Mothers’ perceptions of sex education for adolescents with intellectual disabilities

A Systematic Literature Review

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Adolescents with Intellectual disabilities (ID) have the same sexual and physiological developments as typically developing adolescents, including the same sexual feeling and sexual needs. However, because of cognitive limitations and lack of self-care abilities, they have a higher risk of sexual assault than others. As all other youth they need sex education to prevent sexual exploitation and to learn how to protect themselves. Since parents often are the primary caregivers of adolescents with ID, and they are also the primary educators of adolescents’ sexual education, parents play a crucial role in the development of adolescents’ sexual behavior. It is vital to understand what parents’ perceptions on sex education are. In the past, there have been few studies on the perceptions of parents on sexual education for adolescents with ID. Therefore, this paper aims to explore their perceptions through a systematic literature review. A series of electronic databases were searched, and three studies were identified for the review based on inclusion criteria. Content analysis was used to synthesize the results of the included studies. Findings show that mothers want to provide appropriate sex education for their children, including how to protect themselves and education on inappropriate sexual behavior, and family planning is not included in sex education, and believed that school could be the best choice regarding on providing sex education. The study also found that mothers have barriers to providing sexual education, such as lack resources and supports, poor knowledge about the sexuality, lack of confidence and sexuality is a very private matter. But there are also facilitators, the important role and responsibility of the mothers in providing sex education in the family, and the open and honest way in which the mother communicates with her children about sexual issues. These findings will help teachers or practitioners to consider the situation of parents when developing sex education programmes for adolescents with ID.

Keywords: Intellectual disabilities parents’ perception sex education
**Abbreviations**

<table>
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<th>ID</th>
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ICD-10 The International Statistical Classification of Diseases and Related Health Problems 10th Revision
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Introduction

Adolescence is a period of transition and change, both physiologically and socially (Forbes & Dahl, 2010). One important area of change in this period is sexual development. During puberty, adolescents need to go through development of secondary sex characteristics, including increased genital and breast growth and increased levels of sex hormones, which leads to an upsurge of sexual interest (DeLamater & Friedrich, 2002). In addition to physical changes, psychology has begun to change. Adolescents become interested in romantic and sexual relationships (Furman et al., 1999).

In order for children to develop healthy sexual development during adolescence, most young people have the opportunity to receive sex education at school (Baams, Overbeek, Dubas, & van Aken, 2014; McDaniels & Fleming, 2016). However, not all children have access to sex education, and many young people with disabilities have not received sex education at school or at home (Isler, Beytut, Tas, & Conk, 2009).

The World Health Organization clearly states that persons with disabilities have the right to the same sexual health and sex education services as others (WHO, 2009). However, the reality is that it is easy to be reluctant and confused about sex education for adolescents with intellectual disabilities (ID) (McDaniels & Fleming, 2016). Due to cognitive limitations and lack of self-care ability, the prevailing stereotype is that individuals with ID are either asexual or too sexually promiscuous (Bazzo, Nota, Soresi, Ferrari, & Minnes, 2007; Christian, Stinson, & Dotson, 2001). Other research has shown that individuals with ID are more vulnerable to sexual assault than others (Swango-Wilson, 2009).

For Children with ID, during adolescence, their physiology become more mature, but the psychological development has not yet reached maturity (McClennen, 1988a; McDaniels & Fleming, 2016). They have to bear their own physiological and psychological imbalance, and lack of appropriate sexual knowledge, so they will produce much panic and anxiety. Sex education allows them to enjoy personal sexual satisfaction and protect themselves from sexual assault and inappropriate behaviour (Gürol, Polat, & Oran, 2014a). The committee on children with disabilities (1996) points out that the purpose of sex education for children with ID: to expect children to have satisfying adult relationships in the future and to be sexually attractive to their peers; children are able to protect the privacy of their bodies and to report sexual abuse to trusted adults; providing sexual knowledge to protect children from unplanned pregnancy and sexually transmitted diseases (CCD, 1996).
In sex education, the cooperation of parents, teachers and health care providers is extremely important (Isler, Beytut, et al., 2009). In school education, teachers are often given the responsibility and expectation to teach students sexual knowledge and sexual attitudes, but the place of teaching students sex education should not be limited to schools (Liu & Edwards, 2003). Considering the dependence of children with ID on their families and the amount of time spent with their parents, parents should play a crucial role in sex education in family education and provide support for their sexual education with the help of the school (Gürol et al., 2014a). Health care providers can also support sex education for children (Isler, Beytut, et al., 2009).

Most parents as shown by Cuskelly and Bryde (2004) have a positive attitude towards sex education for their children with ID and also recognizes their right to express their sexuality (Aunos & Feldman, 2002; Cuskelly & Bryde, 2004). In practice, parents’ over-protection of their children might reduce children access to proper information about sexual behavior (Evans, McGuire, Healy, & Carley, 2009).

For adolescents with ID, properly providing their understandable sex education is extremely important to their social well-being. Therefore, this study will examine the perception parents have on sex education for their children who have ID, along with results that will assist practitioners or teachers in considering the parents situation when establishing plans for teaching sex education with children with ID.

2 Background

In the background, relevant topics, definitions of terms and theoretical framework used in order to analyze findings are presented.

2.1 Intellectual disabilities

There has been considerable discussion about how to name and define intellectual disabilities, terms have included idiocy, mental deficiency, feeblemindedness, mental handicap and mental retardation (Brockley, 1999; Carulla et al., 2011; Goodey, 2005). In the current study the term intellectual disability will be used because according to International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), disability describes the interaction of a person’s health conditions and environmental factors leads to impairment of body function and structure, activity limitations and participation restrictions (WHO, 2007). The term “intellectual disability” reflects
the social-ecological conception of disability described by ICF-CY and AAIDD, therefore, increasingly, “intellectual disability” replaced “mental retardation” or other similar terms (Schalock, Luckasson, & Shogren, 2007).

*ICD-10 Version: 2016* defines intellectual disabilities (ID) as “A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.” (WHO, 2006). According to *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, ID is the impairment of intelligence and adaptive functioning limitations at stage of development in the conceptual, social and practical aspects. Among them, intelligence can be described as the ability in reasoning, problem solving, etc.; adaptive behavior refers to the normal functioning with a peer group in the community environment, such as communication, social participation, etc (APA, 2013). And this disability typically manifests before the age of 18 (AAIDD, 2010).

### 2.2 Parents’ perceptions

Perceptions represent a unique source of how to experience something, and it involves the way how to think and understand something (Demuth, 2013; McDonald, 2012). Synonyms in *Webster’s New World Roget’s A-z Thesaurus (1999)* include comprehension, understanding, apprehending, insight, knowledge, observation, discernment, perspicacity, sagacity, and other related terms are: attention, judgement, study, thought, attitude, opinion, plan, thought, viewpoint (Agnes & Laird, 1999). Constructivist theories assume that perception is the result of interaction between stimulus and internal hypotheses, expectations and individual knowledge, while the individual's motivations, and emotions play a crucial role (Demuth, 2013).

A study has shown that adolescents’ views on sexuality depend on social acceptance and the attitudes and opinions of family members (Tarkang, 2014; Van Rossem & Meekers, 2011). Families usually recognize that children with ID have the right to express the aspects of sexuality, however, in practice, parents’ over-protection of their children from social contact and access to sexual knowledge directly affects the sexual attitudes and behaviour of children with ID, children and adolescents with ID may not have access to adequate information about sexual behaviour, which may make them vulnerable to sexual abuse (Aunos & Feldman, 2002; Evans et al., 2009). Therefore, investigating parents’ perceptions on sex education means investigating how parents think about and understand sex education, which often influences adolescents’ views on sexual issues.
2.3 Sexual development of adolescents with ID

People with ID reach their sexual maturity later than their peers. (Kijak, 2011; McClennen, 1988b). Their first menstruation and wet dream are on average two years later than others, but after the first menstruation and wet dreams, they have the same sexual needs as their peers (Kijak, 2011).

