



# Sexual Behavior Problems in Adolescents with Intellectual Disabilities: A Systematic Review

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## Abstract

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**BACKGROUND:** Several studies conducted on adolescents with intellectual disabilities (ID) have reported various problems of sexual behavior that occurs in the group, including HIV-related risky sexual behavior and other health-related concerns.

**AIM:** This review aims to synthesize studies on the problems regarding sexual behavior in adolescents with ID to obtain data on the types of risky sexual behavior problems.

**MATERIALS AND METHODS:** Synthesis was conducted on nine studies of children aged 10–20 years old with intellectual disabilities as subjects who have no other psychiatric comorbidities and met the appraisal criteria based on the checklist for analytical cross-sectional studies of the Joanna Briggs Institute (JBI).

**RESULTS:** Several behaviors were found in the group of adolescents with ID. Masturbation is the type of solitary behavior that appears the most, besides other behaviors like touching genitals and getting naked in public places. Sexual intercourse is the most widely reported in the type of “involving other persons.” Sexual intercourse with more than 1 person without using contraception to protect against sexual transmitted disease (STD) is at risk for HIV infection or other infectious diseases.

**CONCLUSIONS:** The results of this review have indicated that adolescents with ID have sexual needs and experience sexual behavior problems similar to ordinary adolescents in general. They actually have a higher risk for having risky sexual behavior because they lack understanding of sexuality. These findings emphasize the need for sex education so that young people with disabilities can have healthy sexual behavior and a safe life.

## Introduction

The Association for the Treatment of Sexual Abusers (ATSA) Task Force on Children with Sexual Behavior Problems defines problematic sexual behavior as behavior that occurs in children whose ages are less than or equal to 12 years old in the form of behaviors involving their erogenous zones (e.g., genital, anus, buttocks, and breasts) that have the potential to hurt themselves or others [1]. However, Kellogg *et al.* [2] stated that children may experience sexual behavior problems at all age groups. Certain behaviors may appear not in accordance with age groups or may appear with higher frequency. In school-aged children, behavioral problems that emerge include viewing nude photos and pornographic images through various media, masturbation, sexually loaded virtual boyfriend or girlfriend game, and sexual attraction toward peers [3]. Furthermore, behaviors that emerge will be different in adolescence. In this period, the problems are more related to the biological and psychosexual changes, such as sexual intercourse at young age,

homosexuality, and prostitution. Sexual behavior problems in adolescents are generally behaviors that involve other people, but in certain conditions, it can be behaviors that only involve oneself [2]. An older study shown that behaviors that emerge the most are self-stimulating behavior and exhibitionism, while behavior that harms others is not common [4].

Like typically developing adolescents, adolescents with intellectual disabilities have the possibility of experiencing sexual behavior problems, but studies on sexual behavior problems in this group are still rarely conducted [3]. Some studies have reported various sexual behavior problems that occur in adolescents with intellectual disabilities, such as getting naked in public places, masturbation in public, and failure to understand privacy [5]. There are several causes related to the high risk for children with intellectual disabilities to experience sexual behavior problems. The first cause is a gap between cognitive-psychosocial development and physical-sexual maturity [5] so that they have difficulty in making decisions and understanding the consequences of their behavior [6]. Furthermore, sometimes, the people

around them tend to be inattentive, making them receive little information about sexual health. Some of them may have the opportunity to obtain formal education in school [6], but a study by Isler *et al.* [7] found that 51.7% of adolescents with intellectual disabilities do not receive sex education from professionals. A recent study conducted on young people with disabilities in Ethiopia found that most participants (62.2%) received sexual health information from radio and TV, rather than from professionals [8]. According to research, adolescents with intellectual disabilities also rarely talk about sexuality with their parents [7] and 77.9% of 426 adolescents with disabilities stated that they never talk about sexuality with their parents [8].

Another sexual behavior problem that occurs in adolescence is risky sexual behavior. According to the Centers for Disease Control and Prevention (CDC), risky sexual behavior is a behavior that causes certain health problems, such as human immunodeficiency virus (HIV) infection, sexually transmitted disease (STD), and unintended pregnancies. Surveillance conducted in the USA and Africa listed risky behaviors in adolescents, which are sexual intercourse, multiple sexual partners, not using condoms, not using contraceptives, and alcohol and drugs involvement in sexual intercourse [9], [10].

