

## A Phenomenological Study on Sexuality Education for Children and Adolescents with Autism Spectrum Disorder in Jakarta

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### Abstract

This research is motivated by the researchers' concern about children, especially adolescents with autism. Autism is not a mental illness but it is a disorder that affects the brain, causing it to not function properly. This can be seen in the behavior of children with autism. The purpose of this research is to find out the experiences of parents of children and adolescents with autism spectrum disorder. This research uses a qualitative research design with a research approach to phenomenology. The result of this research showed that sex knowledge of children with autism spectrum disorder is still limited to knowledge of differences between male and female sexes. They obtained sexual knowledge education from schools, while some received it from teachers, therapists, and parents. The level of independence is high. Sexual prohibition is important to give children the knowhow to maintain behavior towards the opposite sex. To improve the sexual health education of parents who have children with autism spectrum disorder, they can attend sexual education seminars.

**Keywords:** Adolescents; Autism; Children; Sexual Education; Sexual Health.

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### Introduction

As Indonesia's capital city, Jakarta is a huge megacity that serves as both the country's administrative and commercial hub and a nexus for cultures from around the archipelago. The city, which is home to millions of people, is where the glistening lights of contemporary skyscrapers harmoniously blend with traditional Indonesian elegance and the remnants of the

country's national past, with the National Monument towering proudly at its center.

There is something for everyone in the capital city, a metropolis that never sleeps with 24-hour entertainment and first-rate recreational facilities. Jakarta is truly a capital of varied splendors, offering everything from international music concerts to a thriving nightlife, fascinating recreational and theme parks, a wide variety of shopping options, culinary presentations from around the

archipelago and the world, as well as its distinctly distinct traditional art and culture (Universitas Mercu Buana, 2021).

Particularly in the nation's capital, sex education for young people is crucial. Conflict cannot be avoided as a factor in the growth and development of the city, and this conflict can undoubtedly contribute to the emergence of crime in urban areas (Tutrianto, 2018). The bigger the city, the more crime that could occur due to that matter, and that children should be introduced to sex education as early as possible.

When it comes to finding trustworthy information, people with disabilities are particularly vulnerable (Hafiar et al., 2022). Sexual health and relationship education (SHRE) can provide knowledge, motivation, and skills to help people to: (1) understand the potential consequences of their sexual behavior; (2) make informed decisions about sexual relationships; (3) more comfortably communicate about sex, sexuality and sexual health, and (4) protect themselves against sexually transmitted infections (Sheikhansari et al., 2021).

This research is motivated by the researchers' concern about children and adolescents with autism. Autism is not a mental illness but it is a disorder that affects the brain, causing it to not function properly. This can be seen in the behavior of children with autism. The most important thing that needs to be noted through the results of previous studies is that autism disorder is not caused by psychological factors. Therefore, any deficiencies in these aspects can be attributed to a lack of understanding of sexual information (Sheikhansari et al., 2021).

Adolescence is certainly one of the stages of natural development that occurs in humans and is something that cannot be avoided. Physical changes and sexual maturity become important challenges that occur in it. There is no exception, for adolescents with autism. According to the National Commission on Adolescent Sexual Health (NCASH), sexuality is a natural part of life. Sexuality includes a knowledge of sex, attitudes, values, and individual behavior. It deals with the anatomy and physiology of a person's sexual response system to roles, identities, and personalities. Sexuality is certainly closely related to thoughts, feelings, behavior, and relationships (Nugroho, 2009).

Realmuto & Ruble (1999) suggested that adolescents with autism learn information about sex through everyday social experiences. The social experience in question is an explanation that comes from family or formal education. The importance of this is based on research conducted by Ruble & Dalrymple (1993) on 100 adolescents with autism. This research shows the prevalence of adolescents with autism who engage in inappropriate sexual activities, including touching private parts (65%) and removing clothes in public places. (28%), masturbating in public (23%), touching the sex organs of the opposite sex (18%), and masturbating using strange or inappropriate objects (14%). Therefore, sex education for children and adolescents with autism is very important (Nugroho, 2009).

Sex education is rarely mentioned when talking about autism, perhaps because it is still considered taboo. Whereas good sex education can help prepare the child to become an independent adult individual (MPATI, 2010)

Parents have a significant effect on how their autistic children develop and deal with adolescence. They will be more able to accept the changes that come with puberty if parents prepare them, explain things to them, and provide them with advice (Nugraheni & Tsaniyah, 2020). The role of parents for children with autism in their daily lives is very important. As with sex education, the role of parents, especially mothers of adolescents with autism, is very dominant.

