

## EXPLORING THE UNDERSTANDING OF SEXUAL EDUCATION IN ADOLESCENTS WITH INTELLECTUAL DISABILITIES

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### Abstract

The importance of understanding sexual education among teenagers cannot be denied, but how teenagers with intellectual disabilities process this information is an aspect that is often overlooked. This research aims to deepen the understanding of sexual education for adolescents with intellectual disabilities, explore the challenges they may face, and offer insights that can enrich the practice of inclusive sexual education. The results of the study concluded that (1) Knowledge of sex education for each teenager with intellectual disabilities in this study was included in the good category. This is seen based on awareness of physical or biological changes in oneself in the form of menstrual/menstrual experiences, changes in body posture, growth of fur (hair), and emotions or psychology. They also know about norms in interacting with the opposite sex, knowledge about HIV/AIDS, and sexually transmitted diseases (STDs), (2) Teenagers with intellectual disabilities receive knowledge about sex education from various media, namely from parents, social media such as Instagram, Google, teachers in learning activities in class, and counseling from the nearest Community Health Center, (3) The sexual knowledge needs expected by teenagers with intellectual disabilities are also not much different from normal teenagers, namely the need for information on healthy relationships, approaches before marriage, and child care (parenting).

**Keywords:** Sex Education, Adolescents, Intellectual Disabilities.

### INTRODUCTION

Sexual and reproductive health is a right for everyone, including people with intellectual disabilities (Carter et al, 2022; Medina-Rico et al, 2018). Adolescents with intellectual disabilities are also sexually active like adolescents without disabilities. Unfortunately, this sexual interest is not balanced by sexual education. Groups with intellectual disabilities have difficulty gaining sexual knowledge both because it is still considered taboo and because teachers lack knowledge (Michielsen & Brockschmidt, 2021). Plus, there are assumptions from a society that still consider people with intellectual disabilities to be eternal children who will not have sexual experiences (Azzopardi-Lane, 2022). This makes them vulnerable to sexual violence, unwanted pregnancy, and sexually transmitted diseases (Carter et al, 2022).

Sexual education needs to be delivered according to the developmental stage of individuals with intellectual disabilities, whether from parents, friends, or therapists. This is also in line with the World Health Organization (WHO) (2016) which states that reproductive and sexual health rights include the right to feel safe and happy in sexual activity, equality, privacy, marriage, reproductive rights, and to obtain information about sexuality and reproduction.

The keys to learning sexual education include (1) relationships, (2) values, rights, culture, and sexuality, (3) gender, (4) violence and safety, (5) the ability to maintain

sexual and reproductive health and well-being, (6) growth and development of sexuality and reproduction, (7) sexuality and sexual behavior, and (8) knowledge of sexual and reproductive health (Unesco. et al., 2018). Frawley & Wilson (2016) found that young people with intellectual disabilities do not yet know the mechanisms of sexual relations and building relationships with partners. This research is expected to be able to map the extent of sexual knowledge in each adolescent with intellectual disabilities.

Adolescents with intellectual disabilities often face obstacles in understanding important aspects of sexual education. Despite increasing inclusivity efforts in the education sector, the context-specific understanding of youth with intellectual disabilities still needs to be further explored. This research provides in-depth insight into the dynamics of understanding sexual education among this group.

The formulation of the research problem is: (1) What is the knowledge of sex education among adolescents with intellectual disabilities? (2) Where do teenagers with intellectual disabilities get knowledge about sex education? (3) What are the sexual knowledge needs expected by adolescents with intellectual disabilities?

The research aims to find out in depth the sex education knowledge of each teenager with intellectual disabilities and the sources of sex education knowledge. In addition, it is hoped that this research can further explore the sexual knowledge needs of adolescents with intellectual disabilities. It is hoped that the results of this research will be useful in understanding the sexual education knowledge needs of adolescents with intellectual disabilities. It is also hoped that this research can enrich the perspective of sexual education for therapists and other health workers.

## **METHOD AND DESIGN**

### **Research Approach and Design**

Qualitative research methods were used to explore the understanding of sexual education for adolescents with intellectual disabilities. In-depth interviews, observations, and content analysis were used to detail the perspectives and challenges faced by the youth. This research aims to explore the understanding of sexual education for each individual with intellectual disabilities using semi-structured interviews.

