

## **Sexuality Education for Children and Youth with Autism at Rumah Autis Depok, Indonesia**

**Fitria Ayuningtyas<sup>1,\*</sup> and Fatmawati Moekahar<sup>2</sup>**

**<sup>1</sup>Communication Department, Faculty of Social and Political Sciences, Universitas Pembangunan Nasional Veteran Jakarta, Indonesia**

**<sup>2</sup>Communication Department, Faculty of Communication Sciences, Universitas Islam Riau, Indonesia**

**\*Corresponding author's e-mail: fitria.irwanto@upnvj.ac.id**

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### **Abstract**

Physical changes and sexual maturity become fundamental challenges that occur in it-no, except for youth with autism. According to the National Commission on Adolescent Sexual Health (NCASH), sexuality is a natural part of life. Autism is a developmental disorder of a person's nervous system, mainly caused by heredity factors. The research question: How was sexuality education for children and youth with autism conducted at Rumah Autis Depok? The research method used a qualitative method with a phenomenology approach. The research result was that an introduction to the human body to children and youth with autism is significant. Detail the human body parts so that children or youth with autism can recognize well which others should not touch body parts. Sexuality education for children and youth with autism is a shared responsibility. So it is undeniable that apart from parents, teachers and therapists have a big enough contribution to this education.

**Keywords:** Sexuality, Education, Autism, Children, Youth

### **Introduction**

Autism is undoubtedly one of the stages of natural development that occurs in humans and is something that cannot avoid. Physical changes and sexual maturity become fundamental challenges in it-no, except for youth with autism. According to the National Commission on Adolescent Sexual Health (NCASH), sexuality is a natural part of life. Sexuality includes 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 undoubtedly closely related to thoughts, feelings, behavior, and relationships (Nugroho, 2009).

Sex education is essential for all humans. Effective sex education should ideally begin informally at home. People's needs for sexuality education grow as they age. Sex education

should be developmentally appropriate and ongoing throughout a person's life. The goals of sex education are to provide basic information, teach skills required for sexual well-being, and promote positive attitudes toward sexuality (Cornelius et al., 1982; Boehning, 2006).

Autism is a developmental disorder of the nervous system primarily caused by genetic factors. Autism is a developmental disorder part of the autism spectrum disorders (ASD) and one of five disorders classified as Pervasive Development Disorder (PDD). Autism has no boundaries in terms of race, ethnicity, social status, family income, lifestyle, or education level, and it can affect any family and any child. Although the global incidence of autism is consistent, boys are substantially more likely than girls (Ayuningtyas et al., 2021; See, 2011).

Autism is not a mental disorder because it is a brain disorder that causes the brain not to function correctly, as evidenced by the behavior of children with autism. The most important thing to take away from previous research findings is that autism disorder is not caused by psychological factors, such as parents' unwillingness to have children while pregnant. Therefore, any deficiencies in these aspects can be attributed to a lack of understanding regarding sexuality information. We, as eastern people, often feel reluctant to talk about sexuality issues. Especially in youth with autism, who do require special treatment? Realmuto and Ruble (1999) suggested that youth 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, and this is important because it is based on research conducted by Ruble and Dalrymple (1993) on 100 youth with autism, where this study shows the prevalence of youth with autism who engage in inappropriate sexual activities, including touching private parts (65%), 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, education about sex education for youth with autism is essential (Astuti & Andanwert, 2016).

Expressing sexuality is part of the human experience, yet sexual health is often ignored regarding persons with disabilities. Individuals with disabilities are at risk of sexual abuse and exploitation, unwanted pregnancies, and sexually transmitted diseases. Additionally, many adolescents with disabilities lack the knowledge needed to develop a healthy sexual identity, increasing their vulnerability. Young people with disabilities are no different from other kids in their need to understand their bodies and relationships: they, too, need to understand how their bodies work and may have romantic longings and sexual interests (Treacy et al., 2018).

Refer to the explanation above, and the authors can conclude the research question: How was teachers' experiences for children and youth with autism to give sexuality education in the classroom at Rumah Autis Depok, Indonesia?

### **Literature review**

Children with autism will have communication societal inequalities interactions with other children because children with autism have three meaningful communication, social interaction, and behavioral disorders. Children with autism tend to be preoccupied on their

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own, so those around them sometimes misunderstand the disturbances they experience (Yuwono, 2012).