Based on the explanation above, the researchers would like to research the importance of sex education for children and adolescents with an autism spectrum disorder in Jakarta.

### **Theoretical Framework**

The history of the emergence of term autism for the first time was coined by Eugen Bleuler, a Swiss psychiatrist, in 1911, when the terminology was used for sufferers of juvenile schizophrenia at the time. In 1943, Leo Kanner of Johns Hopkins University described autism in childhood. This finding is based on observations of 11 children from 1938 to 1943 (Ayuningtyas et al., 2020; Yuwono, 2012).

In Indonesia itself, the issue of children with autism emerged only in the 1990s. Autism began to be widely known around the 2000s in Indonesia. Data on the number of

children with autism disorders are not exactly known until now. However, the number of children with autism showed a very striking increase. As per the practical experience of a psychiatrist based in Jakarta, before the 1990s the number of patients diagnosed as having autism disorders in a year was only about five. Now in just a day he diagnoses three new patients (Yuwono, 2012).

Communication disorders in autism may include, within broad parameters, multiple deficits in lexical terms, linguistic development, the subjects autistic people choose to relate to, and the way they communicate and engage in social situations (Ayuningtyas & Moekahar, 2022; Wood, 2018).

To strengthen the communication characteristics of children with autism, Christopher Sunu (2012) states several indicators of communication and language behavior that may exist in children with autism. Among them are flat facial expressions, do not use body language or gestures, rarely initiating communication, do not imitate actions or sounds, speaking little or nothing, parroting words, speaking strange intonation, don't seem to understand words, and understanding and using words correctly limited (Yuwono, 2012).

As per many characteristics listed above, parrots or echolalia or echolalia are the main characteristics of children with autism as qualitative disorders in the development of communication. An example of echolalia is children with autism can continuously repeat a word or sentence or song without understanding its meaning. This feature of echolalia is usually owned by people with fairly good verbal skills. However, the feature of echolalia is not important because in general child development there is also a phase where children begin to imitate and always repeat new words they know. To distinguish it from children with autism, parents can find out whether the child understands the meaning of the word she/he hears or says.

If we have a dialogue about autism about 15-30 years ago, maybe many people don't know about autism. Autism began to be widely known by ordinary people around the 2000s. Many laypeople say that autism is a disease. Whereas autism is not a disease so it is not appropriate to call it a sufferer or a person because it is carried for life. Although

until now there are still pros and cons, there are several camps related to autism.

There are an estimated 400,000 individuals with autism in the United States. In Indonesia, no accurate data on the number of people with autism is available. But there seems to be a tremendous increase in autism cases in Indonesia. Widodo Judarwanto, pediatrician and editor-in-chief of <http://www.klinikautis.com>, suspects that, like in other parts of the world, there has been a tremendous increase in the number of children with autism in Indonesia. The number of autism cases is predicted to increase every year. In Indonesia, it is estimated that one out of every 250 children experience autism spectrum disorders in 2015. The number of children with autism and people with autism spectrum in Indonesia is estimated to reach 12,800 and 134,000 respectively in 2015. (Ayuningtyas et al., 2021; Rumah Autis, 2019).

Other information obtained by researchers shows that there is currently an increase in the number of people with autism in the world. According to the latest data released by The Center for Disease Control (CDC) in 2015, the prevalence of autism disorders in the United States is estimated at 1:45, while the prevalence of autism disorders in Asia, Europe, and North America is estimated at around 1%. In South Korea alone, the average is around 2.6%. Among the current disabilities, autism is the fastest growing disability, increasing from 1:10 in 2000, to 1:68 in 2010 and then to 1:45 in 2014, or growing by around 6-15% per year. The CDC also released data showing that autism is almost five times more common in men (1:42) than in women (1:189) (Wijayanti, 2016).

### *Sexuality*

Autism is a neurodevelopmental disorder that affects language acquisition, social development, and behavior (Gita, 2020). Where any deficiencies in these aspects can be related to a lack of understanding of sexual information and the absence of the ability to express sexual feelings adequately, weak social development is one of the main causes. Realmuto and Ruble (1999) suggest that children with special needs to learn information about sex through everyday social experiences. The social experience in question

is an explanation that comes from family or formal education (Nugroho, 2009).

Children with special needs including autism experience the same sexual needs and desires as other people. Research by Trani and Colleagues (2011) found that more than half of adults with disabilities reported being more active in their sexual lives. But they are having a lot of difficulties fulfilling their needs. The public has an inverse understanding that people who are "deficient" do not have sexual desires such as reproduction (WHO & UNFPA, 2009; Nugroho, 2009).

