Healthy Sexual Growth Phenomenon in Children with Mild Retardation and the Role of Parents in Providing Sex Education

Arbania Fitriani

Faculty of Psychology, Universitas Esa Unggul, Jl Arjuna Utara No. 9, Jakarta, Indonesia

Keywords: Retardation, Mild Retardation, Sex Education, Parents.

Abstract: This Study aims to investigates what is the role of parents with mild retardation children in efforts to provide sex education. The researcher also wants to see the health of sexual development as well as the problems that arise in connection with these aspects. The method used in this research is a qualitative method. The technique used in collecting data is interview and observation techniques. Data collection tools in this study were interview guidelines, observation sheets, and tape recorders. The number of subjects is 4 people, 3 of them are mothers and 1 subject is significant others/aunts. From the results of the study, it was found that all subjects had implemented sex education within the guidelines of the American Association of Pediatrics without them knowing it. The average subject applies democratic parenting and sometimes is overprotected. All subject children experienced healthy and normal sexual development. In the sexual aspect, the support needed for children who are female is greater than men. The party most involved in providing sex education is the mother. The factor that makes the subject willing to apply sex education is fear if the child experiences something unpleasant in the aspect of his sexuality.

1 INTRODUCTION

Basically, mentally retarded children can have characteristics that are not much different from normal individuals. Today, many experts use the term educated mentally retarded individuals who do not receive stimulation from the environment due to inadequate parenting or due to genetic factors (Hallahan & Kauffman, 1994). Education can be said as one form of stimulus that becomes an important and meaningful thing for mentally retarded persons. The provision of education for individuals with mental disabilities / mental retardation in Indonesia has a strong legal foundation since 1945 (Mangunsong & Dkk, 1998).

One form of education needed by mentally retarded persons who are able to educate is sex education. According to Grossman (Payne & Patton, 1981) mentally retarded people also have a sex drive, can fall in love, and desire to get married. What Grossman has mentioned is consistent with what is written in the American Academy of Pediatrics in the Sexually Education of Children and Adolescents with Developmental Disabilities (With & Policies, 2019), "persons with disabilities have similar curiosities, drives, and interests in their own bodies and in the bodies of the bodies of the bodies of others". This makes it clear that people with intellectual disabilities especially those who are able to educate apparently also have sexual needs as normal individuals. The existence of sexual needs automatically gives right birth to the need for sufficient information about fulfilling those needs in accordance with the values that can be accepted by the surrounding community.

Sex education during the formation of children is very important. This education needs to avoid the occurrence of hidden experiments that can cause guilt, shame, fear, or other difficulties in adulthood later (Marisa, 2019). The attitude of parents who are ashamed to provide sex education will make children afraid to ask. Whereas for mentally retarded people who are able to educate, lack of information is a dangerous condition because they might carry out sexual experiments so as to have a negative impact on the child. This sex education then becomes very important to be given to mentally retarded persons because as revealed by (Thompson & Grabowski, 1978), one of their characteristics is sexually promiscuous or having sexual relations with anyone (freesex). This is certainly not healthy for the individual.

108 Fitriani, A

Healthy Sexual Growth Phenomenon in Children with Mild Retardation and the Role of Parents in Providing Sex Education DOI: 10.5220/0009567401080120 In Proceedings of the 1st International Conference on Health (ICOH 2019), pages 108-120 ISBN: 978-989-758-454-1 Copyright © 2020 by SCITEPRESS – Science and Technology Publications, Lda. All rights reserved Van Dyke (Dyke, McBrien, & Sherbondy, 1995) states that as humans, individuals with disabilities have the same rights as normal individuals in expressing their sexual needs so as to get satisfaction. A similar thing was also expressed by Fegan & Rauch (Fegan & Rauch, 1993) that the right to express sexual needs in individuals with disabilities is a fundamental right. Like normal individuals, mentally retarded people also need to get sex education to avoid hidden experiments that can cause difficulties in the future.

Providing sex education to persons with intellectual disabilities - especially those who are capable of educating - is important for developing intellectual levels, helping to achieve healthy sexuality, preventing unwanted pregnancies and sexually transmitted diseases, and overcoming other problems relating to their sexual functions (Schwab, 1992). Cognitive and cultural limitations in the adaptive function of people with intellectual disabilities make them often experience sexual problems that are quite alarming. Van Dyke (Dyke et al., 1995) state that the cognitive and language barriers they experience can predispose to unwanted pregnancy, sexually transmitted diseases, and sexual exploitation.

Much research has been done relating to the existence of sexual exploitation and sexual abuse experienced by people with intellectual disabilities. Schwab (Schwab, 1992) states that:

Numerous expect in physical and sexual abuse acknowledge that mentally disabled individual is particularly vulnerable to sexual exploitation and abuse.

Ridington in The Disabled Women's Network of Canada (Nosek & Howland, 1998) examined 245 women with disabilities and found 40% of them were exploited, and 12% were 'molested'. Another study conducted by Sobsey & Doe (Nosek & Howland, 1998) found that of 166 cases of exploitation, 70% of them were individuals who experienced impairment in cognitive aspects. In a survey of 62 women by The Ontario Ministry of Community and Social Services (Nosek & Howland, 1998), it was found that the ratio between women with disabilities and normal women who experienced violence was 33% vs. 22%. While those who experience sexual abuse the comparison is 40% vs. 37%. It was also reported from the recorded history of sexual abuse, it was found that 25% of adolescent women with mental retardation experienced unhealthy sex treatment.