Sexual development refers not only to the physical development of sex, but also to the psychological development of sex (Murphy & Young, 2005). Adolescents with ID cannot at all, or often do not (depending on their level of disability) understand physiological development, but they can still develop complex emotions, including fear or guilt (Isler, Tas, Beytut, & Conk, 2009). And their biological sexual arousal can also lead to masturbation as with all other youth (Murphy & Young, 2005). Naturally adolescents with ID need sex education as all other youths do, but adapted to their level of understanding in order to support a healthy sexual development (Aunos & Feldman, 2002).

2.4 Sex education

Sexuality not only includes sexual behavior, it also includes self-image, emotion, values, belief, and interpersonal relationship and so on (Koller, 2000). Therefore, sex education for adolescents is provided not only to give sexual knowledge, but also to teach how to build romantic relationships (Hayashi, Arakida, & Ohashi, 2011).

The Sexuality Information and Education Council of the United States (SIECUS) Guidelines for Comprehensive Sexuality Education shows that sex education helps youth to explore feelings, values and attitudes through the information they provide and to develop communication, decision-making, and critical thinking skills (SIECUS, 2004). Sex education is teaching and learning about cognition, emotion, physical and social aspects of sexuality to children and young people. It can involve sexual and reproductive health issues, including but not limited to: sexual and reproductive anatomy and physiology; puberty and menstruation; reproduction, contraception, pregnancy and childbirth; and sexually transmitted infections, including HIV and AIDS, while emphasizing the development of respectful social and sexual relationships (UNFPA, 2014).

2.5 The importance of providing sex education for adolescents with ID

Individuals with ID are at high risk of sexual assaults (Swango-Wilson, 2009). Also, caregivers overestimate the sexual knowledge of people with ID, making them vulnerable for sexual abuse as they have limited sexual understanding and knowledge about how to protect themselves.
Therefore, adolescents with ID need sex education to prevent sexual exploitation and to learn how to protect themselves (McConkey & Leavey, 2013).

Although, there are more and more sex education courses for people with ID (Kempton & Kahn, 1991). The Isler, Tas, Beyrut and Conk (2009) study of 60 adolescents with mild to moderate intellectual disabilities from Turkey found that 51.7 percent of the adolescents had no sex education and about 50 percent had never discussed sex issues with their parents, getting sexual knowledge from friends, the internet or the media, these sources provide a lot of misinformation (Isler, Tas, et al., 2009).

Some studies have demonstrated the importance of providing effective and appropriate sex education for persons with ID. One study from the United States, found that young adults with ID effectively increase their sexual knowledge by Positive Choices curriculum including relationships and self-awareness, maturation, the life cycle, sexual health and being strong, stay safe (Graff et al., 2018). Hayashi, Arakida, and Ohashi (2011) conducted sex education training involving social skills for 17 people with ID in Japan, the results showed that their social and gender skills were significant improvement (Hayashi et al., 2011).

### 2.6 Parental influence on adolescents with intellectual disability

Parents play a vital role in all adolescents life, so in adolescents with ID. Their involvement are vital in preparing adolescents for a life as adults. The development of sexual relationships and sexual behaviour for adolescents with ID is strongly influenced by social norms and the attitudes of parents and caregivers (Löfgren-Märtenson, 2004). Parental sex education and communication with adolescents about sexual issues may influence the decision-making process regarding sexual intercourse later in life (Angera, Brookins-Fisher, & Inungu, 2008). Research has shown that, in some families, the father’s failure to provide children with sex education reduces girls’ self-esteem and increases boys’ aggressiveness, which in turn affects the development of children's sexual behaviour, and mothers’ over-protection of their children on sexual issues leads to a sense of dependency and increases children's sexual vulnerability (McKenzie & Swartz, 2011).

Parents are generally concerned about the sexual issues of children with ID, and believe that their children are vulnerable to sexual abuse, but they rarely talk about sexual issues with children and help children develop healthy relationships (Howard - Barr, Rienzo, Pigg, & James, 2005). Rouvier, Campero, Walker and Caballero (2011) identified the capacity of parents and children to perceive risk, lack of accurate sexual knowledge, personal beliefs and social and cultural values as
important factors that influence communication between parents and their children for sexual issues (Rouvier, Campero, Walker, & Caballero, 2011). Ballan (2001) argues that the over-protection of children with ID by parents deprives them of their sexual rights and inhibits their sexual behaviour, thus making them less knowledgeable about dealing with sexual experiences and possibly more vulnerable to sexual abuse. In the United States, most parents expect schools to provide sex education programs to teach sex issues, because parents themselves have no practical strategies to help their children avoid sexual abuse (Gürol, Polat, & Oran, 2014b; Liu & Edwards, 2003).

Some argue for the importance of training parents and caregivers of persons with ID in sex education, which will help encourage parents to support sons or daughters in expressing sexuality safely in any way they choose (Gardiner & Braddon, 2009). Parents' views on sex education are important predictors of parents' implementation of sex education, and parents' attitude towards sex education and sexual behavior is more positive and can talk more about sexual issues with their children (Liu & Edwards, 2003). Therefore, it is vital to examine parents' perceptions of sex education.

2.7 Theoretical framework: Bronfenbrenner’s Bio-ecological system model

Bronfenbrenner’s Bio-ecological system model shows that human development occurs through the most recent processes, the increasingly complex interactions of people, things, and symbols in their immediate environment (Bronfenbrenner & Evans, 2000). Such a model can identify both the proximal processes that have a direct impact on the development of adolescents, and the distal processes that have a direct impact on the development of adolescents (Bronfenbrenner & Morris, 1998). The development of adolescents is the result of multiple environmental factors at different levels of influence and interaction.

The environment involves four interrelated systems. Bronfenbrenner defines the microsystem as the direct interaction of the developing individuals and environments in a direct setting, including family, school, peer, and workplace (Bronfenbrenner, 1977, 1994). In a microsystem, relations between persons are bi-directional influence, for example, a child's parents can be influenced by their own beliefs or behaviors, but children can also influence their parents’ beliefs and behaviors (Bronfenbrenner & Evans, 2000; Ryan, 2001). The mesosystem comprises connections and processes between two or more microsystems (e.g., school and home) containing the developing
person (Bronfenbrenner, 1977). And the exosystem consists of interactions and processes between two or more environments, at least one of the environments does not include a developing person, but in which events occur that affect the processes of the immediate environment containing the developing person (Bronfenbrenner, 1994). For example, the relationship between the parent’s jobs and parenting of the child, parent’s jobs does not directly affect the experience of the child, but parent’s jobs affects the interaction between the parents and the child. Finally, the macrosystem consists of the overarching pattern of microsystem, mesosystem, and exosystem that include cultural, subcultural, or other broader social contexts, which that can determine society, structures, and activities in the immediate system level (Bronfenbrenner, 1994). In the system, belief, knowledge, material resources, culture, lifestyles and life experiences ultimately affect the individual and its immediate environment in the microsystem (Bronfenbrenner, 1994).

In this context, the model assumes that parents’ perceptions of sex education are due to a complex interplay between characteristics of the individual and family and interactions within and among five nested systems: microsystem, mesosystem, ecosystem, macrosystem and chronosystem (Bronfenbrenner, 1977, 1994). Microsystems represent contexts in which parents are directly involved, such as their dynamic relationships between parents, children, family, and friends. Mesosystems represent the relationships among the members of child-centred microsystems. For example, interactions between parents and sex education providers. The exosystems indicate contexts in which parents are not directly involved, but which influences parents’ perceptions on sex education and indirect influences on their children’s development. The macrosystems represent social and cultural contexts and influences the perceptions of children's sex education in society. The bio-ecological system model is shown in Figure 1 (Vélez-Agosto, Soto-Crespo, Vizcarondo-Oppenheimer, Vega-Molina, & García Coll, 2017).