Children with autism have a higher risk of sexual violence than children in general. The danger of sexual abuse is four times higher for children with special needs compared to normal children. Children will experience physical changes during puberty or adolescence such as starting to grow facial hair, changing voice (in boys) and beginning to get menstruation (in girls). However, emotional changes in children with special needs tend to be more difficult because their interest in the opposite sex is often prohibited by the environment around them (Schwier & Hingsburer, 2000; Nugroho, 2009).

It is still common in Indonesia when it comes to discussing sex education or sexuality. Whereas one of the learning curricula on reproductive health education that can be used for autistic children is the curriculum model developed in the TEACCH program (Schopler, 1997 in Sullivan, 2008). TEACCH is an approach to help deal with children in a structural, neutral, and integrated manner. The approach is taken to understand children to increase motivation and be predictable and organized. TEACCH stands for Treatment and Education of Autistic and related Communication Handicapped children (Alokla, 2018).

The educational curriculum developed by TEACCH has four levels of development based on the child's cognitive level. The levels used are as follows: The first level, this level focuses on discriminatory learning and what to do, when, and how. The second and third levels, at this level, explain personal hygiene, and an understanding of the anatomy of the body and its functions. The fourth level is reserved for individuals with higher social functions and various types of social relationships.

According to Sullivan (2008), sex education for children with autism includes several things, namely body parts and functions; physical development, personal health, and self-care; health; appropriate social and sexual behavior; privacy issues; understanding emotions and passions; self-image; prevention of sexual crimes; curiosity; interpersonal relationships (Nugroho, 2009).

Entering adolescence, the desire for sexual urges in children will usually begin to appear, as well as in children with autism. Therefore, parents as role models must be able to guide and provide the right understanding to children, especially in sexual matters. Coordinator of Integrated Clinic, Faculty of Psychology, University of Indonesia Dr. Adriana S. Ginanjar, M.S said that before entering their teens, parents of autistic children should have provided their children with sexual education (Chandra, 2018b).

#### *Adolescent*

Adolescence is a time of rapid physical, psychological, and intellectual growth and development; it also affects adolescents with autism. with all of its benefits and drawbacks. Adolescents typically have a strong sense of curiosity, enjoy challenges and adventure, and are willing to take risks without giving their choices much thought. If the choices made in handling the conflict are poor, individuals may engage in dangerous conduct and have to deal with the short- and long-term effects in the form of numerous physical and psychosocial health issues. Adolescent care services, particularly reproductive health treatments, must be available to fulfill the unique needs of these teens due to their nature and risky behavior (Kemenkes RI, 2012).

According to the WHO, adolescents are people who are 10–19 years old; according to the Republic of Indonesia's Minister of Health's Regulation No. 25 of 2014, adolescents are people who are 10–18 years old; and according to the Population and Family Planning Agency (BKKBN), adolescents are people who are 10–18 years old, 24 years old, and single. In Indonesia, there are 43.5 million people aged 10 to 19 years as per the 2010 Population Census, or roughly 18% of the country's total population. Youth make up an estimated 1.2 billion people worldwide, or 18% of the total population (WHO, 2012).

WHO (World Health Organization) asserts that the definition of youth is based on three factors: biological, psychological, and socioeconomic. To clarify that adolescence is a developmental stage that lasts from the moment a person first exhibits secondary sexual indications until they attain social maturity. People who shift from a condition of reliance to one that is comparatively more autonomous, as well as people who experience psychological growth and identify patterns from childhood to adulthood (Sarwono, 2011).

### Material and Methodology

This research uses a qualitative research design with a research approach to phenomenology. Phenomenology is one of the methods in qualitative research. The phenomenological method focuses on fact-finding a social phenomenon and trying to understand human behavior based on the participant's perspective.

The empirical phenomenological approach entails going back to the experience to gather thorough descriptions that serve as the foundation for a reflective structural analysis that captures the core of the experience. The methodology "seeks to unveil and illuminate the behavioral phenomena as they occur in their perceived immediacy" (van Kaam, 1966). By analyzing the initially provided descriptions of the circumstances in which the experience occurs, the human scientist can determine the underlying structures of an experience (Moustakas, 1994).

When praxis—the core of social research methodologies—is used to observe people's behavior patterns as social actors in society, the role of phenomenology has greater

significance (Nindito, 2013). Schutz's phenomenology is more of an offer of a fresh viewpoint on the subject matter of research studies and the investigation of meanings derived from the realities of daily life contained in that research, especially, and within the overarching framework of social scientific progress (Nindito, 2013).