The history of the first emergence of the term autism for the first time was coined by Eugen Bleuler, a Swiss psychiatrist, in 1911. This terminology is used for juvenile people living with Schizophrenia then, in 1943, Dr. Leo Kanner described autism as infantile autism. His findings are based on the research results conducted 11 people children by Dr. Leo Kanner from 1938-1943. Dr. Leo Kanner explained that children with autism have very severe disorders in communication. Autism is a developmental disorder that affects several aspects of how children see the world and learn from their experiences (Yuwono, 2012). Current data indicate an increasing number of people diagnosed with autism worldwide. According to the latest data announced by The Center for Disease Control (CDC) in 2015. The prevalence of autism disorders in the United States it is 1:45. Prevalence of autism disorders in Asia, Europe, and Australia, North America is estimated at 1%. In Korea, about 2.6. The CDC also mentions that there are more boys (1:42) than girls (1:189) (Wijayanti, 2016). So far, no official data has been found in the Government of Indonesia, due to a national survey related to people with Autism in Indonesia. However, data officially published by the Association of Indonesian Pediatricians (IDAI) in 2013 showed that autism reached 2% of the total population in Indonesia. This number is also considered an iceberg phenomenon. On the other hand, the number of people with autism means the number is greater than the existing data but is not recorded correctly (Wijayanti, 2016).

According to the DSM IV (Diagnostic Statistical Manual, 1994), a child is diagnosed with autism when speech development is slow or non-existent, and there is no attempt to balance communication in other ways; if the child can talk, the speech is not for communication; frequently uses strange and repetitive language; children's play patterns are less varied, less imaginative, and less able to imitate. Christopher Sunu (2012) identifies several communication and language behavior indicators that may exist in children with autism to strengthen their communication characteristics. Flat facial expressions, no use of body language or gestures, rarely initiate communication, do not imitate actions or sounds, speak little or nothing, parrot words, speak with strange intonation, do not appear to understand words, and understand and use words correctly are among them (Ayuningtyas et al., 2020b; Yuwono, 2012).

“Young people with disabilities are no different from other kids in their need to understand their bodies and relationships: they, too, need to understand how their bodies work and may have romantic longings and sexual interests” (University of Michigan Health System-Your Child, 2010, p. 1). Individuals with disabilities and their families have a long history of fighting for social justice and civil rights to end exploitation, maltreatment, and injustice (Bruinius, 2006). This conflict resulted in social justice legislation that protects the rights of people with disabilities, particularly in employment and education (Americans with Disabilities Act, 1990; Gargiulo, 2015; Individuals with Disabilities Education Act, 2004); The Rehabilitation Act, 1973). As a result of this legislation, our society has seen significant

changes in the treatment, healthcare, and education of people with disabilities over the years (Treacy et al., 2018).

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 risk of sexual abuse and exploitation, unwanted pregnancies, and sexually transmitted diseases due to a lack of sexual health knowledge (Treacy et al., 2018).

### **Research methodology**

Many experts define qualitative research in different ways. In brief, qualitative research is interpretive (using interpretation) research that employs various methods to investigate the research problem (Mulyana, 2018). Qualitative research is a series of material interpretation practices that make the world visible. This method transforms the world into a collection of representations that include various field notes, interviews, documentation, and personal notes. Qualitative research entails taking a naturalistic interpretive approach to the world (Creswell, 2013).

The term phenomenology is derived from the word phenomenon, which comes from the Latin word *phaenesthai*, which means “to show oneself”. Therefore phenomenology can be interpreted as knowledge that appears in consciousness, the science to describe what people perceive, feel, and know in their current awareness and experience (Mulyana, 2018).

A researcher will use this method to present aspects of a qualitative approach, such as conceptual analysis and qualitative data analysis (Moustakas, 1994; Sobur & Mulyana, 2020). This research employs a qualitative approach with a phenomenological approach. Phenomenology has been described as a descriptive, interpretive, and exciting research approach because it seeks to capture the essence of an individual's or person's experience.

The empirical phenomenological approach involves returning to experience to obtain a comprehensive description that provides the basis for a reflective structural analysis that describes the essence of experience. This approach “seeks to reveal and explain behavioral phenomena as they manifest themselves in their perceived closeness” (Moustakas, 1994; Sobur & Mulyana, 2020).