In addition to the possibility of experiencing sexual exploitation, persons with intellectual

disabilities who have cognitive limitations that have implications for understanding the sexual aspects they have are also very at risk for contracting sexually transmitted diseases. In a study conducted by Stone (Van Dyke et al 1995), it was found that individuals with disabilities have an increased risk of contracting sexually transmitted diseases (STDs) 50–90% of which are the risk of contracting gonorrhea. Jacobs et al (Jacobs & Et al, 1989) stated that the presence of special characteristics such as impairment in the intellectual aspect of people with intellectual disabilities causes the risk of becoming infected with the HIV virus to be as high as the normal population.

Another form that may be experienced by persons with intellectual disabilities as a result of their inheritance is child neglect. One form of child neglect according to Ann (Welfare & Gateway, 2019) is Educational neglect which is an error in providing education in special needs. One of those special needs is sex education.

Parents have the right to demand the best service for their children who experience obstacles in every aspect of a child's life, especially difficult aspects such as sexual aspects (Fegan & Rauch, 1993). Along with these rights, the obligation to provide education to children, which must be fulfilled by parents, where parents have the biggest responsibility in fulfilling children's education (Pohan, 2011). The education referred here is not only formal education but includes informal education which includes sex education. According to Brock & Jenning (Aini, 2001) parents are an element that is often missing in sex education. It has been mentioned before that underdeveloped children including mentally retarded people who are also able to educate also need sex education. The consequence of these needs is the emergence of demands that must be met by parents of mentally retarded persons.

It should be recognized that the provision of sex education to people with intellectual disabilities especially those who are capable of educating is still a matter of controversy. Talks about sex education are often rejected by parents of people with intellectual disabilities. Rejection is caused by several things as mentioned in the Journal of Pediatrics vol. 97, no.2 (1996). The first refusal was due to the parent's focus on the inability of the child rather than the child itself. Furthermore, it is caused by the fear that if the talk about sexuality will encourage unwanted sexual behavior and fear of pregnancy or exploitation. Another reason is the difficulty in deciding what to say and how. The final reason is the parents' uncertainty about the extent to which the child will understand what has been said.

During this time many misunderstandings about people with intellectual disabilities associated with efforts to provide education to them. One of the biggest misconceptions according to Thompson (Thompson & Grabowski, 1978)is "it is not appropriate and / or not worthwhile to attempt to educate and train the retarded resident". Mangunsong et al. (Mangunsong & Dkk, 1998)says that,

The consequence of a negative view of mentally retarded children is that they are not only prevented from doing what they can do but also to develop the skills they are actually able to do. ... Only because of his intelligence, mentally retarded children are distinguished, exploited and deprived.

This assumption that mental retardation is not suitable for education or training has a negative implication on the effort to provide information in the form of sex education to persons with intellectual disabilities.

Moving on from the aforementioned phenomena along with the lack of research on the importance of sex education for mentally retarded persons especially those who are capable of educating in Indonesia, the problem arises to be investigated. The problem to be investigated is how the role of mentally retarded children's parents can be educated in efforts to provide sex education. Another problem to be investigated is how the description of the sexual development aspects of mentally retarded people can be educated and the forms of support needed in order to achieve sexual development that is physically and psychologically healthy.

The subjects in this study were parents of mentally retarded children who are able to educate. However, the researcher will only interview one parent or significant others. The reason of the subject chosen because based on Thornburg's research (Aini, 2001) it was found that 17% of sex education comes from mothers and approximately 2% comes from fathers. In addition, according to Hassiotis and Heller et al. (Porter & McKenzie, 2000) mothers are more active in the care of children. Mothers are also those who pay more attention to emotional stress in the family in relation to child obstacles and also demands for care and other support needed by children with disabilities (Koegel et al. In Porter & McKenzie, 2000). And most importantly the mother who is often more involved in providing therapy or providing education to children with disabilities (Padeliadu in Porter & McKenzie, 2000). Another consideration is the stage of development of children in general, as seen in everyday life and in literature such as Papalia, Olds, & Feldman (Papalia, Olds, & Feldman, 2001),

it is the mother who follows the stages of the child's development more than the father. Therefore, researchers assume that the mother will be better in order to answer the research questions, especially for things that are still very sensitive, namely the aspects of child sexuality. The method used by researchers is a qualitative method using interviews and observation methods. The choice of this method was based on consideration of the sensitivity of the problem, namely the aspect of child sexuality which is still classified as a taboo in Indonesia (Pohan). In addition, by using qualitative methods it is expected that in-depth information can be explored even more broadly.

2 METHOD

2.1 Subject Research

Sample in this study is one of the parents of individuals with mild retardation or significant others. Characteristics of mentally retarded people who are classified as able to educate that can be known through a child's IQ that is 55-69 (Wechsler) or 55-68 (Stanford-Binet). Another characteristic that must be possessed by persons with intellectual disabilities to be subjected to this study is adolescents aged at least 15 years with the consideration that the most late age for mentally retarded children is experiencing puberty is 14 years (Elkins et al. In Van Dyke et al, 1995). While parents are one of the subjects' parents and mothers are preferred because based on research the mother is the biggest contributor in providing sex education to children so that the information obtained can be richer and more in-depth. But it is also possible to interview fathers or other significant others if it turns out that in the field it is difficult to meet these standards. Parents or significant others to be interviewed have a minimum high school education background. This limitation because the subject's education level will affect the subject's ability to understand and answer the researcher's questions.