Alfred Schutz is a social scientist who is skilled at monitoring the advancement of phenomenology. He connected social science and the phenomenological approach. Schutz is one of the innovators of the phenomenological method as an analytical instrument for capturing all the symptoms that occur in this environment. There are quite a few social scientists that pay attention to the development of phenomenology in addition to Schutz. Schutz also created a phenomenological technique that is beneficial for capturing a variety of social phenomena that is more systematic, comprehensive, and practical (Nindito, 2013).

The focus of the research can be formulated into what are the experiences of parents regarding children and adolescents with an autism spectrum disorder.

According to Creswell in Kuswarno (2009), the criteria for a good informant are "all" individuals studied represent people who have experienced the phenomenon". Sofian (2014). Therefore, the researcher chose informants who have children and/or adolescents with autism so that they can articulate their experiences and views about something that is being asked. Researchers decide on informants who can provide relevant information and can help answer their research questions (Kuswarno, 2007).

**Table 1.** Informants

No	Name	Informant	Age of Children or Adolescents (year)	Location
1.	Informant 1	1	22	Jakarta
2.	Informant 2	2	10	Jakarta
3.	Informant 3	3	21	Jakarta
4.	Informant 4	4	17	Jakarta
5.	Informant 5	5	16	Jakarta
6.	Informant 6	6	12	Jakarta

Source: Pre-observation Results (2022)

The data collection technique carried out in this research is in-depth interviews, observations, and literature studies. The data collection activities carried out by researchers refer to the data collection activities from

Creswell, namely A Data Collection Circle (Kuswarno, 2011). Activities done with Creswell's model show that each other is interconnected, beginning with the determination of places or individuals (Sofian,

2014). This research uses NVIVO 14 for the data analysis process. By processing data based on the following themes:

**Table 2. Research Themes**

No	Themes
1	Sexual Knowledge Education for Children and Adolescents with Autism
2	Sexual Health Knowledge
3	Sexual Health Education for Children and Adolescents with Autism
4	Independence for Children and Adolescents with Autism
5	Sexual Prohibition
6	Recommendations for Improved Sexual Health Education in Jakarta

Source: Pre-observation Results (2022)

**Table 3. Data Analysis and Representation Techniques**

Data Analysis and Representation	Phenomenological Research
Data processing	Create and organize data.
Read and recall data	Read the text, mark off the borders, and make the first codes.
Describing data	Describe how events affected the researcher's perspective and experience.
Classifying data	Find meaningful statements, and make a list of them. Grouping the same statements into certain meaning units.
Data interpretation	Construct a textural description (what happened). Put together a structural description (how the event was experienced). Create a comprehensive account of what happened (the essence of the event).
Data visualization and presentation	A summary of the major events that include statement tables.

Source: Pre-observation Results (2022)

*Data Validation Technique*

According to Bungin, triangulation is checking the veracity of the data obtained from other trusted parties (Ruslan, 2008). Meanwhile, Triangulation, according to Moleong, is a strategy of verifying the accuracy of data that uses something different from the data used for verification or comparison with the data. Source checking is

the method of triangulation that is most frequently utilized (Moleong, 2009). As Humphrey said, in phenomenological research, data validation techniques can be carried out by sending research results to each informant and asking them to correct or provide input (Kuswarno, 2007).

**Result and Discussion**

The results of the research data were obtained from interviews with 6 informants who have children with autism spectrum disorders. The interviews were conducted through *Zoom meetings* and/or face-to-face. The results of the research are based on the Themes that have been determined by the researchers, as follows:

*Sexual Knowledge Education for Children and Adolescents with Autism Spectrum Disorder*

Based on the results of interviews with informants regarding a knowledge of sex education for children with autism spectrum disorders, the researchers found answers from 6 informants, as follows:

Mrs. SS's child's knowledge of sex was based on his religious education which was quite good, and he also knows sex education. Mrs.SS as informant 1, said:

“His religious education is quite good, so he understands his obligations as a religious person. He is very knowledgeable about worship, ablution, obligatory baths, etc. His knowledge of sex education is mostly obtained from the school and his teacher, some from his parents, so he gets a lot of input” (Informant 1).

Whereas Mrs. DPS’s child does not understand sex knowledge, his mother has introduced sex education into his daily life. Mrs. DPS as informant 2, said:

“Do not have a knowledge of sex because of retardation, slow in thinking so they do not understand well. It has been introduced in daily life. As related to male and female genitalia, when bathing, they must be separated from his sister because of the different sexes”. (Informant 2).

