sexuality and people with intellectual disabilities: Assessment of knowledge, attitudes, experiences, and needs. *Mental retardation*, 44(4), 283-294.
- Sınanmış, N., & Kolburan, S. G. (2019). Kardeşi otizmli olan ve olmayan ergenlerin kardeş ilişkileri ve sosyal kaygı düzeylerinin karşılaştırılması. Aydın Sağlık Dergisi, 5(1), 13-50.
- Smith, E. A., & Udry, J. R. (1985). Coital and non-coital sexual behaviors of white and black adolescents. American Journal of Public Health, 75(10), 1200-1203.
- Swango-Wilson, A. (2009). Perception of sex education for individuals with developmental and cognitive disability: A four cohort study. Sexuality and Disability, 27(4), 223-228.
- Treiber, I. (2011). Menschenrechte trotz Behinderung: Zur Sexualität, Partnerschaft, und Sterilisationsproblematik geistig behinderter Menschen. http://bidok.uibk.ac.at/library/treibermenschenrechte.html . Stand: 01.12.2011.
- Tuzcuoğlu, N., & Tuzcuoğlu, S. (2004). Çocuğun cinsel eğitimi. İstanbul: Morpa Kültür.
- Varol, N. (2006). Aile eğitimi. Ankara: Kök.
- Vrijmoeth, C., Monbaliu, E., Lagast, E., & Prinzie, P. (2012). Behavioral problems in children with motor and intellectual disabilities: Prevalence and associations with maladaptive personality and marital relationship. Research in Developmental Disabilities, 33(4), 1027-1038.
- Walton, K. M., & Ingersoll, B. R. (2015). Psychosocial adjustment and sibling relationships in siblings of children with autism spectrum disorder: risk and protective factors. *Journal of Autism and Developmental Disorders*, 45(9), 2764–2778. https://doi.org/10.1007/s10803-015-2440-7
- Wilkinson, V. J., Theodore, K., & Raczka, R. (2015). 'As normal as possible': sexual identity development in people with intellectual disabilities transitioning to adulthood. Sexuality and Disability, 33(1), 93-105.
- Yıldırım, A., & Şimşek, H. (2006). Nitel araştırma yöntemleri. Ankara: Seçkin.
- Yıldız, M. C. (2020). Siblings of children with special needs in the context of inclusive counseling and guidance services. *Journal of Inclusive Education in Research and Practice*, 1(2), 1-15.
- Yılmaz, F. E. (2015). Engellilerde cinsel gelişim ve cinsel eğitim programları ailelere ve öğretmenlere yönelik. Ankara: Akademisyen.



Genişletilmiş Türkçe Özet

Aile bir sistem olarak düşünüldüğünde, ailede zihin yetersizliği ve özel gereksinimleri olan bir bireyin varlığı bu sistemdeki tüm bireyleri etkileyecektir. Olumlu ya da olumsuz etkilerden diğer kardeş ya da kardeşler de payını alacaktır.

Alan yazın incelendiğinde zihin yetersizliği olan yetişkin bireylerin cinselliklerine ve cinsel gelişimlerine ilişkin çok az çalışma olması ve kardeşlerin bu süreçten nasıl etkilendiklerine, neler deneyimlediklerine ve zihin yetersizliği olan kardeşlerine ilişkin bakış açılarına değinen bir çalışmanın olmaması araştırmanın önemini arttırmaktadır. Bu çalışmadan elde edilecek verilerin zihinsel yetersizliği olan bireylerin cinselliği ve yetersizliği olmayan kardeşlerinin ruh sağlığı açısından araştırma yapacak uzmanlara, zihin yetersizliği olan bireylerin birlikte yaşadıkları ailelerine ve toplumun bütününe yararlı olacağı düşünülmektedir. Bu çerçevede araştırmanın amacı; zihin yetersizliği olan bireylerin cinselliklerini zihinsel yetersizliği olmayan kardeşlerinin bakış açısıyla ortaya koymaktır. Araştırmada aşağıdaki sorulara yanıt aranmıştır:

- 1) Zihin yetersizliği olan bireyin cinselliğine ilişkin, kardeşinin bakışı nasıldır?
- 2) Zihin yetersizliği olan bireyin cinsel içerikli eylemlerine yönelik, kardeşinin tepkileri nelerdir?
- 3) Zihin yetersizliği olan bireyin cinselliğinin, kardeşinin kendi cinselliğine yansımaları nasıl olmuştur?

Araştırma nitel araştırma modellerinden fenomenoloji (olgubilim) olarak tasarlanmıştır. Çalışma grubu, yaşları 19-32 arasında, normal gelişim gösteren, 5 kadın ve 5 erkek toplam 10 kardeşten oluşmaktadır. Zihin yetersizliği olan bireyler (1 kadın ve 9 erkek) ise 18-33 yaş aralığında, hafif-orta ya da ağır derece zihinsel yetersizliği olma özelliklerine sahiptir. Çalışma grubu belirlenirken nitel araştırmalarda kullanılan amaçlı örnekleme yöntemlerinden kartopu örneklemeden yararlanılmıştır. Veri toplama aracı olarak araştırmacılar tarafından hazırlanan demografik bilgi formu ve yarı-yapılandırılmış görüşme formu kullanılmıştır.