The strategy used in this research is phenomenology where each individual's experience regarding sexual education is described by teenagers with intellectual disabilities. Phenomenology seeks to describe meaning from the perspective of the individuals involved (Svend Brinkmann, Michael Hviid Jacobsen, and Søren Kristiansen in Leavy, 2014). The benefits of this strategy can be felt by teaching therapists, health workers, and policymakers thanks to a deep understanding of the phenomena that individuals have experienced (Creswell, 2013).

### **Data sources**

Data sources used in research include primary and secondary data. Primary data was obtained directly from respondents, namely, individuals with intellectual disabilities who were the subjects of this research. Secondary data is used to support the results of primary data originating from books, journals, and archives.

## Sampling Techniques

The sampling technique uses non-probability with purposive sampling. In the purposive sampling technique, the author emphasizes exploration based on sample criteria. Inclusion criteria in this study include; (1) a sample of individuals with intellectual disabilities with mild and moderate functional levels of intellectual disability. Because individuals with mild intellectual disabilities can learn the ability to care for themselves and their health and have better communication skills. (2) Female who attends SMALB Negeri Surakarta. Sex is a taboo topic of discussion, so to explore more accurate data and subject comfort, the author chose female subjects.

The author will observe and ask questions regarding the sexual knowledge that teenagers with intellectual disabilities have acquired. Creswell (2014) stated that it is very important to observe respondent behavior during data collection to understand the phenomenon more deeply. Interviews were conducted in-depth (in-depth interviews) to understand in-depth the phenomena that occurred (Abdussamad, 2021). In the data collection process, the author used a cellphone to document the results of the interview.

To test the trustworthiness of the data the author uses triangulation. Triangulation techniques combine the results of observations, interviews, and documentation. The author obtained data from several teenagers with intellectual disabilities so he used source triangulation. To obtain more comprehensive analysis results, the author uses a comparison of theories called theoretical triangulation.

## Data Analysis

To review the data, the author used thematic analysis proposed by Braun & Clarke (2006). Thematic analysis is a data processing process by exploring data, finding patterns, systematic coding, realizing themes, and creating narratives. The steps that must be taken include:

1. Study the data you have by reading, observing, and recognizing patterns in transcript results.
2. Make initial coding on all data. Coding is the process of grouping into several categories. To make the coding process easier, create coding that indicates patterns and meaning in the data.
3. Determine the quotes that will be included in the coding process. Find magnetic quotes and group them with inappropriate coding.
4. Bring together the excerpts that have been coded into several themes and sub-themes.
5. Change and ensure the theme is supported by strong quotes.
6. Interpretation of qualitative data contains what can be learned from the data that has been obtained starting from culture, history, and the experiences of the individuals involved in narrative form.

This research is expected to reveal various understandings and views of adolescents with intellectual disabilities regarding sexual education. Findings may include communication barriers, understanding social norms, as well as efforts to increase inclusivity in sexual education programs.

The interviews were conducted at the Surakarta State Special School because apart from accepting individuals with intellectual disabilities, this school also accepts students with visual impairments, hearing impairments, physical impairments, and ASD. So, students have the opportunity to interact with more individuals. It is hoped that students with intellectual disabilities at the Surakarta State Special School will have better social interaction skills.

The interview process was carried out using the focus group discussion method. Focus group discussions were conducted. Questions semi-closed questions are used so that problems can be discovered more openly where the subject is asked for opinions and ideas based on the subject's perceptions, beliefs, fears, and information. Students act as moderators and note-takers. The tool used to document this interview session was a cellphone which was used to record sound. During the interview session, students combined women and men but were separated because the subjects were less open when asked about puberty.

## RESULT

A description of the data on the characteristics of the research subjects is presented in Table 1.