At least, the method that underlies phenomenology includes four stages: (1) bracketing, namely the process of identifying by “postponing” any preconceived beliefs and opinions about the phenomenon being studied, (2) intuition, which occurs when a researcher remains open to associating meaning. The meaning of certain phenomena with the people who experience them, (3) analyzing, analysis involves processes such as coding, a categorization which makes experiences have significant meaning, and (4) describing, namely describing. At this stage, researchers begin to understand and define phenomena into phenomena (phenomena that become) (Sobur & Mulyana, 2020).

Habermas developed the concept of the life-world (*Lebenswelt*) to complement the concept of communicative action. The Theory of Communicative Action divides action into four types: teleological, normative, dramaturgical, and communicative (Sobur & Mulyana, 2020). In teleological action, actors consider specific goals, and to achieve them, appropriate

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and appropriate means are needed, namely decisions. A strategy model is needed to consider the success of the actor's actions and the anticipation of decisions that are added to the goals to be achieved.

In normative action, this action is not directed at the behavior of solitary actors (alone) but is more directed at social groups. In dramaturgical action, what is essential is not individuals or group members but the “participants” who act towards the general public or their “listeners”. In communicative action, refers to interacting with at least two people who can speak and act and form relationships, both verbally and non-verbally. Here, the actor understands the action situation, his plan of action, and the best course of action based on agreement. The basic concept in this action is interpretation. In interpretation, the discussion becomes the most critical place (Sobur & Mulyana, 2020).

This study uses a phenomenological approach that focuses on teachers' experiences for children and youth with autism to give sexuality education in the classroom at Rumah Autis Depok, Indonesia.

## **Result and discussion**

### **1. Autism spectrum disorder**

Children with autism will have communication societal inequalities interactions with other children because children with autism have three meaningful communication, social interaction, and behavioral disorders. Children with autism tend to be preoccupied on their own, so those around them sometimes misunderstand the disturbances they experience. Let us look at the communication patterns or characteristics of children with autism based on our previous understanding of communication (Yuwono, 2012).

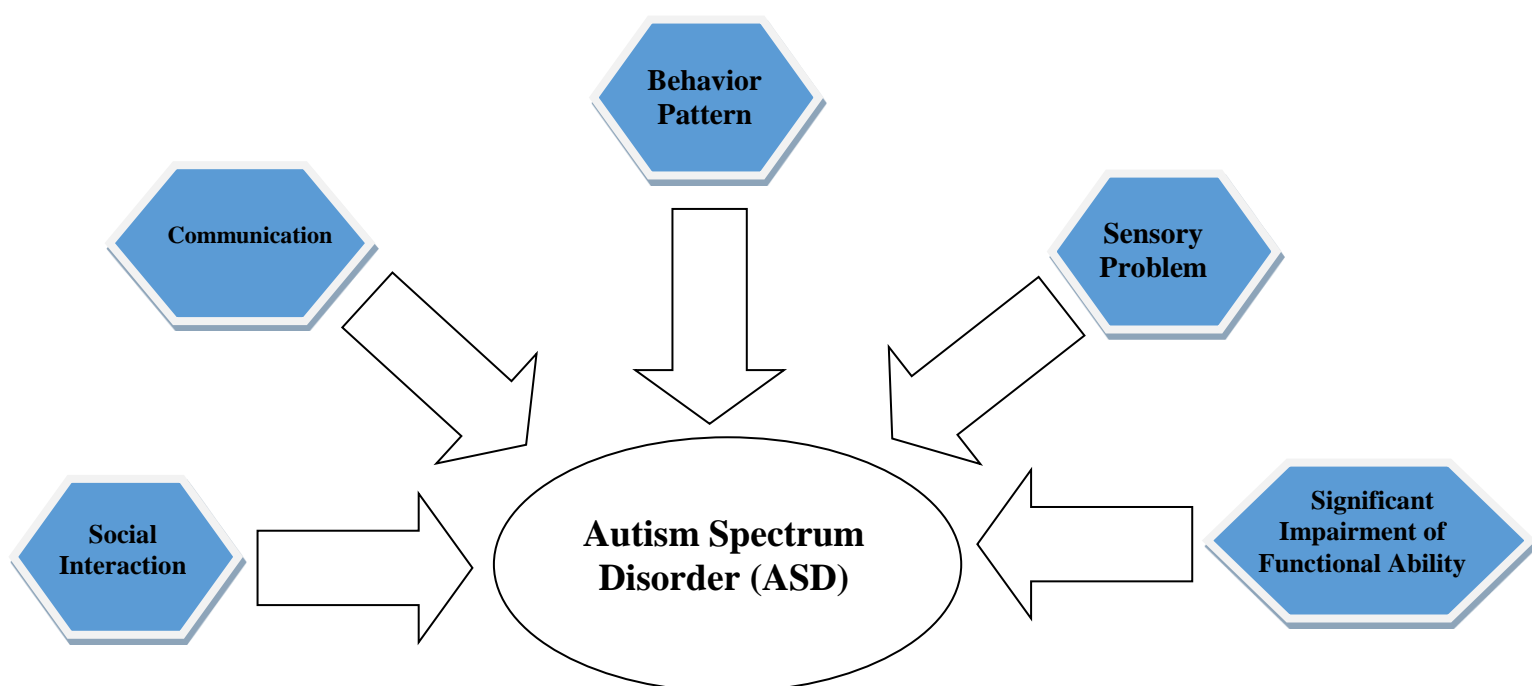
Founded Rumah Autis in 2004 aimed to meet the needs as a place of therapy and a school for children with autism and other IBK at affordable or even accessible costs. This Rumah Autis is under the Cahaya Keluarga Fitrah Foundation (CAGAR Foundation). The background of the presence of Rumah Autis is because there is much information obtained from parents about how difficult it is to finance and handle children with autism and other IBK. Moreover, the costs to be borne are costly even for the upper-middle class. The vision and mission of Rumah Autis are to become a solid humanitarian institution in building an independent and quality life for Specially Capable Persons (Rumah Autis, 2019).