The issue of sexuality in individuals with intellectual disabilities has been reviewed with a focus on knowledge about sex [11] and sexual violence [12], [13]. Ellen *et al.* [14] conducted a review on sexual behavior but only on behavior related to HIV infection. Moreover, all those reviews were not specifically conducted on research with adolescent populations, so there has not been yet a comprehensive review on sexual behavior problems in adolescents with intellectual disabilities. This review provides an overview of the types of problematic and risky sexual behavior that often occurs in adolescents with intellectual disabilities.

Specifically, the research questions are:

- a. What are the types of sexual behavior problems in adolescents with intellectual disabilities?
- b. What are risky sexual behaviors shown by adolescents with intellectual disabilities?

## Materials and Methods

### Search strategy

The initial search was conducted through three databases, namely, MEDLINE, EBSCO, and ProQuest. The keywords used for search were “intellectual disability” and “sexual behavior.” Synonyms and equivalent words for intellectual disability used were “intellectual development disorder,” “mental retardation,” “idiocy,” “mental deficiency,” “learning

disability,” or “Down syndrome,” while synonyms used for sexual behavior were “sex behavior,” “sex behavior,” “sex activity,” or “sex orientation.” The studies used were those published in the past 30 years, or from 1988 to 2018. Hand searching was done to provide relevant study results, especially studies from Asian countries. The studies included in this review were studies written in English.

### Inclusion criteria

The inclusion criteria in this study were as follows: (1) Articles focusing on the population of adolescents aged 10–21 years old with intellectual disabilities; (2) articles describing sexual behavior problems; (3) articles of which participants were parents, teachers, and caregivers of adolescents with intellectual disabilities; and (4) articles that employed cross-sectional design.

### Exclusion criteria

Studies excluded were studies focusing on intellectual disabilities which were comorbid with other disabilities such as cerebral palsy, autism, and other developmental disorders.

### Search outcome

In the first phase, 3431 articles were obtained, where 34 of them were duplicated. In the next phase, titles and abstracts were selected so that 48 articles corresponding to the population and the concept of this review were obtained. Full-text reading was then conducted to exclude articles that did not meet the inclusion criteria and/or have established exclusion criteria. At this phase, 16 articles were included in the next phase, which was quality appraisal. This final phase obtained nine studies that met the criteria for synthesis. The selection phase is explained in detail using the PRISMA flow diagram [15], as shown in Figure 1.

### Quality appraisal

Two reviewers read 16 selected full texts and conducted critical appraisal using Joanna Briggs Institute (JBI) checklist for analytical cross-sectional studies [16]. The considerations used to determine the quality of articles that fit into the synthesis phase were research samples, research subjects, validity and reliability of measuring instruments, confounding factors, and statistical analysis used in the study.

### Data extraction and analysis

Data were extracted from nine studies that had been obtained in the previous phase. Data were