**Table 1: Demographic Data**

| Data Demographic |     |        |        |                      |
|------------------|-----|--------|--------|----------------------|
| Name             | Age | Gender | Status | Religion             |
| DEA              | 18  | Female | Single | Islam                |
| NANDA            | 23  | Male   | Taken  | Islam                |
| NOVA             | 18  | Female | Single | Protestant Christian |
| VANYA            | 18  | Female | Single | Islam                |
| ANISA            | 18  | Female | Taken  | Islam                |
| ENGGAR           | 18  | Female | Single | Orthodox Christian   |

Based on the results of the thematic analysis, the research results are presented as follows:

### Sexuality of Adolescents with Intellectual Disabilities

Participant 1 D (female) said that she experienced the puberty phase like other teenage girls, namely menstruating in the 6th grade of elementary school or at the age of 12 years. D remembers the frequency of her menstruation every month like women in general. During menstruation, it is also felt that you cannot move, which means you are not comfortable, so you just lie down. Then he also admitted that there were changes in body posture such as breast growth.

Participant 2 N (male) stated that he did not feel a change in voice before and after puberty, but he felt a change in height, where the body became taller and there was a change in voice as a secondary symptom of puberty. In the biological aspect, he said that he had gone through puberty, but N explained that he had never had a wet dream even though he was now 23 years old.

Participant 3 Nv (female), said that she experienced menstruation for the first time in early 2016, when she was in class 6, semester 2. When Nv was about to go home and take a shower, she continued to feel blood coming out. So, you are still unsure whether you are experiencing menstruation. At the beginning, it is said that blood does not come out immediately, spots come out first. After fasting/Eid, Nv panicked

because she hadn't had her period for two months. Perhaps because of stress, Nv felt distrustful.

Participant 4 V (female) revealed that she first experienced menstruation when she was in grade 7 of junior high school. Apart from that, it was revealed that he also experienced physical changes such as the growth of feathers (hair).

Participant 5 A (female) stated that she experienced menstruation for the first time and was unable to participate in teaching and learning activities at school because she felt sick. He explained that his body felt all the pain. She complained about the discomfort of moving while menstruating.

Participant 6 E (female) said that she felt uncomfortable doing activities, and felt lazy to move when she was menstruating.

Based on the description from the resource person above, it can be concluded that the subject felt that there were physical or biological changes in himself in the form of menstruation/menstruation experiences, changes in body posture, and growth of fur (hair) from children to teenagers. Apart from that, the subject also felt a change in emotional and psychological control from the influence of changes in sexual characteristics on the individual.

### **Knowledge of Sexual Education for Adolescents with Intellectual Disabilities**

The results of interviews with research subjects obtained the following information:

Participant 1 D revealed that the first time he experienced menstruation he asked his parents to tell them about their first experience of menstruation. So, he feels he knows what menstruation is through the role of a parent.

Participant D stated that he had liked the opposite sex when he was still in junior high school. Honestly, he answered that at that time he only liked friends (friend zone). D also realized that he had experienced unrequited love. Even though he revealed that he is someone who doesn't like hanging out with friends of the other sex.

Participant 3 Nv revealed that she once thought that she would be worried if she became pregnant when she did not menstruate. So, there is a misunderstanding that she once thought that if she didn't menstruate without fertilization, she would get pregnant. Nv also revealed that he is an introverted and anti-social person. He feels insecure about building relationships (approaches) with people he likes. Participant Nv also revealed that he knows that having a relationship with the opposite sex must be done after the two are married. He stated that if sexual intercourse is carried out before marriage, it can cause illness due to viruses which will be transmitted to children.

Participant E stated that he also liked the opposite sex when he was in junior high school. Meanwhile, participant A stated that he did not like the opposite sex when he was in middle school. But there was a feeling of liking when he was in high school. However, participant E could not answer when asked what sex is like.

All female participants revealed that they had felt like the opposite sex in middle school, except for participant A in high school. Participant D also stated that adults must be able to reflect on themselves and have a way of speaking like a complete adult.

Participant Nv revealed that he wanted to know about human development by studying it. He wants to feel like he wants to be mature in terms of thinking.

Based on the results of the interviews in the research, it can be concluded that teenagers with intellectual disabilities also experience feelings of liking for the opposite sex, although with varying intensities. This feeling of liking the opposite sex is still interpreted as friendship. Adolescents with intellectual disabilities also know their privacy and body boundaries which cannot be touched by other people.