2.2 Data Collection Technique

In general, a qualitative approach uses a purposive approach in which samples are not taken randomly but are instead chosen according to criteria (Poerwandari, 1998). Based on this fact, the researcher will use a purposive technique in selecting research subjects as the main technique, namely sampling based on a particular theory, or based on operational constructs (theory-based operational construct sampling). This respondent is chosen based on willingness and availability.

According to Sarantakos (in Poerwandari, 1998), sampling techniques in qualitative research generally display characteristics (1) directed not at large sample sizes, but in typical cases according to the specificity of the research problem; (2) not determined rigidly from the start, but can change both in terms of the number and characteristics of the sample, according to the conceptual characteristics developed in the study; and (3) it is not directed at representativeness (in the sense of a random number/event) but rather on a context match.

Furthermore, Patton (in Poerwandari 1998) said that a qualitative study could conduct in-depth research on a single case (n = 1) that were chosen purposively. Therefore, the number of subjects in this study was set at 4 (four) people, parents or significant others who are considered to understand the child's history of growth and development broadly, especially all matters relating to aspects of child sexuality. The reason for choosing the sample size of 4 people is because with this amount it is expected to be able to dig up all the information needed to answer this research question. It is also possible that the number of samples selected will increase or decrease according to the availability of subjects to be studied, as well as the developing conceptual understanding.

In qualitative research, there are several methods that can be used to collect data including interviewing techniques, observation, focus group discussions, analysis of documents or relics (film works, written works, or other works of art), or analysis of audiovisual material (Poerwandari, 1998). In this study, the author will use in-depth interviews with mentally retarded children's parents. The author will also use the method of observation of the subjects being interviewed as additional data to understand the answers given by the subject to the researcher's questions.

In this study, variations that will be used are interviews with standardized guidelines. The use of this variation is intended so that the discussion does not extend to things that are not relevant to the research objectives. In addition, this technique is expected to facilitate the classification of information. The researcher must also pay attention to the guidelines in the formulation of the interview. According to Smith et al. (in Poerwandari, 1998) questions must be neutral, avoiding using sophisticated, official, or too high terms, especially in interviewing individuals who do not represent the scientific or professional circles. Finally, researchers should also use open-ended questions.

2.3 Data Collection Tools

2.3.1 Interview Guidance

This interview guide is useful so that the interview does not widen from the predetermined themes. This interview guide is made based on the problem to be examined and adjusted to the existing theory. The following is a list of the questions in the interview guide.

2.3.2 Observation Sheet

This sheet will be used to record important things that happened during the interview situation and also during the research. What will be done by researcher in accordance with Banister et al (in Poerwandari, 1998), namely: (a) description of the context (including date, time, and place of observation); (b) a description of the characteristics of the people observed; (c) a description of who made the observation; (d) a description of the behavior of the person being observed; (e) the interim researcher's interpretation of the observed event; (f) consideration of alternative interpretations; (g) exploration of feelings and appreciation of the researcher towards the observed event.

2.3.3 Recorder Device

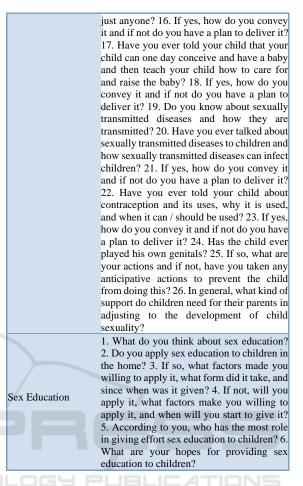
A recording device is used to record the dialogue that occurs during the interview process so that it can facilitate researchers in the processing. This recording device is in the form of a tape recorder that is used if the respondent agrees to use the device during the interview process.

2.4 Research Procedure

2.4.1 Research Preparation

a. Making research instruments. Before the research is carried out, the researcher first prepares a research instrument in the form of interview guidelines and observation guidelines. Interview guidelines are made based on the problems in this study and adjusted to the theory. While the observation guidelines are based on guidance in qualitative research theory. After getting feedback from the supervisor, the researchers then tested the research instruments that were made on the mothers of mentally retarded individuals. This trial aims to find out how far the instrument is able to dig up the data needed to answer the research problem.

Table 1: Interview Guidance.							
Dimension	Items						
Child Growth and Development	 What is the condition of the mother and the environment around the mother when she is pregnant? 2. What is the condition of the child while still in the womb? 3. What are the child's birth history and health? 4. What is the child's growth and development history before schooling? 5. What are the child's overall growth and development history? 6. What form of parenting is given to children to stimulate their growth and development? 7. Since when did you know that your child is different from a normal child? How did you react when you first found out and what were the next actions? 9. What kind of support does your child need for you in relation to the obstacles experienced by the child? 						
Factors Affecting Parenting	1. Are there different forms of parenting form before and after learning that the child is experiencing obstacles? 2. Are there different forms of parenting form in childhood and in adolescence? 3. Do siblings, childhood friends, neighbors, office friends (if you have one) give support to you in caring for children in order to help children to adjust to their environment? 4. In general what form of parenting do you apply to children (specifically for the subject)?						
	 What age does the child experience menstruation and what is the child's 						
Child Problems Related to the Aspects of Child Sexuality and the Roles of Parents	menstrual cycle? 2. How does the child adjust to the menstruation he experiences and how is your role in helping the child to adjust? 3. Does the child's secondary organs (eg breast growth, hair growth, etc.) develop normally? 4. How does the child adjust to the changes he/she experiences in the secondary organs and your role in helping the child to adjust? 5. Does the child ever date or have the intention of dating or have shown interest in the opposite sex? 6. If yes, what is your role in providing understanding to children about dating/attraction with the opposite sex?						