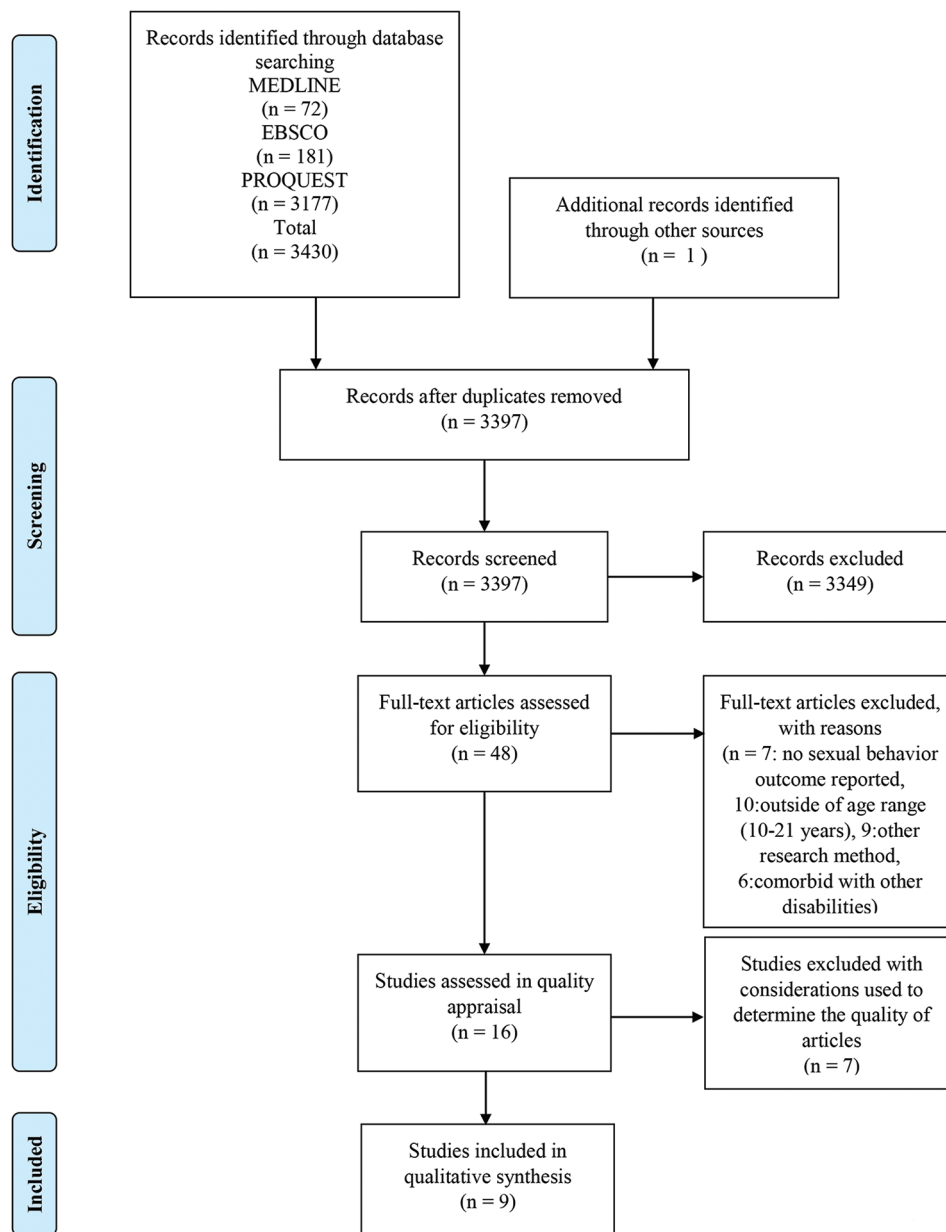


Figure 1: Flow diagram for this review

then grouped based on some information suggested by Peters *et al.* [17], namely: (1) Author (s), (2) year of publication, (3) source origin or country of origin, (4) aims or purpose, (5) study population and sample size, (6) how outcomes are measured, and (7) key findings that relate to the review of question studies.

The first analysis was conducted to divide the results into two major groups, namely, "solitary" sexual behavior and involving other person's sexual behavior [2]. Solitary sexual behavior is defined as sexual behavior involving oneself, such as masturbation and genital stimulation using objects or fingers that will cause children to be stressful when they are not allowed to do it. Sexual behavior involving other persons is behavior that involves or impacts others and may cause sexual harassment and genital-oral sexual contact. The second one was to identify risky sexual behavior problems found

in the studies. Risky sexual behavior problems in school-aged children or adolescents in this review refer to the definition used by the Centers for Disease Control and Prevention (CDC), which is a risky behavior that can cause certain health problems, such as HIV infection, sexually transmitted disease, and unintended pregnancies [9].

## Results

### *Descriptive characteristics of studies*

These nine selected studies were published between 1988 and 2018. There was one study conducted in Asia [18], two studies conducted in Africa [19], [20],

two studies conducted in the USA [21], [22], and four studies conducted in Europe [7], [22], [23]. The ages of adolescents with intellectual disabilities in this study varied from 13 to 21 years old and the number of adolescents in each study was different. There were three large-scale studies with participants more than or equal to 300 people [19], [22], [23]. Most studies were conducted on adolescents with mild and moderate intellectual disabilities and only two studies involved adolescents with severe intellectual disabilities [22]. Meanwhile, one study did not provide clear information about intelligence quotients of the children or the classification of intellectual disability [18]. Eight studies involved male and female children with intellectual disabilities, while one study did not provide clear information about subjects' sex [18].