### **Sources of Intellectual Disability Sexual Education Information**

Participant D revealed that his parents had explained that other people were prohibited from touching his body. Physical touch is not permitted when interacting with members of the opposite sex because you have to be married before you are allowed to touch, let alone have sex.

Participant Nv revealed that he also knows that having a relationship with the opposite sex must be done after the two are married. He stated that if sexual intercourse is carried out before marriage, it can cause illness due to viruses which will be transmitted to children.

Participant A also revealed that it was his parents who told him about the prohibition on touching and being touched by other people. Participant E stated that in his opinion, he should not touch or be touched by other people (of the opposite sex). And touching is allowed if you are married. Participant E also could not explain the meaning of sexual harassment.

Based on the results of interviews with research subjects, all subjects revealed that their parents were a source of sexual education information. If the subject is female, he is more open to asking about physical changes such as menstruation in his mother. Meanwhile, male subjects tend to remain silent.

### **Information on Sexuality and Reproduction that Adolescents with Intellectual Disabilities Want and Need**

People with disabilities have very little access to sexual and reproductive information, even though everyone has the right to receive sexual and reproductive health information. People often forget that people with disabilities are also sexual creatures who need attention.

The sexuality and reproductive information needed by adolescents with intellectual disabilities is described in interviews with research subjects as follows:

Participant D explained that information about sexuality and reproduction was provided at school through teachers in the form of video shows during classroom learning activities. There is also information obtained in the form of images during class learning. Participant D also explained that community health center employees had visited the class to provide sexual education. The role of health workers is to convey sexual education regarding sexual education material to adolescents with intellectual disabilities, in the form of preventing casual sex and overcoming sexual harassment.

According to Participant D, information and knowledge about reproduction and sexuality was obtained from social media such as Instagram because Participant D

also filled his Instagram content with parenting videos. He looked for information about sexuality on Google.

D also wants to gain knowledge about healthy relationships and establishing relationships with other people. D's desires are the same as those of normal humans who want to get married, have children, and take care of children (parenting).

Participant A admitted that he also knew about sex education from books, pamphlets, and counseling from community health center officers. He also obtained information about HIV/AIDS from counseling provided by Community Health Center officers.

Participant E also admitted that he also wanted to know information about reproduction and sexuality. Apart from that, he also wants material about dating and relationships with lovers, marriage, and having children. The desired knowledge also includes sexually transmitted diseases.

Participant Nv revealed that he had a desire to gain knowledge about relationships with long-term commitment. He also wants to obtain information and health services, both physical and mental. Because mental (spiritual) health also needs to be maintained, not only physical health. NV admitted that he obtained knowledge related to sexual education from books, tutoring, and spirituality. Books and pamphlets are a medium for sexual education for teenagers here. Nv also admitted that I had previously attended training at the Manahan Health Center with my friend, studying about the HIV/AIDS virus and sexually transmitted diseases (STDs).

In terms of knowledge about sexuality and reproduction education, it appears that Participant D knows more information than the other participants. Participant D explained more about how to obtain information about sexuality and reproduction through Instagram, Google, and counseling from the Community Health Center. The information that Participant D knew made him feel more afraid of contracting a sexually transmitted disease that could not be cured.

Based on the results of research through interviews with research subjects, information was obtained that subjects as teenagers with disabilities also wanted to obtain information about reproduction and sexuality, including knowledge about diseases caused by sexual relations that pose a risk of sexually transmitted diseases.

## **DISCUSSION**

### **Sexual and Reproductive Knowledge of Adolescents with Intellectual Disabilities**

Sex is still considered taboo by society, including teenagers with intellectual disabilities. When asked about how STDs and HIV spread, they used the implicit sentence 'that' as a reference to sexual activity. Talking about sex causes embarrassment so people tend to use indirect euphemisms to make themselves comfortable when talking about sex (Crespo-Fernández, 2018a).

They were able to describe their menstruation and some even remembered their first experience of menstruation. Some ask about menstrual patterns "Interview results". Adolescents with intellectual disabilities have high curiosity about sexual and reproductive health. Some complain of irregular menstrual patterns.