2.8 Rationale, Aim and Research Questions

People with ID have the same sexual psychological and physiological developments as typically developing adolescents, including the same sexual feelings and sexual needs (Kijak, 2011; McClennen, 1988b). However, because of cognitive limitations and lack of self-care ability, they have a higher risk of sexual assault than others (Bazzo et al., 2007; Swango-Wilson, 2009). So they need sex education to prevent sexual exploitation and to learn how to protect themselves (McConkey & Leavey, 2013).

Parents are important in the implementation of sex education. They can directly educate their children themselves, or they can indirectly block their children from participating in sex education (Fader Wilkenfeld & Ballan, 2011). They can also be a source of informal support, knowledge and advice (Angera et al., 2008; Liu & Edwards, 2003). Their perceptions and attitudes to sex education for their disabled children are therefore vitally important.
Therefore, this study aimed to explore parents' perception on sex education for adolescents with ID, rather than how to or why they provide sex education. The study would identify and synthesize research literature on parents' perception on sex education for adolescents with ID, and the results of the study would help teachers or practitioners to take into account the situation of parents when developing plans on sex education for adolescents with ID.

The aim of this systematic review is to examine parents’ perceptions of sex education for adolescents with intellectual disabilities. The PEO (Population, Exposure, Outcomes) framework was used to help design research questions (Butler, Hall, & Copnell, 2016). Table 1 shows the PEO framework.

<table>
<thead>
<tr>
<th>PEO</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>Population</td>
<td>Parents of children with ID</td>
</tr>
<tr>
<td>Exposure</td>
<td>Provide sex education to children with ID</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Any perceptions and/or barriers and facilitators</td>
</tr>
</tbody>
</table>

Based on the PEO, two research questions to be formulated in this study are as follows:

a) How do parents perceive sex education for their children with ID?

b) What are the perceived barriers and facilitators to provide sex education?

3 Method

This section describes the study design, search strategy, selection criteria, selection process, Data extraction, quality assessment and data analysis applied in this study.

3.1 Study design

A systematic review was conducted in this study. This design applies an explicit, reproducible methodology to identify relevant literatures that would fit the eligibility criteria to answer specific research questions (Moher et al., 2015)

3.2 Search strategy

The electronic literature search for this systematic review was conducted in October 2019 using the following databases: CINAHL, Pubmed, Web of sciences, PsycINFO and ERIC. These databases were chosen because they integrate information from the fields of social sciences, psychology, education and health, all of which are subjects relevant to the subject of this thesis.
A preliminary hand search of the literature was completed in order to identify the specific search terms. Search terms addressed the concepts of parents, perception, intellectual disabilities and sex education. Terms were combined with appropriate Boolean operators to help narrow the search to relevant research field. In databases, truncations (*) were used to broaden range of results. The databases searched, search terms used, and lateral searching measures are detailed in Table 2.

The reference lists of each of the articles that met the inclusion criteria were reviewed, if the title might be relevant to this study, the corresponding article will be searched and screened on abstract and in-text level. This was done to ensure that no related articles were missed.

### Table 2. Study search terms

<table>
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<tr>
<th>Concept</th>
<th>Search terms</th>
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<tbody>
<tr>
<td>Intellectual disabilities</td>
<td>Mental* retard*, intellectual disabilit*, learning disabilit*, developmental disabilit*, cognitive disabilit*, intellectual impairment, mental deficiency</td>
</tr>
<tr>
<td>Sex</td>
<td>Sex, sexual*, condom use, safe sex, birth control, contraception, family planning, homosexual*, gay, lesbian, bisexual*</td>
</tr>
<tr>
<td>Education</td>
<td>Educat*, intervention, curriculum, teaching, training, course, instruction, learning, class, therapy</td>
</tr>
</tbody>
</table>

The Boolean operator AND was used to contain the search terms it separates.

**OR** was used to connect more synonyms.

? Wildcard was used to replace any character in a search term.

* Truncations were used to broaden range of results.

### 3.3 Selection Criteria

The selection criteria are shown in Table 3. Only full-text articles published in peer-reviewed journals and written in English were included in this search, because that the quality of the study may more uncertain due to lack of peer review. And other forms of grey literature, book chapters, case studies, papers, reviews, and abstracts were excluded. The search was limited to articles published during or after 2009 to identify current relevant articles.

Qualitative studies were chosen to be included in the review. Because qualitative research methods are appropriate when researchers need to explore and gain insight into people's perceptions, motivations, attitudes, and experiences about a certain phenomenon (Creswell, 2018). Although
quantitative research methods can also capture people's attitudes and perceptions about a certain phenomenon by collecting accurate and objectively measured data, such as how many parents have a particular attitude or perception on sex education, but quantitative research emphasizes statistical information rather than individual perceptions (Campbell, 2014; McCusker & Gunaydin, 2014). Therefore, the subjective perceptions of parents on sex education can be described using qualitative research methods.

The participants of interest in this review were parents of adolescents with intellectual disabilities. The articles included in this review were restricted to those that included parents of adolescents with age of 10 to 19 years or where more than 50% participants’ children were aged between 10 to 19 years. The age limit was set to 19 years old, based on the WHO which identified adolescents as age range from 10 -19 years of age (WHO, 2019). Because during adolescence, their sexual psychology and physiology begin to develop, so they also begin to need sex education. Participants thus needed to be parents of children from birth to 10-19 years of age.

Considering the aim and research questions, studies that they explored parental perceptions about sex education in adolescents with ID, and/or barriers and facilitators to sex education, in any setting would be included.

To ensure that important information was not missed, the children's age range and sex education related concepts were purposefully kept broad during the initial search process. Further differentiation in age ranges and topics was completed manually during the screening process.

**Table 3 Inclusion and exclusion criteria**

| Population | Parents of adolescents with intellectual disabilities | Parents of adolescents with other disabilities |
| Outcomes | Adolescents between 10-19 years old | Children under the age of 19 years old |
| Study design | Studies where at least one of the primary aims is to identify parents’ perceptions (attitudes, opinions, views, behavior) towards sex education of their children | Studies focused on non-parents’ perceptions |
| Publication type | And/or barriers and facilitators to sex education, in any setting qualitative studies | Systematic reviews or literature reviews quantitative or mixed method |
| | Full-text articles published in peer-reviewed journals | Abstracts, book chapters, case studies, theses, reviews, and other grey literature |
| | Publication in English | Published in other languages |
3.4 Selection process

The selection process consisted of three steps, the first step was comprised of title and abstract screening, followed by a full text screening of selected articles. Finally, quality of the articles chosen articles was completed. A total of 3176 articles were found after the initial search in the five databases (CINAHL, ERIC, Pubmed, Web of science and PsycInfo). Removing a total of 789 non-peer review articles. In order to obtain the last decade of available research, limiting the publication date from the first of January 2009 to October 2019 decreased the number of results by 1058 (n=1329). By setting the search to only academic articles, 1177 articles were included. Additionally, setting the language of the publication to English, the number of articles was reduced to 1135. The 1135 articles which were then imported into an EndNote bibliographic database and following a process of electronic elimination of duplicates, this number was reduced to 862 records. The 862 articles were screened on title and abstract process, and the included articles were screen on full text process.