Elde edilen veriler neticesinde sonuçların üç ana tema etrafında şekillendiği tespit edilmiştir: (1) kardeşlerinin gözünde zihinsel yetersizliği olan bireylerin cinselliği ve cinsel gelişimi, (2) zihinsel yetersizliği olan bireylerin cinsel yaşamlarına ilişkin kardeşlerinin görüşleri ve (3) zihinsel yetersizliği olan bireylerin cinselliklerinin tipik gelişim gösteren kardeşlerinin cinselliklerine ve sosyal katılımlarına yansımaları.

İlgili amaç doğrultusunda çalışmamızda ulaşılan ilk sonuçlar; zihin yetersizliği olan bireylerin cinsel içerikli davranışlarının daha çok sürtünme ve mastürbasyon şeklinde gerçekleşmesi, bu davranışların evde ve ev dışında olması ve davranışlar esnasında heyecan, utanma gibi duyguların eşlik etmesidir. Bu gözlemler başta da belirtildiği gibi



zihin yetersizliği olan bireylerin kardeşlerine aittir. Araştırmaya katılan kardeşlerin bir kısmı zihin yetersizliği olan kardeşlerinin "çocuk gibi" olduğunu belirterek aslında herhangi bir cinsel içerikli davranışla karşılaşmadığını vurguladıkları görülmüştür.

Araştırmadan elde edilen bir başka sonuç ise zihin yetersizliği olan bireylerin cinselliğine dair kardeşlerin tepkilerinin oldukça farklı içerikte olmasıdır. Elde edilen sonuçlar kardeşlerin duygusal açıdan mutluluktan endişeye ve öfkeye uzanan geniş bir yelpazede tepki verdiklerini göstermektedir.

Özellikle cinsel içerikli davranışların uygun olmayan ortamlarda ve uygun olmayan kişilere yönelik gerçekleşmesi kardeşlerin utanmalarına, öfkelenmelerine neden olduğu görülmektedir. Yine zihin yetersizliği olan bireyin cinsel istismara uğraması ihtimali ve zihin yetersizliği olan kardeşlerine süreçte nasıl destek olacaklarını bilememe konusu kardeşleri endişelendirdiği görülmüştür.

Araştırmanın duygusal tepkiler dışında bilişsel tepkiler ile ilgili verilerde ise kardeşlerin önemli bir kısmının zihin yetersizliği olan kardeşinin gelecekteki yaşamına ilişkin olarak "evlenmemeli" düşüncesine sahip olduğu görülmektedir. Bu düşüncenin temelinde ise zihin yetersizliği olduğu için uzun süreli bir beraberlik kuramayacağı, evleneceği kişinin onunla yaşam boyu ilgilenmek istemeyeceği ve çocuk sahibi olması durumunda bunun çocuğa olumsuz etkileri olabileceği düşünceleri yatmaktadır. Çoğunluk benzer fikre sahip olsa da aksini düşünen kardeşler de vardır. Ayrıca araştırmaya katılan katılımcıların zihin yetersizliği olan kardeşlerinin cinsellik ve cinsel gelişimine ilişkin konularda cinsel eğitim alma taleplerinin olduğu da tespit edilmiştir.

Araştırmaya katılan katılımcıların, zihin yetersizliği olan kardeşlerinin cinselliklerinin kendi cinselliklerine olan etkileri ve toplumsal yaşama katılımlarına ilişkin sonuçlara bakıldığında; çoğu katılımcı zihin yetersizliği olan kardeşlerinin cinsel içerikli davranışlarından dolayı kendilerinin toplumsal yaşama dahil olmada herhangi bir olumlu-olumsuz etkilenme olmadığını belirtirken, katılımcıların birkaçı, özellikle erken dönemlerde taklit yoluyla bazı cinsel içerikli davranışlarda bulunduklarını ya da cinsellikten uzun süre iğrendiklerini ve yeni yeni bu durumu aşmaya çalıştıklarını belirtmişlerdir.

Araştırmadan elde edilen sonuçlar göz önünde bulundurulduğunda zihin yetersizliği olan bireylerin cinselliği hem psikolojik hem de sosyolojik bağlamda tartışılması gereken bir konudur. Zihin yetersizliği olan bireyle yaşamak daha çok annelerin bakış açısıyla ele alınsa da bireyin aynı odayı paylaştığı, sokağa birlikte çıktığı kardeşi ile kurduğu ilişki, cinsel içerikli davranışlar, bunun yansımaları vb. oldukça önemli konulardır. Ancak şimdiye dek bu konuya çok fazla değinilmemiş olması, zihin yetersizliği olan bireylerin kardeşlerinin göz ardı edilebilen bir grup olduğunu düşündürmektedir. Bu konuyla ilgili daha fazla çalışma yapılması elzemdir.



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