Another aim is to find out how far this instrument can be understood by the subject. After that, the researcher re-consulted the research instrument to the supervisor and then made improvements until it was ready to be used in field research.

b. Selection of research subjects. The subjects chosen in this study were subjects who had criteria previously determined by the researcher.

c. Contact Dr. Soemiarti Patmonodewo to ask permission to conduct research at the foundation that she manages namely SLB-C Swakarya.

d. Contacting the head of SLB-C Swakarya to ask for help to provide subjects in accordance with the criteria needed by researchers.

e. Contact one by one of the subjects who have been willing to participate in this study to make an interview appointment.

f. Conduct interviews at the home of each subject in accordance with the agreement that has been made.

2.4.2 Research Implementation

Interviews were carried out in some time. For the first subject, interviews were conducted three times,

namely on 17 March, 24 May and 9 June 2019. For the second subject, interviews were carried out twice, on 7 March and 9 June 2019. For the third subject, interviews were conducted twice, on March 17 and June 14, 2019. While for the fourth subject, interviews were conducted on April 3 and June 14, 2019. The interview process was carried out for approximately 45 minutes. Interviews were conducted using a tape recorder. When one side of the tape runs out the researcher hears the recording again to ensure that the dialogue is recorded properly. At the time of the interview, the child who was the focus of the study was not far from where the interview took place so that sometimes the researcher or subject interviewed asked the child something to confirm the answer given. After completing the interview process, the researcher then typed the results of the interview verbatim to be further analyzed.

2.4.3 Data Analysis Technique

In analyzing the data that has been obtained, the researcher tries to follow the steps in the analysis of data put forward by Patton (in Poerwandari, 2001: 85),

- 1. Change the raw data in the form of sound recordings into written form verbatim, through the transcription process of recorded discussions and interviews.
- 2. Read the data over and over to find out the topics that emerge and get an overview of the overall data.
- 3. Coding and grouping data on each subject into categories according to the research problem.
- 4. Arrange chronological data summaries. Analyzing data that has been coded and categorized. The analysis was carried out individually for each subject in the interview to find out their dynamics and experience.
- 5. Make a comparison of the images and analysis results and all subjects in the interview to get the general analysis results.
- 6. Trying to explain the results of the analysis based on the theory that has been compiled.

3 RESULT

3.1 Overview of Subject Demographics

The following table provides a general description of the personal data of the interviewees.

Toble	·	Subject		VOTUOW
I abie	<i>L</i> .	Subject	L.	verview.

	I	п	III	IV
Age	46	51	33	38
Religion	Moslem	Moslem	Christian	Moslem
Ethnic	Java	Java	Java	Betawi
Education	High School	Academy	High School	High School
Occupatio n	Housewive	Housewive	Housewive	Housewive
Age of children	22	20	18	19
Relation	Mother of Subject		Sister of subject	Mother c Subject

3.2 Subject I (S)

3.2.1 Form of Support

In general, S gets all the forms of support he needs. Subjects have also provided adequate stimulation to S. The greatest support was obtained from the parents, especially from the subjects themselves. In the aspect of emotional support, the subject tried to support S by paying attention in the form of empathy to the activities he was doing so S felt that he was noticed by his parents.

Through the emotional support obtained by S from the subject of the activity that S is doing, the subject indirectly has fostered in him the feeling of being able and valued. In addition to information support and appreciation, subjects also provide instrumental support both short-term such as S daily needs and long-term needs such as assets for the future of S.

The subject also always gives S direction, advice, and information about important things in life that need to know both personal and social.

Socially, S gets meaningful support from where S usually moves. The most significant support from the social environment S is praise for the activities that S is doing so that it indirectly fosters confidence and feelings of respect. In addition, according to the subject, S also gained a lot of understanding about the aspects of sexuality from the surrounding environment ie from the S study site.

Among all the support S received from both the subject and S social environment, the most significant support related to his inheritance was love and understanding. In addition, another support is assistance that the subjects provide in terms of meeting their personal needs.

For the aspect of sexuality, S needs support, especially in terms of understanding and assistance if S experiences problems in terms of sexuality such as the venereal disease that he is experiencing.

3.2.2 Sex Education

In general, aspects of sexuality of S develop like normal individuals. S secondary organs such as voice changes and secondary hairs grow normally. S is quite able to adapt well to the changes that he experiences in relation to changes in secondary organs even though he still needs some help from the subject.

Like men in general, S also has wet dreams. Based on information from the subject, S also knew the concept of shame related to aspects of sexuality since S was a child.

Regarding the desire to date and get married, according to the subject, S has not thought too much. However, subjects still hope that someday S will get married.

Until now, the subject and husband have not provided yet an understanding of the concept of marriage because they think S is still too small now. Subjects plan to provide an understanding of marriage after S is considered to be mature enough. The subject also sometimes gives advice or informs about norms in dating or marriage matters. Giving an understanding of aspects of marriage or dating is usually done by S parents when relaxed and as a joke.

For a life partner, S don't want a girlfriend or a wife, those who experience disabilities like him. S prefers a woman who is normal and can give full affection. Related to the sexual aspect, S encountered venereal disease.

For the issue of sexual harassment itself, subjects said that S had never experienced it. To prevent sexual harassment, the subject reminds S to always be careful and also monitor to whom and to where S went. Based on the subject's knowledge, S seems to understand the concepts of reproduction, parenting, sex and their effects if done freely. This understanding is obtained from every day's observations or from the subjects themselves. Usually the subject gives an understanding to S about sex when S asks.