After screening through the titles and abstracts of 862 articles, a total of 5 articles were selected for full-text review. Full-text resulted in the selection of 3 articles, while scanning the reference list of selected articles to find relevant articles to ensure that no important information was left out. However, none of the articles were found to meet the criteria. Finally, 3 articles are selected for data extraction. Figure 2 shows a flow chart of the database search and article selection process.
Figure 2 Flowchart of selection process

Records identified through database searching
CINAHL (n=249)
ERIC (n=517)
PsycINFO (n=1063)
PubMed (n=873)
Web of science (n=474)

2314 excluded studies:
- Non-peer reviewed (n=789)
- Published before 2009 (n=1058)
- No journal articles (n=152)
- Written in other language (n=42)
- Duplicates (n=273)

Records reviewed for title and abstract (n=862)

857 exclude based on inclusion criteria
- Irrelevant
- Quantitative design
- Focus on sexual issues of children with disabilities
- Perceive sexual desire of individual with ID
- Caregivers’, nurses’ and social workers’ perceptions
- The reproductive problems of children with ID
- The causes of ID in children

Full-text articles assessed for eligibility (n=5)

Two articles excluded:
- Quantitative research was used
- Parents’ perception about sexuality not education

Final records included in systematic review (n=3)
3.4.1 Title/abstract screening
A checklist based on inclusion and exclusion criteria was used for title and abstract screening, as shown in Appendix A. During the title and abstract screening, the reviewer can choose “Yes”, “No”, or “?” in response to each item. If the answer to all items was “Yes”, then the article was included. “?” means unknown, the answer “?” was considered as “Yes” and would be followed up with a full text screening. This is to ensure that no relevant articles were missed, even though the title or abstract was unclear.

A total of 862 articles were subject to title and abstract screening. After screening these articles by checklist, 857 articles were excluded as they did not meet the inclusion criteria. For example, some of articles focused sexual issues of children with disabilities, and some articles related to how to perceive sexual desire of individuals with ID from caregivers', nurses' and social workers’ perspectives. Studies that focused on the reproductive problems of children with intellectual disabilities and the causes of individual disabilities in children were excluded, since the focus of this thesis is parents’ perceptions on sex education. In addition, studies such as focusing on parental perceptions of sexual behavior in children with ID and conducting quantitative and/or mixed studies were also excluded. Thus, the 5 articles were used for full text screening.

3.4.2 Full-text screening
A checklist was used for the full-text screening, as shown in Appendix B. The checklist was developed based on inclusion and exclusion criteria and included items with the option “Yes” or “No”. “Yes” means the article can be included in full-text screening.

In the full text screening, the remaining 5 articles were checked one more time to assess whether they met the inclusion and exclusion criteria. In this step, the qualitative design must be used in articles, thus 1 article was excluded (Pownall, Jahoda, & Hastings, 2012), one article related to parents’ perceptions about sexual behaviors for children with ID (O’Neill, Lima, Bowe, & Newall, 2016). The final selection for the review was therefore a total of 3 articles.

3.5 Quality assessment
To evaluate the quality of the articles, a quality assessment tool was created, as shown in Appendix C. The tool was adapted from the CASP Qualitative Checklist (CASP, 2018) and the Critical Review Form-Qualitative studies (Letts et al., 2007). Questions from the two quality assessment tools were combined into a more appropriate and complete quality assessment tool to address qualitative designs. In CASP, the answer to a question is "yes", "No", or "can't tell". In another
evaluation list, the answer is "yes" or "No". To make the quality assessment more clear, the quality assessment tool used in this study included the scoring options "yes" (2 points), "insufficient" (1 points) and “No” (0 points), with the total score ranging from 0 to 30. In addition, three quality categories as the total score range in order to identify the quality range of the article. When the quality score of an article is below 50% (<15 points), the article is given low quality. An article is given medium quality when it is equal to or between 50%-75% (15-22 points). An article is given high quality when it is equal to or above 75% (≥ 23 points).

The full version of the adapted tool consists of 15 items with five themes: (1) study design; (2) data collection; (3) data analysis; (4) findings; and (5) ethical considerations. The results of the quality assessment are shown in Appendix D. Two of the articles were assessed as high quality (Pownall, Jahoda, Hastings, & Kerr, 2011; Pryde & Jahoda, 2018), one article was assessed as medium quality (Gürol et al., 2014a).

Despite these quality ratings, due to the limited number of articles on parental perceptions of sex education, all selected studies have been applied to the results of this paper in order to provide the reader with better information about the quality of the research and reliability of results of research produced on this topic.

### 3.6 Data extraction

The data was extracted and analyzed through a protocol, see Appendix E. An extraction protocol can help researchers to integrate and analyze information from selected articles. The extraction criteria included the basic information, results and conclusions of the full text. It also included information related to sample size, sample group, age, sex, study design, data collection and analysis.

The protocol is filled out in an excel table, and the author can provide the whole data extraction content as needed. Appendix F outlined the data extraction for these articles.

### 3.7 Ethical consideration

The ethical issues of systematic reviews are different from those at original researches, because systematic review is a scientific method for searching and analyzing the literatures on a particular issue and synthesizing all the information (Vergnes, Marchal-Sixou, Nabet, Maret, & Hamel, 2010; Weingarten, Paul, & Leibovici, 2004). And the ethical consideration in the systematic reviews will help to improve the ethical and methodological quality of the field of study (Vergnes et al., 2010).
According to Weingarten et al. (2004), an ethical evaluation guide was developed in 2004 to assess ethical issues in systematic reviews (Vergnes et al., 2010). The guide considers ethical issues four aspects. The first is related to the object of the study, including financial support for the selected articles, conflicts of interest, and publication bias; the second is related to the responsibility of the researcher; the third concerns ethics relating to the rights of participants and the approval of the research ethics committee (Vergnes et al., 2010; Weingarten et al., 2004). However, selected articles are difficult to include all of the above ethical considerations, the authors of the systematic review should ensure a minimum level of evaluation, including informed consent of the participants and approval by the research ethics committee (Vergnes et al., 2010).

Therefore, based on the ethical evaluation guide, this study examines the ethical issues in the 3 articles in four aspects. All included articles were approved by the Ethics Committee and informed consent was given by the participants. Two of the articles stated that there was no conflict of interest in the content of their studies (Gürol et al., 2014a; Pryde & Jahoda, 2018). One article discussed the rights of participants, including including the confidentiality of participant status and interview content (Pryde & Jahoda, 2018).

Because topics related to sexual issues are considered sensitive, researchers and participants are susceptible to these studies, in order to protect the physical and mental health of all, consideration should be given to reducing potential risks in the research process (Shirmohammadi, Kohan, Shamsi-Gooshki, & Shahriari, 2018). All three articles chose environments where participants were familiar and felt safe. One of the studies was conducted in the participants' own home (Pownall et al., 2011), and another study selected the “Education Practice Centre and Job Training Centre” that participants had registered (Gürol et al., 2014a). In addition, a study was conducted in a private and undisturbed setting (Pryde & Jahoda, 2018). Both articles considered how to make participants feel safe and secure during the interview process (Pownall et al., 2011; Pryde & Jahoda, 2018). One study attempted to establish a rapport with participants before the interview to make them relaxed, and they could take a break at any time (Pryde & Jahoda, 2018). Another study used an experienced female researcher to interview participants about sexual issues, which helped to establish an effective conversation (Pownall et al., 2011).

### 3.8 Data analysis

Content analysis was used to this systematic review because the selected articles were qualitative studies (Elo & Kyngäs, 2008). Content analysis is a flexible text data analysis approach that codes
raw data into conceptually consistent categories (Cavanagh, 1997; Elo & Kyngäs, 2008; Hsieh & Shannon, 2005).

In qualitative studies, the selected unit for content analysis can be a symbol, a word a sentence, paragraph or a theme, among others (Polit & Beck, 2004; Robson, 1994). In the process of analyzing three articles included, the meaning unit must first be identified, then the text must be coded and numbered (Elo & Kyngäs, 2008). A total of 23 codes were created. When reading the code again, the different codes get compared for similarities and differences, and then separated by category and sub-category (Burnard, 1991; Downe-Wamboldt, 1992). Six categories emerged. Finally, the category’s potential content gets developed into a theme (Graneheim & Lundman, 2004).