Not all studies obtained data from interviews with children with intellectual disabilities. Two studies obtained data on child sexual behavior based on interviews with parents [7], [21]. In one study, teachers were the only source of information about sexual behavior in children [18]. Meanwhile, the study of Savage and Bouck [22] combined information from children, parents, and teachers. Six studies included in this review employed questionnaire to obtain information about sexual behavior in adolescents with intellectual disabilities. Research conducted by Aderemi *et al.* [19] employed images as a method to illustrate the questions in the questionnaire. Three other studies analyzed secondary data, therefore, they did not obtain information directly using a questionnaire [22], [23], [24]. A complete description of the characteristics of each study is shown in Table 1.

### Types of sexual behavior

In general, all studies included in this review were studies describing sexual behavior of adolescents with intellectual disabilities, but some studies have specific objectives on certain behavior such as HIV/AIDS risk behavior [19], [20] and risk behavior in

sexual violence [22], [24]. The main findings of the nine studies provide information that there are two studies which described solitary sexual behavior problems, six studies which described involving other persons behavior problems, and one study detailing both types of sexual behavior problems. Six studies were identified in the group of risky sexual behavior (Table 2).

### Solitary

Sexual behavior problems included in the solitary type are sexual behaviors shown by children without involving other persons. The study by Pueschel and Scola [21] found that 40% of parents who have sons with Down syndrome and 22% of parents who have daughters with Down syndrome saw their children masturbate. These parents argue that this behavior is actually acceptable, but if done in public places, they become embarrassed. Isler *et al.* [7] also conducted research on parents and found that 45% of parents were aware that their children masturbate. However, this study did not clearly state the percentage based on the sexes of the children. About 32% of parents stated that masturbation is normal if it is done in private.

Masturbation was also reported by 34.6% of teachers who were respondents to the study of Tsuda *et al.* [18]. However, touching genitals in public are behavior with the largest percentage based on teacher observation (60.8%). The study also identified removing pants in public places as another problem in the solitary sexual behavior.

### Involving other persons

Sexual intercourse was found mostly in the type of sexual behavior problems involving other persons. Research by Isler *et al.* [7] found that 3.3% of participants had experienced sexual intercourse. Dawood *et al.* [20] obtained higher results, which were 14%, either in the category of active sexual intercourse or having sexual

**Table 1: Characteristics of studies**

Author (s), year of publication	Country	Purpose	Study population				Participants
			n	ID level	Age range	Sex	
Pueschel and Scola, 1988 [21]	USA	Providing information on parental perceptions of sexual concerns of their children with Down's syndrome	36	Mild and moderate	13–20	Male and female	Parents
Dawood <i>et al.</i> , 2006 [20]	South Africa	Investigating the knowledge, attitudes, and sexual practices of adolescents with mild intellectual disability in relation to HIV/AIDS	90	Mild	14–16	Male and female	Adolescents with ID
Almond and Giles, 2008 [24]	United Kingdom	Investigating the similarities and differences between groups of perpetrator with learning disability and non-learning disability in respect of their perpetrator, victim, and abuse characteristics	51	Mild, moderate, and severe	14.78 (mean age)	Male and female	Adolescents with ID
Isler <i>et al.</i> , 2009 [7]	Turkey	Determining the knowledge, opinions, attitudes, and concerns of the parents regarding sexuality of their children with intellectual disabilities	40	Mild and moderate	15–21	Male and female	Parents
Isler <i>et al.</i> , 2009 [7]	Turkey	Investigating development, knowledge, opinions, and attitude regarding sexuality among adolescents with intellectual disability	40	Mild and moderate	15–21	Male and female	Adolescents with ID
Aderemi <i>et al.</i> , 2013 [19]	Nigeria	Investigating the level of HIV knowledge and sexual practices among low moderate intellectual disability (LMID) compared to non-disabled learner (NDL)	300	Mild and moderate	12–19	Male and female	Adolescents with ID
Savage and Bouck, 2017 [22]	USA	Determining level of engagement in risky behaviors and offending for adolescents with mild and moderate/severe intellectual disability	205,899	Mild, moderate, and severe	13–20	Male and female	Student/parent/teacher
Tsuda <i>et al.</i> , 2017 [18]	Indonesia	To evaluate the sex behaviors of children and adolescents with disabilities from selected special schools in Yogyakarta, Indonesia	57	Unclear	Adolescent	Unclear	Teacher
Baines <i>et al.</i> , 2018 [23]	UK	Analyze the sexual activity and sexual health among young people with mild/moderate intellectual disability	527	Mild and moderate	19–20	Male and female	Adolescents with ID