Rumah Autis Depok is a very innovative branch, and the teachers are super creative in the teaching and learning process both inside and outside the classroom. Rumah Autis Depok carries out many activities that are highly appreciated. The location of Rumah Autis Depok is in Sukmajaya Raya, Depok, Indonesia.

In the United States, the International Institute for Democracy and Electoral Assistance (IDEA) is a federal law that governs special education services. Autism defines by IDEA as a significant disability that affects communication, both verbal and nonverbal communication, and social interactions, and is typically seen before the age of three years. The most apparent characteristics of autism are that the child engages in repetitive activities, resists changes in daily routines, and receives responses, particularly fine and gross sensory responses, in an

unusual manner. If a child's educational performance suffers primarily as a result of an emotional disorder, the term autism does not apply (United States Department of Education, 2000) (Powell & Powell, 2010).

So far, no clinical test that can directly diagnose autism has been discovered. The most appropriate diagnosis is made by carefully observing the child's behavior in communicating, acting, and paying attention to the child's developmental level. Autism manifests itself in a wide range of ways. A single observation cannot use to draw definitive conclusions about a child's abilities and behavior (Ayuningtyas et al., 2022; Gunadi, 2011).



**Figure 1** Types of disorders in autism spectrum disorder

**Source:** Ayuningtyas et al. (2020b)

Learning is an activity that requires an orderly and systematic arrangement because learning is related to what is to be achieved (objectives and competencies that must be mastered); this means that a learning process that will be implemented must begin with a careful planning process so that its implementation can be carried out effectively (Supriadie & Darmawan, 2012). But of course, the explanation about the learning is specifically for normal children because learning for children with autism is very different from learning for normal children.

The 2013 curriculum specifically for Special Schools (*SLB*), commonly referred to as *KURTILAS SLB*, was adopted as Rumah Autis' curriculum. However, when implementing the 2013 curriculum specifically for *SLB*, it was often hampered so that the daily implementation in schools is adjusted to the capacity and ability of each child. IEP or Individual Education

Program as a measuring tool in individual teaching as an evaluation material related to the behavior development of students with unique abilities. IEP is used as a reference in implementing this curriculum, but of course, it is adjusted to the capacity and ability of the child. Based on the interview results with LS, IEP was given when the child first joined Rumah Autis Depok, after initial observations were made. So this IEP is obtained based on these initial observations (Ayuningtyas et al., 2020a).

Initial observations made before the child joined Rumah Autis Depok included his/her ability in various things such as communication, social interaction, intelligence, emotional, behavior, and sensory problems, both fine and gross sensory, and other disorders. Essential observations are made to determine which class the child will enter in the end.