In terms of knowledge of relationships with partners, teenagers with intellectual disabilities tell many stories about love stories at school. They also told the story of

their unrequited love. Some have rejected declarations of love. E, who has been in a relationship, stated that when they were dating, they spent time walking around and holding hands. This rejects the myth that teenagers with intellectual disabilities do not have sexual desires. Individuals with intellectual disabilities view love as an important part of fulfilling well-being (Mattila et al., 2017).

Adolescents with intellectual disabilities can differentiate between feelings of love for friends and romantic relationships. This is proven when they tell stories of unrequited love. In sexual education, someone needs to be able to differentiate feelings of love for friends, friends, lovers, parents, and children.

They also have opinions about romantic relationships that are influenced by religion. They have the opinion that dating people of different religions is forbidden and they will not have sexual relations before marriage. As stated by Santinele Martino (2022), religion influences views and attitudes regarding sexuality.

### **Sources of Sexual Education**

Parents in Powell et al's scoping review (2020) helped people with intellectual disabilities manage menstruation. Parents help explain to individuals with intellectual disabilities that menstruation is a process during puberty and is normal during adolescence.

Parents act as the first teachers for their children. However, sometimes parents become overprotective of children with intellectual disabilities and take control over their sexuality and relationships (Powell et al., 2020; Puyaltó et al., 2022). They worry that their child will experience an unwanted pregnancy. They should be guided in planning pregnancy and preventing pregnancy (Powell et al., 2020; Unesco. et al., 2018).

Training regarding knowledge of sexuality and reproduction for parents must be emphasized so that individuals with intellectual disabilities have the right to express their sexuality. The media plays a role in disseminating information about sexuality and reproduction. Interviewee D uses social media to look for information about parenting. Short video-based content is easier to understand. Videos can help individuals with intellectual disabilities improve work skills, independence in carrying out daily activities, using free time, and academic skills with video modeling and prompting (Park et al., 2019).

However, with the large amount of information spread on the internet, individuals must be able to filter out true and false information. Misinformation tends to become popular and spread more quickly on social media than correct information. Often this misinformation uses fear, worry, and distrust in related institutions (Wang et al., 2019).

They have received sexual education regarding sexual harassment from health workers. They were able to understand the material presented by the health worker and still remember it to this day. Individuals with intellectual disabilities expect material regarding parenting and relationships with partners. This is by the findings of Frawley and Wilson (2016) that individuals with intellectual disabilities need knowledge regarding relationships and long-term relationships.



However, health workers face challenges in delivering sexual education. Parents are one of the reasons why sexual education is so difficult to convey. This is because they still consider sexuality to be taboo and must be suppressed (Azzopardi-Lane, 2022). As Crespo-Fernández (2018) states, sexuality is a taboo topic that is often avoided. Lam et al, (2021) found that health workers are often involved in moral dilemmas in delivering sexual education.

### **Required and Desired Materials**

When asked about the material they wanted, teenagers with intellectual disabilities wanted material about dating and relationships with lovers. This is by the findings of Frawley and Wilson (2016) regarding the subject's desire to know and understand how to relate to partners both romantically and sexually. Individuals with intellectual disabilities expect training to increase satisfaction in relationships (Puyaltó et al., 2022).

To meet a lifelong partner, some people need to participate in social life. APA (2013) states that individuals with intellectual disabilities can only interact using simple language, while individuals with mild intellectual disabilities are still able to interact even though they are not compatible with their peers. Unfortunately, individuals with intellectual disabilities have more limited opportunities for social participation (Puyaltó et al., 2022). This causes individuals with intellectual disabilities to have difficulty finding the right life partner for them.

In sexual education at the point of long-term commitment, they will learn to understand that there are always twists and turns in long-term relationships and marriages and differentiate between healthy and unhealthy relationships (Unesco. et al., 2018). This is what must be taught to individuals with intellectual disabilities to fulfill their rights to express sexual behavior.

Healthy long-term relationships are characterized by mutual respect and support, communicating openly, spending quality time together, sharing the same life principles and values, having realistic expectations in a relationship, feeling safe, the partner's involvement in making joint decisions, and a sense of believe (Psikolog Masuk Sekolah, 2020).