**Table 2: Summary of sexual behavior studies**

References	Measure type	Key findings	Behavior type	Risk of behavior
Pueschel and Scola, 1988 [21]	Questionnaire	Masturbation	Solitary	No
Dawood et al., 2006 [20]	Questionnaire	Sexually active with low condom use	Involving other person	Yes
Almond and Giles, 2008 [24]	The data are derived from extensive and detailed retrospective review of available case files	Abusive behavior	Involving other person	Yes
Isler et al., 2009 [7]	Questionnaire	Masturbation	Solitary	No
Isler et al., 2009 [7]	Questionnaire	Kissing and sexual intercourse	Involving other person	Yes
Aderemi et al., 2013 [19]	Questionnaire with pictorial card to illustrate questions	Sexual intercourse with inconsistent use of condom and multiple sexual partners	Involving other person	Yes
Savage and Bouck, 2017 [22]	Secondary data from National Longitudinal Transition Study-2 (NLTS2)	Sexually active	Involving other person	Yes
Tsuda et al., 2017	Questionnaire	Sexual behaviors in public area	Solitary, involving other person	No
Baines et al., 2018 [23]	Secondary analysis of data collected in Waves 1 to 7 of <i>Next Step</i> (an annual study that followed a cohort from early adolescence into adulthood)	Unsafe sexual intercourse, experience of STD, and high percentage of pregnancy	Involving other person	Yes

intercourse experiences. Two other studies obtained much higher results, which were 57.1% in the study by Baines et al. [23] and more than 60% in the study by Aderemi et al. [19]. Sexual activity is the highest risk behavior in adolescents with intellectual disabilities, compared to other high-risk behaviors, such as smoking, alcohol and drug abuse, physical aggression, and imprisonment [22].

Experience of sexual intercourse in adolescents with intellectual disabilities can be distinguished by sexes. Aderemi et al. [19] found that women had a higher percentage than men, even though the scores were not much different. However, the study by Baines et al. [23] obtained the opposite result, in which there were more male adolescents with intellectual disabilities who had experienced sexual intercourse.

There is a significant relationship between experience of sexual intercourse and level of intelligence. Bivariate analysis conducted by Aderemi et al. [19] found that the more severe the intellectual barrier is, the more the record of sexual intercourse. However, Savage and Bouck [22] obtained the opposite result, in which adolescents with mild intellectual disabilities had higher sexual activity than adolescents with moderate/severe disabilities. Adolescents with intellectual disabilities also have fewer records of sexual intercourse compared to their peers [23].

Eight other types of sexual behavior involving other people were reported by Almond and Giles [24], Isler et al. [7], and Tsuda et al. [18]. Almond and Giles [24] conducted research on adolescents with intellectual disabilities who were sexual violence perpetrators and reported sexual behaviors in the form of oral contact with genitals, anal penetration, exhibitionism, genital touching, breasts touching, and kissing. The experience of kissing was also reported by Isler et al. [7] and Tsuda et al. [18], but kissing is not reported as sexual violence. Teachers in the study of Tsuda et al. [18] mentioned two other behaviors, namely, talking to the opposite sex at close range and embracing the opposite sex, as visible sexual behaviors in adolescents with intellectual disabilities.

### **Sexual risk behavior**

In accordance with the data presented in the previous section, sexual intercourse is one of the sexual

behavior problems reported in the group of adolescents with intellectual disabilities (Table 3). The record of sexual intercourse was followed by other behaviors included in the category of risky sexual behavior, such as early sexual intercourse, sexual intercourse without condoms or other contraceptives, multiple sexual partners, and abortion.