The presence of children with autism at Rumah Autis Depok encourages teachers to pay more attention (hence, per class is only limited to a maximum of 6 students accompanied by 2 teachers, as shown in Table 1), starting from providing special learning tailored to Individual Education Program (IEP), responding to behavioral disorders and emotions, as well as having to consult and coordinate with various related parties both inside and outside the classroom, especially with therapists and their parents. The biggest challenge that teachers at Rumah Autis Depok must face is that teachers are required to meet the learning success achievements for children with special abilities, especially children with autism, by running the IEP that has been previously set in each semester. Here, teachers must ensure that children always behave well when learning takes place, and teachers must quickly adapt to children with special abilities with various characteristics.

**Table 1** Profile of Informant(s) at Rumah Autis Depok

No	Name of Informant	Position	Age	Joined at Rumah Autis Depok
1	<b>SY</b>	Head of Branch	55	2015
2	<b>LS</b>	Head of Program and SKF A's Teacher	31	2012
3	<b>MG</b>	Transition's Teacher	26	2009
4	<b>IC</b>	SKF B's Teacher	24	2018
5	<b>NA</b>	SKF C's Teacher	34	2019

**Source:** Results of interviews with SY

## 2. Sexuality education for children and youth: What is needed?

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 risk of sexual abuse and exploitation, unwanted pregnancies, and sexually transmitted diseases due to a lack of sexual health knowledge (Treacy et al., 2018).

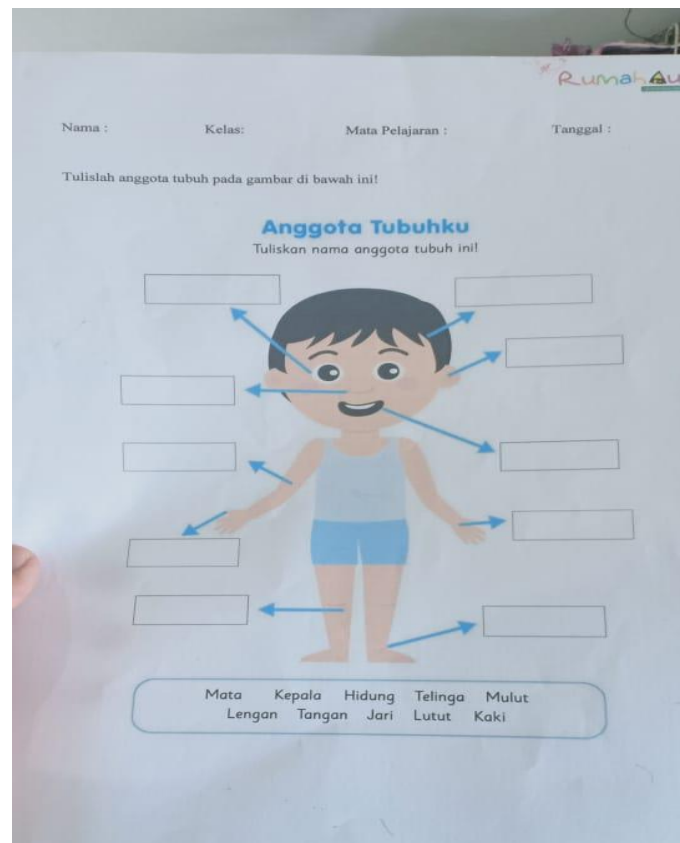
Sex education is a problem for general education students, and students with emotional and behavioral disorders, who are more likely to engage in risky behaviors such as drug and alcohol use, and sexual activity. “Premature sexual activity and parenthood are frequently accompanied by emotional or behavioral problems in teenagers and their children...” (Kauffman, 2005, p. 360). In fact, according to Kauffman, early sexual activity can also be a warning sign of an emotional and behavioral disorder, as it is also seen in those individuals already diagnosed with disorders. Delinquency, sexual activity, and substance abuse are often linked to individuals with emotional and behavioral disorders (Kauffman, 2005; Boehning, 2006).

According to Miller (2002), adolescent and young adult sexually transmitted disease (STD) cases account for more than two-thirds of all STD cases in the United States. This statistic is surprising, but it also emphasizes providing students with disabilities with an appropriate sex education curriculum. “Adolescents with psychological problems are at a particularly high risk of contracting Acquired Immunodeficiency Syndrome (AIDS) and other STDs through casual sexual encounters”, writes Kauffman (2005) (Boehning, 2006).