4 Results

The research characteristics of the 3 included studies first were summarized, including study design, method, participants’ characteristics and major results (Appendix F). Secondly, the results related to research questions were shown

4.1 Description of included studies

These articles were published between 2011 and 2018. Two of the articles used semi structured interviews (Pownall et al., 2011; Pryde & Jahoda, 2018), and one article used a focus group approach (Gürol et al., 2014a).

Regarding the research questions raised in this study, all of the articles included in this study address parents’ perceptions on sex education for adolescents with ID. On the second research question, two articles describe the barriers and facilitators faced in providing sex education (Pownall et al., 2011; Pryde & Jahoda, 2018).

Two studies were carried out in Scotland (Pownall et al., 2011; Pryde & Jahoda, 2018), and the focus group in Turkey (Gürol et al., 2014a). Although the study was intended to focus on parental perceptions, all of the participants in the included articles were mothers, which reflect the fact that women as primary caregivers for children in most societies (Gürol et al., 2014a; Pownall et al., 2011; Pryde & Jahoda, 2018). Of these, seven mothers had daughters with ID and 15 mothers
had sons with ID. Most children with ID are between the ages of 12 and 19. Appendix F provides a more comprehensive description of the participants and main results of the included articles.

4.2 Findings

After the data were analyzed, 6 categories related to parents’ perceptions on sex education emerged: ‘Necessity of sex education’, ‘The content of sex education’, ‘Providers for sex education’, ‘Acceptance of mothers’ roles and responsibilities’, ‘Being open in communication of sexual issues’ and ‘Individual(mother) factors’. Three main themes includes ‘Perceived sex education’, ‘Facilitators to provide sex education’ and ‘Barriers to provide sex education’. Codes and categories are shown in Table 4.

Table 4 Codes and Categories

<table>
<thead>
<tr>
<th>Codes</th>
<th>Categories</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Requirement for providing sex education</td>
<td>Necessity of sex education</td>
<td>Perceived sex education</td>
</tr>
<tr>
<td>• Being needed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Developing relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Avoiding appropriately touch behaviors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Start mastrubating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Understanding social norms and rules</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Basic sexual knowledge</td>
<td>The content of sex education</td>
<td></td>
</tr>
<tr>
<td>• Protecting themselves</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Forbidding mastrubating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Safety sexual behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• School as useful information</td>
<td>Providers for sex education</td>
<td></td>
</tr>
<tr>
<td>• Providing sex education training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Good school nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• School as best choices</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Significant roles</td>
<td>Acceptance of mothers’ roles and responsibilities</td>
<td></td>
</tr>
<tr>
<td>• Taking responsibility</td>
<td>Facilitators to provide sex education</td>
<td></td>
</tr>
<tr>
<td>• Being honest</td>
<td>Being open in communication of sexual issues</td>
<td></td>
</tr>
<tr>
<td>• Being open</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Gain insight to children’s sexuality</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
• Lack of resources and support
• Lack of knowledge
• Difficulties in communication
• Lack of confidence

<table>
<thead>
<tr>
<th>Individual(mothers) factors</th>
<th>Barriers to provide sex education</th>
</tr>
</thead>
</table>

4.2.1 Perceived sex education

4.2.1.1 Necessity of sex education

In all of three articles, mothers reported that when their children with intellectual disabilities began their sexual development, they realized that their children needed sex education to help them understand the importance of social rules and norms (Gürol et al., 2014a; Pownall et al., 2011; Pryde & Jahoda, 2018). Mothers describe their education about inappropriate sexual behaviors (Gürol et al., 2014a; Pryde & Jahoda, 2018), and the need for developing relationships in their children (Pownall et al., 2011). Inappropriate sexual behaviour by children includes exposure to themselves in public (Gürol et al., 2014a), inappropriate touching of others (Gürol et al., 2014a), and masturbation in the family area of the home (Pryde & Jahoda, 2018). One participant stated that it was important to teach children not to be naked in front of others: “My son enters the room and walks around the house as naked after toilet or bathing, which makes me feel shame when we have guests.” (Gürol et al., 2014a). One mother reported that for children not to touch others inappropriately, they need to be provided with sex education:

A few days ago, as my son’s sexual organ was aroused he became scared and called me and them I caught him pulling down the pants of my neighbor’s little son and caressing his legs a few times. He occasionally watches me in secret when I have a bath. Therefore I am scared of leaving him alone with his sister at home. (Gürol et al., 2014a)

Mothers described some success in helping their sons learn about suitable places for masturbation (Pryde & Jahoda, 2018). One participant described that since the child started masturbating, she gradually aware of the need to teach her child where to masturbate and where should to take off clothes: “I can’t, I can’t get him not to do this, because it’s a natural thing, so […] at least I try to teach him not to do it in front of people, especially his brother.” (Pryde & Jahoda, 2018). Some participants described how they were very concerned about supporting their children with ID to develop relationships because their social networks were limited or non-existent and to help them move forward into adulthood (Pownall et al., 2011).

4.2.1.2 The content of sex education
Some participants stated that sex education should include behaviors that hurt children, how children protect themselves, and under what circumstances they should respond immediately, but that family planning should not be involved in sex education (Gürol et al., 2014a). Therefore, some mothers stated that children should learn the basic knowledge about sexuality, such as not exposing themselves in public, one of whom said: “I will be pleased if they teach my child to get dressed after going to the toilet or bathing and not to take off his clothes while with others.” (Gürol et al., 2014a). One mother believed that it is important to teach children not to masturbate in family areas at home: “It will be sufficient that they teach my child to go to the bathroom or his room when he gets stimulated and take a shower after ejaculation.” (Gürol et al., 2014a).

Some mothers indicated that they had discussed safety issues related to sexual behaviour with their children, but because of concerns about the vulnerability of children with ID, their dialogue would focus on appropriate and inappropriate sexual behaviour, one of whom said:

[…] you can see, if he’s watching something on the television and he gets aroused, you know, his hand will go down there, “Mark!,” his hands are right up again. So, and I’ll say if you feel that way you go to your room and you’ve got to try and control how you feel when you’re watching the television cause there’ll be other people about sometimes in the room as well and that if he wants to go to his room there’s nothing wrong with doing that. (Pownall et al., 2011).

Other participants believed that before discussing the content of sex education for children, it is necessary to have an in-depth understanding of children’s sexual behavior so that the content of sex education could be clear and unambiguous, one of whom described the experiences with her child: “I need to be more open and honest and there is no point beating about the bush with Chris. […] There is no embarrassment, I have to know exactly what he is doing, […]. Because ultimately, we are trying to keep him safe.” (Pryde & Jaboda, 2018).

4.2.1.3 Providers for sex education

In two articles, all participants identified schools as useful information sources for providing sex education (Gürol et al., 2014a; Pownall et al., 2011). Some participants argued that schools should offer sex education by organizing lectures or seminars, as well as sex education training for mothers (Gürol et al., 2014a; Pownall et al., 2011). One participant said:

I think the school nurse is good because, I think she will get up-to-date information. Parents are good because they like open the door for communication about it but I think obviously things move on, […]. I think if you’ve got up-to-date, like the school itself, the school nurse or groups that come in, I know there are other groups, you know,
about various aspects of sex education but I think anywhere that you can get information from is good but I think the school is because it’s neutral. (Pownall et al., 2011)

One participant explained why schools are the best way to provide sex education: “I cannot provide it and since everyone may not have the chance to go to a doctor or an institution, the school seems to be the best choice.” (Pownall et al., 2011). Some mothers stated that rather than shifting responsibility for sex education to schools, schools can provide more comprehensive information and avoid the embarrassment of mothers communicating with their children about sexual issues (Pownall et al., 2011).