In this review, sexual intercourse is categorized as “early” intercourse that was done at the age of <16 years old. The study by Dawood et al. [20] was conducted on adolescents aged 14–16 years old with intellectual disabilities, therefore, all children who have records of sexual intercourse in this study belong to the category of early sexual intercourse. Most adolescents (68.09.7%) who are sexually active in the study of Baines et al. [23] had sexual intercourse for the 1<sup>st</sup> time when they were <16 years old. A lower percentage, which was 19.24%, was reported by Aderemi et al. [19], while in this study, there was one child who had sexual intercourse at the age of 7 years old. Both studies have reported that boys had a higher percentage of sexual intercourse than girls. In addition, sexual violence was found to be one of the first causes of sexual intercourse at a very young age [19], [20].

Unsafe sex, or sexual intercourse without using condoms or contraception [23], was found in adolescents with intellectual disabilities who are sexually active. The study by Dawood et al. [20] found that only one in three adolescents used condoms when they have sexual contact. Two other studies stated that more than 70% have unsafe sex, with higher percentage in boys than in girls [19], [23].

One study reported that all adolescents with intellectual disabilities who are sexually active have records of multiple sexual partners [19]. Some of them even have sexual intercourse with more than 1 person. This study also found that compared to men, more women were in relations with more than 1 person in the past 6 months.

Another risk behavior found in this review is abortion. Baines et al. [23] found that female adolescents with intellectual disabilities have a greater risk of becoming pregnant than the non-disabled group. Some of them then had abortions, while others

**Table 3: Type of behavior problems based on others involvement**

Behavior	References	Percentage
Solitary		
Masturbating	Pueschel and Scola, 1988 [21] Isler <i>et al.</i> , 2009 [7] Tsuda <i>et al.</i> , 2017 [18]	31.5 (male 20.5, female 10.9) 45 34.6
Touching the sex organ in a public area	Tsuda <i>et al.</i> , 2017 [18]	60.8
Removal of underwear in a public area	Tsuda <i>et al.</i> , 2017 [18]	21.5
Involving other person		
Sexual intercourse	Dawood <i>et al.</i> , 2006 [20] Almond and Giles, 2008 [24] Isler <i>et al.</i> , 2009 [7] Aderemi <i>et al.</i> , 2013 [19] Baines <i>et al.</i> , 2018 [23]	14 22 3.3 62.2 (male 29.9, female 32.3) 57.1 (male 35.3, female 21.8)
Oral contact with genitals	Almond and Giles, 2008 [24]	8
Anal penetration	Almond and Giles, 2008 [24]	16
Exhibitionism	Almond and Giles, 2008 [24]	25
Touching genital	Almond and Giles, 2008 [24]	47
Touching breast	Almond and Giles, 2008 [24]	18
Kissing	Almond and Giles, 2008 [24] Isler <i>et al.</i> , 2009 [7] Tsuda <i>et al.</i> , 2017 [18]	22 30 49.2
Talking with someone of the opposite gender at a close distance	Tsuda <i>et al.</i> , 2017 [18]	39.2
Affectionate hugs with someone of the opposite gender	Tsuda <i>et al.</i> , 2017 [18]	30.8

continued with their pregnancy and had children at the age of less than 20 years old (Table 4).

**Table 4: Sexual risk behavior**

Behavior	References	Percentage (in sexually active persons)
Sexual intercourse before 16	Baines <i>et al.</i> , 2018 [23] Aderemi <i>et al.</i> , 2013 [19]	68.09 (male 42.85, female 25.24) 19.24% (male 12.65 female 7.59)
Sexual intercourse without precautions or contraception	Dawood <i>et al.</i> , 2006 [20] Baines <i>et al.</i> , 2018 [23] Aderemi <i>et al.</i> , 2013 [19]	31 73.09 (male 46.18, female 26.91) 78.47 (male 48.1, female 30.37)
Multiple sexual partners	Aderemi <i>et al.</i> , 2013 [19]	100 (male 48.1, female 51.9)
Abortion	Baines <i>et al.</i> , 2018 [23]	13

## Discussion

The findings of this review reinforce the opinion that adolescents with intellectual disabilities have a high risk of experiencing sexual behavior problems that emerge as a result of their developmental delay and the lack of information about sexuality from parents and teachers [25]. The findings of this research clearly demonstrate the needs for education and intervention for appropriate sexual behavior. The rights of adolescents with disabilities to receive sexual and reproductive health services are also clearly stated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [26]. The results of this review have clearly shown that this group of adolescents has sexual behavior problems which involve themselves or other people and some of these are behaviors that are at risk of HIV infection and other health problems.