Sexuality education at Rumah Autis Depok is carried out almost every day and is included in the subjects, but specifically, it is in self-development lessons that focus on social independence. Sexuality education is critical, but it is still a taboo to discuss in everyday life, mainly because we live in Eastern culture. It’s the same as at Rumah Autis Depok, but the teacher continuously reminds us about the importance of ‘do not touch the body of others’. Especially for those of the opposite sex. Every individual must have limbs. As per Figure 2, the teacher introduces all body members that humans own. Such as hair, eyes, nose, cheeks, hands, fingers, feet, thighs, ears, and knees. The introduction of the human body is considered very important, especially for children, especially for children with autism. To facilitate the introduction of the human body, the teacher uses Picture Exchange Communication System, or PECS so that children with autism can easily understand it. Based on an in-depth interview with MG, PECS is a technique that combines in-depth knowledge of speech therapy with understanding communication where children who cannot interpret words or have a poor understanding to communicate using pictures.

Figure 2 shows an introduction to the human body to children and youth with autism. Figure 2 is to know the parts of the human body so that children or youth with autism can recognize well which others should not touch body parts.





**Figure 2** Introduction to human body

**Source:** Research documentation

### 3. The importance of the role of parents and teachers

Sexuality education for children and youth with autism is a shared responsibility. So it is undeniable that apart from parents, teachers and therapists have a big enough contribution to this education. Figure 3 shows sexuality education for youth with autism in the classroom.

Figure 3 is related to Figure 2. In every lesson, both inside and outside the classroom, the teacher continuously reminds us about the importance of 'do not touch the body of others', especially for those of the opposite sex.

The communication process about importance of the role of parents and teachers especially about sexuality education for children and youth of autism through communication strategies, communication barriers, dominant actors, and effective communication channels.



**Figure 3** Sexuality education for youth with autism in the classroom

**Source:** Research documentation

In addition to the role of teachers in schools, it turns out that the role of parents is very influential in the development of children with autism in dealing with their teenage years. With parents' preparation, explanation, and guidance, they will be better prepared to accept the changes that occur during puberty (Nugraheni & Tsaniyah, 2020). The role of parents for children with autism in their daily lives is significant. As with sex education, the role of parents, especially mothers of the youth with autism, is very dominant for children with autism. Brain disorders in children with autism generally cannot be cured (but can be overcome by intervention as early as possible through early, integrated and intensive therapy).

Occasionally when discussing sexuality education, children with autism do not understand it, which is one of the communication barriers. Therefore, the teacher usually uses PECS to make it easier for children with autism to understand what the teacher explains, both inside and outside the classroom as an effective communication channel.

### **The development of independence**

The family has a vital role in developing of independence because it is where individuals are raised, starting from children, and teenagers to adults. It can be said that the family, especially parents. This also applies to children with autism; parents have a very big role in building their independence. Parental assistance is the best way to increase discipline in children, especially in terms of independence. Independence is a condition in which individuals can do everything themselves (independently) without help-and help from others. One of the factors that can influence the occurrence of developing independence in children is parental care. Parenting positively or known as positive parenting, will provide a sense of security and comfort for children with autism. Children are taught to get used to doing everything themselves to get used to it when they grow up.

Therefore, with the help of teachers and therapists, parents must train and develop the independence of children with autism so that their achievements are not only academic. This

focus on training and developing the independence of children with autism aims to reduce their dependence on others in their daily routine activities because they will become adults one day. If it is not trained and taught as early as possible, it will not be accessible later, and will not get used to it (Ayuningtyas, 2020).

### **Conclusion**

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 risk of sexual abuse and exploitation, unwanted pregnancies, and sexually transmitted diseases due to a lack of sexual health knowledge. Sexuality education at Rumah Autis Depok is carried out almost every day and is included in the subjects, but specifically, it is in self-development lessons that focus on social independence. Sexuality education is an essential and critical education. However, it is still taboo to discuss in everyday life, mainly because we live in an influential eastern culture. It's the same as at Rumah Autis Depok. Detail the human body parts so that children or youth with autism can recognize well which others should not touch body parts. In every lesson, both inside and outside the classroom, the teacher continuously reminds us about the importance of "do not touch the body of others", especially for those of the opposite sex. To facilitate the introduction of the human body, the teacher uses Picture Exchange Communication System or PECS so that children with autism can easily understand it. Sexuality education for children and youth with autism is a shared responsibility. So, it is undeniable that apart from parents, teachers and therapists have a big enough contribution to this education.

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