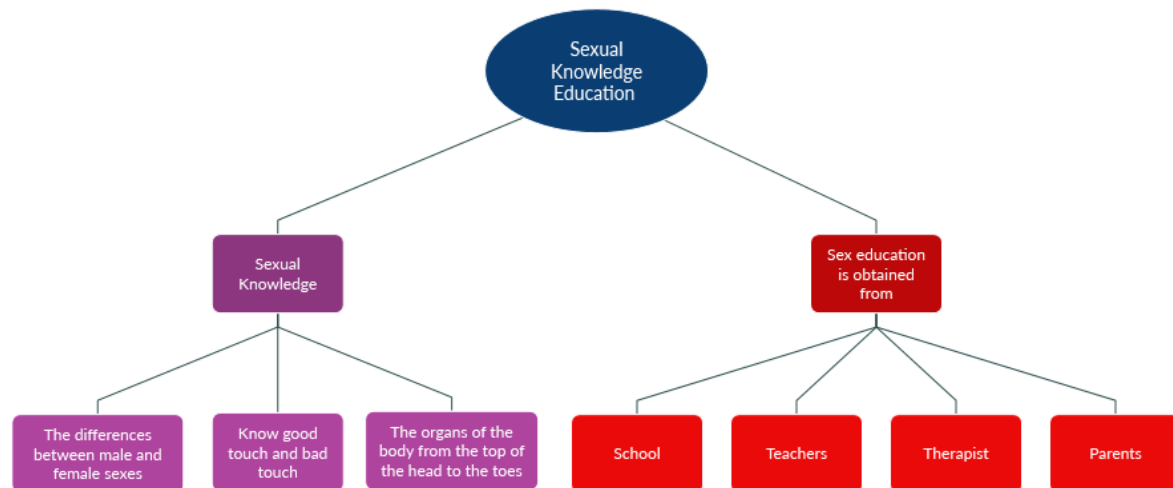
Furthermore, the responses from informants 3, 4, and 5 were almost similar. They are Mrs. JS, Mrs. N, and Mrs. EY, their children got a knowledge of sex education from their school, there is also one child who

got knowledge from his therapist, and also from their parents at home. Their school uses PECS (pictures and visuals) in sex education lessons. Regarding the basic knowledge of sex, their children can distinguish between boys and girls, know good touch and bad touch, and know the organs of the body from head to toe. Besides that, their children already understand that masturbation is obligatory for baths and that it must be done in a room, not in an open space.

Then, the last from informant 6, Mrs. ANU, her child does not know much about sex, but he knows the organs of the body, she said:

“I’ve never given much knowledge about sex, so he doesn’t know much about the topic either. Knowledge is limited to the differences between male and female sexes”. He knows the organs of the body from head to toe and by pointing to each part that needs to be known, I have also explained them according to their names without being hidden” (Informant 6).

Figure 1. Mind Map Result - Sexual Knowledge Education



Source: Data analysis by NVIVO 14 (2022)

Based on the results of the interviews above with 6 informants, it can be concluded that the sex knowledge of children with autism spectrum disorders is still limited to knowledge of differences between male and female sexes. In addition, they also know the organs of the body from the top of the head to the toes, and know the parts of the body that are allowed to be touched and not to be

touched by others. Children with autism spectrum disorders obtained sex education mostly from schools, while some received it from teachers, therapists, and parents at home.

*Sexual Health Knowledge*

Based on the result of interviews, the question of how does your child gets sexual health knowledge. Informant 1, Mrs. SS, her

child gets sexual health knowledge well. It is because her child has had a good religious foundation since childhood, she said:

“...So if he knows the law of his religion he runs it well. So it is his understanding of his religion that leads him to how to relate to other people, especially the relationship between women and men. If he masturbates, do the obligatory baths perfectly according to the procedure” (Informant 1).

Then, the researchers found a different answer from Mrs.DPS as informant 2, if her child does not have sexual health knowledge. Whereas, the responses from informants 3, 4,

5, and 6 are almost the same. Their children just have a little bit sexual health knowledge.