Sexual intercourse is the most commonly exhibited behavior, either continuously or only once. There were two studies showing high percentage of more than 50% of subjects who had sexual intercourse [19], [23]. In the study of Aderemi *et al.* [19],

a higher percentage was found in adolescents with intellectual disabilities, compared to adolescents without disabilities, while in the other study, the opposite result was found. However, these results still show that adolescents with intellectual disabilities have the same sexual behaviors as ordinary adolescents.

The findings in this review demonstrate the dangers of adolescents having sexual intercourse before attaining the age of 16 years old, having sexual intercourse without using condom, and having multiple sexual partners. The conditions of emotional and cognitive development that is not equal to sexual development increase the risk of unsafe and inappropriate sexual intercourse. Early sexual activity becomes a special concern because when a disabled person has early sexual activity, their risk of having sexually transmitted infection within a 12-month period will be higher [10].

Some records of sexual intercourse reported in the study were sexual intercourses resulting from sexual violence. A number of studies conducted on individuals with intellectual disabilities have shown that the levels of sexual violence are varied from low to high [12], [27]. People with intellectual disabilities have a higher vulnerability to sexual violence because they lack understanding of appropriate sexual behavior and have difficulties in negotiating equal relationships and in reporting abuse [28]. On the other hand, people with intellectual disabilities also have the possibility to be reported as perpetrators of violence, as shown in the study of Almond and Giles [24]. This problem arises because it is difficult for them to communicate their sexuality and they do not have the ability to manifest sexuality in ethically acceptable ways, or in other words, they fail to understand complex social ethics and legal issues regarding sexual behavior and how to establish relationships [6].

While masturbation is sexual behavior that is not included in the risk behavior, still it needs to be a concern for both male and female adolescents with intellectual disabilities. The results of this review indicate that masturbation is the most common type of solitary behavior in children, based on the observation of parents and teachers. Masturbation, a rhythmic stimulation in the genital area, is a sexual behavior that appears in children at all age groups and is not categorized as a psychiatric disorder [29], [30]. Walsh [31] has noted that masturbation actually functions as a primary sexual expression for many people with intellectual disabilities. However, masturbating in public places, as reported by Tsuda *et al.* [18], is not a normative behavior because it is done by children whose ages are over 12 [29], therefore, prevention or treatment should be done as soon as possible. Furthermore, masturbation done by individuals with intellectual disabilities tends to be inappropriate because it causes genital injuries, disrupts daily activities, and causes stress to themselves and others [31].

## Limitations

There are several limitations that could be affected the quality of this study. Only three databases were used to find studies that match the specified keywords. In addition, the hand searching process was also limited to the studies that have been found by the author. Therefore, adding a database should be done to obtain the results of other studies on sexual behavior problems of adolescents with intellectual disabilities. Another limitation is the different of measurement type in each study that allowing different criteria of behavioral problems found in this study.

## Conclusions

This review identified that adolescents with intellectual disabilities experience various problems, both in behaviors involving themselves and others as well as in behaviors categorized as risk behavior. The results of this review indicate that adolescents with intellectual disabilities have the same problems as adolescents in general. Certain behaviors like masturbation in public places involve specific behavior problems that appear in the group of adolescents with intellectual disabilities. The high records of sexual intercourse have also shown that they have the same sexual needs as ordinary adolescents and even encounter a higher risk for having unhealthy sexual intercourse because they lack understanding of sexuality. These findings denote the need for sex education so that adolescents with disabilities can have healthy sexual behavior and a safe life. Therefore, further research is needed to formulate comprehensive sex education for adolescents with intellectual disabilities.

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