4.2.2 Facilitators to provide sex education

4.2.2.1 Acceptance of mothers’ roles and responsibilities

Both articles also mentioned that mothers believed they played significant roles in providing information to their children about sexuality, because their children lack the same opportunities as their peers to learn about sexuality including socializing with peers (Pownall et al., 2011; Pryde & Jahoda, 2018). One mother stated: “I am used to a certain level of intimacy in terms of personal care, and I am used to that and it’s just an extension of that.” (Pryde & Jahoda, 2018).

Some mothers perceived that sex education in schools makes it difficult for children to understand sexuality, so they take responsibility for sex education (Pownall et al., 2011). One mother noted:

I mean they get taught it in school but it’s not, it wasn’t frequently enough I think for it to sink in with Andrea so I would constantly, for a good while, drain it up you know, not that we must sit down and chat about it but any opportunity that there might be a link into it we would chat about it. (Pownall et al., 2011)

4.2.2.2 Being open in communication of sexual issues

The Scotties ones, mothers believe in being open and honest when communicating with their children about sexual issues (Pownall et al., 2011; Pryde & Jahoda, 2018). Mothers generally want to be able to understand their children's sexual behavior in order to better protect their children (Pryde & Jahoda, 2018). Mothers also hope that when their children ask about sexuality, they will not hesitate to tell them, as long as they know this knowledge (Pownall et al., 2011). One the mother said:

I think if they asked anything then I would try as best as I can, I probably wouldn’t broach the subject but if they asked I would maybe…As long as I could say it, as long as I knew what I was talking about…I would have to actually know what they were talking about first…And as I say I am, I am still quite naive…(Pownall et al., 2011).

4.2.3 Barriers to provide sex education

4.2.3.1 Individual (mother) factors
The Scotties ones, mothers reported what they thought were barriers to providing sex education to their children (Pownall et al., 2011; Pryde & Jahoda, 2018). Mothers believe that their children need all kinds of resources and support, but they lack resources and supports targeted at sex education (Pownall et al., 2011; Pryde & Jahoda, 2018). Mothers feel that they are not provided with adequate resources to meet their children's needs (Pryde & Jahoda, 2018). One participant stated: “I am surprised to learn that resources aren’t just there, it’s something I am quite surprised about – it seems to be the one area of development that is brushed over a lot.” (Pryde & Jahoda, 2018) Some participants described that they want to help their child with developing sexuality, but they don’t know what supports are available (Pownall et al., 2011).

Lack of knowledge about the sexuality of children with ID is another barrier to providing sex education (Pownall et al., 2011; Pryde & Jahoda, 2018). Some mothers believe that their knowledge of their children's sexuality is very limited and that they have no idea how to solve their children's sexual issues (Pryde & Jahoda, 2018), or some mothers felt that they lack more specific knowledge to determine the impact of their children's disability on sexual behavior and reproductive function, One mother stated:

[...] She could become pregnant, I know that, but I remember reading when she was born that she probably wouldn’t be able to carry a baby to term. I don’t know, and that’s a stupid thing, but maybe in my head I’m just thinking well, you know, it’s maybe not going to, there’s not going to be as much as opportunity for her. That’s maybe a bit naive, I don’t know? (Pownall et al., 2011)

Another barrier is that sexuality is a very private matter in the minds of many mothers. Mothers realized that it's important to educate their children about sexuality (Pownall et al., 2011), but some mothers admitted that it is very difficult and uncomfortable to know the child’s sexuality:

As far as I am his mother and [my husband] is his father and we didn’t know any about [my other son’s] sex life and we don’t feel like we want to be prissy to too much sort of personal detail, about the specifics because we feel in many ways that would be obstructive. But the other side of it is that we recognise that James is a vulnerable adult and we love him more than any of the professionals […] it’s very difficult because we don’t want to know about the personal stuff because we are his parents, but we would want to be protective of him and we wouldn’t want anyone making decisions that aren’t the best decisions for him. (Pryde & Jahoda, 2018).

In addition, lack of confidence is also a barrier. Mothers recognized the importance of meeting their child's sexual needs, but mothers said they lack confidence when discussing sexual issues, which meant that the mothers were reluctant to initiate any discussion (Pownall et al., 2011).
Some mothers believed that they lack confidence in what information to share and when to provide it:

*I don’t want him to think it’s wrong because it’s absolutely not wrong, but we are going to have to work on the bow’s and the when’s and when it is appropriate and how are we going to manage that? Because […] his understanding of language at that point was very limited […] so I suppose I was trying to work out how to tackle that but, how, I had absolutely no idea.* (Pryde & Jaboda, 2018)

## 5 Discussion

This study investigated parents’ perceptions of sexual education in adolescents with ID and also explored the facilitators and barriers to providing sex education. The current review indicates that all mothers believed that sex education is necessary for their children with ID, but the content of sex education is indeed inconsistent. Most mothers agree that sex education in family planning should not be provided to their children, but should be directed at inappropriate behavior and learn to protect themselves. This review identified the main barriers to providing sex education, such as lack of resources and support, lack of sexual knowledge, discomfort in talking about sexual issues, and lack of self-confidence. The evidence in this review also shows that in addition to these barriers, there are two facilitators. Mothers have accepted the important roles and responsibilities of sex education, and they have maintained an open mind to communicate with their children about sexual issues.

### 5.1 Reflection on findings

In a bio-ecological system model, the development of a child or adolescent is achieved through interaction between the external environment directly associated with the child, including the child or adolescent and other persons, objects or symbols. And the process of interaction in such an immediate environment is known as a proximal process (Bronfenbrenner & Morris, 2007). Therefore, strengthening these proximal processes can promote positive development in children.

This review found that discovering that the barriers and facilitators to providing sex education can be mapped into microsystems of Bronfenbrenner’s model. For example, among the barriers to providing sex education identified in our study, lack of resources and support, lack of knowledge, and lack of self-confidence can all be attributed to microsystems. The mother’s open mind and sense of responsibility can also be classified as personal factors and mapped into microsystems.
Since the results of this review are only relevant to microsystems, the microsystems that affect parents’ perceptions were discussed in depth.

According to the findings, all mothers supported sex education, but most mothers considered that schools were the main place where sex education should be provided. Also a main finding is the lack of articles focusing on this topic, indicating that lack of awareness of the issue at hand. For parents, schools provide an important source of information as well as sex education for their children, for example, parents can get more up-to-date information about various aspects of sex education through school-organized seminars or sex education training. In particular, not every parent has the opportunity to take their child to an institution or to a doctor, and school seems to be the best option for helping children and parents gain knowledge about sexuality. In addition, sex education in schools can avoid the embarrassment of parents communicating with their children about sexuality.

However, according to the bio-ecological model, the development of children's sex education is influenced not only by the interaction between school and children, but also by the interaction between parents and children. It is difficult for parents and adolescents to communicate on sexual issues, but the frequency of communication between parents and children depends on the topic of communication (Diiorio, Pluhar, & Belcher, 2003). According to Clark, Baldwin and Tanner (2006), the most common topics of sexual issues that parents feel comfortable and can communicate with children of any age are: love, the name of the correct sex organ and the body image (Clark, Baldwin, & Tanner, 2006). There are many sexual topics between parents and children that are not discussed, such as reproduction, sexual behavior, and masturbation (Diiorio et al., 2003). The topics and methods of communication between parents and children about sexual issues can influence children's sexual attitudes and behaviors. Tinsley, Lees and Sumartojo (2004) has noted that open, supportive family communication patterns can promote positive parent-child relationships and reduce risky sexual behaviors among adolescents (Tinsley, Lees, & Sumartojo, 2004). When adolescents and their parents maintain active communication on sexual issues, the age of sexual behavior will be delayed, and they will be more aware of protection after sexual behavior (Martino, Elliott, Corona, Kanouse, & Schuster, 2008).