Apart from his parents, S also gained an understanding of sexual relations from religious lectures he used to attend at the mosque and also from TV or from pictures in magazines. For sexually transmitted diseases, subjects often remind S of the dangers of the disease and also explain how it is transmitted. The subject gives understanding to S usually if it happens to be being broadcast on TV. S already understands the rules in the religion that he adheres to the Shari'a which he must follow if he releases sperm after he has masturbated or after a wet dream. The subject also often gives an understanding of the risks that would be experienced if he frequently masturbates.

An understanding of contraception has not been given to S because the subjects consider that S is still too small and that one day S will understand himself after marriage. In addition, the subject also considers that even if she explain to S, he will not understand due to the lack of intellectual function of S.

An understanding of contraception has not been given to S because the subjects consider that S is still too small and that one day S will understand himself after marriage. In addition, subjects also assume that even if explained S will not understand the lack of intellectual functions due to lack of S.

A form of sex education that is preferred by the subject to be given to S is the provision of understanding of hygiene care. As for other understanding such as understanding about dating, marriage, reproduction, care, sexually transmitted diseases, and contraceptives, subjects said that S will know for themselves over time. The most important role in providing sex education is the subject itself. Subject's expectation in implementing sex education is S does not fall into undesirable things and be a good person.

3.3 Subyek II (N)

3.3.1 Form of Support

With the disabilities that N has, the form of support needed by N from other parties, especially parents, is even greater. In general, subjects have provided enormous support in every phase of N's life, such as love, appreciation, material, or information support. The subject give more emotional support as part of parenting to N more intensive than normal children.

Even though N was different from other normal children, he was still involved in environmental activities. In addition, the subject's actions that do not differentiate between her and her sister can be a particular tribute to N.

As for instrumental support for N, subjects call therapists and teachers to the house. In addition, to give N independence, all N requests, for example, wanting to buy and choose their own clothes, are always fulfilled by both the subject and husband, although they are still accompanied. The subject also continues to support and assist in various daily needs of N.

From the subject's explanation, it was found that the form of support needed by N in childhood and adolescence had several differences. When N was a child, support of daily necessity had to be given intensely. Whereas when N was a teenager, the most needed support was greater in the emotional aspects and occasionally still had to be assisted in a number of daily needs.

In the form of providing information, the subject always provides information, advice, and main advice in terms of knowledge about aspects of sexuality N.

3.3.2 Sex Education

Aspects sexuality of N develops as teenagers generally. N secondary organs such as breasts or secondary hairs grow as other teenagers. In adapting to the physical changes that experienced by N, she must still be assisted by the subject especially in terms of cleaning care.

According to the subject's explanation, N had a menstruation at the age of 11 years with a regular cycle. There was a time when N menstrual cycle was interrupted but could be resolved quickly after being taken to the doctor and given hormone therapy and reflexology.

In adjusting to the changes experienced by N related to aspects of menstruation she experienced, the most important role came from the subject itself. The role of the subject, in this case, is not only in the form of giving an understanding of N but also in technical terms. In addition to the technical assistance, the subject also explained how N should behave in accordance with N's developmental tasks after N got a period.

Like teenage girls in general, N also once dated fellow SLB children. They related for about a year until then N partners decided to separate. The difference that was seen in the form of a dating relationship between N with normal teenagers that is they are never talked specifically about each other's feelings. In addition, according to the subject, N also expects to be able to date normal men like teenagers in general.

The subject also teaches and provides understanding to N about the norms in dating that are healthy and acceptable to the community. Although the subject is quite open in accepting N's desire to date, but sometimes the subject feels worried if N asks to date seriously with a normal man. Regarding marriage, N once expressed his desire to get married to the subject. But N did not want to accept the consequences of marriage such as living apart from parents because N is still dependent on her parents. For the concept of reproduction and parenting, subject also provides an understanding that can be understood by N. For the concept of sex and contraception, until now the subject has never discussed it to N despite having plans to convey things about it.

As for the provision of information about sexually transmitted diseases, the subject does not have plans to submit information regarding this matter. The reason for the subject to postpone the provision of information about the concept of sex, contraception, and sexually transmitted diseases because the subject considers N will not understand due to her disabilities.

Regarding cases of sexual harassment, the subject also had never conveyed this to N in an effort to protect N. Until now, the subject still feels quite safe by always asking someone to accompany N wherever N goes.

The problem with N is not from sexual harassment, but from venereal disease. According to the subject's explanation, one of the causes was N's dirty hands during N's masturbation. After suffering from the disease and based on a subject closely watch to N intimate activity, N finally stopped masturbating.

For the understanding of sex education itself, the subject understands it as an explanation of free sex. The party most involved in providing sex education to N at home is the subject itself.

The form of sex education that is mostly offered by subjects to be given to N is how to care for bodily hygiene with a very intense frequency. In addition, the subject will occasionally provide information regarding the ethics of courtship to N. Apart from the subject, N also obtained information about aspects of sexuality from TV and magazines and from his friends.

Subject implement sex education in the home because of concerns if their children have a pregnancy out of wedlock. The subjects' expectations in providing sex education to N is her daughter be able to know the norms about things that should not be done before N was married.

3.4 Subject III (D)

3.4.1 Form of Support

The biggest support that D got came from his family. As long as the mother is still alive, the mother plays the most role in providing support. But after his mother died, the role was taken over by the subject (sister of D). Among the forms of emotional support, appreciation, instrumental, direction, and social network support, the biggest form of support obtained by D is emotional support in the form of excessive affection.