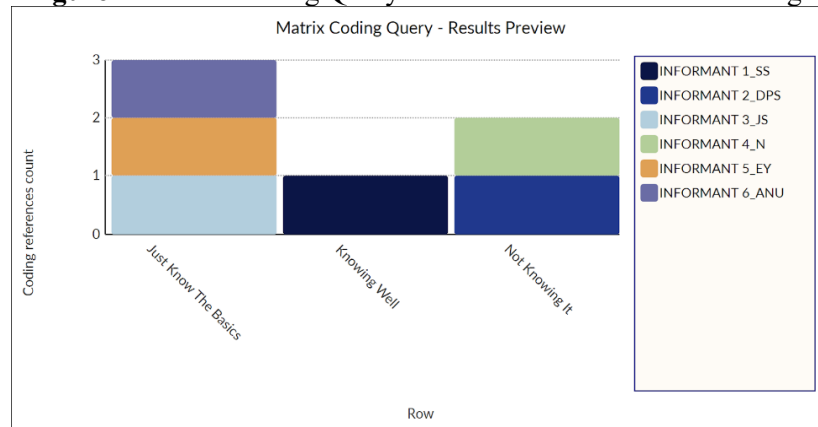
“Just knowing how to clean the genitals and also have to maintain behavior towards the opposite sex” (Informant 3).

“Do not have details of sexual health knowledge. Do not understand the results of having sex between men and women” (Informant 4).

"So far he only knows the basics about sexual health, has not reached sexual relations between men and women and what not to do before marriage" (Informant 5).

“Does not fully know about sexual health” (Informant 6).

**Figure 2. Matrix Coding Query Result - Sexual Health Knowledge**



Source: Data analysis by NVIVO 14 (2022)

Based on the results of the research above, it can be concluded that children with autism spectrum disorder don't fully have sexual health knowledge. From figure 3 above, only one, the child knows about sexual health well. Then, there are 3 children who just get the basics of sexual health knowledge, and 2 children don't know it. This is something that parents should pay full attention to their children regarding sexual health knowledge.

### *Sexual Health Education for Children and Adolescents with Autism Spectrum Disorder*

Based on the interviews, the research found the answers from 6 informants. Sexual health education for their children starts from puberty preparation, behavioral changes, and emotional changes. Informant 1, Mrs. SS said:

"Preparation for puberty is obtained from schools during formal education, for example, there is a puberty preparation seminar, etc. If

it's from family and parents, it just goes as it should". " ... when he entered puberty he wanted to be thin. Since there was already someone he liked, he tried to improve his appearance. He is on a strict diet and exercise". "Tantrums never at all. So the emotional changes are not too significant" (Informant 1).

The response from Mrs. DPA is different, it's because her child has not entered the puberty stage. There has been no change in emotion or behavior. But she has been prepared before her child's puberty, she said:

“The preparation is informed and communicated slowly every day” (Informant 2).

Informant 3, Mrs. JS makes preparations for her child's puberty, through sex education from an early age, so that her child is not surprised. For the behavioral and



emotional changes, there is no change in behavior, but there is ego. She said:

“...So that he knows the boundaries with the opposite sex when he hit puberty, and how to behave with the opposite sex”. “...sometimes he doesn't want to be blamed. But if he is told he will obey, he can be directed” (Informant 3).

The researcher found from informants 4, 5, and 6 that they make no preparations for their children's puberty. They allow the process of puberty experienced by their children as a natural process. But as parents, they still remind their children to keep their genitals clean. Furthermore, there is a change in behavior and emotions when their children enter puberty. Mrs.N as informant 4, said:

“There is a change in behavior and he becomes more sensitive when he's entering puberty, such as being more difficult to tell and taking more time to receive information”. “...becoming more emotional and easily distracted by little things when entering puberty” (Informant 4).

Then, informant 5, Mrs. EY, the tantrums her child significantly reduced. She said:

“There's a change in behavior to being more talkative and wanting more things as he enters puberty” (Informant 5).

Thereafter, informant 6, Mrs. ANU's child when her child enters puberty, there is a change in behavior and emotion, said:

“...namely an increase in the level of ego like wanting everything to be done quickly”. “...is becoming more talkative and he will comment on something that he feels is not appropriate” (Informant 6).

Based on the results of the research above, it can be concluded that for children with an autism spectrum disorder, to prepare them for puberty, all parents do not make special preparations. There is one child who gets preparation for puberty from his school, while the other children only get a little preparation from their parents. Furthermore, there is a change in behavior and emotions when children with autism spectrum disorder enter puberty.

### *Independence for Children and Adolescents with Autism Spectrum Disorder*

Based on the results of research from 6 informants, all of their children are already independent. The level of independence is quite good and high. Informant 1, Mrs. SS, whose child's level of independence is quite good, said:

“...even taught to start using public transportation while in junior high school. Even now it is possible to ride a vehicle but do not dare to go to the highway” (Informant 1).

Whereas informant 2 Mrs. DPS whose child can defecate, urinate, and bathe by himself, not depending on somebody else, said:

“...He can eat on his own, but he is fed often by his mother and he hasn't been released to feed by himself. He can wear clothes and choose his clothes” (Informant 2).