The findings of this study also indicated that parents' barriers to providing sex education include: fear of sex education and lack of self-confidence, lack of correct sexual knowledge and discomfort in communicating with children. These barriers reduce the frequency of parent-child communication, so parents need more resources and support to understand their children's sexuality. Geasler,
Dannison and Edlund (1995) also found that parents’ concerns about providing sex education to their children included uncertainty about the appropriateness of sexual knowledge, not knowing when to provide it, and fear of giving too much information to their children (Geasler, Dannison, & Edlund, 1995). Therefore, parents’ concerns about the sex education of children with ID hinder the positive role of parents in the development of children's sex education (Fader Wilkenfeld & Ballan, 2011). Mothers' facilitators in providing sex education include “active parenting,” such as helping children understand the sexual knowledge taught at school. In addition, some mothers are actively involved in the children's sexual issues to help children solve problems. In the review, most mothers stressed the importance of being open and honest about their children's sexual issues, which also promoted the communication between mothers and children to help children's sexual development.

In the three including articles, all participants were mothers. This may be due to the fact that sex education is often provided to children by their mother (McKenzie & Swartz, 2011). On the other hand, we do not know the fathers involvement nor their perception regarding this topic. Comparing to adolescents with ID and without ID, regarding on their mothers' views and attitudes towards their children's sexual development, the mothers of children with ID often express concerns about their children's vulnerability on sexuality, rarely discuss sex issues with their children and they take a cautious approach to the issues of contraception and intimate relationships (Pownall et al., 2012).

Mothers’ barriers to sex education may be related to psychological factors within individuals. According to Bandura’s (1986) reciprocal determinism, environment, personal factors and behavior are independent and interact with each other, and personal beliefs, motives often strongly dominate and guide behaviour (Maehr, Karabenick, & Urdan, 2008). If parents think they can discuss and educate their children about sexuality, then they will be more active in sex education. In order to enhance parents' ability in sex education, parents of adolescents with ID need professionals to provide sex knowledge and family support to help parents obtain sufficient sex information to enable them to have confidence in providing knowledge to their children. The cooperation of this sex education resource belongs to the mesosystem in the bio-ecological model. The ability to guide children's sexuality is a special ability, and parents can get this ability from some special training. Sex education for parents can reduce barriers to providing sex education for parents and promote parents as primary instructors for sex education for children (Liu & Edwards, 2003). Through sex education for parents, parents could understand children's sexual development and facilitate communication between children and parents on sexual issues, including romantic relationships, and increase the comfort when talking about sex issues (Kakavoulis, 2001).
5.2 Methodological discussion and limitations

5.2.1 Methodological discussion
Although the systematic review fully described the background of the study, the methodology and results of the study to promote other researchers to determine whether the finding could be transferred to another context (Graneheim & Lundman, 2004). However, there are methodological limitations to the study. First, the current study used five databases (Eric, PsyInfo, CINAHL, Pubmed and Web of science) to retrieve articles published in English and during and after the first of January 2009, which may limit the study because some of the relevant articles may have been missed. This may be why only three studies met all inclusion criteria. In order to be able to find more articles that meet the criteria, it should include more databases, Google scholar, expanded publication dates and articles in other languages to provide a broader range of articles.

In addition, all articles included in this systematic review used qualitative design. Therefore, the quality assessment tool of this study was adapted from the CASP Qualitative Checklist (CASP, 2018), and the Critical Review Form-Qualitative studies (Letts et al., 2007). However, this adapted tool has never been tested for reliability and validity, and its internal validity cannot be guaranteed. In addition, the researcher independently completed the selection process, quality assessment, and data analysis, although the author attempted to assess and describe these results in an objective manner to reduce the possibility of bias in the study. However, because of the subjectivity of this method, the author's unconscious presupposition cannot be excluded. Peer review and other researchers' review of the entire process can reduce research bias. In fact, to ensure credibility, researchers should analyze data from different angles with other researchers (Patton, 1999). However, this study did not collaborate with other researchers, so this is one of the most important limitations of this study.

Only three articles were reviewed in this systematic review, and the sample size was very small. Therefore, too small a sample size can limit the transferability and confirmability of the results.

5.2.2 Limitations of the articles
The purpose of this study was to explore parents' perceptions on sex education for adolescents with ID. However, all three articles were chosen to explore the perceptions of mothers, possibly because mothers are the primary caregivers for their children. Therefore, it is difficult to know whether the fathers' perceptions would make the results different. Second, two of the studies in the literature review were conducted in Scotland and one in Turkey. It is not known whether the different cultures and religious beliefs of the two countries had an impact on the results of the
study, as the three articles did not explore the views of parents from a cultural and religious perspective.

5.3 Future research and Practical Implications

There is not a lot of research in this area on parents' perceptions on sex education for children with intellectual disabilities, and future research on this area is necessary. This is a neglected field, especially regarding fathers' view, another aspect is that the three articles came from only two countries, indicating that perceptions from other cultures are completely lacking.

In order to better understand parents' perceptions of sexual education of children with intellectual disabilities and to provide support for sexual development of their children, future research needs to investigate the perceptions of sexual education of all persons associated with children with intellectual disabilities, which includes the perceptions of mothers and fathers, caregivers, teachers and children. Related to this, future research may also attempt to explore the factors that influence parents' perceptions on sex education in order to help children improve the current situation of children with ID regarding sexual issues. Another possibility for future research is family centered interventions to improve communication between parents and their children about sexual issues. In addition, future research should not only address the perceptions of parents of children with intellectual disabilities, but also explore how to support sexual education for children with ID in the effective way, and which support can effectively help the sexual development of children with ID.

6 Conclusion

The stigma of people with Intellectual disabilities are not completely broken, at the lack of attention on parents view on their children sexual education shows this clearly. Something about the view about sexuality for id, that also are mentioned in introduction. Also focusing back to this group’s vulnerability and that increasing research and awareness is one way to increase knowledge about the need for support regarding sexual health in adolescents with ID.

The purpose of this study was to explore parents' perceptions on sex education for adolescents with intellectual disabilities. The results show that parents are very supportive of sex education and hope that their children will receive sex education, and parents also believe that school is the best choice for sex education. Parents want to get supports and information to help them build confidence and support their child’s sexual needs. In the family, the mother plays an important
role in providing sex education and also assumes the responsibility for educating the child about sexuality. Considering how to communicate with your child about sexual issues, mothers want to keep an open and honest mind about their child's sexuality.

In summary, the results of this study are not transferability and credibility, because the sample size is too small, but the result can serve as a reference for professionals in the fields of education, intervention, and clinical psychology. For psychologists, it is possible to study why parents approach sex knowledge or education differently, in thought and in practice. Special educators can explore a family-centred interventions to sex education for children with ID that takes into account the perceptions of parents.
7 References


### 8.1 Appendix A Checklist for title/abstract screening

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<th>Topic</th>
<th>Checklist item</th>
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<td>Population</td>
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<tr>
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<td>Parents’ adolescents with intellectual disabilities</td>
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<tr>
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<td>and/or barriers or facilitators to promote sex education</td>
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### 8.2 Appendix B Checklist for full-text screening

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<tr>
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<td>More than 50% participants were parents to adolescents aged between 10 to 19 years</td>
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<tr>
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<tr>
<td></td>
<td>And/or barriers or facilitators to promote sex education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study design</td>
<td>Qualitative/design</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## 8.3 Appendix C Quality assessment tool

### Quality assessment tool

<table>
<thead>
<tr>
<th>Section A</th>
<th>Study design</th>
<th>Was there a clear statement of the aims of research?</th>
<th>(2) Yes</th>
<th>(1) Insufficient</th>
<th>(0) No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Was relevant background literature reviewed?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Was a theoretical perspective identified?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Is a qualitative methodology appropriate?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Was the process of purposeful selection described?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Are the participants described in detail?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Did it specify trustworthiness?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
<tr>
<td>Section B</td>
<td>Data collection</td>
<td>Was the recruitment strategy appropriate to the aims of the research?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Procedural rigor was used in data collection strategies?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
<tr>
<td>Section C</td>
<td>Data analysis</td>
<td>Was the data analysis sufficiently rigorous?</td>
<td>(2) Yes</td>
<td>(1) Insufficient</td>
<td>(0) No</td>
</tr>
</tbody>
</table>