In addition to emotional support, the direction that is often given both from parents and from the subject is very useful for D especially in the form of concepts relating to aspects of sexuality D. Oftenly, the subject consulted and asked for D's opinions. This indirectly became a separate appreciation for D, for the emergence of feeling respect by hearing D.'s opinions.

The instrumental support given to D is in the form of parents' efforts to choose the best school for D where he can adjust well in it. Neighbors or teachers often provide support for D. This becomes a form of support from social networks where is very useful for D especially in the aspect of adaptation.

According to the subject, the form of support that D needed when he was a child and when he was a teenager had some differences. When D was a child, support was most needed, especially in general matters. Meanwhile, when a teenager, the most needed support is mainly in aspects of sexuality. The subject said that the mother always advised the subject that in providing support to D required considerable patience because of the characteristics of D which is very slow.

3.4.2 Sex Education

Sexuality Growth and development of D shows normal even though the growth of secondary organs such as breast and secondary hair only grows at the age of 17 years. This age can be said to be late for the size of adolescents. According to the subject, D is quite familiar with the changes that occur in his physical form because all his sisters and D can understand through observation of his brother, especially when bathing.

D experiencing menstruation at the age of 13 years with a regular cycle. For the first time, D was shocked by the change that she experienced. This happens because previously there has been no notification either from the parent or from the subject of D about the possibility that D will experience menstruation when D is a teenager.

The subject said that in adjusting to the menstrual period experienced by D, the role for assisting D was taken by the mother. Mother not only helps in giving understanding to D until D can adjust but also helps D for the technical aspect. However, this assistance is not given forever because after the first two months, D has begun to be able to do everything herself even though some times she still assisted by mothers or subjects in certain matters.

Regarding the concepts of courtship and marriage, subjects said that D was able to understand clearly. However, until now D still does not have the desire to date or get married even though most of D's friends are men and have been recommended by the subjects. The reason of the subject encouraged D to date was because the subject was afraid that D did not want to date because of trauma after seeing the subject's being experience of broken-hearted. D's understanding of the concept of dating, norms in courtship, the concept of marriage and the consequences of marriage are mostly obtained from the subject and part of D.'s observation.

According to the subject, D also has a well understanding of the consequences of marriage, sex, reproductive concepts and childcare. As with the concepts of courtship and marriage, an understanding of this concept is also largely derived from the information of the mother and subject. The subject began to give an understanding of various aspects of sexuality to D since D sat in junior high school.

The subject said that D had been sexually abused once on the bus. To avoid this from happening again, the subject always gives an understanding of D about how to avoid it.

Until now, parents or subject have not provided an understanding of sexually transmitted diseases and contraceptives. This is because there has been no notification to D about it. Specifically for AIDS, subjects had told D about the dangers of the disease and how it could be transmitted. As for contraception, although it has not been submitted to D, there are plans to provide understanding to D about the concept later.

In providing sex education to D, the parties most involved in it are the mother and the subject. For subjects, sex education is understood as teaching how to have sex. Subject strongly agree on the application of sex education both at school and at home.

The most preferred form of sex education by subject for D is the provision of a correct understanding of how healthy sex should be to prevent unwanted pregnancy. The provision of material on these aspects is given at leisure. Apart from the subject, D also obtained the information needed about aspects of sexuality from TV. The subject's expectation in the application of sex education is so that D can understand the concept of marriage, sex, and the consequences of that relationship.

3.5 Subject IV (A)

3.5.1 Form of Support

In connection disabilities of A, he needs more support from both the subject and the environment. The greatest support obtained by A came from the subject. The form of emotional support given by subject to A is more in the form of attention and accompaniment to A.

Other forms of support provided by subjects to A are support in the form of providing information and supervision to A both in general and more specific terms such as information on aspects of sexuality. Another support given by the subject to A is instrumental support in the form of meeting basic and secondary needs. In this case, there is a significant difference between the form of support needed when A was a child and when he was a teenager until now. An also received social support from the environment, especially from the teacher.

3.5.2 Sex Education

In terms of growth and development aspects of sexuality, A does not find too many difficulties, especially for aspects of adjustment to changes that occur in him. Secondary organs grow like other normal individuals. After experiences physical changes, he recognizes the concept of shame.

In adjusting to changes in secondary organs that occur in A, the subject has a large role. The role is in the form of giving directions to A about what he should do and what he should not do regarding his age.

A also had a wet dream once. Once upon a time, subjects had found A had a porn book. This is an indication that A also has a desire and has a curiosity in the aspect of sexuality. The reaction of the subject who is not immediately angry with A after finding the pornographic book, because it will have a positive effect on fostering trust and openness of A to the subject.

A once dated a classmate in SLB. At that time, A did not admit that he was dating, so the subject did not feel the need to give direction regarding social norms in dating.

In addition, the subject also considers that A is able to judge for himself which are good and which are bad. However, the subject still has plans to inform A about the norm in courtship.

For the problem of marriage, until now A has no desire to go there. According to the subject, A was quite understanding about the concept through the explanation given by the subject regarding the concept of marriage and the consequences of marriage itself as well as about the concept of reproduction. In terms of sexual harassment, so far A has never experienced that. The subject often gives understanding and control A to prevent this situation from happening to A.

For other aspects are also not too problematic such as masturbation. According to the observations of subjects, A had never done that. But the subject also did not dare to guarantee because A was not fully open to the subject. Even though A has never seen A doing masturbation, the subject still gives A direction to not do that.

For an understanding of contraception and sex, the subject has been briefly explained. The subject has not planned to give a clear explanation about this for now, unless A has questions about it.