Then, informant 3, Mrs. JS' child, the level of independence for daily activities is good. She said:

“...When he has internships he has also begun to be left behind, because he cannot be accompanied by his parents. However, he hasn't dared to take public transportation himself” (Informant 3).

A similar answer is from informant 4, Mrs. N whose child is the same as other children, he is already independent.

“Parents do not need to take care of his own needs and the overall level of independence is high.” (Informant 4).

Informant 5, Mrs. EY whose child also has a high level of independence because he has been able to help his parents at home, said:

“...such as tidying clothes, cleaning and washing dishes. Besides that he has been able to eat, drink, bathe and dress” (Informant 5).

Lastly, informant 6, Mrs. ANU said that her child still needs help to do something even though he needs to be verbally instructed,

"... he has been able to bathe on his own despite the need to be verbally instructed, still needs help when he wants to prepare clothes, but has been able to choose his simple clothes. He knows how to prepare school supplies, although sometimes he still needs to be reminded." (Informant 6).

The researchers can conclude that children with autism spectrum disorder are already independent, even though the level of independence is high. They can fulfill their own daily needs, such as eating, bathing, defecating, urinating, preparing clothes, helping parents, and others. Thus, parents are greatly helped by the independence of their children.

### *Sexual Prohibition*

The researcher gets data from 6 informants about sexual prohibition. Children with autism spectrum disorder have sexual prohibitions that they get from their parents and also know about sexual prohibitions from their teachers.

Informant 1, Mrs. SS said her child gets a lot from his teacher and religious education,

"... who tells a lot about what is forbidden and what is allowed. He even understands that he can't date, if he likes it, it's better to just get married. Like how men and women should behave. That understanding was ingrained in him" (Informant 1).

Different from informant 2, Mrs. DPS's child, there is a sexual prohibition against touching the genitals. She said:

"Because he likes to unconsciously hold his genitals, especially when he is watching tv/youtube. I gave directions/prohibitions not to touch her genitals" (Informant 2).

"Then, he is not allowed to take a bath with his sister, ... Sometimes I like to forbid the two of them together" (Informant 2).

Furthermore, the answers from informants 3, 4, 5, and 6 were almost similar. A sexual prohibition comes from their mother that has prepared sex education earlier. Informant 3, Mrs. JS said:

"...So that he knows the boundaries with the opposite sex when he hit puberty, and how to behave with the opposite sex. The boundaries, he must have shame, body limits that can be touched and should not be touched by other people" (Informant 3).

"It is taught and forbidden to carelessly hold somebody else such as stroking and taking other people's hands, especially of the opposite sex" (Informant 4).

"The prohibition of touching the genitals of others, especially those of the opposite sex; not looking at other people for a long time because it is rude, must dress every time when he is out of the room and in public (not naked)" (Informant 5).

Based on the data above, it can be concluded that children with autism spectrum disorder have sexual prohibition given by their parents through sexual education. Sexual prohibition includes prohibiting them to touch genitals in public, not allowing them to bathe with siblings of the opposite sex, limiting and maintaining their behavior towards the opposite sex, and not letting other people touch parts of the body that shouldn't be touched.

### *Recommendations for Improved Sexual Health Education in Jakarta*

According to the responses of 6 informants to their recommendations to improve sexual health education, each of the informants conveyed several different opinions. Informant 1, Mrs. SS said there were no significant recommendations for sexual health education because her child already knew about sexual health thanks to a strong religious background. Mrs. EY as informant 5, said the same thing. It can help children to understand what is permissible and what is not permissible by deepening religious knowledge.

"So far there are no significant recommendations because he already knows about sexual health because his religious basis is very good" (Informant 1).

"Gaining a knowledge of religion to find out what is allowed and various prohibitions." (Informant 5).

Whereas informant 2, Mrs. DPS, said that two things can be recommended in improving sexual health education.

"... First, there is control from family and parents. Second, a lot of monitoring is carried out intensively by family or parents, because those who know their children well are certainly the closest family, not someone else." (Informant 2).

Informant 3, Mrs. JS gave a statement related to information on sexual health education messages in the form of seminars that could be attended by teachers, parents, and therapists.

"... Parents need to be fond of attending seminars on sex education because sex education is very important for children. The seminars are also important not only for teachers and therapists but also parents. There are still many people who consider close family a normal thing, even though it is not allowed." (Informant 3).

Meanwhile, informants 4 and 6, namely Mrs. N and Mrs. ANU, mentioned personal hygiene issues such as the cleanliness of outer and inner clothing as well as the cleanliness of genitals.