Social observer and Vocational communication lecturer at the University of Indonesia Devie Rachmawati, S.Sos, M.Hum in *Femina Magazine* (2016) said that today's marriage relationships aim to seek happiness, not to continue offspring. Plus, technological developments have developed a short-cut mentality, making divorce prone to occur if the marriage relationship is unhappy.

Social media that displays happy couples can create expectations of what kind of couples they see in the media. Still reported by *Femina magazine* (2020), Roslina Veraluli M.Si stated that the lack of time for oneself disrupts sexual relations because women need emotional comfort to have sexual relations while domestic and work activities sometimes make women more emotionally sensitive.

Religion influences the choice to marry and divorce. Although religion more often functions as an intermediary than intimidation in romantic relationships and marriage (Kelley et al, 2020). Economics is also a factor in marriage and divorce decisions (González-Val & Marcén, 2018). This is something you should think about before getting married.

They also want to learn parenting. In the curriculum created by UNESCO (2018), sexual education is not only about sexuality and reproduction but also about relationships with family, friends, children, and the social environment, including parenting. Parenting is a pattern of raising children that has the aim of maintaining the health and safety of children, preparing children to become productive individuals, and interpreting culture and values by norms in social life (American Psychological Association (APA), accessed 25 December 2022). Parenting is carried out from the prenatal period until the child reaches adulthood.

Individuals with mild ID can still function in practical areas in line with their peers, including caring for children (American Psychiatric Association (APA), 2013). Unfortunately, research on parenting education is still limited and has low evidence-based (Coren et al., 2018).

Plus, research shows that children with intellectual disabilities are at risk of committing violence against children (Slyter & Jensen, 2019). Parenting involves a complex process involving encouragement and support both physical, emotional, social, and cognitive from infancy to adulthood.

This makes individuals with intellectual disabilities considered incapable of parenting by both the public and professionals. Even though cognitive is not the only factor that influences parenting style, the past and present history of parents, children, and family environment are also influencing factors (Lam et al., 2021).

Although there are teenagers with intellectual disabilities who use social media to learn about parenting, support from professionals is needed to improve the information about parenting that has been obtained via the internet (Bäckström et al., 2022). Programs to practice the parenting knowledge that has been learned are very necessary.

Reproductive health and sexuality also need to be taught more deeply, especially regarding reproduction. Especially in menstrual management and the problems that can be experienced during menstruation.

The limitations of this research can be explained as follows:

1. The time for this research, especially the time for interviews with research subjects, is limited, whereas obtaining complete information/data will take longer.
2. There was only one male research subject, causing him to be less open in conveying information to researchers. So, the interpretation of the results of this research is more dominant from a woman's perspective.

## CONCLUSION

1. Knowledge of sex education for each teenager with intellectual disabilities in this study is included in the good category. This is seen based on awareness of physical or biological changes in oneself in the form of menstrual/menstrual experiences, changes in body posture, growth of fur (hair), and emotions or psychology. They also know about norms in interacting with the opposite sex, knowledge about HIV/AIDS, and sexually transmitted diseases (STDs).

2. Adolescents with intellectual disabilities receive knowledge about sex education from various media, namely from parents, social media such as Instagram, and Google, teachers in classroom learning activities, and counseling from the nearest community health center.
3. The sexual knowledge needs expected by teenagers with intellectual disabilities are not much different from normal teenagers, namely the need for information on healthy relationships, approaches before marriage, and parenting.

### Practical Implications

Exploring the understanding of sexual education for adolescents with intellectual disabilities has important implications for the formation of inclusive sexual education. This research encourages a deeper understanding of their perspectives, embraces diversity, and strengthens the foundation of a more holistic approach to sexual education. With the understanding gained from this research, it is hoped that it can help develop more inclusive pedagogy and curriculum in sexual education. Provides rich insight into how to approach and support young people with intellectual disabilities in understanding and navigating aspects of their sexuality.

### Conflict of interest disclosure

In the research, writing, and/or publication of the paper, the author(s) state, there is no conflict of interest.

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