In terms of understanding of sexually transmitted diseases, the subject has given an understanding of A about the disease and how it is transmitted. The subject also always gives concrete examples of the material explained to A.

Regarding the notion of sex education, the subject understands it as a relationship between men and women which then leads to sex. The subject himself felt that she had implemented sex education even though she did not really agree with sex education based on what she understood.

The aspect of sex education that is most emphasized by the subject to be given to A is the aspect of hygiene care. In addition to getting information from the subject directly, A also gained a lot of understanding about aspects of sexuality from TV. Subject's expectation in applying sex education is A can understand the concept of sexuality correctly so that he does not explore himself which will negatively impact for A.

4 **DISCUSSION**

4.1 Form of Parenting

The form of parenting provided by the four subjects is almost similar. Average of them give attention, privilege, or give full affection to the subjects related to their disability. They tend to be more controlling and directing almost all children's activities. In general, they try to care for children democratically, such as the merging of positive things from permissive and authoritarian forms of care (Baumrind, 1997 in Aini, 2001). But among the subjects such as subjects II and IV, they sometimes tend to be authoritarian in certain matters such as in the case of letters not posted by subject II or restrictions on space as did subject IV.

There is no difference in the form of care between childhood and adolescence of subjects I and III, This is because they are not too demanding of various kinds of care. As for subjects II and IV, the provision of care between childhood and adolescence shows differences. This difference is more to the form of technically care when they had menstruation. For subject II, the difference that arises is when the child become a teenager, the care and support from the subject are not as great as when they were still a child who could not do everything alone. But the subjects still have to accompany them constantly after they become a teenager. In contrast to subject II, the difference in subject IV is that when the child of the subject is a teenager, the subject is even more stringent in looking after his child and his worries are also greater. The difference in parenting is related to the characteristics of mentally retarded special adolescents, including those who are able to educate such as the emergence of a desire to socialize broadly (Porter & McKenzie, 2000). Changes in the character of individuals with mild retardation during adolescence causes a different response from each subject.

4.2 Characteristics of Parents

In dealing with the reality of their son's disability, the four subjects reacted the same, which were shocked and sad. This is consistent with what was expressed by Porter & McKenzie (2000) that the reactions that often arise in the parents of individuals with mental retardation are sadness, loss, and chronic sorrow. For subjects II and IV, they were stressed but did not last long. For the subject, I, coping with stress was obtained from a religious approach. In subjects II and IV, all of them managed to overcome the sadness after seeing the fact that not only their children experienced the same thing, there were even many other children whose problems were even worse. As for subject III, parents successfully overcome it after getting advice from other children.

Except for subject III, all three subjects checked the truth of the claim given by the subject's teacher that their child was unable to attend public school to a psychologist. Among the four subjects, those who were overprotected against children were subjects II and IV. Cases in subjects II and IV correspond to what Jhonson stated (in Thompson & Grabowsky, 1978) that usually parents tend to be overprotected and will usually be stressed and shocked when they find out the fact that their child is not normal like others.

4.3 Form of Support

In general, four subjects provide support in all aspects as expressed by Sarafino (1998, in Aini 2001) such as emotional support, appreciation, instrumental, information and networking. The biggest support that is most needed and received by the 4 children of the subjects is emotional support where each subject, pays more attention to and privileges their child in connection with the child's disability. All subjects provide full understanding and patience in dealing with children so that children are greatly helped by this support.

In addition to the form of affection and attention, another support of providing information and direction from the subject is very helpful for children to be able to behave adequately. The provision of such information also includes matters regarding child sexuality. With this information, children are able to adapt to the changes that occur in themselves both at the personal level and at the social level.

For subjects who have male children (I and IV), the support that still needs to be provided in the aspect of sexuality is not as great as the support needed by subjects who have daughters (II and III). The support needed most for the aspect of sexuality is more in the form of providing correct information. For the child of the subject I the support that he needs from other parties, especially from the subject is greater than the child of subject III, both support for daily needs and support for technical aspects of sexuality. This is caused by a child's disability.

In subjects II and III, support is needed by them when they are menstruating. The support needed includes providing information about menstruation issues including maintaining hygiene and providing technical assistance to them. Compared to subject III, the daughter of subject II needs greater support during menstruation. This is most likely due to secondary impairment in the form of cerebral palsy which causes weak motor coordination. In addition, stricter subject attitudes in looking after children also contribute to the child's independence in terms of menstruation. Whereas for subject III, the greatest support that she needs related to menstruation is only needed in the first two months when she gets a period. Furthermore, they can do everything themselves even though sometimes they still need help from parents or from the subject.

Among the four subjects studied, the ones who needed the most support especially from the parents were children of subject II. Almost all the needs of children must still be assisted by the subject. While other subjects only need support in certain aspects. For children of subject I, even though almost all their needs still need support, but this is more due to the spoiled nature of the child and also because the child has a physical disability at hand.

4.4 Sex Education

According to Van Dyke et al (1995) issues regarding child, sexuality includes sexual development and behavior including hormonal and physical changes. Other issues include dating and marriage, reproduction and care, sexual relations and contraception, and sexually transmitted diseases.

In the aspect of sexuality, the four individuals with mental retardation can be said to be normal. The secondary organs of each individual develop like normal teenagers. This is consistent with what was expressed by Schwab (1992) that children with mental retardation have a series of physical and hormonal changes like other normal children. For subjects who have male children (I and IV), they experience wet dreams while for subjects who have female children (II and III) experience menstruation. This is an indication that within them there has been a series of hormonal changes and also shows that they are all fertile (Elkins et al, 1987 in Van Dyke et al, 1995).