"Keeping his genitals clean, especially after masturbating and taking a bath is mandatory after having a wet dream." (Informant 4).

"Change his outer and inner clothes at least twice a day, especially if he has been doing outdoor activities to keep his own body clean. Bathing has also been taught to do at least twice a day and washing his hands and feet after school." (Informant 6).

Based on the various recommendations made by all of the informants, it can be concluded that several things can be recommended to improve sexual health education, such as increasing religious understanding, monitoring by family or parents, maintaining clean clothes and genitals, and attending sexual education seminars for parents, teachers, or therapists.

The researchers found that the sex knowledge of children with autism spectrum disorders is still limited to knowledge of differences between male and female sexes. They also know about the organs of the body from the top of the head to the toes, as well as the parts of the body that have a good touch and bad touch. Sexuality is a part of being human, but sexual health is often overlooked,

particularly in the case of people with disabilities. Individuals with disabilities are at a risk of sexual abuse and exploitation, undesired pregnancies, and sexually transmitted diseases due to a lack of sexual health knowledge (Ayuningtyas & Moekahar, 2022).

Meanwhile, sex education for children with autism spectrum disorders is mostly obtained from schools, and some are received from teachers, therapists, and parents at home. Then, children with autism spectrum disorder don't fully have sexual health knowledge. There is only one child who has good sexual health knowledge. 3 children just know the basics of sexual health knowledge, and 2 children don't know it. This is something that parents should pay full attention to their children regarding sexual health knowledge. Realmuto and Ruble (1999) suggest that children with special needs learn information about sex through everyday social experiences. The social experience in question is an explanation that comes from family or formal education (Nugroho, 2009).

Based on the findings of this research, to prepare for puberty, all parents of the children with an autism spectrum disorder do not make special preparations. There is one child who gets prepared for puberty from his school. Meanwhile, the other children receive only minimum preparations from their parents. Furthermore, when children with autism spectrum disorder reach puberty, their behavior and emotions change. They are already self-reliant, and their level of independence is high. They can take care of their own daily needs, such as eating, bathing, defecating, urinating, preparing clothes, assisting parents, and so on. As a result, parents benefit greatly from their children's independence. It is described as individuals who experience psychological development and identification patterns from children to adults as well as individuals who experience the transition from dependence to a relatively more independent state (Sarwono, 2011).

Children with autism spectrum disorder have sexual prohibition given by their parents through sexual education. Sexual prohibition includes prohibiting them to touch genitals in public, not allowing them to bathe with siblings of the opposite sex, limiting and maintaining their behavior towards the

opposite sex, and not letting other people touch parts of the body that shouldn't be touched.

According to Chandra (2018), entering adolescence, the desire for sexual urges in children will usually begin to appear, as well as in children with autism. Therefore, parents as role models must be able to guide and provide the right understanding to children, especially in sexual matters. Before entering their teens, parents of autistic children should have provided their children with sexual education (Chandra, 2018a).

In a conclusion, based on various recommendations from 6 informants, there are several things that parents, teachers, or therapists can do to improve sexual health education, such as improving religious understanding, monitoring children by family or parents, maintaining body hygiene, and trying to get more information about sexual education by joining seminars. The role of parents is very influential in the development of children with autism in dealing with their teenage years. With preparation, explanation, and guidance from parents, they will be better prepared to accept the changes that occur during puberty (Karningtyas et al., 2009).

### Conclusions

The findings of this research provide information about sexual knowledge education for children and adolescents with an autism spectrum disorder. Sexuality is a part of being human, but sexual health is often overlooked, particularly in the case of people with disabilities. Individuals with disabilities are at a risk of sexual abuse and exploitation, undesired pregnancies, and sexually transmitted diseases due to a lack of sexual health knowledge.

First, sexual knowledge education is important, it can be obtained from schools as well as from teachers, therapists, and parents at home. Second, there is currently a shortage of knowledge about sexual health among children and adolescents with autism spectrum disorders. Therefore, parents should pay full attention to their children's sexual health knowledge. Third, with regards to sexual health education, there is a change in behavior and emotions when they enter puberty. They have to keep their genitals clean and personal hygiene. Fourth, the level of independence is

high, so that they can fulfill their own daily needs and can help their parents at home.

Fifth, sexual prohibition is important to give children the knowhow to maintain their behavior towards the opposite sex and not let other people touch parts of the body that shouldn't be touched. Sixth, recommendations for improved sexual health education for parents who have children with autism spectrum disorder, can be attending sexual education seminars.

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