### Answer Hint

- **What was the goal of the research?**
- **Why it was thought important? Is it relevance?**
- **Describe the justification of the need for this study. Was it clear and compelling?**
- **Describe the theoretical or philosophical perspective for this study e.g., researcher’s perspective.**
- **Describe the research design is the right methodology to address the research aim.**
- **Describe sampling methods and the sampling is the appropriate method to research aim and question.**
- **Sampling (who; characteristics; how many; how was sampling done?)**
- **Consider four aspects of trustworthiness, credibility, transferability, dependability and confirmability.**
- **The researcher has explained how the participants were selected. /Why did they choose the participants?/ there are any discussions around recruitment (e.g. why some people chose not to take part)?**
- **Do the researchers provide adequate information about data collection procedures.**
- **There is an in-depth description of the analysis process. The researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. Sufficient data are presented to support the findings. The**
<table>
<thead>
<tr>
<th>Section D</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Is there a clear statement of findings? | (2) Yes  
(1) Insufficient  
(0) No |
| The findings contributed to theory development or further research? | (2) Yes  
(1) Insufficient  
(0) No |
| Were limitations in the study addressed? | (2) Yes  
(1) Insufficient  
(0) No |

<table>
<thead>
<tr>
<th>Section E</th>
<th>Ethical consideration</th>
</tr>
</thead>
</table>
| Have ethical issues been taken into consideration? | (2) Yes  
(1) Insufficient  
(0) No |
| Was an informed consent obtained | (2) Yes  
(1) Insufficient  
(0) No |

### 8.4 Appendix D Quality assessment scores

<table>
<thead>
<tr>
<th>Quality questions</th>
<th>Articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was there a clear statement of the aims of research?</td>
<td>Pryde, Jahoda, 2018: 1; Gürol, Polat, Oran, 2014: 2; Pownall, Jahoda, Hastings, Kerr, 2011: 2</td>
</tr>
<tr>
<td>2. Was relevant background literature reviewed?</td>
<td>1; 1; 2</td>
</tr>
<tr>
<td>3. Was a theoretical perspective identified?</td>
<td>2; 0; 2</td>
</tr>
<tr>
<td>4. Is a qualitative methodology appropriate?</td>
<td>2; 2; 2</td>
</tr>
<tr>
<td>5. Was the process of purposeful selection described?</td>
<td>2; 1; 2</td>
</tr>
<tr>
<td>6. Are the participants described in detail?</td>
<td>2; 1; 2</td>
</tr>
<tr>
<td>7. Did it specify trustworthiness?</td>
<td>1; 0; 0</td>
</tr>
<tr>
<td>8. Was the recruitment strategy appropriate to the aims of the research?</td>
<td>2; 1; 1</td>
</tr>
<tr>
<td>9. Procedural rigor was used in data collection strategies?</td>
<td>2; 2; 2</td>
</tr>
<tr>
<td>10. Was the data analysis sufficiently rigorous?</td>
<td>2; 1; 2</td>
</tr>
<tr>
<td>11. Is there a clear statement of findings?</td>
<td>2; 2; 1</td>
</tr>
<tr>
<td>12. The findings contributed to theory development or further research?</td>
<td>1; 1; 2</td>
</tr>
<tr>
<td>13. Were limitations in the study addressed?</td>
<td>1; 0; 0</td>
</tr>
<tr>
<td>14. Have ethical issues been taken into consideration?</td>
<td>1; 1; 1</td>
</tr>
<tr>
<td>15. Was an informed consent obtained?</td>
<td>1; 2; 1</td>
</tr>
<tr>
<td>Total scores (30 points)</td>
<td>23; 17; 22</td>
</tr>
<tr>
<td>Quality range: low (&lt;15 points), medium (15-22 points), high (≥ 23 points).</td>
<td>high; medium; high</td>
</tr>
</tbody>
</table>
### 8.5 Appendix E Data extraction protocol

<table>
<thead>
<tr>
<th>General information</th>
<th>Author(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Year</td>
</tr>
<tr>
<td></td>
<td>Title</td>
</tr>
<tr>
<td></td>
<td>Journal</td>
</tr>
<tr>
<td></td>
<td>Study purpose</td>
</tr>
<tr>
<td></td>
<td>Research Question</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recruitment</th>
<th>Where?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>How?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sampling strategy</th>
<th>How?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th>Sample size?</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Age</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
</tr>
<tr>
<td></td>
<td>Key demographic descriptors</td>
</tr>
<tr>
<td></td>
<td>Socioeconomic status</td>
</tr>
<tr>
<td></td>
<td>Living situation</td>
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</table>

<table>
<thead>
<tr>
<th>Study design</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>● Content analysis</td>
</tr>
<tr>
<td></td>
<td>● Phenomenon</td>
</tr>
<tr>
<td></td>
<td>● Grounded theory</td>
</tr>
<tr>
<td></td>
<td>● Narrative</td>
</tr>
<tr>
<td></td>
<td>● other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data collection</th>
<th>Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>structured interview</td>
</tr>
<tr>
<td></td>
<td>Semi-structured interview</td>
</tr>
<tr>
<td></td>
<td>Focus group</td>
</tr>
<tr>
<td></td>
<td>Case studies</td>
</tr>
<tr>
<td></td>
<td>Longitudinal studies</td>
</tr>
<tr>
<td></td>
<td>More than one method</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data analysis</th>
<th>Content analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Thematic analysis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Results</th>
<th>Primary results pertaining to parents’ perceptions on sex education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Primary results pertaining to barriers and facilitators</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conclusion</th>
<th>Authors conclusions pertaining to parents' perceptions on sex education</th>
</tr>
</thead>
</table>

| Clinical/practical implications | |
|---------------------------------||
### 8.6 Appendix F Outline of included articles

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Title</th>
<th>Country</th>
<th>Aim</th>
<th>Participants, their children gender and age</th>
<th>Qualitative method</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pownall, Jaycee D., Jahoda, Andrew, Hastings, Richard, Kerr, Linda</td>
<td>2011</td>
<td>Sexual understanding and development of young people with intellectual disabilities: Mothers’ perspectives of within-family context</td>
<td>Scotland</td>
<td>Examining the knowledge, opinions, attitudes and concerns of the parents regarding sexuality of their children with intellectual disability.</td>
<td>Mother (n=8) Daughter (n=4) Son (n=4) Children’s age(17-19)</td>
<td>Semi-structured interview</td>
<td>high</td>
</tr>
<tr>
<td>Gürol, Ayşe, Polat, Sevinç, Oran, Tolga</td>
<td>2014</td>
<td>Views of Mothers Having Children with Intellectual Disability Regarding Sexual Education: A Qualitative Study</td>
<td>Turkey</td>
<td>Evaluating the views of the mothers having children with intellectual disability regarding providing sexual education for their children</td>
<td>Mother (n=9) Daughter (n=3) Son (n=6) Children’s age(average 12.11 ± 3.91)</td>
<td>Focus group</td>
<td>medium</td>
</tr>
<tr>
<td>Pryde, Rebecca, Jahoda, Andrew</td>
<td>2018</td>
<td>A qualitative study of mothers’ experiences of supporting the sexual development of their sons with autism and an accompanying intellectual disability</td>
<td>Scotland</td>
<td>Address the gap in the literature by undertaking an exploration into the lived experience and views of mothers of sons with ASD and an intellectual disability, in relation to their sons’ sexuality and sexual development.</td>
<td>Mother (n=5) Son (n=5) Children’s age(three=16, two=24)</td>
<td>Semi-structured interview</td>
<td>high</td>
</tr>
</tbody>
</table>