Regarding the desire to date, there are children who have already dated their fellow at SLB as in children of subjects II and IV. Whereas the children of other subjects do not yet have the desire to date. For the child of the subject I, he does not want a mentally retarded couple either to be his girlfriend or wife. He prefers relationships with normal women. While the children of subject III, so far do not have the desire to date or get married. In the child of subject II, he already has a desire large enough to be able to get a partner like a normal teenager. This can be seen from his efforts to find a partner through teen magazines. Children have also expressed their desire to get married but do not want to bear one of the consequences of being separated from parents. Whereas in children of subject IV, even though they have dated once but the subjects have not considered about marriage yet.

In terms of providing an understanding of sexuality, the four subjects have provided their children with sufficiently clear information. The concept includes norms in courtship, marriage and its consequences, reproduction and parenting. Except for subject II, all three subjects have also provided information about sexual harassment and ways to protect themselves from the possibility of this occurring. Subject II did not provide this information because the subjects considered that the assistance he had done was sufficient to protect their children from possible sexual harassment.

Regarding the concept of sex, the four subjects have provided information to the child quite clearly. However, for contraception, all subjects have not provided adequate explanations except for subject IV, she once giving brief information because at that time the child had ask the subject. One reason that arises in accordance with what was revealed in the journal pediatrics vol.97 no.2 which states that parents are reluctant to discuss issues of sexuality, especially sex with children because of fears of parents if the discussion about sexuality will encourage the emergence of unwanted sexual behavior and fear of pregnancy or exploitation. In addition, parents also admit that there are difficulties in deciding what to say and how. Another reason is parents' uncertainty about the extent to which children will understand what has been conveyed. But there are also subjects like those in subjects I who assume that one day the subject will understand itself. Except for subject II, the most subject has explained several types of sexually transmitted diseases and how they are transmitted to children.

In general, subjects understand sex education as a lesson about sex between men and women. All subjects felt that they had applied sex education to the children. For subjects I, II, and III, all agreed with the provision of sex education at home. Whereas the subject IV did not really agree with sex education based on what he understood, such as teaching children to have sex by watching pornographic VCDs. In the aspect of child sexuality, the greatest role of the subject is in the form of providing information and direction on concepts relating to aspects of child sexuality. For subjects I, II, and IV, the most important role in sex education in the home is the mother's side. As for subject III, the role of sex education at the time the mother was still alive was held by the mother. But after the mother dies, the role is completely taken over by the subject (sister).

For subjects I, II, and IV, the most emphasized aspect of sex education is regarding aspects of body hygiene care. In contrast to other parties, the aspect of sex education most emphasized by subject III is a correct understanding of sex to prevent unwanted pregnancy before marriage. Regarding expectations to the provision of sex education, all subjects have almost the same expectation, children do not experience problems in aspects of sexuality that will have a negative impact on them.

REFERENCES

- Aini, I. N. (2001). Peran Orang Tua dalam Memberikan Pendidikan Seks pada Anak Usia Remaja. University of Indonesia.
- Dyke, D. Van, McBrien, D., & Sherbondy, A. (1995). Issues of sexuality in Down syndrome. *Down Syndrome Research and Practice*, 3(2), 65–69. https://doi.org/10.3104
- Fegan, L., & Rauch, A. (1993). Sexuality and People With Intellectual Disability (2nd ed.). Sidney: Maclennan+Petty.
- Hallahan, D. P., & Kauffman, J. M. (1994). Exceptional Children; Introduction to Special Education (6th ed). USA: Allyn & Bacon.
- Jacobs, R., & Et al. (1989). Developing an AIDS Prevention Education Program for Persons with Developmental Disabilities. *Mental Retardation*, 27(4), 233–237. Retrieved from
- https://www.ncbi.nlm.nih.gov/pubmed/2586313
- Mangunsong, F., & Dkk. (1998). *Psikologi dan Pendidikan Luar Biasa*. Depok: LPSP3 UI.
- Marisa. (2019, September). Nasib Malang Giyono 11 Anaknya Cacat Mental. *Majalah Kartini Online*. Retrieved from https://majalahkartini.co.id/?s=giyono
- Nosek, M. A., & Howland, C. A. (1998). Abuse and Women with Disabilities. Minnesota: MINCAVA.
- Papalia, D. E., Olds, S. W., & Feldman, R. D. (2001). *Human Development* (8th ed.). Boston: McGraw Hill.
- Payne, J. S., & Patton, J. R. (1981). *Mental Retardation*. Columbus: A Bell and Howel Company.
- Poerwandari, K. E. (1998). Pendekatan Kualitatif dalam Penelitian Psikologi. Jakarta: LPSPS3 F.Psikologi UI.
- Pohan, M. I. (2011). Seks dan Kehidupan Anak Sebuah Buku Pedoman untuk orang Tua. Jakarta: PT. Asri Media Pustaka.
- Porter, L., & McKenzie, S. (2000). Proffesional Collaboration with Parents of Children with Disabilities. Sidney: Maclennan+Petty.
- Schwab, W. (1992). Clinical Info: Sexuality in Down Syndrome. Wisconsin: SESA.
- Thompson, T., & Grabowski, J. (1978). Behavior Modification of the Mentally Retarded. London: Oxford University Press.
- Welfare, C., & Gateway, I. (2019). Definitions of Child Abuse and Neglect, 2010(March), 1–98.
- With, C., & Policies, D. (2019). American Academy OF Sexuality Education of Children and Disabilities Adolescents With Developmental, 97(2).